



BMJ Open Using co-creation focus groups to customise a remote multidomain programme designed to increase dementia literacy

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ABSTRACT

Objectives To adapt the content and functionalities of *Brain Health PRO*, a web-based multidomain program designed to increase dementia literacy, to the context and needs of users, providers and community organisations across Québec, Canada.

Design Five consecutive qualitative co-creation focus group sessions 30–90 min in duration each, exploring potential barriers and facilitators to usability, accessibility, comprehensibility, participant recruitment and retention.

Setting Virtual meetings.

Participants A 15-member team based in Québec and Ontario, Canada, consisting of 9 researchers (including a graduate student and the project coordinator), representing occupational therapy, sensory rehabilitation, neuropsychology, psychology, health science and research methods, 3 informal caregivers of older adults living with cognitive decline and 3 members of the Federation of Quebec Alzheimer Societies.

Data analysis Session recordings were summarised through both qualitative description and thematic analysis.

Results The synthesised recommendations included adjustments around diversity, the complexity and presentation styles of the materials, suggestions on refining the web interface and the measurement approaches; it influenced aspects of participant recruitment, retention efforts and engagement with the content of *Brain Health PRO*.

Conclusions Co-creation in dementia prevention research is important because it involves collaboration between researchers, community support and service providers, and persons with lived experience as care providers, in the design and implementation of clinical studies. This approach helps to ensure that the content and presentation of educational material is relevant and meaningful to the target population and those involved in its delivery, and it leads to a greater understanding of their needs and perspectives.

The challenges associated with dementia remain among the most urgent research and care priorities in the global health context,¹ with the WHO estimating that the number

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The involvement of service providers and persons with experience as care providers for individuals living with dementia strengthens the relevance of the recommendations.
- ⇒ The findings are supported by geographic diversity (urban and rural) across the province of Quebec, and an ample number of focus group sessions, resulting in data saturation.
- ⇒ The time available for participants to familiarise themselves with all aspects of *Brain Health PRO* was limited due to logistic reasons.
- ⇒ The findings may be influenced by the unique cultural context of a French language province within Canada, given that the sessions were held in French; however, this choice also supports the local priorities of the community partner and potential participants.

of individuals living with dementia will rise to around 139 million in 2050.² There is currently no cure for Alzheimer's disease and related disorders, but research shows that up to 40% of dementia risk is attributable to modifiable factors such as physical inactivity, social isolation, sensory limitations and vascular health.³ Non-pharmacological interventions, targeting lifestyle and health management years before dementia onset, are therefore proposed as critical tools that could prevent a large proportion of dementia cases.⁴ Interventions targeting modifiable lifestyle variables may have a positive effect on cognition in older adults at risk for dementia, a finding that has led to several large prevention trials to be conducted around the world.⁵ Since the causes of neurocognitive disorders are likely multifactorial, most of these prevention trials rely on multidomain risk reduction



programmes where different risk factors are targeted based on goal setting or risk profiles.^{6,7}

DIGITAL TECHNOLOGIES DURING A PANDEMIC

Lifestyle and environmental factors can have a noticeable effect on older adults' brain and cognitive health.⁸ Conditions and behaviours that are known to be favourable to the brain (eg, physical activity, cognitive stimulation, social interaction, adequate sleep and mental health) have been severely challenged by the COVID-19 pandemic and the resulting confinement of older adults. Isolation, lack of cognitive and physical activity, stress and fear of contamination have increased their vulnerability leading to an urgent need to develop ways to better meet their cognitive health needs, especially during a pandemic.⁹⁻¹¹ The use of new digital technologies has the potential to radically change the way in which older adults can be empowered to take care of their brain health, thereby creating conditions conducive to independence and quality of life.

