



Developing a Decision Aid for Older People Who Pay for Social Care

RESEARCH

LYNDSAY LINDLEY

MAXINE WATKINS

DAWN DOWDING

LOUISE OVERTON

ALANNAH FRIEND

MARK WILBERFORCE**

YVONNE BIRKS

*Author affiliations can be found in the back matter of this article

**Co-editor of the journal



ABSTRACT

Making informed decisions about social care in later life can be challenging and emotional, particularly for self-funders who organise and pay for care, often with little or no statutory support. Decision aids can guide complex decision making by bringing together information and associated risks and benefits. This project aimed to create such a resource to support self-funders in navigating social care planning and funding. A prototype decision aid, Care Confidence, was co-designed with involvement of self-funders, carers and professionals, including care providers, information and advice services, later life advisers and others whom self-funders approach for information. The methods, adapted from design of patient decision aids in clinical settings, involved scoping and consultation, development workshops, and iterative testing and modification. This paper discusses the application of these methods in relation to the striking complexities of decision making in social care, particularly for self-funders. The resulting digital decision aid provides information on care options and funding strategies, as well as generating a user-centred action plan that empowers self-funders and their supporters to make confident, informed decisions about care. The development of this unique decision aid contributes to improving the evidence-informed support available to self-funders in England. In relation to accessibility, Care Confidence would benefit from further research to address language and digital exclusion of self-funders and scope to implement the resource in adult social care and third sector providers.

CORRESPONDING AUTHOR:

Lyndsay Lindley

University of York, UK

lyndsay.lindley@york.ac.uk

KEYWORDS:

Decision aid; Co-design; Social care; Self-funders; Shared decision making

TO CITE THIS ARTICLE:

Lindley, L., Watkins, M., Dowding, D., Overton, L., Friend, A., Wilberforce, M. and Birks, Y. 2025. Developing a Decision Aid for Older People Who Pay for Social Care. *Journal of Long-Term Care*, (2025), pp. 142–153. DOI: <https://doi.org/10.31389/jltc.406>

INTRODUCTION

BACKGROUND

Making decisions about social care in later life can be complex and emotional (Heavey et al., 2024). For people who pay for their care privately (known as self-funders), navigating the care system and paying for care with little or no formal guidance or support is particularly difficult (Baxter et al., 2017; Baxter et al., 2020; Henwood and Hudson, 2008).

The growing self-funder population in England is estimated at over 250,000, most of whom are older people (Office for National Statistics (ONS) report, 2023a, ONS report, 2023b). The cost of residential care averages £1000 per week but varies significantly across regions and facilities (Age UK, 2025). Self-funders do not know where to look for reliable information about their options (Baxter et al., 2020), for example, possible alternatives that may help them remain in their own home. Funding social care is means-tested such that individuals with assets or savings above an upper capital limit must pay for their social care in full (Department of Health and Social Care, 2025). Legislation in 2014 (Care Act, 2014) established a duty on local councils to provide information to self-funders about managing and paying for care, including guidance on consulting financial advisers. However, self-funders seldom receive effective support (Baxter et al., 2021; Heavey et al., 2024).

Many people are concerned about how long their funds will last (Baxter et al., 2017) yet few people seek professional advice in this respect. Seeking advice can lead to greater understanding about options for care and funding and feelings of greater control over self-funding social care (Baxter et al., 2018). Conversely, a lack of information and advice can lead to self-funders making poorly informed decisions that could have long-term detrimental consequences for them and their families. For example, choosing to rely on unpaid care to protect savings can affect current and future income for relatives providing care (Petrillo and Bennett, 2023; Watkins and Overton, 2024) or raising funds using equity release could affect self-funders' entitlement to allowances to pay for care (Fox O'Mahony and Overton, 2014). Key barriers to seeking financial advice include a lack of understanding of the potential benefits, perceptions of poor value and high cost, lack of trust in financial advisers and institutions (Putting People First Consortium et al., 2011; Moss et al., 2024) and fear of approaching a financial adviser. This, in part, stems from not knowing what to expect or how to prepare for a consultation (Heavey et al., 2019).

DECISION-MAKING AND PLANNING SOCIAL CARE

Decision-making is broadly understood as the process of deliberately selecting an option from a set of alternatives to attain a specific, optimal, outcome (Ernst & Paulus,

2005; Galotti, 2002). The principles of empowerment and choice that underpin the notion of personalisation in social care services within the United Kingdom (Department of Health and Social Care, 2021) assume that if information and advice is made available, self-funders and/or their families will make rational decisions that result in optimum outcomes. However, literature concerned with financial decision-making suggests that the process is not always guided by rationality but is instead influenced by contextual and psychological factors, such as social relationships and expectations (Preda and Muradoglu, 2019) and the 'messy emotional realities' of people's lives (Dibb et al., 2021: 826). Baxter et al., (2020) note that older people tend to make decisions about social care at a time of crisis (for example, discharge from hospital) and may therefore not have sufficient time to navigate the complexities of the social care system and to fully consider all the options available to them. Since critical life events, such as a hospital discharge, are often also laden with emotional responses, such as guilt and anxiety (Ewing et al., 2018; Shyu, 2000), people arranging social care may make sub-optimal decisions at these critical times. Evidence suggests that effective preparation for ageing requires that people acknowledge potential risks and identify available resources (Sörensen et al., 2021) and that people could benefit from guidance through the decision-making process during times of stress (Sörensen et al., 2011).

