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A "Patient Preference" Model of Recruitment for Research from Primary-Care-Based Memory Clinics: A Promising New Approach

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Article

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Résumé

Il peut être difficile de recruter des personnes vivant avec un trouble neurocognitif pour des essais cliniques. Un groupe d'intervenants clés s'est réuni pour mettre au point un processus standardisé de recrutement pour la recherche à partir d'un guide initialement conçu pour soutenir les efforts des cliniques de la mémoire établies en milieu de soins primaires pour promouvoir la recherche. Le processus prévoit la participation des patients, des proches aidants, des chercheurs et des cliniciens. Au cours de cette rencontre d'une demi-journée, les discussions ont porté sur les désirs et les besoins des patients et des proches aidants, les politiques et procédures auxquelles les chercheurs doivent se conformer, l'information fournie aux patients et les implications pour les cliniques de la mémoire. Les patients et les proches aidants ont apprécié cette occasion de contribuer à la science et ont fourni d'importants éclairages sur la meilleure façon de faciliter le recrutement. Les discussions concernant les processus et procédures de recrutement pour la recherche ont fait ressortir la nécessité d'une nouvelle approche axée sur les patients. En conséquence, les intervenants clés ont conçu un programme de recrutement pour la recherche dans les cliniques de la mémoire (« Memory Clinic Research Match ») qui vise à surmonter les obstacles actuels et à accroître le recrutement pour la recherche relative aux troubles neurocognitifs.

Abstract

Recruiting persons with dementia for clinical trials can be challenging. Building on a guide initially developed to assist primary-care-based memory clinics in their efforts to support research, a key stakeholder working group meeting was held to develop a standardized research recruitment process, with input from patients, care partners, researchers, and clinicians. Discussions in this half-day facilitated meeting focused on the wishes and needs of patients and care partners, policy and procedures for researchers, information provided to patients, and considerations for memory clinics. Patients and care partners valued the opportunity to contribute to science and provided important insights on how to best facilitate recruitment. Discussions regarding proposed processes and procedures for research recruitment highlighted the need for a new, patient-driven approach. Accordingly, a key stakeholder co-designed "Memory Clinic Research Match" program was developed that has the potential to overcome existing barriers and to increase recruitment for dementia-related research.

Introduction

With the aging of the Canadian population and concurrent increases in the prevalence of dementia anticipated over the next two decades, advances in dementia care and treatment are paramount (Alzheimer Society of Canada, 2016). However, low recruitment to clinical trials challenges clinical advancements (Grill & Karlawish, 2010). Many factors have been identified as impacting recruitment to dementia-related studies, including restrictive eligibility criteria; patients being diagnosed too late in the disease process reducing their eligibility for some trials; physician reluctance to refer patients for research due to concerns regarding potential harms; loss of control over patient care; and limited awareness of research opportunities (Clement et al., 2019; Watson, Ryan, Silverberg, Cahan, & Bernard, 2014). Moreover, a health care culture that does not embed research into dementia care limits researcher access to potential participants and limits patient access to new interventions. From the patient perspective, relevant factors include

reluctance to burden care partners and family members with having to accompany them to research appointments, lack of understanding of research, the overwhelming nature of study information sheets, and fear of invasive procedures (Clement et al., 2019; Watson et al., 2014).

A number of strategies have been developed to increase research capacity in primary care to increase recruitment rates for dementia-related studies and clinical trials. The United Kingdom (U.K.) has established primary care research networks across the country that vary in how they operate but that essentially provide central coordination to link primary care practice settings interested in research to academic centres that conduct researcher and industry-led research studies (Sullivan, Butler, Cupples, & Kinmonth, 2007). These networks have transitioned from local networks to national networks that facilitate large-scale clinical trials in primary care (Carr et al., 2014). Similarly, trial networks have been established to address challenges related to implementing Alzheimer disease drug trials such as high costs, long time to completion, and participant recruitment (Scott, O'Connor, Link, & Beaulieu, 2014). As an example, the Global Alzheimer Platform Network (GAP-NET) is an American-based network of clinical trial sites that are fully resourced to conduct trials for academic and industry partners. GAP-NET uses a web-based registry to collect demographic and clinical information from interested individuals and from which algorithms select potential participants matched to specific trial eligibility criteria (Cummings et al., 2016). GAP-NET has partnered with other international research collaboratives, including the Canadian Consortium for Neurodegeneration and Aging (CCNA) initiative, which is a national centre that supports collaboration in dementia research. Individuals interested in participating in research can review available research studies on the CCNA website and be directed to more information and/or a study coordinator (CCNA, 2021).

Research registries have also been developed to create a pool of potential participants upon which researchers can draw. Recruitment to these registries is often broad-based, with promotion in primary care, community and social services, awareness raising campaigns, and social media (Krysinska et al., 2017). Typically, web-based, family physicians can register on behalf of their patients, or patients can register directly, entering demographic (age, gender, geographic location) and health information (e.g., diagnosis, comorbid conditions, medications). Algorithmic-based registries have the potential to select the most appropriate candidates for trials, reducing failure rates, increasing recruitment rates, and accelerating the recruitment process (Cummings et al., 2016).

There are few volunteer registries focused on dementia research; a review of research registries identified six dementia-specific research volunteer registries globally (Krysinska et al., 2017). A study examining the effectiveness of a volunteer registry found that while the registry was helpful to research recruitment, there were some limitations related to recruiting underrepresented populations and participant inability to access the research facility due to lack of transportation or assistance with travelling, as well as limited researcher understanding of the registry in terms of registrant characteristics and what information was available (Karagiannidou, Stevens, Knapp, & Cyhlarova, 2021). Challenges also exist for registries maintained explicitly by physicians. A study of a consent for contact method in a single primary care practice setting, in which all patients over 18 years of age were asked to provide consent to be contacted by researchers, found that this approach led to only a small proportion of a practice population (15%) participating in the registry, which was deemed not viable for clinical trial recruitment (Coe et al., 2021). Barriers to the success of this approach included workload issues for primary care providers and patient mistrust of sharing their information with commercial (industry) researchers (Coe et al., 2021). A similar consent for contact approach spread across a larger geographical region proved more successful in recruiting a larger number of registrants. However, more research is needed to fully understand the advantages and disadvantages of this approach (Grady, Gibson, & Bower, 2019).