Older adults have been shown to benefit from educational materials about dementia risk reduction, improving their knowledge of the disease, while also benefitting from improved mood and self-efficacy.¹² The benefit of web-based educational programmes on dementia risks has been demonstrated in middle-aged adults,¹³ leading us to hypothesise that participation in an educational online programme could potentially engage participants in ways to promote their brain health. Such engagement could have a positive effect on risk reduction while also improving participants' willingness and interest towards behavioural change in the context of their modifiable risk factors. To maximise the meaningful effect of such a programme, the conditions that facilitate their uptake need to be optimal, and we need to better understand the ways in which community partner organisations can contribute to their successful implementation. These variables are especially important in the context of regional circumstances that directly influence access and uptake, such as language or culture. In Canada, for example, all provinces are home to Indigenous populations, some regions operate predominantly in English (eg, British Columbia or Alberta), whereas others use mainly French (eg, Quebec) or are bilingual (eg, New Brunswick). Language also influences immigration patterns, making Quebec a unique environment within Canada.¹⁴

Favourable conditions for digital technology

Even though there is considerable variation in internet access and user skill among older adults,¹⁵ up to 81% of older adults in Quebec, Canada, have access to an internet connection, a number that has continuously grown over the last 5 years.¹⁶ A recent survey of 2026 older adults in Canada indicated that they substantially increased their use of technology and online services because of the COVID-19 pandemic.¹⁷ This includes social media, video calling, lifestyle apps and online activities. About two-thirds consider that technology can reduce

the detrimental impact of COVID-19 on their life by reducing social isolation, maintaining their physical and mental health, and helping them to remain safe, independent and active.¹⁷ In this context, web-based delivery can be a powerful means of scaling dementia risk reduction programmes^{18,19} that would remain viable during and after a pandemic. It reduces geographic or mobility constraints and allows individuals who are isolated—due to health conditions, living in remote regions and/or the pandemic—to have access to scientific knowledge tailored to their needs. People can access the programme anytime according to their schedule. The web-based format contributes to sustainability because it allows for the addition of new modules, new information and/or modification of the content as science progresses. There are also features only available through a digital platform, such as using reminders and tailoring the programme to people's risk profiles.

Challenges to the use and implementation of a web-based program

Although some studies have shown that older adults can benefit from online interventions,^{13,20} there are challenges in using and implementing these interventions. A major challenge is that technologies are not always well adapted to the needs and capacities of older adults, resulting in a low level of satisfaction, adherence and buy-in,²¹ and consequently, disappointing effects. This is particularly critical during the development of technologically based programmes for older adults, as technical constraints (eg, ease of use, ease of navigation) and content adaptation (eg, easy to understand, interesting) are among some of the important barriers/facilitators in the use of existing web-based prevention.^{18,19,21} A participatory approach, engaging users in co-creation during the development process, is therefore extremely important. Unfortunately, very few studies have used a participatory research approach involving older adults in the design of technology-based prevention programmes, and in measuring its usability and acceptability or acceptance.²¹

Another important challenge is linked to creating favourable conditions that optimise successful implementation in real life. Community organisations such as the Alzheimer Societies can be critical in communicating risk reduction programmes to older adults and promoting their uptake. Those organisations are frequently approached by older adults for information and often have programmes to help influence change toward dementia prevention. However, organisations need access programmes that are scientifically valid as well as adapted to their reality and constraints.²² Community organisations need to trust those programmes to encourage their use by their constituencies. It is now recognised that successful implementation and meaningful impact require collaborative efforts with all stakeholders from development to deployment of the technology and that users and community organisations must engage with researchers and developers throughout the process.²² In

addition, participatory research is the ethically correct way of project planning, involving the people for whom the project is intended, right from its design: as they have a stake in it, they should have a say in it as well.²³

Brain Health PRO

Over the last 2 years, our team has used a collaborative co-creation research process^{24–26} to develop *Brain Health PRO*,²⁷ a user-friendly evidence-based online risk reduction programme tailored to Canadians.²⁸ The *Brain Health PRO* programme, currently ongoing and available in English and French, is educational, interactive and designed for older adults at risk of cognitive decline. It offers practical solutions to challenges related to healthy brain ageing, information about neurocognitive disorders and tips and guidance on lifestyle changes that can reduce the risk of developing these diseases. *Brain Health PRO* promotes older adults' ownership of their cognitive health, and its content was developed in collaboration with a Citizen Advisory Group composed of 9 older adults from across Canada, as well as 31 researchers from the Canadian Consortium on Neurodegeneration in Aging.²⁹

