

Partnered research to evaluate adult day programs for persons with dementia across four Canadian provinces

MATTHIAS HOBEN, ASSOCIATE PROFESSOR & HELEN CARSWELL CHAIR IN DEMENTIA CARE, YORKU

ANDREA UBELL, DIRECTOR, PROGRAMS & CLIENT SERVICES, ALZHEIMER SOCIETY OF YORK REGION

HOM SHRESTHA, PHD STUDENT, PERSON WITH LIVED EXPERIENCE, YORKU

HUNG NGUYEN, POST-DOCTORAL TRAINEE, YORKU

health | **YORKU**



Province	Researchers	Trainees	Lived experience	Advocates	DP staff, managers	Health system, Gvt.	Staff
Ontario	Matthias Hoben NPA, YorkU	Hung Nguyen Post-doc	Ron Beleno Caregiver	Andrea Ubell KU-PA, ASY	Cassandra Calbert Social Worker ASY	Kelly Kay PGLO	Gabriel Dusing Data analyst
	Saleema Allana PA, UWO	Behnoosh Zarandi PhD student	Shelley Resaul-Nowrattan Older adult, caregiver	Kari Quinn-Humphrey ASY	Karen Johnson McCormick	Maria Singh MHLTC	Stella Medvedyuk Research coordinator
	Colleen Maxwell PA, UWaterloo	Hom Shrestha PhD student	Anne Vatistas Older adult, caregiver	Cathy Barrick ASON	Laura Letassey DP manager, ASY	Don Embuldeniya MSA	Casey Arguelles Research assistant
	Whitney Berta Co-I, UofT	Genevieve Thompson PhD student		Lauren Bates OCC	Chantelle Morello DP manager, ASY		Soroush Shirazi Research assistant
	Jennifer Bethell Co-I, UHN Toronto	Suad Azar Prosp. PhD student		Samantha Peck FCO	Melanie Rowe DP manager, CHATS		
	Tamara Daly Co-I/Collab., YorkU	Simran Rooprai Prosp. PhD student					
	Liane Ginsburg Co-I, YorkU	Toby Onwurah Prosp. MA student					
Manitoba	Malcolm Doupe PA, UMB			Erin Crawford ASMB		Laurel Rose WRHA	Jennifer Pietracci Research Prog. Mgr.
	Lori Mitchell Collab., UMB					Joanne Dinicola WRHA	
Alberta	Zahra Goodarzi PA/Co-I, UofC		Patricia Kostyk Caregiver	Barb Ferguson ASC	Ali Cada DP director, ASC	Allison Lacey AB Health	Emily Dymchuk Study coordinator
	Holly Symonds-Brown PA/Co-I, UofA		Kevin Lazaruk Caregiver			Jennifer Salt AHS, Calgary	
	Sienna Caspar CO-I, ULethbridge		Bernie McCracken Older adult, caregiver			Cassi Wadsworth AHS, Edmonton	
	Greta Cummings Co-I, UofA					Michelle Podmore AHS, Edmonton	
	Kaitlyn Tate Co-I, UofA					Heather Tomaszeski AHS, Calgary	
	Adrian Wagg Co-I, UofA						
	David Hogan Co-I/Collab., UofC						
British Columbia	Kim McGrail PA/Co-I, UBC		Jim Mann PlwD	Heather Cooke ASBC	Karen Littleton Interior Health	Aaron Miller Interior Health	Kyle Corbett Study coordinator
	Jennifer Baumbusch Co-I, UBC		Katrina Prescott Caregiver	Sarah Wu ASBC	Jessica Howard Interior Health	Michelle Smith Interior Health	
			Linda Woo Caregiver	Barb McLean FCBC			

