Clients and professionals elicit long-term care preferences by using 'What matters to me': A process evaluation

Catharina Margaretha van Leersum (karin.vanleersum@maastrichtuniversity.nl)
Maastricht University https://orcid.org/0000-0002-1003-0794
Albine Moser
Zuyd Hogeschool
Ben van Steenkiste
Universiteit Maastricht
Judith R.L.M. Wolf
Radboudumc
Trudy van der Weijden
Universiteit Maastricht

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Abstract

Background: ‘What matters to me’ is a five-category preference elicitation tool to assist clients and professionals in choosing long-term care. This study aimed to evaluate the use of and experiences with this tool.

Methods: A mixed-method process evaluation was applied. Participants were clients, relatives, and professionals. They were all involved in decision-making on long-term care. Data collection comprised online user activity logs (N=71), questionnaires (N=38), and interviews (N=20). Descriptive statistics was used for quantitative data, and a thematic analysis for qualitative data.

Results: Sixty-nine percent of participants completed one or more categories in an average time of 6.9 (±0.03) minutes. The tool was rated 6.63 (±0.88) out of seven in the Post-Study System Usability Questionnaire (PSSUQ). Ninety-five percent experienced the tool as useful in practice. Suggestions for improvement included a separate version for relatives and a non-digital version. Although professionals thought the potentially extended consultation time could be problematic, all participants would recommend the tool to others.

Conclusion: ‘What matters to me’ seems useful to assist clients and professionals with preference elicitation for long-term care. Evaluation of the impact on consultations between clients and professionals by using ‘What matters to me’ is needed.

1. Background

The growing demand for long-term care causes changes in the setting and delivery of healthcare(1,2). In the Netherlands, the Dutch health policy is to try, assist and keep people in their own home rather than in institutional care. The increasing number of elderly people and the prevalence of chronic disease has caused this growing demand for long-term care, and the Dutch health policy caused the growing demand for care at home. Besides the economic burden of long-term care, this means an increase in the workload of healthcare professionals(3).When professionals discuss options of care with their client, their intention is to take the client’s whole situation into account in a collaborative manner(4). Discussing and considering a client’s preference, whether someone is able to stay in their own home or whether someone would rather be in institutional care.

Shared decision-making (SDM) is an approach whereby clients who are faced with a decision receive information from their professionals about the best available evidence on which to base their decision(5). SDM starts with the ‘team talk’. The client is invited to cooperate in the decision-making process, options are explained, support is given, and information about goals is elicited. The second stage - the ‘option talk’ - covers possible options and their harms and benefits. Lastly comes the ‘decision talk’ at which time preference-based decisions are made(4). SDM is important in order to be able to understand the client’s situation and to decide on the best course of action(6). To provide personalized care, the SDM dialogue should include preferences in order to discover those things that matter most to clients while taking the

options into account(7). These things play an important role in the decision-making process in which the views and preferences of professionals and clients are elicited and discussed(8). Clients in need of long-term care might experience challenges in articulating preferences, and without the assistance of preference elicitation, decision-making could be difficult for these clients(9,10).

Attempts to address the demand for long-term care benefit from the application of digital technology(11,12). Digital technology is regarded as improving client-centeredness, self-management, engagement in consultations, quality of care, and as lowering the costs of healthcare(13-15). It can make clients feel secure and in control, while simultaneously appreciating the immediate professional responses and peer support during decision-making(16). To assist preference elicitation, digital technology can improve SDM by addressing needs and preferences(12). This also supports professionals in understanding their clients and building a relationship(17). Currently, digital technologies to assist preference elicitation are investigated and under development(15). Most of the technologies ensuring a preference-guided decision are single-disease oriented(18,19,20). These tools are designed to evaluate goals, preferences, capabilities, values, or wishes in health and life. The model of Positive Health, for example, aims to visualize someone's state of health by means of physical and mental functioning, spirituality, quality of life, social participation, and daily functioning(21). Another tool, the Outcome Prioritization Tool, supports decision-making for treatment. The tool facilitates a talk and prioritization of preferences for a specific outcome. This results in enhanced engagement of the client and a deepening of the relationship(22).