The challenge

The content development for *Brain Health PRO* relied on co-creation with older adults. However, its development for a diverse population of older adults at risk of cognitive decline, as is the case in Québec, lacked involvement of community organisations, which is essential for sustainability. Therefore, our team aimed to optimise the adaptation and implementation of *Brain Health PRO* with the guidance of members of community organisations, given that their role in the implementation of *Brain Health PRO* was not part of its original development. The mission of community organisations, such as the Federation of Quebec Alzheimer Societies (FQAS), is to meet the needs of older adults living with Alzheimer's and related diseases, as well as those of their caregivers. The prevention of neurocognitive disorders is a priority of the FQAS because people at risk for cognitive decline often turn to them for information and recommendations on prevention strategies. Currently, these organisations are not sufficiently equipped to meet these demands. Being able to benefit from a scientifically based risk reduction programme is therefore a major asset for them. However, to be successfully implemented, programmes need to be adapted to the local context of community organisations by considering users (older adults engaged in the programme), providers (here the staff and volunteers) and community factors (FQAS) to determine the important facilitators and barriers for using and scaling *Brain Health PRO*. Therefore, our aim was to adapt the content and functionalities of *Brain Health PRO* (which was cocreated with older adults for the general Canadian audience), to the context in the province of Quebec. The goal was to explore how *Brain Health PRO* could best be adjusted to the needs of a diverse group of local users, providers and the community partner organisation

(managers within the FQAS) with their specific cultural, linguistic and geographical needs in mind.

METHODS

The presentation of the methodology and results follow the Consolidated criteria for Reporting Qualitative research wherever applicable.³⁰

Study design

To adapt *Brain Health PRO*, we used a co-creation process, a proactive strategy traditionally used by commercial enterprises to modify a product based on consumer feedback.³¹ The co-creation process is suitable for remote modalities and was therefore chosen to enable the research team to gather important feedback on the *Brain Health PRO* application and its potential dissemination across the province of Québec. Québec's multi-cultural and multilingual realities create heterogeneous needs across its 17 administrative health regions. Access to necessary resources to complete the programme (eg, stable internet connection) also differs depending on the administrative regions. Therefore, the use of the co-creation process can assess which needs are general to the entire province versus those specific to certain parts of the province (ie, rural vs urban). Moreover, the co-creation process helps pinpoint facilitators and barriers in the usage of *Brain Health PRO* specific to our targeted population.

Patient and public involvement

Our co-creation approach specifically included individuals with personal experience as topic experts. The co-creation team comprised 15 members (14 women and 1 man), 9 of which came from the research team, including a graduate student and the project coordinator, and representing different disciplines, that is, occupational therapy, psychology, health science and research methods. The remaining members were three informal caregivers of seniors living with cognitive decline, and three members of the Alzheimer Society responsible for service delivery within this organisation (see [table 1](#)). The expert panel members attended between one and all of the five co-creation sessions, depending on their availabilities. All participants were based in either Québec or Ontario.

Recruitment

Recruitment and participation were only limited by the availabilities of potential participants, as everyone who was approached initially agreed to participate. Participants with a background in research were recruited by the two project leads (SB and WW). As for the participants from the FQAS and the informal caregivers, they were recruited through a team executive of the FQAS (NB). Participants needed to be able to express themselves either in French or English and have access to a computer with internet to join the remote meeting platform. Participants also

**Table 1** Participants' perspectives and implications

Participant, n	Perspectives	Type of role(s)
1 (cohost)	Research	University professor, caregiver
2	Research	University professor, caregiver
3	Research	Clinical psychologist
4	Research	Occupational therapist
5	Research	Occupational therapist
6 (cohost)	Research	University professor, caregiver
7	Research	PhD student
8	Informal caregiver	Caregiver
9	Informal caregiver	Lead of senior group, caregiver
10	Informal caregiver	Volunteer, caregiver
11	Service delivery	Alzheimer Society executive
12	Service delivery	Alzheimer Society employee
13	Service delivery	Alzheimer Society employee
14	Research	Knowledge transfer and exchange specialist
15	Research	Project manager

needed to understand basic concepts related to dementia and its effects, have an interest in *Brain Health PRO* and have enough time to complete some assigned readings and to go through *Brain Health PRO* between the co-creation sessions.