DECISION AIDS IN HEALTH AND SOCIAL CARE

People making complex health care decisions are encouraged to engage in shared decision-making processes, often assisted by a decision aid. The three-talk model of shared decision-making originally developed by Elwyn et al. (2017) suggests that during a clinical encounter, clinicians and patients talk about options available to them for a specific clinical condition. The model suggests that clinicians and patients work together as a team to identify options available (team talk), discuss the alternatives using data on the probabilities or risks associated with each option (option talk) and make informed decisions based on the patient's preferences (decision talk).

In health care settings, decision aids have been developed to provide information to patients to help them participate in this decision process, mainly focusing on the option talk element of the process. They are specifically designed to support people's decisions by making them explicit, providing current information on the options and any associated risks and benefits helping people clarify, and take account of, their personal values and preferences (BMJ, 2013; Stacey et al., 2017). Decision aids are mainly used independently by patients either prior to or after a clinical consultation with the aim of improving the quality of a decision. They are often presented as a series of interactive questions, online or on paper.

Decisions taken in social care may be as critical as some of those made in health care settings. It is equally important for individuals receiving social care to consider the risks and benefits of different care and funding options and to take their own preferences into account when making decisions. However, decision aids such as those used in health care are rarely available for use in social care settings to help with the decision-making process.

EVIDENCE OF EXISTING SOCIAL CARE DECISION AIDS

A scoping review (Baxter et al., 2021) that drew evidence together on the development and availability of decision aids in adult social care identified just five evidence-based tools. These decision aids aimed to help in preparing to plan and pay for later life care. The tools were developed in North America using multi-phase methods including focus groups and interviews and were then field-tested for acceptability and usability. The target audience for the decision aids varied; some aimed to support older people at the time of need, others were for professionals and mid-aged people to prepare and plan for future long-term care. A further search for decision aids used by councils and third sector providers in the English social care system returned twelve items that may be described as tools or aids that aimed to inform and support decisions about housing, wellbeing or costs (Baxter et al., 2021). Three of these were cost calculators that focused on statutory funding eligibility or illustrated costs of care. These tools did not bring information, potential costs and risks and benefits together to help self-funders make informed, personally relevant decisions. None evidenced how the tool was developed or detailed sources of information; but their presence on council and support organisations' websites suggest that a social care decision aid could be an acceptable means to support decisions of self-funders in England.

There is a lack of support for self-funders to make informed decisions about planning and paying for social care in later life. This paper describes the development of a prototype decision aid to address this lack of support in England; and to help older people and

their family members think through care options and personal preferences and overcome reluctance to seek professional guidance or advice. The paper sets out, in detail, our approach to developing the first evidence-informed social care self-funders online planning tool to aid decision making.

METHODS

The study was conducted in four stages: scoping; developing; testing and modifying; and field-testing. Figure 1 shows the research activities in each stage. This paper reports on stages 1–3. While the aim of the study was to develop a decision aid for individuals self-funding social care, the process was based on the design and testing of tools for shared decision-making in health care (Coulter et al., 2013; Matlock and Spatz, 2014) and hence it was expected that the process would be adapted to work for social care planning. A favourable opinion was received from the Health Research Authority, Social Care Research Ethics Committee to conduct the study (21/IEC08/0029).

STAGE 1: SCOPING

Activities in Stage 1 were designed to help outline the content and to understand how self-funders would potentially use the decision aid. A scoping review of the availability of decision aids for social care was undertaken prior to this study, as indicated above (Baxter et al., 2021).

To supplement the review, secondary analysis of 60 qualitative interviews conducted in two previous studies on the experience of organising and self-funding social care (Baxter, 2022; Baxter et al., 2020) was undertaken. This aimed to ascertain the attributes of social care decisions and whether a tool, introduced at a salient time, could potentially be of benefit. The transcripts were analysed using NVivo data analysis software.

An additional consultation took place with 22 adult social care and allied professionals across England (by telephone or video call) covering: financial and legal sectors (10); local council adult care and assessment (3); care providers, both domiciliary and residential (5);

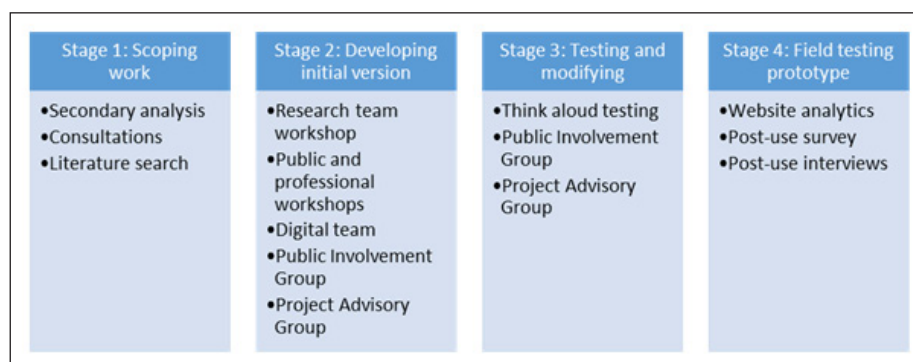


Figure 1 Study design.

online service and information providers (2); and a care navigation provider and a member of Citizen's Advice. These consultations explored how each sector provides support and information to self-funders and their representatives and, specifically, the risks and benefits of funding social care that are the focus of self-funders' enquiries. The consultations helped to clarify how such information could be included and how, and at what stage, the decision aid could be introduced to self-funders. Consultations ran in parallel with, and drew on findings from, the secondary analysis.