O
u
r

T
e
a
m



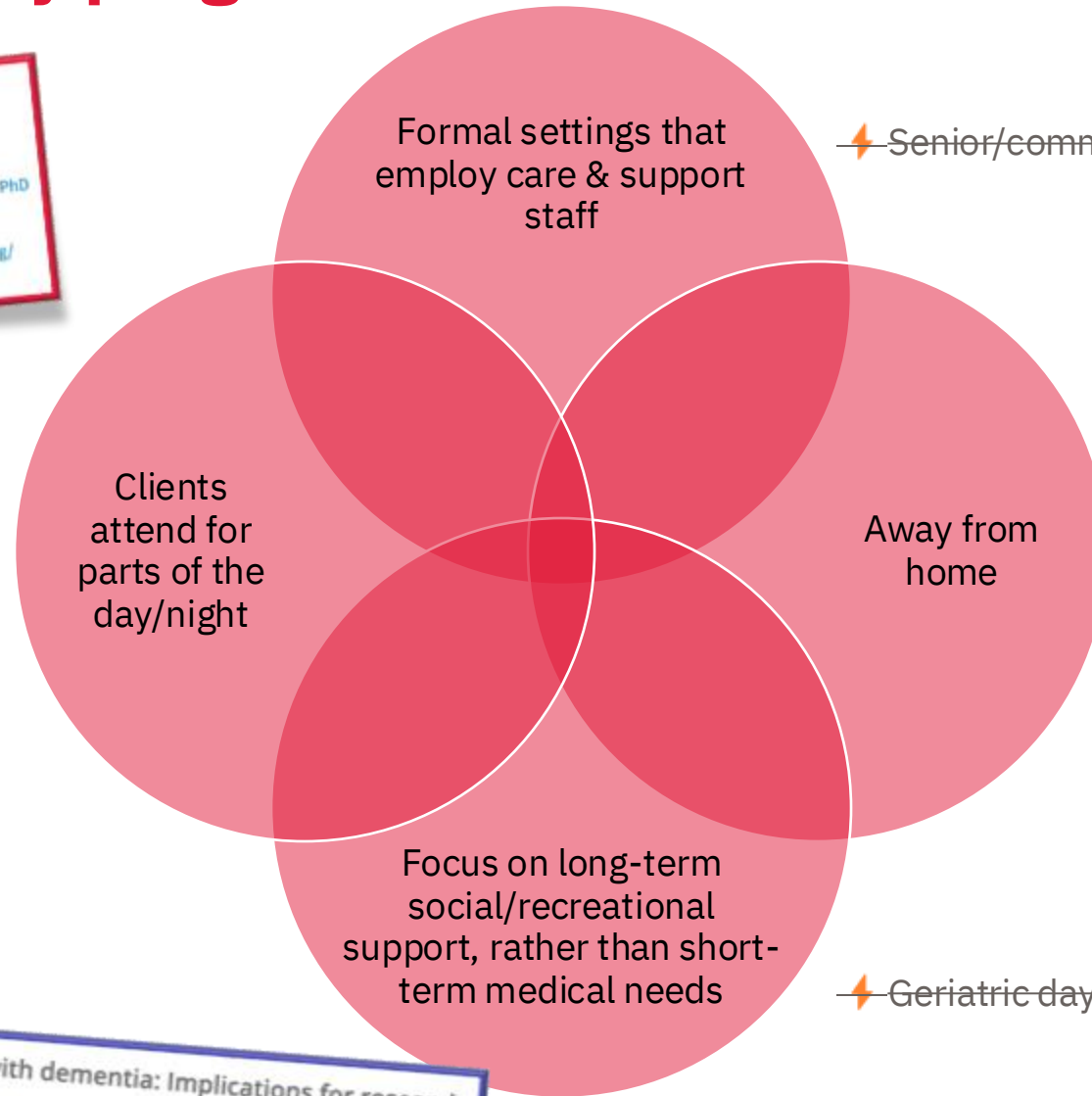
To the funders, all team members who are supporting this work, and to the persons living with dementia, their caregivers, and care settings who have agreed to participate in the various parts of this research



What are adult day programs?

Adult Day Center Programs and Their Associated Outcomes on Clients, Caregivers, and the Health System: A Scoping Review
Moriah E. Ellen, MBA, PhD, Peter Demaio, BA, Ariella Lange, PhD, Michael G. Wilson, PhD
Author Notes
The Gerontologist, Volume 57, Issue 6, December 2017, Pages e85–e94, <https://doi.org/10.1093/geront/gnw165>

⚡ Short-term institutional care



⚡ Senior/community centres

⚡ Home care, In-home respite services

⚡ Geriatric day hospitals

Re-thinking the nature of day programs for people with dementia: Implications for research
Belly Symonds-Brown, Christine Cecil, and Mary Ellen Purkis
Volume 20, Issue 1
<https://doi.org/10.1177/1471301219884429> View all authors and affiliations

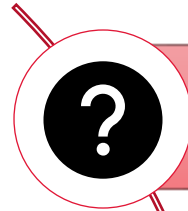
Knowledge gaps

2,501 studies screened

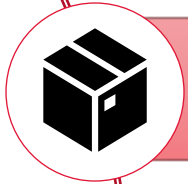
80 studies included

Only 28 Canadian reports

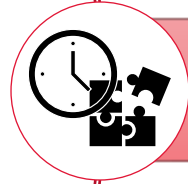
>20 are older than 10 years, 8 are expert opinions, only 1 (22 years old) was cross-provincial



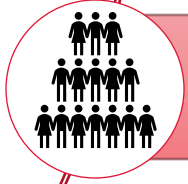
Results inconclusive, some studies suggest positive effects on clients and caregivers, others suggest no or negative effects



Lack of understanding of how and why day programs may have positive, negative, or no effects on different groups of people in different context



We especially **lack robust, longitudinal, cross-provincial** Canadian research, and we lack an understanding of the **characteristics of day programs** and how they differ within and across provinces



We have no idea about the **number and characteristics of people attending or not attending day programs and their caregivers**, how they differ from those not attending, reasons for non-attendance, attendance patterns, ...

