

Sept 15, 2022

Engaging People Living with Dementia in Decision-Making

Summary of themes for participant feedback

About the CCEL

The CCEL conducts research, and develops reports and educational tools about legal and policy issues related to aging.

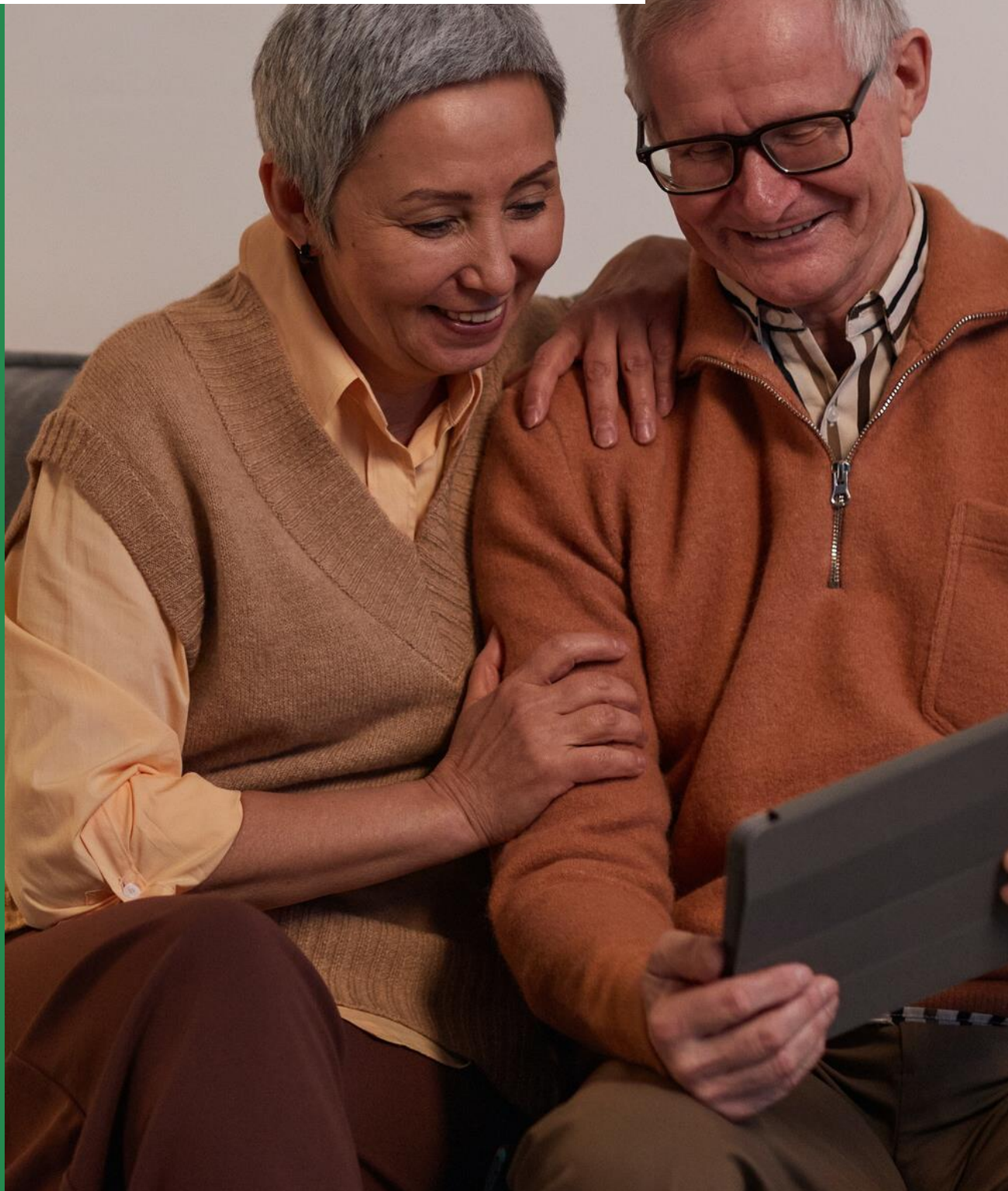
The CCEL is part of the BC Law Institute, BC's non-profit independent law reform agency

www.bcli.org/ccel

Our work = Law reform + Consultation
+ Research + Legal education



Engaging People Living with Dementia in Decision-Making



PROJECT GOAL

To change how healthcare decision-making is approached so that the rights of people living with dementia are respected and they participate as much as possible in the decisions that matter to them.