Co-creation session format

Before the first session, all participants provided informed written consent, either in electronic or paper format. The co-creation process took part remotely, over a virtual video platform (Zoom Video Communications, San Jose, California). The meetings were conducted in French, with simultaneous translation into English for research team members who were unilingual or felt more comfortable with English. The five online co-creation sessions were held over a period of 6 months (October 2021–March 2022) and lasted between 30 and 90 min each. The sessions were organised by the project manager and hosted by two bilingual researchers (EK and WW) that were present to facilitate the discussion and the flow of ideas. They (one woman and one man) both have extensive experience in conducting qualitative research and leading focus group and consensus studies.^{32–36} Participants were encouraged to share their thoughts and ideas independently of potential budget limitations. The PhD student (GA) took field notes during each session. Between sessions, participants were given access to *Brain Health PRO* chapters so they could become familiar with the platform and begin

reflecting on how it could be adapted to the population of Québec and to the needs of community organisations. They were also asked to access and interact with other parts of the *Brain Health PRO* experience, including the questionnaires for determining risk factors for dementia in potential participants.

Co-creation session content

To ensure a proper course of the sessions and make efficient use of the limited time of the participants, the project manager (AF) and the two hosts planned each session. The number of sessions was planned to accommodate the predetermined discussion topics. The first session opened with general introductions, an overview of *Brain Health PRO*, and the establishment of general communication and confidentiality rules. The two hosts ensured that the sessions were conducted in an environment of respect and active listening. The *consolidated framework for advancing implementation science*³⁷ identifies five domains of interest: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved and the process of implementation constructs for each domain. Our questions for the co-creation meetings emerged from these domains. Objectives and topics to be addressed were determined prior to each co-creation session and were previewed at the end of each prior session. A review of and reflection on relevant materials was assigned as homework for the upcoming session. The topics that were discussed over the sessions were: a general introduction to the structure and purpose of *Brain Health PRO*, including the interface, the gamification features, the notebook and the risk factor questionnaires; possibilities for adaptation of the visual and recorded audio materials used within *Brain Health PRO* to include a diverse population; potential interactive activities hosted by the FQAS; development of training/consultation activities for FQAS staff, peers and volunteers; refinement of dissemination/communication strategies specific to the target population; and streamline measurements for administrative and organisational issues that may arise during the implementation process. Participants were welcome to deviate from those topics if they felt like other aspects of *Brain Health PRO* needed to be discussed.

Data analysis

Together with the graduate students (GA), the two hosts of the sessions began the analysis process with condensation of the data contained in the video recordings and the field notes.³⁸ They selected, focused and simplified the content of the data into bullet points (see online supplemental file 1), with specific attention on information relevant to the focus group questions. We used *analytical questioning* as our approach to analyse the data.³⁹ Within this approach, data are explored in an inductive way, but with specific focus to extract information that answered the questions we were asking during the focus group interviews. At the same time, the analysis was open for the discovery of ideas that were relevant to the research

goals, but that may not have been specifically addressed within the prepared questions. When such ideas emerged during the process, the analysis team revisited the data from previous focus groups to check whether information may have been missed before this new idea emerged.

The results of this analysis were then grouped according to the topics of the research questions that corresponded with different aspects of the *Brain Health PRO* intervention, that is, (1) *Brain Health PRO* format and content, (introductory video, images, notebook), (2) technical aspects (the internet platform and technical assistance), (3) research-related questions (questionnaires at programme beginning, participant recruitment, data collection, contact between the research team and the participants, and other research issues), (4) aspects increasing participants' adherence to the 1-year programme (gamification, contact among participants, interactive activities). To support scientific rigour, we ensured consensus among the three analysts regarding data condensation accuracy and data interpretation during the analysis process. The resulting topics were presented to participants in the last session to verify, through member checking,^{40 41} whether the synthesis accurately represented the session content, and whether any aspects could be more adequately addressed.