In attempts to recruit research participants in early, preclinical stages of cognitive decline, a community-based, case-finding approach used advertisements in local newspapers to identify persons with memory concerns interested in undergoing a cognitive assessment and potentially participate in research (Dube et al., 2019). Using this approach, 209 individuals completed an assessment, of whom 203 were suspected of having clinical (mild cognitive impairment [MCI] or dementia; 53%) or subjective (47%) cognitive decline; of these 203 individuals, 61 (30%) enrolled in one or more studies. Using a similar pre-screening, case-finding approach, other studies have found research recruitment rates among those identified as cognitively impaired ranging from 15–82 per cent (Aisen et al., 2016; Vidoni, Bothwell, Burns, & Dwyer, 2018).

As much of the dementia research in Ontario takes place at a tertiary or specialist clinic level, recruitment can be limited as these clinics often see patients with unusual or more complex types of dementia, making them ineligible for some trials, such as those recruiting individuals in the early disease stage (Clement et al., 2019). At this specialist level, clinician researchers depend on consultation referrals from primary care, which have historically been fruitful given that family physicians refer up to 80 per cent of patients with memory concerns to specialists for assessment (Pimlott et al., 2006). In Ontario, Canada, the advent of primary-care-based Multi-specialty Interprofessional Team (MINT) Memory Clinics has reduced the percentage of patients referred to specialists to 10 per cent, thus reducing their pool of potential research participants with less complex conditions who may be appropriate and willing to participate in research (Lee et al., 2010). MINT Memory Clinics were designed to increase capacity for comprehensive assessment and management of dementia at a primary care level. These clinics reflect a collaborative approach to dementia care between primary care clinicians; specialists representing geriatric medicine, geriatric psychiatry, and cognitive neurology; and community home care and support services (Lee, Hillier, Locklin, Lumley-Leger, & Molnar, 2019; Lee, Molnar, Hillier, Patel, & Slonim, 2022). MINT Memory Clinics exist in over 100 primary care settings across Ontario and have recently spread to 10 locations in western Canadian provinces. Consistent with ideal models of chronic disease management, MINT Memory Clinics maintain care for most persons with dementia at the primary care level and refer to specialists only the most complex of cases that require high intensity management (Lee et al., 2010; Scott, 2008). With this new dementia care model, specialists wanting to recruit research participants with MCI or in early disease states have limited access to this participant pool. To increase their access to research participants, researchers have attempted to recruit participants directly from the MINT Memory Clinics with mixed reception and often limited success.

A recent study examining MINT Memory Clinic clinician attitudes and barriers impeding research recruitment found that team members were minimally comfortable with or willing to recruit patients for research studies, particularly clinical trials (Lee,

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Locklin, Patel, Lu, & Hillier, 2022). Barriers to recruitment included limited time and resources to support recruitment, limited information about research studies to share with patients and care partners, and a lack of knowledge about and experience with research among team members. Participants thought it very important to have a standardized process for recruitment from MINT Memory Clinics. As the busy nature and structure of primary care pose a challenge to allocating additional time and resources to determine study eligibility and provide patients with study details, there is interest in recruitment processes within primary care that lessens the burden on clinicians (Mason et al., 2007).

There is limited information on how best to recruit participants for dementia research (Clement et al., 2019; Watson et al., 2014), and there are limited standardized processes for recruitment to dementia studies in Ontario. To increase recruitment from MINT Memory Clinics, a guide for research recruitment was developed. The guide was intended to outline policies and procedures to assist MINT Memory Clinics in managing requests received from researchers or research organizations, to support recruitment for clinical trials and studies, and to guide requests for access to patients or care partners as potential participants in clinical trials and studies. This guide was aimed at helping clinics support research while ensuring the privacy rights of patients and their care partners. These policies and procedures were adapted from a research recruitment guide developed by the Alzheimer Society of Canada to support recruitment efforts from Alzheimer Societies (Chambers, Harris, Lusk, & Benczkowski, 2017) and were informed by discussions with MINT Memory Clinic team members, researchers, patients, and care partners. The guide provided a checklist of considerations that clinics needed to be aware of, such as study applications and approvals (e.g., Research Ethics Boards, Health Canada), an information letter outlining study requirements, risks and benefits of participation, confidentiality and recruitment procedures, potential for perceived conflict of interest, and impact on continuity of care within the clinics. Guidance was given to physicians about reviewing the medical-legal considerations with clinical research contracts. Information and considerations were provided to share with patients and care partners to assist them in making decisions about research participation, such as understanding what is expected of them, the time commitment required, and their rights as a participant, such as the right to leave a study early. An overview of the contents of this draft guide is presented in Table 1. It was intended that this guide would be available for use by all 110 and over MINT Memory Clinics across Ontario.

With interest from researchers and MINT Memory Clinics in developing a standardized approach for research recruitment from these clinics, key stakeholders representing researchers, MINT Memory Clinic clinicians, patients, and care partners came together to review the draft MINT Memory Clinic Guide for Recruitment of Participants for Clinical Research and ultimately to provide recruitment recommendations that would optimize study recruitment rates, while meeting the needs of memory clinics, patients, and care partners for an easy and seamless recruitment process.

In this paper, we describe the proceedings of the key stakeholder working group meeting to clarify and develop a standardized approach for recruiting research participants from MINT Memory Clinics, meeting outcomes, and key discussion themes identified related to research recruitment. We also describe next steps for the development and evaluation of a standardized approach to support dementia research in Ontario.