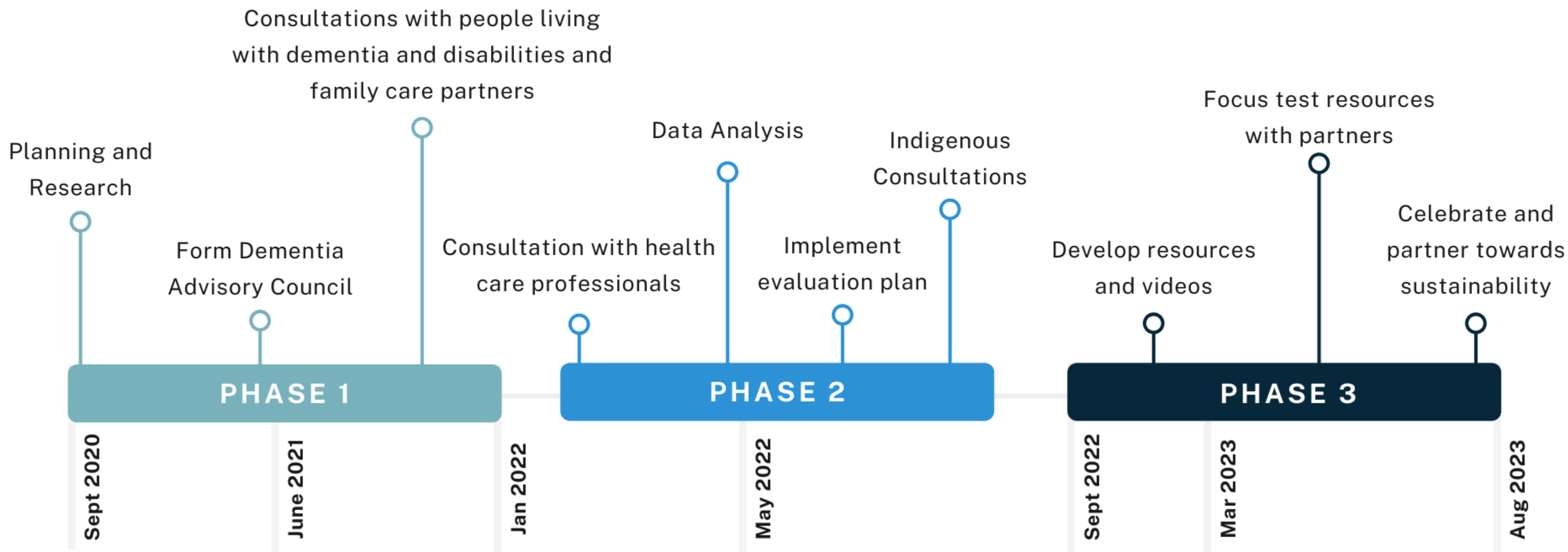


Project Objectives

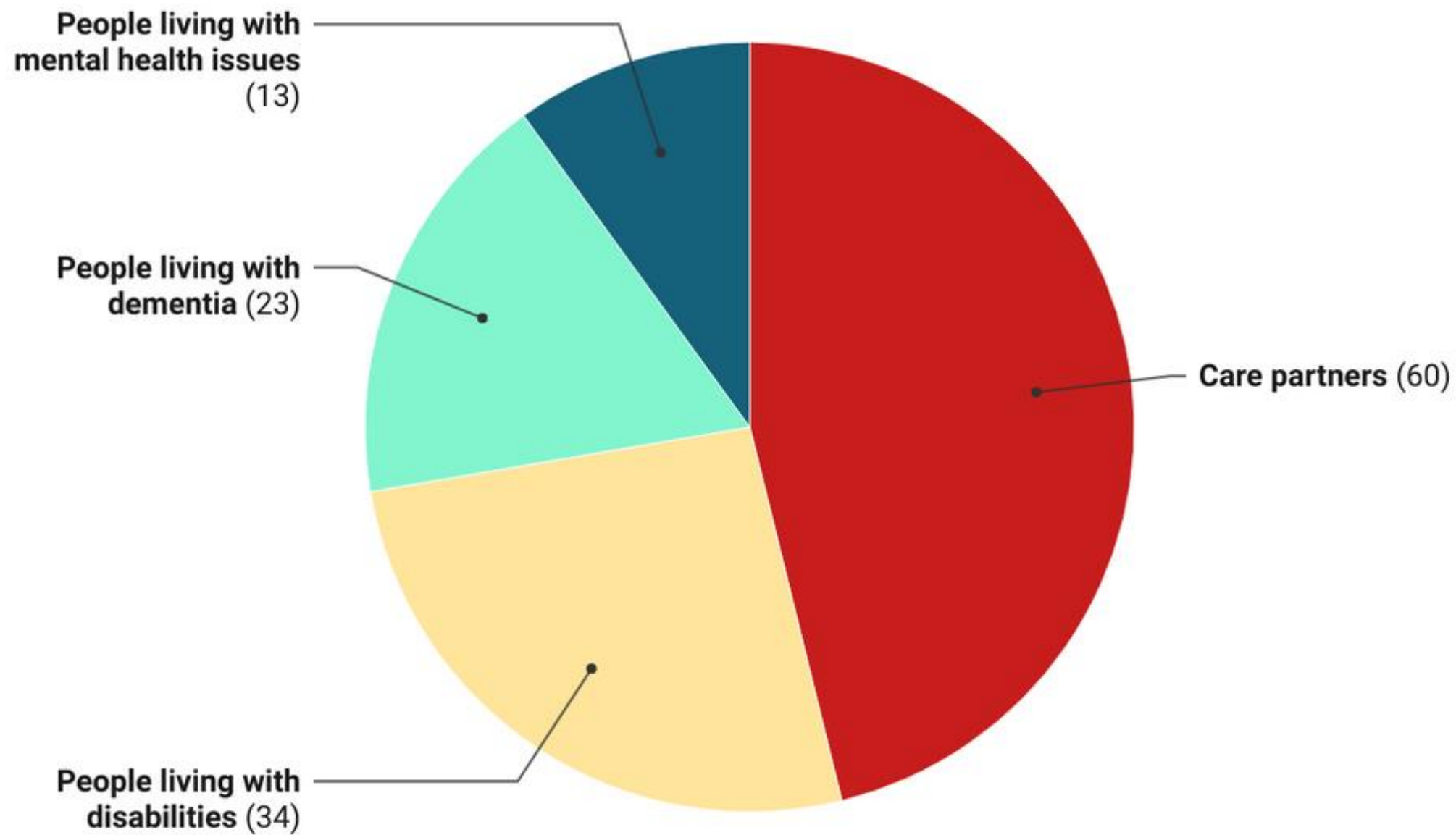
1. Partner with people with different kinds of disabilities, including dementia, their family care partners and health care professionals to identify strategies and barriers to decision-making
2. Identify ways to support families and healthcare professionals' capacities to engage people living with dementia in decision-making.