The digital preference elicitation tool 'What matters to me' is designed to elicit preferences for long-term care. The tool aims to assist in the construction and discussion of preferences during client-professional consultations in four long-term care sectors in the Netherlands: nursing and care of the elderly, mental health care, care of people with disabilities, and social care. Examples of preferences could include the desire to have a pet, to take meals with other people, or the importance of a 'click' with a caregiver(10,23). Preference elicitation may indeed assist professionals in acquiring insight into client preferences and in discussing the clients' view on the long-term care options. The problem is that these open conversations on preferences and values are not or rarely spontaneously performed in daily practice. The aim of tools like What matters most to me is to stimulate and facilitate such conversations, not to replace these conversations (Box 1).

The implementation of new interventions remains a challenge for healthcare, as implementation is often difficult due to lack of knowledge about healthcare environments(11,24). Furthermore, there are barriers to implementation, such as costs, time, and difficulty in fitting it into the current workflow(15). To increase the knowledge about the use of tools in real practice, evaluation is needed to assist implementation(14,24-27). The aim of this study is to perform a process evaluation to evaluate the use of, and experiences with, the preference elicitation tool 'What matters to me'. This process evaluation was guided by the research question. *To what extent was 'What matters to me' used and how was using 'What matters to me' experienced?* The question was studied from the perspectives of both professional and client.

Box 1. 'What matters to me'(23,28)

The tool 'What matters to me' is designed to assist with preference elicitation for long-term health and social care: nursing and care of the elderly, mental healthcare, care of people with disabilities, and social care. The design was based on existing tools and a qualitative study into preferences of clients in long-term care settings(23). The preference elicitation tool 'What matters to me' comprises five categories.

- 'Health' is defined as client's care needs and their preferences how to receive care. This domain helps clients identify to what extent they are self-reliant in providing their care, and in what areas they need assistance; it also includes preferences for care professionals.
- 'Family and friends' is defined as the importance of relatives and all kind of social contacts, addressing all people important in someone's life.
- 'Living conditions is defined as client's preferences regarding housing, different options, and environment as well as social interaction in their living environment.
- 'Daily life' is defined as client's preferences for all kinds of activities ranging from work to sport, and culture to religion.

'Finances', is defined as financial resources and considers the role money or debts plays in life, and the preferences for assistance with finances or administration.

'What matter to me' is web-based consisting of four essential pages (Additional file 1 shows illustrations of the pages).

1. On the homepage, the user can read information about the purpose and the use of the tool. The homepage also has the function of portal towards the preference elicitation section, by clicking the start-button.
2. After clicking the start button, the 'category page' opens. The user can choose one or more categories to his or her preference, and is invited to click on a category symbol to answer the propositions belonging to this category.
3. When choosing a category, different proposition pages will follow. Each category has a different amount of propositions. Each proposition belonging to the category of choice appears on separate pages. Users can click on the answers that match their opinion and continue with the subsequent proposition. After the last proposition of a category, the user will be automatically return back to the category page.
4. When a user finished answering the propositions of one or more categories, he or she can click on the button 'overview'. The overview lists all the answers a user has given. The answers are shown per category and users are able to change their answers. This overview can be printed or send to the user by email.

2. Methods

2.1. Design

A process evaluation was chosen to describe the actual use of the tool in practice and to gain insight into the experiences of the users with the tool. This process evaluation aims to plan strategies for successful implementation in practice(26,27). The process evaluation is based on six process components, i.e.

context, fidelity, dose delivered, dose received, reach, and recruitment(29). These components generate insight into the mechanisms of a program and investigate its impact and outcome(29). The component ‘context’ refers to the environment in which ‘What matters to me’ was evaluated. ‘Fidelity’ is the extent to which it was implemented as originally proposed in the blueprint. ‘Dose delivered’ covers the materials provided or delivered by the professionals, and ‘What matters to me’. ‘Dose received’ and ‘satisfaction’ question the extent to which participants interacted and used the tool as recommended, and their satisfaction with its use. ‘Reach’ or ‘participation rate’ is the proportion of the intended stakeholders who actually participated in the process. Lastly, ‘recruitment’ covers approaching and including users. The components context, fidelity, dose delivered and received, and reach were used to study the use of the tool. The components fidelity, dose delivered, satisfaction, reach, and recruitment were used gain insight into the experiences with the tool. Table 2 at the end of the methods section shows the components of the process evaluation with the quantitative and qualitative data sources.

