

Persons living with dementia who go missing: What do we know and how can we manage the risks?

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Presented to brainXchange

November 17, 2020



**UNIVERSITY OF
WATERLOO**



Aging Gracefully across Environments using Technology
to Support Wellness, Engagement, and Long Life



International Consortium on Dementia and Wayfinding



COMMUNITY HEALTH AND
SOCIAL INNOVATION HUB

WEBINAR OVERVIEW



- Persons living with dementia who go missing:
Background
- Prevalence and antecedents of missing occurrences involving persons living with dementia
- Managing risks of going missing

UNIVERSITY OF WATERLOO RESEARCH TEAM



Lili Liu



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WATERLOO



Larissa Kowalski



**COMMUNITY HEALTH AND
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Body of missing senior discovered in wooded area in southwest Calgary

Record number of Japanese people with dementia go missing in 2017



Two years after Shin Noh disappeared, Coquitlalm family seeks answers

JEREMY DEUTSCH, TRI-CITIES NOW | 09.10.2015 |



Rising rate of missing dementia patients challenges police forces

JILL MAHONEY
The Globe and Mail
Published Friday, Nov. 18, 2016 4:35PM EST

How did an 83-year-old man with dementia survive for five days without food, medication?

Detroit police looking for missing elderly man with early signs of dementia

More than 500,000 old people go missing in China every year: report

WANDERING: TERMINOLOGY TO USE OR TO AVOID?

- Challenge assumption that dementia-related wandering is “aimless behavior”
- Confusion between “wandering” and “getting lost” → *critical wandering*
- Stigma attached to using “wandering” around the world → *wayfinding*



Becoming Lost: What do we know? How can police data help?

Larissa Kowalski, MA
Lead Researcher,
Community Health and Social
Innovation Hub
University of the Fraser Valley



The Results of the Study



DESCRIPTIVE CHARACTERISTICS

Demographic and health characteristics of older adults who were reported missing



INDIVIDUAL FACTORS

Individual factors that emerged as relevant to becoming lost for older adults, particularly those living with dementia

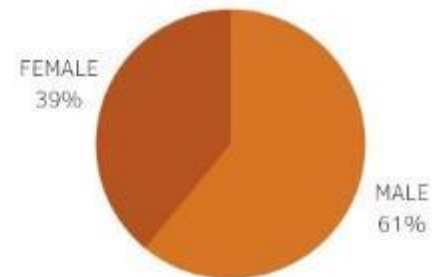


ENVIRONMENTAL FACTORS

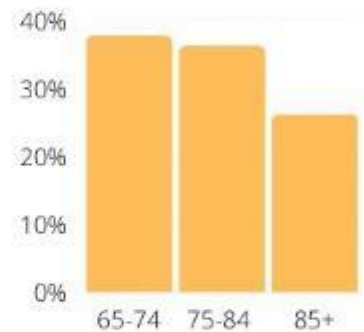
Environmental factors that emerged as relevant to becoming lost for persons living with dementia

Overview of Demographic Characteristics

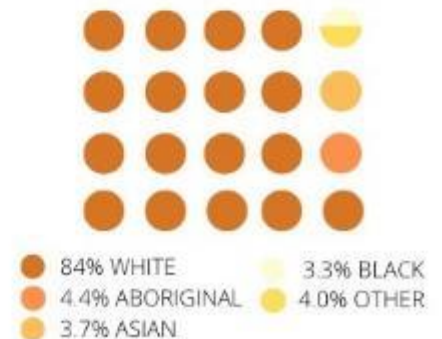
MEN OUTNUMBER WOMEN IN ELDERLY MISSING PERSON REPORTS



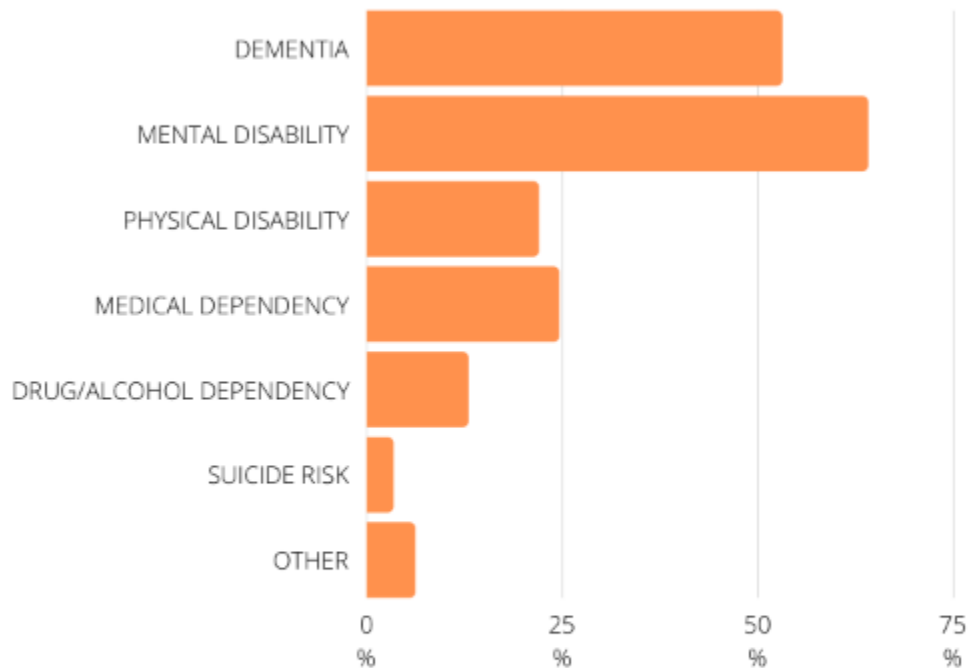
THE AVERAGE AGE OLDER ADULTS ARE REPORTED MISSING IS 78 YEARS



NO RACIAL OR ETHNIC CATEGORY WAS OVER OR UNDER REPRESENTED



Notable Health Characteristics

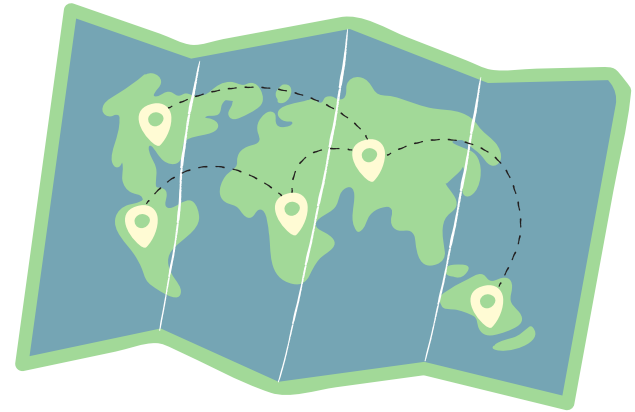


THE MOST FREQUENTLY OCCURRING HEALTH CONDITION WAS MENTAL DISABILITY (64%)



Reason for Going Missing

The most common reasons for going missing include...