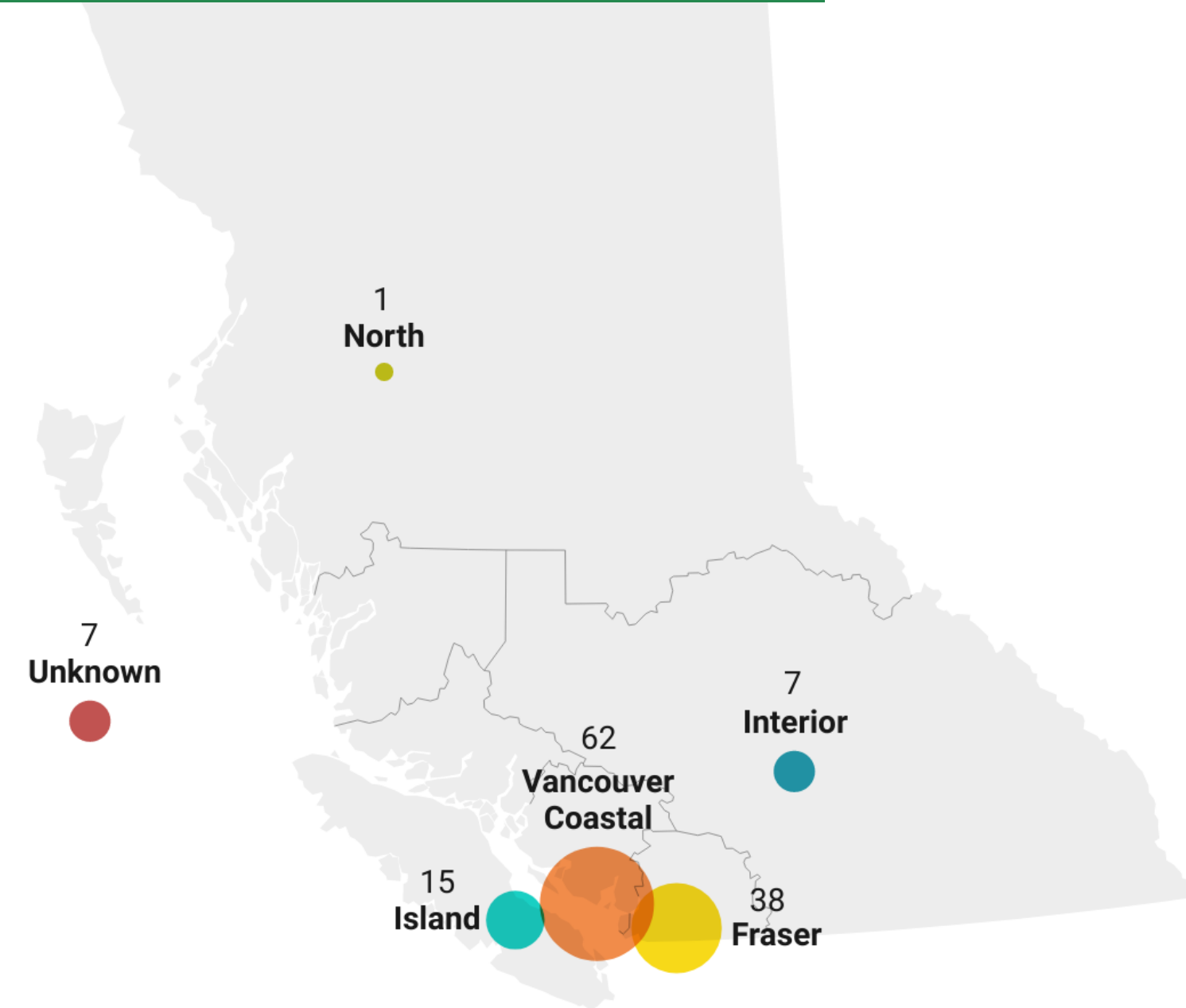
CCEL ENGAGING PEOPLE LIVING WITH DEMENTIA IN DECISION-MAKING PROJECT TIMELINE



Community consultations