RESULTS

The results of the co-creation meetings were numerous, varied and rich in reflecting different life experiences; many of them were ultimately used during the implementation process (see [table 2](#) for an overview). As the represented FQAS offices were in different regions, we benefited from a diversity of perspectives and contexts that provided a rich and diverse picture of the needs, barriers and facilitators to the implementation of *Brain Health PRO*.

Brain Health PRO format and content

While the research-based content had already undergone revisions based on feedback from Citizen Advisors, its implementation in the province of Québec was envisioned. Team members suggested more diversity of the *Brain Health PRO* images, reflecting different ethnic backgrounds, body images, inclusion of persons with handicaps and different settings and landscapes of the province of Quebec. It was suggested that images should realistically reflect the life of all citizens and could thus help in recruiting and retaining participants. Images of proposed activities should be positive to increase programme adherence. As a digital notepad, integrated within the programme, already existed, a hard-copy notepad was suggested since *Brain Health PRO* regularly asks participants to reflect on life goals or experiences. Such a printed notepad could also serve as a motivational gift, financed through the community partners, sponsoring or donations. *Brain Health PRO* includes an introductory video which several members found too long, too detailed

and complicated. They suggested to present the introductory material over more than 1 week, in a more engaging way, and to start quickly with the content chapters. They also suggested a glossary of technical terms used in the programme.

Technical aspects

The members stressed the importance of including a webmaster or another form of regular technical assistance as well as a Q&A page. While technical assistance was already included in *Brain Health PRO*, their comments stress the importance of maintaining this kind of support for the implementation phase of this project. They reiterated the need for existing features such as the ability to personalise the size and font colour of the text within the chapters. Given the breadth of the research project, members suggested a dynamic, short video explaining all the research aspects linked to the programme for participants of the implementation study and to provide links to research related to the programme.

Research aspects

Several ways to increase participant recruitment were suggested: using positive images from *Brain Health PRO* on recruitment material, existing partnerships with community organisations, word of mouth and reaching out to persons living in retirement homes. Suggestions were made to maintain contact with the study participants, that is, the possibility of personalised emails on participants' progress, an online chat room and a short, engaging, recurrent newsletter, containing personal stories as well as highlights, successes and pitfalls.

Brain Health PRO has questionnaires embedded within the programme to determine the participant's risk profile and additional ones used as outcome measures for the research project. Regarding the questionnaires used as study outcomes, members suggested to identify them more clearly, to present them after the questionnaires to determine the risk profile and in a more dynamic manner. They suggested to shorten the questionnaires or present questions in the form of tables. They suggested to explain concepts in the beginning of each chapter, to avoid ambiguous questions and to pay attention to participants' sensitivity regarding questions on Alzheimer's disease, to avoid or reduce test anxiety.

Improving participant adherence

Members suggested interactive activities as a promising means to increase participants' adherence to, and effectiveness of, *Brain Health PRO*. They proposed cognitively engaging activities, personalised feedback, activities designed to retain new knowledge, and quizzes, texts, images and action plans. They also suggested activities to not be compulsory, to be presented early within the programme and to propose optional challenges. Members deemed contact and interaction among participants, as well as social activities an important means to increase programme adherence. They specifically