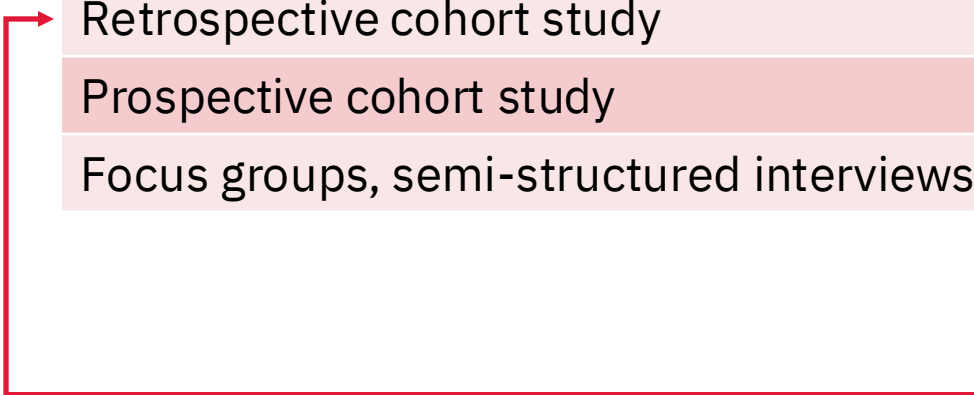
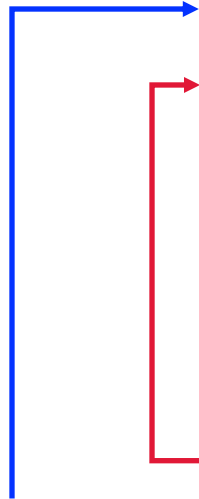


Experiences of day program attendees/non-attendees and their caregivers, especially those with multiple, intersecting vulnerabilities

Research program overview

Realist Evaluation, integrated knowledge translation

Study	ON	MB	AB	BC
Realist synthesis	✓	✓*	✓*	✓*
Retrospective cohort study	--	(✓)	✓	✓
Prospective cohort study	✓	✓**	✓**	✓**
Focus groups, semi-structured interviews	✓	✓*/**	✓*/**	✓*/**



***Brain Health Knowledge Synthesis**
\$100,000, 1 year



Funding start: Nov 1, 2023
End date: Mar 31, 2026



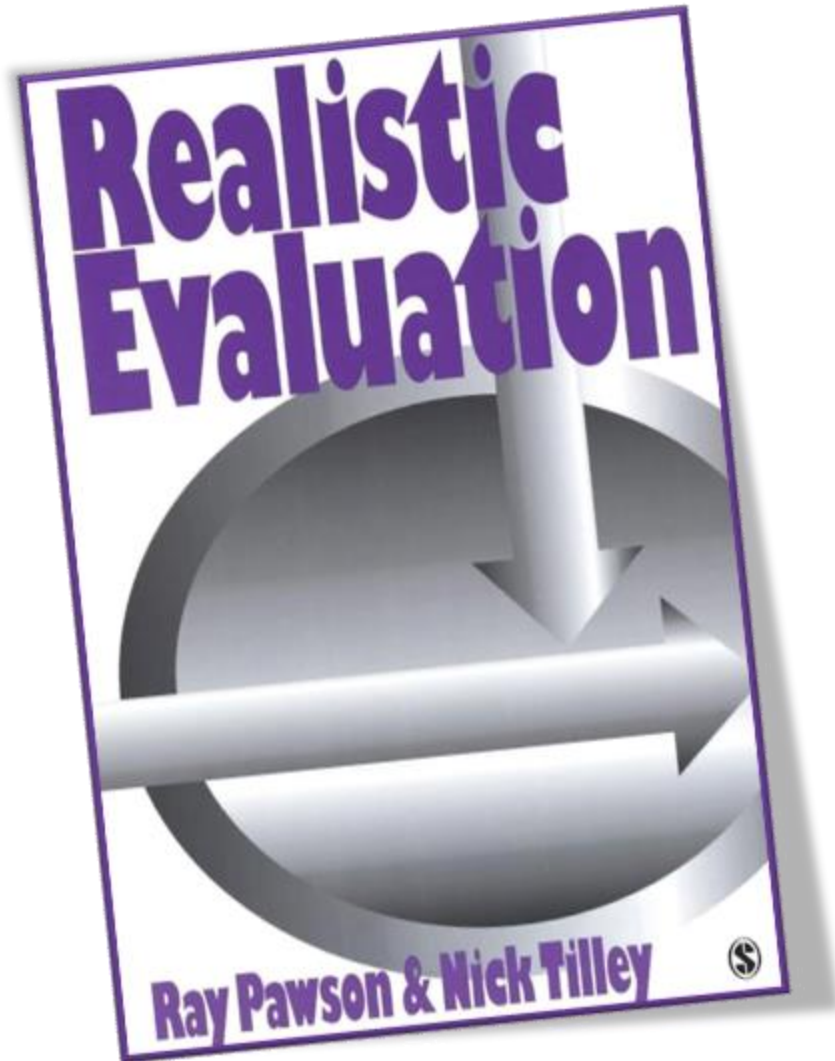
Funding start: Jul 1, 2022
End date: Jun 30, 2027