49%

Became Lost*

15%

Eloped

6%

Ran Away

9%

Other

21%

Unknown

Where do most people go missing from?

HOME



48%

CARE FACILITY



20%

HOSPITAL



11%

STREET OR ROADWAY



8%

OPEN AREA



3%

OTHER



11%

Missing occurrences over the past five years

Percentage of missing occurrences in two Canadian cities from 2014-2018



1:53 PM

Average time most older adults
are reported missing

2:46 PM

Average time most older adults
are located



Most older adults are found within:

4 ½ hours from the time they were last seen

2 ¼ hours of police involvement

83.4% are found within 24 hours of the time they were last seen

90.2% are found within 24 hours of the time they were reported missing



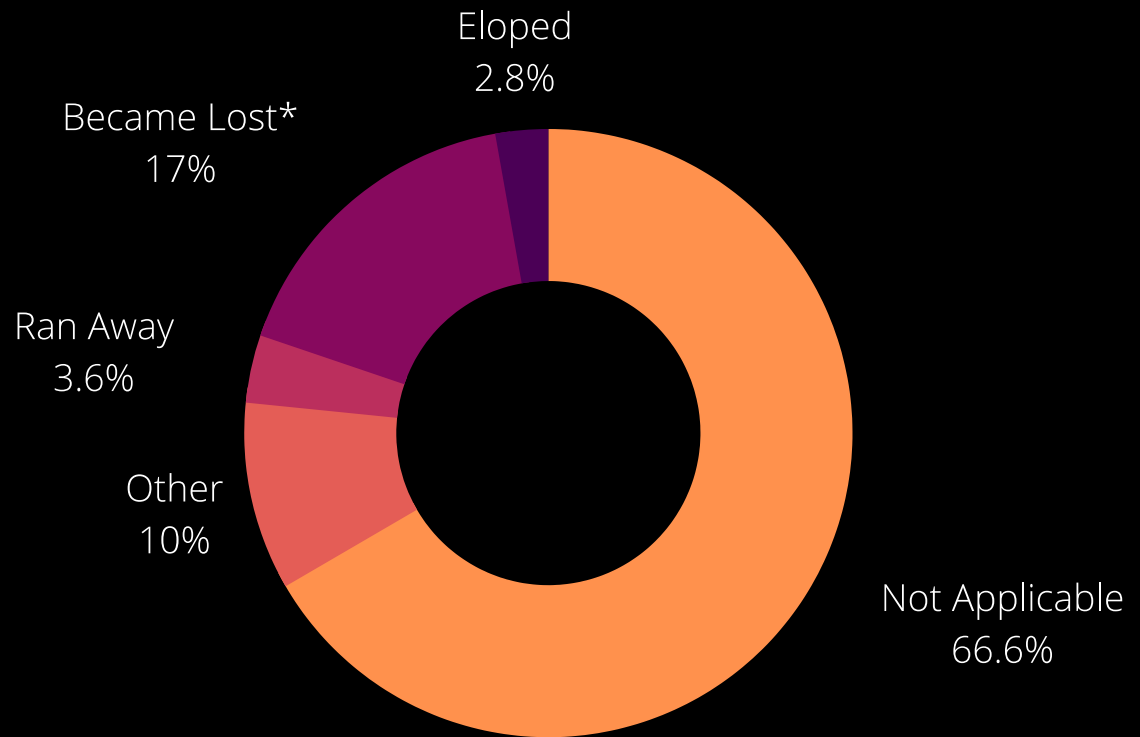
41%

**OF OLDER ADULTS WHO ARE
REPORTED MISSING HAVE A
REPEAT MISSING HISTORY**

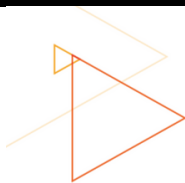
33% of the sample
had a repeat
missing
occurrence within
five years

Previous Cause of Missing Occurrences

The most frequent cause of repeatedly going missing was becoming lost



Key Finding: Older adults with a history of becoming lost* were more likely to have dementia than any other health condition



Individual Factors

AGING WITH A PATHOLOGY

Becoming lost often emanated from dementia-related changes, such as gradual, persistent or progressive changes in cognition, functioning and behaviour

STRIVING TO MAINTAIN INDEPENDENCE

Older adults often alluded to a strong desire to maintain independence, which sometimes prevented help-seeking behaviours while lost

REQUIRING ENHANCED PERSON- CENTRED CARE

Dissatisfaction with one's care-environment sometimes pushed older adults to exit-leave or leave their place of residence

AGING WITH A PATHOLOGY

Bernie is in the later stages of Alzheimer's. He is unaware of his surroundings and would not realize he had wandered away. He also would have no concept of how to return home or seek safety. He has Parkinson's as well and visibly shakes



Ben was in good spirits, jovial with officers. He appeared in good physical health, despite having chilly feet. He was lucid, aware that he was lost and wanted to go home. Ben could not explain why he was out, but acknowledged it was "silly", stating "This is no good! I'm in my pajamas and I have no shoes!"

Bruno advised he enjoys going for walks and had no specific destination. Bruno was fully aware of his current location in [redacted] and advised of the exact route he took. When questioning Bruno about not letting his daughter know where he went, Bruno advised he's a grown man and does not need to let people know.