**Table 2** Overview of the resulting recommendations and the level of implementation in *Brain Health PRO*

	Change types/suggestions	Explanation
<i>Brain Health PRO</i> format and content.	Diversity Images should reflect different ethnic backgrounds, body images, inclusion of persons with handicaps, settings and landscape.	The content was revised to include more diversified images.
	Notepad Provide a hard-copy notepad. Assess the possibility for the notepad to be part of sponsors' contribution.	A printable notepad was already available online; however, the team explored whether partners might provide access to a printed version. This is a possibility but could be determined locally as a function of the partners' resource availabilities.
	Glossary for technical terminology Provide a brief description of terminology that participants may not be familiar with. Add a brief explanation of the issue identified in each chapter.	The research team will collect items from the Q/A section to construct Q&A document and identify the terms that could be defined.
	Introduction video Too long, too many details. Make shorter videos. Make them more engaging.	The initial introductory video was split into two shorter videos and their content was simplified to make them more accessible and engaging.
	Gamification Make gamification optional.	The gamification components are integrated into the web framework; as it would have been technically complex and costly to make it optional, the decision was made not to implement this suggestion.
Research aspects.	Modifiable dementia risk factors questionnaires Change the order of the questions, provide a more dynamic format, some questions are ambiguous, present them during different chapters of the programme. Questionnaires are too long.	It was not possible to change or shorten the questionnaires because they were based on validated questionnaires but some of the instructions were clarified.
	Contact with participants Provide personalised email providing feedback on progress.	Visual components (eg, speedometers measuring progress) already provide personalised feedback on the progress on lifestyle risk factors. Adherence notifications (included in the gamification aspects) provide automated emails and reminders, should participants stops using the programme.
	Interactive activities Optional activities which could increase contact among participants, be cognitively engaging, provide an ability to probe more deeply into complex questions, and be designed to retain acquired new knowledge. Meetings could be virtual or in-person. Toolkit should be prepared for facilitators and format adapted to local constraints.	Monthly social activities facilitated by staff or volunteers from the Alzheimer Society will be provided on an optional basis. There will be a possibility for face to face and online. Training is provided and material is constructed by the research team including a tool kit for facilitators.
	Data collection Document the pattern in which participants complete the programme (eg, daily, condensed on 1 day per week, length of sessions).	The protocol includes the option to explore such aspects qualitatively at the end of the implementation.
	Communication Prepare and send newsletters.	One-page summary materials were prepared for the general programme, and each topic is available to be sent to participants and interested parties.
	Video Record short videos from expert on topics not covered by the programme.	As a first step, expert videos were prepared summarising the highlights of each existing topic and some tips. Each module already covered all the topics deemed necessary and relevant. Additional future topics will be explored after implementation of the current content is complete.

suggested: online presentations, personal meetings, including persons with lived experiences, and meetings supported by local libraries or community halls.

When strong interest in personal meetings became apparent, details for such social activity meetings were proposed, enriched and discussed during the last two co-creation meetings. It was suggested that the FQAS as

the principal partner organisation should identify and train group session moderators and organise this type of activity. The moderators would need training and guidance, and several types of activities were suggested. Discussions favoured an introductory meeting between a *Brain Health PRO* expert and the different facilitators, and in consecutive sessions, activities allowing a deepened understanding of the programme and means for its application. Several potential challenges and pitfalls for these meetings were mentioned. The length of the meetings was deemed critical: on one hand, older adults who often are also caregivers have limited time available; on the other hand, meetings, particularly in person, must be long enough to justify the effort to attend them. The number of meetings would also depend on their nature: a greater number of virtual meetings could be arranged than for meetings in person. Meetings should be based on *Brain Health PRO* chapters, but those should have been seen beforehand by the attendees: the order, however, in which they are seen may depend on a participant's risk factors, interests and/or preferences. It was suggested to record short video clips by experts on specific topics of interest not covered in *Brain Health PRO*, for example, new treatments or self-treatments referenced in the general media or social media. Such recordings could be shown and discussed during the social activity meetings. Finally, two questions were raised: what is the minimum number of participants needed for an in-person-meeting, and will such meetings be an ongoing part of the programme or are they entirely optional? Two suggestions were unanimously accepted: (1) toolkits should be prepared for the moderators and (2) meeting content and modality should be adapted according to local or regional requirements. Finally, the benefit of gamification for programme adherence was discussed. Team members felt that perceiving progress in programme completion was more important than 'game points'. It was suggested that the gamification interface be an optional feature for those wanting it rather than automatically provided. Winning of game points might need some explanation and contextualisation for programme participants who are not familiar with videogames.

