Evaluation of a French adaptation of a community-based advance serious illness planning decision aid

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A B S T R A C T

Objective: The Plan Well Guide™ (PWG) is a decision aid that empowers lay persons to better understand different types of care and prepares them, and their substitute decision-makers, to express both their authentic values and informed treatment preferences in anticipation of serious illness. We aimed to determine the acceptability of the newly translated French PWG and to evaluate decisional readiness and decisional conflict following its use by lay people.
Methods: This is an acceptability and exploratory outcomes evaluation. Participants were requested to read and complete the French PWG and to engage in an online interview. We used the Acceptability Scale to determine the acceptability and the Preparation for Decision-making Scale and decisional conflict Scale to evaluate decisional readiness.
Results: Forty-two (42) people participated. The average score on the Acceptability Scale was 18.1 (scale range: 4–20 [high–better]) and 26.6 on the Preparation for Decision-Making Scale (scale range: 6–30 [high–better]). A significant number of respondents reported needing more support to help them make better decisions.
Conclusion: The French PWG has been deemed acceptable and relevant for lay people not currently facing clinical decisions.
Innovation: The Plan Well Guide is innovative as it is the first decision aid empowering lay people for advance serious illness planning.

1. Introduction

In North America, prolonging life at all costs with all available life-sustaining interventions, including CPR attempts and admission to an intensive care unit (ICU), has become the de facto default option [1-3]. Thinking and discussing values and preferences regarding life-sustaining treatments and admission to intensive care units (ICU) has become more crucial than ever due to the global COVID-19 pandemic [4]. Between 14% and 17% of hospitalized COVID-19-positive patients during the pandemic's first wave required ICU admission [5]. Of those patients who required mechanical ventilation, 50–97% died in the hospital [6]. Seriously ill patients are frequently incapable of communicating and getting involved in decisions regarding their care. As a result, families are left making decisions with healthcare professionals about initiating, withholding, and withdrawing mechanical ventilation [7]. Long-term psychological consequences such as depression and post-traumatic syndrome affect a significant proportion of relatives who were called upon to make life-or-death decisions on behalf of a critically ill loved one [8]. To engage fully in serious

illness decision-making, one needs realistic and accurate information about care options and likely outcomes [9]. In general, people must have a high level of death literacy [10] which is defined as a set of knowledge and skills that make it possible to gain access to, understand, and act upon serious-illness, and end-of-life options [11].

1.1. From advance care planning (ACP) to advance serious illness planning (ASIP)

Advance Care Planning (ACP) has long been considered the solution to aligning care with values and preferences. ACP entails becoming knowledgeable about life-sustaining treatments, selecting preferred treatment options beforehand, talking with family members about end-of-life preferences, and completing advance directives [12].

ACP relies on many assumptions that are rarely confirmed in actual clinical settings. Expectations of laypersons' abilities to express their values, preferences, and care goals in a meaningful and reliable way. Furthermore, there is a reliance that clinicians will read directives and take patient

preferences into account when speaking with supportive decision-makers [13]. ACP tools are structured for patients following one of the three trajectories of chronic illnesses: terminal disease, major organ failure, and frailty [14], not for serious illness [15]. When it comes to serious illness, no one knows with certainty whether the patient will live or die or how survivors will be affected by long-term adverse outcomes [16]. In these situations, ACP documents made under the conditions of a certain death or permanent condition are invalid, leading to medical errors [17] and contributing to the stress people experience trying to apply end-of-life plans to a seriously ill person [16].