Striving to Maintain Independence

“ Bradley is not happy that his license is suspended and made slight indications that he would drive again if allowed access to his vehicle. ”





Striving to Maintain Independence

Edmund has early indications of dementia and is a diabetic. He has had two heart attacks in the past and is on numerous medications. While police were working the investigation at his residence, Edmund arrived home in his vehicle. He stated that he was in [another city] visiting a friend however he was unable to provide details and his story is therefore unbelievable. It is believed that he got lost and was too embarrassed to ask for help.

Potentially not missing, is stubborn and may not tell anyone he is lost. Used to live at [redacted] and sometimes gets confused and could potentially attend. He enjoys walking with no destination. He was located walking on the sidewalk almost 8 hours after.



Geoffrey advised he hated the nursing home and would continue to leave whenever he wants. He complained about the nursing staff being pushy and intrusive. Geoffrey barricades his door during the day so that he is not bothered by anyone. After speaking with Geoffrey, it was apparent he is very much aware of his surroundings and was pretty much impossible to detect he has dementia [even though he does have dementia]. Geoffrey found it amusing that the nurses need to call the police to come find him.



REQUIRING ENHANCED PERSON-CENTRED CARE

UNMET NEEDS AND HEALTH CARE SHORTAGES

Several reports alluded to older adults being unfit to age at home or indicated that some older adults were on waitlists for home and community care, as well as long-term care, but were not receiving it due to shortages.

SHORTCOMINGS OF EXISTING SAFEGUARDING EFFORTS

Shortcomings with existing safeguarding efforts, such as the use of technology, seemed to magnify rather than minimize challenges relating to the successful location of missing persons.

**Environmental
Factors**

"HOME AND COMMUNITY CARE
OFTEN OPERATES WITHIN
TIGHT AND UNPREDICTABLE
BUDGETS"

Aronson, 2020



Unmet Needs and Health Care Shortages

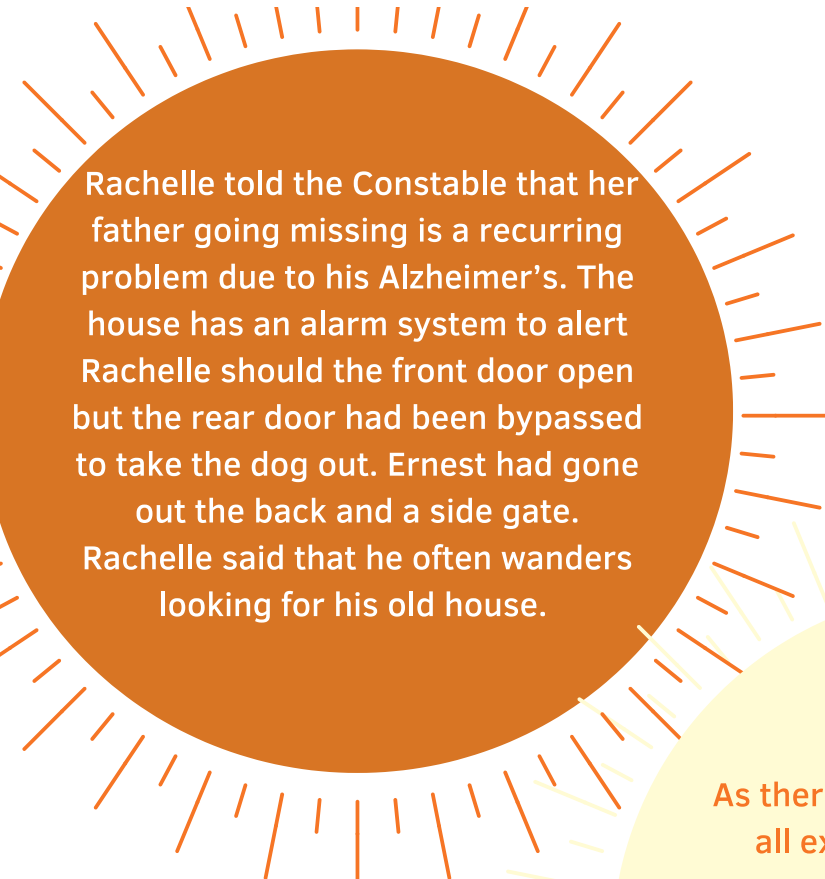
Wife called police to report that her husband had gone missing from home but has severe dementia and is not able to care for himself. He is unfit to live at home.

Cyrus is 83 years old and has trouble dealing with ongoing care issues and the fact that it is becoming more and more unmanageable to keep his wife, Margret, from going missing. Cyrus stated that he did not wish for Margret to return to the residence since he fears she will leave and go missing again.

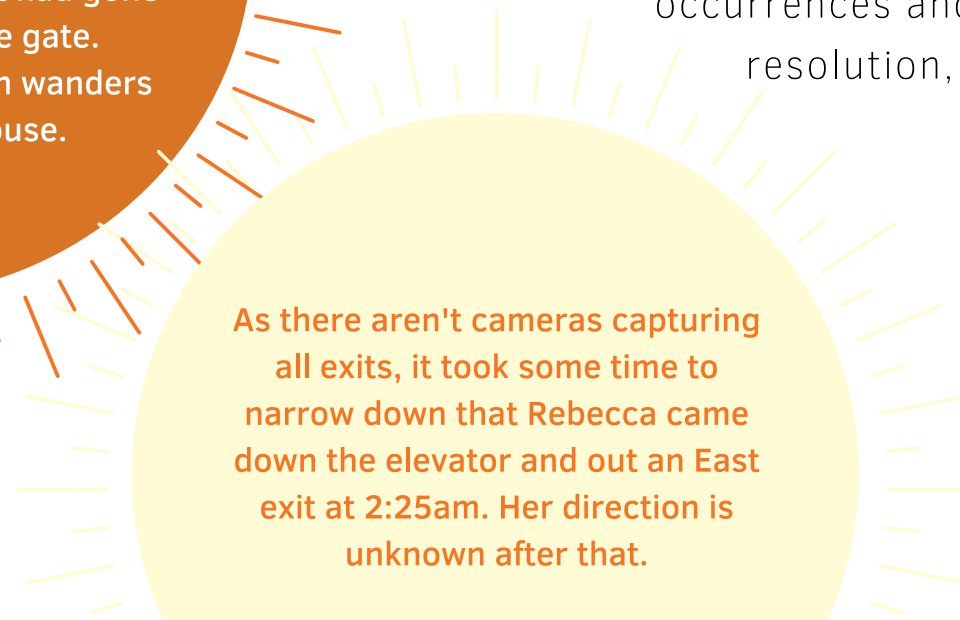
Unmet Needs and Health Care Shortages

Michelle [daughter] stated that Bernard has intermittent bouts of dementia and becomes annoyed with them when they continually ask his whereabouts. He further added that his father is currently on a waiting list for a long-term care facility, but advised the process is slow going. He expressed his frustrations, as Bernard is physically independent and becomes frustrated easily.