DISCUSSION

The purpose of this co-creation study was to adapt the content and functionalities of *Brain Health PRO*²⁸ to the context and needs of a diverse group of users and service providers in the Province of Quebec, Canada, including how it could be used by community organisation, such as the FQAS. To this end, we convened a group of 15 individuals with relevant experiences to participate in five online sessions, to benefit from their feedback, expertise and perspective. The resulting recommendations influenced aspects of participant recruitment, retention efforts and engagement with the content of *Brain Health PRO* before its launch.

Remote multidomain programmes, such as *Brain Health PRO*, that are designed to reduce dementia risk have taken on specific importance in the context of a pandemic, in addition to their utility for reaching persons in remote regions, or who are home-bound for mobility reasons. Even though the overall benefits of such programmes have previously been demonstrated,^{18 19} we chose a co-creation process to further optimise access and to customise the programme implementation to the regional culture, that is, to the province of Quebec, Canada. Co-creation in dementia prevention research involves collaboration among researchers, healthcare or service providers and persons with lived experience in the design and implementation of intervention studies. This approach helps to ensure that the study is relevant and meaningful to the target population of users and leads to a greater understanding of their needs and perspectives. Additionally, we believe that our co-creation approach will result in improved participant engagement with *Brain Health PRO*, especially through the adaptations to the needs of community organisations, facilitate recruitment and retention and may ultimately lead to better health outcomes for our participants and future users of this remote multidomain programme. By including all stakeholders in the process, co-creation helps to promote trust and transparency and contributes to the development of more effective and user-centred interventions.

As shown in table 2, several suggestions were made and subsequently implemented regarding the diversity of cultural, racial and body-type representation across images, the notepad feature, the creation of a glossary for technical terminology, the format of the introduction video and the gamification features. In addition, research aspects of the project were critically appraised, such as the questionnaire administration, personalising contact, as well as the creation, planning and delivery of the social activities to further engage participants with the material (for consolidation) and each other (to reduce social isolation). The development of these materials and their delivery strategies were specifically influenced by the needs and priorities of the community partner representatives. Given limitations in time and resources, the research team had to make strategic choices as to the level of implementation of these suggestions. The highest consensus was achieved on the development and incorporation of social activities, leading the team to develop a training programme and toolkit for staff members of the FQAS to lead monthly interactive in-person or remote sessions for participants. The FQAS recruited interested staff members across the different regions of Quebec to offer these sessions, depending on the interest of *Brain Health PRO* participants, as an optional activity. Additional suggestions were retained, such as the creation of an online chatroom, and a short, engaging, recurrent newsletter containing personal stories as well as highlights, successes and pitfalls; however, their conceptual development and implementation has been delayed until the current study phase is completed.

The generalisation of the specific results may be limited by the localised context in the province of Quebec, Canada; however, the data highlight the beneficial aspects of the co-creation process and the importance of taking the particular social and cultural context into account, in which the programme will be implemented. It is possible that additional team members, more extended access to all *Brain Health PRO* chapters, or supplemental meetings might have given rise to further suggestions for improvements; however, the time and financial constrictions of the project limited the team to the current data. In addition, the recruitment of participants was limited to individuals that expressed interest, resulting in the inclusion of only one man (a researcher with lived experience as a care provider) on the team. It is possible that increased representation by men may have resulted in additional gender-specific suggestions. Fortunately, the implementation of *Brain Health PRO* foresees a qualitative evaluation of the participants' experience, as well as the experience of the members of the community organisation, where additional future refinements will be explored, together with the possible addition of items from the current study that have not yet been addressed. The next steps include the finalised implementation of the recommendations presented here, and the evaluation of the efficacy of *Brain Health PRO* to reduce dementia risk through targeted and personalised education aimed at influencing modifiable risk factors for the development of dementia.

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Patient consent for publication Consent obtained directly from patient(s)

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Data availability statement Data are available upon reasonable request. A complete list of all themes and comments is available in Appendix 1. Access to the complete recording and transcripts of the focus group sessions is possible through the research team, pending additional ethics approval.

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2016;26:1802–11.