The concept of ASIP is centered on empowering laypersons in preparation for a future serious health crisis. Ideally, before an acute medical episode, ASIP aims to motivate people to learn about the various types of care, their risks and benefits, and to reflect on their values in a way that highlights the trade-off with their competing values [16]. The Plan Well Guide™ (PWG) helps demystify the different types of care and prepares future patients (or their supportive decision-makers) to express their authentic values and informed treatment preferences. PWG was evaluated in two randomized trials. In the first one, conducted in an outpatient setting in Ontario, exposure to PWG increased the engagement of supportive decision-makers in ACP [18]. In the second one, conducted in three primary care practices in Alberta, the PWG reduced patient decisional conflict. Moreover, physicians spent less time finalizing goals of care documents with patients in the intervention group (mean 9.7 v. 13.2 min, adjusted mean difference -3.5, 95% CI -5.5 to -1.5 min) [19]. The PWG is currently being used and promoted in English-speaking Canadian provinces [20].

In Canada, French-speakers are the minority and face increased barriers to accessing information and care [21]. A study found that the end-of-life experiences of French-speakers and English-speakers in Ontario, Canada, were statistically different. French-speakers spent more time in long-term care facilities, used less home care, and died more often in hospitals than English-speakers [22]. Until recently, PWG was available in English only. No similar tools were accessible in French, which was a driving force behind translating and adapting the decision aid from English to French. The process of translation and adaptation was done with the participation of 12 experts and 15 laypersons from Quebec, Canada. From the beginning of the translation and adaptation process, both groups of stakeholders had a favourable opinion towards the PWG and indicated that they would recommend the final adaptation [23].

Our overall objective was to improve access to ASIP for French-speaking Canadians. The specific goals were to determine if the French adaptation of PWG was acceptable and to evaluate further decisional readiness and decisional conflict associated with the use of PWG. We also explored the participants' values and preferences regarding serious illness preparations and planning.

2. Methods

2.1. Study design

This is an acceptability and exploratory outcomes evaluation.Using online questionnaire interviews, we conducted the data collection 100% online during the COVID-19 pandemic. The SUNDAE checklist (standards for universal reporting of patient decision aid evaluation) was used to compose the manuscript [24]. The study was approved by the Queen's University Health Sciences and Affiliated Teaching Hospitals Ethics Board (HSREB).

2.2. Plan well guide (PWG)

PWG is an evidence-based person-centered decision aid developed within the framework of the domains and items of the International Patient Decision Aid Standards criteria [25]. The PWG is a 20-page educational document containing information about ASIP and the benefits, harms, and expected outcomes of the different types of care. PWG also includes a section on the deliberation and communication of health care

preferences to family members and those who will serve as their representative if they become incapacitated. PWG has two unique features: an interactive grid that helps users transparently translate their values into potential medical orders for the use or non-use of life-sustaining treatments (Fig. 1) and a unique method for instructing the public on the different levels of care that include full ICU care with or without a cardiopulmonary resuscitation attempt, short-term admission to ICU with or without a cardiopulmonary resuscitation attempt, medical care, and comfort care (Fig. 2).

The PWG [20] and its French translation and cultural adaptation [23] were made with end-users and healthcare professionals as part of the design process. The public can use PWG with or without professional help. Many financial, legal and healthcare planners such as end-of-life doulas are currently using the PWG with their clients. The Plan Well Guide's English and French versions are free at www.planwellguide.com.

2.3. Participants and recruitment

2.3.1. Partners

We developed partnerships with non-profit groups that promote patients' rights. The task of the partners was to assist with gaining access to community members that would be interested in joining the research project. The partners hosted webinars, during which an expert explained the concept of ASIP.

2.3.2. Participants and recruitment

Webinar attendees who chose to participate and others recruited by word of mouth contacted the research team. Participants had to be of legal age as per provincial law, be able to give informed consent, and have the ability to speak and write French. We did not include laypersons who took part in translating and adapting the decision aid [23]. After reviewing a consent form and completing the evaluation interview, participants received a $10 gift card.

2.4. Data collection

The French version of the PWG was emailed to participants. They were asked to read and fill out the decision aid by themselves. Next, they participated in a 30-min interview over Zoom held in French.

2.4.1. Questionnaire material

The questionnaire included 30 closed-ended questions and one open-ended question asking participants to clarify their previous reply. The questionnaire's purpose is to measure how well the decision aid is accepted, how it affects decision-making readiness, and how it affects decision-making conflict. Participants' values and preferences about using life-sustaining treatments and going to the ICU were also captured.