Rachelle told the Constable that her father going missing is a recurring problem due to his Alzheimer's. The house has an alarm system to alert Rachelle should the front door open but the rear door had been bypassed to take the dog out. Ernest had gone out the back and a side gate. Rachelle said that he often wanders looking for his old house.

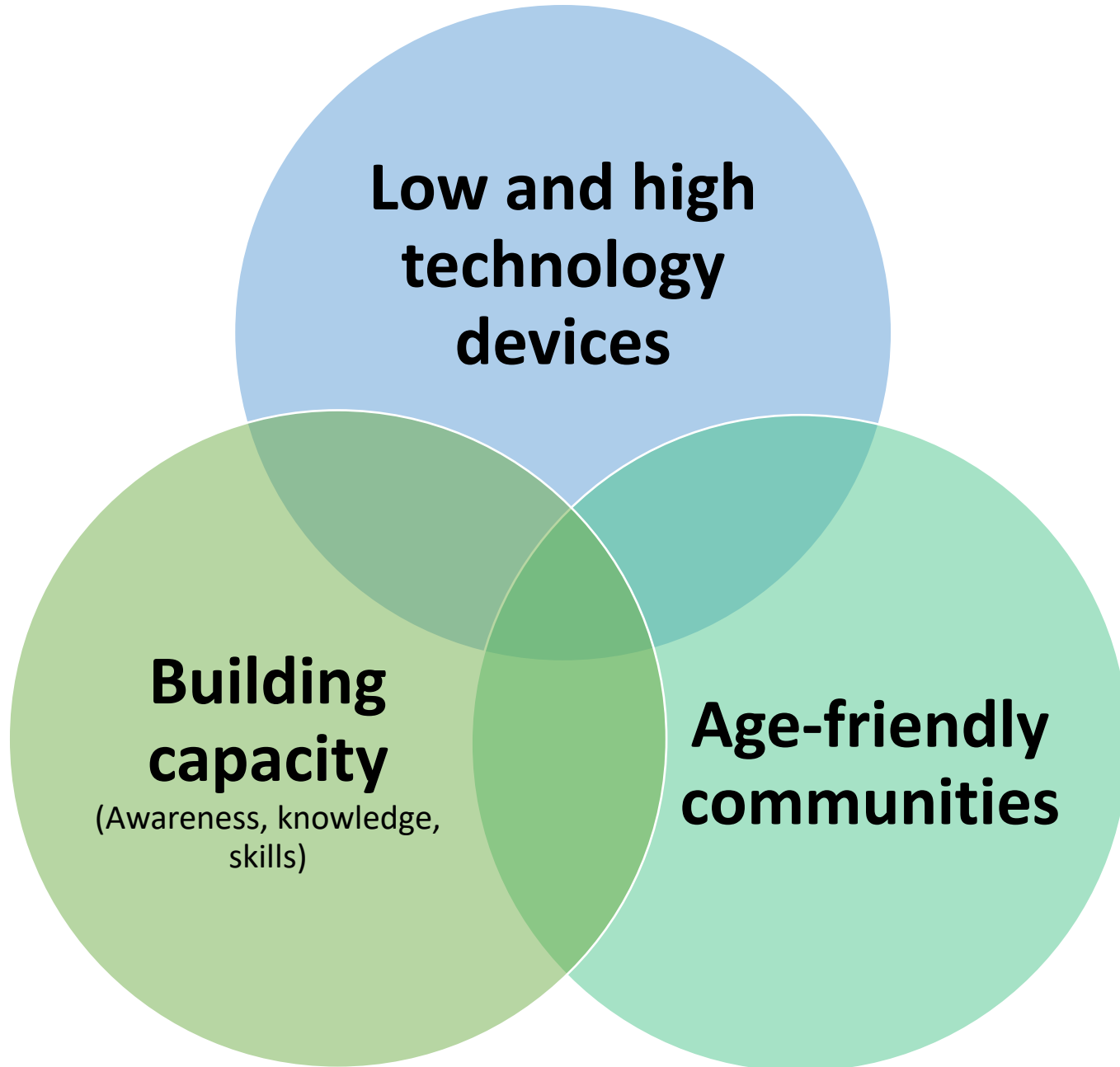


As there aren't cameras capturing all exits, it took some time to narrow down that Rebecca came down the elevator and out an East exit at 2:25am. Her direction is unknown after that.

Shortcomings of Existing Safeguarding Efforts

Although care providers often employed various techniques and technologies to prevent missing occurrences and facilitate their timely resolution, they were not immune from error.

