

The Senior Toronto Oncology Panel (STOP) Study: Research Participation for Older Adults With Cancer and Caregivers

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Abstract

Background: Patient engagement in research may lead to better-designed studies and improved health outcomes. The objectives of this study were to identify the research priorities of older adults with cancer (OAWCs) and their caregivers and examine how to engage these individuals in research teams and what supports are needed. **Methods:** We conducted 3 public meetings and 7 focus groups to delineate research priorities and the supports needed to facilitate integration of OAWCs and their caregivers on research teams. **Results:** A total of 33 older adults and 19 caregivers attended a public meeting and 27 older adults and 17 caregivers participated in a focus group. Most of the OAWCs and their caregivers had never participated in research before. Three themes were identified from the focus groups: (1) motivation to be on a team; (2) ability to make meaningful contributions; and (3) logistical considerations to facilitate engagement. Most participants were motivated to be a research team member and be involved in all steps of research if it could benefit them or future patients and caregivers. OAWCs and their caregivers were highly motivated to improve outcomes. Required logistics included flexibility regarding time and location, accessibility to computer technology, transportation support, materials worded in lay language, and attending/having short training sessions, as well as the presence of peer support. **Conclusions:** OAWCs and their caregivers are very motivated and willing to participate in research and to be research team members. Logistics and the social aspects of being on a team are important.

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Older adults are underrepresented in clinical cancer research.^{1–7} Evidence shows that engaging patients in the research process can lead to increased enrollment and retention rates^{8–11} and enhanced credibility of the

findings, which in turn increases translation of research into clinical practice.¹² Patient engagement in research is expected to lead to improved health outcomes and better uptake of findings because the research is

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expected to be more relevant for patients.¹³ Stakeholder participation in determining crucial areas of research and healthcare services has been recognized in the United Kingdom by the British National Institute of Health since 1996, leading to the project INVOLVE.¹⁴ Additionally, the US Patient Centered Outcomes Research Institute (PCORI; established in 2010) strongly emphasizes the importance of stakeholders and patient engagement in the research process.^{15,16}

There is also a movement in Canada to engage patients in research. Patient engagement has been defined by the Canadian Institutes of Health Research as “meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context, patient-oriented research may also engage people who bring the collective voice of specific, affected communities.”¹³

Despite the increasing requirements of funding agencies to engage patients on research teams, there are few data to suggest the most effective approach.⁸ Additionally, there is a paucity of research on what older adults with cancer (OAWCs) see as research priorities for cancer, how they feel about being research team members, and what supports and resources they require to participate in this process; this is important to examine because engagement can lead to patient frustration.¹⁷

The goals of this study were to understand the research priorities of OAWCs and their caregivers, and examine how OAWCs and their caregivers can be engaged in research teams and what supports are needed.

Methods

Study Design

This study was designed with OAWCs and caregiver representatives on the team and was conducted in 2 phases (Figure 1): public meetings followed by focus groups. At the end of each phase, participants were invited to join the participant panel aimed at engaging them to be on a future research team.

The study was approved by the Research Ethics Board of the University of Toronto. All participants provided consent before participating in the surveys and focus groups.

Participant Recruitment

Partners for this project included hospitals in the region, health charities, and advocacy organizations for patients and older adults. For the public meetings and focus groups, older adults aged ≥ 60 years who had been diagnosed with any type of cancer in the past 10 years and their caregivers were recruited separately using several strategies, including study Web site; recruitment posters and business cards in oncology waiting areas in partner hospitals and senior