****Brain Health Impl. Sci. Team Grant**
\$750,000, 3 years



Funding start: Apr 1, 2024
End date: Mar 31, 2028

Realist approach



Context **C**

Social and physical conditions in which mechanisms operate

Mechanisms **M**

Intervention **X** → Outcome **O**

Underlying entities, processes or structures which operate in particular contexts of interest to bring about the outcomes. May be single or collective reasoning, choices and (re)actions, not directly observable, but accessible through theory building and testing



<https://www.ramesesproject.org/>

Integrated knowledge translation (iKT)

Integrated knowledge translation (IKT) in health care: a scoping review
Anna R. Gagliardi , Whitney Berta, Anita Kothari, Jennifer Boyko & Robin Urquhart
Implementation Science 11, Article number: 38 (2015) | [Cite this article](#)

Essay
Integrated knowledge translation: digging deeper, moving forward
Anita Kothari ¹, C Nadine Wathen ²
Correspondence to Dr Anita Kothari, School of Health Studies, The University of Western Ontario, Labatt Health Sciences Building, Room 222, London, Ontario, Canada N6A 5B9; akothari@uwo.ca

Patient engagement in research related to dementia: A scoping review
Jennifer Bethell , Elana Comisso, L.-J., and Katherine S McGilton  [View all authors and affiliations](#)
Volume 17, Issue 8 | <https://doi.org/10.1177/1471301218789292>

National advisory committee of 32 experts

Older adults,
some with
dementia

Caregivers

Alzheimer
Societies

Caregiver
advocacy
organizations

Day program
staff, managers,
operators,

Government &
health system
decision makers

Roles, activities, collaboration with advisory committee members

Committee is co-chaired by MH (NPA) & a knowledge user (Andrea Ubell, ASY)

Collaboratively developed and agreed on Terms of Reference

Share lived experience, expertise with research team

Help identify and prioritize knowledge and improvement needs

Agree on a research plan and related budget

Partner on grant proposals (letters of support, input on proposal, methods, ...)

Help prepare for recruitment and data collections (discussing most suitable approaches)

Advertise the research project to potential participants and encourage their participation

Help the research team prevent/overcome challenges

Provide input on preliminary findings, help researchers contextualize them

Input on dissemination materials to make sure they are tailored to target audiences

Help disseminate findings, facilitate uptake of findings in ADP practice and policy

Perspectives of Andrea, Hom, Hung

- Knowledge user perspective (Andrea), perspective of a person with lived experience (Hom), and trainee (Hung/Hom)
- Experiences of working with a research team, using this kind of an iKT/partnered approach
- Benefits, challenges, approaches to make this work

Questions?



Matthias Hoben (he/him), RN, Dr rer medic
Associate Professor, Helen Carswell Chair
in Dementia Care

School of Health Policy and Management
Faculty of Health | YORK UNIVERSITY
Room 301E Stong College
Toronto ON, Canada

Email: mhoben@yorku.ca

Additional slides

(If needed for discussion)

Protocol registered with *PROSPERO* and published with *Systematic Reviews*

NIHR | National Institute for Health and Care Research

International prospective register of systematic reviews

PROSPERO

Adult Day Programs and Their effects on individuals with Dementia and their Caregivers (ADAPT-DemCare): A realist review developing program theories on the how and why

Matthias Hoben, Hung Nguyen, Zahra Goodarzi, Kaitlyn Tate, Jennifer Baumbusch, Lori Weeks, Saleema Ailana, Holly Symonds-Brown, Adrian Wagg, S M Aliqur Rahman, Andrea Ubell, Saleema