2.4.2. Demographic questionnaire

Participants were asked to report their age, gender, country of birth, place of residence, education level, and length of time it took to read and complete the French PWG.

2.4.3. Acceptability

We used the Acceptability Scale to assess the acceptability of the French PWG [26]. The Acceptability Scale has face and content validity and features four statements assessing clarity of language, endorsement, amount of information and overall rating of utility. Response options are 5-point Likert scales (scale range: 4–20 [high–better acceptability]). The scale also features open-ended questions asking participants to explain their previous replies.

2.4.4. Decisional readiness

We used an adapted version of the Preparation for Decision-Making Scale [27] to determine how using the French PWG affected the decisional readiness of participants. The adapted Preparation for Decision-Making
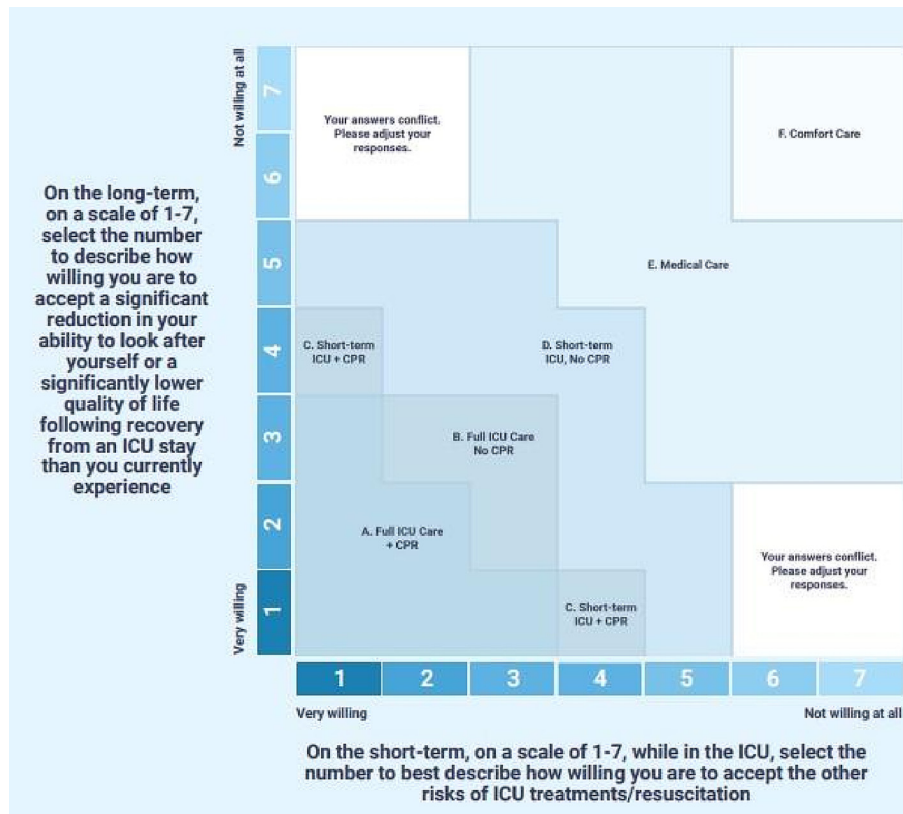
Fig. 1. PWG Interactive Grid.

Fig. 2. PWG Levels of Care.

Scale features six statements related to decisional process and decisional quality and a 5-point Likert scale (scale range: 6–30 [high–better readiness). In its validation study, the Preparation for Decision-Making Scale correlated with the informed ($r = -0.21$, p0.01) and support ($r = -0.13$, $p = 0.01$) subscales (DCS) and differentiates between patients who found the decision aid helpful and those who did not (p.0.0001). Internal consistency was 0.92 to 0.96 [27].