2.2. Setting

Long-term care in the Netherlands comprises four sectors: nursing and care of the elderly, mental health care, care of people with disabilities, and social care. Twelve long-term care organizations spread over three provinces of the Netherlands participated. These organizations provide home care or residential care. Three organizations operated in the field of nursing and care for elderly, three in the care of people with disabilities, one in mental health care, three in social care, and two provided services in all care sectors. The professionals were caregivers, independent care coordinators, and professionals responsible for intake. They shared information with clients during the decision-making process, and discussed options clients might have.

2.3. Participants and recruitment

The participants in this study were professionals and clients. Professionals were included if they were actively involved and consulted by clients during their search for long-term care. These professionals will guide their client throughout the decision-making process. They could work within a care facility or work as independent advisers belonging to the municipality. The clients were actual clients, and their relatives or informal caregivers. Inclusion criteria were active searching and decision-making for long-term care and consulting a professional for support in decision-making. Exclusion criteria were the inability to use ‘What matters to me’, and a command of the Dutch language below level A2(30).

There were four strategies followed during the recruitment. First, the researchers contacted 18 long-term care organizations divided over the four long-term care sectors. Information about ‘What matters to me’ and the study was given on visits to these organizations. Twelve organizations were included through purposeful sampling. Second, the professionals recruited clients by means of an information letter, a card with a link to ‘What matters to me’, and a questionnaire. The professionals were contacted by the researchers every two weeks by email or telephone to follow the progression of the recruitment. All professionals together recruited 24 clients for the study by means of an information letter, a card with a link to ‘What matters to me’, and a questionnaire. Third, clients were also able to participate independent

of professional referral. Two clients were recruited via a pop-up built into the open access tool ‘What matters to me’. These participants received the information letter and questionnaire by mail. In total 26 clients completed the questionnaire. At the end of the questionnaire, clients could indicate if they were willing to participate in a follow-up interview. As a result, 20 clients agreed to an interview by phone (convenience sampling). And fourth, there was self-recruitment of users. The tool was visited and used by 102 unique visitors of which 71 completed one or more categories of the tool.

2.4. Ethics

Approval was obtained from the Ethics Committee of Zuyderland Zuyd (dossier number 17-N-79). The participants gave written informed consent and were informed about the goal and process of the study, and their right to withdraw at any time. Data were anonymized and confidentiality was maintained.

2.5. Intervention

The study intervention comprised four steps: (1) the participating professionals received one hour on the spot training on ‘What matters to me’ and information about research procedures. During the training, the professionals were advised to give the link to their clients to prepare for a follow-up consultation. However, some professionals chose to discuss and use the tool during the consultation. The professionals were free to choose the most suitable procedure for their clients. During the training, the possibilities to share and save the preferences as filled-in by the client were explained. The advice, as given to the professionals, was to ask the client to share the preferences with them as well as to save the preferences in case the client would like to discuss them with someone else. (2) During a consultation with their professional, clients received a link to ‘What matters to me’ and oral or written information about the study. When a relative was present, the relative was invited as well to assist the client in the use of the tool. When clients were unable to use the tool by themselves, the relatives were invited to use the tool and complete the propositions considering the preferences of the client. (3) The clients used ‘What matters to me’ to prepare for the follow-up consultation. (4) The clients returned to their professional for the follow-up consultation to discuss the overview and preferences generated by the tool.

2.6. Data collection

Data were collected between April and August 2018. Quantitative data were collected by 71 user activity logs of the tracking system of the website. These logs show the number of hits, the route a participant took through the website, which categories were used, and the time spent on particular pages.

Second, 26 client questionnaires considered use, usability, and user-friendliness. The questionnaire included the Post System Study usability Questionnaire (PSSUQ), and additional questions on experiences and the time they spent on it (Table 1). The PSSUQ is an instrument specifically designed to measure the usefulness, information quality, and interface quality of a system(31). The questionnaire evaluates usability characteristics such as perceived time taken to complete the work, ease of learning, quality of documentation and information, functional adequacy, and speed of acquisition(32,33).