Systematic Reviews

Protocol | [Open access](#) | Published: 23 October 2024

Adult day programs and their effects on individuals with dementia and their caregivers (ADAPT-DemCare): a realist synthesis to develop program theories on the how and why

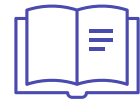
Hung Nguyen, Aliqur Rahman, Andrea Ubell, Zahra Goodarzi, Colleen J. Maxwell, Saleema Ailana, Kaitlyn Tate, Holly Symonds-Brown, Lori Weeks, Sienna Caspar, Jim Mann & Matthias Hoben

Systematic Reviews 13, Article number: 265 (2024) | [Cite this article](#)

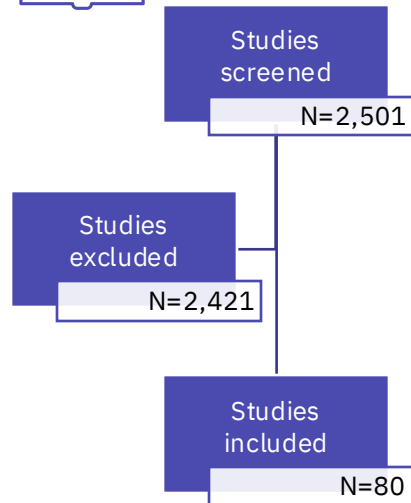
Adult Day Programs and Their effects on individuals with Dementia and their Caregivers (ADAPT-DemCare): A realist synthesis



Develop program theories on how and why day programs do or do not produce positive or negative outcomes for different groups of persons with dementia, and caregivers



Literature review



Focus groups

5 focus groups, total of 31 individuals

- Decision makers
- Day program managers
- Advocates and caregivers
- Day program staff
- Social workers



190 CMO statements

Examples of CMO statements:

1. In day programs with hospital-like environments (**C**), clients feel like they are in a place for sick people (**M**), which makes them feel unsafe and increases their agitation (**O**)
2. In day programs in which a social worker supports caregivers (**C**), caregivers feel less overwhelmed with navigating the challenges of caregiving (**M**), which helps to reduce caregiver distress (**O**)



Elements essential to day program effectiveness include appropriate space, staffing, programming (individual, tailored, person-centered). However, we lack research on the Canadian day program context. We especially lack studies comparing day program policies, number and nature of day programs, and effects of day programs across provinces and over time.



Older adults living with dementia and attending adult day programs and their family or friend caregivers