2.4.5. Decisional conflict

We used the 4-item Scale SURE (Sure of myself; Understand information; Risk-benefit ratio; Encouragement) to assess participants' decisional conflict. The SURE screening tool was developed to help health professionals identify patients with significant clinical decisional conflict [28]. In its validation study, the internal consistency of SURE was 0.7 (KR-20). There was a significant correlation between the score of the Preparation

for Decision-Making Scale and SURE scores (Spearman's ρ = −0.45, $P < 0.0001$). Sensitivity and specificity of SURE ≤3 to detect clinically important decisional conflict were 94.1% (95% CI 78.9–99.0) and 89.8% (95% CI 87.1–92.0), respectively [28].

2.4.6. Content of value clarification and deliberation sections

Participants were asked to share their answers to three questions from the section on clarifying and discussing values:

- How willing are you to accept the risks of ICU treatments or cardiopulmonary resuscitation?;
- How willing are you to accept a significant reduction in your ability to look after yourself or a significantly lower quality of life following ICU discharge?
- If life support were needed to keep you alive, which type of care would you prefer?

2.5. Data analysis

We used thematic analysis to review the replies to the open-ended question asking participants why they would or would not recommend the decision aid. Two researchers identified four emerging themes and classified the material independently. Conflicts were solved through discussion.

We analyzed quantitative data using descriptive analysis and basic statistics (means, standard deviations, and percentages).

3. Results

3.1. Participants' characteristics

The study was conducted from January to November 2022. Partners were located in Ontario ($n = 3$), Nunavut ($n = 2$), British Columbia ($n = 1$), and Quebec ($n = 1$). We held eight webinars in French, with a total of 69 attendees, resulting in 31 participants (44.9% of webinar attendees) signing up to participate in the study. An additional 11 participants were acquired through word of mouth (Table 1).

3.2. Acceptability

The overall score on the Acceptability Scale was 18.1 (scale range: 4–20 [high–better acceptability]). The sole item causing participants' dissatisfaction was the amount of information provided, which 23.8% considered more than what they wanted and 7.1% less than what they wanted

Table 1
Participants' socio demographics information.

Sociodemographic information	N = 42
Age, mean (SD)	55.5 (16.5)
24–44, n (%)	8 (19.0)
45–64, n (%)	17 (40.5)
65 and over, n (%)	17 (40.5)
Gender	
Female, n (%)	35 (83.3)
Country of birth	
Canada, n (%)	37 (88.1)
France, n (%)	3 (7.1)
Vietnam, n (%)	1 (2.4)
Ivorian Coast, n (%)	1 (2.4)
Province/territory of residence	
Quebec, n (%)	22 (52.3)
Ontario, n (%)	12 (28.6)
British Columbia, n (%)	6 (14.3)
Nunavut, n (%)	2 (4.8)
Education	
Elementary school	1 (2.4)
High school or professional diploma	2 (4.8)
College degree	4 (9.5)
University degree	35 (83.3)

Table 2
Scores for the acceptability scale.

Questions	N = 42
How clear is the language used?	
Clear/very clear, n (%)	40 (95.2)
Neither clear nor unclear, n (%)	2 (4.8)
Very unclear/ unclear, n (%)	0 (0)
How likely would you be to recommend the final version of PWG to someone?	
Probably/definitely would recommend, n (%)	42 (100)
Might recommend, n (%)	0 (0)
Definitely/probably would not recommend, n (%)	0 (0)
The amount of information provided in the Plan Well Guide is	
About right	29 (69.1)
Less than I wanted	3 (7.1)
More than I wanted	10 (23.8)
Overall, how would you rate the guide?	
Good/very good, n (%)	39 (92.5)
Fair, n (%)	3 (7.5)
Very poor/poor, n (%)	0 (0.0)

(Table 2). The participants said it took them an average of 47 min (SD: 20) to read and fill up the guide. (See Table 3.)

3.3. Thematic analysis

Four themes emerged from the analysis of the open-ended questions. In order of importance were: the high significance of the matter, the absence of such reflection triggers in society, the quality of the French PWG, and concerns about it would benefit everyone.