A non-systematic review of evidence was employed to collate available information that could be used in the decision aid. This involved searching relevant academic or other published literature, websites (e.g. government, local council, third sector, financial sector) and national databases (e.g. NHS Digital). The aim was to seek data on risks and benefits for self-funders, including risk for self-funders depleting and falling back on their local council for funding.

STAGE 2: DEVELOPING AN INITIAL VERSION OF THE DECISION AID

Informed by the scoping work, an initial plan for the prototype decision aid was co-designed with lay contributors and professional experts. Advisory groups were involved throughout the project to consider and prioritise content for, and design of, the decision aid. A group of seven public individuals with experience of arranging and/or paying for social care for themselves or others was convened, plus a panel of professionals with expertise in matters relating to self-funding older people's social care. This second group comprised professionals from digital innovations in health, financial planning, information services for self-funders, local council social care and finance for self-funders, the Money and Pensions service and the Department for Work and Pensions, 50+ team. Further development was undertaken based on established co-design principles (INVOLVE, 2019) including workshops with storyboarding and design work.

Five workshops were attended by a total of 42 contributors, including self-funders, potential/future self-funders and carers as well as professionals from care providers, care navigation organisations and legal and financial services. Due to ongoing restrictions relating to the COVID-19 pandemic, a flexible approach was adopted to ensure participants were comfortable to take part in workshops either face-to-face or online. Providing the option for online workshops meant that people could attend from across the country. The in-person workshops recruited participants from local project centres in York, Manchester and Birmingham.

The workshops comprised whole-group and small group discussions facilitated by members of the research team. Discussions were stimulated through video

extracts of self-funders talking about the challenges and solutions of arranging and paying for care. These videos were captured during an earlier study (Baxter, 2022) with consent for future use in research. The workshops were held sequentially, with each building on developments from previous workshops. A visual illustrator assisted with facilitating the face-to-face workshops to stimulate creative development of the draft decision aid.

A period of at least two weeks elapsed between each workshop to allow the study team to reflect on the output in collaboration with the project advisory and public involvement groups.

Digital developers provided examples that demonstrated options for graphics, navigation, and ways to present information in the decision aid. These alternatives were presented at the later workshops. Throughout the workshops, themes of accessibility and inclusion were highlighted by participants. After the final workshop, the proposed content was delivered to the developers to produce the digital decision aid.

STAGE 3: TESTING AND MODIFYING

The purpose of stage 3 was to improve the draft digital decision aid in line with user feedback. This was an iterative process following the methods of Thompson et al. (2015). Using 'think aloud' techniques (Jaspers et al., 2004), participants were asked to work through the decision aid at their own pace, describing their thoughts as they occurred. This technique is used commonly in the design and testing of new products and helps designers to understand the user experience and how they interface with the decision aid.

A series of think aloud interviews were conducted that gathered feedback on the decision aid, which was then modified and subsequently reviewed by further interviewees and modified again. Based on discussions with digital design experts, up to 10 iterations of the aid were anticipated. However, this was open-ended as previous decision aid development had taken up to 19 iterations in other contexts (Thompson et al., 2015).

Over a period of 16 weeks, a total of 43 think aloud tests were completed. Since the prototype decision aid is an online resource, participants needed to have internet access and a basic level of online competence. Participants were given the choice to perform the test in-person or remotely; all but two took place online. Participants included 14 self-funders (or potential self-funders/carers), of which three had taken part in workshops, 22 practitioners (of which one had taken part in a workshop), and seven members of the Public Involvement group. The duration of the think aloud tests was between 19 minutes and an hour and 38 minutes, averaging 32.5 minutes.

The participants' actions, when working through the decision aid, were observed by the researcher and, once the participant had finished the task, the

researcher asked supplementary questions about their experience. The interviews were audio-recorded and/or recorded on the video meeting platform. The data were analysed, driven by key themes aimed at improving the content (e.g. understandability, accuracy, terminology, how much people are prepared to read), design (e.g. appearance and structure) and function (e.g. usability, digital malfunctions) of the decision aid. After every 4–6 interviews, the research team, along with the advisory groups, reviewed the feedback and worked with the digital developers to improve the decision aid. When subsequent think aloud interviews produced no substantive new issues, with consensus from the research team and agreement from the project advisory and public involvement groups, the decision aid was finalised for public evaluation.

RESULTS

STAGE 1: SCOPING

Secondary analysis of interviews with self-funders

Cross-cutting themes arising from secondary analysis highlighted the cost and complexity of arranging and financing social care. Self-funders sought solutions to their challenges around paying for social care by searching online, approaching health care professionals or charities (e.g. dementia organisations if this was the cause of care needs), or a combination of sources. Some expected to receive guidance from their local council but described being disappointed as the ‘shutter came down’ once it was established that they would be self-funders. Self-funders described their experiences as inherently unfair although ultimately some found solutions for funding care that they were comfortable with. This included paying for professional help to arrange care, or consulting regulated financial advisers. Feelings of independence and control were important factors, which were achieved, in part, through professional services including making wills, putting in place Lasting Powers of Attorney and talking to trusted financial experts. Nevertheless, it was common to find that people did not think that financial advice would be helpful when planning care. Those who did seek financial advice often reflected that, had they done so sooner, they could have used financial products to help make their money go further to pay for social care. However, some people explained they did not want to plan ahead or would just ‘get old and hope for the best’.