APPROACHES TO MANAGING RISKS



REVIEW OF WANDER MANAGEMENT STRATEGIES

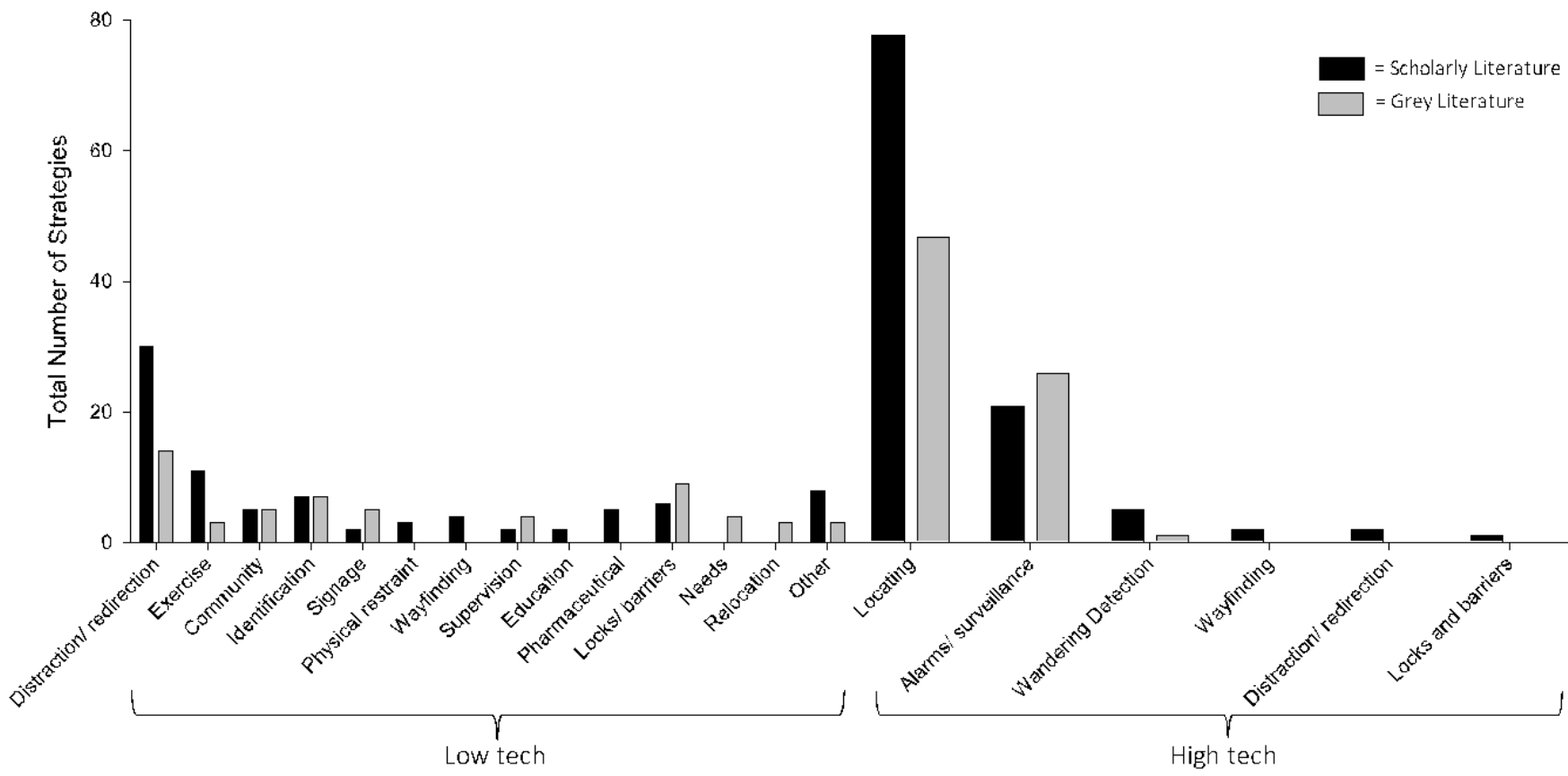


Figure 1 . Number of wander-management strategies that were high (n=183) and low (n=142) tech (Neubauer et al., 2018)

(Neubauer et al., 2018)

GPS LOCATOR DEVICE STUDY



Gave me comfort to know where he was at all the time

Peace of mind that if he got mixed up or lost that we would have a way of locating him

AGE-FRIENDLY COMMUNITIES

Push for Silver Alert in Canada



E-1588

PETITION TO THE GOVERNMENT OF CANADA

Whereas:

- There are over 550,000 Canadians living with dementia and this number will double by 2030;
- 60% of people with Alzheimer's will wander at least once during their disease. Wandering is common as the disease progresses;
- Silver Alert is a public notification system to quickly help find seniors who wander because of Alzheimer's disease and related dementias;
- A Silver Alert would provide information to media outlets and activate an emergency alert system through law enforcement agencies; and
- The Provinces of Alberta and Manitoba have established a Silver Alert, through an amendment to their Missing Persons Amendment Act.

We, the undersigned, **citizens of Canada**, call upon the **Government of Canada** to develop a National Silver Alert strategy for all Canadian provinces and territories.

National Post View: Ontario shouldn't have shelved its plan for a 'Silver Advisory' system

A public alert system would make it possible for more seniors to live at home with their families, rather than in institutions

Manitoba MLA to table bill calling for Silver Alert to help find missing seniors

System for seniors modelled off of Amber Alert to find abducted children

Erin Brohman · CBC News · Posted: Mar 02, 2017 5:00 AM CT | Last Updated: March 2, 2017

U.S. has Silver Alert for missing seniors -- why not Canada?

BY NEWS STAFF

POSTED APR 5, 2016 1:06 PM EDT LAST UPDATED APR 5, 2016 AT 1:13 PM EDT

Upcoming Event



ONLINE NATIONAL FORUM on Alert Systems for Vulnerable Older Adults

Coming together to inform "made for Canada" approaches to alert systems for missing vulnerable older adults.

Thursday, November 26th, 2020, 2:30-5:30PM EST

Visit <https://bit.ly/3owkCk6> for details and to register for FREE



Alzheimer Society
ONTARIO

Alzheimer Society
KATYIH KOLUMBIK



COMMUNITY ASAP



Concerns associated with release of personal information in a community alert system

- Disclosure of personal information puts people at risk of being taken advantage of.

The risk is that the volunteers would prey upon this person if he/she is found and returned home, identified to have dementia. They are already vulnerable to scammers, to people who would be able to redirect them and take advantage of them. (Service provider 1)

- **Privacy may be comprised, and in turn, autonomy too.**

I was tired of people almost panicking about where I was and what I was doing. It was like I had no privacy anymore, and our privacy needs to be respected. We're still humans. And yes maybe at 80 your privacy should be a little less important, but for the younger onset it's a huge importance. (Person living with dementia 12)



- **Release of information may result in stigma.**

There is stigma around it. So even if when the person is found, the story it's a happy ending... that disclosure has happened, that they are living with dementia, and so people talk. (Service provider 17)

- **Permanency of data released in the public realm.**

Do I want my data out there and it's forever out there, so after I pass away my data still gonna be around there? (Service provider 17)

One person with dementia is one person with dementia. (Service provider 2)

RAPID RESPONSE PROJECT

- Purpose is to develop a best police practice resource for lost persons with dementia
- Advisory committee
- Resource launched on findingyourwayontario.ca