First, 24 participants (57.1%) stated that they would recommend the French PWG because the matter at hand is of great significance:

"I would recommend PWG because it helps to be aware of the power we have."

Second, 16 (38.1%) participants highlighted the appealing visuals and the capacity of the PWG to make important information available:

"I would recommend PWG because the language is accessible, with a lot of relevant information to lead to a free and informed decision. It is visually appealing."

Third, 15 participants (35.7%) stated that they would recommend the French PWG because it is relevant and contains information that is unique:

Table 3
Scores of the preparation for decision-making scale.

Did the PWG	N = 42
Help you recognize that a decision needs to be made?	
Quite a bit/a great deal	39 (92.9)
Somewhat	0 (0)
Not at all/a little	3 (7.1)
Prepare you to make a better decision?	
Quite a bit/a great deal	39 (92.8)
Somewhat	2 (4.8)
Not at all/a little	1 (2.4)
Help you think about the pros and cons of each option?	
Quite a bit/a great deal	40 (95.2)
Somewhat	2 (4.8)
Not at all/a little	0 (0.0)
Help you think about which pros and cons are most important?	
Quite a bit/a great deal	35 (83.4)
Somewhat	4 (9.5)
Not at all/a little	3 (7.1)
Help you know that the decision depends on what matters the most to you?	
Quite a bit/a great deal	36 (85.8)
Somewhat	3 (7.1)
Not at all/a little	3 (7.1)
Help you organize your own thoughts about the decision?	
Quite a bit/a great deal	38 (90.4)
Somewhat	2 (4.8)
Not at all/a little	2 (4.8)

Table 4

Scores for the SURE scale.

Questions	Yes (N = 42)
Do you feel sure about the best choice for you?	36 (85.7)
Do you know the benefits and risks of each option?	38 (90.4)
Are you clear about which benefits and risks matter most to you?	41 (97.6)
Do you have enough support and advice to make a choice?	24 (57.1)

"I would recommend PWG because it is very relevant. We just did our will with our lawyer and now I see that I have to work again".

"Because it's information that's not at our fingertips. We are not naturally inclined to plan. Culturally speaking, it's not in our culture to plan".

Finally, ten participants (23.8%) said they would recommend the French PWG but qualified their answer by mentioning the characteristics of those they would recommend it to (people with a high level of literacy, elderly people).

"This is good, but the complexity of the information is not for everyone".

3.4. Decisional readiness

The overall score on the Preparation for Decision-Making Scale was 26.6 (SD: 3.3) (scale range: 6–30 [high–better preparation])

3.5. Decisional conflict

Three of the four items on the SURE scale received >85% agreement, but only 57% agreed on the item about support and advice (Table 4).

3.6. Content of value clarification and deliberation sections

Overall, participants were more willing to accept the short-term risks of admission to the ICU than the long-term risks. Two-thirds of participants (n = 28, 66.6%) would prefer a short-term admission to the ICU with or without a cardiopulmonary resuscitation attempt (Table 5).

4. Discussion and conclusion

4.1. Discussion

In this acceptability and exploratory outcomes evaluation, we assessed the usefulness and acceptability of the first French ASIP decision aid from the perspective of its intended end-users. During the COVID-19 pandemic, we conducted the entire study online, exploring innovative recruitment and data collection methods. Overall, participants found this innovative tool aid acceptable and useful in leading to person-centered decision-making. Analysis of the content of value clarification and deliberation sections informed us of future directions.

Participants found that the PWG was acceptable. The majority (69%) thought the amount of information was "just right," yet some (7%) would have wanted more, and 24% would have wanted less. The amount of information included in a decision aid is challenging for developers, as users typically desire as much information as possible in a straightforward format [29,30]. Ninety-three (93) percent thought the decision aid was good or very good, and 100% were either likely or very likely to recommend it to others. However, due to the content's complexity, the document's length, or the high level of literacy needed to understand the content, 24% of participants would only recommend it to some types of people (e.g. educated, older). Overall, participants thought the PWG was accessible, thought-provoking, relevant, and led to informed decisions.

