

Measuring what matters to older persons for active living: part I content development for the OPAL measure across four countries

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Accepted: 11 June 2024

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Abstract

Aims Many older persons do not think of themselves as "patients" but as persons wishing to live as actively as possible for as long as possible. However, most health-related quality of life (HRQL) measures were developed for use with clinical populations. The aim of this project was to fill that gap and to develop, for international use, a measure of what matters to older persons as they age and seek to remain as active as possible, Older Persons for Active Living (OPAL).

Methods For content development, interviews about active living were conducted with older persons from Canada, USA, UK, and the Netherlands in English, French, Spanish and Dutch, respectively with subsequent thematic analysis and harmonization.

Results Analyses of transcripts from 148 older persons revealed that active living was a "way of being" and not merely doing activities. Saturation was reached and a total of 59 content areas were identified. After grouping similar "ways" together and after conducting a consensus rating of importance, 19 unique and important "ways" remained. In some languages, formulating was challenging for three of the 19, resulting in changes to two English words and dropping two other words, yielding a final list of 17 "ways of being" with harmonized wording in 4 languages.

Conclusion This study underscores the significance of listening to older adults and highlights the importance of considering linguistic and cultural nuances in measure development.

Keywords Active aging · Quality of life · Community programs · Qualitative methods · Translation

Background

As the world's population ages, the need to measure what matters to older people and then to develop population-level programs to address these "matters" is pressing. Traditionally, the measurement focus in the area of aging was felt to be adequately addressed through measures of quality of life [1] and most specifically through measures of health-related quality of life (HRQL) [1]. For the most part, these measures [2–9] have arisen from the need to evaluate the physical and mental health of older persons in a clinical context but not all issues of importance for older persons relate to their health or lack thereof.

There is a strong international movement towards more positive aging paradigms, such as active aging [10], which is defined as "...the process of optimizing opportunities for

health, participation, and security in order to enhance quality of life as people age". Active aging considers growing older as a process that encourages people to realize their full potential and to participate in society according to their needs, desires, and capacities. The concept of active aging has been critiqued because of its emphasis on individual behavior and responsibility. As critics of the term suggest, aging and other contextual factors may be outside of the person's control and can prevent people from being active in the physical sense of the word, which may contribute to reinforcing ageism by suggesting that there is one correct way to age [11, 12]. Others have pointed out the myriad of terms that refer to how persons might live their lives more positively in their later decades to counter the deficit models of aging: active living, active aging, aging fit, or independent, healthy, successful, robust, positive, optimal, well, or productive aging [13, 14]. Most of these concepts are based on a biomedical model [14-16] and stress the avoidance of disabilities and chronic conditions. As

Extended author information available on the last page of the article

Published online: 05 July 2024



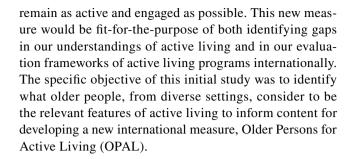
alternatives to these normative models that stress individual responsibility or the biomedical models, there is strong support for a shift to more holistic views of understanding aging. These acknowledge the diversity of older adults, take into account the contextual factors that enable aging well, and aim to foster well-being in older adults, rather than managing disease processes [12, 16–18]. Despite these shifts, the majority of these models and their underlying conceptualization of aging are strongly focused on the activities that older people do (physical, mental, social) rather than on how they understand what it means, as a person, to live fully throughout their lives. While the active aging model has been operationalized into specific actionable components [17], there is no measurement framework beyond a list of activities that people could or should do to remain active and thus to achieve well-being. As emphasized by thought leaders on aging in the 1990s, "Aging is not a problem to be solved rather a mystery to be lived", [19] and "the strong modern bias toward medicalizing the problem of aging needs forcefully to be fought" [20].

