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Features of patient decision aids to limit their complexity for older people with dementia and their caregivers: multiple case study of Decision Boxes

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Abstract

Objectives: To identify patient decision aids' features to limit their complexity for older people with dementia and their family caregivers.

Design: Mixed method, multiple case study within a user-centred design (UCD) approach.

Setting: Community-based healthcare in the province of Quebec in Canada

Participants: 23 older persons (65+) with dementia and their 27 family caregivers.

Results: During three UCD evaluation-modification rounds, participants identified strengths and weaknesses of the patient decision aids' content and visual design that influenced their complexity. Weaknesses of content included a lack of understanding of the decision aids' purpose and target audience, missing information, irrelevant content, and issues with terminology and sentence structure. Weaknesses of visual design included critics about the decision aids' general layout (density, length, navigation) and their lack of pictures. In response, the design team implemented a series of practical features and design strategies, comprising: a clear expression of the patient decision aid's purpose through simple text, picture and personal stories; systematic and frequent use of pictograms illustrating key points and helping structure patient decision aid's general layout; a glossary; removal of scientific references from the main document; personal stories to clarify more difficult concepts; a contact section to facilitate implementation of the selected option; GRADE ratings to convey the quality of the evidence; a values clarification exercise formatted as a checklist and presented at the beginning of the document to streamline navigation; involvement of a panel of patient/caregiver partners to guide expression of patient priorities; editing of the text to a 6th grade reading level; UCD process to optimize comprehensiveness and relevance of content, and training of patients/caregivers in shared decision making.

Conclusions: The revised template for patient decision aids is designed to meet the needs of people living with dementia and their caregivers better, which may translate into fewer evaluation-modification rounds.

Strengths and limitations of this study

- The multiple case design allow suggesting general features for adapting patient decision-aid templates to user needs.
- Integration of user feedback in a UCD approach allowed an in-depth study of decision aid features influencing adoption of shared decision making.
- Caregivers offered their feedback on the Decision Boxes in the presence of the person in their care, and this could have influenced our conclusions.
- The presence of caregivers may also have caused some of the seniors with dementia to be less spontaneous, particularly if their caregivers played a dominant role in the dyad.

Introduction

In 2015, 46 million people were living with dementia worldwide. This number is expected to increase to 131.5 million by 2050.[1] The medications available to treat dementia are of limited efficacy and can cause major side effects.[2] Non-pharmacological alternatives may help with some symptoms, but patients, their caregivers, and their primary healthcare professionals are less familiar with their benefits and harms.[3] Moreover, patients experience adverse health outcomes and reduced autonomy and capacities, which result in difficult life-management or non-medical decision.[4] In such clinical situations, the shared decision making model calls for healthcare professionals and patients to work together to reach joint decisions based on the best evidence available regarding the benefits and harms of all available options (including watchful waiting) as well as patient values and preferences with regard to those options.[5]

However, involving older people living with dementia in decision-making may be a challenge given their cognitive decline. Their older age also puts them at greater risk that other factors limit their participation in decision making compared to the general population, such as lower levels of literacy and numeracy,[6,7] the presence of caregivers,[8–10] sensory deficits such as deafness or visual impairment, and a greater propensity to rely on health professionals to make health decisions.[11] Healthcare professionals may also perceive older persons with dementia as being too vulnerable to participate in decision making, and thus exclude them from the process.[12]

Patient decision aids are standardized evidence-based interventions designed to help people make informed and deliberated choices among options.[13–16] At a minimum, they provide information about the options and their associated relevant outcomes.[15] Only a few studies so far have described the development of a decision aid for people living with dementia and their healthcare team.[17–19] Hence, knowledge gaps remain on the most efficient design strategies and on the specific features of patient decision aids to meet the decision-making needs of this population. To begin to fill this gap, we have prioritized difficult decisions that older adults with NCDs and their caregivers frequently face.[4] We then synthesized the evidence of potential benefits and harms for all the options involved in some of those decisions and integrated them into Decision Boxes, which are the patient decision aids template developed at Laval University (Quebec City, Canada).[20,21]

Our previous results suggested that including user feedback is instrumental in designing Dboxes better adapted to their needs.[20] Preliminary evidence indeed suggests that user-centred design (UCD) may enhance the implementation in practice of patient decision aids.[22–27] UCD builds on an explicit understanding of users, tasks, and environments to address the whole user experience.[28] It is driven and refined by iterative user-centred evaluation, and involves a design team with interdisciplinary skills and perspectives.[28]

User experience looks broadly at the individual's interaction with a product, as well as the thoughts, feelings, and perceptions that result from that interaction.[29]

In the current study, we used a UCD approach to tailor three Decision boxes to the literacy level of older adults with dementia and their caregivers, and improve their experience using them. As we observed users interacting with the Dboxes, we sought to identify patient decision-aid features that reduced their complexity and prepared patients and caregivers to participate in shared decision making.

Methods

Study design and approach

We used a multiple case study evaluation across three Decision Boxes (Dboxes). The evaluation comprised interviews and questionnaires within an iterative UCD approach. We used three rounds of questionnaires and semi-structured interviews to have patient and caregiver dyads evaluate the three Dboxes (Figure 1). After a first evaluation round with a subsample of nine dyads, we analysed the data and, based on the findings, refined the Dboxes to limit their complexity and improve the user experience. We then used the same evaluation/tailoring process again in two more rounds, with new participants each time.

Case selection

Based on an earlier Delphi study,[4] and using a rapid review approach,[30] we created five Dboxes to support decision making regarding five difficult and frequent decisions faced by older adults with NCDs and their caregivers: (1) choosing a non-pharmacological treatment to manage agitation, aggression, or psychotic symptoms; (2) deciding whether or not to stop driving following diagnosis; (3) deciding whether or not to prepare a power of attorney, called a *Protection Mandate* in Quebec (Canada) covering health, property and financial matters; (4) choosing a support option to decrease caregiver burden; and (5) choosing an option to improve quality of life. For the current study, we used a maximum variation sampling strategy to select three of these five Dboxes as different cases. We chose #1 because it was the longest of the five and compared several options, whereas #2 and #3 compared only two options each. We chose #2 because it covered a very sensitive topic and thus allowed identifying features of decision aids to facilitate shared decision making in emotionally-charged contexts. We selected #3 because it used a more technical and complex vocabulary than any of the others. We excluded #4 because caregivers were the target users.

Theoretical framework

We chose the Health Literacy Skills framework[31] to structure data collection and allow comparability across cases. This framework hypothesizes the relations between health literacy and health-related outcomes and reflects how factors external to the individual (e.g., family, setting, community, culture, and media) influence the constructs represented. The framework incorporates health-related stimuli that people receive in their daily life, such as the Decision Box. According to the framework, after exposure to a stimulus, the health literacy demand of the stimulus interacts with a person's health literacy skills to influence comprehension of the message. Health literacy demand is defined as the complexity and difficulty of a stimulus, and it was the focus of the data collection in the current study.

Population and sampling strategy

All healthcare professionals from eleven outpatient geriatrics clinics in the Quebec City area, Canada, were invited to participate in this project. Those who agreed were asked to identify patients (aged 65+ years) diagnosed with dementia of any severity among their clientele, and the patients' informal caregivers. They contacted those patients or their caregiver, asking permission for the research team to contact them and explain the project. The research team then followed up with each willing patient or caregiver. We aimed to recruit 27 patient/caregiver dyads, a large enough sample size for this type of testing.[32]

Study procedure

Decision Box prototypes development

We used a rapid review approach[30] and the Ottawa decision support framework[33] to create Dboxes prototypes that respected the international standards for patient decision aids.[14] The Dboxes provided information on the health problem of interest, included an exercise to help patients and caregivers clarify what mattered most to them, explained the probabilities of experiencing benefits or harms for each of the available options, and listed resources to guide those experiencing decisional conflict. Between two and four experts in the care of older people with dementia (among healthcare professionals, informal caregivers, managers, representatives of community-based organizations devoted to these seniors, or clinical researchers involved in the organization of primary care or services delivered to seniors with dementia) reviewed and validated each Dbox.

Data collection

Nine patient/caregiver dyads were randomly selected as a subsample of all participants at each round and randomly assigned one of the three Dboxes (Dbox #1 to #3) studied, for three dyads/Dbox at each round (Figure 1). Copies of the Dbox were sent to study participants about one week prior to the interviews for them to review first. A trained moderator, a nurse trained in geriatric care (GB)—the same for all participants—then met them at their homes for data collection. Patients and the caregivers initially completed a questionnaire comprising questions on socio-demographic characteristics (age, gender, race, marital status, education level, income) and the type and duration of the relationship between caregiver and patient. In cases when patients were unable to complete the questionnaire, the caregiver completed it on their behalf. Then, using an interview guide, the moderator assessed participants' opinions of the strengths/areas of improvement of the Dboxes in fostering a shared decision-making behaviour, which was "to express their priorities to their healthcare professional regarding the decision to be made". The moderator also asked participants for suggestions to improve the Dboxes.

The moderator initially addressed all questions to the patient. If the patient did not participate actively in the discussion, then the moderator systematically sought the caregiver's suggestions (1) on how to get the older person to express their opinion and (2) how to modify the document to facilitate use by the older person. The caregivers' own perspectives on the strengths/weaknesses of the Dbox were also welcomed.

At the end of the session, able patients and caregivers completed a self-administered questionnaire, comprising : (1) the Chew three-item health literacy scale[34] adapted to French (personal communication, Holly Witteman, Laval University), (2) the patient version of the Information Assessment Method (IAM) for assessing the value of information[35] (3) eight items built from the Technology Acceptance Model (TAM-2),[36] to assess how useful and easy to use the Dbox was in *expressing their priorities to their healthcare professional regarding the decision to be made*, and (4) level of satisfaction with the Dbox on a 5-point smiley-face rating scale ranging from 1 (sad face) to 5 (smiling face).

The moderator took written notes during and after the interviews to describe non-verbal communication and interactions between the older person and his or her caregiver.

The interviews were recorded and transcribed verbatim.

Analysis of participants' experience between rounds

To tailor the DBoxes between rounds, the transcripts and notes were entered as project documents into specialized software (N'Vivo 10, QSR International, Cambridge, MA, USA). Two researchers (GB, AMCG) analysed the data using deductive/inductive thematic qualitative data analysis, first by searching for factors set out in the Health Literacy Skills framework,[31] then by integrating any new themes that emerged from the data. To this end, the two researchers reviewed the interview transcripts separately. They then compared their results and came to a consensus on a list of themes. They noted these themes in a codebook, labelled and defined them, and entered them in N'Vivo as nodes. One of the researchers (GB) then applied these preliminary codes to all the interview transcripts. Coding was updated as necessary, and the second reviewer (AMCG) checked the new codes to ensure consistency with the chosen framework.

Tailoring the Dboxes

To tailor the Dboxes, we assembled an expert panel that comprised graphic designers, a healthcare professional specialized in the care of older adults (GB), knowledge translation researchers (AMCG, HOW, GB), a human factors engineer (HOW), and on one occasion, a health literacy expert (EF). Between each round, this expert panel met to review the qualitative and quantitative findings and tailor the Dboxes to improve the participant experience, i.e. (1) limit their complexity (2) add any missing information, and (3) ensure that participants felt more empowered to express their priorities to the healthcare professional regarding the decision to be made.

We used the same evaluation/tailoring process after each of the three round.

Quantitative analysis and triangulation

We completed a descriptive statistical analysis of the questionnaire data at the end of the study using SAS (version 9.4, copyright SAS Institute Inc.). We then interpreted the results in light of the qualitative findings to understand further which factors would make it easier for patients and caregivers to express their priorities to their healthcare professional. We further synthesized insights from individual case studies in a cross-project analysis to reveal a pattern of findings across all cases.

Patient and public involvement

A caregiver to a person living with dementia (JB) participated in the study as a coinvestigator. This person participated to the study design and contributed in the development of the Decision Boxes by providing critical feedback before user testing.

Ethical issues pertaining to human subjects

When persons living with dementia were deemed able to provide consent by their healthcare professionals, they were directly invited to participate. To ensure minimal risk to the health of incapacitated adults, the research team sought informed consent from the caregivers of patients who could not themselves provide informed consent, in conformity with the Civil Code of Quebec.

Results

Participant characteristics

Healthcare professionals from six ambulatory geriatric clinics out of the 11 invited to participate recruited patients and their caregiver. These healthcare professionals invited

34 patients to take part, 23 of whom accepted (74%). Either one or two caregivers accompanied the participating patients, for a total of 27 participating caregivers.

Most of the 23 patients were aged 85 or more and had a high school education (Table 1A). They reported a mean level of health literacy competency of 2.0 ± SD of 1.5 (on a scale of 0 to 4, with 4=low literacy). We did not have access to their medical records, but the moderator—a registered nurse—qualitatively classified the severity of their dementia as moderate (n=9), severe (n= 9), or very severe (n=5).

Most of the 27 caregivers were aged between 45 and 85 and had completed undergraduate degrees (Table 1B). Caregivers reported a mean level of literacy competency of 0.8 ± SD of 1.1.

Research processes

Before the interviews, several caregivers offered suggestions on how to reduce the emotional burden of the information on the patient, such as changing some words in a sentence or adding pictures. As caregivers were the ones who knew the person best, they were able to warn the moderator to avoid certain subjects to limit the person's distress or anger (e.g., driving abilities).

Factors influencing adoption of shared decision making

Despite the main interview focus on identifying patient decision-aid features influencing their complexity, participants reported additional factors influencing their adoption of shared decision making. These factors were divided among individual moderators, professional practice mediators, social environment mediators, and healthcare organization mediators (Figure 2) in keeping with the Health Literacy Skills Framework.[31] Additionally, despite the main interview focus on participants' intention to express their priorities to their healthcare professional regarding the decision to be made, participants spontaneously discussed several other shared decision-making behaviours, which are listed in Figure 2.

Factors influencing the complexity of patient decision aids

Factors that were found to influence the complexity of patient decision aids were structured under three main themes: informational content, visual design, and values clarification (listed in Figure 2). The next sections describe these factors as they were brought up during the interviews and the features or strategies that were proposed to limit complexity and improve the user experience (Tables 2). Supplementary files #1 and #2 respectively present samples of the initial and final versions of one of the three Dboxes studied.

Informational content of the Dboxes

Purpose/Topic

Clarifying the purpose of the Dboxes was a more important concern in the first and second rounds, as participants devoted more time to commenting on these aspects. They often did not understand what the DBox was intended for, as illustrated in this comment from a caregiver:

> *"My father was starting to experience mild dementia, and when he read the document he got stressed thinking he would be evaluated. I knew he had read it, because he talked about it to me and I knew this is what he was talking about." (Caregiver #6, DBox #2)*

Several participants could not understand who the Dboxes were aimed at:

> *"That has nothing to do with us. It's not for us (caregiver) or the patient. So who is it for?" (Caregiver #9B, DBox#1).*

The team prioritized this issue and consequently added two statements to improve understanding—in large font at the top of the first page—describing whom the document was aimed at and what it was supposed to achieve. A pictogram was also added showing a person reading a printed document to represent the purpose of the Dbox. In the last version (Appendix 1B), these features were emphasized even more by isolating them on a separate cover page, but we could not test this new layout as it was added in the last version. Personal stories were also added to the prototypes, to provide context for the Dbox and its use and purpose. Participants appreciated the stories, which increased their interest in the content. They also mentioned that the stories helped them relate the content to their personal situations, as described by this patient:

> *"The disorder that this man has [note from the author: the patient is referring to a character in the personal story], the memory loss and other memory problems… I thought about all that, my memory's slipping away, I hope it's going to be awhile before I lose it completely." (Patient #23, DBox #2)*

Missing information

In the first evaluation round, several participants formulated requests, often several, for very specific information missing from the DBox. They asked for more information on the health problem itself, on how it was assessed, on options that were not quite clear, on specific outcomes to an option, or on how to implement an option. Some of these questions were too specific to generate a change in the DBox template, and we could generally address them easily by adding to or modifying the text. For example, one caregiver asked for more information on driving skills assessment:

> *"When you're driving and you can't see the street name, then you can get lost. It's a physical issue [that makes driving dangerous], because your eyes are not working properly. But when does dementia make it dangerous to drive?" (Caregiver #11, DBox #2)*

Most of these issues were resolved after the first round.

Some of the requests for more information could be grouped together into broader categories and the template modified accordingly, so that future Dbox will have the missing information, before user evaluation. Firstly, we added a detailed description of each option to the Dbox template to address the needs for more information on the options. Secondly, we added a section listing contacts and resources (Appendix 1B), to provide information on the services related to implement the options. People regularly asked whom to contact about the less familiar options, such as music or massage therapy, as illustrated in the following discussion between two caregivers:

> *Caregiver #1: "[…] Perhaps something you could add here would be 'refer to such and such a social worker, psychologist, psychotherapist' but for psychosocial needs, maybe you should indicate how to find those resources, which resources and where. That would be really important." (Caregivers #9A, DBox #1)*

Participants reported fewer issues with missing information as the rounds progressed. Most mentioned that they would use the information and that they were better equipped to discuss the health issue with someone, as demonstrated by this quote:

> *"But I think that document is more to know what's best for the person's well-being: drugs or no drugs. . . . And there are options if you don't want to be taking drugs. That's the purpose of the document. . . . In that regard I find the document to be complete." (Patient #1, DBox #1)*

<u>Relevance</u>

In every round, several participants mentioned that they found the Dboxes to be relevant, credible, interesting, or useful. They explained how the Dboxes provided good information and made them aware of the options available:

> *"It's well presented because we can see the advantages and disadvantages next to each other. It would definitely help someone to decide who has not made their mind up yet. It gives you all sides of the coin for the various options we have. It's important to plan ahead as you get older." (Caregiver #15, DBox #3)*

They also mentioned that the Dboxes gave them something to think about:

> *"It gets you thinking. It really gives you a good idea. If you think 'I want more protection, I don't want to be taken advantage of or something,' then that tells you to draw up advance directives. It points you in the right direction."(Patient #8, DBox #3)*

On the other hand, participants found some parts to be of little relevance, use, or interest. A number of caregivers mentioned that the DBox was of no use to patients who could not participate in the decision-making process because of cognitive decline. To address this issue, the DBox template was modified to give the caregiver equal billing as a target user, specifically on the cover page in the bottom line (Appendix 1b, p. 2) and in the values clarification exercise (Appendix 1b, p. 4).

Other participants' comments were to the effect that the information on evidence, GRADE ratings, and benefit and harm probabilities was for clinicians and was irrelevant to them, as this quote shows:

> *"Anyway, I mean this page, to be practical—page 4—the harms, I would take it out altogether. I would leave it up to the clinicians to read that. We have no use for the studies that've been done." (Caregiver # 9, DB #1)*

No strategy was found to address this in the DBox template. In the first prototype, the DBox already recommended that the healthcare professional share the decision with the patient, so we emphasized this in the last version of the template by using a visual representation of SDM and by putting the message in a box in the last version to highlight it (Supplementary file #2, p. 3), but this was not tested in the current study.

Other comments were more topic-specific and could not be addressed by adjusting the DBox template. For example, the introduction to DBox#2 (Stopping driving) described the healthcare professional's responsibilities with regard to driving assessment. Patients and caregivers considered this irrelevant.

> *"Take the section aimed at the healthcare professionals […], in any event, I think you probably shouldn't put the emphasis on that, or at least you should make the part that really concerns the patient bigger so that they can really concentrate on what's essential." (Caregiver #6, DBox #2)*

Clarity of content

The participants consistently mentioned the complex terminology and sentence structure as important barriers, as this quote shows:

> *"Physical activity, touch therapy, music therapy, aroma therapy: for me, sure, but for them at their age, I'm not sure they know what they mean. Those who don't have much education definitely don't know what these are." (Caregiver #13, BD#1)*

To address this issue, we added a step to the development process, before user testing. It consists in checking the text reading level with online freeware (e.g. https://www.webpagefx.com/tools/read-able/, WebpageFX Inc, US) so that it corresponds to a 6th grade level. We also added a glossary to the DBox template, to define more complex terms for which we could not find simpler synonyms. The notation "see definition in the glossary on p. x" in parentheses after the term referred users to the glossary. In the last version (Supplementary file #2), the word was also highlighted and underlined—but this was not tested in the current study.

Participants also commented on the risk communication strategies used. One person thought that percentages were obvious and did not understand that the Dbox also used natural frequencies:

> *"It reads 'Out of 100 people, 33 will experience stress symptoms.' People are going to think 33% rather than to keep the two figures separate. . . . It depends on the person, but a dog is a dog. You don't need to draw it, you can just write 'dog'." (Caregiver #20, DBox #3)*

In addition, participants were often surprised by the harms (for example that stopping driving led to an increased risk of dying). As mentioned above, some respondents thought that this type of content should be provided to clinicians and that it was irrelevant to them.

Several participants did not understand the GRADE scale. They noted the lack of explicit link between the GRADE rating beside the evidence and the legend at the bottom of the page. To address this, the Dbox template now has an invitation to "see legend" in parentheses after each GRADE symbol. One participant suggested using green, yellow, and red instead of the '+' for a more intuitive representation of the quality of the evidence. This idea was not implemented because the Dbox needed to be usable in a black & white version.

Several participants grasped the essence of the GRADE scale displaying the quality of the evidence, as this quote shows:

> *"No, it's all very clear. And also when you look at the legend, it's even easier to see how advanced the research is from that viewpoint. Some are quite obvious, but others you can see don't have a lot of data from what is shown." (Caregiver #16, Dbox #3)*

Visual design

Participants shared several recommendations on the Dbox visual design, which we further categorized into layout, pictures, colour, and font (Figure 3).

Layout

'Layout' comprised participants' comments on navigation, organizers, length and density. Navigation proved difficult in the first rounds as several participants became lost when they moved from one section to another, such as between the health options and the contact section (located at the end of the document). We thus adjusted the DBox template by adding organizers and textual cues to the related section (e.g. "see glossary," "see the list of resources on page x").

We also removed the reference list, as the reference numbers in the text caused confusion. We chose to provide the reference list on the DBox website instead for those (e.g., caregivers) who might be interested in reviewing the sources of evidence.

Participants also recommended adding a table of contents at the beginning of the document to help navigation, and to allow choosing the sections relevant to them, as this quote shows:

> *"Maybe say, 'There are a number of activities available. Choose those that interest you.' Or have an index like in a book: animal therapy, see page 3. Because maybe they felt obligated to see all the activities and read them all. Maybe it was confusing. Maybe give them the option, or say, 'Here are several activities that can reduce aggressiveness…'" (Caregiver #7, DBox #x)*

To meet this need, we moved the Values Clarification Exercise to a position right after the Introduction. This allowed people to choose their priority first, and then read only about the options meeting those priorities, instead of having to read about all the options. In addition to improving navigation, this also shortened the time required to read the document.

Dbox #3 (power of attorney) received several comments on how complex the information was and how hard it was for respondents to compare the three legal options. After receiving several questions from participants on the legal concepts in the first version of the Dbox, we added more information in the second round, which upped the number of pages from 5 to 9 in Round #2. Users disliked this longer version, as the quantitative finding below shows, despite the fact that it was much more comprehensive. In the third version, we therefore clarified this information in a large table setting out the legal implications of the various options (Supplementary file #2). This addition improved users' experience, made the Dbox shorter, and reduced their complexity.

Pictures

In the first round, several people found the Dboxes hard to read because they consisted mainly of text. Some people, such as this caregiver, suggested adding pictures to make things more engaging:

> *“I don’t think you can get away from having text, but maybe not so much detail... Maybe you could add some pictures… maybe a little drawing, a car in an accident, to provide illustration and so that people don’t have to concentrate so hard to read the sentence right to the end.“ (Caregiver #6, BD#2)*

In the second round, we therefore added pictograms strategically to draw attention to the most important text. These generated positive comments, but we did not use them systematically, nor consistently, and some participants found them unclear. In the last Dbox template that has not yet been evaluated (Supplementary file #2), we systematically added pictograms specially designed by a graphic designer to illustrate (1) the purpose of the Dbox on the cover page, (2) each of the activities covered in the Dbox (Introduction, Clarifying priorities, Exploring the options, Choosing an option, Glossary), (3) the bottom line on page 2, (4) each option, and (5) the Contacts section.

Colours

Participants found the Dboxes’ colors attractive and helpful to facilitate reading:

> *“It’s well presented. Colourful documents like that are attractive and nice to consult. It’s also easy to spot information from page to page. Benefits and harms can be compared side by side and the other. I really liked the document.” (Caregiver #15, DBox #3)*

Values clarification exercise

The values clarification exercise underwent major changes throughout the study. Most participants did not understand the first version of the exercise, which was designed using the Ottawa Decision Support Framework.[33] We initially observed that a number of participants did not understand the meaning of the word “preference,” so we replaced it with “priorities”. This resolved the issue and improved participants’ understanding of the purpose of the exercise.

