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Development of a decision support tool for older people who pay for social care, and their families

ABOUT THE RESEARCH

Making decisions about self-funded social care in later life can be complex and emotional. There is so much information available that it can be hard to find the right information or know who to talk to. Self-funders often arrange care with little formal guidance and can lack confidence about who to talk to and what to ask, especially in relation to financial advice.

Decision support tools are resources designed to support people's decisions by providing information on options and any associated risks and benefits, and helping people clarify and take account of their personal values and preferences.

This study aimed to develop a prototype of a decision support tool to help older self-funders and their families make informed decisions about paying for social care.

METHODS

This study aimed to produce a prototype decision support tool to help people feel more confident in seeking professional financial guidance or advice by removing the fear of the unknown, to facilitate people to think through their care options and personal preferences, and understand what different professionals can offer in terms of guidance or advice.

Methods included re-analysis of existing interview data and consultations with a range of professionals alongside literature and website searches to identify content for the tool. This was followed by five sequential workshops, consultations with the project's public and professional advisers, and work with a digital design team to create the tool.

The alpha version of the tool was tested using 'think aloud' techniques to improve accuracy, usability and acceptability. The resulting beta version was tested with support from the MoneyHelper website and subject to a formative evaluation comprising interviews and an online survey to assess whether it had helped prepare people for making self-funded care decisions.

FINDINGS

Co-producing Care Confidence

The decision support tool, entitled Care Confidence, was developed through consultations and workshops with members of the public and professionals from social care, finance and related backgrounds. Each group of workshop participants offered valuable insights about the content and style of Care Confidence.

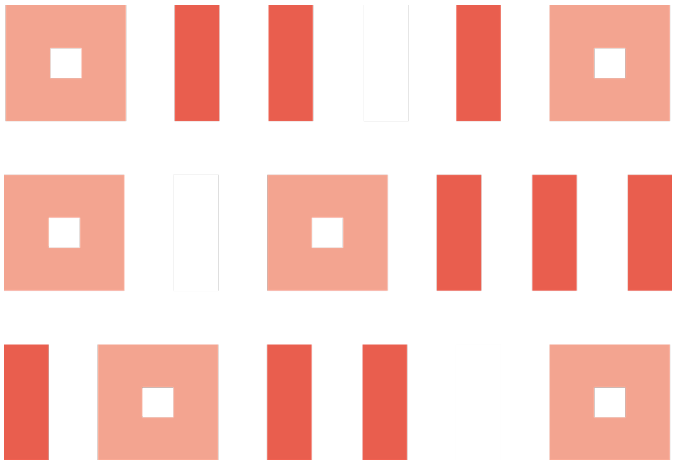
Members of the public with experience of navigating the social care system felt strongly that it should be empowering and empathetic, as well as simple and honest about care options and costs without further raising the anxieties that people are known to have when making self-funded care decisions for themselves or others. They were keen for the tool to promote positive 'living well' messages and introduce less well-known care options to people. Professionals and the public were keen to find a balance between providing accurate information, especially about costs, and keeping that information up to date.

Overall, people wanted a concise and easy to navigate tool that included sufficient information to feel confident to move forward with decisions about self-funded care, but without being overwhelming.

An overview of Care Confidence

The Care Confidence prototype is available at www.careconfidence.org.uk.

It begins with introductory pages explaining its purpose and providing generic information about adult social care. These are followed by information about self-funded care, provided under



three headings: making life easier at home; moving to a different home; and moving to a care home. A fourth heading called 'thinking about the money' focusses on the financial side of self-funding care. This section explains the different sources of money that people can use to pay for care; the meaning of financial advice and how this differs from information or guidance; and tips to help choose and prepare to meet with a financial adviser.

Each of the four sections offers written information about care options and costs, useful search terms, video clips of people talking about their experiences of self-funded care, and a written scenario illustrating the pros and cons of different situations and choices.

The final section of Care Confidence offers people lists of topics to find out more about, and of people to talk to, which includes professionals as well as family and friends. Selected items can be saved as a PDF file for future reference.

Evaluation of Care Confidence

People who used Care Confidence could do so anonymously, but they were prompted when exiting the tool to complete a short survey about their experiences and to record some information on their personal characteristics. We achieved 94 responses to the survey by the end of the

evaluation phase. To obtain a small sample of users (10) who could tell us about their experiences in more depth, the survey also provided the opportunity for people to volunteer contact information.

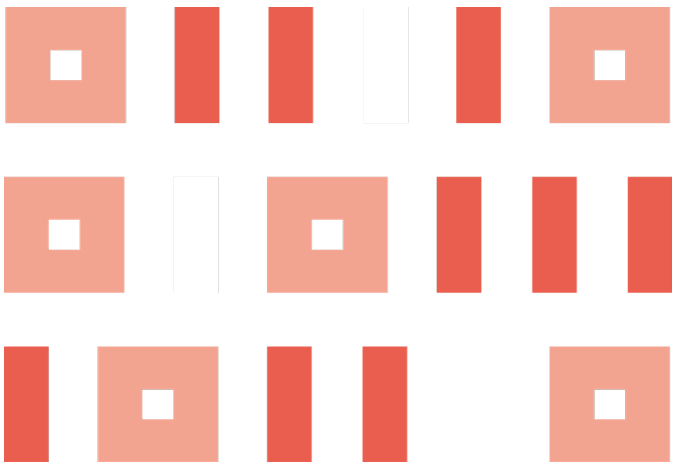
Survey findings

The survey data show that women in the 41-65 age bracket were most likely to use the tool. Users tended to be friends or relatives or those in need of care. These findings are unsurprising given what we already know about finding and funding care, and serve to support a number of the deliberate design decisions made by the research team in consultation with the advisory group and workshop participants in the earlier stages of the project.