Participants were asked for their opinion on statements using 7-point Likert scales, ranging from 1 “strongly disagree” to 7 “strongly agree”, scores were used to calculate the average score over all statements(33,34).

Third, 12 professionals answered a questionnaire about their experiences by rating it on a 1-10 scale, their involvement with the clients during consultations, the time they spent on using the tool, and their experiences with ‘What matters to me’ during consultations.

Table 1. Post-Study System Usability Questionnaire Items(32).

	Question	Scoring
1	I am satisfied with how easy it is to use this system.	1-2-3-4-5-6-7
2	It was simple to use this system.	1-2-3-4-5-6-7
3	I could effectively complete the tasks and scenarios using this system.	1-2-3-4-5-6-7
4	I was able to complete the tasks and scenarios quickly using this system.	1-2-3-4-5-6-7
5	I was able to efficiently complete the tasks and scenarios using this system.	1-2-3-4-5-6-7
6	I felt comfortable using this system.	1-2-3-4-5-6-7
7	It was easy to learn to use this system.	1-2-3-4-5-6-7
8	I believe I could become understand quickly how to use this system.	1-2-3-4-5-6-7
9	The system gave error messages that clearly told me how to fix problems.	1-2-3-4-5-6-7
10	Whenever I made a mistake using the system, I could recover easily and quickly.	1-2-3-4-5-6-7
11	The information (such as online help, on-screen messages, and other documentation) provided with this system was clear.	1-2-3-4-5-6-7
12	It was easy to find the information I needed.	1-2-3-4-5-6-7
13	The information provided for the system was easy to understand.	1-2-3-4-5-6-7
14	The information was effective in helping me complete the tasks and scenarios.	1-2-3-4-5-6-7
15	The organization of information on the system screens was clear.	1-2-3-4-5-6-7
16	The interface of this system was pleasant.	1-2-3-4-5-6-7
17	I liked using the interface of this system.	1-2-3-4-5-6-7
18	This system has all the functions and capabilities I expect it to have.	1-2-3-4-5-6-7
19	Overall, I am satisfied with this system	1-2-3-4-5-6-7

Qualitative data were collected by semi-structured phone interviews with 20 clients or relatives. The interview guide was developed and reviewed by two client representatives. The interview guide consisted of the following questions (English translation of Dutch original):

1. How did you hear about ‘What matters to me’?
2. What was your reason for using ‘What matters to me’?
3. Which categories did you use of ‘What matters to me’?

4. What was your first impression when opening ‘What matters to me’?
    a. What was convenient, what was difficult? Can you explain?
    b. How did you find answering the questions? What made this easy/difficult?
    c. What did you expect before starting? Was it different from expected?
5. How would you grade ‘What matters to me’ on a scale 1-10?
    a. You gave a …, on which qualities do you base this grade?
    b. Are you satisfied with the overview? Can you explain?
    c. Did you discuss the overview with someone? Who with? What did you discuss? How did you find that discussion?
    d. Would you recommend using ‘What matters to me’ to others? Can you explain?
    e. What should we improve in order to upgrade to a 10? What would you change?
6. Summarize the answers. Ask for confirmation and further questions or remarks considering ‘What matters to me’, the consultation, and implementation in practice.

The interviews lasted approximately 15 minutes, audiotapes were made, and field notes taken. Another data source was 59 emails and 47 phone calls with the professionals. Field notes contain failures and successes in asking clients to participate and use ‘What matters to me’.

2.7. Data analysis

To analyse the quantitative data, SPSS was used for descriptive statistics. To analyse the qualitative data, interviews were transcribed verbatim. Content analysis with a deductive approach(35) was performed on all transcripts guided by the six components of the process evaluation model of Saunders et al.(29). During the organizing phase of the analysis(35), a matrix was developed comprising the components of context, fidelity, dose delivered, satisfaction, reach, and recruitment. Categories were created within each of the components of the analysis matrix (Additional file 2). Two researchers performed the analysis. The analysis and findings were discussed during weekly meetings with the research team. In the resulting phase(35), the researchers compared the components with the categories. The findings of the analyzed data based on the six components are described in the results section. Data management was performed using the NVivo version 11 software package.