RAPID RESPONSE PROJECT

Review

For reprint orders, please contact: reprints@futuremedicine.com

What do we know about best police practices for lost persons with dementia? A scoping review

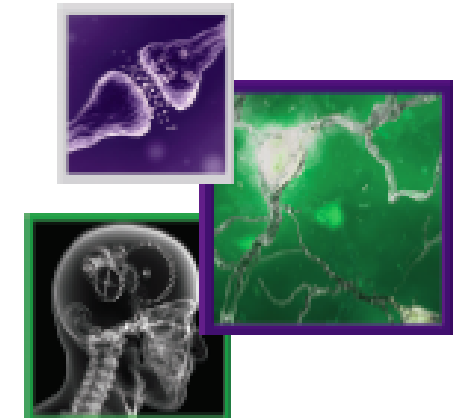
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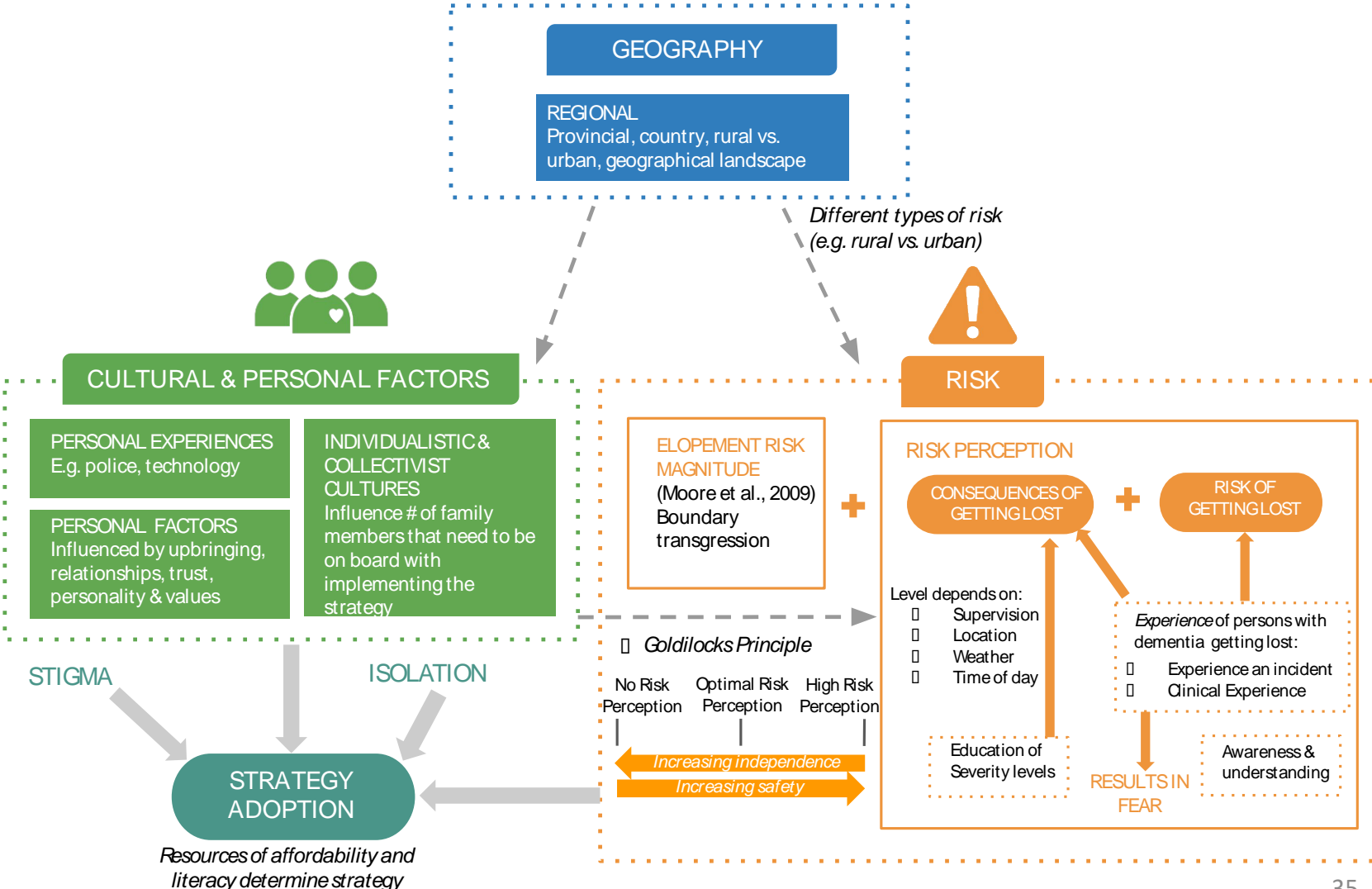
Neurodegenerative Disease Management



Practice points

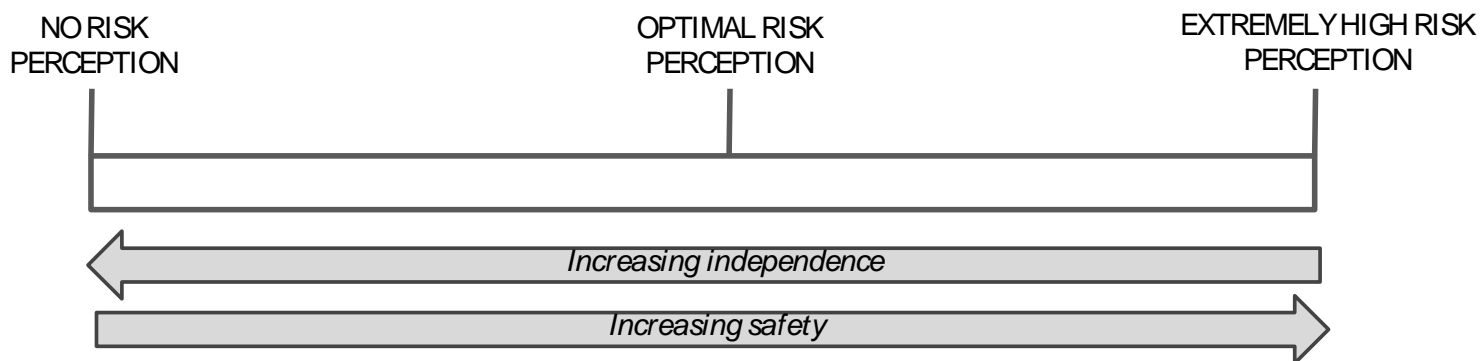
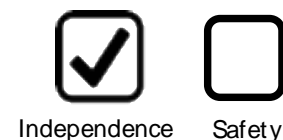
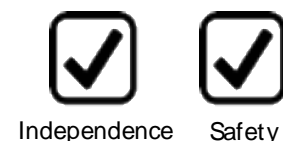
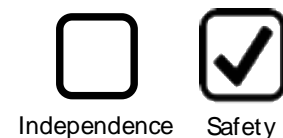
- Strategies ranged from identification tools, successful field techniques, locating technologies and community engagement and education.
- Overall scientific evidence was low, with only three studies evaluating the usability and effectiveness of the suggested strategies.
- Future research could demonstrate the usability and effectiveness of these available strategies and could determine what factors need to be considered for successful adoption among police services in different jurisdictions.