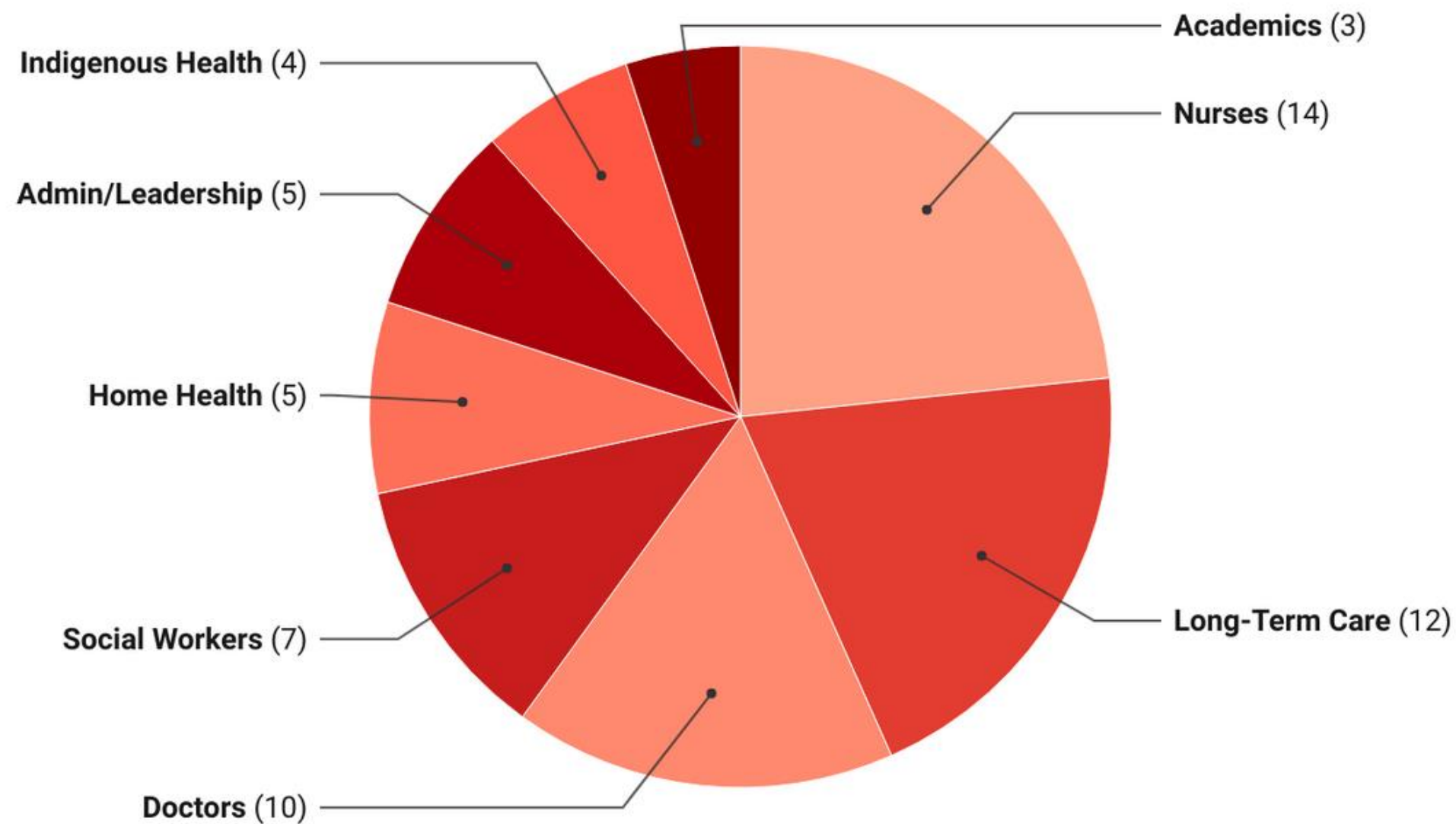


130 community members

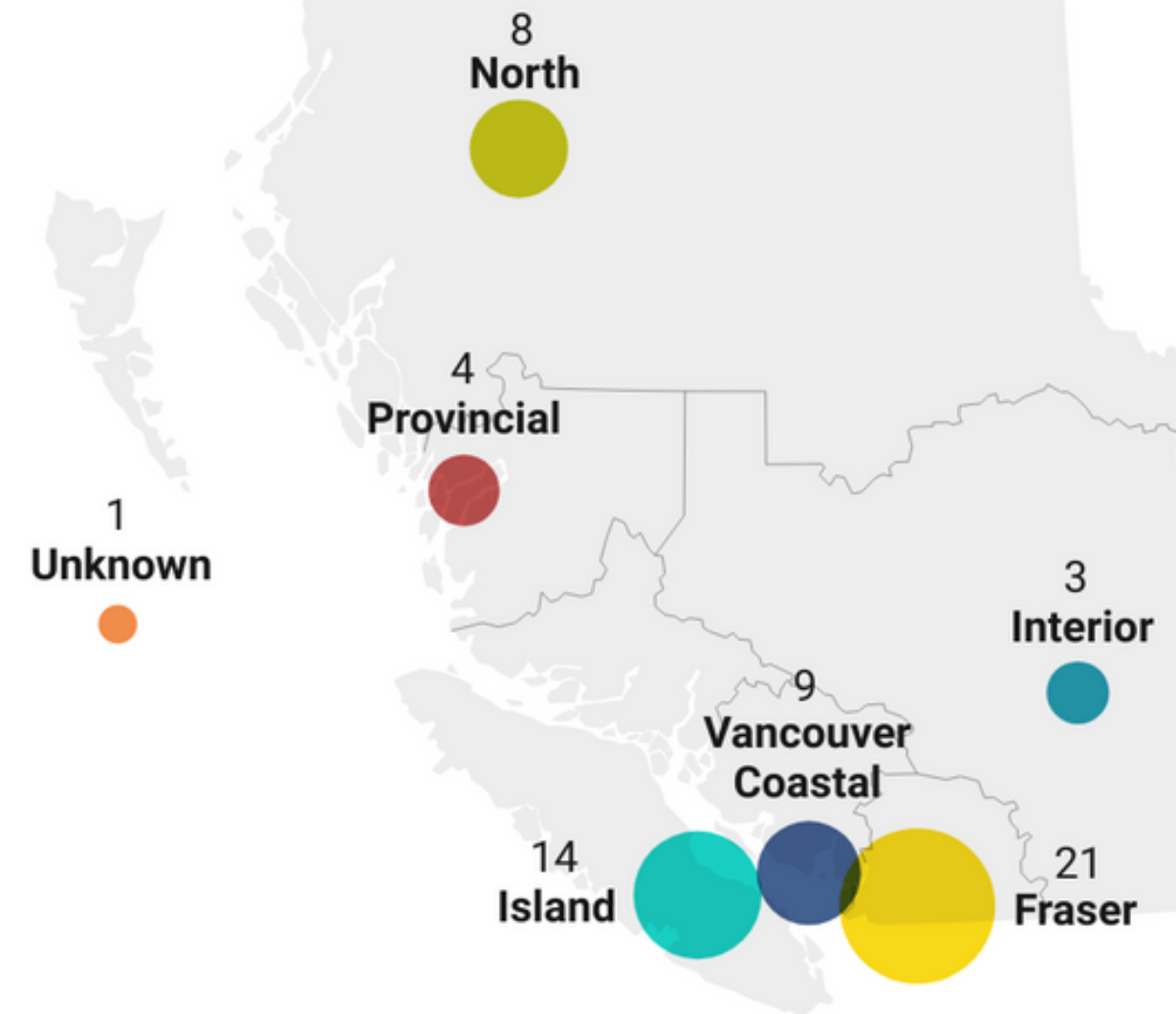


5 regions

Health Care Worker Consultations