2.8. Validity

Validity was established by means of triangulation and face validity(36). Data triangulation was established by including four different quantitative and qualitative data sources: log data files, questionnaires from clients, questionnaires from professionals, and interviews. Methodological triangulation was reached by including clients twice with a short time interval in the quantitative and qualitative data collection. Two researchers read, analysed, and compared findings multiple times. The project team was informed about the findings at weekly meetings at which the scientific and

organizational aspects were discussed to reach investigator triangulation. Face validity was reached by acknowledging the use of the six components to apply a process evaluation. Member checking was performed by sharing the interview transcripts with participants, and by an invitational conference. All participants and those who had an interest in this research were invited to the conference where the findings of the process evaluation were presented and discussed. Five participants of this study were present during the conference. Their feedback given during the discussions of the conference was used for further development of the tool and to develop plans for further implementation of the tool.

Table 2. Summary of the methodology. The first and second column contain the six components of a process evaluation(27) and the categories within these components. For each component the quantitative and qualitative data sources are shown.

Components	Categories	Quantitative data source	Qualitative data source
Context	Environment of use	Questionnaires	Interviews
Fidelity	Quality	Questionnaires	Interviews
	Actual use and implementations	Log-data	Interviews
Dose delivered	Provided materials	Questionnaires	Interviews
Dose received and satisfaction	Use as recommended	Log-data and questionnaires	
	Satisfaction		Interviews
Reach	Participation	Log-data and questionnaires	Interviews
Recruitment	Way of inclusion		Phone calls and email conversations with profs

3. Results

The result section begins with a description of the participants involved in this study. Thereafter, the results are structured by the use of the tool, and the experiences with the tool. The components context, fidelity, dose delivered and received, and reach are used to describe the use of 'What matters to me', and the components fidelity, dose delivered, satisfaction, reach, and recruitment are used to describe the experiences with the tool. A division is made between those data obtained from the professionals and from the clients. At the end of the results section table 3 shows the six components of the process evaluation with a summary of the findings.

3.1. Participants

Twelve professionals filled-in the questionnaire at the end of the study. Seventeen percent were male, and the average age of the professionals was 46 (±14.6 years) ranging from 19-63 years. All had Dutch nationality and a higher educational level. Seven professionals worked in the care of people with disabilities, one in mental health care, two in social care, and two provided care in more than one sector.

The professionals recruited 24 clients and two clients were reached via the pop-up built in 'What matters to me'. These 26 clients used the tool and completed the additional questionnaire as part of this study. Of the 26 clients 54% were male, and the average age of the clients was 45 (±24.9 years), ranging from 18-92 years. Forty-two percent had a low educational level. Twenty-three participants had Dutch nationality, the others were of Turkish or Indian origin. Five clients received care in the nursing and care of elderly sector, nine clients in the care of people with disabilities sector, three clients in the mental health care sector, seven clients in the social care sector, and two clients received care in more than one sector. Fifteen clients used 'What matters to me' independently, three relatives, four professionals, and four clients completed it together with a professional.

3.2. Use of 'What matters to me'

To explore the use of the tool the process evaluation component context was described, and the components fidelity, dose delivered, dose received, and reach were explored. The context of the professionals and clients is described in the previous section.

Considering the components dose delivered and reach, the 12 professionals asked 50 clients to use 'What matters to me'. Six professionals asked all their clients who fulfilled the inclusion criteria, to take part in the study and use 'What matters to me'. Four professionals asked a small number of clients, and two did not ask their clients. Some professionals gave information and asked their clients to use the tool without mentioning the additional questionnaire. Twenty-one users knew about 'What matters to me' via their professionals, and five already heard about it through informal routes, a friend or partner.