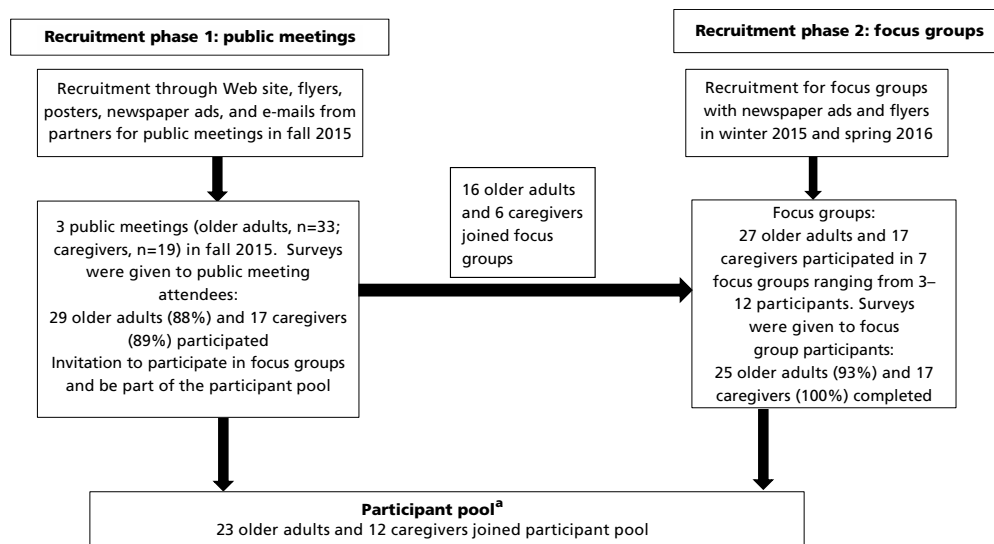


Figure 1. Study timeline and participant flow through the phases of the study.

^aDue to anonymity in the survey, as well as a few incomplete surveys, we could not determine precisely how many participants in the participant pool came from phase 1, phase 2, or both.

community centers; advertisements in local newspapers in the Greater Toronto Area (GTA), Kijiji, and Craigslist, and on the Volunteer Toronto Web site; and advertisements through our partner organizations (via newsletters and e-mails).

Attendees who needed transportation arrangements were provided with taxi services to and from the venue for both public meetings and focus groups, and lunch was provided.

Public Meetings

Three public meetings were held to better understand the research priorities of OAWCs and caregivers. The public meetings took place on Saturdays at 3 different University of Toronto locations in September, October, and November of 2015 and lasted for 3 hours, with half an hour for a reception and farewell. Research priorities were identified in small group discussions and notes were taken by nursing students. The research priorities from the public meetings were summarized.

Surveys were administered at the end of the public meetings to measure satisfaction, understand how to improve future meetings, and invite OAWCs and caregivers to participate in a focus group and join the participant pool. The survey collected information on age, sex, education level, cancer diagnosis, years since diagnosis, and self-rated health. Completion of the survey was voluntary.

Focus Groups

Focus groups aimed to explore what OAWCs and caregivers felt about being co-researchers on the team and to identify supports needed to enable/facilitate older adults and caregiver participation as research team members. The 7 focus groups were held in public libraries across the GTA from December 2015 through April 2016 and lasted 2 hours. All focus groups included both OAWCs and their caregivers in the same group, and were moderated by an experienced moderator and audio-recorded ([a guide with the moderation questions is provided in supplemental eAppendix 1, available with this article at JNCCN.org](#)). A second member of the research team took notes. At the end of the focus groups, participants were asked to complete the survey, which was voluntary. Participants were also invited to join the participant panel. The num-

ber of focus groups was determined based on data saturation (eg, no new themes emerged).

Data Analysis

Survey responses were entered into a Microsoft Excel spreadsheet and descriptive analyses (frequencies, median, and range) were used to describe the characteristics of the participants.

The audio recordings from the focus groups were transcribed verbatim and the content then analyzed, along with the handwritten field notes using thematic content analysis.^{18–20} The team explored and identified emerging themes through reading and coding the focus group transcripts and notes taken by team members. The findings of OAWCs and caregivers were analyzed together because the discussion was held together, and no differences in answers were noted by the team members. A summary of the findings of each focus group was sent to each participant with a prestamped return envelope. Participants could correct the findings, add missing information, and return the modified summary to the research team as a form of member checking.