Consultations with professionals

Consultations with professionals highlighted three key areas which could inform the development of the decision aid:

Purpose: Professionals recognised that most people were likely to use the decision aid at a point of crisis but

felt strongly that whilst the aid should be as simple as possible it should also be a ‘wake-up call’ that resulted in people taking action. They felt many websites already provided information and the decision aid needed to stand out by offering something additional. In consultation with the advisory group, it was agreed to aim for a balance between providing sufficient detail but avoiding overload, and to include a ‘call to action’ without alarming people.

The relationship between the new decision aid and other tools and guides was explored. Existing resources for people considering a range of social care or finance options were identified; for example, a checklist from Age UK for people thinking about moving to a care home and cashflow tools used by financial advisers to help people model future finances. The advisory group felt that the new aid needed to complement rather than compete with other tools and guides.

It was agreed that the decision aid should inform but not advise or influence people. This was particularly important in relation to content about finance, which is strictly regulated and highly emotive.

Content: Initial consultations indicated how emotional the topics of receiving, arranging and paying for social care can be, not least because many members of the public articulate significant resentment at having to fund their own care. Professionals recommended that the decision aid should be positive and reassuring without being emotional or making the system feel unfair.

The need for the aid to be designed for dynamic use was highlighted so that it could be used and returned to as circumstances changed or as people learned more about their options.

There were many suggestions for content of the decision aid and the types of questions people felt would be important. It was agreed that the main sections of the aid should cover care, housing and finances.

Audience: Professionals spoke about the range of different people who might use the decision aid, including self-funders themselves, their spouses, adult children or other relatives, and stressed the importance of ensuring that the content spoke to these different groups. For example, they queried whether the decision aid would refer to ‘you’ or ‘the person you care for’. Some suggested different versions for different users. Such queries were discussed with the project advisory groups and together the initial decision was made to write the content as if the user was the (potential) self-funder (rather than a carer or family member), since they were the core service user, but to review this in development.

Professionals also highlighted that people often have limited knowledge about social care or paying for care, and struggle to find answers because they do not know what questions to ask. Again, this was discussed with the project advisory groups and a decision made to primarily assume limited knowledge of social care or self-funding.

Review of risk and benefits data

Limited data were located that related to risks and outcomes for self-funders that could be included in the decision aid. An ONS report (2021) estimated the proportion of care home residents in England, prior to the COVID-19 pandemic. However, the estimate was based on incomplete data and did not encompass self-funders of domiciliary care. Data on costs of care proved to vary significantly across regions and were rapidly superseded due, in part, to the effects of the pandemic.

STAGE 2: DEVELOPING AN INITIAL VERSION OF THE DECISION AID

Outcomes of workshops

Themes discussed at the series of workshops were generated based on the outcomes of previous workshops and on other existing evidence. All contributions were accorded equal value and incorporated in material to be considered for inclusion in the decision aid. Final content was refined with the advisory groups.

In this way, solutions were found to complex problems arising in the workshops. For example, participants felt that financing care was alarming, and being explicit about depleting resources could turn people away from using the decision aid. At early workshops, participants stressed the importance of information being current and that users should not be required to enter personal data. We, therefore, explored alternative ways of presenting risks (or benefits) of funding care that would be acceptable and informative. This resulted in simple cost calculators in relevant sections that illustrated potential costs for domiciliary or residential care. While the cost calculators do not attempt to identify exact

costs in different regions, the range gives an indication, and users can select a more or less costly regional setting. This solution meant that users would not be required to enter personal information, such as location or income. Also, the decision aid could be kept up to date with current information without being overly complex to maintain.

Resolving digital challenges

Transferring the on-paper design to a digital solution introduced challenges for the digital team. Decision aids used in clinical decision-making often make use of explicit self-reflection. In the social care decision aid, this was presented as a 'confidence scale' for weighing-up how the user felt about making decisions about funding social care. The challenge was how these data would be captured and incorporated into an action plan. The digital team found that a five-point numerical 'confidence' scale translated most effectively to the action plan.

Working with the public involvement group, short video extracts were selected to present key messages about care and funding options to help illustrate issues within the decision aid.

One month after the fifth workshop, the first digital 'alpha version' of the decision aid was delivered.

Table 1 sets out ideas and solutions generated at each of the five workshops.

STAGE 3: TESTING AND MODIFYING

Iterative testing interviews were audio- and/or video-recorded and observed by the researcher who noted on a checklist the sections visited and any problems or glitches that occurred. Data collection in these 'think

	WORKSHOP CONTENT	FINDINGS/RECOMMENDATIONS/OUTPUT	POST-WORKSHOP DEVELOPMENT
Workshop 1 (York)	Discussions about: • 7 public contributors (Self-funders and carers) • Visual illustrator/facilitator • 2 members of the digital design team Discussions prompted by: • Basic content • Look and feel • Relationship between personal data and the decision aid • Videos of self-funders' experiences • Examples of clinical decision tools	Decision aid should: • Be empowering and empathetic • Engender trust and confidence • Be simple • State financial thresholds for self-funders • Provide a solution or plan • Not require input of any personal data	Visual illustration of discussions Research team drafted initial content on paper at this stage. Design team began creating brand options
Workshop 2 (online)	Whole group discussion about care options to be included Small group discussions a) costs of care at home and b) residential care	Decision aid should: • Prompt users to consider their current and future circumstances, preferences and changing needs • Detail what is included in different types of care and housing options • Provide information about care costs • Highlight potential social aspects of care, including pets and care	Research team: • updated draft content about care options • added self-complete scale for reflecting on knowledge and confidence • drafted options for presenting information about costs, including interactive calculator Design team produced two initial brand and navigation styles (landing pages only)

(Contd.)