Table 1. Summary of the draft Guide for Recruitment of Participants for Clinical Research from MINT Memory Clinics

Contents:

1. **Policy and Procedures**
- Policy and procedures for managing requests to recruit from MINT Memory Clinics
- Checklist of information to request from investigators
  - Study applications and approvals (Research Ethics Board, Health Canada)
  - Study information (purpose, funding sources, participant expectations, risks, benefits, confidentiality procedures)
- Similar checklist of information to provide to investigators
- Response to researchers within 60 days of request

2. **Patient/Care Partner Checklist for Participating in Research**
- Information for potential research participants
- A declaration that whether they choose to participate in a study will not affect services offered by the memory clinic
- Information on types of research (clinical trials, observational studies)
- Worksheets on which to take notes of the details of studies of interest, including:
  - Name of the study; investigator contact information
  - Contents of the study information sheet (purpose, funding sources, participant expectations, risks, benefits, confidentiality procedures)
  - Ongoing care during the study (most responsible physician, medication changes)
  - Time commitments
  - Types of procedures, tests, and assessments involved
  - Need for accompaniment
  - Potential costs and compensation
  - Information specific to clinical trials
    - Previous research on the intervention
    - Group assignment (intervention, control)
    - Blinding
    - Access to information (test results, abnormal test results)

3. **Checklist of Considerations for MINT Memory Clinics**
- Ethical considerations (from Canadian Medical Protective Association, Canadian Institutes of Health Research, College of Physicians and Surgeons of Ontario)
- Checklist of questions to consider when making decisions about recruiting patients for a research study
  - Potential for perceived or actual conflicts of interest
  - Financial compensation for physicians
  - Patient/care partner suitability/eligibility for participation
  - Effect of research participation on clinic continuity of care
  - Patient and care partner awareness of study expectations and their right to decline or withdraw at any time
  - Medical-legal considerations as outlined by the Canadian Medical Protective Association

Methods

The key stakeholder working group meeting was hosted and supported by the Ontario Brain Institute, a not-for-profit, government-funded, organization that aims to foster collaborative brain research to deliver innovative products and health care and to improve the quality of life of persons living with brain disorders. A small planning group representing some of the stakeholder groups attending the meeting was responsible for articulating consensus meeting objectives, planning the meeting, establishing the agenda, and identifying participants. The agenda and meeting were facilitated by Dr. Linda Lee, Founder and Executive Director of MINT Memory Clinics. The agenda was focused on ensuring that the needs of all key stakeholders were addressed in the recruitment guide through a discussion of (a) the wishes and needs of patients and care partners, (b) policy and procedures for researchers, (c) research information provided to patients, and (d) considerations for memory clinics. The half-day meeting was held on November 22, 2019, in Toronto, Ontario.

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Meeting Participants

In total, 31 individuals participated in the working group meeting. Key stakeholders represented in the meeting are described in Table 2. A research support staff member was in attendance to document the meeting proceedings; detailed notes were taken of all large group discussions. Seventeen participants attended in-person at the meeting site in Toronto; 14 participants attended the meeting via videoconference. Ten Dementia Advisory Group (DAG) members (persons living with dementia, care partners) gathered at a remote site in Waterloo, Ontario, and attended via videoconference, and although they were invited to attend the entire meeting, they elected to participate in only one agenda item (wishes and needs of research participants). Four additional participants (Memory Clinic clinician, health system representative, two research coordinators) attended via videoconference and participated in large group discussions but not the small group activities. The DAG met in advance of the meeting to review and discuss the meeting agenda in preparation for the meeting discussion.

Agenda and Process

All attendees received the draft research recruitment guide, agenda, and key discussion questions in advance and were asked to review these prior to the meeting and come prepared for discussion. Two members of the planning group (LL, SG) met with the DAG prior to the key stakeholder meeting to review and discuss the agenda in preparation for the meeting. The agenda design included determining a process and key discussion questions that would support meeting objectives and that it was grounded in knowledge transfer and exchange practices (Baumbusch et al., 2008). The meeting agenda aimed to facilitate collaborative discussions, through large and small group activities, towards addressing existing challenges with research recruitment to guide and inform next steps (Figure 1). Participants were informed at the outset of the meeting that it would be audio recorded for accuracy of reporting and that there were no intentions to identify speakers or attribute names to statements made during the meeting. Dr. Linda Lee welcomed meeting participants with an opening statement about the intent and aims of the meeting; all attendees introduced themselves and described their affiliations/roles.

Table 2. Meeting participants (n = 31)

Stakeholder Group	# (%)
Dementia Advisory Group*	10 (32.3)
MINT Memory Clinic clinicians**	5 (16.1)
Specialists*** supporting memory clinics	5 (16.1)
Specialist clinician-researchers	*5/5 (100)*
Health system organization representatives†	3 (9.7)
Alzheimer Society of Ontario	1 (3.2)
Research Institute representatives††	4 (12.9)
Research coordinators	2 (6.4)
Support staff	1 (3.2)

*Persons living with dementia, care partners of persons living with dementia.
**Including physicians (3), pharmacist (1), social worker (1).
***Geriatric medicine, neurology.
†Representing regional care of older adults/geriatric service governance bodies.
††Ontario Brain Institute; Ontario Neurodegenerative Disease Research Initiative.

Wishes and Needs of Research Participants

To keep persons living with dementia and their care partners central to proceedings, the meeting started with a discussion of the wishes and needs of research participants. This virtual, 30-minute open discussion with the DAG was guided by five questions (presented in Figure 1) that were provided to participants prior to the meeting; opportunities were provided for other stakeholder groups to make comments or pose additional questions to the DAG. Key discussion points made during this discussion were recorded on a white board in the Toronto meeting room location.