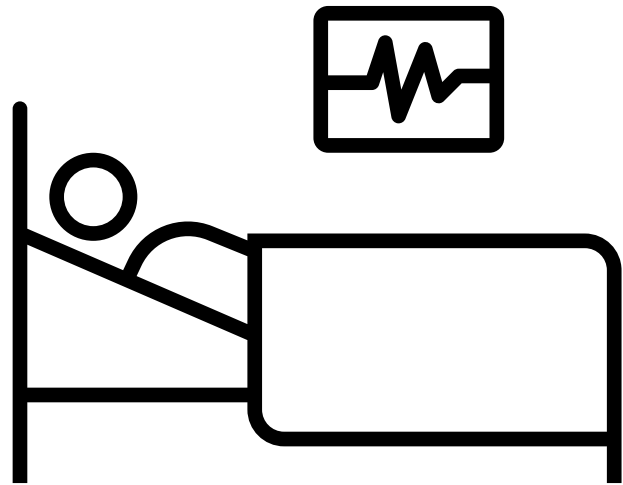


60 health care professionals



5 regions in BC

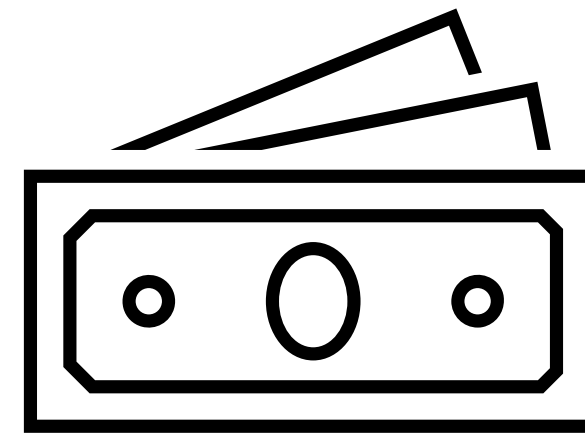
What decisions?



