

# Patient-Centred Research Priorities Relating to Healthcare of Frail Older Canadians

Canadian Frailty Network Annual National Conference

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graph TD; A[Elicit "top 10" research priorities from Canadians affected by frailty] --> B[Share priorities with researchers and research funders]; B --> C[More research addressing priorities of Canadians affected by frailty]; C --> A;
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Elicit “top 10” research priorities from Canadians affected by frailty

Share priorities with researchers and research funders

More research addressing priorities of Canadians affected by frailty

# Outline

## **Context**

- Research priority-setting
- “Patient engagement”

## **James Lind Alliance (JLA)**

- Priority setting partnerships
- Principles
- Process

## **Canadian Frailty Priority-Setting Partnership**

- Steering Group
- Partner organisations
- Identifying research questions
- Respondent data
- Next steps

## Context: Research priority-setting

- Research priorities are typically set by researchers, less often involving other knowledge users (including patients, care providers, policy makers, etc.)

# Context: “Patient engagement”

## Patient Engagement:

- 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.

# Context: “Patient engagement”

## Patient:

- An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.

From: Canadian Institutes of Health Research (CIHR), <http://www.cihr-irsc.gc.ca/e/48413.html>

# Context: “Patient engagement”

Why?:

- Arguments for patient engagement include:
  - Methodological (i.e., better, more relevant research and knowledge translation → greater impact)
  - Moral/ethical (i.e., democratizing the allocation of scarce research funds)

James Lind Alliance (JLA)



# James Lind Alliance

## Priority Setting Partnerships

- JLA: non-profit, established in 2004, funded by UK National Institute for Health Research (NIHR)
- Priority setting partnerships “bring patients, their carers and clinicians together to identify and prioritize unanswered questions about the effects of treatments in specific conditions or areas of healthcare for research, using the JLA methods”



James  
Lind  
Alliance

Priority Setting Partnerships

# JLA Principles

- **Transparency** of process
- **Inclusion** of patient, carer and clinician interests and perspectives
- **Exclusion** of non-clinician researchers for voting purposes
- **Exclusion** of groups that have significant competing interests, e.g., pharma
- **Maintained audit trail** of original submitted uncertainties, to final prioritized list

# JLA Process

Convene Steering Group

Identify and invite potential partner organisations

Identify research questions

Agree on “top 10” priorities at an in-person workshop

Disseminate “top 10” research priorities



# Canadian Frailty Priority-Setting Partnership

# Canadian Frailty Priority Setting Partnership: Steering Group

Chair: **Katherine McGilton**

Members:

- **Melissa Andrew**, Geriatrician, Dalhousie University
- **Patricia Ayala**, Information Specialist, University of Toronto
- **Howard Bergman**, Family physician, McGill University
- **Andy Choate**, patient, patient advisor committee, Cancer Care Ontario volunteer
- **Barry Clarke**, Medical Director, Continuing Care, Nova Scotia Health Authority
- **Katherine Cowan**, James Lind Alliance (JLA) Senior Advisor, England
- **Carlo DeAngelis**, Pharmacist, Clinician Scientist, Sunnybrook Health Sciences Centre
- **Chris Frank**, Family physician, Queens University
- **Jacobi Elliott**, Project Manager, GHS Research Group; School of Public Health & Health Systems, University of Waterloo
- **Marg Fitch**, Associate Professor, Lawrence S. Bloomberg Faculty of Nursing; Expert Lead, Patient Reported Outcomes, Canadian Partnership Against Cancer, Sunnybrook Health Sciences Centre
- **Kathryn Hominick**, Clinical Social Worker Geriatrics, Nova Scotia Health Authority
- **Margaret Keatings**, Caregiver
- **Janet McElhaney**, Geriatrician, Health Science North (Sudbury)
- **Sandra McKay**, Manager of Research & Evaluation, VHA Home Healthcare
- **Eric Pitters**, patient, mentor for the Leukemia & Lymphoma Society and Lymphoma Canada
- **Jenny Ploeg**, Professor, School of Nursing and Scientific Director of Aging, McMaster University
- **Souraya Sidani**, Professor & Canada Research Chair at the School of Nursing, Ryerson UniversityInstitute