Review of the MINT Memory Clinic Guide for Recruitment of Participants for Clinical Research

For the review of the MINT Memory Clinic Guide for Recruitment of Participants for Clinical Research, participants (not including the DAG) were assigned to three small groups, each with five to six participants, ensuring representation from each stakeholder group to facilitate a rich discussion. Each group was assigned a section of the recruitment guide to discuss and provide feedback as guided by four key questions (see Figure 1). Additional questions were asked for each specific section. The review of the Patient/Care Partner Checklist included questions about how the tool would be used, and how the information could be shared in a way that does not place undue pressure on patients to participate. Related to the review of the Policy and Procedures Checklist/Researcher Checklist, questions were asked regarding the specific criteria that would assist clinics in deciding whether or not to support recruitment for a study. Related to the Checklist of Considerations for Memory Clinics, additional questions were asked about how the considerations would be used/addressed and by whom. Each group self-assigned a recorder to capture discussion notes, using a template document with the assigned questions and someone to report their key summations to the larger group. Following a 20-minute discussion, each group was given an opportunity to synthesize and report on its key discussion points to the larger group. Other meeting attendees were also invited to make comments or ask questions.

Prioritization and Logistical Support for Research Participants

A second, 30-minute, small group activity session focused on prioritization and logistical support for research study participation. Meeting attendees were assigned to a different group than previously, with representation across stakeholder groups, as implemented with the first group activity. Each group was given four scenarios, posing questions related to the prioritization of studies for which clinics would recruit participants or logistical issues related to recruitment. These scenarios were based on issues that MINT Memory Clinics have faced; the intent of discussing these issues was to provide some guidance in the recruitment guide to assist the clinics with decision making regarding their research involvement. Each group was to use the scenarios to draft recommendations about recruitment from MINT Memory Clinics. Some of the scenarios were reviewed by more than one group. The scenarios given to each group are presented in Figure 1. As with the previous small group activity, each group self-assigned a recorder to document agreed upon responses to the scenarios and someone to report to the larger group.

Research Recruitment Recommendations

The larger group discussion that followed was focused on creating some key recommendations regarding research recruitment. This

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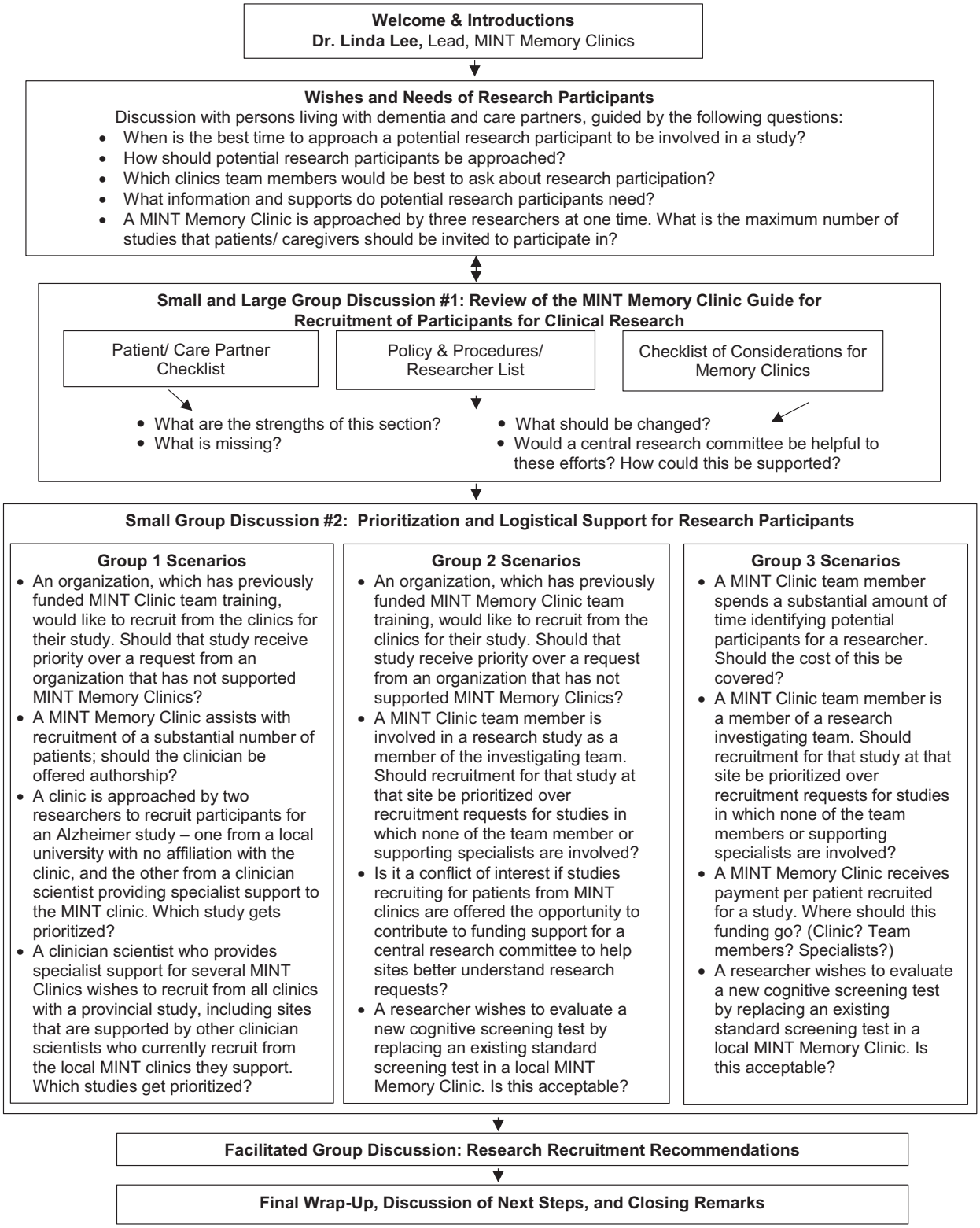

Figure 1. Meeting agenda and processes.

group discussion provided participants an opportunity to provide input on priorities and needed support as related to all scenarios, not just the ones assigned to their group. Key points within the large group discussions were recorded on a whiteboard in the meeting room.