	WORKSHOP CONTENT	FINDINGS/RECOMMENDATIONS/OUTPUT	POST-WORKSHOP DEVELOPMENT
Workshop 3 (Manchester) 13 public contributors - Visual illustrator/facilitator	Whole group discussion about brand and navigation styles. Small group discussions about draft written content: - care options (8 pages) - financial information (3 pages)	Decision aid should: - Include solutions - Introduce less well-known care options - Be empowering and promote independence - Use simpler language and consider screen readers - Remove ‘tool’ from name - Include text to explain why users should click on navigation buttons - Use clearer font style and text colours - Use alternative media to deliver key messages	Visual illustration of discussions Research team: - redrafted written content - discussed accessibility of text, images and videos with design team - changed name to ‘Choices for Care’ - Identified short video extracts to embed in the decision aid Digital team: - removed white font and increased colour contrast - redesigned landing page to include large buttons with more explanatory text
Workshop 4 (Birmingham) 3 public contributors 2 care professionals	Whole group discussion: - Improving draft financial and cost information - Brand, accessibility and usability of digital version	Decision aid should: - Promote positive ‘living well’ messages - Include scenarios to help people recognise their situations - Include answers to key questions about financing care and to increase confidence to approach financial advisers - Include information about risks/benefits/costs of financial advice - Avoid stating any costs that are subject to change - Be accessible via a range of digital devices	Visual illustration of discussions Research team: - Continued to liaise with designers about accessibility - Added case studies to each section to illustrate pros and cons of different care situations - Added self-complete scale for reflecting on knowledge and confidence to seek financial guidance or advice - Designed a printable plan of action as output of using the decision aid
Workshop 5 (online) 8 care professionals (two meetings to aid accessibility, each person attended one meeting)	Whole group discussion: - Updated flowchart - Content of care option pages - Content and accuracy of finance pages - Content and style of plan of action	Decision aid should have sections on: - Where to start when considering financial advice - Preparing to consult a financial adviser and what to expect - Questions to ask a financial adviser	Research team: - Updated/corrected financial information - Added sections on financial advice Digital team: - Redesigned plan of action - Linked self-complete scales reflecting on confidence to plan of action

Table 1 The role of workshops in developing the decision aid.

aloud’ interviews (Jaspers et al., 2004) was intended to record the thoughts and feelings (in the form of a monologue) of the participants as they worked through the decision aid. While some participants were able to do this, others found it difficult to articulate and instead would read through a section and then give their feedback. This was particularly noticeable with practitioners who would comment on the usefulness or accuracy from their professional perspective. Despite these differences in approach, the data provided the intended rigorous, contemporaneous commentary on using the decision aid rather than reflective ‘after the event’ feedback.

During the testing period, six iterations of the decision aid were implemented with additional minor corrections as needed. The key changes are shown in Table 2. Feedback was collated and discussed among the project and advisory teams to prioritise matters, especially where feedback was contradictory.

The decision aid is now publicly available under the name of ‘Care Confidence’ with on-going evaluation taking place employing analytic software and user feedback.

DISCUSSION

This paper reports the development of a publicly available social care planning decision aid (www.careconfidence.org.uk). Care Confidence is the first evidence-informed online planning tool for self-funders in the English social care system. Early feedback indicates it to be perceived as being comprehensive, reliable and independent in its provision of information about social care and funding choices.

MESSY DECISIONS: CHALLENGES AND SOLUTIONS

The aim of decision aids in both health and social care is to improve the quality of decision making, which involves

ROUND OF TESTING	CHANGES TO CONTENT	CHANGES TO USABILITY
Changes following round 1	Added more instructions about using the decision aid and creating an action plan	Changed questions on introductory page to quiz Merged care-related confidence scales to reduce repetitiveness
Changes following round 2	Deleted section about how to get financial information, guidance or advice. Moved narrated video about arranging self-funded care from money section to introductory page	No changes
Changes following round 3	Explanation of costs used in calculators improved terminology in finance section made clearer	Changed style of answers to quiz questions Scenarios relabelled as 'pros and cons' and given consistent look throughout Made money-related confidence scale mandatory to avoid it being overlooked
Changes following round 4	Text on landing page reduced and simplified Added text explaining how care and money-related confidence scales were used in action plan	Made care-related confidence scale mandatory to avoid it being overlooked Layout of action plan improved
Changes following round 5	None	Duration and brief description of content of videos added to help users choose which to watch Pop-up added inviting users to take part in evaluation
Changes following round 6	Minor adjustments to terminology	Some vibrant colours muted Added 'X' at top right to close pop-ups Inbuilt text to speech function removed Minor adjustments to ensure consistency of layout and navigation prompts

Table 2 Key changes resulting from iterative testing.

being prepared, informed and comfortable with decisions (Baxter et al., 2021). Whereas clinical decisions are often binary (for example, medication versus surgery), social care decision-making is often dynamic in terms of options, relationships and changes over time.