The study team:

- **Jen Bethell**, Postdoctoral Research Fellow, Principal Investigator, Toronto Rehabilitation Institute
- **Katherine McGilton**, Principal Investigator & Senior Scientist, Toronto Rehabilitation Institute, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto
- **Martine Puts**, Principal Investigator & Assistant professor, CIHR New Investigator, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto
- **Schroder Sattar**, study coordinator/Doctoral student, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto

# Canadian Frailty Priority Setting Partnership: Partner organisations

Alberta Continuing Care Association	Canadian Society of Palliative Care Physicians	Speech-Language and Audiology Canada
BC Care Providers Association	Canadian Society of Respiratory Therapists	The 519 Church Street Community Centre
CACC-Central East	Canadian Therapeutic Recreation Association	The Arthritis Society
CACC-Central West	Clinical Nurse Specialist Association of Canada	The Canadian Cancer Survivor Network
CCAC-Hamilton Niagara Haldimand Brant	The College of Family Physicians of Canada	The Canadian Orthopedic Foundation
Canadian Academy of Geriatric Psychiatry	Community Health Nurses of Canada	The Kidney Foundation of Canada
Canadian Association for Rural and Remote Nursing	Denominational Health Association	The Lung Association/ Ontario Respiratory Care Society
Canadian Association of Critical Care Nurses	Geriatric Education and Research in Aging Sciences (GERAS)	National Association of Federal Retirees
Canadian Association of Occupational Therapists	GTA Rehab Network	The North East Specialized Geriatric Centre
Canadian Association of Social Workers	Heart and Stroke Foundation of Canada	
Canadian Geriatrics Society	Hypertension Canada	
Canadian Hospice Palliative Care Association	National Initiative for the Care of the Elderly (NICE)	
Canadian Society of Consultant Pharmacists	New Brunswick Association of Nursing Homes	
Canadian Society of Hospital Pharmacists	Ontario Long Term Care Association	

# Canadian Frailty Priority Setting Partnership: Identifying research questions

- Questionnaire:
  - developed from JLA template, other PSPs and external input, including from Seniors Helping as Research Partners (SHARP) group, coordinated by Jacobi Elliott.
  - promoted to “Canadians affected by frailty”, including
    - Older adults who are concerned about frailty
    - Friends, family and caregivers of frail older adults
    - Health and social care providers (e.g. doctors, nurses, occupational therapists, personal support workers, pharmacists, social workers, etc) who work with frail older adults and/or can advocate for them
    - People not yet affected by frailty but who are interested in the topic
  - available in English and French
  - on-line (“limesurvey”) and in paper format (with postage paid envelope)
  - “open” from March 2017 to May 2017