Considering the fidelity and dose received, the average estimate professionals made of the time they spent together with their clients ranged from less than ten minutes to 30 minutes. The total number of spontaneous and referred visitors of the tool was 102, of which 71 clicked and filled-in on one or more categories of the tool. The log data showed that 33 of these 71 visitors filled in all five categories. 'Daily life' was filled in by most participants, but none of the categories was filled in less frequently than the others. The option to write free text comments on the answers was used by 27% of the participants. The average actual time the participants spent was 6.9 (±0.03) minutes, ranging from two to more than 30 minutes. The generated overview with preferences was printed or emailed by 74% of the clients. Six out of 12 professionals discussed the overview with their client. However, the interviews revealed that more clients would have liked to discuss the overview with their professional.

Client 3: "Coincidentally, the next day I had a consultation and wanted to show the overview to my coach, but my coach was not interested and did not even look at it."

3.3. Experiences with 'What matters to me'

The process evaluation components fidelity, dose delivered, satisfaction, reach, and recruitment were explored to gain insight in the experiences with using the tool. .In the user context, all clients were in need of care in the near future, but their need was not classified as urgent. For example, the father of an autistic son acknowledged he was ageing and was uncertain about the future care for his son:

Client 1: "My son is autistic, he is 46 now and has just received a long-term care indication. I am 72 and have just had an intestinal operation. This has made me worry about the future. My wife died last January, and of course I worry about what will happen to my son."

When questioned about the dose delivered and dose received, all clients said that they were told about 'What matters to me' by a professional or relative, and had received the link to the tool and relevant use information from them.

Client 5: "Someone came to discuss housing and living conditions for my future with us. It is not immediately necessary at this time, but I would like to be covered for later on. Then she told me about a tool that could help us and asked if I was willing to use it. I said 'I would really like to use it.'"

Considering the component recruitment in the process evaluation, some professionals hesitated to ask clients to participate due to work pressure of the professional, but also based on their assumption that the client would not be willing to participate. Other professionals were hesitant at first, but the clients were motivated to use and discuss their preferences.

Professional 5: "Together with colleagues, I handed out some flyers with the link to 'What matters to me'. Although our population (mental disabilities) does not seem to be very motivated to take part in research, we often discussed the 'What matters to me' questions during consultations. We looked at the questionnaires a few times, and this clearly added value to the conversation."

Clients thought about possibilities to extend the reach by naming professionals and organisations that could help in commercial advertising of 'What matters to me' to their clients. They also suggested using the media, social media, and diverse awareness-raising channels, and posting reports or recommendations to others.

Client 7: "A sort of 'like' button that can be shared in all kinds of ways, a share button and somewhere to leave a comment. I think these things could help people when they generate a search, because when I googled 'What matters to me' you were not really near the top."

Considering the fidelity, participants who did not fill-in all categories were questioned for their reasoning. All replied that the categories of which they did not answer the propositions were considered not useful for their situation. The professionals graded the quality of the tool at a mean of 7.73 (±0.75, range seven to nine) out of 10. Recommendations for improvements were given in the comment field, including a map showing organizations where a client could receive assistance or care, a read-aloud function, a non-

digital version, and a separate section for informal caregivers. The clients evaluated ‘What matters to me’ by answering the PSSUQ, and gave it a mean score of 6.24 (±0.76) out of seven. During the interviews, clients graded the user-friendliness at an eight or nine (out of 10). Relatives who used ‘What matters to me’ wished to label their role as the client’s proxy.

Relative 2: “The thing I missed from ‘What matters to me’ was that there is nowhere to indicate that you are filling in the answers on behalf of someone else, not for yourself.”

All clients and professionals would recommend ‘What matters to me’ to others. Satisfaction was further explored by asking how clients experienced the use of the tool. All clients who used the tool wanted to talk about the overview with a professional. The clients and professionals who used the overview at the follow-up consultation were positive about its usefulness. It was helpful to prepare for consultations, set the agenda, and to build a relationship with someone in a short time since the issues that mattered in someone’s life were directly on the table.

Professional 7: “‘What matters to me’ is useful to get to know someone a bit better. Thus, asking the person to fill in the questions will save a lot of time, and I will acquire more knowledge in a shorter time.”

Client 4: “I really liked the idea of having the overview with me. It could help me to remember things during the consultation. We had to drive there, then find the right place, and then getting there on time, very stressful situation. Having this overview gave me a good feeling. We now have something in reserve, and I have discussed all the important things.”

Table 3. Summary of findings, quantitative and qualitative results are presented for each component(29).