Additionally, the exercise asked users to assess the extent to which each priority mattered to them, using a 6-level Likert scale. Some people perceived it as too detailed, and some caregivers mentioned that patients might have difficulty using this scale, as they were unfamiliar with rating scales:

> *“Well, it’s my generation but not his [speaking of the person in his care], so when I look at this form, I look which side is important and which side is not important, then Bingo I complete it. . . . But for him…” (Caregiver #6, DBox #2)*

After the first round, we thus removed the Likert scales and used a checklist instead, asking people to select a single priority from a list (Supplementary file #2, p. 4). For each item on the list, the Dbox then proposed a list of options for meeting that priority, and the page number to view evidence of that option's benefits and harms. These modifications improved participants' understanding of the purpose of the exercise—participants reflected more on the benefits vs. harms, and before and during the interview they talked more about their priorities for that decision. For example, with this new format, some people understood perfectly well that they had to choose what mattered most to them among the list of items, but they were reluctant to do so considering the decisional conflict they had to face:

> *"If I have to choose only one—live longer or maintain a good health—who wouldn't pick to live as long as possible? For sure, I would. Or stay in good general health, of course, I would pick that. I wouldn't go saying I don't want to drive anymore. So I don't know. It's a strange question." (Caregiver #16, DBox #2)*

We revised the sentences expressing each of the priorities several times, as participants considered some to be unclear or illogical.

Quantitative results and triangulation with qualitative findings

The quantitative data from the questionnaires suggest that participants' perceptions of the Dboxes were generally positive, with TAM-2 mean scores mostly above 4 (scale of 1-7, with 7 indicating positive perceptions), and satisfaction mean scores above 3 (scale of 1 to 5, with 5 indicating positive perceptions).

However, the patients who evaluated Dboxes #2 (driving) and #3 (power of attorney) in round #2 reported lower satisfaction and lower perceptions of Dbox usefulness than did the patients in rounds #1 and #3 or the caregivers (Figures 4 and 5). They also gave lower understanding and relevance scores on the IAM questionnaire (Table 3). During the interviews, these five patients commented repeatedly on the lack of clarity of the content and on the inappropriate terminology in the Dboxes, for example:

> *"I have trouble understanding. When you start talking about legal stuff, you lose me." (patient #15, BD #3)*

The participants in the first round and second rounds frequently reported problems with the information, but these were mostly resolved in the third round (Tables 3-4: cognitive impact of the information). Only three people—1 caregiver (#23) and 2 patients (#22, #19)—still reported problems with the information in round 3. The interview transcripts reveal that these patients only talked about how hard they found the text to understand, how long it was, or how much trouble they had remembering what they had just read. As for the caregiver, he commented that he thought it was inappropriate for the DBox to list taxicabs or public transit as resources for people who need to stop driving due to dementia:

> *"It's okay for people who don't have driver's licences anymore, but still want to go out and still have the ability. But there's no way she could ever take a cab or assisted transport. It depends on how serious your cognitive loss is. . . . At first, things were fine. She would take cabs to go places. She would travel to and from her sister's by cab. But I'm not sure I'd let her do that now. There are lots of options, and they help lots of people, but it depends on how bad your memory loss is." (Caregiver #23, BD#2)*

Patients and caregivers most frequently reported in the questionnaire that they expected the information to help them be better equipped to discuss something with someone else, to have more confidence in deciding about something with someone else, and to prevent an issue (Tables 3 and 4).

Caregivers' perceptions of DB#3 (power of attorney) were also generally observed to improve as the rounds progressed (Figure 5B).

Discussion

We studied which features of patient decision aids may limit their complexity and improve the experience of older people living with dementia and their caregivers as they prepare for shared decision making with healthcare professionals. We described a series of practical features and design strategies to improve the user experience of patient decision aids and limit the number adjustments required during user testing. Some participants considered scientific evidence to be for healthcare professionals' use only and thus had no interest in such content. Other participants understood concepts related to the quality of scientific evidence and methodological biases. Quantitative measures allowed collecting distinct feedback from patients and caregivers.

Strength and weaknesses of the study

A strength of this research project lies in its multiple case design that allowed suggesting general features for adapting patient decision-aid templates to user needs. Integration of user feedback in a UCD approach also represents a strength of this study. However caregivers may have been less spontaneous in some of their opinions because of the presence of the person in their care, and this could have influenced our conclusions. The presence of caregivers may also have caused some of the seniors with dementia to be less spontaneous, particularly if their caregivers played a dominant role in the dyad. On the other hand, inviting caregivers to reflect on the changes needed for the patient decision aids to address the needs of the person in their care provided an opportunity to benefit from caregivers' own expertise in dementia while still receiving direct input from the patients themselves.

Relation to other studies

This is the first study focused on identifying general design features to tailor patient decision aids to the needs of seniors with dementia. It is also unique in its focus on the primary care offered to older persons living with dementia. Indeed, we found only three other reports on the impacts of patient decision aids, which targeted caregivers of older people with advanced dementia recruited in nursing homes or acute care settings.[18,19,37] Their development and evaluation were guided by the Ottawa Decision Support framework,[33] which the authors adapted minimally. Other web-based support tools for this population have been studied, but did not qualify as patient decision aids.[38–40]

Interestingly, some of the current study participants understood the GRADE level of confidence display, which provides a deeper understanding of the uncertainty associated with each risk estimate. GRADE ratings communicate one of the types of uncertainty related to the outcomes of medical interventions, which is the ambiguity about the strength or validity of evidence about risks,[41] also named 'epistemic uncertainty'.[42] Despite the influence of uncertainty on patients' choices, there is considerable variation in approaches to communicate it in the patient decision aids currently available, and more than half do not communicate epistemic uncertainty.[43] The current project thus adds observations on the potential of the GRADE strategy to communicate epistemic uncertainty to patients/caregivers.

Participants requested that we enliven the documents by adding pictures. Research on health communication suggests that combining well-designed pictures with written or spoken text enhances attention, recall of health education information, and understanding, especially among groups with lower literacy.[44] Pictures should illustrate key points, be accompanied by text using simple language, be simple to minimize distracting details, and be selected with people from the intended audience to ensue cultural relevance.[44] While several studies focus on the inclusion of graphs in patient decision aids to improve risks understanding,[45,46] fewer focus on the impacts of other types of pictures on user experience of these tools. Importantly, a recent qualitative study described how pictures conveying important and detailed information combined with icon arrays in a patient decision aid were perceived as explanatory and easy to understand by women of low socioeconomic status.[22] There is also some evidence on the pictures characteristics to support informed decision-making,[47] but high-quality evidence on the impacts of pictures–and their key features–on decision quality is still lacking.

Meaning and implications of findings

Some comments by participants were useful to suggest features to be used systematically so that the same issues would not come up again when new patient decision aids are developed. On the other hand, some of the reported issues cannot be addressed generally, as they were specific to a given health problem, intervention, or outcome. UCD thus remains essential to help users clarify their needs. For example, some topics require the use of technical terminology, such as BD #3 on the power of attorney that included a lot of legal terminology. Some topics may also elicit a very strong emotional response, which might be impossible to foresee and may lengthen the design process.

The glossary proved essential for patient decision aids targeting older people with dementia and their caregivers, but navigation to access it was a challenge. Web-based decision aids should use popups or other methods to provide definitions without further navigation.

When patient decision-aid templates require major changes to address topic-specific issues, developers should plan one or several additional evaluation rounds. In the current study, the DBox on the power of attorney required adding much information on the various legal options in the second round, generating lower scores before the table comparing the various options and their features was incorporated in the third round.

The wording used to express priorities required several rounds before we were able to arrive at the best expression, which suggests that the list of priorities would benefit from the input from a patient/caregiver expert panel. Moreover, the panel could be involved early in the rapid review process, to help identify those priorities, accelerate the review process, and streamline the literature search to identify patient priorities early on.

Having questionnaires made it possible to collect patients' perceptions independently from their caregivers'. This might be a good way to ensure that patients with caregivers nevertheless make their preferences known and questionnaires could be validated in this regard specifically with people with dementia.

Unanswered questions and future research

Several participants questioned the provision of scientific evidence on the benefits and harms of the available options in the DBoxes. Such comments might reflect a negative attitude toward the shared decision making approach, but more likely demonstrates a lack of understanding of shared decision making principles, namely that patients should be informed of the benefits and harms of each option to partake in decision-making. This suggests that patient/caregiver education is required to change attitudes toward SDM before patients and caregivers can really partake in shared decision-making. Training is a promising strategy to address this issue.[48]

To improve understanding of risks, the Dboxes provide probabilities formulated in two different ways, i.e., in natural frequencies (e.g., for every 100 persons, 30 experience an effect) and in percentages (30%). Our risk communication strategy thus conforms with the current literature to the effect that risks should be presented in several formats to ensure that a broader audience is attained.[49] However, we did not use icon arrays, to avoid lengthening the DBox, which we designed as a printable pdf. With as many as 10 options and 62 health outcomes in some of the Dboxes for this population, icon arrays seemed inappropriate. A future study on a web-based Decision Box would be useful to assess older people's perceptions of icon arrays displayed in pop-up windows.

More research is required to evaluate whether the modified DBox template, which now comprises several features intended to improve understanding, will allow designing more satisfactory patient decision aids for this population in fewer UCD rounds.

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Contributors

AMCG designed this study with JL-B, PV, EK, HOW, and FL. AMCG and GB collected, analysed, and interpreted the data. JL-B, PV, EK, AMCG, and GB critically revised and co-authored one or several Decision Boxes studied herein. AMCG, GB, HOW and M-CT participated in the initial drafting of the manuscript. All authors drafted, critically revised and gave final approval of the article. AMCG acts as guarantor.

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Competing interest

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) All authors have support from their employing organizations for the submitted work; (2) No authors have had relationships with organizations that might have an interest in the submitted work in the previous 3 years; (3) Their spouses, partners or children have no financial relationships that may be relevant to the submitted work; and (4) Authors have no non-financial interests that may be relevant to the submitted work.

Ethical approval

This study was approved by the *Comité Central d'Éthique de la Recherche* (CCER) of the *Ministère de la Santé et des Services Sociaux* (#15-16-05).

Data sharing

No additional data available.

Transparency

The guarantor (AMCG) affirms that the manuscript is a honest, accurate, and transparent account of the study bring reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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Table 1. Demographic characteristics of participating (A) patients, and (B) caregivers.

A-Patients

Characteristic		Frequency (%) n = 23
Female		13 (57)
Age	65-74	0
	75-84	8 (35)
	85 and more	15 (65)
Education	No education	0
	Elementary	5 (22)
	High school	11 (48)
	College	2 (8.7)
	University	5 (22)
Income ($)	0 – 24,999	12 (52)
	25,000 – 34,999	6 (26)
	35,000 – 49,999	1 (4.3)

	50,000 – 74,999	3 (13)
	75,000 – 99,999	1 (4.3)
	100,000 – 150,000	0 (0)
	150,000 +	0 (0)
Health literacy		
Self-reported frequency of having someone helping read medical materials	(0) Never	7 (30)
	(1) Occasionally	4 (17)
	(2) Sometimes	4 (17)
	(3) Often	4 (17)
	(4) Always	4 (17)
	Mean (± SD)	1.7 (±1.5)
Self-reported confidence with forms	(0) Extremely	4 (17)
	(1) Quite a bit	4 (17)
	(2) Somewhat	3 (13)
	(3) A little bit	3 (13)
	(4) Not at all	9 (39)
	Mean (± SD)	2.4 (±1.6)
Self-reported problems learning about medical condition because of difficulty reading medical materials.	(0) Never	5 (22)
	(1) Occasionally	7 (30)
	(2) Sometimes	2 (8.7)
	(3) Often	4 (17)
	(4) Always	5 (22)
	Mean (± SD)	1.9 (±1.5)
Marital status	Single	1 (4.4)
	Married or common-law partner	11 (48)
	Widow	11 (48)
	Separated	0 (0)

	Divorced	0 (0)
Living with caregiver, n (%)		11 (48)

B-Caregivers

Characteristic		Frequency (%) n= 27
Female		15 (56)
Age	24 and less	0 (0.0)
	25-44	0 (0.0)
	45-64	13 (48)
	65-84	11 (41)
	85+	3 (11)
Education	No education	0 (0.0)
	Elementary	2 (7.4)
	High school	8 (30)
	College	9 (33)
	University	8 (30)
Self-reported frequency of having someone helping read medical materials	(0) Never	16 (59)
	(1) Occasionally	4 (15)
	(2) Sometimes	5 (19)
	(3) Often	2 (7)
	(4) Always	0 (0.0)
	Mean (± SD)	0.7 (± 1.0)
Self-reported confidence with forms	(0) Extremely	16 (59)
	(1) Quite a bit	8 (30)
	(2) Somewhat	1 (4)
	(3) A little bit	0 (0.0)
	(4) Not at all	2 (7)
	Mean (± SD)	0.7 (± 1.1)
Self-reported problems	(0) Never	9 (33)

learning about medical condition because of difficulty reading medical materials.	(1) Occasionally	10 (37)
	(2) Sometimes	6 (22)
	(3) Often	0 (0.0)
	(4) Always	2 (7)
	Mean (± SD)	1.11 (± 1.1)
Relationship with the patient	Family member	26 (96)
	Friend	1 (4)
	Professional	0 (0.0)
	Other	0 (0.0)
Approximate number of years in the care of the patient, mean (±SD)		10.3 (± 14)

Table 2 Features of patient decision aids and design strategies to limit their complexity and improve users' experience

Finding	**Feature or design strategy to limit issue**
Unclear purpose/topic of the patient decision aid	• Clear statements in larger fonts describing who the decision aid is aimed at, and what it aims to achieve • Pictogram or images showing people using the patient decision aid to represent its purpose • Personal story displaying the context of use, and purpose of the patient decision aid
Irrelevance of patient decision aid to people with dementia	• Recognizing caregivers' role in decision-making through explicit statements that the patient decision targets caregivers equally to patients
Arduous read or unclear content	• Systematic and frequent use of high-quality pictograms to illustrate text • Glossary to define complex terminology • Write out the text at a 6th grade reading level; • Removal of the references within the text; reference list included on the DBox website • Use "priority" instead of "preference"
Missing information on the options	• Detailed and comprehensive **description of each option** • For the more complex options: propose **personal stories** displaying a person going through the option
Missing information on the next steps to implement the selected option following decision-making	• **Contact section** listing contacts, resources and available services to implement each of the option
Missing topic-specific information, irrelevant content	• Use a **user-centred design process** until information needs are met and all sections are perceived as relevant
Quality of the evidence	• Offer information on the quality of the evidence to those interested
Challenge using the Likert rating scales in the values clarification exercise	• Asking users to select a single preference in a **checklist**; avoid rating scales

Proposing meaningful priorities in the values clarification exercise	• Involve a **panel of patient/caregiver partners** at start of development with mandates to (1) propose a list of priorities to guide the literature review, and (2) revise the wording of priorities extracted from the scientific evidence (further evaluation required)
Navigation challenges	• When the patient decision aid comprises more than two options, use the **values clarification exercise** to streamline navigation by inviting users to read more on the options meeting their priorities • Use **textual cues** to refer to GRADE ratings and to the glossary • Use **visual cues** (e.g. pictogram of the options) and **colours** to structure the general layout
Irrelevance of scientific evidence to patients/caregivers	• Explain the targeted shared decision making behaviours in text and, if possible, with pictures • Train patients/caregivers in shared decision making to prepare them to review information on the benefits and harms of the options (further evaluation required)

Table 3. Patients' report of the value of decision boxes per round: ratings based on the patient version of the Information Assessment Method (IAM)[35]

	Frequency (n/N)			
	Round 1	Round 2	Round 3	All Round
Relevance				
This information is...				
... totally relevant	3/9	0/7*	0/5*	3/21
... relevant	6/9	4/7*	5/5*	15/21
... somewhat relevant	0/9	1/7*	0/5*	1/21
... irrelevant	0/9	2/7*	0/5*	2/21
Understanding				
They understood this information...				
... completely	3/9	3/7*	1/5*	7/21
...mostly	4/9	1/7*	2/5*	7/21
...poorly	1/9	2/7*	2/5*	5/21
...not at all	1/9	1/7*	0/5*	2/21
Cognitive impact of the information				
They learned something new	4/9	0/8	2/6	6/23
This information allowed them to confirm what they do, or did	5/9	3/8	2/6	10/23
They are reassured	6/9	1/8	3/6	10/23
They were reminded of something they already knew	5/9	1/8	1/6	7/23
They are motivated to learn more	4/9	2/8	4/6	10/23
There is a problem with the presentation of this information	5/9	1/8	2/6	8/23
They disagree with the content of this information	0/9	0/8	0/6	0/23
This information is potentially harmful	1/9	1/8	0/6	2/23
Information use				
They will use this information	5/9	4/8	2/6	11/23
This information will...				
...help them improve their understanding of a particular issue and make a decision	3/5	1/4	0/2	4/11
...help them do something when they did not know what to do	2/5	0/4	0/2	2/11
...convince them to do something that they already wanted to do	1/5	1/4	0/2	2/11
...allow them to change the way they do something	2/5	1/4	0/2	3/11

…allow discussing something with someone else (a relative or a healthcare professional)	5/5	2/4	1/2	8/11
Expected benefits of the information				
They expect the information to help…				
…be less worried	2/5	0/4	0/2	2/11
…be better equipped to discuss something with someone else (a relative or a healthcare professional)	4/5	3/4	2/2	9/11
…have more confidence in deciding something with someone else (a relative or a healthcare professional)	3/5	1/4	1/2	5/11
…handle an issue	2/5	1/4	0/2	3/11
…prevent an issue (or prevent it from getting worse)	4/5	0/4	0/2	4/11
They expect no benefits	2/5	0/4	0/2	2/11
Expected consequences				
They expect that the use of this information can have a negative impact on their well-being of their health	1/5	1/4	0/2	2/11

*One missing data

Table 4. Caregivers' report of the value of decision boxes per round: ratings based on the patient version of the Information Assessment Method (IAM)[35]

	Frequency (n/N)			
	Round 1	Round 2	Round 3	All Round
Relevance				
This information is…				
… totally relevant	3/11	6/10	2/6	11/27
… relevant	8/11	4/10	3/6	15/27
… somewhat relevant	0/11	0/10	1/6	1/27
… irrelevant	0/11	0/10	0/6	0/27
Understanding				
They understood this information…				
… completely	4/11	8/10	3/6	15/27
…mostly	6/11	2/10	3/6	11/27
…poorly	1/11	0/10	0/6	1/27
…not at all	0/11	0/10	0/6	0/27
Cognitive impact of the information				
They learned something new	2/11	5/10	5/6	12/27
This information allowed them to confirm what they do, or did	6/11	5/10	2/6	13/27
They are reassured	1/11	4/10	4/6	9/27
They were reminded of something they already knew	3/11	3/10	2/6	8/27
They are motivated to learn more	4/11	6/10	2/6	12/27
There is a problem with the presentation of this information	4/11	2/10	1/6	7/27
They disagree with the content of this information	2/11	0/10	0/6	2/27
This information is potentially harmful	1/11	0/10	0/6	1/27
Information use				
They will use this information	7/11	9/10	6/6	22/27
This information will…				
…help them improve their understanding of a particular issue and make a decision	1/7	2/9	4/6	7/22
…help them do something when they did not know what to do	0/7	0/9	1/6	1/22
…convince them to do something that they already wanted to do	2/7	2/9	3/6	7/22

…allow them to change the way they do something	0/7	1/9	2/6	3/22
…allow discussing something with someone else (a relative or a healthcare professional)	2/7	6/9	2/6	10/22
Expected benefits of the information				
They expect the information to help them…				
…be less worried	0/7	4/9	4/6	8/22
…be better equipped to discuss something with someone else (a relative or a healthcare professional)	6/7	7/9	4/6	17/22
…have more confidence in deciding something with someone else (a relative or a healthcare professional)	2/7	3/9	2/6	7/22
…handle an issue	1/7	3/9	2/6	6/22
…prevent an issue (or prevent it from getting worse)	2/7	3/9	6/6	11/22
They expect no benefits	0/7	0/9	0/6	0/22
Expected consequences				
They expect that the use of this information can have a negative impact on their well-being of their health	0/7	1/9	0/6	1/22

Figure captions:

Figure 1: User-centred design process of three Decision Boxes (Dboxes) for seniors with dementia and their caregivers.

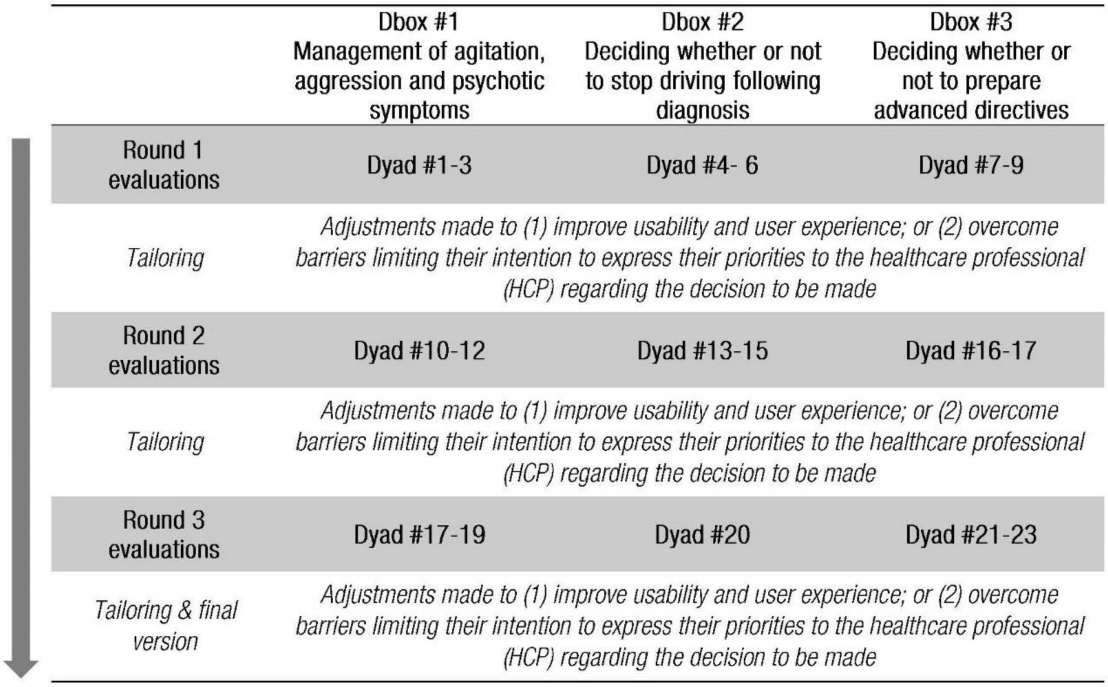
Figure 2: Factors influencing adoption of shared decision making behaviors by patients/caregiver dyads, adapted from Squiers' Health literacy skills framework.

Figure 3: Satisfaction, ease of use, and usefulness of the Decision Box #1 (agitation, aggression, psychotic symptoms) as evaluated by (A) older people with dementia; and (B) their caregivers.

Figure 4: Satisfaction, ease of use, and usefulness of the Decision Box #2 (driving) as evaluated by (A) older people with dementia; and (B) their caregivers.

Figure 5: Satisfaction, ease of use, and usefulness of the Decision Box #3 (power of attorney) as evaluated by (A) older people with dementia; and (B) their caregivers.