CANADIAN GUIDELINE FOR SAFE WANDERING

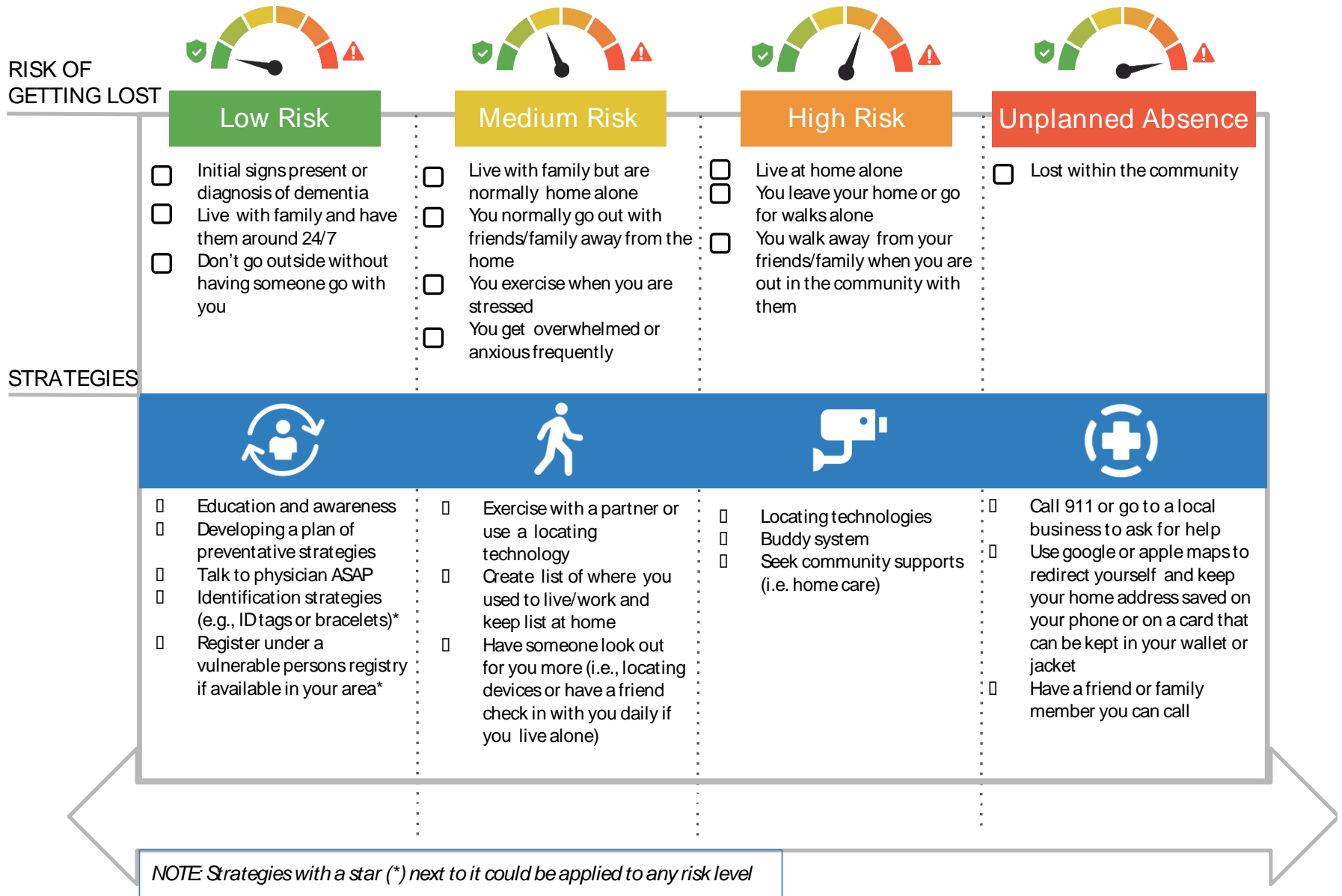


★ Goldilocks Principle

- *Extremely high risk perception:* Fears the risk of getting lost to the point that all levels of independence are removed (e.g. home confinement, locked dementia units)
- *Optimal risk perception:* Sees the risk of getting lost that causes proactive strategy adoption, however enables some level of independence for the person with dementia (e.g. early adoption of GPS devices)
- ▮ *No risk perception:* Doesn't see the risk of the person with dementia getting lost. Results in no strategy adoption until a serious lost event has occurred. Leads to reactive strategies and the potential for risk perception to move to the opposite end of the spectrum (i.e. extremely high risk)



PERSONS LIVING WITH DEMENTIA VERSION



LIST OF AVAILABLE STRATEGIES

Low Risk

- Education and awareness
 - o Finding Your Way Program (<http://findingyourwayontario.ca>)
 - o Alzheimer Society (<http://alzheimer.ca/en/on>)
- Register yourself with the Vulnerable Person Registry (ask local police or Alzheimer Society to determine if your community has one in place) or with an identification program
 - o MedicAlert (<https://www.medicalert.ca>)