Results

Public Meetings

Table 1 presents a description of the participants. A total of 33 OAWCs and 19 caregivers attended a public meeting. Although 29 OAWCs completed at least part of the survey, only 26 (79%) answered the sociodemographic questions. The median age for OAWCs was 71 years; most (n=23; 79%) lived at home and one-third (n=9) lived alone. A total of 17 OAWCs (60%) rated their health as “good” or “excellent”; 9 (31%) were receiving some form of active cancer treatment.

The median age of caregivers was 71 years; 11 were a spouse or partner. All respondents had a high school education or higher. The median number of caregiving was 3.5 years (range, 0–21 years), and 13 caregivers (76%) considered their health to be “good,” “very good,” or “excellent.”

Research Priorities of OAWCs and Caregivers

Table 2 lists the research priorities identified by OAWCs and caregivers at the public meetings. The most commonly voiced priorities were finding a cure for the disease and integrating complementary and

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Table 1. Sociodemographic Characteristics of Participants

Older Adults (n=29)	Public Meeting Participants		Focus Group Participants	
	Older Adults (n=29)	Caregivers (n=17)	Older Adults (n=25)	Caregivers (n=17)
Median age (range), y	71 (61–89)	71 (25–88)	72 (55–88)	67 (29–80)
Education				
9–12 years (high school)	(n=6) 21%	(n=2) 12%	(n=12) 48%	(n=4) 24%
≥13 years (post-secondary)	(n=18) 62%	(n=11) 65%	(n=13) 52%	(n=12) 71%
Prefer not to say	(n=5) 17%	(n=2) 12%		(n=1) 6%
Living at home	(n=23) 79%	(n=16) 94%	(n=24) 96%	(n=16) 94%
Currently living alone	(n=9) 31%	(n=6) 35%	(n=7) 28%	(n=4) 24%
Comorbidities ^a				
Median number (range)	1 (0–6)	0 (0–6)	1 (0–5)	0 (0–3)
Arthritis	(n=9) 31%	(n=4) 24%	(n=8) 32%	(n=6) 35%
Heart conditions	(n=6) 21%	(n=1) 6%	(n=7) 28%	(n=2) 12%
Stroke	(n=1) 3%	(n=1) 6%		
Diabetes	(n=5) 17%	(n=3) 18%	(n=3) 12%	(n=2) 12%
Hypertension		(n=1) 6%	(n=2) 8%	(n=1) 6%
Digestive problems	(n=5) 17%	(n=2) 12%		(n=2) 12%
Asthma	(n=3) 10%	(n=1) 6%	(n=1) 4%	(n=2) 12%
Kidney problems	(n=1) 3%			
Vision problem		(n=1) 6%		(n=2) 12%
Multiple sclerosis				(n=1) 6%
Brain aneurysm		(n=1) 6%		(n=1) 6%
Median years since cancer diagnosis (range)	3 (1–21)	N/A	4 (1–21)	N/A
Cancer type ^b				
Prostate	(n=6) 20%		(n=4) 17%	
Colorectal	(n=3) 10%			
Breast	(n=3) 10%		(n=3) 13%	
Hematologic	(n=5) 17%		(n=10) 38%	
Gynecologic	(n=3) 10%		(n=5) 18%	
Head & neck	(n=4) 14%	N/A	(n=1) 4%	N/A
Kidney & bladder	(n=1) 3%		(n=2) 8%	
Pancreatic	(n=1) 3%		(n=1) 4%	
Melanoma	(n=1) 3%			
Lung	(n=1) 3%			
Liver	(n=1) 3%			
Caregiver who has cancer (caregiver only)	N/A	(n=5) 29%	N/A	(n=5) 29%
Self-reported health status good to excellent	(n=17) 60%	(n=13) 76%	(n=19) 76%	(n=13) 76%
Types of cancer treatment received				
Surgery	(n=12) 41%		(n=10) 40%	
Radiation	(n=13) 45%		(n=8) 32%	
Chemotherapy	(n=7) 24%	N/A	(n=9) 36%	N/A
Targeted therapy	(n=3) 10%		(n=4) 16%	
Hormonal	(n=2) 7%		(n=3) 12%	
Currently on treatment	(n=9) 31%	(n=1) 6%	(n=11) 44%	(n=0) 0%
Median years of caregiving (range)	N/A	3 (0–21)	N/A	3.5 (0–21)
Relationship to patient				
Spouse/partner		(n=11) 65%		(n=7) 41%
Child		(n=1) 6%		(n=2) 12%
Friend/neighbor		(n=2) 12%		(n=3) 18%
In-laws	N/A	(n=1) 6%	N/A	(n=2) 12%
Other				(n=2) 12%
Prefer not to say		(n=2) 12%		(n=1) 6%