Figure 1. User-centred design process of three Decision Boxes (Dboxes) for seniors with dementia and their caregivers



	Dbox #1 Management of agitation, aggression and psychotic symptoms	Dbox #2 Deciding whether or not to stop driving following diagnosis	Dbox #3 Deciding whether or not to prepare advanced directives
Round 1 evaluations	Dyad #1-3	Dyad #4- 6	Dyad #7-9
Tailoring	*Adjustments made to (1) improve usability and user experience; or (2) overcome barriers limiting their intention to express their priorities to the healthcare professional (HCP) regarding the decision to be made*		
Round 2 evaluations	Dyad #10-12	Dyad #13-15	Dyad #16-17
Tailoring	*Adjustments made to (1) improve usability and user experience; or (2) overcome barriers limiting their intention to express their priorities to the healthcare professional (HCP) regarding the decision to be made*		
Round 3 evaluations	Dyad #17-19	Dyad #20	Dyad #21-23
Tailoring & final version	*Adjustments made to (1) improve usability and user experience; or (2) overcome barriers limiting their intention to express their priorities to the healthcare professional (HCP) regarding the decision to be made*		

Figure 2: Factors influencing adoption of shared decision making behaviors by patients/caregiver dyads, adapted from Squiers' Health literacy skills framework

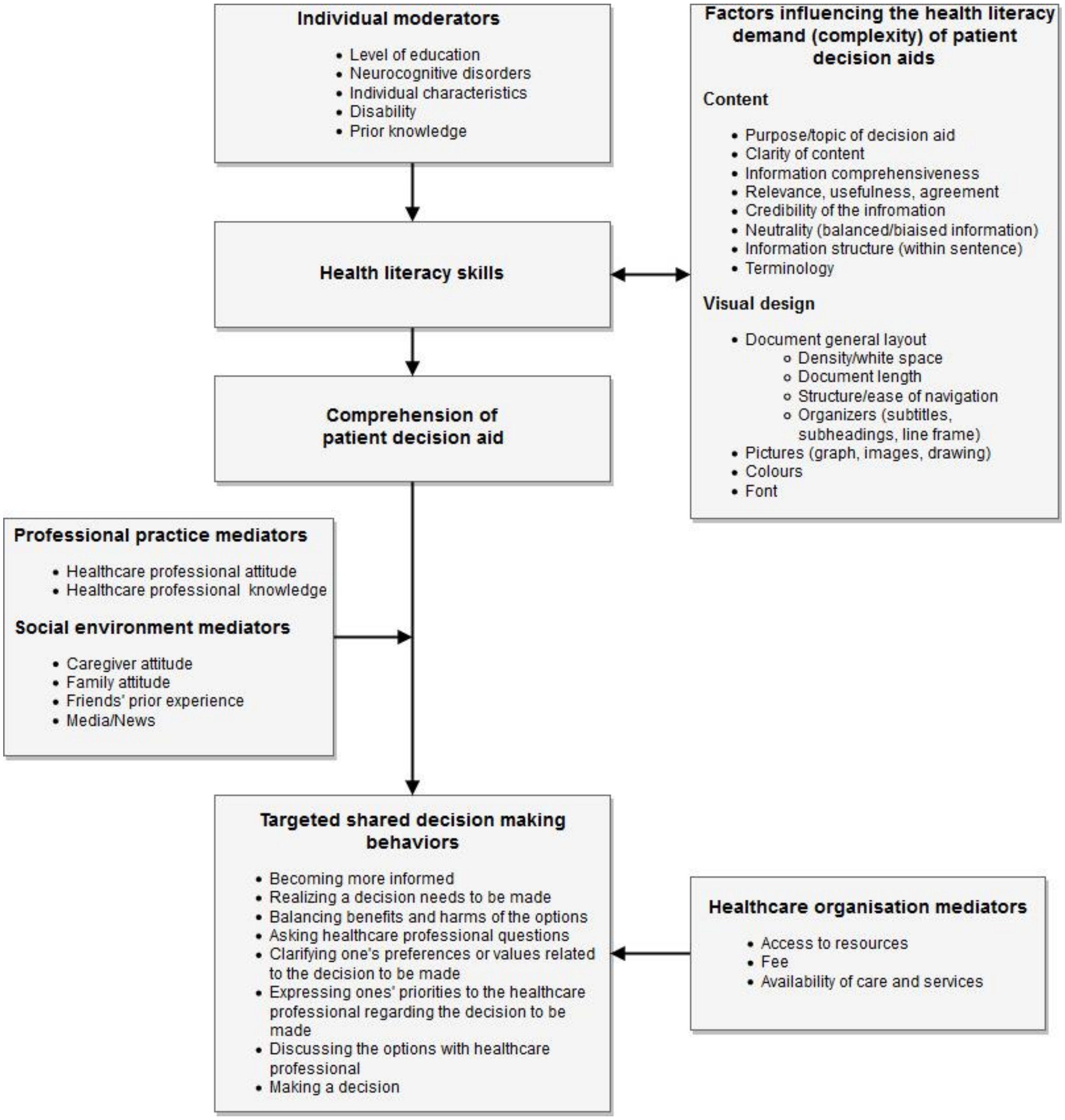
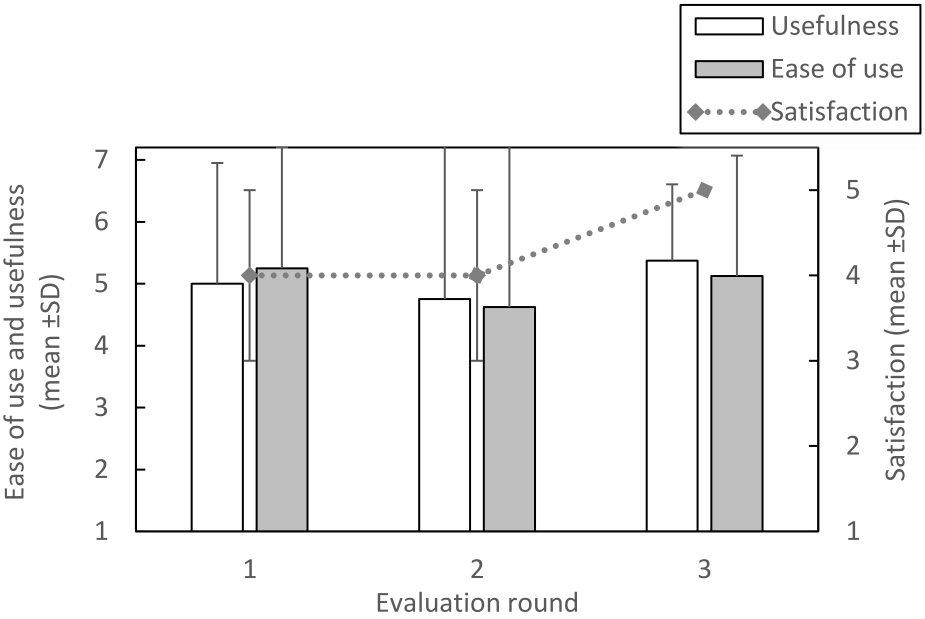


Figure 3. Satisfaction, ease of use, and usefulness of the Decision Box #1 (agitation, aggression, psychotic symptoms) as evaluated by (A) older people with dementia; and (B) their caregivers.

A-Older people with dementia



B- Caregivers

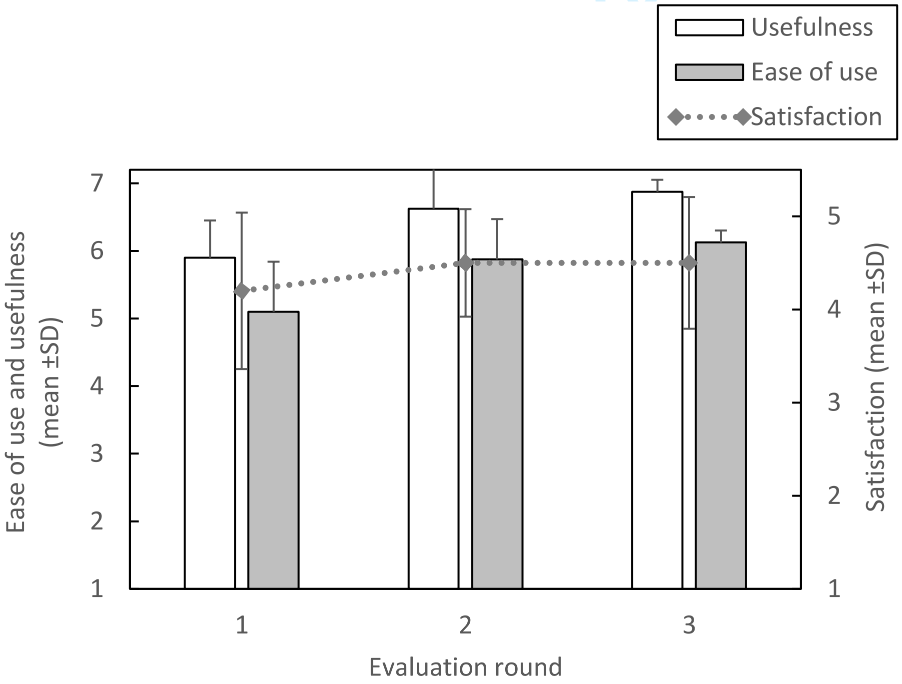
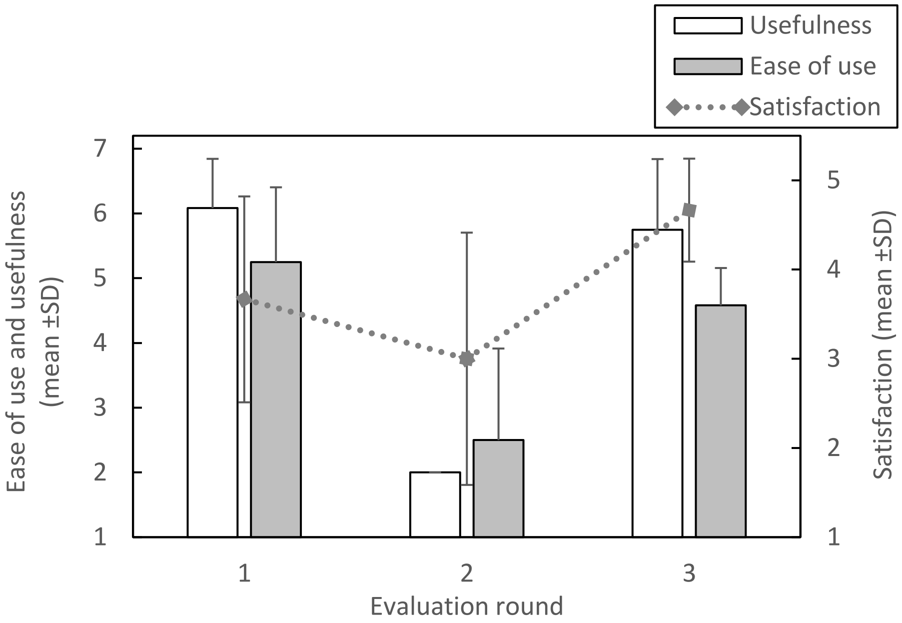


Figure 4. Satisfaction, ease of use, and usefulness of the Decision Box #2 (driving) as evaluated by (A) older people with dementia; and (B) their caregivers

A - Older people with dementia



B- Caregivers

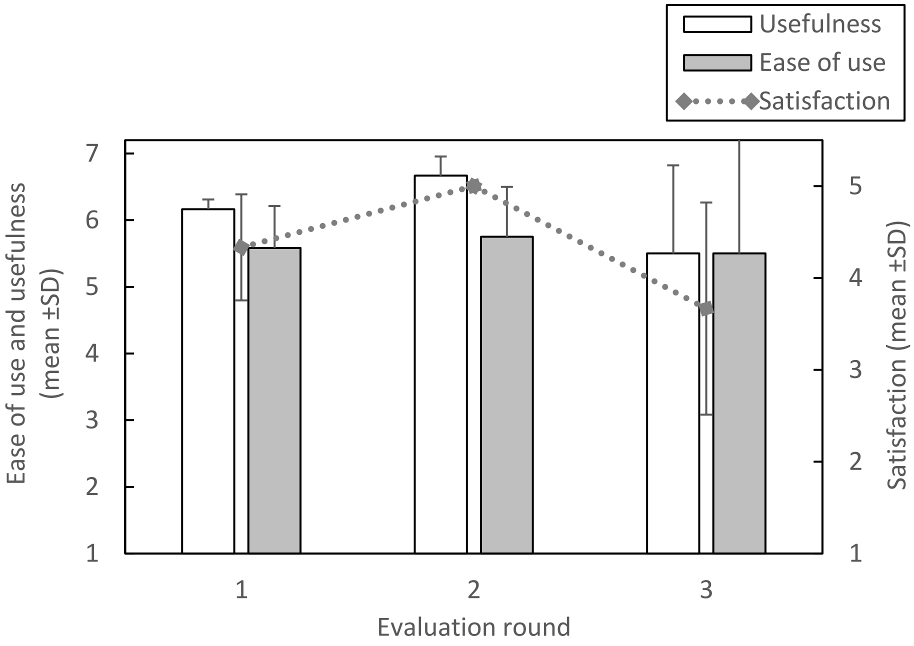
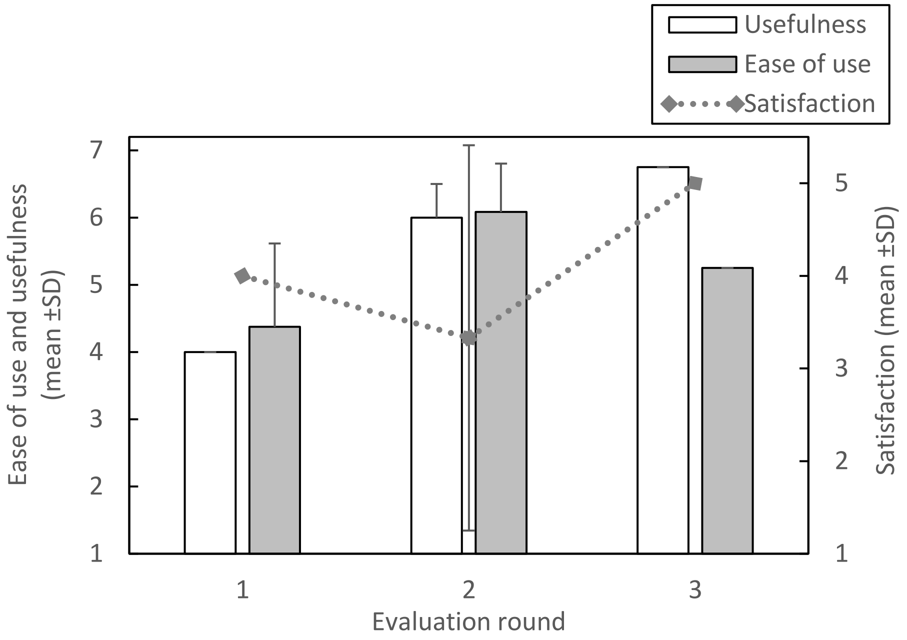
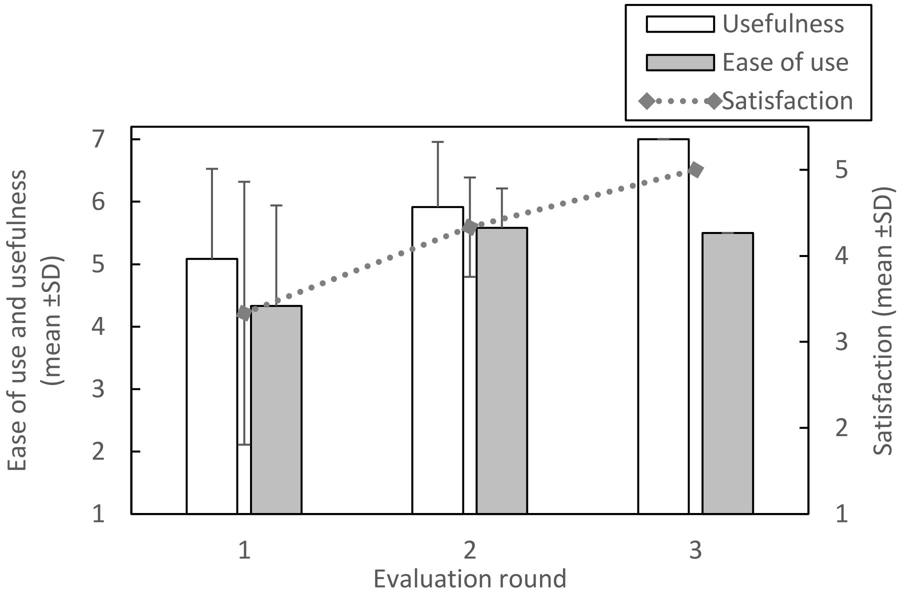


Figure 5. Satisfaction, ease of use, and usefulness of the Decision Box #3 (power of attorney) as evaluated by (A) older people with dementia; and (B) their caregivers.

A- Older people with dementia



B- Caregivers



Decision Box **PATIENT**

to help you reach a decision

UNIVERSITÉ LAVAL

*Choosing Whether or Not to Prepare a Protection Mandate**

What are the other options ?

▷ Presenting the protection mandate to older people and their loved ones

What is meant by incapacity ? [1]

- Incapacity is the inability to accomplish a specific task at a given moment, or to analyze or understand the implications of this inability or the consequences of one's decisions. A person may be considered incapacitated due to their physical or mental state.
- A person who is incapacitated may maintain their legal capacity, provided the court has not deprived them of such capacities, however the person can no longer give their valid consent for a medical act. [1]
- **Legal incapacity can only be declared through a court ruling once the person has been found to be incapacitated, and results in a protection mandate or the homologation of a protection mandate.**

What is a protection mandate ? [2]

- A notarized or non-notarized document (holograph).
- Comes into effect once the incapacity has been documented in a medical and psychosocial assessment and after the court has homologated the mandate.

Allows the senior to… [2-4]

- Express how they wish their property and well-being to be managed in the event they become incapacitated;
- Express their end-of-life care preferences;
- Knowingly appoint the person of their choice to act on their behalf in the event they are incapacitated;
- Protect themself against abuse and negligence, thanks to the investigative powers of the Public Curator

Who should consider a protection mandate ?

- Any person considered of sound mind, especially those with a medical condition that puts them at greater risk of becoming incapacitated and unable to care for themselves or their property.
- Persons with neurocognitive impairment who are more likely to need to make decisions related to end-of-life treatments5 and who have a more limited capacity for making such decisions.[5]

*This document is also known in jurisdictions outside Quebec (Canada) as a **lasting power of attorney**, **power of attorney for personal care**, **representation agreement**, **personal directive**, **advance healthcare directive**, or **healthcare proxy**, among others.

▷ Why should the preferences of patients and their natural caregivers be taken into account?

- **There are pros and cons to preparing a mandate.** For example, a protection mandate allows the older adult to choose their end-of-life care, maintain their autonomy, retain their civil rights, and limit stress on their loved ones who are required to make decisions on their behalf. However, a protection mandate entails costs and a wait time of several months. It can also lead to financial abuse by the mandatary.
- **There is a lack of scientific information on the impacts of preparing a protection mandate.**
- **There are other protection options for patients who are of sound mind:** [3 6-8]
  - Ordinary mandate:
    - A written document (notarized or not) that allows you to name one or more persons to act on your behalf for certain predetermined administrative acts;
  - Adviser for adults (legal measure) :
    - To assist and advise patients in managing their property;
    - They are not authorized to take legal action on the person's behalf;
  - End-of-life care directives or living will: [9]
    - Indicates the patient's preferences with regard to treatment to prolong life and to relieve pain;
  - Advance medical directives (as per Bill 52, Quebec's Act respecting end-of-life care): [10]
    - Sets out the medical care a patient agrees to, or refuses, in specific clinical situations.

▷ Both preparing and not preparing a mandate are acceptable options, so we propose that…

1. The decision take into account the patient's and caregiver's **values** and **preferences**
2. The healthcare professional **share this decision** with the patient and the caregiver

Benefits
Associated with Preparing a Protection Mandate

The person appointed makes decisions ⊕⊕○○

- Of 100 mandataries appointed by the person in a mandate, **92 actually make decisions on behalf of the person** (92%). [5]

You choose your care yourself ⊕○○○

- Of 100 people who set out their end-of-life care wishes, between **50 and 97 receive their desired care**:[5]
  - 97 % receive comfort care, as requested.[5]
  - 83 % receive more limited care, as requested.[5]
  - 50% receive all possible care, as requested.[5]

You maintain the right to exercise your civil rights

- A protection mandate allows the older adult to continue to **exercise their civil rights** (e.g., the right to marry). This is possible only with a protection mandate or an adviser to a person of legal age.

Cancelling a mandate is difficult

- The mandate remains legally valid until proven otherwise. It can only be rendered invalid by the courts, by proving that the patient was incapacitated at the time the mandate was prepared.

Shorter legal proceedings

- There are fewer steps required to homologate the mandate than to institute a tutorship or curatorship.
- When a person has been shown to be incapacitated, the mandate can be homologated even if protection is not yet required, because the person has expressed their desire for such protection by drafting the mandate.

See more on the next page

Harms
Associated with Preparing a Protection Mandate

Risk of mistreatment or abuse

- Unlike in a tutorship or curatorship, it is not the Public Curator's role to supervise how mandataries manage the person's property and money. The Public Curator intervenes only when someone reports a possible case of mistreatment or abuse. The protection mandate can, however, include certain clauses to limit the powers of the mandatary and reduce the risk of abuse.

Directives sometimes not applicable ⊕○○○

- Of 100 people appointed to make decisions for the patient, 11 report that the advance medical directives regarding end-of-life care do not apply to most of the decisions they will have to make.[5]
- Of 100 people appointed to make decisions for the patient, 14 report experiencing difficulties in applying the patient's directives[5]

Risk of financial abuse

- Since the mandatary is not held accountable until the mandate ends, there is a risk of financial abuse. However, the older adult can choose to include a clause that obliges the mandatary to report to a designated individual at a set frequency.
- If the mandatary has full administrative authority, this increases the risk of financial abuse, since the mandatary can make any investments, guaranteed or otherwise, unlike in a tutorship or curatorship.

Non-compliance with advance medical directives by loved ones or medical staff ⊕○○○

- Of 100 older adults who indicated their resuscitation preferences in an advance medical directive, 37 do not receive their desired treatment.[15]

See more on the next page

* https://www.curateur.gouv.qc.ca/registre/pcurateur_man_html/criteres.jsp

Confidence in these results

⊕○○○ : Very low
⊕⊕○○ : Low
⊕⊕⊕○ : Moderate
⊕⊕⊕⊕ : High

Benefits
Associated with Preparing a Protection Mandate

Access to the patient’s protection status

- Medical staff, notaries, and government agencies can **easily check the protection status** of the patient in the registry of homologated mandates maintained by the Public Curator.*

You maintain your autonomy

- Le patient n’est pas considéré comme incapable au plan juridique.
- Le patient peut faire élaborer des actes juridiques selon les restrictions qu’il s’est lui-même imposées en rédigeant le mandat.

Less stress for loved ones ⊕○○○

- Of 100 people who may have to make a decision for a patient at some point, **33 will experience symptoms of post-traumatic stress.**[11]
- A protection mandate can make it easier for loved ones to make end-of-life treatment decisions.

Improved communication between patients and loved ones ⊕○○○

- Of 100 patients (with their loved ones) who plan to prepare a protection mandate, the 28 who discuss the matter amongst themselves will be in greater agreement than those who do not communicate with one another (28%).[12 13]

No additional anxiety or symptoms of depression ⊕○○○

- Patients who discussed plans to prepare a protection mandate experience no additional anxiety or symptoms of depression compared to those who didn't.[13 14]

Harms
Associated with Preparing a Protection Mandate

Wait time of several months

- Preparing a protection mandate and having it homologated usually takes several months. However, during this period, certain temporary provisions can be put in place, as needed, to protect the person (e.g., management of their affairs, domestic mandate, administration by a third party, or emergency legal measures).

Only the mandatary can ask for the mandate to be homologated

- If the mandatary cannot or no longer wishes to assume their functions, the task falls to the replacement mandatary, if there is one.

Must be homologated in its entirety

- The protection mandate must be homologated as is. For example, if the person is able to care for themselves, but not their property, while the mandate stipulates protection of both, then it cannot be homologated solely for management of the person's property. In this case, a protection regime will need to be instituted, however the court may take into consideration the wishes set out in the mandate.

Generates costs

- Mandate preparation fees are in effect (drafting: $30; homologation: $1,000; bailiff, etc.), however, these fees are lower than those incurred to institute a curatorship or tutorship (institute proceedings: $2,000; bailiff; summoning of witnesses; property management fees, where applicable; protection of the person, where required: $1,000/year).
- Requires medical and psychosocial assessments, for which fees may be charged if done in the private sector.
- May be covered in part or fully by legal aid or paid out of the patient’s pocket.

† http://www.avocat.qc.ca

Confidence in these results

⊕○○○ : Very low
⊕⊕○○ : Low
⊕⊕⊕○ : Moderate
⊕⊕⊕⊕ : High

Making My Decision

Discuss it with your health professional!