Some participants noted that PWG provides information not available elsewhere and different from information and documentation obtained from legal services. Completing advance medical care planning documents with a lawyer under conditions of certainty is not useful in making

Table 5

Content of the value clarification and deliberation sections.

Questions	N = 42
Short-term Risk Assessment	
On the short-term, on a scale of 1–7, while in the ICU, select the number to best describe how willing you are to accept the other risks of ICU treatments/resuscitation (pain, loss of mobility or ability to talk, etc.):	
1 Very willing	6 (14.2)
2	12 (28.6)
3	4 (9.5)
4 Equally important	12 (28.6)
5	2 (4.8)
6	2 (4.8)
7 Not willing at all	4 (9.5)
Long-term Risk Assessment	
On the long-term, on a scale of 1–7, select the number to describe how willing you are to accept a significant reduction in your ability to look after yourself or a significantly lower quality of life following recovery from an ICU stay than you currently experience:	
1 Very willing	1 (2.4)
2	3 (7.1)
3	6 (14.3)
4 Equally important	10 (23.8)
5	7 (16.7)
6	7 (16.7)
7 Not willing at all	8 (19.0)
Which treatment options are right for you?	
A Full ICU care with cardiopulmonary resuscitation attempt	4 (9.5)
B Full ICU care without cardiopulmonary resuscitation attempt	3 (7.1)
C Short-time ICU care with cardiopulmonary resuscitation attempt	17 (40.5)
D Short-time ICU care without cardiopulmonary resuscitation attempt	11 (26.2)
E Medical care	3 (7.1)
F Palliative care	4 (9.5)

informed clinical decisions during a serious illness and may contribute to high prevalence of medical errors in serious illness decision-making and the stress of supportive decision-makers [16]. Part of the problem is that health planning with a lawyer is framed around end-of-life wishes and not about planning for a serious illness and these wishes get codified in such a way that they are considered 'treatment decisions' when in fact, they are not fully informed treatment decisions.

The overall score on the Preparation for Decision-Making Scale was relatively high, 26.6 on a maximum of 30. When considering the risks and benefits of life-sustaining interventions, the vast majority of participants (95%) were confident in their knowledge. However, fewer participants (83%) were confident when asked about life-sustaining interventions they would want for themselves. Having to decide on life-sustaining interventions is a new, disruptive necessity that may go against societal values and our nature of thinking [31].

After reading and completing the PWG, most participants (67%) expressed that they would opt for a short ICU stay, with or without cardiopulmonary resuscitation attempts. This is not even reflected in the options available in most hospitals in Canada and elsewhere, as most GOC forms do not include the option of a short-term ICU admission. In a study conducted in Canada, 395 GOC forms were assessed. It appeared that the open-ended section was frequently used to add a second goal of care applicable in the event of health deterioration. This indicated that the GOC form could not capture the patient-centered nuances required regarding values and preferences in the event of severe illness [33].

This problem likely exists because of the North American norm of prolonging life at all costs with all available life-sustaining interventions, including CPR attempts and admission to an intensive care unit (ICU) [1-3]. Stemming from the ethical principle of beneficence, is the idea that all patients should receive life-saving treatments, and that the sanctity of life is the most important value. However, life-saving care happens without considering the risks and benefits for each patient, their family, and society as a whole [34]. Research in cognitive psychology shows that default options are often interpreted as recommendations or guidelines or as the path of least resistance [35]. Using default decisions to care for patients is a blanket approach that leads to over use of full ICU care even when it brings little or

no benefit and risks harm [1]. A new GOC form featuring more treatment options, including short-term admission to an intensive care unit with or without cardiopulmonary resuscitation attempts, should be implemented in the health care system to allow patient's informed treatment preferences to be honored. A draft of such a medical order form is currently available (www.planwellguide.com).