Biased perceptions towards older persons, termed "ageism", has much in common with biases towards people with disabilities or "ableism". Both are predicated on values that render judgement on those bodies that do not live up to social norms of productivity or success [21]. Both of these biases favor younger, able-bodied persons as the ideal and characterize those who deviate from this ideal as in need of fixing [22]. Our current measurement frameworks replicate these ageist and ableist values, in content and structure, as they place people on a scale from least able or least functional to most able or most functional.

This context has led to a rethinking of how to measure, in an anti-ableist way, how older persons wish to live fully and actively from their point of view. This is essential to ensure that we, as a society, are prepared to offer programs that are aligned with what matters to them. In the context of disability, Titchkosky [23] postulates that disability offers a perspective and can be an identity that "makes it possible to insert into the world alternative ways of being and of knowing". Likewise, it is our position that this framing could be applied to the situation of aging. Aging gives one a perspective and an identity that makes alternate ways of being and knowing, not just doing, possible. To this end, an international group of researchers, many of whom are themselves aging, came together to expand the measurement framework for older persons living in the community to embrace concepts beyond health.

Objectives

The overall aim of this project was to develop a measure of what matters to older persons as they age despite ageand illness-related health challenges, so that they could



Methods

The process followed the recommendations for the development of new patient or person-reported outcome measures (PROMs) [24, 25]. A qualitative evaluation using thematic analysis was conducted on the material from the transcripts followed by the extraction of themes that then informed the items for the OPAL measure. A purposeful sampling strategy was used to recruit older people, taking into account the different characteristics associated with active living, reflecting the diversity of older people as well, such as age, education, ethnicity, culture, and socio-economic status. A saturation grid was used to keep track of the themes was developed from the content emerging in the different languages [26]. Figure 1 summarizes the steps used to develop the final item set for the questionnaire.

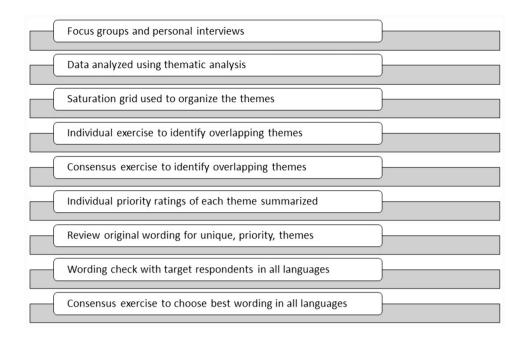
Population

The target population for this new measure are women and men 65 years of age or older who live freely in the community, who do not have an illness requiring on-going hospital treatment (e.g., malignancy, kidney or liver failure), without severe hearing or vision loss, and who do not have severe symptoms associated with mental illness [27, 28] or an inability to comprehend the content of the consent form [29]. These criteria are described in Supplementary Material Appendix 1. The sample was recruited from three provinces of Canada (Ontario, Quebec, and Manitoba), two states in the United States (Texas and California), two communities in the United Kingdom (Oxford and Exeter), and the Rotterdam area of the Netherlands.

The team members comprised eight women and two men all academics located in affluent countries in North America and Northern Europe. All were able-bodied but with diversity of ethnic backgrounds and ages, including some within the target age group in our study. The investigator team was supported by research staff and graduate students, 6 men and 12 women, all able-bodied, mostly young, and from a diversity of ethnic backgrounds.



Fig. 1 Methodological steps to developing the older persons for active living (OPAL) questionnaire



Procedures

Each site managed recruitment locally using flyers posted on websites for seniors' organizations, seniors' residences and through personal or research contacts. A local email address was posted and anyone contacting the site was invited to complete the screening questionnaire (Supplemental Material Appendix 1) hosted on the "Research Electronic Data Capture" (REDCap) platform. REDCap is installed on a secure server and follows the security guidelines required of McGill University. The project was approved by the Research Ethics Board of the McGill University Health Center (HRQL-OPAL/2021-7254).

Consent was carried out in two stages. First there was a consent to be screened as personal data was to be collected. For people making contact through email, a login was sent to the electronic consent module of REDCap. The unique login generated an identification number linked to personal information held only at the local site. This way, the REDCap database contained only the questionnaire information and the local site held the personal information.