Government and health system decision makers

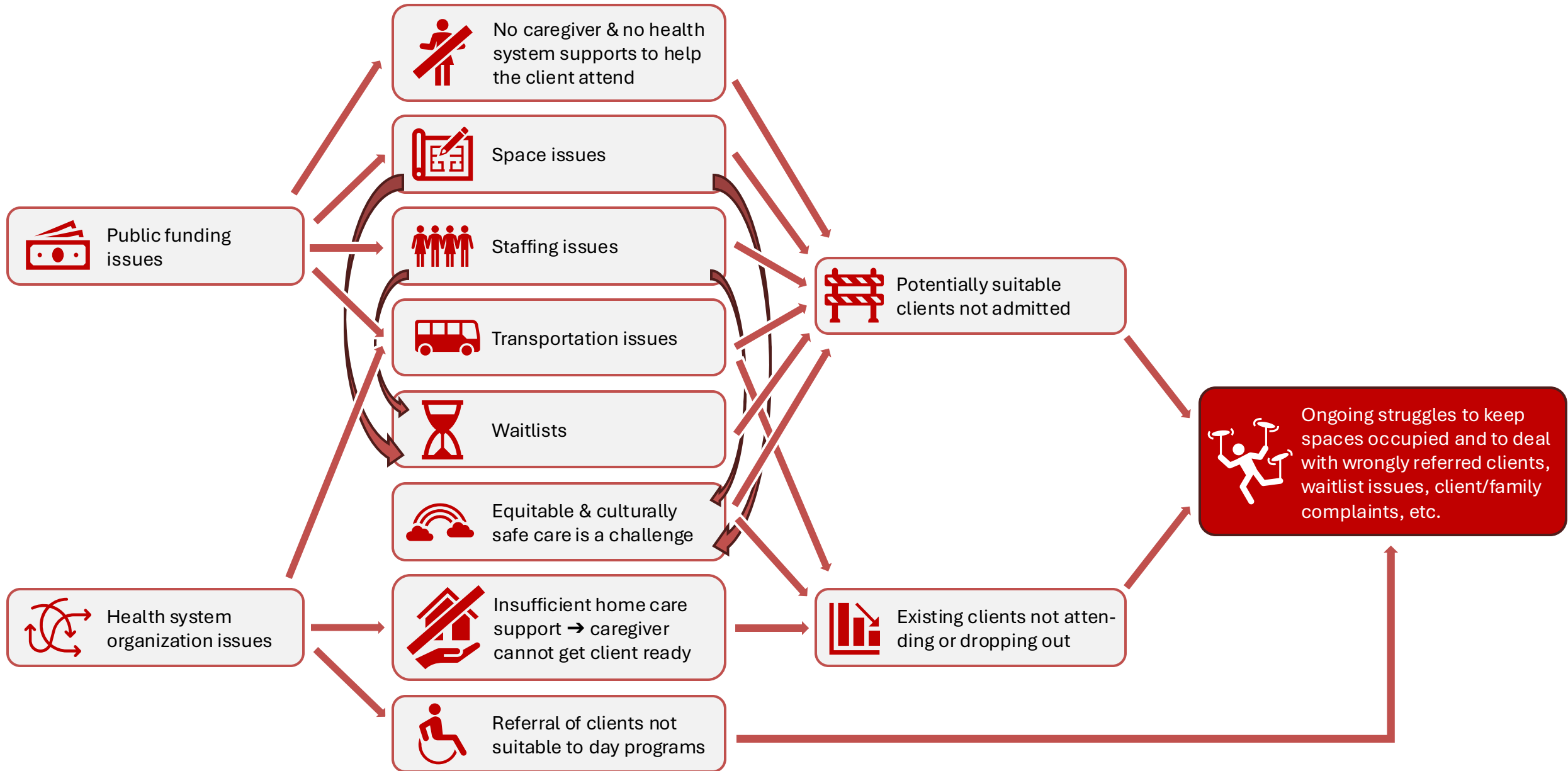


A diverse, inter-disciplinary, cross-Canadian team, with members in various stages of their career, and from multiple backgrounds, provided multi-dimensional perspectives → theoretical richness of findings and high relevance to practice and policy; but also at times logistically complex, time consuming, challenging to navigate



Empirically testing pathways suggested by our program theories in 2 cohort studies (in the field), combined with comprehensive qualitative work and engagement with experts (interest holders).

Policy brief directed to ON Health & ON Health teams



Four policy briefs developed by the OCC

Based on a caregiver survey (612 responses) plus extensive consultations



5th policy brief coming soon: Caregiving and employment

<https://www.ontariocaregivercoalition.ca/>

Study registered and protocol published



EXploring Patterns of Use and Effects of Adult Day Programs to Improve Trajectories of Continuing Care (EXPEDITE): Protocol for a Retrospective Cohort Study