In preparation for making decisions about social care, identifying potential costs is a challenge. Residential fees are often not stated online and while some support organisations give an indication of cost (e.g. Age UK, 2025) this is with a proviso that the actual cost will vary. Identifying hourly rates for domiciliary care may be clearer but there remains variation in how much care an individual will need as well as further considerations, such as minimum calls or double handed calls (if a person's needs cannot safely be met by a single carer). In addition, people funding care may draw on a combination of paid care workers, unpaid carers and other facilities, such as day centres or support hubs. Care may be funded with income, savings, sale of a property or other means or, as is most common, a combination of these sources, which are adapted to meet changing (and often increasing) needs. These complex and overlapping constellations of care and funding must be navigated by self-funders and their families, often with little support.

The Care Confidence decision aid breaks down these options, informing people of a range of possibilities for care and support: 'Making life easier at home', 'Moving to a different home' (downsizing or sheltered housing), and 'Moving to a care home'. A fourth section 'Thinking about

the money' looks at ways to fund care and how to find, and to prepare for consulting with regulated financial advisers.

A feature of clinical decision aids is the presentation of quantifiable risks and benefits relating to, for example, side effects. During the scoping phase of the study, it was established that equivalent quantifiable social care risks and benefits could not be identified. It is also a challenge to quantify the financial costs of any given care option since variables—that include care needs, geographical location and market forces—mean there is a wide range of costs to consider. However, by using interactive cost calculators to indicate potential costs of domiciliary and residential care, users can estimate potential costs without the need to enter personal information. Care Confidence also uses short case studies to highlight risks and benefits to a range of care and funding choices.

Research to develop decision aids that support shared decision-making in clinical settings found that professionals were concerned that patients could be overloaded with confusing information (Smith et al., 2020). A comparable challenge arose in developing Care Confidence. Participants involved in co-designing the decision aid felt it important to present costs in a sensitive and contextualised way, fearing that the alarming cost of care could turn users away before they could access the information they need. To mitigate this concern, short video clips - that presented people talking about their own lived experiences of planning social

care – are presented alongside the financial information. This was found to be an acceptable approach by participants in the development and testing stages. In this way Care Confidence succeeds in presenting accessible information in a variety of media including video and case studies which users find relatable.

Decisions in health care are often time-limited, that is, patients must decide before a procedure can take place. However, the need for social care can be insidious or can be acute. Care Confidence incorporates an interactive action plan to empower self-funders to make choices and enact plans including the opportunity to revisit and adapt to new scenarios. The action plan includes two sections: ‘I’m going to find out more about:’ and ‘I’m going to talk to:’ each with a list of suggested actions. The user may select from the list as many items as they wish and can type notes in a free text box. Their personalised action plan can then be printed or saved as a PDF and used to mobilise decisions and to generate conversations between self-funders and those who support and advise them.

LIMITATIONS

Knowledge of the characteristics of self-funding populations at scale is limited and knowledge of subgroups within that even more so. Previous research has identified the challenges of engaging a diverse sample of self-funders and this project faced similar challenges. For example, while we recruited from ethnically diverse regions, participation from ethnically diverse populations has been limited. The decision aid prototype was developed in English; future studies could explore other languages and culturally relevant information. Older people without children or significant care partners to assist in planning care can find it difficult to access information, particularly online, and are another group whose needs will require further exploration, as will the issue of digital literacy and access.

There are further areas to address, including an acknowledgement that decisions are often made in family groups with multi-person and multi-generational considerations with different individuals playing different roles. These areas will be further explored through a future evaluation of Care Confidence.

Technical support for Care Confidence is in place until 2030, which allows the decision aid to be maintained and its content updated. Further work could optimise the use of Care Confidence in organisations where self-funders seek information and support. Additional funding may be sought to sustain the decision aid beyond 2030 and to raise awareness through ongoing publicity campaigns.

IMPLICATIONS AND NEXT STEPS

Navigating the social care system is difficult, but it can be particularly challenging for older people (Baxter

et al., 2020; Baxter et al., 2023; Jasper et al., 2023). Care Confidence is a unique resource (Baxter, 2020), grounded in evidence and the experience of older self-funders, that is now freely available online. The process of, and commitment to, codesign throughout all phases of the project is something we would strongly recommend to others who may be considering the development of similar aids or tools. This approach enabled the research team to be responsive to ongoing feedback and to develop a more effective decision aid that will help self-funders to recognise their personal values and preferences when considering social care and help them to understand more about their financial options in a defined and clear way. Accessing Care Confidence early could help older self-funders and their carers to weigh up choices and make a plan for care before situations escalate, allowing time to fully consider options and implications. However, not everyone knows about Care Confidence and not everyone who could benefit from this resource will be able to access it in its current form. In this project, we worked closely with the UK government-backed money and pensions advice service, (MaPS) and Care Confidence has been hosted on their Money Helper website and signposted by their practitioners. In the longer term, we envisage the decision aid being available through a range of organisations that self-funders approach for information and guidance.

Care Confidence also has the potential to support and improve adult social care practice by facilitating practitioners to proactively help self-funders improve the process and quality of decision making about care and paying for care. Practitioners are not always confident in their own knowledge of options for self-funders and the decision aid could act as a guide for them to have care planning conversations. Future research should therefore explore ways that Care Confidence could be used by local councils and other service providers to improve their information and advice offer to older self-funders. This could enhance both the decision aid’s reach and its accessibility, for example, making it possible for people who are digitally excluded or who have English as a second language to be supported to make care decisions using [Care Confidence](#).

FUNDING INFORMATION

This study is funded by the National Institute for Health and Care Research, School for Social Care Research.

COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR AFFILIATIONS

Lyndsay Lindley  orcid.org/0000-0002-5982-9679

School for Business and Society, University of York, UK

Maxine Watkins  orcid.org/0000-0002-1080-661X

School of Social Policy and Society, University of Birmingham, UK

Dawn Dowding  orcid.org/0000-0001-5672-8605

Division of Nursing, Midwifery and Social Work, School of Health Sciences, University of Manchester, UK

Louise Overton  orcid.org/0000-0002-3757-4257

School of Social Policy and Society, University of Birmingham, UK

Alannah Friend  orcid.org/0009-0007-5166-6127

School for Business and Society, University of York, UK

Mark Wilberforce  orcid.org/0000-0001-6977-4483

School for Business and Society, University of York, UK

Yvonne Birks  orcid.org/0000-0002-4235-5307

School for Business and Society, University of York, UK

REFERENCES

- Age UK.** (2025) Available at: <https://www.ageuk.org.uk/information-advice/care/paying-for-care/paying-for-a-care-home/> [accessed 03/03/2025].
- Baxter, K.** (2022) 'Experiences of those who self-fund care', *NIHR Our stories*. Available at: <https://www.nihr.ac.uk/story/experiences-those-who-self-fund-care> [accessed 20/10/2024].
- Baxter, K., Gridley, K. and Birks, Y.** (2023) 'The role of uncertainty in planning for self-funded social care for older people with a diagnosis of dementia', *Ageing & Society*, pp. 1–21. Available at: <https://doi.org/10.1017/S0144686X23000594>
- Baxter, K., Heavey, E. and Birks, Y.** (2017) *Older self-funders and their information needs*. London: NIHR School for Social Care Research.
- Baxter, K., Heavey, E. and Birks, Y.** (2018) *Independent financial advice about funding social care in later life*. London: School for Social Care Research.
- Baxter, K., Heavey, E. and Birks, Y.** (2020) 'Choice and control in social care: experiences of older self-funders in England', *Social Policy & Administration*, 54(3), pp. 460–474. Available at: <https://doi.org/10.1111/spol.12534>
- Baxter, K., Mann, R.C., Birks, Y. and Overton, L.** (2021) 'A scoping review of evidence on the use and effectiveness of decision aids in adult social care', *Journal of Long-Term Care*, pp. 100–113. Available at: <https://doi.org/10.31389/jltc.56>
- BMJ.** (2013) 'An introduction to patient decision aids', *British Medical Journal*, 347, f4147. Available at: <https://doi.org/10.1136/bmj.f4147>
- Care Act.** (2014) Care Act 2014; Chapter 23. Available at: <https://www.legislation.gov.uk/ukpga/2014/23/contents> [accessed 14.03.2025].
- Coulter, A., Stilwell, D., Kryworuchko, J., Mullen, P.D., Ng, C.J. and van der Weijden, T.** (2013) 'A systematic development process for patient decision aids', *BMC medical informatics and decision making*, 13(Suppl 2), pp. 1–7. Available at: <https://doi.org/10.1186/1472-6947-13-S2-S2>
- Department of Health and Social Care.** (2021) 'People at the Heart of Care: Adult Social Care Reform White Paper'. Available online at: <https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper> [accessed 30.10.2023].
- Department of Health and Social Care.** (2025) <https://www.gov.uk/government/publications/social-care-charging-for-local-authorities-2025-to-2026/social-care-charging-for-care-and-support-2025-to-2026-local-authority-circular> [accessed 11.03.2025].
- Dibb, S., Merendino, A., Aslam, H., Appleyard, L. and Brambley, W.** (2021) 'Whose rationality? Muddling through the messy emotional reality of financial decision-making', *Journal of Business Research*, 131, pp. 826–838. Available at: <https://doi.org/10.1016/j.jbusres.2020.10.041>
- Elwyn, G. et al.** (2017) 'A three-talk model for shared decision making: multistage consultation process', *British Medical Journal*, 359, j4891. Available at: <https://doi.org/10.1136/bmj.j4891>
- Ernst, M. and Paulus, M.P.** (2005) 'Neurobiology of decision making: a selective review from a neurocognitive and clinical perspective', *Biological psychiatry*, 58(8), pp. 597–604. Available at: <https://doi.org/10.1016/j.biopsych.2005.06.004>
- Ewing, G., Austin, L., Jones, D. and Grande, G.** (2018) 'Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach', *Palliative medicine*, 32(5), pp. 939–949. Available at: <https://doi.org/10.1177/0269216318756259>
- Fox O'Mahony, L. and Overton, L.** (2014) 'Financial advice, differentiated consumers and the regulation of equity release transactions', *Journal of Law and Society*, 41(3), pp. 446–469. Available at: <https://doi.org/10.1111/j.1467-6478.2014.00677.x>
- Galotti, K.M.** (2002) *Making Decisions That Matter: How People Face Important Life Choices*. Mahwah: Taylor & Francis Group.
- 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*, pp. 51–65. Available at: <https://doi.org/10.31389/jltc.8>
- Heavey, E., Baxter, K. and Birks, Y.** (2024) 'Care chronicles: Needing, seeking and getting self-funded social care as biographical disruptions among older people and their families', *Ageing and Society*, 44(4), pp. 916–938. Available at: <https://doi.org/10.1017/S0144686X22000599>