How important is it for you…	NOT important … VERY important	Possible Options
… to determine, yourself, how your property, well-being, and end-of-life care will be managed if you become incapacitated?	⓪ ① ② ③ ④ ⑤	Prepare a protection mandate
… that decisions about your end-of-life care be taken by the person of your choice?	⓪ ① ② ③ ④ ⑤	Prepare a protection mandate
… that you continue to be able to exercise your civil rights?	⓪ ① ② ③ ④ ⑤	Prepare a protection mandate
… that you reduce the stress on your natural caregivers?	⓪ ① ② ③ ④ ⑤	Prepare a protection mandate
… that you avoid the risk of financial abuse?	⓪ ① ② ③ ④ ⑤	Do not prepare a protection mandate
… that you avoid medical and psychosocial assessments?	⓪ ① ② ③ ④ ⑤	Do not prepare a protection mandate
… that you avoid extra costs?	⓪ ① ② ③ ④ ⑤	Do not prepare a protection mandate
… that you avoid a wait time of several months if you require protection?	⓪ ① ② ③ ④ ⑤	Do not prepare a protection mandate

Other considerations? ____________________

Which option do you prefer ? ____________________

Are you comfortable with your decision ?		Yes	No
Sure of myself	1) Do you feel SURE about the best choice for you?	☐	☐
Understand the information	2) Do you know the benefits and risks of each option?	☐	☐
Risk-benefits ratio	3) Are you clear about which benefits and risks matter most to you?	☐	☐
Encouragements	4) Do you have enough support and advice to make a choice?	☐	☐

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References : Available at www.boitedecision.ulaval.ca

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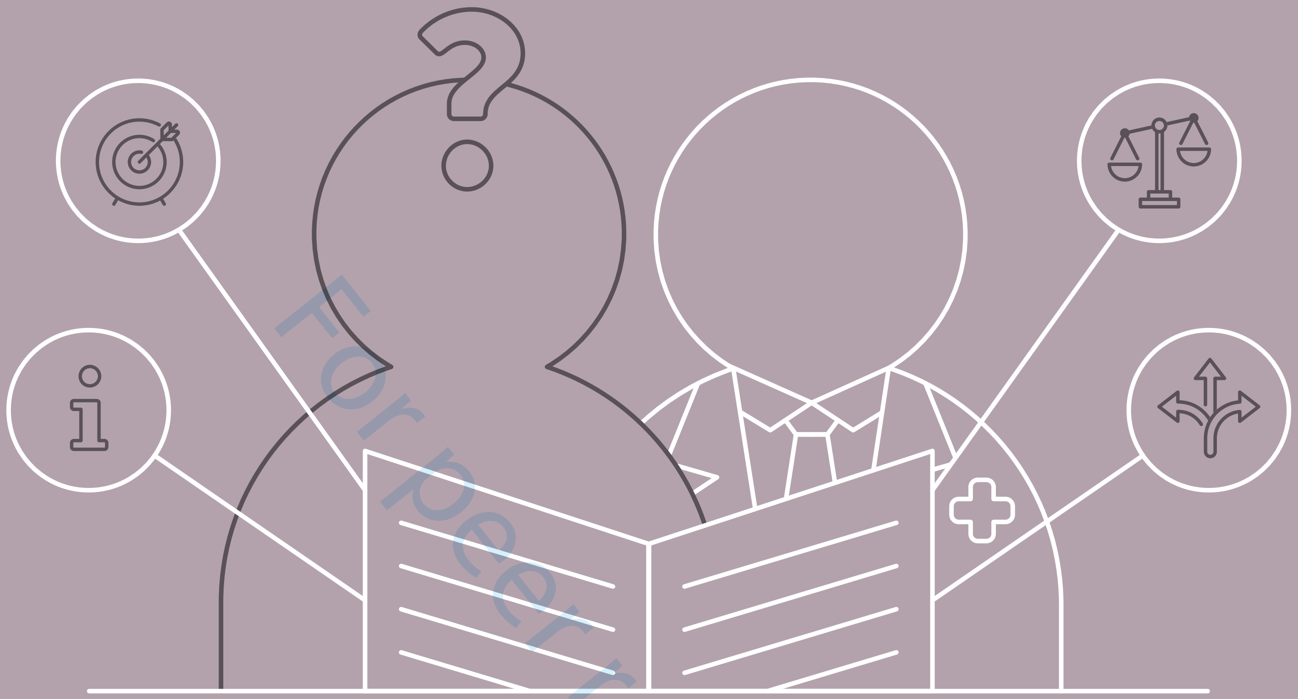

Decision Box for patients

Incapacity in Older People

Choosing Whether or Not to Prepare a Protection Mandate*

THIS DOCUMENT IS AIMED AT...

- Patients with memory and attention disorders who live in the community
- Natural caregivers of patients with memory and attention disorders

THIS DOCUMENT IS DESIGNED TO...

- Inform patients and their loved ones about some of the options available
- Help prepare the person and their loved ones for discussions among themselves and with health professionals
- Help patients and their loved ones choose an option that reflects their priorities and capacities

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* This document is also known in jurisdictions outside Quebec (Canada) as a ***lasting power of attorney***, ***power of attorney for personal care***, ***representation agreement***, ***personal directive***, ***advance healthcare directive***, or ***healthcare proxy***, among others.

INTRODUCTION
Who and why?

Incapacity

- A person is considered incapacitated when they are **unable to take care of themselves, manage their property, or express their wishes.**
- Incapacity can be caused by a mental or degenerative illness, a stroke, an intellectual disability, a head injury, or a weakened state as a result of disease.
- Persons who are incapacitated may continue to manage their affairs and make decisions regarding their health themselves, **provided the court has not deprived them of their legal capacities.**
- The courts may determine legal incapacity further to an incapacity finding*.

Examples of behaviours of an incapacitated person

- Difficulty following a familiar recipe.
- Hesitation when performing simple tasks like locking the door or getting dressed.
- Changes in their spending habits or budget management.

Protection Mandate*

- An official, notarized* or holograph document*
- Allows a person to:
    - **Express their wishes** about how they would like to be looked after and how their property is to be managed in the event they are incapacitated.
    - Knowingly **appoint the person of their choice to act on their behalf** in the event they are incapacitated (mandatary*).
- **Includes advance medical directives** that allow the person to express their care preferences (consent to care, end-of-life care wishes), for example, to avoid non-beneficial medical care.
- The protection mandate allows you to **appoint one or more persons to look after you and your property while you are still alive.**
- A protection mandate is **not a will.** The purpose of a will is strictly to state how and to whom your property will be distributed after your death.
- The protection mandate **annuls all the powers of attorney** authorized by the person (e.g., for their banking, or to look after them or manage their property).

* See Glossary p. 8

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* This document is also known in jurisdictions outside Quebec (Canada) as a ***lasting power of attorney***, ***power of attorney for personal care***, ***representation agreement***, ***personal directive***, ***advance healthcare directive***, or ***healthcare proxy***, among others.

INTRODUCTION (CONT'D)

Who and why?

Who can consider preparing a protection mandate?

Any person considered of sound mind, especially those with a medical condition that puts them at greater risk of becoming incapacitated and unable to care for themselves or their property.

Steps for preparing a protection mandate

1. Choose what you want to indicate in the mandate, e.g., mandatary, housing preferences, consent to care, preferences regarding property management, end-of-life wishes.
2. Discuss with your loved ones your desire to draw up a protection mandate.
3. Choose one or more mandataries.
4. Prepare your mandate with the help of a professional (lawyer or notary) or using the online form (see list of resources on page 7).
5. Let your loved ones know about your protection mandate, and keep a copy of it in a safe place.

Example of Mrs. Rose Gibson

Mrs. Gibson is a widow who suffers from Alzheimer's disease. She has no children and is no longer capable of taking care of herself. For instance, she forgets to pay her bills and to take her medication. When her husband was still alive, she drew up a holograph protection mandate in which she named her husband as mandatary, in the event she became incapacitated. Her husband has since passed away, but she had taken the precaution of naming a nephew and niece as replacement mandataries. Her mandataries will ask that the mandate be homologated, will ensure that Mrs. Gibson receives the care she needs, and will look after paying her bills. They will also make sure that the instructions she set out in her protection mandate are followed.

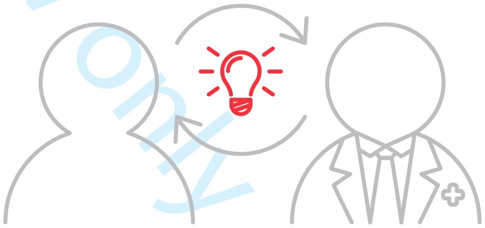
What if the court determines that a person is incapacitated and they don't have a protection mandate?

Another type of protection regime will be instituted, and a tutor or curator will be appointed (see page 5 for details).

Taking patient priorities into account

Depending on their priorities, patients **may decide to prepare a protection mandate or not**. The choice is up to them because...

- There are **pros and cons** to preparing a mandate.
- There is a **lack of scientific information** on the impacts of preparing a protection mandate.



We recommend that...

- The decision take into account the patient's and caregiver's values and priorities.
- The healthcare professional share this decision with the patient and, if necessary, with the caregiver.

PRIORITIES

Exercise to clarify your priorities
For patients and their natural caregivers

SELECT WHAT IS MOST IMPORTANT TO YOU.

✓ CHECK ONE ITEM ONLY.

○ **Decide myself HOW my property, well-being, and healthcare will be managed**

POSSIBLE OPTIONS:

- Protection mandate **(see p. 5)**

○ **Protect myself against financial abuse**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**
- Tutorship **(see p.6)**
- Curatorship **(see p.6)**

○ **Express my wishes and preferences**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**
- Tutorship **(see p.6)**

○ **Decide myself WHO will make decisions about my care**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**

○ **Retain my civil rights (like the right to vote)**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**

○ **Limit the stress on my loved ones**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**

○ **Limit the legal costs**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**

○ **Other:**

List the options **(see p.5-6)** that allow respecting this priority:

CLARIFYING MY PRIORITIES

OPTIONS

Explore the options

Protection Mandate

previously known as "mandate in case of incapacity"

BENEFITS

Decisions are taken by the mandatary ⊕⊕○○

Of 100 mandataries appointed by the person in a mandate, 92 **actually make decisions on behalf of the person** (92%).

Choice to consent to certain care or not ⊕○○○

Of 100 people who set our their end-of-life care wishes, between 50 and 97 **receive their desired care**:

- 97% receive comfort care, as requested.
- 83% receive more limited care, as requested.
- 50% receive all possible care, as requested.

Less stress for loved ones ⊕○○○

Of 100 people who may have to make a decision for a patient at some point, 33 **will experience significant symptoms of stress** (33%).

A protection mandate can **make it easier for loved ones to make end-of-life treatment decisions**.

↑ Communication between patients and loved ones ⊕○○○

Of 100 patient (with their loved ones) who plan to prepare a protection mandate, the 28 who discuss the matter amongst themselves will will be in **greater agreement** than those who do not communicate with one another (28%).

No additional anxiety or symptoms of depression ⊕○○○

Patients who discussed plans to prepare a protection mandate experience **no additional anxiety or symptoms of depression** compared to those who didn't.

HARMS

↑ Risk of mistreatment or abuse

Unlike in a tutorship or curatorship, it is not the Public Curator's role to supervise how mandataries manage the person's property and money. The Public Curator intervenes only when someone reports a possible case of mistreatment or abuse.

The protection mandate can, however, include certain clauses to limit the powers of the mandatary and reduce the risk of abuse.

Directives sometimes not applicable ⊕○○○

Of 100 people appointed to make decisions for the patient, 11 report that the advance medical directives regarding end-of-life care do not apply to most of the decisions they will have to make (11%).

Of 100 people appointed to make decisions for the patient, 14 report experiencing difficulties in applying the patient's directives (14%).

Non-compliance with advance medical directives by loved ones or medical staff ⊕○○○

Of 100 older adults who indicated their resuscitation preferences in an advance medical directive, **37 do not receive their desired treatment** (37%).

Must be homologated (enter into effect) in its entirety

The protection mandate m**ust be homologated** as is. For example, if the person is able to care for themselves, but not their property, while the mandate stipulates protection of both, then it cannot be homologated solely for management of the person's property. In this case, a protection regime will need to be instituted, however the court may take into consideration the wishes set out in the mandate.

CONFIDENCE IN THESE RESULTS:

⊕⊕⊕⊕ **High:** Further research is very unlikely to change our confidence in the estimate of effect.
⊕⊕⊕○ **Moderate:** Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.
⊕⊕○○ **Low:** Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.
⊕○○○ **Very low:** Any estimate of effect is very uncertain.

	PROTECTION MANDATE	TUTORSHIP	CURATORSHIP
GENERAL DESCRIPTION	Allows the person who is of sound mind to express how they wish their property and well-being to be managed, and to choose the person who will act on their behalf in the event they become incapacitated.	Required by the court for a person who has not prepared a protection mandate and who becomes temporarily incapacitated	Required of persons who have not prepared a protection mandate and who become permanently incapacitated. Last-resort solution.
CHOOSING THE PERSON IN CHARGE	The person chooses the mandatary (see Glossary, page 8) who will act on their behalf.	A tutorship council chaired by a judge appoints a tutor in accordance with the recommendations of the person's loved ones. The person is not consulted during this process.	A tutorship council chaired by a judge appoints a curator (private or public, see Glossary, page 8) inv accordance with the recommendations of the person's loved ones. The person is not consulted during this process.
MAKING DECISIONS	The mandatary is obliged to ensure the person's decisions are complied with, as described in the mandate.	The tutor makes all the decisions for the person, in accordance with their wishes, if they are known, but is not obligated to respect them. Allows the person to express their wishes, insofar as they are capable of doing so.	The curator makes all the decisions for the person, in accordance with their wishes, if they are known, but is not obligated to respect them.
RISK OF ABUSE	The mandate must include certain clauses to reduce the risk of abuse by the mandatary.	The tutor is supervised by the Public Curator.	The Public Curator requires that persons providing care and services to the individual submit reports.
CIVIL RIGHTS, E.G., RIGHT TO VOTE	Upheld	Lost	Lost
DURATION OF LEGAL PROCEEDINGS	Relatively short proceedings	Longer proceedings	Longer proceedings
RELATED COSTS	**Mandate preparation fees:** • Drafting ($30) • Notary ($350-500) • Homologation of protection mandate ($1,000) • Medical and psychosocial assessments ($1,025 to $1,500) **Annual fee:** $0	**Preparation fees:** • Instituting protective supervision ($2,062) • Legal fees ($1,000) • Bailiff ($20) • Medical and psychosocial assessments ($1,025 to $1,500) **Annual fees:** Property management fees vary according to the person's needs: protection of the person ($1,030/year). The tutor can ask to be paid a salary.	**Preparation fees:** • Instituting proceedings ($2,062) • Legal fees ($1,000) • Bailiff ($20) • Medical and psychosocial assessments ($1,025 to $1,500) **Annual fees:** Property management fees vary according to the person's needs: protection of the person ($1,030/year).
RISK OF CONFLICT	Between loved ones and mandatary	Between the tutor and the person's loved ones	Between loved ones and the curator
STRESS FOR LOVED ONES	Less	More	More

CHOOSING AN OPTION

Do you prefer to prepare a protection mandate, or not?

____

Are you comfortable with you choice?

		YES	NO
Sure of myself	Do you feel SURE about the best choice for you?	○	○
Understand information	Do you know the benefits and risks of each option?	○	○
Risk-benefits ratio	Are you clear about which benefits and risks matter most to you?	○	○
Encouragement	Do you have enough support and advice to make a choice?	○	○

SURE TEST © O'CONNOR & LÉGARÉ 2008

RESOURCES AND CONTACTS

Protection Mandate form:

www.curateur.gouv.qc.ca/cura/en/outils/publications/mon_mandat.html

How to prepare a protection mandate:

Notary: 1-800-NOTAIRE (1-800-668-2473) or www.cnq.org/en/famillies-couples.html

Curator: www.curateur.gouv.qc.ca/cura/en/outils/publications/mon_mandat.html

To report a situation of mistreatment, negligence, or abuse of a person under a protection mandate:

Public Curator: www.curateur.gouv.qc.ca/cura/en/outils/joindre/index.html or 1-800-363-9020 (toll free)

For more information on elder abuse:

La ligne Aide, Abus, Aînés: www.aideabusaines.ca or 1-888-489-2287 (toll free)

Other resources:

Association des proches aidants de la Capitale-Nationale: 418-688-1511 or www.apacn.org

Société Alzheimer de Québec: 418 527-4294 or www.societealzheimerdequebec.com/wp/

GLOSSARY
Definitions

Mandatary

The person who receives a mandate or power of attorney to represent their mandatee in a legal act.

Tutorship council

One to four persons with an interest in the person and who are named by the court to take part in decisions regarding the management of the individual's property or well-being.

Incapacity finding

Incapacity is determined by a medical and psychosocial assessment.

Notarized document

Document that is signed before a notary, indicating it has been authenticated. Notarized documents are harder to challenge in court. The notary will register the notarized document in the register of mandates at the Chambre des notaries du Quebec.

Document in the presence of witnesses, or holograph

Document prepared without the help of a notary that is signed by the person and two witnesses who attest that the person is of sound mind. In the case of a holograph mandate, it will be homologated by the court at the time of the incapacity finding. This type of document can also be completed with the help of a lawyer.

Curator

Legal representative named by the court to represent the person who has become incapacitated, ensure their protection, and manage their property. The curator is named following a recommendation by the tutorship council made up of one to three people with a close relationship to the patient, insofar as possible.

Private curator

Anyone in the circle of friends and family of the adult needing protection can be named as their curator, as long as the person is an adult or emancipated minor: spouse, partner, family member, friend, or another person close to the protected person.

Public Curator

If no one in the person's circle of friends and family can or wants to be the curator, the court will name the Public Curator to act as the person's curator.

Management of property

Consists of partial or complete management of all the property belonging to the person (e.g., building and objects), and of their financial affairs (e.g., income, interest, and investments). Under a tutorship, the tutor is obligated to preserve and maintain the value of the property for which they are responsible. They can also make investments provided they are presumed to be sound. Under a curatorship, the curator must preserve the value of the property, and also has a duty to try and make it increase in value. In a curatorship, all financial decisions, such as selling or hypothecating a building, are considered legitimate actions, while in a tutorship, the tutor requires the approval of the court before taking out any loans, selling any property, or hypothecating a building.

Management of well-being

Includes all decisions relating to the health and well-being of the incapacitated person. The tutor responsible for managing the person's well-being, and the curator, are tasked with authorizing or refusing medical care, looking after the custody and care of the person, and obtaining a re-evaluation of the incapacity of the person every three years (tutorship) or every five years (curatorship). Responsibility for the custody and care of the person can be transferred to an establishment like a long term care facility or any other institution offering such essential services.

PROTECTION MEASURE

for patients of sound mind

Ordinary mandate

A written document (notarized or not) that allows you to name one or more persons to act on your behalf for certain predetermined administrative acts.

Adviser for adults (legal measure)

The adviser's role is to assist and advise patients in managing their property. They are not authorized to take legal action on the person's behalf.

End-of-life care directives or living will

Indicates the patient's preferences with regard to treatment to prolong life and to relieve pain.

Advance medical directives

(as per Bill 52, Quebec's Act respecting end-of-life care)

Sets out the medical care a patient agrees to or refuses in specific clinical situations.

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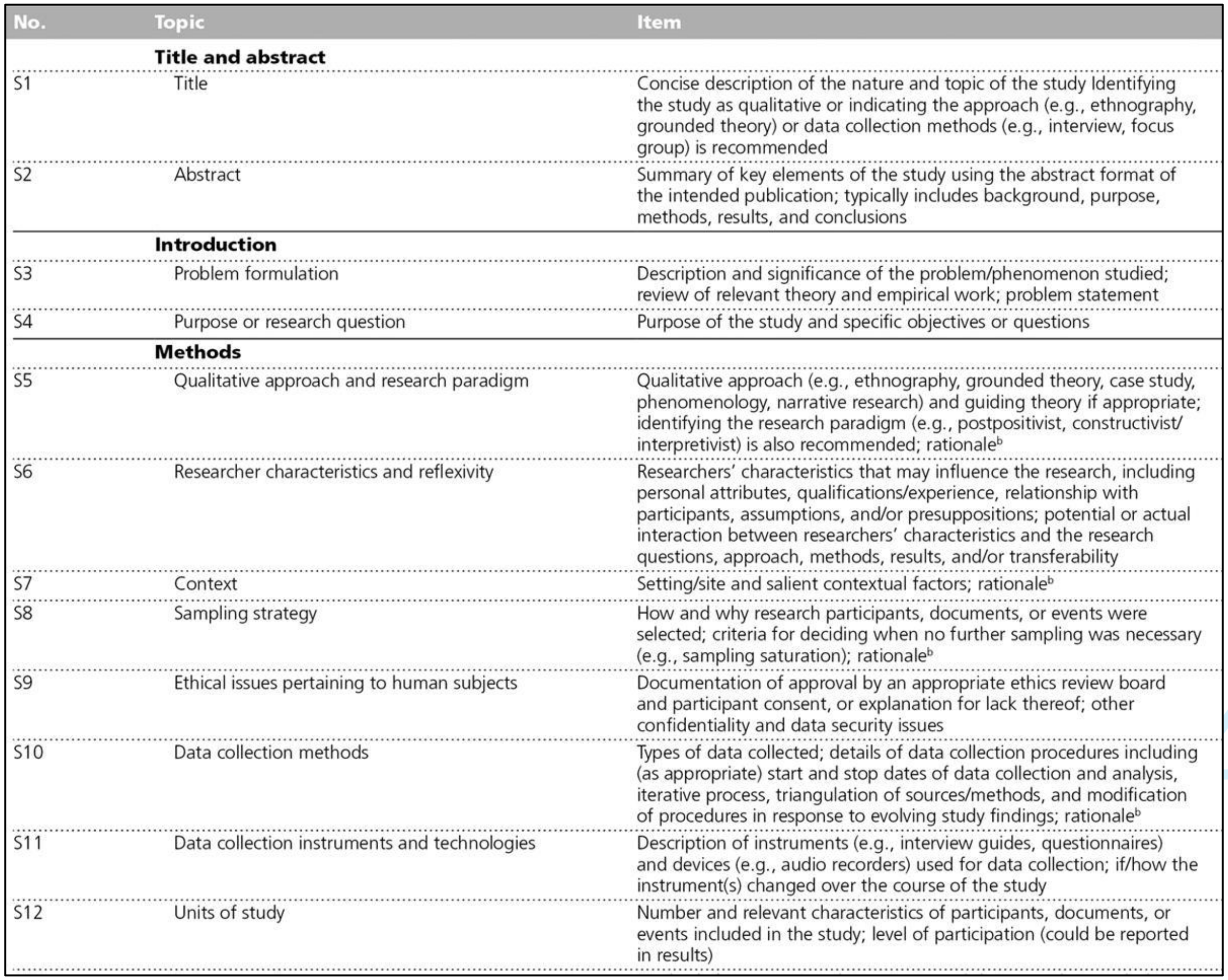
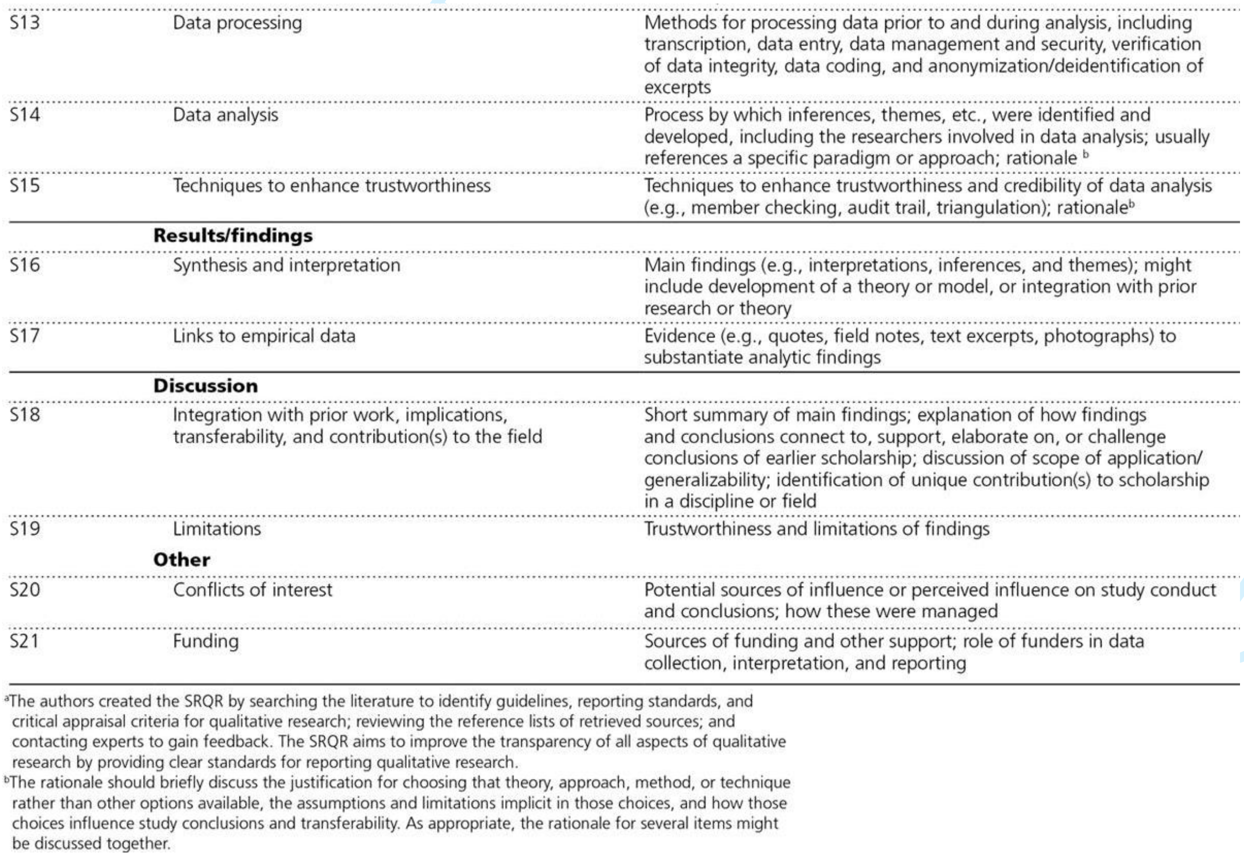
Supplementary file #3: **SRQR guidelines to report qualitative research (**O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251)



No.	Topic	Item	**Manuscript page**
	Title and abstract		
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	p. 1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	p. 2
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	p.4
S4	Purpose or research question	Purpose of the study and specific objectives or questions	p.5
	Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale[b]	p.5
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	p.7
S7	Context	Setting/site and salient contextual factors; rationale[b]	p.3
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]	p.6
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	p.22
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]	p.6
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	p.7
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	p.8-9



S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	p.7
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale [b]	p.7-8
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]	p. 16
	Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	p. 18-20
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	p. 10-17
	Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	p. 18
S19	Limitations	Trustworthiness and limitations of findings	p. 18
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p. 21
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	p.21

[a] The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

[b] The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

p. 3

BMJ Open

Reducing complexity of patient decision aids for community-based older adults with dementia and their caregivers: multiple case study of Decision Boxes

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Reducing complexity of patient decision aids for community-based older adults with dementia and their caregivers: multiple case study of Decision Boxes

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Abstract

Objectives: To identify patient decision aids' features to limit their complexity for older adults with dementia and their family caregivers.