For people making telephone contact, the research assistant called to provide more detailed information. If the potential participant was interested, a second call elicited their consent to screen and the process was carried out orally. The data was then entered into REDCap by research personnel. People who met our screening criteria were then contacted for the interview stage, and verbal consent was obtained for this phase.

Interviews and focus groups took place in four different countries, sometimes with multiple locations in the same country. For example, interviews took place in Texas and California in the case of the United States and in Quebec, Manitoba, Ontario in the case of Canada. Interviews were conducted in the primary language of participants, English, French, Spanish, or Dutch, by interviewers speaking the same language. Focus groups and individual interviews were conducted through Zoom and facilitated through an interview guide, the content of which is summarized in Table 1.

The processes took both personal and local context into account in accordance with the International COVID protocols that were in place at the time for data collection. In-person or on-line focus groups were conducted as well as personal interviews by telephone or a web platform.

Table 1 Topic areas covered by the interview guide

Торіс	Sub-topic or Prompt
What does active living mean to you?	
What does an older person who is living actively look like?	What sorts of things do they do? What kind of behav- iors are needed to live actively? What does an older person who is not living actively look like?
What helps older people to live actively?	Such as organiza- tions, services, people What prevents an older person from living actively?
What can other people contribute to help a person to live actively?	



All interviews were audio-recorded and later transcribed verbatim.

Our protocol stipulated that the interviews, transcriptions, coding and preliminary analysis take place sequentially, to ensure that lessons learned could be shared and consensus reached on what could be transferred from one context to another. A first thematic analysis with one set of transcripts was carried out, the results of which were then discussed. Following this, other research teams used the initial thematic codes as a comparative base to adjust and discuss differences and similarities. Adjustments were made in light of the differences between countries and languages resulting in a more consistent approach to data collection.

The experienced members of the research team either conducted interviews themselves or assisted research personnel during the interviews. Focus groups were conducted with an interviewer and an observer, personal interviews were conducted with only the interviewer. All interviewers were knowledgeable about the rigors of qualitative research, underwent training, and participated in practice sessions prior to interviewing. Interviews were conducted between June 2021 and March 2022.

In parallel, another focus group of older people was assembled to appraise the usefulness of existing measures of QOL and HRQL that have been used to evaluate active living programs. The concept of a measure to evaluate active living programs was explained to the group as "fit-for-purpose". The focus group was conducted in person, in both English and French, respecting COVID restrictions for masking and social distancing. The focus group that appraised the value of existing were given 11 measures to discuss: SF-36 [30], EQ-5D [31], PROMIS-Global [32], PROMIS-29 [32], WHOQOL-BREF [33], PBMSI [34], ICECAP [35], EORTC [36], QOL Scale [37], CQolC [38], CDC-HRQL [39], OPQOL [40], AQOL [41], CASP-19 [42]. Four groups of 5 to 6 people were assembled, three groups of English speakers and one group of French speakers, although all were capable in both languages. Each group was given a set of measures to discuss and one spokesperson per group orally presented their overall appraisal of the measure, the items in the measure, and the group's consensus on its strengths and weaknesses and suitability for evaluating active living programs. Other sites also appraised QOL and HRQL and measures using a smaller number of focus groups. As a result of this appraisal process, members of the group suggested what they deemed necessary for active living. These suggestions were then compared with the themes arising from the focus groups and interviews taking place in the other countries.

Analysis

As summarized in Fig. 1, the data from the interviews were analyzed and first put into rough categories paying close attention to the language and terms being used by interviewees, following the structure of the interview guide, as well as their overall frequency of occurrence. Each site analyzed their own data and shared only the terms that emerged within their groups.