Medium Risk

- Exercise with a partner or wear a locating device. These devices can be purchased (<https://tech.findingyourwayontario.ca>) or you can use the ones already on your phone (e.g. Find My Friend App or Google maps)
- Create a list to keep with a close friend or your care partner of where you used to live and work so in the event you get lost this information can be used to help find you
- Have someone keep tabs as to where you are (i.e., locating devices or a buddy system)

High Risk

- Consider locating technologies:
 - o Commercial GPS (<https://tech.findingyourwayontario.ca>)
 - o GPS devices available on your phone (e.g. Find My Friend App or Google maps)
- Seek community supports (i.e., home care, social workers, etc.)
- Register yourself with the Vulnerable Person Registry (ask local police or Alzheimer Society to determine if your community has one in place) or with an identification program
 - o MedicAlert (<https://www.medicalert.ca>)

Unplanned Absence

- Use google or apple maps on your phone to help you find your way back home and keep your home address saved on your phone or on a card that you can keep in your wallet or jacket
- Have a friend or family member you can call in case you are lost
- Go to a local business to ask for assistance
- Identification strategies (i.e., wear an identification bracelet, or put your care partner's phone number in your jacket or wallet)

CONSUMER GUIDELINE



[VIEW PRODUCTS](#)

[ADMIN/VENDOR ACCESS](#)

Products List

Search



PrimeMobile™
SafeTracks GPS Canada Inc.

[VIEW](#) [+ COMPARE](#)



BlueBeacon™
SafeTracks GPS Canada Inc.
(SafeTracks™)

[VIEW](#) [+ COMPARE](#)



S911 Lola Mobile Personal Emergency Response System
Laipac Technology Inc.

[VIEW](#) [+ COMPARE](#)




GoSafe
Philips Lifeline

[VIEW](#) [+ COMPARE](#)



GPS Guardian Connect Integrated with MedicAlert
MedicAlert Foundation Canada

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Helpline: At Home System
Nortek/Linear

[VIEW](#) [+ COMPARE](#)

tech.findingyourwayontario.ca



CONSUMER GUIDELINE






[VIEW PRODUCTS](#) [COMPARE PRODUCTS \[3\]](#)

[ADMIN/VENDOR ACCESS](#)

RESET

Product Comparison:

Vendor Name	SafeTracks GPS Canada Inc.		Laipac Technology Inc.
Product Name	PrimeMobile™	BlueBeacon™	S911 Lola Mobile Personal Emergency Response System
Product Model			
Product Image			
Product Info Page	Detailed Info	Detailed Info	Detailed Info
Available in Canada	Yes	Yes	Yes
Cost	Device: \$249.95 CAD Activation: \$35 CAD		Device: \$145 USD Activation: \$0 USD
Device cost	Device: \$69.95 CAD		

INTERNATIONAL CONSORTIUM ON DEMENTIA AND WAYFINDING

Representative Stakeholders



Calgary February 2019



Edinburgh March 2019



Liverpool July 2019

- Persons living with dementia
- Care partners
- Industry
- Researchers
- Academics

- Students
- Community organizations (Alzheimer associations)
- Health professionals
- First responders (police, search & rescue)

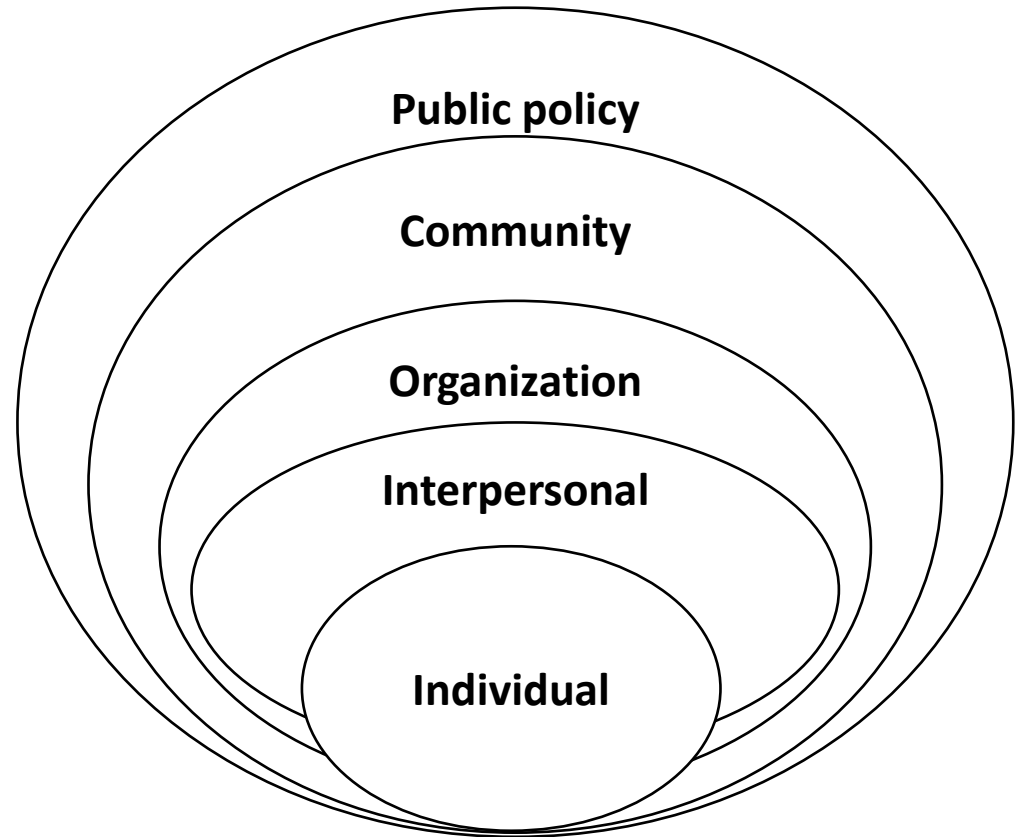
Website: <http://icdw.org>

Members



WHAT HAVE WE LEARNED?

- Multiple realities thus multi-faceted approaches
- Appreciate that there are many experts
- Leverage knowledge (avoid re-inventing the wheel)



HOW TO GET INVOLVED

- Follow our website: <https://uwaterloo.ca/airp>
- Participate in the November 26, 2020 online forum
- Join the International Consortium on Dementia and Wayfinding
- Join one of our advisory committees
- Enroll in one of our studies



OUR CONTACT INFORMATION

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