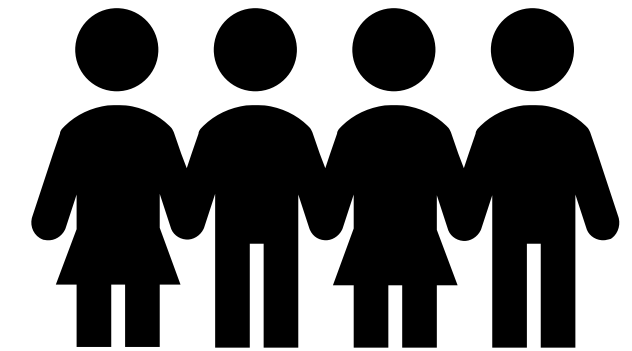
Health care



Lifestyle

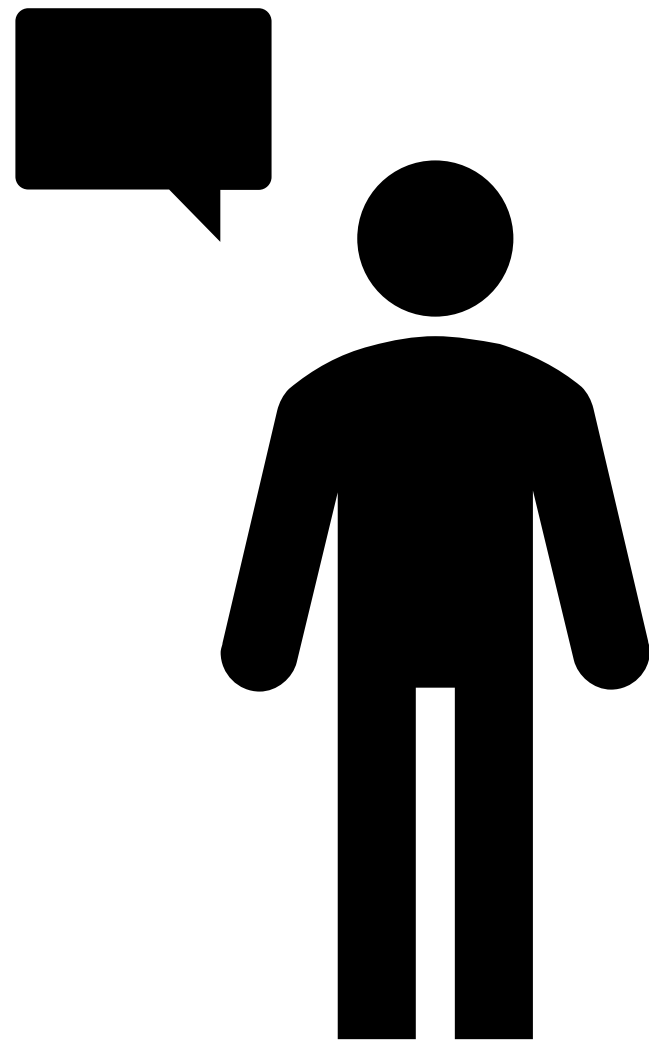