Final Wrap-Up

The meeting ended with a brief "wrap-up" and closing remarks, summarizing key discussion themes and recommendations generated in the meeting for facilitating research recruitment from

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MINT Memory Clinics and next steps towards implementing the identified recommendations.

Analysis

To document the discussions, small group recorders submitted their completed templates, and photographs of the whiteboards were taken following each group discussion. One of the authors (LMH) reviewed the audio recording of the meeting to supplement the detailed notes that were taken during the meeting, which were then integrated with the notes taken during the small group discussions. The resulting detailed notes on the meeting proceedings and outcomes were distributed to all attendees, who were given an opportunity to edit/clarify the documented proceedings or provide additional feedback. No edits or suggestions for revisions were submitted. Consistent with a qualitative descriptive design, the documented proceedings were reviewed by two authors (LL, LMH), using qualitative descriptive content analysis, which analyses verbal data for their informational content and provides a robust understanding of the phenomenon being studied, in this case, research recruitment from MINT Memory Clinics (Patton, 2015; Sandelowski, 2010).This content analysis was used to summarize the key points of the discussion with the DAG and to articulate the key themes generated from the meeting review of the MINT Memory Clinic Guide for Recruitment of Participants for Clinical Research and from the review and discussion of prioritization and logistical support for research study participation.

Results

Discussion with Persons Living with Dementia and Care Partners About Their Wishes and Needs

There was general agreement among members of the DAG that patients and care partners value the opportunity to contribute to science. Regarding the best time to approach patients about research, it was suggested that this be person-focused as this may require a different approach for different patients. Time of diagnosis may be too soon for patients who are overwhelmed by the diagnosis and the amount of information they are provided. Other patients may wish to participate in research immediately as it provides hope and a sense of purpose. It was noted by attending clinicians and researchers that early diagnosis is often an eligibility criterion, so having the conversation about research participation should not be delayed. Similarly, some studies recruit people with normal cognition, so those assessed as not having cognitive impairment should also be approached for research. It was generally agreed that reactions to being asked to participate in research will differ across people, so a multi-pronged approach to recruiting patients may be appropriate, with multiple opportunities available to discuss research as some patients may require more time to consider this option.

Regarding who should approach patients about research, the DAG suggested that it should be someone who has a relationship with the patient and can gauge the best time and way to approach the subject. This could be a specialist, diagnosing physician, or other health professional (e.g., nurse, social worker). The DAG indicated that they wanted information about what was involved in research participation, including potential side effects, benefits, costs, what difference the research is expected to make, and time commitment. Clearly, articulated study expectations were considered necessary so patients could determine how the study would fit with their life plans (e.g., a study requiring biweekly visits would not be appropriate for those who go south for the winter). They emphasized the need for simple messaging and not being inundated with too many study options. Regarding how many studies patients should be approached with, it was noted that this likely depended on each patient's situation; they suggested a maximum of three studies, with one study presented at a time so as not to overwhelm them with information. If more than one study was presented at one time, they felt it important to have someone to talk to about these options. It was also suggested that there be clarity on study goals and an understanding of how patients would benefit from research participation beyond the broad study goals. Researchers noted that study coordinators are key to sharing information about the studies and that this should be done at arm's length from the clinician so that patients do not perceive any coercion regarding participation.

Review of the MINT Memory Clinic Guide for Recruitment of Participants for Clinical Research

The key themes arising from the small group discussion are presented in Table 3. The policy and procedure and patient/care partner checklist sections were well-received, although some additional content was suggested. The checklist of considerations for memory clinics was thought to be too clinic- or recruiter-focused, when the decision to participate in research should be more patient-focused. It was suggested that the focus of this checklist be on patient preferences for research participation, which could then be used to match patients to available research studies. In the larger group discussion, concerns were expressed that the suggested process of having individual memory clinics decide which studies to recruit for would be too cumbersome and did not necessarily address the challenges experienced by the clinics in recruiting for research studies. There was support for a central research committee to assist clinics and reduce burden on the clinics to vet studies themselves. It was noted that, at a minimum, the clinics require a "point person" to coordinate research requests and to match patients to studies; this point person should be trained on the Tri-Council Policy Statement (TCPS2), a Canadian guideline for the ethical conduct of research involving humans, and this should be a funded position. Similarly, there was a great deal of verbalized agreement within the larger group that the process of recruiting patients from the memory clinics for research should be more focused on patient preferences for participation.

Prioritization and Logistical Support for Research Study Participation

The small and large group discussions about the prioritization and logistical support for research study participation highlighted several ethical issues associated with memory clinics, including how studies are prioritized for recruitment or promotion and the provision of compensation for recruitment. The key themes from these discussions are presented in Table 4.

The discussion of ethical issues associated with clinics selecting studies to recruit participants highlighted the need for a different approach to recruiting for research studies. Building on the discussion with the DAG, as well as earlier discussions about the importance of considering patient preferences for research participation, it was recommended that a more straightforward approach to recruitment be developed, which places the memory clinics at

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Table 3. Key themes generated from the review of the MINT Memory Clinic Guide for Recruitment of Participants for Clinical Research

Guide Section	Key Themes
Policy and procedures/ researcher checklist	• Provide clarity about whether research recruitment is passive (e.g., posting recruitment posters) or active (direct participant recruitment). • Ensure MINT Memory Clinics have the final decision about whether or not to participate. • Promote research to patients as optional/voluntary. • Rely on university-based Research Ethics Board approval to ensure the ethical conduct of research. • Prioritize studies that are supported or vetted by the Consortium of Canadian Centres for Clinical Cognitive Research (C5R), Clinical Trials Ontario (CTO), the Canadian Consortium on Neurodegeneration in Aging (CCNA), or not-for-profit organizations that facilitate collaborative partnerships for research on dementia and other neurocognitive disorders.
Patient/care partner checklist for participating in research	• Checklist was perceived as empowering and informative for patients. • Include questions that patients should be asking to help them make decisions about research participation. • Include testimonials of why other patients have participated in research. • Streamline the checklist to be more user-friendly (e.g., list questions as things to consider, rather than questions that require a response). • Provide an explanation about what other opportunities may exist to participate in research if the patient/care partner is deemed ineligible for a study.
Checklist of considerations for memory clinics	• Current checklist is designed more for study recruiters not referrers. • Replace the checklist with a patient preference checklist, which is then used to match patients to research; this checklist would include types of research, time commitment, interest in drug trials, and which routes of administration are acceptable (oral, intramuscular, intravenous, subcutaneous). • Provide support to clinics to assist in coordinating research requests.