Design: Mixed method, multiple case study within a user-centred design (UCD) approach.

Setting: Community-based healthcare in the province of Quebec in Canada

Participants: 23 older persons (65+) with dementia and their 27 family caregivers.

Results: During three UCD evaluation-modification rounds, participants identified strengths and weaknesses of the patient decision aids' content and visual design that influenced their complexity. Weaknesses of content included a lack of understanding of the decision aids' purpose and target audience, missing information, irrelevant content, and issues with terminology and sentence structure. Weaknesses of visual design included critics about the decision aids' general layout (density, length, navigation) and their lack of pictures. In response, the design team implemented a series of practical features and design strategies, comprising: a clear expression of the patient decision aid's purpose through simple text, picture and personal stories; systematic and frequent use of pictograms illustrating key points and helping structure patient decision aid's general layout; a glossary; removal of scientific references from the main document; personal stories to clarify more difficult concepts; a contact section to facilitate implementation of the selected option; GRADE ratings to convey the quality of the evidence; a values clarification exercise formatted as a checklist and presented at the beginning of the document to streamline navigation; involvement of a panel of patient/caregiver partners to guide expression of patient priorities; editing of the text to a 6th grade reading level; UCD process to optimize comprehensiveness and relevance of content, and training of patients/caregivers in shared decision making.

Conclusions: The revised template for patient decision aids is designed to meet the needs of adults living with dementia and their caregivers better, which may translate into fewer evaluation-modification rounds.

Strengths and limitations of this study

- The multiple case design allows suggesting general features for adapting patient decision-aid templates to user needs.
- Integration of user feedback in a UCD approach allowed an in-depth study of decision aid features influencing adoption of shared decision making.
- Caregivers offered their feedback on the Decision Boxes in the presence of the person in their care, and this could have influenced our conclusions.
- The presence of caregivers may also have caused some of the seniors with dementia to be less spontaneous, particularly if their caregivers played a dominant role in the dyad.

Introduction

In 2015, 46 million adults were living with dementia worldwide. This number is expected to increase to 131.5 million by 2050.[1] The medications available to treat dementia are of limited efficacy and can cause major side effects.[2] Non-pharmacological alternatives may help with some symptoms, but patients, their caregivers, and their primary healthcare professionals are less familiar with their benefits and harms.[3] Moreover, patients experience adverse health outcomes and reduced autonomy and capacities, which result in difficult life management or non-medical decision.[4] In such clinical situations, the shared decision making model calls for healthcare professionals and patients to work together to reach joint decisions based on the best evidence available regarding the benefits and harms of all available options (including watchful waiting) as well as patient values and preferences with regard to those options.[5]

However, involving older adults living with dementia in decision-making may be a challenge given their cognitive decline. Their older age also puts them at greater risk that other factors limit their participation in decision making compared to the general population, such as lower levels of literacy and numeracy,[6,7] the presence of caregivers,[8–10] sensory deficits such as deafness or visual impairment, and a greater propensity to rely on health professionals to make health decisions.[11] Healthcare professionals may also perceive older persons with dementia as being too vulnerable to participate in decision making, and thus exclude them from the process.[12]

Patient decision aids are standardized evidence-based interventions designed to help people make informed and deliberated choices among options.[13–16] At a minimum, they provide information about the options and their associated relevant outcomes.[15] An earlier systematic review described some features of patient decision aids to support *understanding* and *values clarification* in adults with limited health literacy skills, namely presenting essential information more prominently, adding videos to verbal narratives, presenting numerical information (1) in tables or pictographs (2) with the same denominator and (3) using higher numbers to display improvements.[17] Health communication research also suggests several features to limit the complexity of health information, such as simple language and the use of pictures,[18] and presenting actionable health information.[19,20] However, no decision aid feature is known to support *communication* between adults with limited literacy and their healthcare professionals.[17] There is also a lack of evidence regarding the features of decision aids to *communicate uncertainty* to adults with limited literacy,[21] and health literacy is still rarely considered in the literature to date.[17]

Moreover, only a few studies so far have described the development of a decision aid for people living with dementia and their healthcare team.[22–24] Hence, knowledge gaps remain on the most efficient design strategies and on the specific features of patient decision aids to meet the decision-making needs of this population. To begin to fill this gap, we have prioritized difficult decisions that older adults with NCDs and their caregivers frequently face.[4] We then synthesized the evidence of potential benefits and harms for all the options involved in some of those decisions and integrated them into Decision Boxes (Dboxes), which are the patient decision aids template developed at Laval University (Quebec City, Canada).[25,26]

Our previous results suggested that including user feedback is instrumental in designing Dboxes better adapted to their needs.[25] Preliminary evidence indeed suggests that user-centred design (UCD) may enhance the implementation in practice of patient decision aids.[27–32] UCD builds on an explicit understanding of users, tasks, and environments to address the whole user experience.[33] It is driven and refined by iterative user-centred evaluation, and involves a design team with interdisciplinary skills and perspectives.[33] User experience looks broadly at the individual's interaction with a product, as well as the thoughts, feelings, and perceptions that result from that interaction.[34]

In the current study, we used a UCD approach to tailor three DBoxes to the literacy level of older adults with dementia and their caregivers, and improve their experience using them. As we observed users interacting with the Dboxes, we sought to identify patient decision-aid features that reduced their complexity and prepared patients and caregivers to participate in shared decision making.

Methods

Study design and approach

We used a multiple case study evaluation across three Dboxes. The evaluation comprised interviews and questionnaires within an iterative UCD approach. We used three rounds of questionnaires and semi-structured interviews to have patient and caregiver dyads evaluate the three Dboxes (Figure 1). After a first evaluation round with a subsample of nine dyads, we analysed the data and, based on the findings, refined the Dboxes to limit their complexity and improve the user experience. We then used the same evaluation/tailoring process again in two more rounds, with new participants each time.

Case selection

Based on an earlier Delphi study,[4] and using a rapid review approach,[35] we created five Dboxes to support decision making regarding five difficult and frequent decisions faced by older adults with NCDs and their caregivers: (1) choosing a non-pharmacological treatment to manage agitation, aggression, or psychotic symptoms; (2) deciding whether or not to stop driving following diagnosis; (3) deciding whether or not to prepare a power of attorney, called a *Protection Mandate* in Quebec (Canada) covering health, property and financial matters; (4) choosing a support option to decrease caregiver burden; and (5) choosing an option to improve quality of life. For the current study, we used a maximum variation sampling strategy to select three of these five Dboxes as different cases. We chose #1 because it was the longest of the five and compared several options, whereas #2 and #3 compared only two options each. We chose #2 because it covered a very sensitive topic and thus allowed identifying features of decision aids to facilitate shared decision making in emotionally-charged contexts. We selected #3 because it used a more technical and complex vocabulary than any of the others. We excluded #4 because caregivers were the target users.

Theoretical framework

We chose the Health Literacy Skills framework[36] to structure data collection and allow comparability across cases. This framework hypothesizes the relations between health literacy and health-related outcomes and reflects how factors external to the individual (e.g., family, setting, community, culture, and media) influence the constructs represented. The framework incorporates health-related stimuli that people receive in their daily life, such as the DBox. According to the framework, after exposure to a stimulus, the health literacy demand of the stimulus interacts with a person's health literacy skills to influence comprehension of the message. Health literacy demand is defined as the complexity and difficulty of a stimulus, and it was the focus of the data collection in the current study.

Population and sampling strategy

All healthcare professionals from eleven outpatient geriatrics clinics in the Quebec City area, Canada, were invited to participate in this project. Those who agreed were asked to identify patients (aged 65+ years) diagnosed with dementia of any severity among their clientele, and the patients' informal caregivers. They contacted those patients or their caregiver, asking permission for the research team to contact them and explain the project. The research team then followed up with each willing patient or caregiver. We aimed to recruit 27 patient/caregiver dyads, a large enough sample size for this type of testing.[37]

Study procedure

Decision Box prototypes development

We used a rapid review approach[35] and the Ottawa decision support framework[38] to create Dboxes prototypes that respected the international standards for patient decision aids.[14] The Dboxes provided information on the health problem of interest, included an exercise to help patients and caregivers clarify what mattered most to them, explained the probabilities of experiencing benefits or harms for each of the available options, and listed resources to guide those experiencing decisional conflict. Between two and four experts in the care of older adults with dementia (among healthcare professionals, informal caregivers, managers, representatives of community-based organizations devoted to these seniors, or clinical researchers involved in the organization of primary care or services delivered to seniors with dementia) reviewed and validated each Dbox.

Data collection

Nine patient/caregiver dyads were randomly selected as a subsample of all participants at each round and randomly assigned one of the three Dboxes (Dbox #1 to #3) studied, for three dyads/Dbox at each round (Figure 1). Copies of the Dbox were sent to study participants about one week prior to the interviews for them to review first. A trained moderator, a nurse trained in geriatric care (GB)—the same for all participants—then met them at their homes for data collection. Patients and the caregivers initially completed a questionnaire comprising questions on socio-demographic characteristics (age, gender, race, marital status, education level, income) and the type and duration of the relationship between caregiver and patient. In cases when patients were unable to complete the questionnaire, the caregiver completed it on their behalf. Then, using an interview guide, the moderator assessed participants' opinions of the strengths/areas of improvement of the Dboxes in fostering a shared decision-making behaviour, which was "to express their priorities to their healthcare professional regarding the decision to be made". The moderator also asked participants for suggestions to improve the Dboxes.

The moderator initially addressed all questions to the patient. If the patient did not participate actively in the discussion, then the moderator systematically sought the caregiver's suggestions (1) on how to get the older person to express their opinion and (2) how to modify the document to facilitate use by the older person. The caregivers' own perspectives on the strengths/weaknesses of the Dbox were also welcomed.

At the end of the session, able patients and caregivers completed a self-administered questionnaire, comprising : (1) the Chew three-item health literacy scale[39] adapted to French (personal communication, Holly Witteman, Laval University), (2) the patient version of the Information Assessment Method (IAM) for assessing the value of information[40] (3) eight items built from the Technology Acceptance Model (TAM-2),[41] to assess how useful and easy to use the Dbox was in *expressing their priorities to their healthcare professional regarding the decision to be made*, and (4) level of satisfaction with the Dbox on a 5-point smiley-face rating scale ranging from 1 (sad face) to 5 (smiling face).

The moderator took written notes during and after the interviews to describe non-verbal communication and interactions between the older person and his or her caregiver.

The interviews were recorded and transcribed verbatim.

Analysis of participants' experience between rounds

To tailor the DBoxes between rounds, the transcripts and notes were entered as project documents into specialized software (N'Vivo 10, QSR International, Cambridge, MA, USA). Two researchers (GB, AMCG) analysed the data using deductive/inductive thematic qualitative data analysis, first by searching for factors set out in the Health Literacy Skills framework,[36] then by integrating any new themes that emerged from the data. To this end, the two researchers reviewed the interview transcripts separately. They then compared their results and came to a consensus on a list of themes. They noted these themes in a codebook, labelled and defined them, and entered them in N'Vivo as nodes. One of the researchers (GB) then applied these preliminary codes to all the interview transcripts. Coding was updated as necessary, and the second reviewer (AMCG) checked the new codes to ensure consistency with the chosen framework.

Tailoring the Dboxes

To tailor the Dboxes, we assembled an expert panel that comprised graphic designers, a healthcare professional specialized in the care of older adults (GB), knowledge translation researchers (AMCG, HOW, GB), a human factors engineer (HOW), and on one occasion, a health literacy expert (EF). Between each round, this expert panel met to review the qualitative and quantitative findings and tailor the Dboxes to improve the participant experience, i.e. (1) limit their complexity (2) add any missing information, and (3) ensure that participants felt more empowered to express their priorities to the healthcare professional regarding the decision to be made.

We used the same evaluation/tailoring process after each of the three round.

Quantitative analysis and triangulation

We completed a descriptive statistical analysis of the questionnaire data at the end of the study using SAS (version 9.4, copyright SAS Institute Inc.). We then interpreted the results in light of the qualitative findings to understand further which factors would make it easier for patients and caregivers to express their priorities to their healthcare professional. We further synthesized insights from individual case studies in a cross-project analysis to reveal a pattern of findings across all cases.

Patient and public involvement

A caregiver to a person living with dementia (JB) participated in the study as a coinvestigator. This person participated to the study design and contributed in the development of the DBoxes by providing critical feedback before user testing.

Ethical issues pertaining to human subjects

When persons living with dementia were deemed able to provide consent by their healthcare professionals, they were directly invited to participate. To ensure minimal risk to the health of incapacitated adults, the research team sought informed consent from the caregivers of patients who could not themselves provide informed consent, in conformity with the Civil Code of Quebec.

Results

Participant characteristics

Healthcare professionals from six ambulatory geriatric clinics out of the 11 invited to participate recruited patients and their caregiver. These healthcare professionals invited 34 patients to take part, 23 of whom accepted (74%). Either one or two caregivers accompanied the participating patients, for a total of 27 participating caregivers.

Most of the 23 patients were aged 85 or more and had a high school education (Table 1A). They reported a mean level of health literacy competency of 2.0 ± SD of 1.5 (on a scale of 0 to 4, with 4=low literacy). We did not have access to their medical records, but the moderator—a registered nurse—qualitatively classified the severity of their dementia as moderate (n=9), severe (n= 9), or very severe (n=5).

Most of the 27 caregivers were aged between 45 and 85 and had completed undergraduate degrees (Table 1B). Caregivers reported a mean level of literacy competency of 0.8 ± SD of 1.1.

Research processes

Before the interviews, several caregivers offered suggestions on how to reduce the emotional burden of the information on the patient, such as changing some words in a sentence or adding pictures. As caregivers were the ones who knew the person best, they were able to warn the moderator to avoid certain subjects to limit the person's distress or anger (e.g., driving abilities).

Factors influencing adoption of shared decision making

Despite the main interview focus on identifying patient decision-aid features influencing their complexity, participants reported additional factors influencing their adoption of shared decision making. These factors were divided among individual moderators, professional practice mediators, social environment mediators, and healthcare organization mediators (Figure 2) in keeping with the Health Literacy Skills Framework.[36] Additionally, despite the main interview focus on participants' intention to express their priorities to their healthcare professional regarding the decision to be made, participants spontaneously discussed several other shared decision-making behaviours, which are listed in Figure 2.

Factors influencing the complexity of patient decision aids

Factors that were found to influence the complexity of patient decision aids were structured under three main themes: informational content, visual design, and values clarification (listed in Figure 2). The next sections describe these factors as they were brought up during the interviews and the features or strategies that were proposed to limit complexity and improve the user experience. A detailed description of these features and strategies are also listed in Table 2. Supplementary files #1 and #2 respectively present samples of the initial and final versions of one of the three Dboxes studied.

Informational content of the Dboxes

Purpose/Topic

Clarifying the purpose of the Dboxes was a more important concern in the first and second rounds, as participants devoted more time to commenting on these aspects. They often did not understand what the DBox was intended for, as illustrated in this comment from a caregiver:

> *"My father was starting to experience mild dementia, and when he read the document he got stressed thinking he would be evaluated. I knew he had read it, because he talked about it to me and I knew this is what he was talking about." (Caregiver #6, DBox #2)*

Several participants could not understand who the Dboxes were aimed at:

> *"That has nothing to do with us. It's not for us (caregiver) or the patient. So who is it for?" (Caregiver #9B, DBox#1).*

The team prioritized this issue and consequently added two statements to improve understanding—in large font at the top of the first page—describing whom the document was aimed at and what it was supposed to achieve. A pictogram was also added showing a person reading a printed document to represent the purpose of the Dbox. In the last version (Supplementary file #2), these features were emphasized even more by isolating them on a separate cover page, but we could not test this new layout as it was added in the last version. Personal stories were also added to the prototypes, to provide context for the Dbox and its use and purpose. Participants appreciated the stories, which increased their interest in the content. They also mentioned that the stories helped them relate the content to their personal situations, as described by this patient:

> *"The disorder that this man has [note from the author: the patient is referring to a character in the personal story], the memory loss and other*

> *memory problems… I thought about all that, my memory's slipping away, I hope it's going to be awhile before I lose it completely." (Patient #23, DBox #2)*

Missing information

In the first evaluation round, several participants formulated requests, often several, for very specific information missing from the DBox. They asked for more information on the health problem itself, on how it was assessed, on options that were not quite clear, on specific outcomes to an option, or on how to implement an option. Some of these questions were too specific to generate a change in the DBox template, and we could generally address them easily by adding to or modifying the text. For example, one caregiver asked for more information on driving skills assessment:

> *"When you're driving and you can't see the street name, then you can get lost. It's a physical issue [that makes driving dangerous], because your eyes are not working properly. But when does dementia make it dangerous to drive?" (Caregiver #11, DBox #2)*

Most of these issues were resolved after the first round.

Some of the requests for more information could be grouped together into broader categories and the template modified accordingly, so that future Dbox will have the missing information, before user evaluation. Firstly, we added a detailed description of each option to the Dbox template to address the needs for more information on the options. Secondly, we added a section listing contacts and resources (Supplementary file #2), to provide information on the services related to implement the options. People regularly asked whom to contact about the less familiar options, such as music or massage therapy, as illustrated in the following discussion between two caregivers:

> *Caregiver #1: "[…] Perhaps something you could add here would be 'refer to such and such a social worker, psychologist, psychotherapist' but for psychosocial needs, maybe you should indicate how to find those resources, which resources and where. That would be really important." (Caregivers #9A, DBox #1)*

Participants reported fewer issues with missing information as the rounds progressed. Most mentioned that they would use the information and that they were better equipped to discuss the health issue with someone, as demonstrated by this quote:

> *"But I think that document is more to know what's best for the person's well-being: drugs or no drugs. . . . And there are options if you don't want to be taking drugs. That's the purpose of the document. . . . In that regard I find the document to be complete." (Patient #1, DBox #1)*

Relevance

In every round, several participants mentioned that they found the Dboxes to be relevant, credible, interesting, or useful. They explained how the Dboxes provided good information and made them aware of the options available:

> *"It's well presented because we can see the advantages and disadvantages next to each other. It would definitely help someone to decide who has not made their mind up yet. It gives you all sides of the coin for the various options we have. It's important to plan ahead as you get older." (Caregiver #15, DBox #3)*

They also mentioned that the Dboxes gave them something to think about:

> *"It gets you thinking. It really gives you a good idea. If you think 'I want more protection, I don't want to be taken advantage of or something,' then that tells you to draw up advance directives. It points you in the right direction."(Patient #8, DBox #3)*

On the other hand, participants found some parts to be of little relevance, use, or interest. A number of caregivers mentioned that the DBox was of no use to patients who could not participate in the decision-making process because of cognitive decline. To address this issue, the DBox template was modified to give the caregiver equal billing as a target user, specifically on the cover page in the bottom line (Supplementary file #2, p. 2) and in the values clarification exercise (Supplementary file #2, p. 4).

Other participants' comments were to the effect that the information on evidence, GRADE ratings, and benefit and harm probabilities was for clinicians and was irrelevant to them, as this quote shows:

> *"Anyway, I mean this page, to be practical—page 4—the harms, I would take it out altogether. I would leave it up to the clinicians to read that. We have no use for the studies that've been done." (Caregiver # 9, DB #1)*

No strategy was found to address this in the DBox template. In the first prototype, the DBox already recommended that the healthcare professional share the decision with the patient, so we emphasized this in the last version of the template by using a visual representation of SDM and by putting the message in a box in the last version to highlight it (Supplementary file #2, p. 3).

Other comments were more topic-specific and could not be addressed by adjusting the DBox template. For example, the introduction to DBox#2 (Stopping driving) described the healthcare professional's responsibilities with regard to driving assessment. Patients and caregivers considered this irrelevant.

> *"Take the section aimed at the healthcare professionals […], in any event, I think you probably shouldn't put the emphasis on that, or at least you should make the part that really concerns the patient bigger so that they can really concentrate on what's essential." (Caregiver #6, DBox #2)*

Clarity of content

The participants consistently mentioned the complex terminology and sentence structure as important barriers, as this quote shows:

> *"Physical activity, touch therapy, music therapy, aroma therapy: for me, sure, but for them at their age, I'm not sure they know what they mean. Those who don't have much education definitely don't know what these are." (Caregiver #13, BD#1)*

To address this issue, we added a step to the development process, before user testing. It consists in checking the text reading level with online freeware (e.g. https://www.webpagefx.com/tools/read-able/, WebpageFX Inc, US) so that it corresponds to a 6th grade level. We also added a glossary to the DBox template, to define more complex terms for which we could not find simpler synonyms. The notation "see definition in the glossary on p. x" in parentheses after the term referred users to the glossary. In the last version (Supplementary file #2), the word was also highlighted and underlined.

Participants also commented on the risk communication strategies used. One person thought that percentages were obvious and did not understand that the Dbox also used natural frequencies:

> *"It reads 'Out of 100 people, 33 will experience stress symptoms.' People are going to think 33% rather than to keep the two figures separate. . . . It depends on the person, but a dog is a dog. You don't need to draw it, you can just write 'dog'." (Caregiver #20, DBox #3)*

In addition, participants were often surprised by the harms (for example that stopping driving led to an increased risk of dying). As mentioned above, some respondents thought that this type of content should be provided to clinicians and that it was irrelevant to them.

Several participants did not understand the GRADE scale. They noted the lack of explicit link between the GRADE rating beside the evidence and the legend at the bottom of the page. To address this, the Dbox template now has an invitation to "see legend" in parentheses after each GRADE symbol. One participant suggested using green, yellow, and red instead of the '+' for a more intuitive representation of the quality of the evidence. This idea was not implemented because the Dbox needed to be usable in a black & white version.

Several participants grasped the essence of the GRADE scale displaying the quality of the evidence, as this quote shows:

> *“No, it’s all very clear. And also when you look at the legend, it’s even easier to see how advanced the research is from that viewpoint. Some are quite obvious, but others you can see don’t have a lot of data from what is shown.” (Caregiver #16, Dbox #3)*

Visual design

Participants shared several recommendations on the Dbox visual design, which we further categorized into layout, pictures, colour, and font (Figure 2).

Layout

‘Layout’ comprised participants’ comments on navigation, organizers, length and density. Navigation proved difficult in the first rounds as several participants became lost when they moved from one section to another, such as between the health options and the contact section (located at the end of the document). We thus adjusted the DBox template by adding organizers and textual cues to the related section (e.g. “see glossary,” “see the list of resources on page x”).

We also removed the reference list, as the reference numbers in the text caused confusion. We chose to provide the reference list on the DBox website instead for those (e.g., caregivers) who might be interested in reviewing the sources of evidence.

Participants also recommended adding a table of contents at the beginning of the document to help navigation, and to allow choosing the sections relevant to them, as this quote shows:

> *“Maybe say, ‘There are a number of activities available. Choose those that interest you.’ Or have an index like in a book: animal therapy, see page 3. Because maybe they felt obligated to see all the activities and read them all. Maybe it was confusing. Maybe give them the option, or say, ‘Here are several activities that can reduce aggressiveness…’” (Caregiver #7, DBox #x)*

To meet this need, we moved the Values Clarification Exercise to a position right after the Introduction. This allowed people to choose their priority first, and then read only about the options meeting those priorities, instead of having to read about all the options. In addition to improving navigation, this also shortened the time required to read the document.

Dbox #3 (power of attorney) received several comments on how complex the information was and how hard it was for respondents to compare the three legal options. After receiving several questions from participants on the legal concepts in the first version of the Dbox, we added more information in the second round, which upped the number of pages from 5 to 9 in Round #2. Users disliked this longer version, as the quantitative finding below shows, despite the fact that it was much more comprehensive. In the third version, we therefore clarified this information in a large table setting out the legal implications of the various options (Supplementary file #2). This addition improved users' experience, made the Dbox shorter, and reduced their complexity.