Having access to professional help when completing ASIP would provide an accurate account of a person's wishes, values, and preferences. Participants (43%) said they would need more support and advice to get the most out of using the PWG. Participants also thought that other persons would need help to find their way through the amount of information and understand the concept of ASIP. Lack of understanding or skills to complete ASIP can lead to inconsistent answers or the abandonment of completion due to the amount of information. In trying to overcome these barriers, we introduced supportive PWG navigators. These navigators provide non-medical, inclusive, and judgment-free planning that empowers PWG users. A supportive PWG navigator can also help improve communication between users, the healthcare team and the caregivers. A similar program was associated with significantly improved self-efficacy in preparing and completing advance care planning and lower rates of resource utilization near the end of life [36]. Creating a low-literacy version of the PWG in collaboration with final end-users and hosting a free scientific café or webinar where advance serious illness planning and the PWG are explained to lay-people are other implementation measures we envision.

Despite our efforts to recruit participants with a variety of educational backgrounds (i.e., men and lower education levels), 83.3% were women with a university degree. Previous research has reported challenges associated with recruiting men [37,38] and people with lower levels of education [39]. Moreover, we aimed to partner with non-profit groups catering to French-speaking citizens in every Canadian province and territory. However, we could only mobilize partners in four of them partly because of access barriers from the labor shortage caused by COVID-19 leaving us unable to evaluate the PWG's effects in all provinces and territories. Lockdowns and social distancing brought about by the COVID-19 pandemic have led researchers to look for alternative recruitment and data collection methods [40].

In an effort to ensure the recruitment of a representative sample (persons located in many parts of Canada), this study was conducted entirely online. Although the interactions were meaningful, we were limited in our ability to observe and interpret participants' nonverbal communication. In human communication, nonverbal signs are as critical as spoken words [41]. This study is the first assessment of the French version of PWG. The recruitment method, inspired by participatory action research, which involved partners and encouraged both individual and collective reflection on ASIP added strength to the study. Community-based methods like these are likely to get more people on board and make it easier to put the PWG into action.

4.2. Innovation

The COVID-19 pandemic has brought to light the fact that many people, especially the elderly, are on the verge of developing a serious illness. Those suffering from a severe COVID-19 infection or other serious disease must decide whether to enter intensive care or use mechanical ventilation. No one knows if they are going to die or not. Under such uncertain outcomes, their end-of-life planning are not valid [16]. In 2022, palliative care experts discussed ACP's current challenges and limitations and concluded that, at best, ACP is only part of the solution. They also wrote that new tools and definitions, like Advance Serious Illness Planning (ASIP), are needed to ensure patients get care that is in line with their goals and meets their needs [42]. As such the PWG is innovative as it is the first decision aid framed around ASIP rather then end-of-life.

4.3. Conclusion

All Canadians should be able to get clear, useful information about their care options in case of a serious illness. The PWG™, a person-centered decision-aid, helps lay individuals demystify different types of care and empowers them (and their supportive decision-makers) to express their authentic values and informed treatment preferences. The results of this evaluation showed that the French PWG is acceptable and relevant for French-speaking lay people who aren't facing significant medical decisions right now. Future research includes an assessment of the supportive PWG navigator services and the development of more inclusive versions in both French and English.

Ethics approval

The study was approved by the Queen's University Health Sciences and Affiliated Teaching Hospitals Ethics Board (HSREB).

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Credit authorship contribution statement

AP made substantial contributions to: conception and design; acquisition of data; analysis and interpretation; and drafting the manuscript. JM made substantial contributions to: data analysis and interpretation; drafting the manuscript, and critically revising the manuscript. AK made substantial contributions to: interpretation of data, and critically revising the manuscript. DKH made substantial contributions to: conception and design; analysis and interpretation; and the critical revising of the manuscript. All authors read and approved the final manuscript.

Data availability

The datasets are available from the corresponding author upon reasonable request.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported.

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