The interview question "What does a person who is living actively look like?" elicited two main themes, the first related to "ways of being" and the second related to "activities that people (I) do". From this preliminary observation and analysis of the data (i.e., the words used by our interviewees), arising for the mainstream sample, a saturation grid under the theme of "ways of being" was created. The characteristics of people in this mainstream sample were also analyzed. A diversity sample was recruited to improve coverage of people of lower socioeconomic status, of men, and of people of Spanish origin.

Once all the terms had been transformed into categories, they were organized using the saturation grid. The next step was to group similar terms used to describe "ways of being" with other synonymous terms using a Delphi process. Because our ethics protocol prohibited us from sharing the original interview transcripts with each other, each of the 8 research sites worked with their local team to group "ways of being" together. After this initial work, the bilingual team members simultaneously worked across languages (English + French, + Spanish, + Dutch) to create a master English list.

A second Delphi process was used where members of the research teams (n = 8) then rated each "way of being" according to priority for inclusion using the scale: must have (scored 1), nice to have (scored 2), and not necessary (scored 3). The group was then presented with the results based on these numerical ratings and the decision was made to remove low priority items, scored 3 by two or more people. The final list was then ready for harmonization across languages. The original transcripts were reviewed, once again, to identify the precise words originally used to place the word on the saturation grid. This was done to ensure that the process of reducing the item pool had not resulted in an alteration of the original wording. The bilingual team members then presented the list of words in the two languages under assessment for accuracy to at least two other bilingual target respondents to appraise the equivalency of the terms. The final step, done collectively as a group, was to choose the best wording for each term across all four languages.



Results

Table 2 presents the numbers of interviews conducted across the sites in four languages. There were 122 initial interviews. An additional 26 interviews were done to increase diversity.

Table 3 presents the characteristics of the participants. The sample averaged 73 years of age (SD: 5.3); over 2/3 were women, over 2/3 were university educated, and the sample was majoritively white (75%). Most were able-bodied and without mental health impairments although almost 20% reported they were sometimes or always depressed; 75% rated their degree of active living as 8.4 or more out of 10 (range 3 to 10, with 10 as the highest).

Impairment related characteristics			
Low vision	7	4.9%	
Difficulty walking for 30 min	27	19.0%	
Nervous			
No	59	41.5%	
Sometimes	76	53.5%	
Often	7	4.9%	
Hopeless			
No	113	79.6%	
Sometimes	25	17.6%	
Often	4	2.8%	
Restless or fidgety			
No	75	52.8%	
Sometimes	62	43.7%	
Often	5	3.5%	
Depressed can't be cheered up			
No	116	81.7%	
Sometimes	25	17.6%	
Often	1	0.7%	
Everything an effort			
No	79	55.6%	
Sometimes	55	38.7%	
Often	8	5.6%	
Worthless			
No	118	83.1%	
Sometimes	22	15.5%	
Often	2	1.4%	

^{*}characteristics for 6 persons were not recorded

As mentioned in the previous section, the interview questions "What does a person who is living actively look like?" elicited two main themes, the first related to "ways of being" and the second related to "activities that people (I) do". A third theme that emerged pertaining to support people need to live actively. (See On line material or illustrative quotes). The saturation grid used in creating the categories under the "ways of being theme is presented in Fig. 2. To complete the saturation grid, each

Table 2 Interviews across language segments

	All	English	French	Spanish	Dutch
Canada		1			
Quebec	42	15	27		
Ontario*	19	19			
Manitoba	15	15			
Texas	21	13		8	
California	14	6		6	
UK	17	17			
Netherlands	22				22
All	148	85	27	14	22

