

Webinar Series  
November 8,  
2017



## Canadian Frailty Priority Setting Partnership

**Katherine McGilton, PhD, RN**  
**University Health Network**  
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[www.cfn-nce.ca](http://www.cfn-nce.ca)



**Canadian  
Frailty  
Network**

**Réseau canadien  
des soins aux  
personnes fragilisées**

# Welcome



- **Q&A session**
- **Please submit your Qs online during presentation**
- **We will answer as many Qs as time permits**



**Carol Barrie,  
Executive Director**



# Reminder: Survey & Webinar



- **Survey will pop up on your screen after webinar**
  - **Feedback on how to improve webinar series**
- **Webinar slides & video available for viewing online within 1-2 days at:**
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# Reminder: Upcoming Webinars



**Register at:**

<http://www.cfn-nce.ca/news-and-events-overview/webinars/>

- **Wednesday, November 22, 2017 at 12 noon ET**

Introducing electronic quality of life assessments in hospital palliative care: A micro-meso-macro framework – CFN-funded Catalyst Grant Program – Rick Sawatzky and Marian Krawczyk, Trinity Western University

- **Wednesday, December 6, 2017 at 12 noon ET**

Exploring the preferences of older Canadians living with frailty for aspects of inpatient care: A best-worst scaling experiment – CFN-funded Catalyst Grant Program – Nick Bansback and Logan Trenaman, University of British Columbia

- **Wednesday, January 10, 2018 at 12 noon ET**

Identifying older patients at high risk of poor outcomes after joint replacement surgery – CFN-funded Frailty Measures Implementation Grant Program – Daniel McIsaac, Ottawa Hospital Research Institute

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# 2017 Catalyst Grant Competition



- **Addresses ongoing concern of polypharmacy and related medication issues in older Canadians living with frailty**
- **Presented in collaboration with the New Brunswick Health Research Foundation (NBHRF) and the Canadian Institutes of Health Research (CIHR)**
- **Applications for those who submitted an Intent to Apply are due by 5 p.m. ET on Monday, November 13<sup>th</sup>**
- **Please visit our website for more details: <http://www.cfn-nce.ca/improving-evidence-through-research-and-kt/funding-opportunities/2017-catalyst-medication-optimization-grant-program/>**



# New Funding Opportunity



- **A competition based on today's webinar results will be launched in the next month**
- **We are currently seeking partner organizations interested in co-funding this competition**
- **Communication of competition**



# Presenters

## Canadian Frailty Priority Setting Partnership



- Senior Scientist at the Toronto Rehabilitation Institute
- Associate Professor in the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto
- Adjunct Scientist at the Kunin-Lunenfeld Applied and Evaluative Research Unit in the Baycrest Geriatric Health Care System



**Katherine McGilton, PhD, RN**

- Completed her PhD in epidemiology at the Dalla Lana School of Public Health in 2012
- Since 2015 she has been a postdoctoral researcher with Dr. McGilton at the Toronto Rehabilitation Institute, working on two priority setting partnerships



**Jennifer Bethell, PhD**

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**Canadian Frailty Network**

**Réseau canadien des soins aux personnes fragilisées**

# **Top 10 Canadian priorities for frailty research:** Outcomes of the Canadian Frailty Priority Setting Partnership

Katherine S. McGilton, Jennifer Bethell, Martine Puts and Schroder Sattar

Canadian Frailty Network webinar  
November 8, 2017



**Canadian  
Frailty  
Network**

**Réseau canadien  
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FACULTY OF NURSING  
UNIVERSITY OF TORONTO



# Outline

## Context

- Patient engagement
- James Lind Alliance (JLA)
- Canadian Frailty Network

## Methods

- Canadian Frailty Priority Setting Partnership

## Results

- The “Top 10”

## Next steps

- Sharing the priorities and translating them into research

# Patient engagement

- Patient engagement occurs when patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in knowledge translation
  - Patient = An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.
  - Depending on the context patient-oriented research may also engage people who bring the collective voice of specific, affected communities.

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

# 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)

- Research priorities are typically set by researchers, less often involving other knowledge users (including patients, care providers, policy makers, etc.)
- JLA: non-profit, established in 2004, supported by UK National Institute for Health Research (NIHR) to conduct **priority setting partnerships (PSPs)** which bring patients, carers and clinicians together to identify and prioritize unanswered questions in specific conditions or areas of healthcare for research
- 50+ PSPs conducted to date



# Canadian Frailty Network

- February 2016: CFN launched a request for proposals (RFP) to provide CFN with “a list of patient-centred research priorities relating to health care of frailty older Canadians”  
**→ Canadian Frailty Priority Setting Partnership was funded through this RFP**

Methods:

# **CANADIAN FRAILTY PRIORITY SETTING PARTNERSHIP**

Establish Steering Group

Invite Partner Organisations

Gather questions

Data processing

Interim prioritisation

Final prioritisation

**Canadian Frailty Priority Setting Partnership Steering Group membership:**

- Melissa Andrew, Geriatrician, Dalhousie University
- Patricia Ayala, Information specialist, University of Toronto
- Howard Bergman, Family physician, McGill University
- Andrew Choate
- Barry Clarke, Medical Director, Continuing Care, Nova Scotia Health Authority
- Katherine Cowan, Senior Adviser, James Lind Alliance (UK)
- Carlo DeAngelis, Pharmacist, Sunnybrook Health Sciences Centre
- Jacobi Elliott, University of Waterloo and Citizen Engagement Committee, Canadian Frailty Network
- Marg Fitch, Sunnybrook Health Sciences Centre and University of Toronto
- Chris Frank, Family physician, Queen's University
- Kathryn Hominick, Clinical Social Worker Geriatrics, Nova Scotia Health Authority

- Margaret Keatings
- Janet McElhane, Geriatrician, Health Sciences North
- Sandra McKay, VHA Home Healthcare
- Eric Pitters
- Jenny Ploeg, School of Nursing, McMaster University
- Souraya Sidani, Ryerson University

**Canadian Frailty Priority Setting Partnership Study Team:**

- Jennifer Bethell, Principal Investigator and Postdoctoral Researcher, Toronto Rehabilitation Institute – University Health Network
- Katherine McGilton, Principal Investigator and Senior Scientist, Toronto Rehabilitation Institute – University Health Network
- Martine Puts, Principal Investigator and Associate Professor, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto
- Schroder Sattar, Research Assistant and PhD Student, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto

# Engaging older adults in the process

- Governance, conduct and dissemination: older adults served on the Steering Group throughout the project
- In addition, through one Steering Group representative, Seniors Helping as Research Partners (SHARP) group, coordinated by the University of Waterloo Geriatric Health Systems Research Group, was also consulted in the study.
  - Eight older adults from the SHARP group met in person, on December 7, 2016, to review the content of the initial survey. Based on their recommendations, revisions were made to the survey's text and formatting.



Establish Steering  
Group

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**Canadian Frailty Priority Setting Partnership Partner Organisations:**

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



- Scope: care, support and treatment of older adults living with frailty
- Promoted - through partner organisations, local newspaper ads and mailing list - to:
  - Older adults who are concerned about frailty
  - Friends, family and caregivers of frail older adults
  - Health and social care providers
- Available in English and French, on-line and in paper
- “Open” for just over 4 months (March-June, 2017)



## “What is frailty?”

We usually associate frailty with noticeable losses in a person’s physical, mental or social functioning. Frailty is a health state continuum ranging from fit to very frail, involving multiple health problems and often associated with getting older. Frailty can result from a range of diseases and conditions where even fairly minor health events can trigger major changes in a person’s health status.”

*Description of responses to the Canadian Frailty Priority Setting Partnership survey to identify research questions, March to June 2017 (n=389 individual and group responses)*

<b>Which of the following best describes you? Check all that apply.</b>	n	%
Older adult concerned about frailty (i.e., experiencing noticeable losses in health and/or physical, mental or social functioning)	52	13.4%
Older adult with no direct experience of frailty, but interested in it	52	13.4%
Partner, relative or friend of a frail older adult	82	21.1%
Caregiver or former caregiver of a frail older adult	72	18.5%
Health and/or social care provider, current profession:	273	70.2%
Dietitian	67	17.2%
Nurse	55	14.1%
Occupational therapist	8	2.1%
Pharmacist	10	2.6%
Physician	89	22.9%
Physiotherapist	9	2.3%
Personal support worker, care aide or community health worker	4	1.0%
Recreation therapist	11	2.8%
Social worker	6	1.5%
Other	26	6.7%

*Description of responses to the Canadian Frailty Priority Setting Partnership survey to identify research questions, March to June 2017 (n=389 individual and group responses)*

<b>How do you identify?</b>	n	%
Male	66	17.0%
Female	304	78.1%
Other	0	0.0%
Prefer not to say/not specified	19	4.9%
<b>In what year were you born?</b>		
1920-1939	47	12.1%
1940-1959	121	31.1%
1960-1979	125	32.1%
1980-1999	71	18.3%
Prefer not to say/not specified	25	6.4%

*Description of responses to the Canadian Frailty Priority Setting Partnership survey to identify research questions, March to June 2017 (n=389 individual and group responses)*

**Which part of Canada do you live in? Check all that apply.**

Alberta	59	15.2%
British Columbia	56	14.4%
Manitoba	13	3.3%
New Brunswick	7	1.8%
Newfoundland and Labrador	3	0.8%
Northwest Territories	0	0.0%
Nova Scotia	12	3.1%
Nunavut	0	0.0%
Ontario	208	53.5%
Prince Edward Island	2	0.5%
Quebec	25	6.4%
Saskatchewan	2	0.5%
Yukon	0	0.0%