Table 4. Summary of key themes and recommendations generated from the review and discussion of prioritization and logistical support for research study participation

Key Themes	Description	Recommendations
There are ethical issues to consider when memory clinics select which studies they will recruit for/promote.	• Studies should not be prioritized one over another as potential exists for conflict of interest. • Studies should not be prioritized based on the principal investigator (e.g., specialist supporting clinics) as this represents a conflict of interest. • While professional relationships may influence interest in particular studies, this should not impact patient choice.	• A registry of studies should exist from which patients, not clinics, decide on participation. • There should be no prioritization of studies by the clinics. • A research "point person," external to the clinics should be designated to assume the role of matching patients to studies, rather than having clinics decide what studies they promote.
There are ethical issues to consider when memory clinics are offered payment for identifying potential research participants.	• Potential exists for perceived conflict of interest; there should be no perception that studies/organizations providing funding support will get their studies prioritized over others.	• To coordinate research recruitment, a funding pool should be created to support a designated provincial or regional "point person" for all MINT Memory Clinics. • The point person should not know which studies are providing compensation for recruitment to clinics, to avoid the perception that some studies are favoured over others based on funding contribution.
While memory clinics can be a "testing ground" for new innovations, usual care cannot be replaced by a study intervention.	• Existing care cannot be replaced with a study intervention, as there would be minimal evidence that it is valid. • A study using a new tool or innovation within the memory clinics would be a validation study, comparing usual care to the innovation.	• Clinics cannot be expected to alter usual care when participating as a study site.

arm's length from research studies, not recommending or prioritizing any studies. It was recommended that this would involve creating a new, designated provincial or regional research point person, or coordinator role, who would coordinate research requests on behalf of all MINT Memory Clinics. This approach would be patient preference-driven in that patients interested in participating in research would identify their preferences for research participation, which would then be matched to available studies. Based on this discussion, meeting attendees created and endorsed a three-step MINT Memory Clinic Research Match Program, based on patient preferences for research participation (Figure 2). This approach involves patients with MCI or dementia, seen within a MINT Memory Clinic, being asked whether they are interested in learning more about participating in clinical research studies. Those who express an interest in learning more would be offered written information about research participation (types of research, what research may entail, what they might expect) and a form to complete that identifies their preferences for participating in research. At this point, patients would be informed that this is completely voluntary, that they are not committing to participating in research, and that any decisions they make about research participation will not influence the care that they receive within the memory clinic. Patient preferences for research participation would then be matched to available studies by a program research coordinator; this coordinator would connect patients to research studies that matched their preferences, including their preference for contacting study research coordinators on their own or having their contact information shared with the appropriate research coordinators. The number of research studies presented to patients depends on the number they indicate on the preference form that they would be willing to consider. This approach would also provide the option of re-asking patients about their interest in

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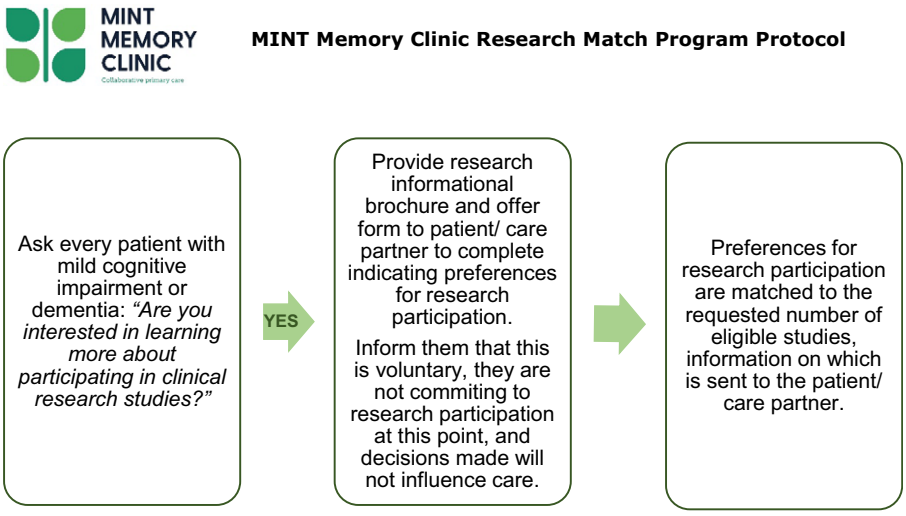

Figure 2. MINT Memory Clinic Research Match Program for research recruitment.

research when there is a change in diagnosis (e.g., from MCI to dementia). The meeting participants recommended that only studies that have documented university-based REB approval or alternatively are reviewed and approved by the Consortium of Canadian Centres for Clinical Cognitive Research (C5R), Clinical Trials Ontario (CTO), the Canadian Consortium on Neurodegeneration in Aging (CCNA), or not-for-profit organizations that facilitate collaborative partnerships for research on dementia and other neurocognitive disorders, be put forth as available research opportunities.

The meeting ended with a clear mandate for MINT Memory Clinics' leadership to pursue further development and implementation of the MINT Memory Clinic Research Match Program. It was recommended that the DAG be consulted on their thoughts of this approach and what would be included in the patient preference form.