^{*}Kingston n = 12; Hamilton n = 7

Table 3 Characteristics of the older persons (n = 148*) interviewed

	Mean	SD	Range	
	N	%		
Socio-demographic characteristics				
Age in years	73.3	5.3	63-88	
Perception of extent of active living**	8.4	1.5	3-10	
Gender				
Women	99	69.7%		
Men	43	30.3%		
Education				
Less than high school	9	6.3%		
High school	18	12.7%		
College or technical diploma	23	16.2%		
Bachelor degree	56	39.4%		
Post-graduate degree	45	31.7%		
Ethnicity				
White European, Canadian, American	106	74.6%		
Latin or South American	18	12.7%		
South Asian	5	3.5%		
Southeast Asian	5	3.5%		
African or Caribbean	4	2.8%		
Japanese	1	0.7%		
Other	3	2.1%		
Type of dwelling				
Single family dwelling	104	73.2%		
Apartment or condominium	38	26.8%		
Current living situation				
Alone	46	32.4%		
Partner/spouse	65	45.8%		
Adult children	6	4.2%		
Other	3	2.1%		
Not recorded	22	15.5%		
Money to meet needs				
Always	122	85.9%		
Not always	20	14.1%		

^{**}Higher is better



^{**2} persons did not rate extent of active living

site was assigned a column, and the grid was completed in the order that the summarized data was received. For example, the first site identified 40 terms relating to "ways of being", these are highlighted in yellow. The second site completing the analysis had 7 of these "ways" in common (shown in yellow) but added an additional 21 (highlighted

Kingston n=12	Texas n=21	UK n=17	Manitoba n=16	Hamilton n=7	Quebec English n=15	NLD n=22	Quebec English	Diversity California English n=6	Diversity California Spanish n=6
	-								
						 			
	 	 	 						<u> </u>

Fig. 2 Saturation grid



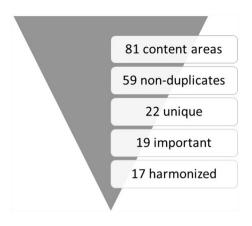


Fig. 3 Item reduction process

in blue). After that there was general agreement on the already identified "ways" with few additions. The first 8 data sets were from the 8 mainstream focus groups, the next three sets of interviews were added to increase diversity for socioeconomic status. In all, 81 expressions of "ways of being" were identified.

The item reduction process is illustrated in Fig. 3. The Delphi process that was used to group similar "ways" together (e.g., accepting and resilient) reduced the original 81 expressions to 59 unique "ways". This more manageable set was presented for a second round of grouping of "like with like" followed by a group consensus exercise and this resulted in 22 "ways". When the individual members of the research teams (n=8) rated each "way" according to priority for inclusion, three items were removed for low priority

(scored 3 by two or more people): financial self-sufficiency, organized, and fortunate. All of these could be considered as contributors to active living rather than active living itself. A final list of 19 "ways of being" was then ready for harmonization across languages. As our focus was to create a measure of positive constructs, some of the difficulty in creating harmonized wording was that the word used deemed positive in one language was not obvious in others. Thinking of opposite words helped the matching process. For example, encouraged was the opposite of discouraged, and energetic was the opposite of fatigued.

Some identified "ways of being" had harmonization challenges. For example, "healthy mentally" was a term used by English respondents. In French, the closest term was "bonne santé mentale", but our typical respondents pointed out "santé mentale" is a less stigmatizing term for mental illness. So, terms for "healthy mentally" and "healthy physically" were retained, and these concepts were available and understandable in the other languages.

Other concepts that were challenging to harmonize were energized, engaged, involved, and included. Energized did not seem to have emerged from the other interviews and did not have obvious words in other languages. The closest term in other languages was energetic and so this became the term, shown in bold in Table 4.

The terms engaged, involved, and included were similar in some ways yet also different. One of the target respondents thought that "included" could mean "batteries included" and did not understand included as engaged or involved. A team member also pointed out that included was the role of "others" not the person. In Dutch, all of three terms were