- 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.
- INVOLVE.** (2019) *Co-production in Action: Number One*. Southampton: INVOLVE [(Updated version: NIHR. Available at: <https://www.learningforinvolvement.org.uk/content/resource/nihr-co-production-in-action-number-one/>) accessed 22.11.2024].
- Jasper, R., Wright, S., Rogers, S., Tonks, S., Morfitt, R., Baxter, K., Birks, Y. and Wilberforce, M.** (2023) 'A Discrete Choice Experiment of Older Self-Funders' Preferences When Navigating Community Social Care', *Health & Social Care in the Community*, 2023(1). Available at: <https://doi.org/10.1155/2023/6642636>
- Jaspers, M.W., Steen, T., van den Bos, C. and Geenen, M.** (2004) 'The think aloud method: a guide to user interface design', *Int J Med Inform*, 73(11–12), pp. 781–795. Available at: <https://doi.org/10.1016/j.ijmedinf.2004.08.003>
- Matlock, D.D. and Spatz, E.S.** (2014) 'Design and Testing of Tools for Shared Decision Making', *Circulation: Cardiovascular Quality and Outcomes*, 7(3), pp. 487–492. Available at: <https://doi.org/10.1161/CIRCOUTCOMES.113.000289>
- Moss, J., Rowlingson, K. and Lymer, A.** (2024) 'Exploring the barriers to accessing personal financial planning advice', *Journal of Financial Services Marketing*, 29(1), pp.17–32. Available at: <https://doi.org/10.1057/s41264-022-00180-x>
- Office for National Statistics (ONS) report.** (2021) *Care homes and estimating the self-funding population, England: 2019 to 2020*. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/carehomesandestimatingtheselffundingpopulationengland/2019to2020#toc> [accessed 10.03.2025].
- Office for National Statistics report.** (2023a) *Care homes and estimating the self-funding population, England: 2022 to 2023*. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/carehomesandestimatingtheselffundingpopulationengland/2022to2023> [accessed 10.03.2025].
- Office for National Statistics (ONS) report.** (2023b) *Estimating the size of the self-funding population in the community, England: 2022 to 2023*. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/bulletins/estimatingthesizeoftheselffunderpopulationinthecommunityengland/2022to2023> [accessed 10.03.2025].
- Petrillo, M. and Bennett, M.R.** (2023) *Valuing Carers 2021: England and Wales*. London: Carers UK. Available at: www.carersuk.org/media/2d5le03c/valuing-carers-report.pdf [accessed 23.01.2024].
- Preda, A. and Muradoglu, Y.** (2019) 'Groups, Social Processes and Decision Making in Finance', *Qualitative Research in Financial Markets*, 11(4), pp. 429–455. Available at: <https://doi.org/10.1108/QRFM-08-2017-0073>
- 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.
- Shyu, Y.I.L.** (2000) 'The needs of family caregivers of frail elders during the transition from hospital to home: a Taiwanese sample', *Journal of advanced nursing*, 32(3), pp. 619–625. Available at: <https://doi.org/10.1046/j.1365-2648.2000.01519.x>
- Smith, S., Alvand, A., Locock, L., Ryan, S., Smith, J., Bayliss, L., Wilson, H. and Price, A.** (2020) 'Partial or total knee replacement? Identifying patients' information needs on knee replacement surgery: a qualitative study to inform a decision aid', *Quality of Life research*, 29(4), pp. 999–1011. Available at: <https://doi.org/10.1007/s11136-019-02381-9>
- Sörensen, S., Mak, W. and Pinquart, M.** (2011) 'Planning and decision making for care transitions', *Annual Review of Gerontology & Geriatrics*, 31, pp. 111–142. <https://doi.org/10.1891/0198-8794.31.111>
- Sörensen, S., Missell, R.L., Eustice-Corwin, A. and Otieno, D.A.** (2021) 'Perspectives on aging-related preparation', *Journal of elder policy*, 1(2), pp. 163–221. Available at: <https://doi.org/10.18278/jep.1.2.7>
- Stacey, D., Légaré, F., Lewis, K., Barry, M.J., Bennett, C.L., Eden, K.B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A. and Thomson, R.** (2017) 'Decision aids for people facing health treatment or screening decisions', *Cochrane Database of Systematic Reviews*, 4(4). Available at: <https://doi.org/10.1002/14651858.CD001431.pub5>
- Thompson, J.S., Matlock, D.D., McIlvennan, C.K., Jenkins, A.R. and Allen, L.A.** (2015) 'Development of a Decision Aid for Patients with Advanced Heart Failure Considering a Destination Therapy Left Ventricular Assist Device', *JACC. Heart failure*, 3(12), pp. 965–976. Available at: <https://doi.org/10.1016/j.jchf.2015.09.007>
- Watkins, M. and Overton, L.** (2024) 'The cost of caring: a scoping review of qualitative evidence on the financial wellbeing implications of unpaid care to older adults', *Ageing & Society*, pp. 1–28. Available at: <https://doi.org/10.1017/S0144686X24000382>

TO CITE THIS ARTICLE:

Lindley, L., Watkins, M., Dowding, D., Overton, L., Friend, A., Wilberforce, M. and Birks, Y. 2025. Developing a Decision Aid for Older People Who Pay for Social Care. *Journal of Long-Term Care*, (2025), pp. 142–153. DOI: <https://doi.org/10.31389/jltc.406>

Submitted: 11 December 2024 **Accepted:** 09 May 2025 **Published:** 27 May 2025

COPYRIGHT:

© 2025 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (CC BY-NC-ND 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

Journal of Long-Term Care is a peer-reviewed open access journal published by LSE Press.