Abbreviation: N/A, not applicable.

^aMay not add up to 100% due to rounding.^bOne patient was diagnosed with 2 different cancers.

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Table 2. Research Priorities Identified

- Finding a cure
- Benefits/harms of alternative and complementary medicine
- Improving communication and information exchange between patient and team
- How to use technology to find best information
- Using technology to prepare videos of patients talking about their experiences for other patients to see when diagnosed and making treatment decisions to provide peer support
- Role of food/nutrients to eat/avoid during and after treatment
- More on treatment side effects that occur in older adults

alternative medicine with traditional therapies to enhance well-being throughout the cancer treatment trajectory.

Satisfaction With Public Meeting

All respondents were satisfied with the meeting except 1, and all were satisfied with the length of the meeting except 2. All but 1 stated that they would attend a future public meeting to learn more about research.

A total of 17 caregivers returned the survey. All said they were satisfied with the meeting; most (n=14) said they would definitely and 3 would possibly attend future meetings on research.

Findings From Focus Groups Discussions

A total of 27 OAWCs and 17 caregivers participated in 1 of the 7 focus groups (Table 1), from which 3 themes emerged (Table 3): (1) motivation to be on a research team; (2) ability to make meaningful contributions; and (3) logistics required to facilitate engagement. Quotes from OAWCs and caregivers are provided in [supplemental eTable 1](#).

Motivation to Be on a Team: Fewer than half of the OAWCs had participated in any type of study; caregivers had even less exposure to studies. Despite the limited exposure to research but based on their experiences as OAWCs and in the cancer treatment environment, most were very motivated to be on a team to improve care. Most OAWCs and caregivers had never been invited to participate in research. Several indicated that they felt they were not invited to participate in research because they perceived that older adults in Canadian society were not valued, even though they believed older adults could contribute very valuable insights based on their experiences. Some recalled having actively looked for clinical trials, which they

saw as valuable for future treatments, but being told they were not eligible to participate. Many OAWCs indicated they did not know how to find clinical trials. Although some said that their physician encouraged them to participate in research studies, others commented that the physician clearance to participation required by some studies was a barrier because it was often difficult to obtain. Participants suggested that all patients (based on characteristics in their electronic medical record) should be automatically invited to participate in a study if they meet the criteria. Lastly, those who had been involved in research wanted to hear the final results of the study, yet most had never received that information from the study team. Almost all OAWCs and caregivers were willing to become team members.

Ability to Make Meaningful Contributions: Few OAWCs and their caregivers had ever heard of the term *patient engagement* in research, yet most said they would be willing to become a research team member if their voices and contributions could benefit them or future patients/caregivers. They had the time to be involved and said they would want to know in advance the objectives of the project and each meeting. They were willing to be involved for longer periods, although they preferred meeting once monthly or more frequently but for less time. Several OAWCs preferred to work in smaller groups, and preferred having more than 1 OAWC on the team so that they could connect with their peers during the project. Furthermore, having more than 1 OAWC on the team would ensure that continuity of the patient's voice was guaranteed. Notably, some OAWCs pointed out that a potential harm of engaging in research would be the possibility of learning that the prognosis and treatment options of their own disease were not as optimistic as previously believed.