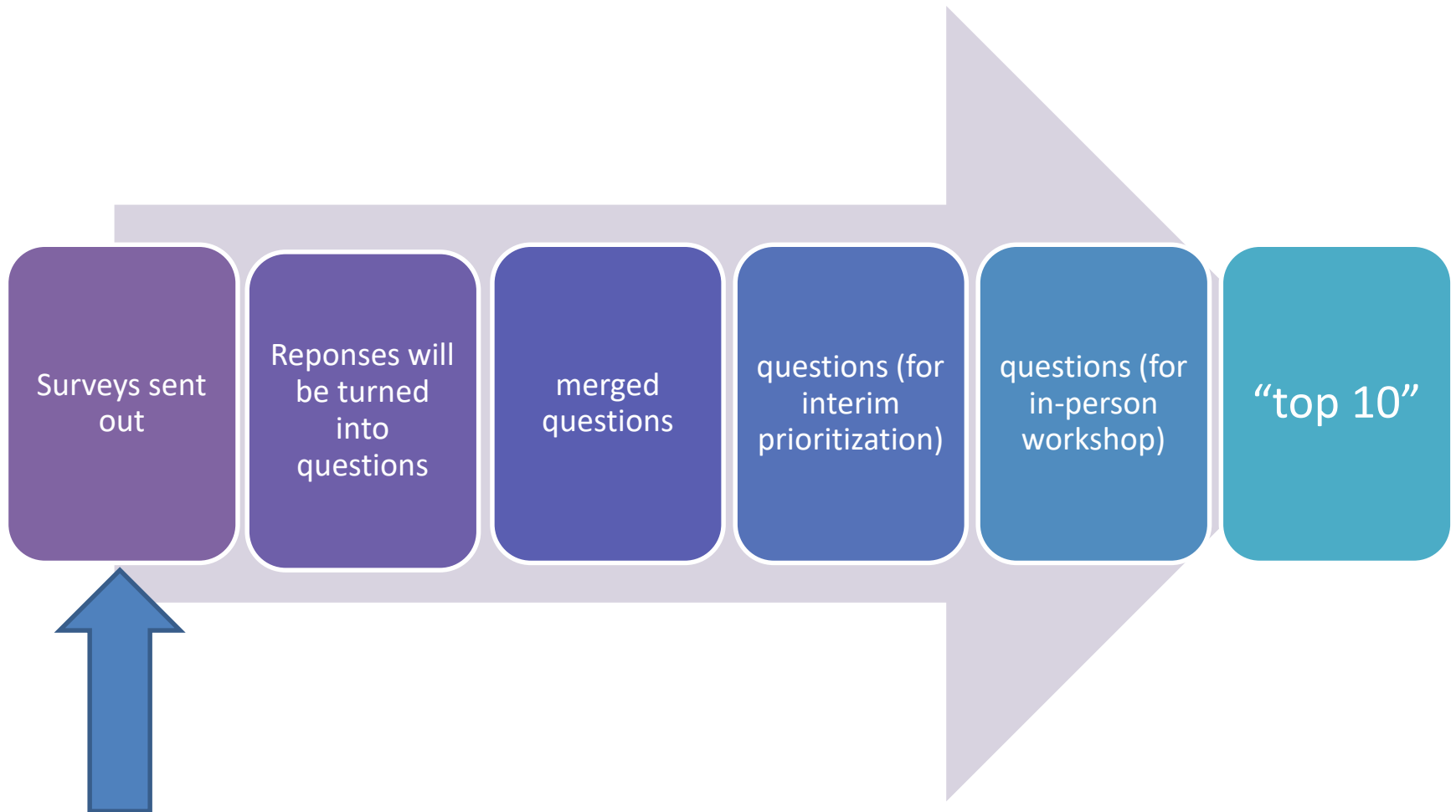
# Canadian Frailty Priority Setting Partnership: Identifying research questions

What question(s) do you have about care, support and treatment for older adults who are frail that could help them to live as well as possible?