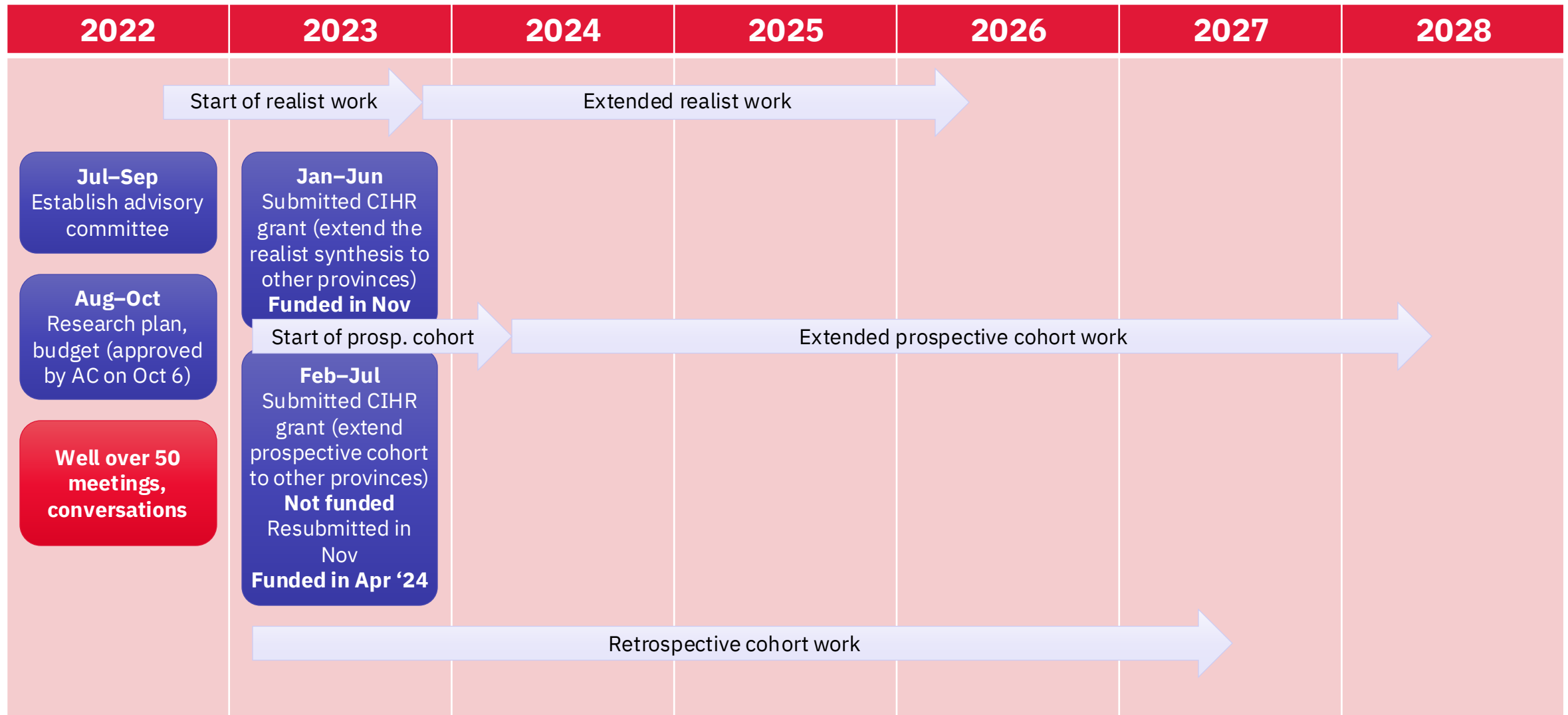
Matthias Hoben^{1, 2}; Colleen J Maxwell^{3, 4}; Andrea Ubell^{5, 6}; Malcolm B Doupe^{7, 8, 9}; Zahra Goodarzi¹⁰; Saleema Allana¹¹; Ron Beleno⁶; Whitney Berta¹²; Jennifer Bethell^{4, 12, 13}; Tamara Daly^{1, 6}; Liane Ginsburg¹; Atiqur SM - Rahman¹; Hung Nguyen¹; Kaitlyn Tate²; Kimberlyn McGrail¹⁴

JMIR Research Protocols

Study registration: [ClinicalTrial.gov NCT06440447](https://clinicaltrials.gov/ct2/show/study/NCT06440447)



Activities and timeline



Retrospective cohort study objectives and methods



Day program attendees (2012-2024)

Objective 1. Explore patterns of day program use (e.g., variations in time to first attendance, monthly hours of attendance, ongoing versus interrupted attendance, and total time of day program exposure), using latent class analyses (LCA), and compare the frequency of each latent use class between provinces and over time.

Retrospective cohort study objectives and methods



Day program attendees (2012-2024)



Home care recipients not exposed to a day program (2012-2024)

Objective 2. Compare older adults' demographic, social, and health characteristics (e.g., age, sex, physical or cognitive disability, area-based deprivation indices, and caregiver availability/distress) by day program use class (including nonuse), province, and time.

Retrospective cohort study objectives and methods



Day program attendees (2012-2024)

Day program eligibility RAI-HC assessment (index date)

Matching variables: RAI-HC variables used to determine day program eligibility: physical functioning (ADLh Scale), cognition (CPS), behavioral symptoms (ABS), bladder or bowel continence (items I1, I3), availability of a caregiver (item G1e), and caregiver distress (items G2a-c) **plus** health and social characteristics identified as important in objective 2



Initial RAI-HC assessment, completed within \pm 3 months of the index date

Propensity score matched control group of non-attendees

Objective 3. Assess whether, compared with a propensity score-matched control group of non-attendees, day program attendees enter care homes at later points in time; use emergency, acute, or primary care less frequently; experience less cognitive and physical decline; have better mental health; and have less distressed caregivers. We will assess potential modification of these effects by day program use/nonuse class, age, sex, and social determinants of health (e.g., area-based deprivation indices).

Progress as of to date

Step	ON	MB	AB	BC
Ethics approvals	✓	In prep.	✓	✓
Operational approvals	N/A	In prep.	✓	✓
Data requests	N/A	In prep.	Approved (in prep.)	Approved (in prep.)
Data analyst hired	N/A	✓	✓	✓

Next steps:

- Data access
- Data analyses
- Summary reports to the advisory committee and other experts
- Feedback summits and focus groups to obtain expert input
- Updated analyses
- Publications

Limitations of the retrospective cohort study approach

Health administrative data in some provinces do not include a variable documenting day program use (study cannot be done there)

Health administrative data include very limited information on social determinants of health, quality of life, caregiver burden, ...