- Submissions were reviewed and 152 responses that were out of scope\* or could not be formulated into a question were removed
  - Remaining 647 questions were categorized, merged and summarized
  - Questions then checked against research evidence (i.e. Medline (including Medline in Process and other non-indexed citations, ePubs and Medline Daily), the Cochrane Database of Systematic Reviews and Database of Abstracts of Reviews of Effects were searched by an Information Specialist to identify any reviews related to frailty in older adults published between January 2014 and June 2017.)
- Produced long list of 41 unanswered questions about care, support and treatment of older adults living with frailty**



- Involved those who participated in initial survey (and indicated interest in ongoing involvement) and promoted through partner organisations
  - Respondents were presented with the list of 41 questions and asked to identify their top 10
  - Available in English and French, on-line and in paper
  - “Open” for roughly 6 weeks (July-September, 2017)
  - 146 groups and individuals across Canada responded
- **Produced short list of 22 questions for final prioritisation**





- 21 participants from across Canada (older adults, friends, family and caregivers of older adults living with frailty, and health and social care providers) + observers (research team, Canadian Frailty Network)
  - 1-day meeting, in Toronto (September 26, 2017)
  - Small and large group discussions of short-listed 23 questions
  - Adaptations to encourage involvement of older adults (e.g., accessible venue, close to public transit and assistance with travel arrangements).
- Consensus to produce “top 10” priorities for research on frailty**

Results:

**THE “TOP 10”**

## 1) HEALTH SYSTEM

How can the health system be organized to provide integrated/coordinated care that would better meet the health and social care needs of frail older adults and their family/caregivers?

## 2) ISOLATED OLDER ADULTS

How can care, services and treatments be tailored to meet the needs of frail older adults who are isolated and/or without family/caregiver support or advocates?

## 3) IMPACT OF COMMUNITY- AND HOME-BASED CARE

What is the impact of community- and home-based services, programs and resources in preventing and managing frailty (including slowing progression and/or minimizing the impact of frailty)?

## 4) ALTERNATIVE MODELS OF HOUSING

What are the costs and benefits of alternative models of housing, including multigenerational or shared living, for frail older adults?

## 5) AVOIDING HOSPITAL

What would help avoid unnecessary hospitalizations and emergency department visits for frail older adults?

## 6) HEALTH AND SOCIAL CARE PROVIDERS

What frailty-related attitudes, skills and knowledge should health and social care providers have? What are effective ways of improving attitudes and providing skills and knowledge about frailty for health and social care providers?

## 7) VIABILITY OF LIVING AT HOME

What would help frail older adults and their family/caregivers recognize when living at home is no longer viable?

## 8) SUPPORTING FAMILY AND CAREGIVERS

What are effective ways of supporting family/caregivers of frail older adults to maintain their own health and wellbeing and/or that of frail older adults?

## 9) INFORMING TREATMENT DECISIONS

How can frailty measures be used by health care practitioners, older adults and family/caregivers to inform treatment and care decisions?

## 10) IMPACT OF EXERCISE AND PHYSICAL ACTIVITY

What is the impact of exercise and physical activity (including type, duration and intensity) in preventing and managing frailty (including slowing progression and/or minimizing the impact of frailty)?

# Challenge: language of frailty

- Obtaining responses from older adults who self-identified as frail was a challenge for the Canadian Frailty Priority Setting Partnership.
- “Frailty” commonly used among researchers and clinicians
- Among older adults living with frailty:
  - illness and frailty may pose barrier for participating in surveys and workshops (Holroyd-Leduc et al, 2016)
  - many who meet criteria for frailty will not perceive themselves as frail (Salter et al, 2015)
  - term will have a negative connotation for some (BritainThinks, 2015)
- Despite operationalizing a definition throughout the survey and workshop, the term “frailty” may have been a barrier for:
  - involving older adults
  - establishing a common understanding for those involved

Next steps:

**SHARING THE PRIORITIES AND  
TRANSLATING THEM INTO RESEARCH**

# Examples of how PSP priorities have been used by others

- Research funding agencies
  - Targeted calls/requests for proposals (e.g., health charities running funding competitions in topics identified by PSPs)
- Researchers
  - Formulating grant applications (based on their own PSP work or that of others)
- Advocates
  - Promoting the priorities with research funding agencies and researchers

# How to use the frailty PSP priorities?

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"TOP TEN" CANADIAN RESEARCH FRAILTY PRIORITIES

## Coming soon ... RFP for frailty implementation/intervention projects

POSTED ON OCTOBER 31, 2017

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CFN will soon be issuing a Request for Proposals for implementation or intervention projects focused on the "top ten" Canadian frailty research priorities (/engaging-canadians/helping-to-set-research-priorities/top-ten-frailty-research-priorities-identified-by-citizens/) generated by the Canadian Frailty Priority Setting Partnership group.

<http://www.cfn-nce.ca/news-and-events-overview/media/announcements/rps-competition-coming-soon/>

# Thank-you!

Questions or comments:

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Martine Puts - [martine.puts@utoronto.ca](mailto:martine.puts@utoronto.ca)



# Post-webinar survey

Survey will pop up on your screen after webinar

- **Feedback on how to improve webinar series**



## Project contacts

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