Discussion

This paper describes the processes, findings, recommendations, and directions forward of a key stakeholder working group meeting to optimize research recruitment from primary-care-based memory clinics. Building on an initial plan to develop a guide to provide MINT Memory Clinics with a standardized approach to recruiting research participants from the clinics, discussions with an advisory group of patients and care partners, researchers, and clinicians, meeting participants identified existing recruitment issues and a potential solution to improve research recruitment. Meeting participants identified the need to reduce the potential for perceived or real conflict of interest and to remove the burden of selecting studies for promotion by the memory clinics. It was emphasized that there should be no prioritization of studies to recruit from the clinics; prioritization should take place at the patient level. Most importantly, it was stressed that the recruitment process needed to consider, first and foremost, patient interests and preferences for research participation. There was much support from the DAG for recruitment of participants from the MINT Memory Clinics; they valued the opportunity to participate in research. While the intent of this new recruitment process is to increase recruitment into research studies, there are many benefits associated with research participation for patients and care partners. Research participation can provide a sense of hope when faced with uncertainty or lack of treatments (Benson, Friz, Mullen, Block, & Gilmore-Bykovskyi, 2021). For some, research participation may represent a potential benefit in that it contributes to well-being by finding purpose and meaning in suffering and stress by fulfilling the altruistic desire that some patients and care partners have to contribute to science to help others or to find a cure for the disease (Edwards & Van Tongeren, 2020; Mastwyk, Macfarlane, LoGiudice, & Sullivan, 2003; Van Tongeren, Hill, Krause, Ironson, & Pargament, 2017). Participation in clinical trials can provide access to dementia experts and new potentially effective treatments that they might otherwise not be able to access (Grill & Karlawish, 2010).

Meeting discussions resulted in a change in focus in the proposed recruitment process. Discussions highlighted the importance of encouraging patients to participate in clinical studies, but to avoid the perception of coercion/conflict of conflict of interest by having MINT Memory Clinics remain at arm's length from recruitment. The clinics would not recommend or prioritize any studies but simply offer patients the opportunity to learn more about research participation and to articulate how they would like to participate. This process leaves the matching of participation preferences with available studies to an independent entity, after which researchers determine eligibility.

A vital feature of this patient preference-based approach to research recruitment is its emphasis on being patient-driven, while also addressing clinic barriers to recruitment. There is support in the literature for recruitment approaches that consider patient and care partner perspectives on research participation, particularly as related to costs (e.g., lengthy or invasive treatments, repetitive surveys, risk of adverse events, transportation and accompaniment) and benefits (e.g., increased social contacts, access to therapy, incentives) (Forsat, Palmowski, Palmowski, Boers, & Buttgereit, 2020; Patel, Doku, & Tennakoon, 2018; Watson et al., 2014). A study examining the perspectives of persons living with dementia and their care partners on research recruitment from acute care highlighted the importance of understanding the patients' current situation, as related to timing of participation and preferences for being contacted (Friz, Benson, Mullen, Block, & Gilmore-Bykovskyi, 2021). Rather than indirectly recruiting patients through memory clinic team members, direct recruitment may be a more successful approach. In a

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comparison of two dementia research recruitment efforts, one targeted to primary care physicians and one targeted to potential participants directly through a community event, targeting directly to participants was more successful in increasing recruitment numbers (Carr et al., 2010). Directly targeting patients was viewed as a way to bypass barriers to recruitment based on physician involvement and proved to be more cost-effective than targeting physicians (Carr et al., 2010).

There are many potential advantages to using a patient preference-based research matching approach to research recruitment. The discussions undertaken at our stakeholder meeting, particularly related to the research scenarios reviewed, highlighted the dilemma faced by memory clinic teams when they are approached about recruiting participants from their clinic. In removing the responsibility from physicians to determine eligibility and explain studies, the MINT Memory Clinic Research Match Program addresses the health professional-related barriers that impede research recruitment, such as concern about risks and burden to patients and potential for perceived conflict of interest, time restraints, and limited understanding of and experience with research and skills to introduce research (Lee, Locklin, et al., 2022; Mason et al., 2007; Wozniak et al., 2016). This approach is essentially a registry of patient preferences for research, not the typical volunteer registry of clinical information used to determine eligibility criteria. As such, this approach eliminates the challenges associated with registries, such as the workload created for physicians to submit clinical data, technological issues associated with electronic/digital platforms, obtaining consent to contact patients, updating clinical information, privacy issues, and sustainability (Fellows, Stark, Berg, & Chatterjee, 2008).

In contrast to patient registries that allow researchers to select potential participants based on eligibility, which may not necessarily meet with patients' preferences causing them to decline participation, our approach is truly patient-driven, putting patients' needs first and matching them to studies accordingly. This preference matching may increase the likelihood that patients will participate in research. Developing a recruitment process that focuses on patients' preferences for research participation may reduce the number of patients screened for research studies, but who then decline because the study focus and/or requirements do not meet their needs or wishes for research participation. It has been estimated that 10 individuals are screened for each research participant recruited to a study; a clinical trial requiring 70,000 participants would then need to screen 700,000 people to reach expected targets (Wozniak et al., 2016). Given these numbers, a preference-based approach to matching patients to available research studies may also prove to be a more efficient and cost-effective way to recruit research participants as patients screened are those most likely to agree to participation if deemed eligible because the study matches their preferences. Moreover, eligibility for studies is likely also increased as the memory clinics provide accurate diagnoses based on comprehensive assessment, which may not be the case for some recruitment registries that are web-based or public-recruitment-based (Krysinska et al., 2017). Providing patients an opportunity to reconsider research participation with changes in diagnosis considers that their interest and motivations may change over time. Interest and participation in research may be facilitated by introducing the concept of research participation using a clinic team with whom patients have an established relationship and whom they trust.