 Table 4
 The harmonization process

English	Français	Español	Netherlands	Measurement focus group	
Active	Actif(ve)	Activo	Actief (zijn)	Active	
Confident	Confiant.e	Seguro de si mismo	Vertrouwen hebben	Confident	
Connected	Connecté.e	Conectado	Verbonden	Connected	
Useful	Utile	Aportando / que aporta	Nuttig		
Creative	Créatif (ve)	Creativo	Creatief	Creative	
Encouraged	Encouragé.e	Animado/a	Gestimuleerd	Hopeful / Positive	
Energetic	Plein d'énergie	Energico	Energiek		
				Engaged	
Нарру	Heureux (se)	Feliz	Gelukkig	Нарру	
Healthy mentally	en bonne santé mentale	Con buena salud mental	Geestelijk gezond		
Healthy physically	en bonne santé physique	Con buena salud fisica	Lichamelijk gezond		
Independent	Indépendant.e	Independiente	Onafhankelijk (zijn)	Independent	
Interested	Intéressé.e	Interesado	Geïnteresseerd (zijn)	Inspired	
Involved	Impliqué.e	Formar parte	Betrokken		
Mentally sharp	Vif.ve d'esprit	Alerta	Geestelijk scherp		
Motivated	Motivé e,	Motivado	Gemotiveerd	Motivated	
Resilient	Résilient.e	Con fortaleza	Veerkrachtig	Able to cope	
Self-sufficient	Autonome	Autosuficiente	Zelfredzaam	In control	



represented by the Dutch word "betrokken". Included and engaged were removed and involved was the term retained. The final measure comprises 17 "ways of being". Table 4 presents the final set of items in the four languages.

During the focus group with older people to appraise existing measures, three rounds of appraisal were carried out and after 9 measures had been reviewed, members of the group indicated that none of these measures were "fit-forpurpose" and could tell us what kinds of questions should be asked. There was an overwhelming majority opinion against asking negative questions. The older people participating in the appraisal of existing measures did not want to be asked if they felt depressed, worthless, hopeless, fatigued, lonely, or isolated, for example. Instead, participants started suggesting more positive ways to reflect active living. To fit the purpose of evaluating active living programs, the suggestion was to ask about how often respondents feel these ways not how much they feel. The terms that they suggested were matched to those arising from the site-specific inteiews. Table 4 shows that 18 areas were proposed, which mapped onto 14 that were identified through qualitative interviewing, with one unique area (supported/valued), providing external content validity evidence. This unique area was not included as it is linked to the role of others rather than the role of self. The focus groups conducted from the other sites also concluded that the items and measures that they had been asked to appraise were not useful for evaluating active living programs.

Discussion

The original protocol aimed to develop a measure similar to other condition-specific HRQL measures. Provisionally called older persons active living measure or OPAL, our HRQL construct put the emphasis on what older people had to say about active living, rather than using a definition of health primarily derived from clinical settings. As mentioned, this shift in focus was determined through the initiation of a rigorous process of appraisal of existing measures by older adults. This focus on active living, rather than quality of life, framed our interview process. However, the term "active living" did not have a representation in Dutch and quality of life was the closest construct. Nevertheless, the content identified was similar to that raised by the other sites. The results of the interviews, and the thematic analysis conducted, revealed that older persons differentiated between activities they do to keep active and the multitude of characteristics associated with a person living actively, which we termed "ways of being". Also identified were external contributors needed to enable active aging such as financial, social, environmental, and spiritual supports. While the activities listed could inform community programs, the activities themselves were of lesser import than the terms used by participants to describe how these activities contributed to their overall well-being, a holistic approach that redefines how older adults experience, understand, and desire from life. It is these "ways of being" that were used to develop the measure aimed to evaluate active living programs. The environmental support content provides additional information in what older people say is needed to optimize active living.

These "ways of being" emerged both directly from our thematic analysis of the content of the interviews and spontaneously by participants in focus groups appraising existing measures. The fact that the interviews were conducted across four nations and with people speaking four different languages and that we reached saturation supports that the proposed content for the OPAL measure is understandable, comprehensive and relevant.

We also contributed evidence that the process of developing the OPAL measure a priori in four languages is feasible, methodologically valuable, and can assist others who plan to undertake this process. Erkut et al. [43] outlined a process for creating measures simultaneously in two languages, called the dual-focus approach. The dual-focus approach is a multi-step process that includes a research team who is bilingual and from the culture in which the measure will be developed. With this process, the research team first comes to a consensus on the conceptual equivalence of terms to be used in the measure, then they jointly develop items representative of these terms, and obtain input from community members on each of the items. Through an iterative process, the items are revised based on feedback obtained from community members.