**“Think about your own personal and/or professional experience with frailty. This is what makes you the expert.”**



# Canadian Frailty Priority Setting Partnership: Identifying research questions

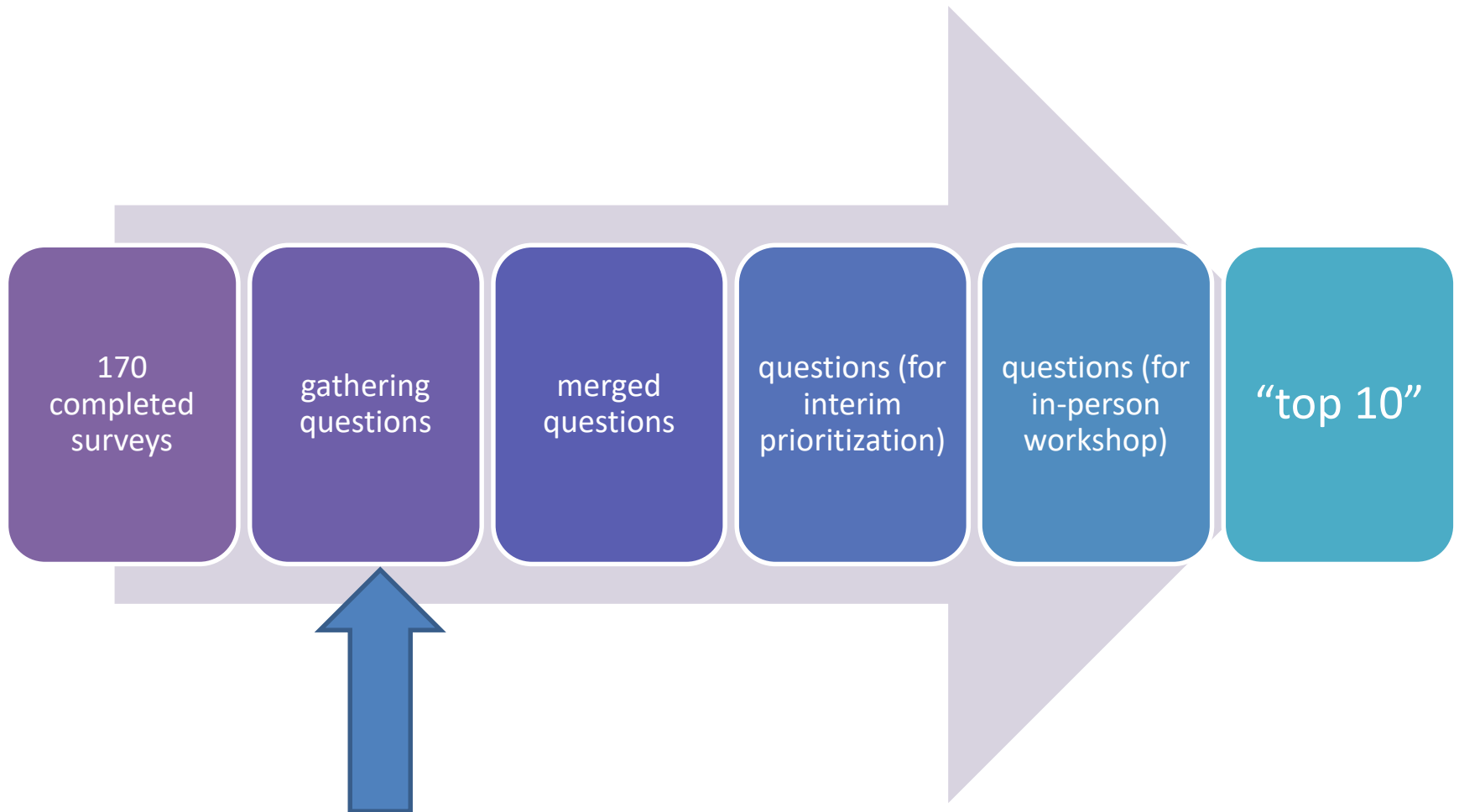


Where we are now

<b>Which of the following best describes you or the members of your pair or group? (check all that apply)</b>	<b>n</b>	<b>%</b>
Older adults concerned with frailty	10	5.88
Partner, relative or friend of a frail older adult	31	18.24
Caregiver or former caregiver of a frail older adult	28	16.47
Health and/or social care provider	130	76.47
Nurse	34	20
Occupational therapist	3	1.76
Pharmacist	9	5.29
Physician	45	26.47
Physiotherapist	9	5.29
Personal support worker, care aide or community health worker	2	1.18
Recreation therapist	14	8.24
Social worker	3	1.76
Other	14	8.24
Older adult with no direct experience of frailty, but interested in it	9	5.29

<b>Which part of Canada do you live in?0</b>	<b>n</b>	<b>%</b>
Alberta	25	14.71
British Columbia	49	28.82
Manitoba	2	1.18
New Brunswick	4	2.35
Newfoundland and Labrador	1	.59
Northwest Territories	0	0
Nova Scotia	6	3.53
Nunavut	0	0
Ontario	57	33.53
Prince Edward Island	2	1.18
Quebec	10	5.88
Saskatchewan	3	1.76
Yukon	0	0

# Next steps



Where we are now

# Next steps: continued

Convene Steering Group



Identify and invite potential partner organisations



Identify research questions



Agree on “top 10” priorities at an in-person workshop



Disseminate “top 10” research priorities

# Thank you!

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