Family care partners can also benefit from opportunities to discuss research participation as they are often impacted by patient participation in research. This is particularly relevant for care partners who would be expected to accompany patients to research appointments, contribute to information gathered (e.g., health history), and oversee research activities (e.g., engagement in research interventions at home). Care partners, particularly if stressed by the caregiving role, may perceive research involvement as burdensome; they may fear adverse events or believe that there are no benefits to participating in research, resulting in their dissuading patients from becoming involved (Grill & Karlawish, 2010). Discussions with trusted health care providers may help dispel misinformation about research participation and may assist patient-care partner dyads to select preferences for research participation best suited to their situation. For example, if care partners are unwilling to drive long distances for patients to attend research appointments, they could select preferences for participation in only local research studies.

An additional advantage of this patient-preference-based approach to research recruitment is that it is inherently dementia-friendly and inclusive as recruitment processes are more patient-centred and driven than recruiter-focused as related to when patients are approached about research, providing multiple opportunities for discussions about research participation and providing written information about research that is easily understood and accessible. Moreover, the co-design with people living with dementia and their care partners of recruitment processes, written information about research, and a form identifying patient preferences for research participation will ensure the appropriateness and dementia friendliness of these processes and materials. The active engagement of knowledge users in designing and informing knowledge translation materials ensures that they are meaningful, user-friendly, and optimize subject matter literacy (Stacey et al., 2014; Thomas, Nguyen, Teherani, Lucey, & Harleman, 2020).

Cost and sustainability are potential challenges for this new approach to research recruitment. Creating a data management system in which memory clinic team members, patients, or care partners can directly enter their preferences for research participation and potentially create an automated matching system may reduce the costs of maintaining the database of patient preferences. This is particularly relevant given that patient registries are known for being extremely expensive to maintain, with some costing millions (USD) in upkeep fees (Krysinska et al., 2017). As this approach requires a coordinator to facilitate implementation and support research recruitment, there will be some costs associated with this approach; the funding of this registry is yet to be decided and could impact its sustainability.

Limitations

A particular strength of our approach to developing a standardized research recruitment process for MINT Memory Clinics was meaningful engagement with key stakeholder groups: persons living with dementia, care partners, researchers, clinicians, and health system representatives. Although the working group meeting was limited to a half-day, time was maximized by requesting that participants review meeting materials in advance and come prepared for discussion; many attendees had been involved in prior discussions on this topic. While persons living with dementia and their care partners participated in part of the stakeholder meeting and later reconvened to review the new recruitment approach, it might have been beneficial to have had their input in the discussions that led to the revised recruitment process. However, while

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ideal, this might have proven unrealistic as many patients and care partners may have found it difficult to attend such a long meeting. Structuring such opportunities to meet their needs may be of value, as there is some evidence in the literature that persons living with dementia are interested and capable of not only participating in research but also informing research design, procedures, and study outcomes (Frank et al., 2021). We acknowledge that our DAG represents only a very small proportion of persons living with dementia that MINT Memory Clinics assess and manage. Future research on this new research recruitment process will aim to capture the perspectives of a broad sample of memory clinic patients and care partners and socio-demographic characteristics (e.g., age, sex, ethnicity, urban and rural/remote clinic locations). The findings and recommendations from our key stakeholder meeting are specific to the MINT Memory Clinic context. However, they may provide learnings and considerations for other disease-specific health services seeking to optimize recruitment to research studies. Researchers attending the stakeholder meeting were mainly clinicians conducting clinical trial research. The perspectives of non-clinician researchers who conduct other types of dementia research (observational, non-drug interventions, participatory action research) are missing; future research will aim to include a broader sample of researchers.

Future Directions

Consistent with recommendations stemming from the key stakeholder working group meeting, in late January 2020, the DAG members who attended the key stakeholder working group meeting met again to review and discuss this new research recruitment approach. DAG members supported this new approach and stressed the importance of developing a simple language approach to written materials about research that would not be overwhelming for patients or care partners to understand. Our next steps in this process are to obtain the perspectives of researchers and memory clinic team members on this new recruitment approach from their perspective, identifying strengths, weaknesses/potential challenges, threats, and opportunities for improvement, further development, and sustainability. When this approach is further refined as informed by key stakeholders, it will be pilot tested to determine its feasibility and potential efficacy.

The information gathered in our key stakeholder meeting can be used to develop some preliminary principles to guide this work moving forward. These principles would include: (a) Patient-facing communications about research should be simple, easily understood, and accessible; (b) patients and care partners should contribute to the design and content of supportive materials (patient preference form, information about research); (c) patient and care partner preferences for research participation are central to the study-match process; (d) patients and care partners should be approached about research participation at an appropriate time, by someone with whom they have an established and trusted relationship and who is knowledgeable about research; (e) the research recruitment process should not be burdensome for memory clinics; (f) each memory clinic should have complete agency over its participation in the recruitment process; (g) additional training and supportive resources should be available to all memory clinics participating in the recruitment process; (h) the "point person" assigned to match patients with appropriate research studies should be knowledgeable about research and the ethical conduct of research; (i) research studies included for matching to patients should be required to provide proof of ethical review; and (j) the potential for conflicts of interest related to study inclusion should be acknowledged and addressed.

Conclusion

Our research recruitment working group meeting brought together various key stakeholders to better understand research recruitment from MINT Memory Clinics, to explore patient and care partner preferences for research involvement and to develop quality improvement solutions for increasing research recruitment from memory clinics. Systematically providing information and opportunities for MINT Memory Clinics patients to participate in clinical, social, and other types of research is an important role for the clinics. As the clinics maintain care for many persons with MCI and early-stage dementia in their aligned practices, sending only the most complex of cases to specialists, a simple, efficient method implemented in our new MINT Memory Clinic Research Match Program may greatly facilitate research recruitment while overcoming existing barriers to recruitment. In particular, the opportunity to recruit persons with memory disorders from community-based primary care practices will support promising research interventions targeted at early-stage conditions. This working group meeting resulted in a dramatic shift in the initially proposed approach for research recruitment from MINT Memory Clinics. In doing so, a common vision for research recruitment among the varied stakeholders was created and a commitment was obtained to fostering and building a recruitment approach that is patient driven and supports their preferences for research participation.

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