Logistics Required to Facilitate Engagement Amidst Patient Preferences and Healthcare Status: OAWCs and their caregivers raised several logistical issues that needed to be addressed in order to facilitate engagement. Meeting flexibility (ie, day of the week) was important, as were length of the meeting (preferably no more than half a day), timing (not during rush hour and not after dark), providing transportation to those who need it, and accounting for winter conditions. OAWCs and caregivers preferred face-to-face meetings over telephone confer-

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Table 3. Findings From Focus Groups

Topics Discussed	Findings
Motivation to be on a research team	<ul style="list-style-type: none"> • Fewer than half of older adults with cancer had participated in any type of study, caregivers had even less participation in studies but were very motivated to join a research team • Most were never invited, others mentioned they were not eligible based on their advanced age • Some had actively looked for clinical trials and were not eligible • Patients indicated they don't know how to find clinical trials • Participants suggested that all patients, based on characteristics in their electronic patient record, should be invited automatically to participate in a study if they meet the criteria
Ability to make meaningful contributions	<ul style="list-style-type: none"> • Almost all older adults have never heard of the term <i>patient engagement</i> (research) • Older adults and their caregivers would be willing to be a research team member if they thought it could benefit them or future patients/caregivers • They want to represent the patient's voice • Potential harm included learning more about own disease (prognosis/treatment) that was not as optimistic as previously believed • They would be mostly interested in research on their "own" disease
Logistics required to facilitate engagement amidst patients' preferences and healthcare status	<ul style="list-style-type: none"> • Flexibility on days of the week, time, and location (prefer close to home, accessible location, and outside rush hour) • Access to computer technology needs to be taken into account (side effects and sensory impairments can make technology use difficult, as do financial barriers to use technology) • Transportation (provision if needed) • Face-to-face meeting is preferred for social contacts; though phone and Skype are useful during bad weather • Winter conditions are a barrier to leaving the house in Canada • Another barrier is not feeling well enough to attend meetings • Meetings must not be too long and not too tiring, and take into account time for slower pace ("we are a little slower but we can get there") • They don't want to be put on the spot and expected to speak but also appreciated the opportunity to provide input • Writing/seeing/language barriers • Divide training into several smaller sessions for ease of retaining information (training over several sessions; in-person training performed, and if done online it should be supplemented by in-person training) • Receive materials in advance so that additional information can be read and if necessary search for more information • Separate session for questions and answers ahead of the research team meeting and accessibility to a dedicated researcher they can interact with prior to and after meetings • Translation of scientific articles and glossary for terminologies • They prefer "learning as you go" instead of learning in courses

ences/Skype for social contact and OAWCs preferred locations that were accessible and close to home. The OAWCs and caregivers also thought that researchers should address access and accessibility to computer technology and remember that not all OAWCs will feel well enough to attend all meetings. In addition, the OAWCs who had completed cancer treatment spoke about how fatigue and treatment side effects made using technology more challenging and in-person meetings preferable. Researchers should also be aware of potential language barriers or sensory impairment on the part of OAWCs and/or their caregivers that could be obstacles to research team participation. Lastly, although OAWCs appreciated the opportunity to provide patient perspective, they did not want to be put on the spot and expected to speak.

OAWCs and caregivers felt that being trained to be a team member (eg, on research conduct and terminology) was important, but that training should be broken up into smaller sessions to facilitate retention of information. They also preferred receiving

written training materials before team meetings and having access to a dedicated research team member who could offer a separate question and answer session before meetings. They commented that researchers should provide "translation for scientific articles and a glossary for terminologies." Most participants agreed that it would be a "learn as you go" process, which was preferred over classes and courses in advance of the project.

Discussion

Our findings show that OAWCs are very interested in participating in studies, especially if they believe it would help them or future patients. Approximately half of the attendees at the public meetings had never been invited to participate in any studies, illustrating older adults' lack of accessibility to research. Although Townsley et al²¹ found that OAWCs do not seem to actively seek out clinical trials, some in our study said that they had done so but had been told that they were ineligible, whereas others did not

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know where to look. Designing protocols with less restrictive inclusion criteria can help increase older adults' access to studies.⁵ Increased involvement of older adults in the research process itself can help democratize the research process, increase accessibility, and enable their voices to be heard.^{12,13}