Pictures

In the first round, several people found the Dboxes hard to read because they consisted mainly of text. Some people, such as this caregiver, suggested adding pictures to make things more engaging:

> *"I don't think you can get away from having text, but maybe not so much detail... Maybe you could add some pictures… maybe a little drawing, a car in an accident, to provide illustration and so that people don't have to concentrate so hard to read the sentence right to the end." (Caregiver #6, BD#2)*

In the second round, we therefore added pictograms strategically to draw attention to the most important text. These generated positive comments, but we did not use them systematically, nor consistently, and some participants found them unclear. In the last Dbox template that has not yet been evaluated (Supplementary file #2), we systematically added pictograms specially designed by a graphic designer to illustrate (1) the purpose of the Dbox on the cover page, (2) each of the activities covered in the Dbox (Introduction, Clarifying priorities, Exploring the options, Choosing an option, Glossary), (3) the bottom line on page 2, (4) each option, and (5) the Contacts section.

Colours

Participants found the Dboxes' colors attractive and helpful to facilitate reading:

> *"It's well presented. Colourful documents like that are attractive and nice to consult. It's also easy to spot information from page to page. Benefits and harms can be compared side by side and the other. I really liked the document." (Caregiver #15, DBox #3)*

Values clarification exercise

The values clarification exercise underwent major changes throughout the study. Most participants did not understand the first version of the exercise, which was designed using the Ottawa Decision Support Framework.[38] We initially observed that a number of participants did not understand the meaning of the word “preference,” so we replaced it with “priorities”. This resolved the issue and improved participants’ understanding of the purpose of the exercise.

Additionally, the exercise asked users to assess the extent to which each priority mattered to them, using a 6-level Likert scale. Some people perceived it as too detailed, and some caregivers mentioned that patients might have difficulty using this scale, as they were unfamiliar with rating scales:

> *“Well, it’s my generation but not his [speaking of the person in his care], so when I look at this form, I look which side is important and which side is not important, then Bingo I complete it. . . . But for him…” (Caregiver #6, DBox #2)*

After the first round, we thus removed the Likert scales and used a checklist instead, asking people to select a single priority from a list (Supplementary file #2, p. 4). For each item on the list, the Dbox then proposed a list of options for meeting that priority, and the page number to view evidence of that option’s benefits and harms. These modifications improved participants’ understanding of the purpose of the exercise—participants reflected more on the benefits vs. harms, and before and during the interview they talked more about their priorities for that decision. For example, with this new format, some people understood perfectly well that they had to choose what mattered most to them among the list of items, but they were reluctant to do so considering the decisional conflict they had to face:

> *“If I have to choose only one—live longer or maintain a good health—who wouldn’t pick to live as long as possible? For sure, I would. Or stay in good general health, of course, I would pick that. I wouldn’t go saying I don’t want to drive anymore. So I don’t know. It’s a strange question.” (Caregiver #16, DBox #2)*

We revised the sentences expressing each of the priorities several times, as participants considered some to be unclear or illogical.

Quantitative results and triangulation with qualitative findings

The quantitative data from the questionnaires suggest that participants’ perceptions of the Dboxes were generally positive, with TAM-2 mean scores mostly above 4 (scale of 1-7, with 7 indicating positive perceptions), and satisfaction mean scores above 3 (scale of 1 to 5, with 5 indicating positive perceptions) (Figures 3A-B, 4A-B, 5A-5B).

However, the patients who evaluated Dboxes #2 (driving) and #3 (power of attorney) in round #2 reported lower satisfaction and lower perceptions of Dbox usefulness than did the patients in rounds #1 and #3 or the caregivers (Figures 4A-4B, Figure 5A-5B). They also gave lower understanding and relevance scores on the IAM questionnaire (Table 3). During the interviews, these five patients commented repeatedly on the lack of clarity of the content and on the inappropriate terminology in the Dboxes, for example:

> *"I have trouble understanding. When you start talking about legal stuff, you lose me." (patient #15, BD #3)*

The participants in the first round and second rounds frequently reported problems with the information, but these were mostly resolved in the third round (Tables 3-4: cognitive impact of the information). Only three people—1 caregiver (#23) and 2 patients (#22, #19)—still reported problems with the information in round 3. The interview transcripts reveal that these patients only talked about how hard they found the text to understand, how long it was, or how much trouble they had remembering what they had just read. As for the caregiver, he commented that he thought it was inappropriate for the DBox to list taxicabs or public transit as resources for people who need to stop driving due to dementia:

> *"It's okay for people who don't have driver's licences anymore, but still want to go out and still have the ability. But there's no way she could ever take a cab or assisted transport. It depends on how serious your cognitive loss is. . . . At first, things were fine. She would take cabs to go places. She would travel to and from her sister's by cab. But I'm not sure I'd let her do that now. There are lots of options, and they help lots of people, but it depends on how bad your memory loss is." (Caregiver #23, BD#2)*

Patients and caregivers most frequently reported in the questionnaire that they expected the information to help them be better equipped to discuss something with someone else, to have more confidence in deciding about something with someone else, and to prevent an issue (Tables 3 and 4).

Caregivers' perceptions of DB#3 (power of attorney) were also generally observed to improve as the rounds progressed (Figure 5B).

Discussion

We studied which features of patient decision aids may limit their complexity and improve the experience of older adults living with dementia and their caregivers as they prepare for shared decision making with healthcare professionals. We described a series of practical features and design strategies to improve the user experience of patient decision aids and limit the number adjustments required during user testing. Some participants considered scientific evidence to be for healthcare professionals' use only and thus had no interest in such content. Other participants understood concepts related to the quality of scientific evidence and methodological biases. Quantitative measures allowed collecting distinct feedback from patients and caregivers.

Strength and weaknesses of the study

A strength of this research project lies in its multiple case design that allowed suggesting general features for adapting patient decision-aid templates to user needs. Integration of user feedback in a UCD approach also represents a strength of this study. However caregivers may have been less spontaneous in some of their opinions because of the presence of the person in their care, and this could have influenced our conclusions. The presence of caregivers may also have caused some of the seniors with dementia to be less spontaneous, particularly if their caregivers played a dominant role in the dyad. On the other hand, inviting caregivers to reflect on the changes needed for the patient decision aids to address the needs of the person in their care provided an opportunity to benefit from caregivers' own expertise in dementia while still receiving direct input from the patients themselves.

Relation to other studies

This is the first study focused on identifying general design features to tailor patient decision aids to the needs of seniors with dementia. It is also unique in its focus on the primary care offered to older persons living with dementia. Indeed, we found only three other reports on the impacts of patient decision aids, which targeted caregivers of older adults with advanced dementia recruited in nursing homes or acute care settings.[23,24,42] Their development and evaluation were guided by the Ottawa Decision Support framework,[38] which the authors adapted minimally. In one study, they added a tutorial regarding study design and the strength of evidence to the patient decision aid, due to limited high-quality evidence regarding the proposed options.[24] In the other, they specified revising the printed decision aid to a sixth-grade reading level, and sizes 16 to 20 font,[23] which agrees with our proposed features.

Other web-based support tools for this population have been studied, but did not qualify as patient decision aids.[43–45] For example, the *FIT* and *DEM-DISC* tools addressed a major gap, by helping caregivers of older adults living with dementia in clarifying their most pressing needs and identifying supportive products and services meeting to meet those needs.[43,44] This converges with the current study findings that patient decision aids for this population should provide a list of the available resources to support users in their implementation of the selected option. Interestingly, among the three designs evaluated for *FIT*, caregivers and healthcare professionals appreciated the exercise that used ticking of checkboxes the most, as it was more familiar to them and allowed people to view all the choices at once.[43] Another such tools worth mentioning is the web-based *DecideGuide* that served to support communication and step-by-step shared decision-making among the network of people involved in the care of the person living with dementia.[45] However, most of the challenges reported by users of the *DecideGuide* concerned web-based and interactive aspects of the tool, and are not applicable to a printed patient decision aid.

Interestingly, some of the current study participants understood the GRADE level of confidence display, which provides a deeper understanding of the uncertainty associated with each risk estimate. GRADE ratings communicate one of the types of uncertainty related to the outcomes of medical interventions, which is the ambiguity about the strength or validity of evidence about risks,[46] also named ‘epistemic uncertainty’.[47] Despite the influence of uncertainty on patients’ choices, there is considerable variation in approaches to communicate it in the patient decision aids currently available, and more than half do not communicate epistemic uncertainty.[21] The current project thus adds observations on the potential of the GRADE strategy to communicate epistemic uncertainty to patients/caregivers. Future research should look into how GRADE ratings are understood by patients, and how they influence patient preferences.

Participants requested that we enliven the documents by adding pictures. Research on health communication suggests that combining well-designed pictures with written or spoken text enhances attention, recall of health education information, and understanding, especially among groups with lower literacy.[48] Pictures should illustrate key points, be accompanied by text using simple language, be simple to minimize distracting details, and be selected with people from the intended audience to ensure cultural relevance.[48] While several studies focus on the inclusion of graphs in patient decision aids to improve risks understanding,[49,50] fewer focus on the impacts of other types of pictures on user experience of these tools. Importantly, a recent qualitative study described how pictures conveying important and detailed information combined with icon arrays in a patient decision aid were perceived as explanatory and easy to understand by women of low socioeconomic status.[27] There is also some evidence on the pictures characteristics to support informed decision-making,[51] but high-quality evidence on the impacts of pictures–and their key features–on decision quality is still lacking.

Our findings also provide new evidence on the factors potentially influencing the health literacy demand of a stimulus, recognized in the Health Literacy Skills Framework [36] as influencing comprehension of the message. Our practical descriptions of content and visual design features of health-related stimuli allow shifting the focus away from the person targeted, towards improvement of the stimuli to reach wider audiences.Meaning and implications of findings

Some comments by participants were useful to suggest features to be used systematically so that the same issues would not come up again when new patient decision aids are developed. On the other hand, some of the reported issues cannot be addressed generally, as they were specific to a given health problem, intervention, or outcome. UCD thus remains essential to help users clarify their needs. For example, some topics require the use of technical terminology, such as BD #3 on the power of attorney that included a lot of legal terminology. Some topics may also elicit a very strong emotional response, which might be impossible to foresee and may lengthen the design process.

The glossary proved essential for patient decision aids targeting older adults with dementia and their caregivers, but navigation to access it was a challenge. Web-based decision aids should use pop-ups or other methods to provide definitions without further navigation.

When patient decision-aid templates require major changes to address topic-specific issues, developers should plan one or several additional evaluation rounds. In the current study, the DBox on the power of attorney required adding much information on the various legal options in the second round, generating lower scores before the table comparing the various options and their features were incorporated in the third round.

The wording used to express priorities required several rounds before we were able to arrive at the best expression, which suggests that the list of priorities would benefit from the input from a patient/caregiver expert panel. Moreover, the panel could be involved early in the rapid review process, to help identify those priorities, accelerate the review process, and streamline the literature search to identify patient priorities early on.

Having questionnaires made it possible to collect patients’ perceptions independently from their caregivers’. This might be a good way to ensure that patients with caregivers nevertheless make their preferences known and questionnaires could be validated in this regard specifically with people with dementia.

Unanswered questions and future research

Several participants questioned the provision of scientific evidence on the benefits and harms of the available options in the DBoxes. Such comments might reflect a negative attitude toward the shared decision making approach, but more likely demonstrates a lack of understanding of shared decision making principles, namely that patients should be informed of the benefits and harms of each option to partake in decision-making. This suggests that patient/caregiver education is required to change attitudes toward SDM before patients and caregivers can really partake in shared decision-making. Training is a promising strategy to address this issue.[52]

To improve understanding of risks, the Dboxes provide probabilities formulated in two different ways, i.e., in natural frequencies (e.g., for every 100 persons, 30 experience an effect) and in percentages (30%). Our risk communication strategy thus conforms with the current literature to the effect that risks should be presented in several formats to ensure that a broader audience is attained.[53] However, we did not use icon arrays, to avoid lengthening the DBox, which we designed as a printable pdf. With as many as 10 options and 62 health outcomes in some of the Dboxes for this population, icon arrays seemed inappropriate. A future study on a web-based DBox would be useful to assess older adults' perceptions of icon arrays displayed in pop-up windows.

More research is required to evaluate whether the modified DBox template, which now comprises several features intended to improve understanding, will allow designing more satisfactory patient decision aids for this population in fewer UCD rounds.

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Contributors

AMCG designed this study with JL-B, PV, EK, HOW, and FL. AMCG and GB collected, analysed, and interpreted the data. JL-B, PV, EK, AMCG, and GB critically revised and co-authored one or several DBoxes studied herein. AMCG, GB, HOW and M-CT participated in the initial drafting of the manuscript. All authors drafted, critically revised and gave final approval of the article. AMCG acts as guarantor.

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Competing interest

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) All authors have support from their employing organizations for the submitted work; (2) No authors have had relationships with organizations that might have an interest in the submitted work in the previous 3 years; (3) Their spouses, partners or children have no financial relationships that may be relevant to the submitted work; and (4) Authors have no non-financial interests that may be relevant to the submitted work.

Ethical approval

This study was approved by the *Comité Central d'Éthique de la Recherche* (CCER) of the *Ministère de la Santé et des Services Sociaux* (#15-16-05).

Data sharing

No additional data available.

Transparency

The guarantor (AMCG) affirms that the manuscript is a honest, accurate, and transparent account of the study bring reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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Table 1. Demographic characteristics of participating (A) patients, and (B) caregivers.

A-Patients

Characteristic	Frequency (%) n = 23
Female	13 (57)

Age	65-74	0
	75-84	8 (35)
	85 and more	15 (65)
Education	No education	0
	Elementary	5 (22)
	High school	11 (48)
	College	2 (8.7)
	University	5 (22)
Income ($)	0 – 24,999	12 (52)
	25,000 – 34,999	6 (26)
	35,000 – 49,999	1 (4.3)
	50,000 – 74,999	3 (13)
	75,000 – 99,999	1 (4.3)
	100,000 – 150,000	0 (0)
	150,000 +	0 (0)
Health literacy		
Self-reported frequency of having someone helping read medical materials	(0) Never	7 (30)
	(1) Occasionally	4 (17)
	(2) Sometimes	4 (17)
	(3) Often	4 (17)
	(4) Always	4 (17)
	Mean (± SD)	1.7 (±1.5)
Self-reported confidence with forms	(0) Extremely	4 (17)
	(1) Quite a bit	4 (17)
	(2) Somewhat	3 (13)
	(3) A little bit	3 (13)
	(4) Not at all	9 (39)

	Mean (± SD)	2.4 (±1.6)
Self-reported problems learning about medical condition because of difficulty reading medical materials.	(0) Never	5 (22)
	(1) Occasionally	7 (30)
	(2) Sometimes	2 (8.7)
	(3) Often	4 (17)
	(4) Always	5 (22)
	Mean (± SD)	1.9 (±1.5)
Marital status	Single	1 (4.4)
	Married or common-law partner	11 (48)
	Widow	11 (48)
	Separated	0 (0)
	Divorced	0 (0)
Living with caregiver, n (%)		11 (48)

B-Caregivers

Characteristic		Frequency (%) n= 27
Female		15 (56)
Age	24 and less	0 (0.0)
	25-44	0 (0.0)
	45-64	13 (48)
	65-84	11 (41)
	85+	3 (11)
Education	No education	0 (0.0)
	Elementary	2 (7.4)
	High school	8 (30)
	College	9 (33)
	University	8 (30)
Self-reported frequency of having someone helping read medical materials	(0) Never	16 (59)
	(1) Occasionally	4 (15)
	(2) Sometimes	5 (19)
	(3) Often	2 (7)
	(4) Always	0 (0.0)
	Mean (± SD)	0.7 (± 1.0)
Self-reported confidence with forms	(0) Extremely	16 (59)
	(1) Quite a bit	8 (30)
	(2) Somewhat	1 (4)
	(3) A little bit	0 (0.0)
	(4) Not at all	2 (7)
	Mean (± SD)	0.7 (± 1.1)
Self-reported problems	(0) Never	9 (33)

learning about medical condition because of difficulty reading medical materials.	(1) Occasionally	10 (37)
	(2) Sometimes	6 (22)
	(3) Often	0 (0.0)
	(4) Always	2 (7)
	Mean (± SD)	1.11 (± 1.1)
Relationship with the patient	Family member	26 (96)
	Friend	1 (4)
	Professional	0 (0.0)
	Other	0 (0.0)
Approximate number of years in the care of the patient, mean (±SD)		10.3 (± 14)

Table 2 Features of patient decision aids and design strategies to limit their complexity and improve users' experience

Finding	**Feature or design strategy to limit issue**
Unclear purpose/topic of the patient decision aid	• Clear statements in larger fonts describing who the decision aid is aimed at, and what it aims to achieve • Pictogram or images showing people using the patient decision aid to represent its purpose • Personal story displaying the context of use, and purpose of the patient decision aid
Irrelevance of patient decision aid to people with dementia	• Recognizing caregivers' role in decision-making through explicit statements that the patient decision targets caregivers equally to patients
Arduous read or unclear content	• Systematic and frequent use of high-quality pictograms to illustrate text • Glossary to define complex terminology • Write out the text at a 6th grade reading level; • Removal of the references within the text; reference list included on the DBox website • Use "priority" instead of "preference"
Missing information on the options	• Detailed and comprehensive **description of each option** • For the more complex options: propose **personal stories** displaying a person going through the option
Missing information on the next steps to implement the selected option following decision-making	• **Contact section** listing contacts, resources and available services to implement each of the option
Missing topic-specific information, irrelevant content	• Use a **user-centred design process** until information needs are met and all sections are perceived as relevant
Quality of the evidence	• Offer information on the quality of the evidence to those interested
Challenge using the Likert rating scales in the values clarification exercise	• Asking users to select a single preference in a **checklist**; avoid rating scales

Proposing meaningful priorities in the values clarification exercise	• Involve a **panel of patient/caregiver partners** at start of development with mandates to (1) propose a list of priorities to guide the literature review, and (2) revise the wording of priorities extracted from the scientific evidence (further evaluation required)
Navigation challenges	• When the patient decision aid comprises more than two options, use the **values clarification exercise** to streamline navigation by inviting users to read more on the options meeting their priorities • Use **textual cues** to refer to GRADE ratings and to the glossary • Use **visual cues** (e.g. pictogram of the options) and **colours** to structure the general layout
Irrelevance of scientific evidence to patients/caregivers	• Explain the targeted shared decision making behaviours in text and, if possible, with pictures • Train patients/caregivers in shared decision making to prepare them to review information on the benefits and harms of the options (further evaluation required)

Table 3. Patients' report of the value of Decision Boxes per round: ratings based on the patient version of the Information Assessment Method (IAM)[40]

	Frequency (n/N)			
	Round 1	Round 2	Round 3	All Round
Relevance				
This information is...				
... totally relevant	3/9	0/7*	0/5*	3/21
... relevant	6/9	4/7*	5/5*	15/21
... somewhat relevant	0/9	1/7*	0/5*	1/21
... irrelevant	0/9	2/7*	0/5*	2/21
Understanding				
They understood this information...				
... completely	3/9	3/7*	1/5*	7/21
...mostly	4/9	1/7*	2/5*	7/21
...poorly	1/9	2/7*	2/5*	5/21
...not at all	1/9	1/7*	0/5*	2/21
Cognitive impact of the information				
They learned something new	4/9	0/8	2/6	6/23
This information allowed them to confirm what they do, or did	5/9	3/8	2/6	10/23
They are reassured	6/9	1/8	3/6	10/23
They were reminded of something they already knew	5/9	1/8	1/6	7/23
They are motivated to learn more	4/9	2/8	4/6	10/23
There is a problem with the presentation of this information	5/9	1/8	2/6	8/23
They disagree with the content of this information	0/9	0/8	0/6	0/23
This information is potentially harmful	1/9	1/8	0/6	2/23
Information use				
They will use this information	5/9	4/8	2/6	11/23
This information will...				
...help them improve their understanding of a particular issue and make a decision	3/5	1/4	0/2	4/11
...help them do something when they did not know what to do	2/5	0/4	0/2	2/11
...convince them to do something that they already wanted to do	1/5	1/4	0/2	2/11
...allow them to change the way they do something	2/5	1/4	0/2	3/11

…allow discussing something with someone else (a relative or a healthcare professional)	5/5	2/4	1/2	8/11
Expected benefits of the information				
They expect the information to help…				
…be less worried	2/5	0/4	0/2	2/11
…be better equipped to discuss something with someone else (a relative or a healthcare professional)	4/5	3/4	2/2	9/11
…have more confidence in deciding something with someone else (a relative or a healthcare professional)	3/5	1/4	1/2	5/11
…handle an issue	2/5	1/4	0/2	3/11
…prevent an issue (or prevent it from getting worse)	4/5	0/4	0/2	4/11
They expect no benefits	2/5	0/4	0/2	2/11
Expected consequences				
They expect that the use of this information can have a negative impact on their well-being of their health	1/5	1/4	0/2	2/11

*One missing data

Table 4. Caregivers' report of the value of Decision Boxes per round: ratings based on the patient version of the Information Assessment Method (IAM)[40]

	Frequency (n/N)			
	Round 1	Round 2	Round 3	All Round
Relevance				
This information is...				
... totally relevant	3/11	6/10	2/6	11/27
... relevant	8/11	4/10	3/6	15/27
... somewhat relevant	0/11	0/10	1/6	1/27
... irrelevant	0/11	0/10	0/6	0/27
Understanding				
They understood this information...				
... completely	4/11	8/10	3/6	15/27
...mostly	6/11	2/10	3/6	11/27
...poorly	1/11	0/10	0/6	1/27
...not at all	0/11	0/10	0/6	0/27
Cognitive impact of the information				
They learned something new	2/11	5/10	5/6	12/27
This information allowed them to confirm what they do, or did	6/11	5/10	2/6	13/27
They are reassured	1/11	4/10	4/6	9/27
They were reminded of something they already knew	3/11	3/10	2/6	8/27
They are motivated to learn more	4/11	6/10	2/6	12/27
There is a problem with the presentation of this information	4/11	2/10	1/6	7/27
They disagree with the content of this information	2/11	0/10	0/6	2/27
This information is potentially harmful	1/11	0/10	0/6	1/27
Information use				
They will use this information	7/11	9/10	6/6	22/27
This information will...				
...help them improve their understanding of a particular issue and make a decision	1/7	2/9	4/6	7/22
...help them do something when they did not know what to do	0/7	0/9	1/6	1/22
...convince them to do something that they already wanted to do	2/7	2/9	3/6	7/22

…allow them to change the way they do something	0/7	1/9	2/6	3/22
…allow discussing something with someone else (a relative or a healthcare professional)	2/7	6/9	2/6	10/22
Expected benefits of the information				
They expect the information to help them…				
…be less worried	0/7	4/9	4/6	8/22
…be better equipped to discuss something with someone else (a relative or a healthcare professional)	6/7	7/9	4/6	17/22
…have more confidence in deciding something with someone else (a relative or a healthcare professional)	2/7	3/9	2/6	7/22
…handle an issue	1/7	3/9	2/6	6/22
…prevent an issue (or prevent it from getting worse)	2/7	3/9	6/6	11/22
They expect no benefits	0/7	0/9	0/6	0/22
Expected consequences				
They expect that the use of this information can have a negative impact on their well-being of their health	0/7	1/9	0/6	1/22

Figure captions:

Figure 1: User-centred design process of three Decision Boxes (Dboxes) for seniors with dementia and their caregivers.

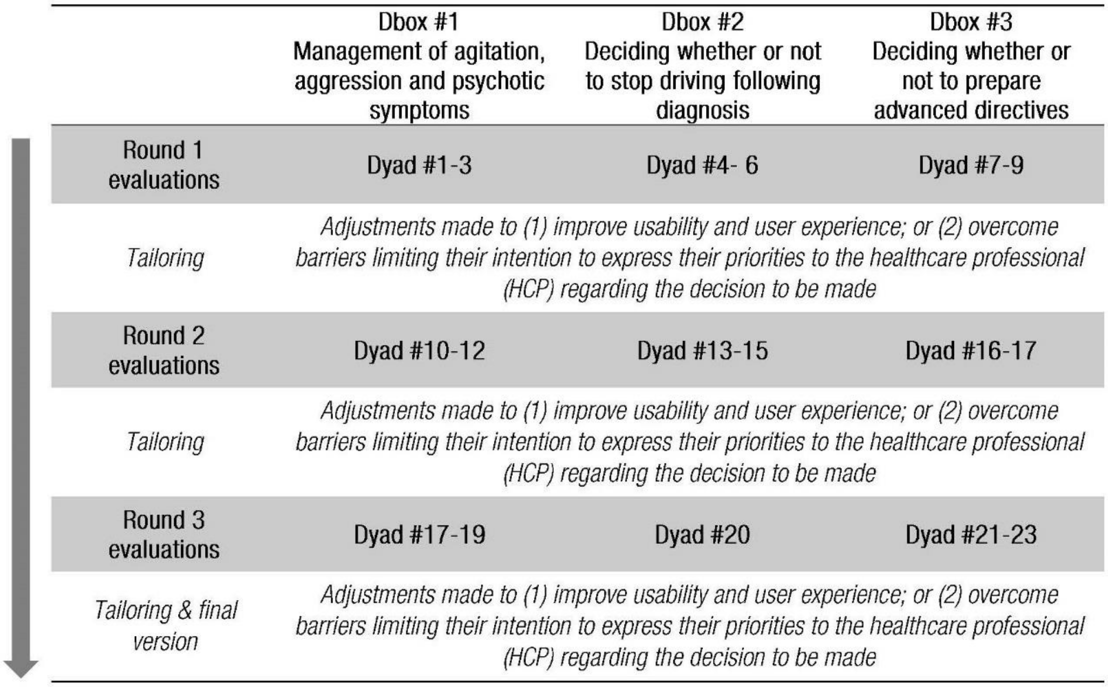
Figure 2: Factors influencing adoption of shared decision making behaviors by patients/caregiver dyads, adapted from Squiers' Health literacy skills framework.