Unclear who the caregiver of an older adult is (cannot link older adult and caregiver data)

Very limited information on characteristics of the day program

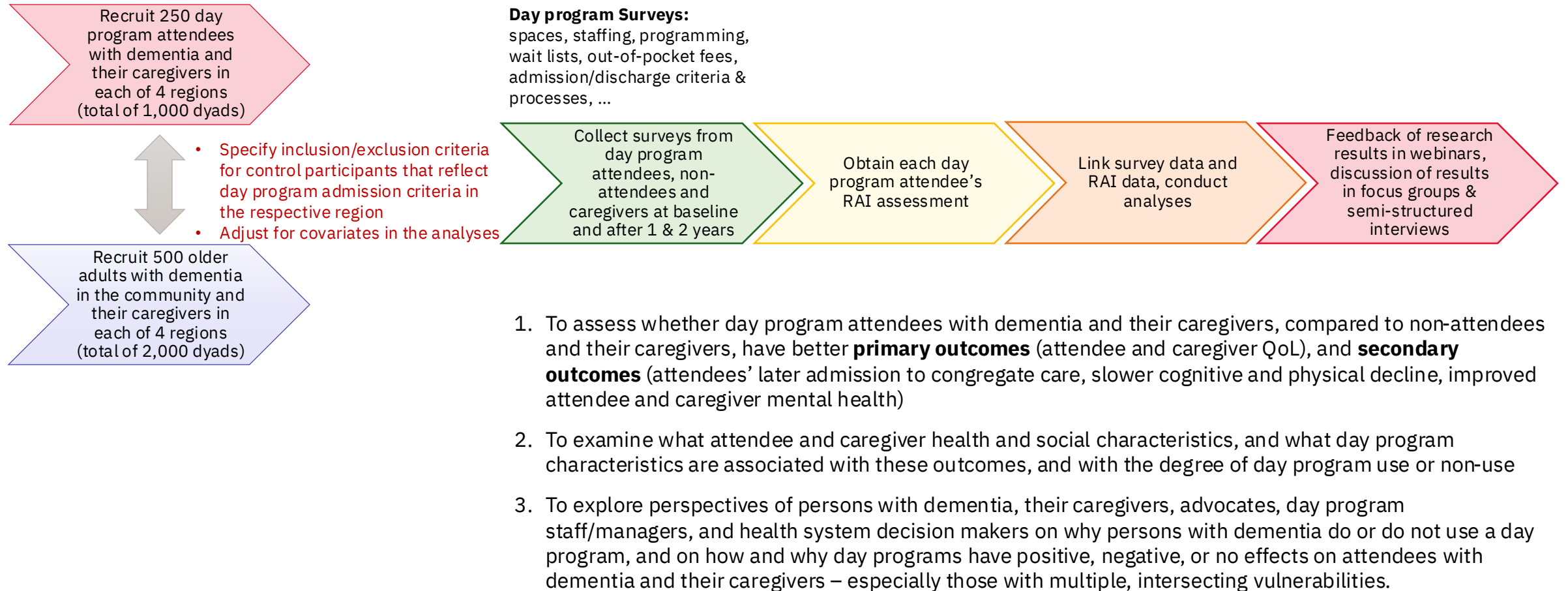
Study registered, protocol under review with BMC Public Health

Hoben M, Ubell A, Maxwell CJ, Allana S, Doupe MB, Symonds-Brown H, Hogan DB, Daly T, Tate KC, Wagg A, Nguyen H, Berta W, Bethell J, Caspar S, Goodarzi Z, McGrail K, Cummings GG, Rowe M, Kay K, Kostyk P, Lazaruk K, MacLean B, Mann J, Prescott K (in preparation). **Assessing the Impact of DAY programs on individuals living with Dementia and their family/friend Caregivers (AIDA-DemCare): Protocol of a prospective cohort study combined with a qualitative evaluation.** To be submitted to *BMC Publ Health*.

Study registration: [ClinicalTrial.gov NCT06496945](https://clinicaltrials.gov/ct2/show/study/NCT06496945)



Prospective cohort study objectives and methods



Progress as of to date

Step	ON	MB	AB	BC
Staff/trainees hired	✓	✓	✓	✓
Ethics approvals	✓	✓	✓	✓
Operational approvals	N/A	In prep.	✓	✓
Recruitment, data collection	Started	–	Started	Started

Next steps:

- Finalize operational approvals
- Data collection
- Data analyses
- Summary reports to the advisory committee and other experts
- Feedback summits and focus groups to obtain expert input
- Updated analyses
- Publications