A recent realist synthesis by McNeil et al²² developed a 5-stage engagement framework that can be used to enhance engagement. The 5 stages include environment, plan, establish, build, and transition. The environment stage refers to opportunities, or lack thereof, to engage patients and the accessibility issues needed for success, clearly discussed by our participants. The plan stage refers to the investigators planning for engagement; our participants clearly described the logistics that need to be taken into account. The establish stage refers to relationship-building among team members, which links back to the social aspects of being on a team—also clearly described by our participants. The build stage refers to the commitment over time, and the transition stage refers to the end of the research project; our participants clearly indicated they wanted to receive the findings of the projects in which they were engaged. Our findings thus align with this framework²² and provide a more detailed insight for engaging OAWCs and their caregivers.

In this study, the top research priorities identified included finding a cure, examining benefits/harms of complementary and alternative medicine for OAWCs, and improving communication. In Australia, the Cancer Council NSW partnered with Cancer Voices NSW to work with cancer consumers through workshops to set the research agenda for cancer care.²³ These workshops included 32 participants ranging in age from 18 to 72 years, and top priorities included exploring how to diagnose cancer earlier (before metastatic disease), the extent to which palliative care guidelines are used, nutrition and lifestyle risk factors for cancer, how to address chemotherapy side effects, how to increase cancer screening rates, and what support is needed to help those affected return to normal activities. Some of the priorities align with our identified priorities but some do not, such as cancer screening and use of palliative care guidelines.²³ This may be due to differences in age of participants (our participants were older and thus some were no longer eligible for the cancer population-based screening

programs in Ontario, Canada). Improving communication and finding a cure for cancer were consistently identified as research priorities across all public meetings and focus groups. In a survey study of similar research priorities at The Royal Marsden Hospital, Moorcraft et al²⁴ reported that the priorities varied by age, with younger patients rating early detection of recurrence and palliative treatment higher, and older adults rating side effect management as more important; these were not mentioned by our subjects.

A common challenge cited by researchers in patient engagement studies is logistics of engaging patients, such as funding and time.⁸ In our study, we arranged or compensated for transportation and were able to complete each session on time. Given the importance of engaging patients in research, it is imperative that more funding be allocated for patient engagement initiatives in order to fully support the efforts to actively involve these important partners in research.

Although our findings may not be generalizable, they do provide greater understanding of the importance of including OAWCs on teams, and their training needs to optimize their engagement. Our study included a small sample of OAWCs; it was an exploratory study using qualitative data collection. However, data saturation was obtained for the focus groups. Another limitation was our recruitment of older adults through flyers and newspaper ads. In fact, more than half of the study participants were not currently receiving any cancer treatment. However, these cancer survivors are the most likely to participate in research teams, because many of our OAWCs indicated that they would not have considered participating during their treatments.

Lastly, we did not specify which type of study when discussing OAWC participation on a research team. The study topic would impact their willingness, but because this was a first exploratory study, we chose a broad (any site/stage/treatment) rather than deep (specific site/stage/treatment) approach. Future studies should explore the willingness of older adults to participate on research teams in a larger, more diverse sample as well as explore more in-depth willingness and support needs for different types of studies (eg, clinical trials vs observational studies) and for different clinical groups (eg, early vs late stage, curative vs palliative treatment intent).

Conclusions

Overall, OAWCs are keen to participate in research and to be research team members, yet they are often not invited. Concerted efforts are needed to increase older adults' access to study participation and opportunities to be included in research teams.^{17,25,26} The social aspect of having older adults as part of a research team is important to take into consideration in future endeavors.

Despite the push for increasing engagement of patients and knowledge users, and despite there being a variety of patient engagement theories, frameworks, and models, the best methods for engagement have not been identified, and the impact of engagement on patients and caregivers is not fully understood.^{8,11,12,15,22} Although many studies have examined engagement, most have used qualitative methods, and there is currently no quantitative measurement tool that measures the impact of the engagement on study outcomes. Such a tool is clearly

needed, and future similar studies should include one so that different methods of engagement can be compared to develop best practices.

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