Figure 3: Satisfaction, ease of use, and usefulness of the Decision Box #1 (agitation, aggression, psychotic symptoms) as evaluated by (A) older people with dementia; and (B) their caregivers.

Figure 4: Satisfaction, ease of use, and usefulness of the Decision Box #2 (driving) as evaluated by (A) older people with dementia; and (B) their caregivers.

Figure 5: Satisfaction, ease of use, and usefulness of the Decision Box #3 (power of attorney) as evaluated by (A) older people with dementia; and (B) their caregivers.

Figure 1. User-centred design process of three Decision Boxes (Dboxes) for seniors with dementia and their caregivers



	Dbox #1 Management of agitation, aggression and psychotic symptoms	Dbox #2 Deciding whether or not to stop driving following diagnosis	Dbox #3 Deciding whether or not to prepare advanced directives
Round 1 evaluations	Dyad #1-3	Dyad #4- 6	Dyad #7-9
Tailoring	*Adjustments made to (1) improve usability and user experience; or (2) overcome barriers limiting their intention to express their priorities to the healthcare professional (HCP) regarding the decision to be made*		
Round 2 evaluations	Dyad #10-12	Dyad #13-15	Dyad #16-17
Tailoring	*Adjustments made to (1) improve usability and user experience; or (2) overcome barriers limiting their intention to express their priorities to the healthcare professional (HCP) regarding the decision to be made*		
Round 3 evaluations	Dyad #17-19	Dyad #20	Dyad #21-23
Tailoring & final version	*Adjustments made to (1) improve usability and user experience; or (2) overcome barriers limiting their intention to express their priorities to the healthcare professional (HCP) regarding the decision to be made*		

Figure 2: Factors influencing adoption of shared decision making behaviors by patients/caregiver dyads, adapted from Squiers' Health literacy skills framework

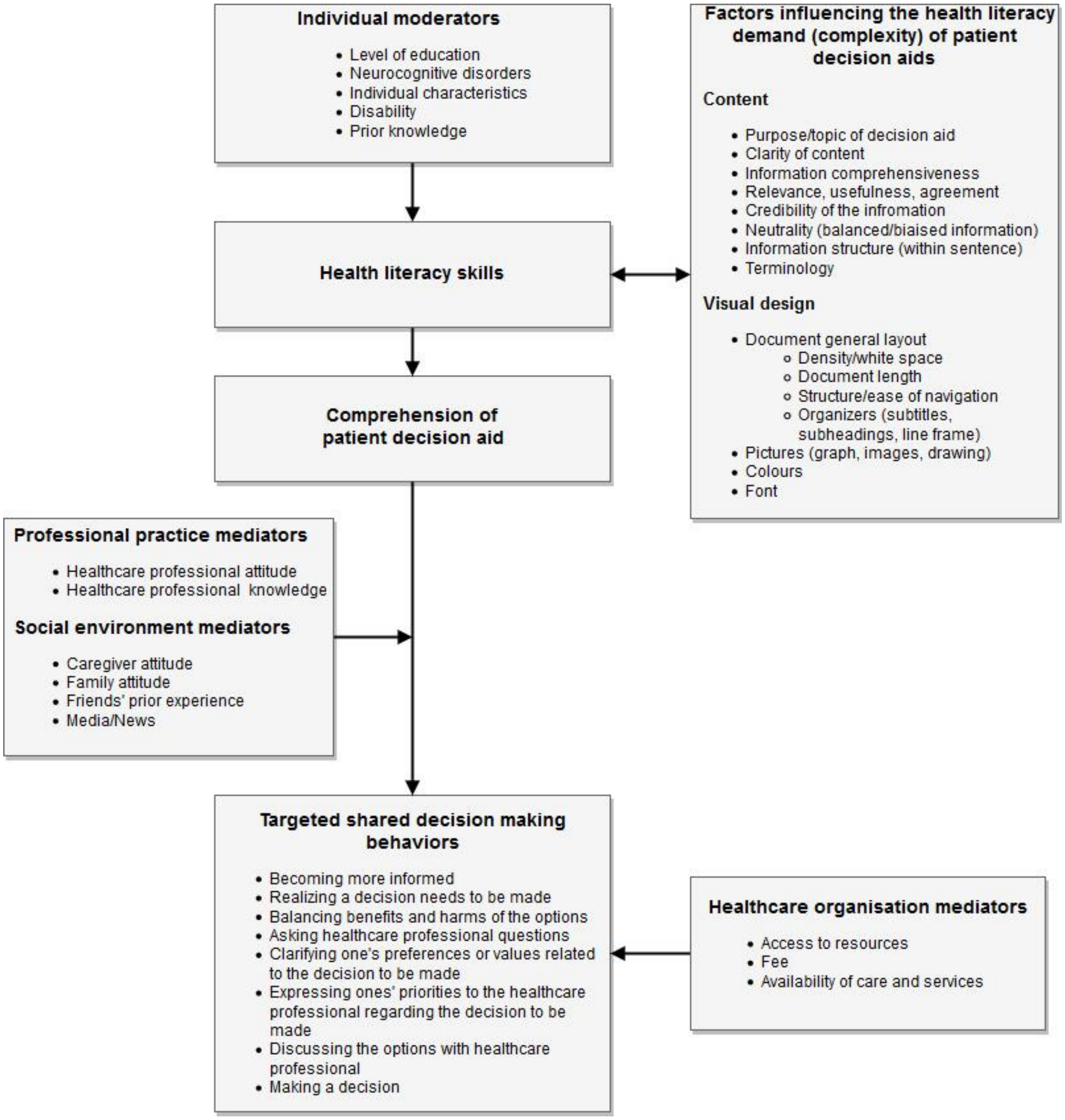
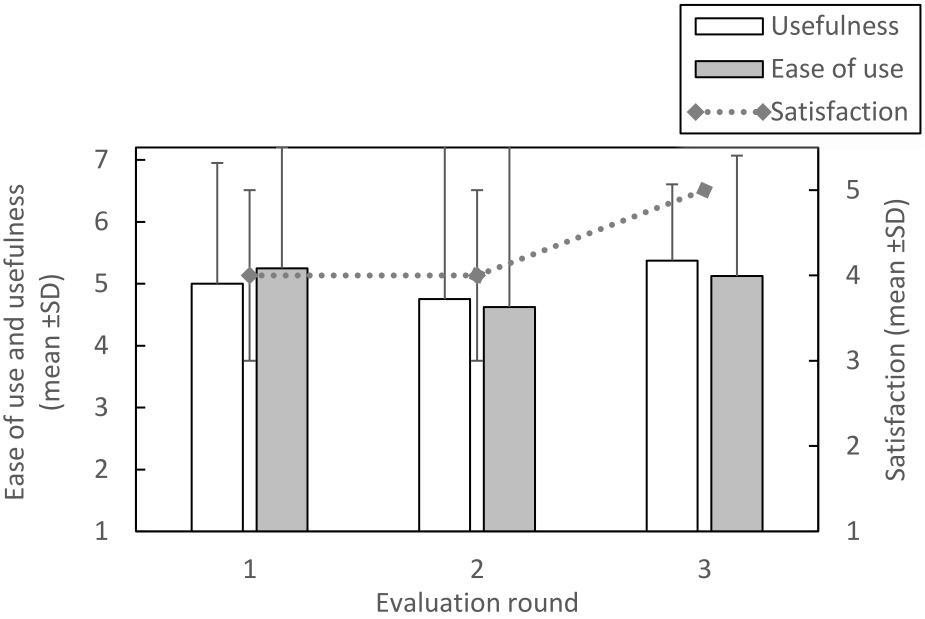


Figure 3. Satisfaction, ease of use, and usefulness of the Decision Box #1 (agitation, aggression, psychotic symptoms) as evaluated by (A) older people with dementia; and (B) their caregivers.

A-Older people with dementia



B- Caregivers

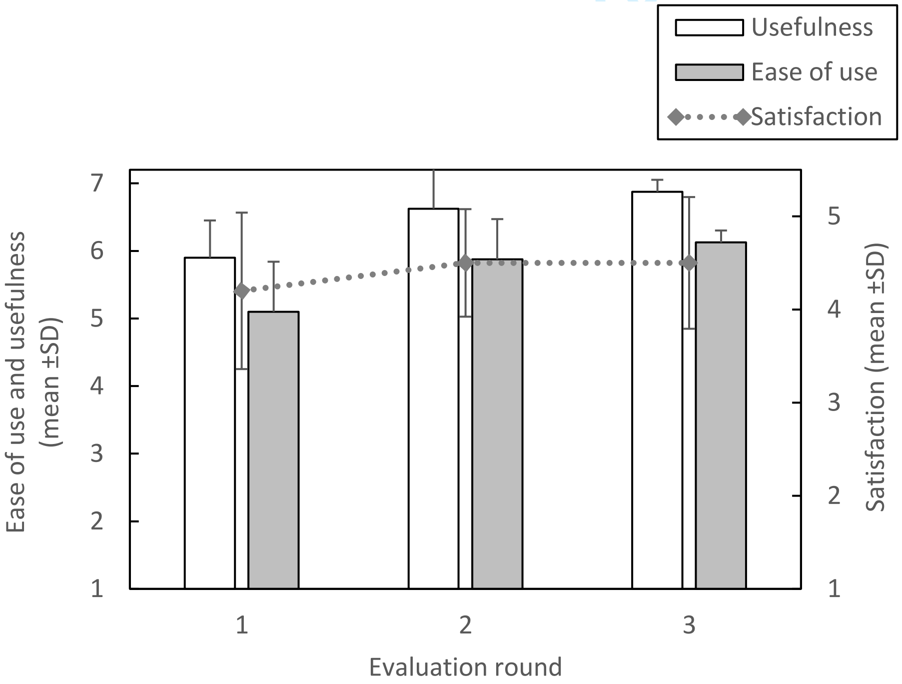
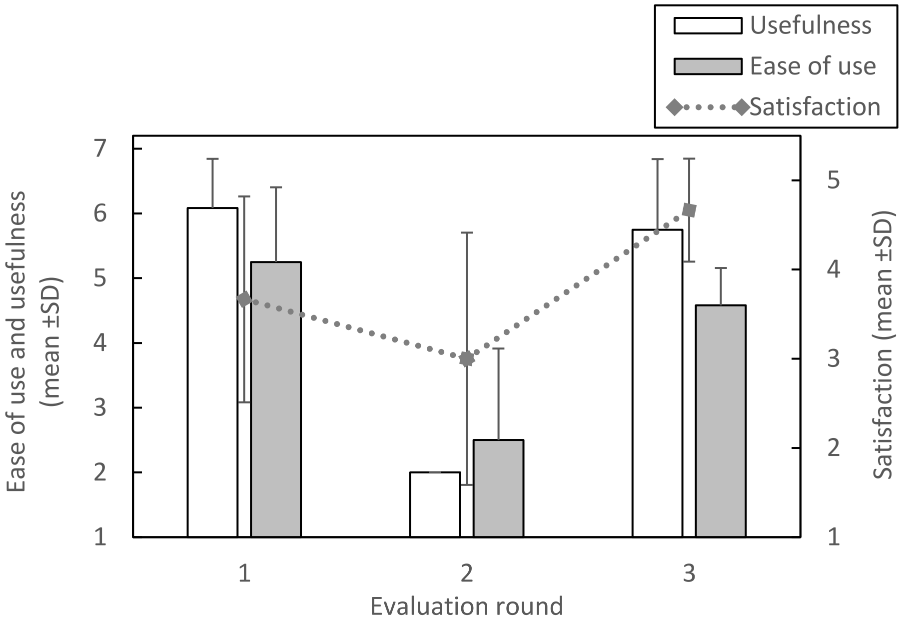


Figure 4. Satisfaction, ease of use, and usefulness of the Decision Box #2 (driving) as evaluated by (A) older people with dementia; and (B) their caregivers

A - Older people with dementia



B- Caregivers

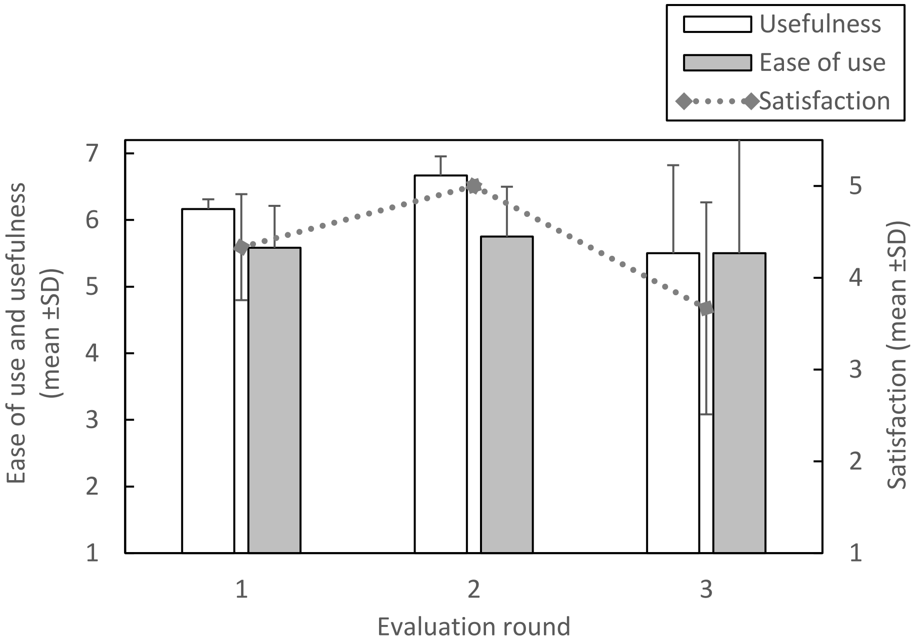
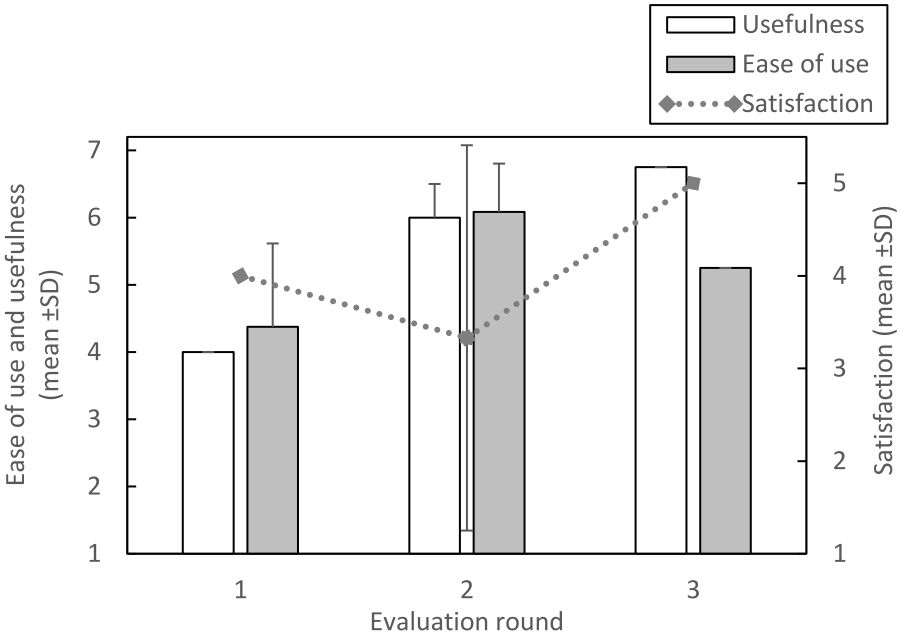
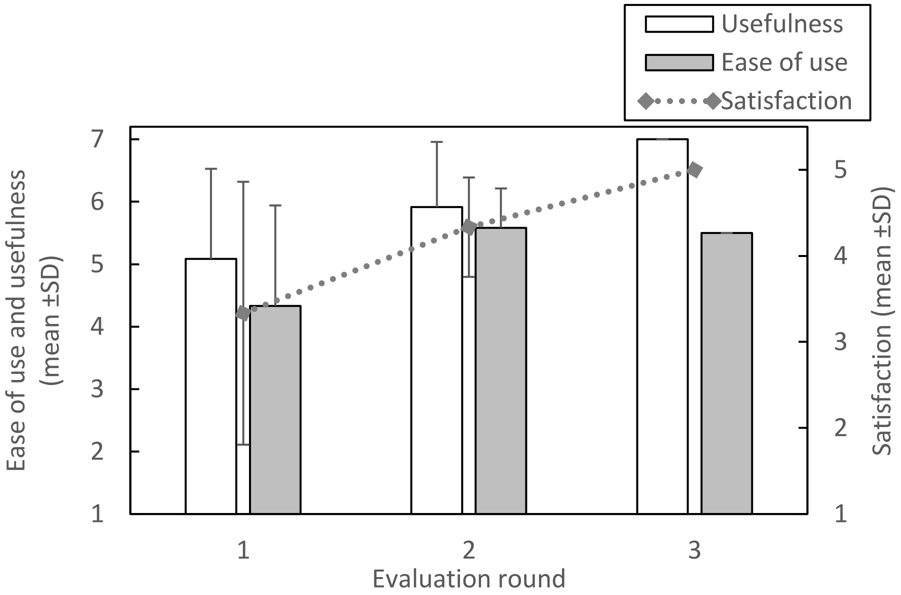


Figure 5. Satisfaction, ease of use, and usefulness of the Decision Box #3 (power of attorney) as evaluated by (A) older people with dementia; and (B) their caregivers.

A- Older people with dementia



B- Caregivers



Prototype

Decision Box PATIENT

to help you reach a decision

UNIVERSITÉ LAVAL

*Choosing Whether or Not to Prepare a Protection Mandate**

What are the other options ?

▷ Presenting the protection mandate to older people and their loved ones

What is meant by incapacity ? [1]

- Incapacity is the inability to accomplish a specific task at a given moment, or to analyze or understand the implications of this inability or the consequences of one's decisions. A person may be considered incapacitated due to their physical or mental state.
- A person who is incapacitated may maintain their legal capacity, provided the court has not deprived them of such capacities, however the person can no longer give their valid consent for a medical act. [1]
- **Legal incapacity can only be declared through a court ruling once the person has been found to be incapacitated, and results in a protection mandate or the homologation of a protection mandate.**

What is a protection mandate ? [2]

- A notarized or non-notarized document (holograph).
- Comes into effect once the incapacity has been documented in a medical and psychosocial assessment and after the court has homologated the mandate.

Allows the senior to… [2-4]

- Express how they wish their property and well-being to be managed in the event they become incapacitated;
- Express their end-of-life care preferences;
- Knowingly appoint the person of their choice to act on their behalf in the event they are incapacitated;
- Protect themself against abuse and negligence, thanks to the investigative powers of the Public Curator

Who should consider a protection mandate ?

- Any person considered of sound mind, especially those with a medical condition that puts them at greater risk of becoming incapacitated and unable to care for themselves or their property.
- Persons with neurocognitive impairment who are more likely to need to make decisions related to end-of-life treatments5 and who have a more limited capacity for making such decisions.[5]

*This document is also known in jurisdictions outside Quebec (Canada) as a **lasting power of attorney**, **power of attorney for personal care**, **representation agreement, personal directive**, **advance healthcare directive**, or **healthcare proxy**, among others.

▷ Why should the preferences of patients and their natural caregivers be taken into account?

- **There are pros and cons to preparing a mandate.** For example, a protection mandate allows the older adult to choose their end-of-life care, maintain their autonomy, retain their civil rights, and limit stress on their loved ones who are required to make decisions on their behalf. However, a protection mandate entails costs and a wait time of several months. It can also lead to financial abuse by the mandatary.
- **There is a lack of scientific information on the impacts of preparing a protection mandate.**
- **There are other protection options for patients who are of sound mind:** [3 6-8]
  - Ordinary mandate:
    - A written document (notarized or not) that allows you to name one or more persons to act on your behalf for certain predetermined administrative acts;
  - Adviser for adults (legal measure) :
    - To assist and advise patients in managing their property;
    - They are not authorized to take legal action on the person's behalf;
  - End-of-life care directives or living will: [9]
    - Indicates the patient's preferences with regard to treatment to prolong life and to relieve pain;
  - Advance medical directives (as per Bill 52, Quebec's Act respecting end-of-life care): [10]
    - Sets out the medical care a patient agrees to, or refuses, in specific clinical situations.

▷ Both preparing and not preparing a mandate are acceptable options, so we propose that…

1. The decision take into account the patient's and caregiver's **values** and **preferences**
2. The healthcare professional **share this decision** with the patient and the caregiver

Benefits
Associated with Preparing a Protection Mandate

The person appointed makes decisions ⊕⊕○○

- Of 100 mandataries appointed by the person in a mandate, **92 actually make decisions on behalf of the person** (92%). [5]

You choose your care yourself ⊕○○○

- Of 100 people who set out their end-of-life care wishes, between **50 and 97 receive their desired care**:[5]
  - 97 % receive comfort care, as requested.[5]
  - 83 % receive more limited care, as requested.[5]
  - 50% receive all possible care, as requested.[5]

You maintain the right to exercise your civil rights

- A protection mandate allows the older adult to continue to **exercise their civil rights** (e.g., the right to marry). This is possible only with a protection mandate or an adviser to a person of legal age.

Cancelling a mandate is difficult

- The mandate remains legally valid until proven otherwise. It can only be rendered invalid by the courts, by proving that the patient was incapacitated at the time the mandate was prepared.

Shorter legal proceedings

- There are fewer steps required to homologate the mandate than to institute a tutorship or curatorship.
- When a person has been shown to be incapacitated, the mandate can be homologated even if protection is not yet required, because the person has expressed their desire for such protection by drafting the mandate.

See more on the next page

Harms
Associated with Preparing a Protection Mandate

Risk of mistreatment or abuse

- Unlike in a tutorship or curatorship, it is not the Public Curator's role to supervise how mandataries manage the person's property and money. The Public Curator intervenes only when someone reports a possible case of mistreatment or abuse. The protection mandate can, however, include certain clauses to limit the powers of the mandatary and reduce the risk of abuse.

Directives sometimes not applicable ⊕○○○

- Of 100 people appointed to make decisions for the patient, 11 report that the advance medical directives regarding end-of-life care do not apply to most of the decisions they will have to make.[5]
- Of 100 people appointed to make decisions for the patient, 14 report experiencing difficulties in applying the patient's directives[5]

Risk of financial abuse

- Since the mandatary is not held accountable until the mandate ends, there is a risk of financial abuse. However, the older adult can choose to include a clause that obliges the mandatary to report to a designated individual at a set frequency.
- If the mandatary has full administrative authority, this increases the risk of financial abuse, since the mandatary can make any investments, guaranteed or otherwise, unlike in a tutorship or curatorship.

Non-compliance with advance medical directives by loved ones or medical staff ⊕○○○

- Of 100 older adults who indicated their resuscitation preferences in an advance medical directive, 37 do not receive their desired treatment.[15]

See more on the next page

* https://www.curateur.gouv.qc.ca/registre/pcurateur_man_html/criteres.jsp

Confidence in these results

⊕○○○ : Very low	⊕⊕⊕○ : Moderate
⊕⊕○○ : Low	⊕⊕⊕⊕ : High

Benefits
Associated with Preparing a Protection Mandate

Access to the patient's protection status

- Medical staff, notaries, and government agencies can **easily check the protection status** of the patient in the registry of homologated mandates maintained by the Public Curator.*

You maintain your autonomy

- Le patient n'est pas considéré comme incapable au plan juridique.
- Le patient peut faire élaborer des actes juridiques selon les restrictions qu'il s'est lui-même imposées en rédigeant le mandat.

Less stress for loved ones ⊕○○○

- Of 100 people who may have to make a decision for a patient at some point, **33 will experience symptoms of post-traumatic stress.** [11]
- A protection mandate can make it easier for loved ones to make end-of-life treatment decisions.

Improved communication between patients and loved ones ⊕○○○

- Of 100 patients (with their loved ones) who plan to prepare a protection mandate, the 28 who discuss the matter amongst themselves will be in greater agreement than those who do not communicate with one another (28%). [12,13]

No additional anxiety or symptoms of depression ⊕○○○

- Patients who discussed plans to prepare a protection mandate experience no additional anxiety or symptoms of depression compared to those who didn't.[13,14]

Harms
Associated with Preparing a Protection Mandate

Wait time of several months

- Preparing a protection mandate and having it homologated usually takes several months. However, during this period, certain temporary provisions can be put in place, as needed, to protect the person (e.g., management of their affairs, domestic mandate, administration by a third party, or emergency legal measures).