Themes	Suggestions/comments
Notebook	<ul style="list-style-type: none"> Use the notebook to make an action plan Use the notebook to write out comments Making notebook public vs. private Make notebook available directly in the application (digital notebook) Possibility to have a printable or orderable notebook Receiving a notebook as a "gift" is motivating Could be used as a reward system (notion of progress)
Images	<ul style="list-style-type: none"> Fostering ethnic diversity Promote body diversity Favoring the diversity of activities Eye-catching and positive images Images allowing for multiple diversities Images with various ethnicities Images with body diversity Image with landscape diversity Image with people with disabilities Realistic rather than idealistic images Using images as an activity Using images as a recruitment tool
Questionnaires	<ul style="list-style-type: none"> Make the questionnaires more dynamic Present the physical activity questionnaire in a table format Define the concepts at the beginning of the questionnaire Too long Some questions are ambiguous Questions not asked in the right order (have a better distinction between sections) Questions about Alzheimer's are abrupt (may cause anxiety) Two "misleading" questions about Alzheimer's disease Better characterize research questionnaires Put <i>Brain Health Pro</i> questionnaires before research questionnaires Distribute the research questionnaires across the chapters
Interactive activities	<ul style="list-style-type: none"> Make activities more interactive (social map, interest list) Have more cognitively engaging activities Revisit the complexity of the questions or have multiple levels of complexity Activities that promote the encoding of information Alternate between text and images in the activities Combine quiz and action plan Add a personal or emotional touch to activities Provide optional challenges in addition to the activities
Contact with participants (emails)	<ul style="list-style-type: none"> Have an automated newsletter/email Personalize the email with the participant's progress

	<p>Concrete and to the point emails (not too long)</p> <p>Include positive and critical testimonials in emails</p>
Contact between participants (social activities)	<p>Addition of online chat</p> <p>Ability to zoom in and out</p> <p>Opportunities for face-to-face meetings</p> <p>Peer support</p> <p>Testimonials from other users</p> <p>Group activity/support groups via municipal libraries</p> <p>Group activity/support groups via community centers</p> <p>Have a group session facilitator</p> <p>Partner organizations offer program and social activities</p> <p>Have a facilitator's guide for group activities</p> <p>Possibility of joining existing organizations</p> <p>Have one meeting with the expert and the facilitator</p> <p>Second meeting to deepen understanding</p> <p>Difficult to follow the groups if people do not start the program at the same time</p> <p>Number of meetings vary according to the modality (virtual vs. face-to-face)</p> <p>Expert vignettes that are recorded and can be listened to before the meeting</p> <p>Time to consider (caregivers have time constraints)</p> <p>Additional activity in the program</p> <p>Order of meetings does not yet follow the order of the modules (because of risk factors)</p> <p>Vary the formula between settings</p> <p>Facilitator Toolkit (with key messages)</p>
Gamification	<p>Move more towards a progress vs. a game perspective</p> <p>The score should not be in the foreground</p> <p>Have a progress bar to estimate how long it will take</p> <p>Choice of interface for people who want the fun aspect</p> <p>Point system is not clear</p> <p>We need to explain the reward system, contextualize it</p>
Introductory video	<p>Very long</p> <p>Too many details</p> <p>See the module right after the questionnaires and the intro video</p> <p>Make it less complex (keep it simple)</p> <p>Make it more engaging</p> <p>Disperse introductory information over several weeks</p> <p>Possibility to have a glossary</p>
Technical assistance	<p>Presence of a webmaster to help participants</p> <p>Presence of frequently asked questions (FAQ)</p>
Platform	<p>Keep the platform very simple</p> <p>Unable to change text size in chapters</p> <p>Poorly chosen color contrast/ colors</p>

Search	Put everything related to the research project in a separate tab Have a dynamic video that explains what people are asked to do in the study
Recruiting	Using images for recruitment Using partnerships to recruit Word of mouth recruitment Recruiting people who are retiring
Data collection	Document the process of how people complete the program Separate questionnaires (individual) and modules (groups) One screen for viewing, but registration for each participant