Components	Quantitative results	Qualitative results
Context	The users are involved in elderly care, care for people with disabilities, mental healthcare, and social support.	All clients were in need of care in the near future.
Fidelity	71 users filled-in the tool and completed one or more categories. All categories were used. The average time spent was 6.9 (±0.03) minutes. The tool was rated 6.63 (±0.88) out of seven by clients and 7.73 (±0.75, range seven to nine) out of 10 by professionals.	Recommendations for implementations were given, including a separate version for relatives and a non-digital version.
Dose delivered	All clients knew about the tool and received the link via a professional or relative.	The professionals handed out information about the tool to some of their clients. The additional questionnaire was less often given to their clients.
Dose received and satisfaction	The tool was filled-in as recommended, but the overview was not discussed by all professionals during consultations with their clients.	The tool was helpful to prepare for consultations, set the agenda, and build a relationship. All clients and professionals would recommend the tool to others.
Reach	26 of the 50 clients asked by professionals fill-in the additional questionnaire. 71 of the 102 visitors of the tool filled-in one or more categories.	The reach was expected to increase by the inclusion of more organisations and professionals, the use of (social) media or other channels.
Recruitment		Professionals hesitated to ask clients to participate based on assumptions of pressure for the client. Due to work pressure it was difficult to recruit professionals.

4. Discussion

4.1 Aim and findings

The aim of the process evaluation was to evaluate the use of and experiences with the tool 'What matters to me'. Considering the six components for a process evaluation, starting with the context component, the participants were involved in elderly care, care for people with disabilities, mental health care, and social support. Sixty-nine percent of the visitors of the tool completed one or more categories, the average time spent was 6.9 (±0.03) minutes, and the tool was rated at 6.63 (±0.88) out of seven in the PSSUQ. Almost all participants, both clients and professionals, experienced 'What matters to me' as useful in practice, and would recommend it to others. Suggestions to improve the tool included a separate version specifically for relatives, and a non-digital version.

4.2 Reflection and interpretation

A new tool should meet the expectations of professionals and fit in with their workflow, for example, time is an important aspect in care settings(3,15). In this study, professionals adapted their workflow by providing information about the tool and the link to 'What matters to me'. During a follow-up consultation, some professionals discussed the overview with the client, other professionals filled in the tool together with their clients. Evaluating the workflow could enhance a long-term implementation and support the healthcare setting in which 'What matters to me' would be used(26). The implement of 'What matters to me' in the workflow of professionals will introduce new tasks and responsibilities for the professional(16). The professionals built relationships with their clients. In the consultations, they will discuss preferences together in order to make a decision for long-term care. 'However, more guidance in using tools in SDM seems necessary(6). Concerning when it should be used in consultations, 'What matters to me' could become part of the team talk, at which exploring important preferences has great potential to discuss the range of options a client has(4). The professionals as well as the client can bring these options into a discussion. In these discussion, the preferences resulted from the tool could serve as agenda setting or exploration of preferred care.

Considering time span, the attention span of eHealth users is short and will shorten even further if the time requirement is too long(37). When using eHealth, the ideal attention span is expected to be six minutes(38).Therefore, the short time spent by the users of the tool will benefit its implementation in real practice. Distractions and difficulties in understanding reduce the attention span(39), therefore, the interface should be attractive with few distractions and simple to understand. Fidelity showed that the tool is attractive and easy to understand, which will be beneficial for the attention span and the willingness to use by professionals and their clients.

Willingness and the actual use of the tool could enhance understanding of the client's preferences. Meeting the client's preferences, with an emphasis on reasons why they have preferences, could result in reaching preferred care and in a higher quality of life for clients in long-term care(40). Assistance to meet the preferences could be provided by 'What matters to me'. Grewal et al.(41) argue that different influences result in different feeling of quality of life for different people. Focussing on capabilities seems important rather than only focussing on functioning or utility(41). Therefore, it is possible to take the capability approach (42). One measure which draws on this approach is the Investigating Choice Experiments Capability Measure (ICECAP)(43). Although this measure is developed to evaluate quality of life, the five attributes stability, attachment, autonomy, achievement, and enjoyment (44) fit in the five categories of the preference elicitation tool 'What matters to me'. The ICECAP shows a value to understand the benefits of healthcare and differences in quality of life (43,45). Comparing the ICECAP and the beneficence for healthcare and evaluation of quality of life, it is expected that the tool will help clients and professionals to evaluate the client's preferences in order to discuss what matters in someone's life and care needs.