Our OPAL project expanded on the work by Erkut et al. [44] who outlined a process for developing measures simultaneously in more than two languages. Our team consisted of researchers with expertise in the content area, and familiarity with the culture and the language the measure was being developed in. Focus groups or interviews were conducted in four languages, that were then thematically analyzed to generate conceptual categories. Saturation grids were used to organize the concepts across languages, and a consensus exercise was conducted to identify overlapping concepts. Older people were consulted on the wording of items in each language, which was then reviewed and finalized by the research team.

The project is limited by the people who agreed to join and to be interviewed and the regions in which the investigators were located. More evidence is needed before the findings from this study are generalizable outside of the demographic profile of participants and countries selected for the initial development.

Another common limitation to many research endeavors is the make-up of the research team. All team members



(eight women and two men) were academics in affluent countries in North America and Northern Europe. All are able-bodied but with diversity of age and ethnic background. The investigator team was supported by research staff and graduate students, 6 men and 12 women.

The majority of the investigators participating in the project are members of the International Society of Quality of Life Research, close colleagues of these members, or come from critical age studies. This common background may have influenced how the data are interpreted perhaps using a quality of life lens rather than other lenses such as function or disability.

The study was also conducted during the COVID-19 pandemic and many people were less active than usual and afraid to be in public. For this reason, the focus groups were conducted mainly over Zoom or individually. This format may have limited the discussion as there is usually a much richer discourse when people can meet face-to-face.

The concept of "ways of being" that emerged from the interviews is another way of thinking about quality of life in older persons when material matters and physical capacity are likely to be fixed. These "ways" can be modified particularly through programs that are available through community organizations and could serve as a method for measuring if what they are offering in their programming actually matters to the people they serve.

Conclusion

The content and wording for a measure of active living for older persons emerged from 148 interviews with older persons across four geographical regions (Canada, US, UK, and Netherlands) and in four languages (English, Canadian French, Spanish, and Dutch) and was derived from a rigorous thematic analysis conducted by an international, interdisciplinary team of qualitative and quantitative researchers, working collaboratively. As a result of this collaboration, active living was reframed as a "way of being" rather than as an "act of doing". This study underscores the importance of listening to older adults, considering linguistic and cultural nuances in measure development, and working across the qualitative/quantitative divide. This iterative process yielded a measure with 17 "ways of being". Subsequent steps will develop and test a scoring system to provide evidence for OPAL's potential as fit for its intended purpose. In addition, testing of the content in other parts of the world is needed. Further studies to provide evidence that OPAL is "fit-forpurpose" to measure gaps in active living and to evaluate active living programs are underway.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s11136-024-03714-z.

Author contributions NEM, AK, MA, RB, JB, HD, IJK, ET, KS, CLW contributed to the study conception and design. Material preparation, NEM, AK, MA, RB, JB, HD, IJK, KKVM, LN, CLW. Data collection and analysis were performed by NEM, AK, MA, RB, JB, HD, IJK, KS, CLW, ZA, FC, JH, MM, LN, SR. The first and final drafts of the manuscript was written by NEM. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript."

Funding This work was supported by the Canadian Institutes of Health Research (PJT-173538). Funding from Healthy Brains for Health Lives (McGill University) supported the Brain Health Outcomes Platform (BHOP) that was used for data entry.

Data availability Data are not available as ethics does not allow us to share qualitative data across sites or with others.

Declarations

Competing interests The authors have no relevant financial or non-financial interests to disclose relative to this work.

Ethical approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Research Ethics Board for the McGill University Health Center (21-06-1011; HRQL-OPAL/2021-7254).

Consent to participate Informed consent was obtained from all individual participants included in the study.

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