Only the mandatary can ask for the mandate to be homologated

- If the mandatary cannot or no longer wishes to assume their functions, the task falls to the replacement mandatary, if there is one.

Must be homologated in its entirety

- The protection mandate must be homologated as is. For example, if the person is able to care for themselves, but not their property, while the mandate stipulates protection of both, then it cannot be homologated solely for management of the person's property. In this case, a protection regime will need to be instituted, however the court may take into consideration the wishes set out in the mandate.

Generates costs

- Mandate preparation fees are in effect (drafting: $30; homologation: $1,000; bailiff, etc.), however, these fees are lower than those incurred to institute a curatorship or tutorship (institute proceedings: $2,000; bailiff; summoning of witnesses; property management fees, where applicable; protection of the person, where required: $1,000/year).
- Requires medical and psychosocial assessments, for which fees may be charged if done in the private sector.
- May be covered in part or fully by legal aid or paid out of the patient's pocket.

† http://www.avocat.qc.ca

Confidence in these results

⊕○○○ : Very low

⊕⊕○○ : Low

⊕⊕⊕○ : Moderate

⊕⊕⊕⊕ : High

Making My Decision

Discuss it with your health professional!

How important is it for you...	NOT important					VERY important	Possible Options
... to determine, yourself, how your property, well-being, and end-of-life care will be managed if you become incapacitated?	⓪	①	②	③	④	⑤	Prepare a protection mandate
... that decisions about your end-of-life care be taken by the person of your choice?	⓪	①	②	③	④	⑤	Prepare a protection mandate
... that you continue to be able to exercise your civil rights?	⓪	①	②	③	④	⑤	Prepare a protection mandate
... that you reduce the stress on your natural caregivers?	⓪	①	②	③	④	⑤	Prepare a protection mandate
... that you avoid the risk of financial abuse?	⓪	①	②	③	④	⑤	Do not prepare a protection mandate
... that you avoid medical and psychosocial assessments?	⓪	①	②	③	④	⑤	Do not prepare a protection mandate
... that you avoid extra costs?	⓪	①	②	③	④	⑤	Do not prepare a protection mandate
... that you avoid a wait time of several months if you require protection?	⓪	①	②	③	④	⑤	Do not prepare a protection mandate

Other considerations? ____________________

Which option do you prefer ? ____________________

Are you comfortable with your decision ?		Yes	No
Sure of myself	1) Do you feel SURE about the best choice for you?	☐	☐
Understand the information	2) Do you know the benefits and risks of each option?	☐	☐
Risk-benefits ratio	3) Are you clear about which benefits and risks matter most to you?	☐	☐
Encouragements	4) Do you have enough support and advice to make a choice?	☐	☐

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References : Available at www.boitedecision.ulaval.ca

VERSION 1.0 | DECEMBER 2018

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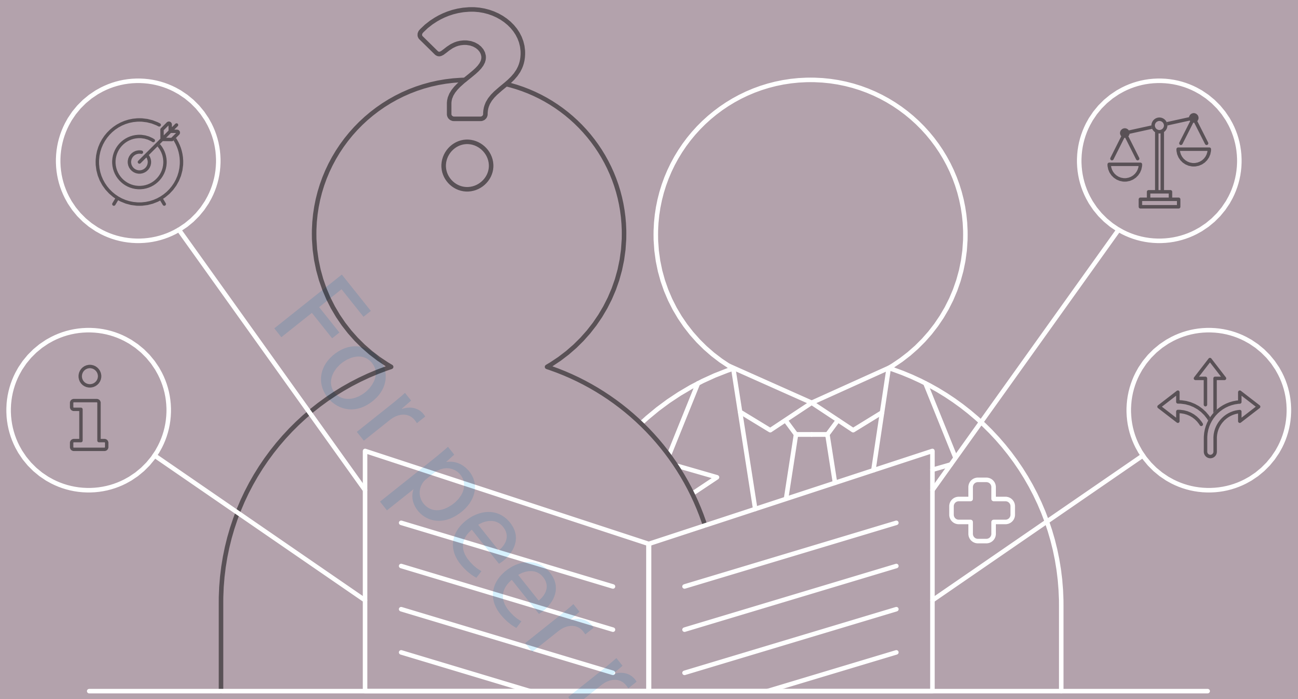

Decision Box for patients

Incapacity in Older People

Choosing Whether or Not to Prepare a Protection Mandate*

THIS DOCUMENT IS AIMED AT...

- Patients with memory and attention disorders who live in the community
- Natural caregivers of patients with memory and attention disorders

THIS DOCUMENT IS DESIGNED TO...

- Inform patients and their loved ones about some of the options available
- Help prepare the person and their loved ones for discussions among themselves and with health professionals
- Help patients and their loved ones choose an option that reflects their priorities and capacities

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* This document is also known in jurisdictions outside Quebec (Canada) as a ***lasting power of attorney***, ***power of attorney for personal care***, ***representation agreement***, ***personal directive***, ***advance healthcare directive***, or ***healthcare proxy***, among others.

INTRODUCTION

Who and why?

Incapacity

- A person is considered incapacitated when they are **unable to take care of themselves, manage their property, or express their wishes.**
- Incapacity can be caused by a mental or degenerative illness, a stroke, an intellectual disability, a head injury, or a weakened state as a result of disease.
- Persons who are incapacitated may continue to manage their affairs and make decisions regarding their health themselves, **provided the court has not deprived them of their legal capacities.**
- The courts may determine legal incapacity further to an incapacity finding*.

Examples of behaviours of an incapacitated person

- Difficulty following a familiar recipe.
- Hesitation when performing simple tasks like locking the door or getting dressed.
- Changes in their spending habits or budget management.

Protection Mandate*

- An official, notarized* or holograph document*
- Allows a person to:
  - **Express their wishes** about how they would like to be looked after and how their property is to be managed in the event they are incapacitated.
  - Knowingly **appoint the person of their choice to act on their behalf** in the event they are incapacitated (mandatary*).
- **Includes advance medical directives** that allow the person to express their care preferences (consent to care, end-of-life care wishes), for example, to avoid non-beneficial medical care.
- The protection mandate allows you to **appoint one or more persons to look after you and your property while you are still alive.**
- A protection mandate is **not a will.** The purpose of a will is strictly to state how and to whom your property will be distributed after your death.
- The protection mandate **annuls all the powers of attorney** authorized by the person (e.g., for their banking, or to look after them or manage their property).

* See Glossary p. 8

* This document is also known in jurisdictions outside Quebec (Canada) as a ***lasting power of attorney***, ***power of attorney for personal care***, ***representation agreement***, ***personal directive***, ***advance healthcare directive***, or ***healthcare proxy***, among others.

INTRODUCTION (CONT'D)

Who and why?

Who can consider preparing a protection mandate?

Any person considered of sound mind, especially those with a medical condition that puts them at greater risk of becoming incapacitated and unable to care for themselves or their property.

Steps for preparing a protection mandate

1. Choose what you want to indicate in the mandate, e.g., mandatary, housing preferences, consent to care, preferences regarding property management, end-of-life wishes.
2. Discuss with your loved ones your desire to draw up a protection mandate.
3. Choose one or more mandataries.
4. Prepare your mandate with the help of a professional (lawyer or notary) or using the online form (see list of resources on page 7).
5. Let your loved ones know about your protection mandate, and keep a copy of it in a safe place.

Example of Mrs. Rose Gibson

Mrs. Gibson is a widow who suffers from Alzheimer's disease. She has no children and is no longer capable of taking care of herself. For instance, she forgets to pay her bills and to take her medication. When her husband was still alive, she drew up a holograph protection mandate in which she named her husband as mandatary, in the event she became incapacitated. Her husband has since passed away, but she had taken the precaution of naming a nephew and niece as replacement mandataries. Her mandataries will ask that the mandate be homologated, will ensure that Mrs. Gibson receives the care she needs, and will look after paying her bills. They will also make sure that the instructions she set out in her protection mandate are followed.

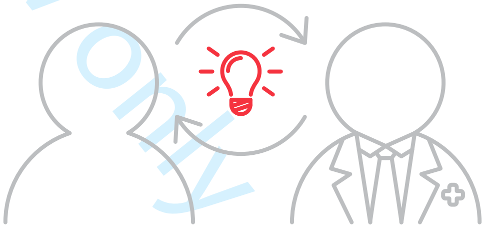
What if the court determines that a person is incapacitated and they don't have a protection mandate?

Another type of protection regime will be instituted, and a tutor or curator will be appointed (see page 5 for details).

Taking patient priorities into account

Depending on their priorities, patients **may decide to prepare a protection mandate or not**. The choice is up to them because...

- There are **pros and cons** to preparing a mandate.
- There is a **lack of scientific information** on the impacts of preparing a protection mandate.



We recommend that...

- The decision take into account the patient's and caregiver's values and priorities.
- The healthcare professional share this decision with the patient and, if necessary, with the caregiver.

PRIORITIES

Exercise to clarify your priorities
For patients and their natural caregivers

CLARIFYING MY PRIORITIES

SELECT WHAT IS MOST IMPORTANT TO YOU.

✓ CHECK ONE ITEM ONLY.

○ **Decide myself HOW my property, well-being, and healthcare will be managed**

POSSIBLE OPTIONS:

- Protection mandate **(see p. 5)**

○ **Retain my civil rights (like the right to vote)**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**

○ **Protect myself against financial abuse**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**
- Tutorship **(see p.6)**
- Curatorship **(see p.6)**

○ **Limit the stress on my loved ones**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**

○ **Express my wishes and preferences**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**
- Tutorship **(see p.6)**

○ **Limit the legal costs**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**

○ **Decide myself WHO will make decisions about my care**

POSSIBLE OPTIONS:

- Protection mandate **(see p.5)**

○ **Other:** ______________________________

____

____

List the options **(see p.5-6)** that allow respecting this priority:

____

____

____

____

OPTIONS

Explore the options

Protection Mandate

previously known as "mandate in case of incapacity"

BENEFITS

Decisions are taken by the mandatary ⊕⊕○○

Of 100 mandataries appointed by the person in a mandate, 92 **actually make decisions on behalf of the person** (92%).

Choice to consent to certain care or not ⊕○○○

Of 100 people who set our their end-of-life care wishes, between 50 and 97 **receive their desired care**:

- 97% receive comfort care, as requested.
- 83% receive more limited care, as requested.
- 50% receive all possible care, as requested.

Less stress for loved ones ⊕○○○

Of 100 people who may have to make a decision for a patient at some point, 33 **will experience significant symptoms of stress** (33%).

A protection mandate can **make it easier for loved ones to make end-of-life treatment decisions**.

↑ **Communication between patients and loved ones** ⊕○○○

Of 100 patient (with their loved ones) who plan to prepare a protection mandate, the 28 who discuss the matter amongst themselves will will be in **greater agreement** than those who do not communicate with one another (28%).

No additional anxiety or symptoms of depression ⊕○○○

Patients who discussed plans to prepare a protection mandate experience **no additional anxiety or symptoms of depression** compared to those who didn't.

HARMS

↑ **Risk of mistreatment or abuse**

Unlike in a tutorship or curatorship, it is not the Public Curator's role to supervise how mandataries manage the person's property and money. The Public Curator intervenes only when someone reports a possible case of mistreatment or abuse.

The protection mandate can, however, include certain clauses to limit the powers of the mandatary and reduce the risk of abuse.

Directives sometimes not applicable ⊕○○○

Of 100 people appointed to make decisions for the patient, 11 report that the advance medical directives regarding end-of-life care do not apply to most of the decisions they will have to make (11%).

Of 100 people appointed to make decisions for the patient, 14 report experiencing difficulties in applying the patient's directives (14%).

Non-compliance with advance medical directives by loved ones or medical staff ⊕○○○

Of 100 older adults who indicated their resuscitation preferences in an advance medical directive, **37 do not receive their desired treatment** (37%).

Must be homologated (enter into effect) in its entirety

The protection mandate m**ust be homologated** as is. For example, if the person is able to care for themselves, but not their property, while the mandate stipulates protection of both, then it cannot be homologated solely for management of the person's property. In this case, a protection regime will need to be instituted, however the court may take into consideration the wishes set out in the mandate.

CONFIDENCE IN THESE RESULTS:

⊕⊕⊕⊕ **High:** Further research is very unlikely to change our confidence in the estimate of effect.
⊕⊕⊕○ **Moderate:** Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.
⊕⊕○○ **Low:** Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.
⊕○○○ **Very low:** Any estimate of effect is very uncertain.

	PROTECTION MANDATE	TUTORSHIP	CURATORSHIP
GENERAL DESCRIPTION	Allows the person who is of sound mind to express how they wish their property and well-being to be managed, and to choose the person who will act on their behalf in the event they become incapacitated.	Required by the court for a person who has not prepared a protection mandate and who becomes temporarily incapacitated	Required of persons who have not prepared a protection mandate and who become permanently incapacitated. Last-resort solution.
CHOOSING THE PERSON IN CHARGE	The person chooses the mandatary (see Glossary, page 8) who will act on their behalf.	A tutorship council chaired by a judge appoints a tutor in accordance with the recommendations of the person's loved ones. The person is not consulted during this process.	A tutorship council chaired by a judge appoints a curator (private or public, see Glossary, page 8) inv accordance with the recommendations of the person's loved ones. The person is not consulted during this process.
MAKING DECISIONS	The mandatary is obliged to ensure the person's decisions are complied with, as described in the mandate.	The tutor makes all the decisions for the person, in accordance with their wishes, if they are known, but is not obligated to respect them. Allows the person to express their wishes, insofar as they are capable of doing so.	The curator makes all the decisions for the person, in accordance with their wishes, if they are known, but is not obligated to respect them.
RISK OF ABUSE	The mandate must include certain clauses to reduce the risk of abuse by the mandatary.	The tutor is supervised by the Public Curator.	The Public Curator requires that persons providing care and services to the individual submit reports.
CIVIL RIGHTS, E.G., RIGHT TO VOTE	Upheld	Lost	Lost
DURATION OF LEGAL PROCEEDINGS	Relatively short proceedings	Longer proceedings	Longer proceedings
RELATED COSTS	**Mandate preparation fees:** • Drafting ($30) • Notary ($350-500) • Homologation of protection mandate ($1,000) • Medical and psychosocial assessments ($1,025 to $1,500) **Annual fee:** $0	**Preparation fees:** • Instituting protective supervision ($2,062) • Legal fees ($1,000) • Bailiff ($20) • Medical and psychosocial assessments ($1,025 to $1,500) **Annual fees:** Property management fees vary according to the person's needs: protection of the person ($1,030/year). The tutor can ask to be paid a salary.	**Preparation fees:** • Instituting proceedings ($2,062) • Legal fees ($1,000) • Bailiff ($20) • Medical and psychosocial assessments ($1,025 to $1,500) **Annual fees:** Property management fees vary according to the person's needs: protection of the person ($1,030/year).
RISK OF CONFLICT	Between loved ones and mandatary	Between the tutor and the person's loved ones	Between loved ones and the curator
STRESS FOR LOVED ONES	Less	More	More

CHOOSING AN OPTION

Do you prefer to prepare a protection mandate, or not?

____

Are you comfortable with you choice?

		YES	NO
Sure of myself	Do you feel SURE about the best choice for you?	○	○
Understand information	Do you know the benefits and risks of each option?	○	○
Risk-benefits ratio	Are you clear about which benefits and risks matter most to you?	○	○
Encouragement	Do you have enough support and advice to make a choice?	○	○

RESOURCES AND CONTACTS

Protection Mandate form:

www.curateur.gouv.qc.ca/cura/en/outils/publications/mon_mandat.html

How to prepare a protection mandate:

Notary: 1-800-NOTAIRE (1-800-668-2473) or www.cnq.org/en/famillies-couples.html

Curator: www.curateur.gouv.qc.ca/cura/en/outils/publications/mon_mandat.html

To report a situation of mistreatment, negligence, or abuse of a person under a protection mandate:

Public Curator: www.curateur.gouv.qc.ca/cura/en/outils/joindre/index.html or 1-800-363-9020 (toll free)

For more information on elder abuse:

La ligne Aide, Abus, Aînés: www.aideabusaines.ca or 1-888-489-2287 (toll free)

Other resources:

Association des proches aidants de la Capitale-Nationale: 418-688-1511 or www.apacn.org

Société Alzheimer de Québec: 418 527-4294 or www.societealzheimerdequebec.com/wp/

GLOSSARY

Definitions

Mandatary

The person who receives a mandate or power of attorney to represent their mandatee in a legal act.

Tutorship council

One to four persons with an interest in the person and who are named by the court to take part in decisions regarding the management of the individual's property or well-being.

Incapacity finding

Incapacity is determined by a medical and psychosocial assessment.

Notarized document

Document that is signed before a notary, indicating it has been authenticated. Notarized documents are harder to challenge in court. The notary will register the notarized document in the register of mandates at the Chambre des notaries du Quebec.

Document in the presence of witnesses, or holograph

Document prepared without the help of a notary that is signed by the person and two witnesses who attest that the person is of sound mind. In the case of a holograph mandate, it will be homologated by the court at the time of the incapacity finding. This type of document can also be completed with the help of a lawyer.

Curator

Legal representative named by the court to represent the person who has become incapacitated, ensure their protection, and manage their property. The curator is named following a recommendation by the tutorship council made up of one to three people with a close relationship to the patient, insofar as possible.

Private curator

Anyone in the circle of friends and family of the adult needing protection can be named as their curator, as long as the person is an adult or emancipated minor: spouse, partner, family member, friend, or another person close to the protected person.

Public Curator

If no one in the person's circle of friends and family can or wants to be the curator, the court will name the Public Curator to act as the person's curator.

Management of property

Consists of partial or complete management of all the property belonging to the person (e.g., building and objects), and of their financial affairs (e.g., income, interest, and investments). Under a tutorship, the tutor is obligated to preserve and maintain the value of the property for which they are responsible. They can also make investments provided they are presumed to be sound. Under a curatorship, the curator must preserve the value of the property, and also has a duty to try and make it increase in value. In a curatorship, all financial decisions, such as selling or hypothecating a building, are considered legitimate actions, while in a tutorship, the tutor requires the approval of the court before taking out any loans, selling any property, or hypothecating a building.

Management of well-being

Includes all decisions relating to the health and well-being of the incapacitated person. The tutor responsible for managing the person's well-being, and the curator, are tasked with authorizing or refusing medical care, looking after the custody and care of the person, and obtaining a re-evaluation of the incapacity of the person every three years (tutorship) or every five years (curatorship). Responsibility for the custody and care of the person can be transferred to an establishment like a long term care facility or any other institution offering such essential services.

PROTECTION MEASURE

for patients of sound mind

Ordinary mandate

A written document (notarized or not) that allows you to name one or more persons to act on your behalf for certain predetermined administrative acts.

Adviser for adults (legal measure)

The adviser's role is to assist and advise patients in managing their property. They are not authorized to take legal action on the person's behalf.

End-of-life care directives or living will

Indicates the patient's preferences with regard to treatment to prolong life and to relieve pain.

Advance medical directives

(as per Bill 52, Quebec's Act respecting end-of-life care)

Sets out the medical care a patient agrees to or refuses in specific clinical situations.

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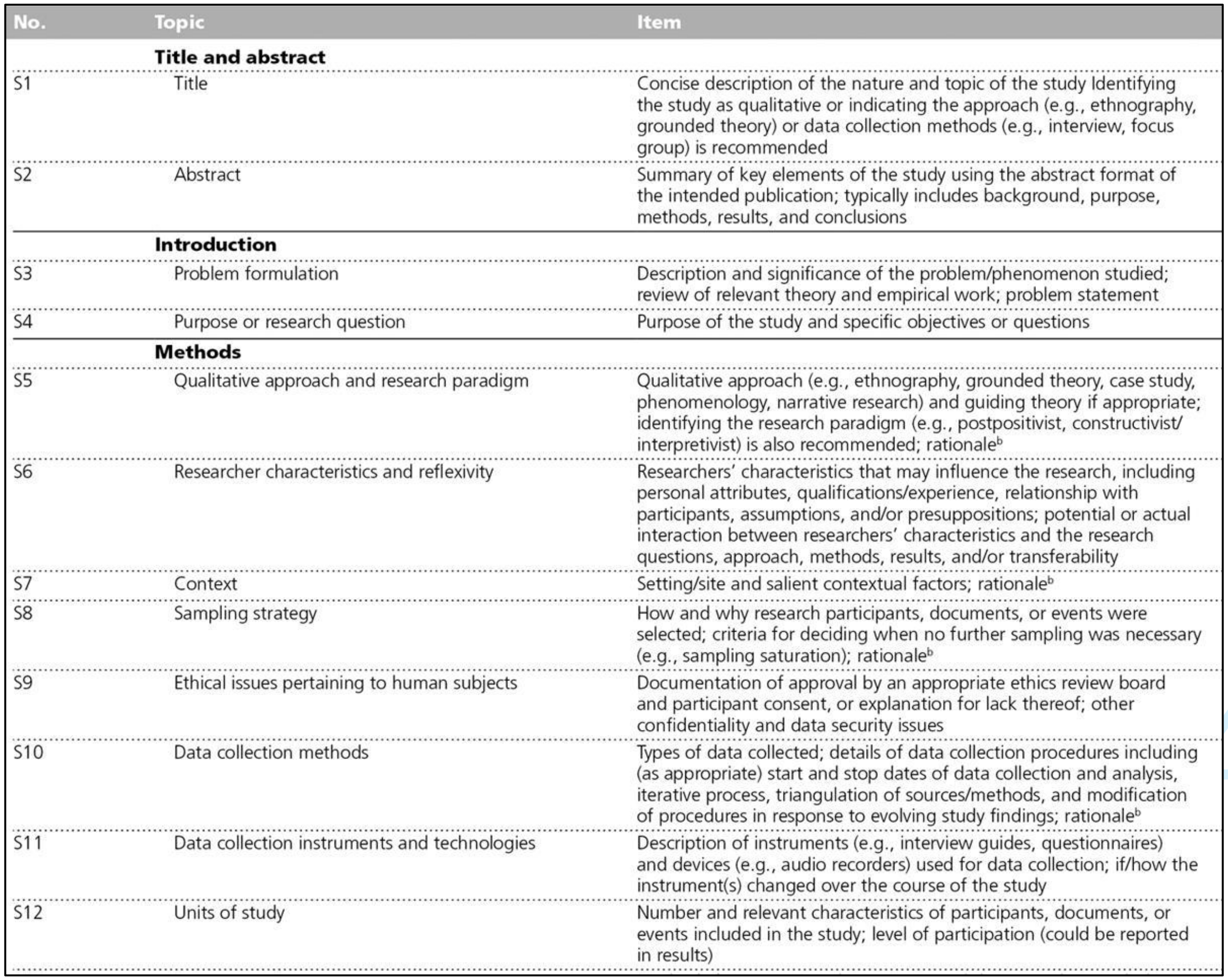
Research Checklist: **SRQR guidelines to report qualitative research (**O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251)



No.	Topic	Item	**Manuscript page**
	Title and abstract		
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	p. 1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	p. 2
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	p.4
S4	Purpose or research question	Purpose of the study and specific objectives or questions	p.5
	Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale[b]	p.5
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	p.7
S7	Context	Setting/site and salient contextual factors; rationale[b]	p.3
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]	p.6
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	p.22
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]	p.6
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	p.7
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	p.8-9

S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	p.7
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale [b]	p.7-8
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]	p. 16
	Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	p. 18-20
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	p. 10-17
	Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	p. 18
S19	Limitations	Trustworthiness and limitations of findings	p. 18
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p. 21
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	p.21

[a] The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

[b] The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.