There was no ethnic diversity in the relatively small number of people who completed the survey, and an even split between those who currently organise care for another person and those who do not.

Participants who took part in the follow up interviews comprised people considering their own future care needs, family members (often adult daughters) of those in need of care, as well as professionals with an interest or practice background in social care. This variation helps to explain the spilt between survey respondents who were, and were not, currently organising care for another person.

Most respondents reported that Care Confidence had helped them, though to varying degrees of success. It appeared most helpful in identifying further questions to ask a professional (two-thirds saying it helped 'quite a bit' or 'a great deal'). However, fewer than half of respondents (48%) said Care Confidence helped 'quite a bit' or 'a great deal' to make better decisions.



Interview findings

People's motivations for using the tool stemmed from the well documented challenges, stresses and strains of finding and funding care, and the tool benefitted users in three key areas.

Firstly, people often have to search for information in many different places and under time pressure, thus, participants found it useful that the tool provided an overview of care options and trusted information all in one place.

Secondly, organising care is difficult because people often need to navigate an unfamiliar system. The tool mitigated this, to some extent, by familiarising them with the system and making them feel more confident and better prepared to advocate for themselves or their loved ones during difficult conversations.

Finally, since organising care can be stressful and upsetting, the tool also served to make people feel reassured and emotionally supported. The video content of people's real-life experiences in particular were welcomed for their ability to make people feel less alone in the care journey.

Interview participants also identified a number of ways in which the tool could be improved. In summary, these were largely

presentational, with many participants expressing a preference for the information to be less dense, and broken down into more digestible chunks. Reducing the amount of scrolling required when accessing the tool on mobile devices was also suggested.

Beyond these issues, some users felt frustrated that whilst the tool provided them with the information needed to support decision making, it did not directly tell them what to do. They wanted a more personalised journey whereby they could enter details of their circumstances into the system and the tool would tell them which next steps they should take.

Finally, it was suggested that the tool should be shared via places individuals go to for health information as this is often the first port of call for care-related concerns. These findings also support the Google analytics data which showed that few people came across the tool via the MaPS website.

MaPS Feedback

The feedback received from MaPS was, in many ways, aligned with the interview user feedback. While they praised the 'rich and useful information' contained within the tool, they suggested that it is 'difficult to navigate and is trying to do too many things within one journey'. Breaking the information down into smaller chunks in different sections or pages within the online tool would help to make it easier to process and navigate.

They also felt strongly that the word 'tool' comes with expectations and suggests that the tool will guide users directly through a single journey. MaPS explained: 'A tool usually has a very clear start and ending point. There is a journey either via a question and answer set with clear outputs at the end. The Care Confidence tool doesn't have one journey but multiple journeys with varying styles like a quiz/ info/guidance/action plan which make it a microsite as there is not one specific starting point'.

They felt that if Care Confidence was renamed a website or microsite, this would more accurately describe the nature of the resource, and users might come to it with different expectations: to learn more information, rather than to be told exactly what to do.

Combined, these findings have provided a number of fruitful avenues for further development of Care Confidence in readiness for a full-scale evaluation.

CONCLUSIONS & IMPLICATIONS

Navigating social care as a self-funder is stressful and time-consuming. It involves making sense of a complex system of financial requirements, legal questions of eligibility, a mixed economy of provider markets, and all in the highly emotional context that commonly includes ageing, frailty, dementia, hospital discharge and family dynamics.

Previous research has demonstrated that families are poorly prepared to navigate this landscape, and do not even know how to start. Current offers from local

authorities appear unsuited to the task.

A new decision-support tool, Care Confidence, has been designed to assist in this journey. The study found that it seems to help with understanding care options, and to prepare people for asking further questions of other professionals. People particularly appreciated viewing videos of others talking about their experiences of navigating social care options.

Further work on enhancing the Care Confidence interface, including a version tailored to mobile devices, and improving 'digestibility' of information, is now needed. There is also a deeper question as to where Care Confidence fits in the decision-making process.

In contrast to existing medical decision-making tools, often relating to binary or limited treatment options, Care Confidence aims to support self-funders in more complex and dynamic choices. Rather than being a 'decision support tool', it may be better to regard Care Confidence as a preparatory guide to promote essential understanding and facilitate more targeted advice seeking.

In the context of future social care funding reforms, local authorities would benefit from examining the information available to self-funders in their area, to consider how they could better-support decision-making. The Care Confidence toolkit is freely available and may be suitable alongside other support, though recognising that further enhancements and research is needed.

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