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 in long-term care. Evaluation of the impact on consultations between clients and professionals by using ‘What matters to me’ is needed.

1. Background

Global demographics show a growing demand for long-term care which is causing changes in the setting and delivery of healthcare(1, 2). The increasing number of elderly people and the prevalence of chronic disease has caused this growing demand. Besides the economic burden of long-term care, this means an increase in the workload of healthcare professionals(3). The demand for long-term care benefits from the application of digital technology, such as eHealth(4, 5). eHealth is considered beneficial to personalized healthcare(3). A paperless healthcare system was envisioned as far back as 1968(6), and healthcare has been investing in eHealth since then. eHealth can be defined as electronic applications for use in healthcare settings(7). It is at the intersection of medical informatics and public health and uses the internet and related new technologies(8, 9). eHealth is regarded as improving client-centeredness, self-

management, engagement in consultations, quality of care, and as lowering the costs of healthcare(7, 10, 11). It can make clients feel secure and in control, while simultaneously appreciating the immediate professional responses and peer support(12). eHealth is particularly valuable when discussing sensitive topics and making difficult decisions. Amongst other things, it assists in communication between care professionals and clients, by facilitating the exchange of information important to the client and being engaged in conversation(3).

When professionals discuss possibilities of care with their client they take the client's total situation into account a collaborative manner(13). With its goal of assisting in communication, eHealth can transform healthcare by enabling the client to participate in consultations(14). 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(15). 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(13). SDM is important in order to be able to understand the client's situation and to decide on the best course of action(16). 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(17). 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(18). Clients in need of long-term care experience challenges in articulating preferences, and without the assistance of preference elicitation, decision-making could be difficult(19, 20).

To assist preference elicitation, current eHealth can improve SDM by addressing needs and preferences(5). This also supports professionals in understanding their clients and building a relationship(21). Our preference elicitation tool 'What matters to me' is designed to elicit preferences. It has similarities to eHealth, as it is offered via the internet and designed for healthcare(22). 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(20). Preference elicitation assists professionals in acquiring insight into client preferences and in discussing the possibilities for long-term care.

The implementation of eHealth remains a challenge for healthcare: 75% of these interventions are thought to fail(14, 23), as implementation is often difficult due to lack of knowledge about healthcare environments(5, 8). Furthermore, there are barriers to implementation, such as costs, time, and difficulty in fitting it into the current workflow.[11] Knowledge about the use of tools in real practice evaluation is needed to assist implementation(8–10, 24, 25). The aim of this study is to evaluate the use of, and experiences with, the preference elicitation tool 'What matters to me'. This study was guided by two research questions. *To what extent was 'What matters to me' used in long-term care settings? How was*

using 'What matters to me' experienced? These questions were studied from the perspectives of both professional and client.

2. Methods

2.1. Design

A process evaluation was chosen to understand the use of the tool in practice (Research question 1) and to gain insight into the experiences of the users (Research question 2). This evaluation assists in planning strategies for successful implementation in practice(25, 26). The process evaluation is based on six process components, i.e. context, fidelity, dose delivered and received, reach, and recruitment(27). These processes generate insight into the mechanisms of a program and investigate its impact and outcome(27). 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. Lastly, 'recruitment' covers approaching and including participants.

To collect quantitative and qualitative data concurrently, a mixed-method approach following the convergent design was applied(28). The quantitative and qualitative results were combined and compared. The quantitative data were extracted from the user activity logs and questionnaires of clients and professionals. The data thus obtained contributed to the components context, fidelity, dose delivered and received, and reach. The qualitative data comprised semi-structured interviews with clients and field notes from phone calls and emails with professionals. The interview guides were based on the components fidelity, dose delivered, satisfaction, reach, and recruitment.

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

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. 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(29).

The researchers contacted 18 long-term care organizations. Information about ‘What matters to me’ and the study was given on visits to these organizations. Twelve organizations were included through purposeful sampling, and the professionals recruited clients through these organizations. The professionals were contacted every two weeks by email or telephone to follow the progression of the recruitment. The professionals 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. Clients were also able to participate independently. Two additional clients were recruited via a pop-up built into the open access. These participants received the information letter and questionnaire by post. 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 a phone interview (convenience sampling).

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 preference elicitation tool ‘What matters to me’ comprises five categories. The category ‘Health’ addresses the preferred care or assistance and the caregivers. ‘Family and friends’ addresses the people important in someone’s life. The category ‘Living conditions’ includes preferred housing options and way of living. ‘Daily activities’ addresses leisure activities and the category ‘money’ considers the cost of care and assistance with administration. Each category contains several propositions. Clients are free to choose which categories they complete. An overview represents the client’s answers to the propositions, and is intended to be discussed at follow-up consultations (Additional file 1). It is preferable that clients use ‘What matters to me’ either before a consultation or together with a professional during the consultation.

The study intervention comprised four steps: (1) the participating professionals received one hour of training on ‘What matters to me’ and information about research procedures. (2) During a regular consultation with their professional, clients received a link to ‘What matters to me’ and oral or written information about the study. (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(30). 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(31, 32). 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(32, 33).