4.3 Strengths and limitations

The context component showed that clients from diverse long-term care sectors were included, which is a strength of this study. However, no professionals working in the nursing and care of the elderly sector participated. The clients in need of nursing and elderly care consulted professionals employed in multiple care sectors, not specifically in elderly care. Professionals had difficulty recruiting clients. The component recruitment showed that the reasons for this were the assumed extra burden for clients to fill in an additional questionnaire, and the time constraints of the professional.

Besides a reach following in 26 questionnaires, an additional 71 online user activity logs were obtained. Activity logs enabled data collection without any extra effort the participants to fill in a questionnaire(46). A limitation is that these logs do not give the complete view of the participant.

A difficulty with the components dose delivered, reach, and recruitment is the possible confusions because by the terminology. The terminology shows overlap with the terminology of a methodology of a study. As defined by Saunders (29), 'dose delivered' covers the materials provided or delivered to a user. 'Reach' or 'participation rate' is the proportion of the intended users who actually participated, and 'recruitment' covers findings considering approaching and including of users. In this paper, the methodology focussed on how to gain information about the six components, and the findings considering these components were presented in the results section. By discussing the components beforehand the researchers had a clear understanding of the differences which helped in the possible confusions caused by similarities in the terminology.

4.4 Recommendations

This process evaluation raises questions on how to effectively implement 'What matters to me' in long-term care settings. The findings provided insight into identifying potential problems related to implementation(47). No participants experienced challenges with the tool as such, clients did not report any problems that might hamper possible implementation. However, professionals identified challenges to its use in practice. The results show that the professionals did not provide the tool to all clients. They were unsure which clients they could or should ask to use it, mainly due to urgency of situations and competences of clients. To foster its use, professionals and clients should be given information on how to access and use it(16). This could become part of the training in advance. The training could include scenarios to show applicability of the tool in different settings with a variety of clients. In the implementation of 'What matters to me' professionals will play a key role in providing access, as even the most active clients might not be aware of the tool.

When the tool will become implemented in long-term care practices, another study towards the perceived impact on SDM and collaboration could be performed. Furthermore, the use of the tool in consultations between professionals and clients in long-term care could be studies to evaluate the implementation and possible effect of the tool in practice.

5. Conclusion

In this study, clients and professionals used ‘What matters to me’ in real decision-making practice for long-term care. The process evaluation demonstrated that the tool seems useful in practice, and may assist with preference elicitation. The evaluation is a useful method to have first insight towards implementation. Although a follow-up study should evaluate the perceived impact on SDM and consultations for long-term care, this study shows that the tool is experienced beneficial to clarify preferences of clients in long-term care. Also, this clarification is shown helpful for the clients and professionals to discuss these preferences for life and care. In health and social care practice, the tool seems to fit as part of consultations considering long-term care needs and preferences.

List Of Abbreviations

PSSUQ: Post-Study System Usability Questionnaire

SDM: Shared decision-making

Declarations

Ethical approval and consent to participate

Ethical review and approval was obtained from the Medical Ethics Committee of Zuyderland Zuyd (17-N-79). The participants gave written informed consent and were informed of their right to withdraw at any time. Data were anonymized and data confidentiality was maintained.

Consent for publications

Not applicable.

Availability of data and materials

The dataset that supports the findings and conclusion of this study is available from the corresponding author on reasonable request. The data are not publicly available due to privacy and/or ethical restrictions.

Competing interests

The authors declare they have no competing interests.

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Authors' contributions

All authors designed the study protocol. CvL contributed to the data collection. CvL performed the analysis of the data, and CvL, AM and BvS contributed to the interpretation of the data. CvL undertook the drafting of the first manuscript. TW was the project leader, with AM and JW co-leading. All authors contributed and critically reviewed the manuscript, and all approved the final version.

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Authors' information

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