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(31)

	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

	Question	Scoring
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'?

   What was convenient, what was difficult? Can you explain?
   How did you find answering the questions? What made this easy/difficult?
   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?

   You gave a …, on which qualities do you base this grade?
   Are you satisfied with the overview? Can you explain?
   Did you discuss the overview with someone? Who with? What did you discuss? How did you find that discussion?
   Would you recommend using 'What matters to me' to others? Can you explain?
   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(34) was performed on all transcripts guided by the process evaluation model of Saunders et al.(27). During the organizing phase of the analysis(34), 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). Data management was performed using the NVivo version 11 software package.

2.8. Validity

Validity was established by means of triangulation and face validity(35). 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.

3. Results

The results are structured by use and experience based on the two research questions. A division is made between those data obtained from the professionals and from the clients.

3.1. Participants

Of the 12 professionals, 17% were male, with an average age of 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 sector, one in the mental health care sector, two in the social care sector, and two were independent of any sector.

Of the 26 clients 54% were male, with an average age of 45 (± 24.9 years), ranging from 18–92 years, and 42% had a low educational level. Twenty-three participants had Dutch nationality, the others were of Turkish or Indian origin. There were five clients 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 were receiving 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 answer the first research question, *To what extent was ‘What matters to me’ used in long-term care settings?* The reach and recruitment of clients were explored and the numbers concerning actual use were gathered.

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-six clients filled in the questionnaire after using ‘What matters to me’. Twenty-one knew about ‘What matters to me’ via their professionals, and five clients heard about it through informal routes, a friend or partner.

Considering the actual use, the log data showed the number of categories used by the clients, the time professionals and clients spend on using and discussing ‘What matters to me’, and whether or not prints were made of the generated overview. The average estimate professionals made of the time they spent together with their clients ranged from less than ten minutes to 30 minutes.

Of the 102 unique visitors, 69% filled in one or more categories. The log data showed that 33 of the 71 participants filled in all five categories. 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 (Table 2).

Table 2
Actual use of 'What matters to me', the categories and time spent, obtained from the log data of the process evaluation.

Variable	Number of participants (N = 71)
Number of categories filled in	20
- 1	11
- 2	6
- 3	1
- 4	33
- 5	
Categories filled in	45
- Health	42
- Living conditions	45
- Family and friends	52
- Daily life	46
- Finances	
Addition of extra comments to answers	18
Time spent	54
- 0–10 minutes	12
- 11–20 minutes	4
- 21–30 minutes	1
- > 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 interviews, field notes, and questionnaires were used to answer the second research question, *How was using 'What matters to me' experienced?* 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."

In the interviews, clients were asked how they knew about 'What matters to me' and what information they had received. They all said that they were told about it by a professional or relative, and had received 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.'"

However, some professionals hesitated to ask clients to participate based on the 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."

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."

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."

All clients would recommend 'What matters to me' to others. 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."

4. Discussion

The aim of the process evaluation was to evaluate the use of (Research question 1) and experiences with (Research question 2) the tool 'What matters to me'. Participants were involved in elderly care, care for people with disabilities, mental health care, and social support. Sixty-nine percent 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 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.

This study showed that 'What matters to me' was user-friendly, with good information- and interface quality. The interviews confirmed both its usability and usefulness. The short time spent by the users of the tool will benefit its implementation in real practice, as the attention span of this group of eHealth users is short and will shorten even further if the time requirement is too long(36). When using eHealth, the ideal attention span is expected to be six minutes(37). Distractions and difficulties in understanding reduce the attention span(38), therefore, the interface should be attractive with few distractions and simple to understand. The results of the PSSUQ showed that the tool is attractive and easy to understand.

The professionals stated that time was often a barrier to using a tool. A new tool should meet the expectations of professionals and fit in with their workflow; time is an important aspect in care settings(3, 11). Our results showed that the time professionals had spent on using the tool varied depending on how they used it. 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. The time these professionals spent with their client ranged from five to fifteen minutes, but those professionals who filled in the tool together with their clients spent approximately 30 minutes doing it. Evaluating the workflow could enhance a long-term implementation and support the healthcare setting in which 'What matters to me' would be used(24). The study showed ways to implement 'What matters to me' in the workflow of professionals. Its implementation introduced new tasks and responsibilities for the professional(12). 'What matters to me' could become part of SDM for clients during the decision-making

process about long-term care, but more guidance in using eHealth in SDM seems necessary(16). 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(13).

The inclusion of clients from diverse long-term care sectors 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 reasons for this were the assumed extra burden for clients to fill in an additional questionnaire, and the time constraints of the professional.

Besides 26 questionnaires, an additional 71 online user activity logs were obtained. Activity logs enabled data collection without any extra effort by the participants to fill in a questionnaire(39). A limitation is that these data do not give the complete view of the participant.

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(40). 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. 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(12). 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.

5. Conclusion

In this study, clients and professionals used ‘What matters to me’ in real decision-making practice in long-term care. The process evaluation demonstrated that the tool seems useful in practice, and may assist with preference elicitation. However, a follow-up study should evaluate the perceived impact on SDM and consultations in long-term care.

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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