Financial / Legal

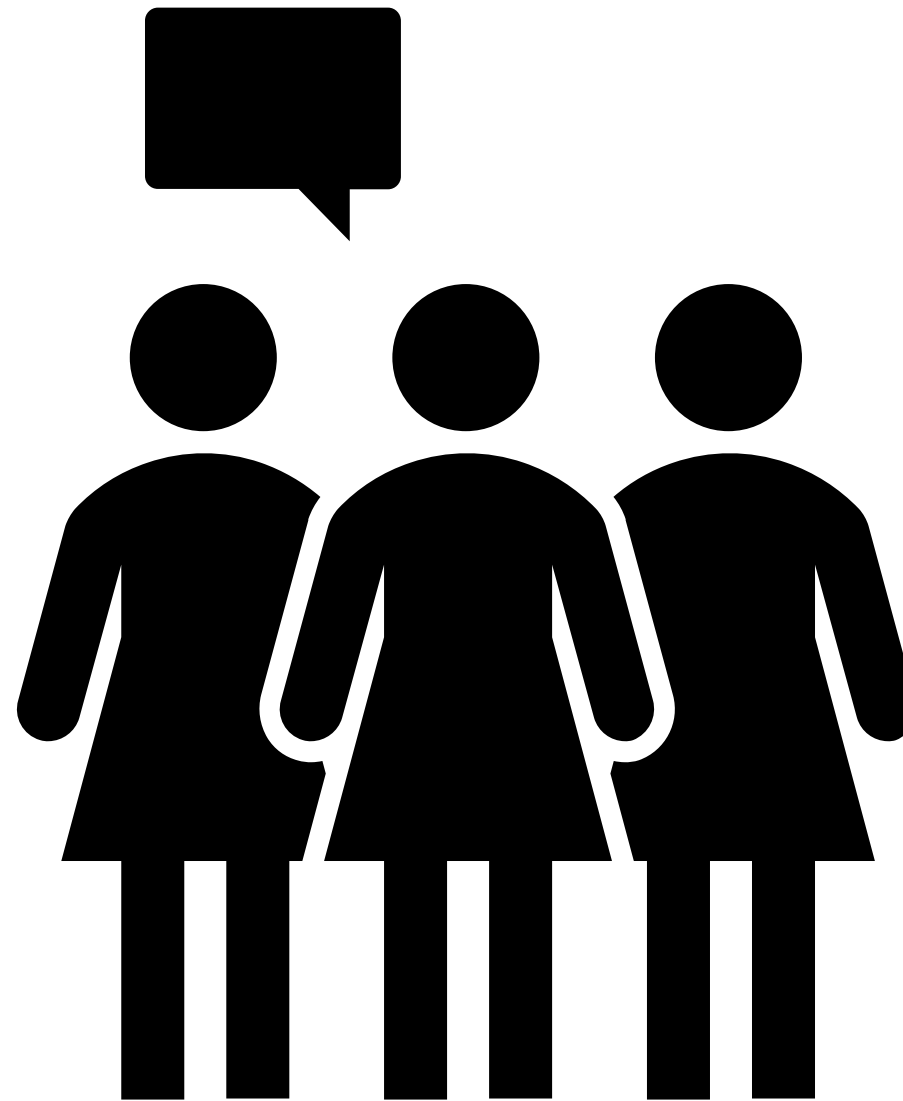


Everyday

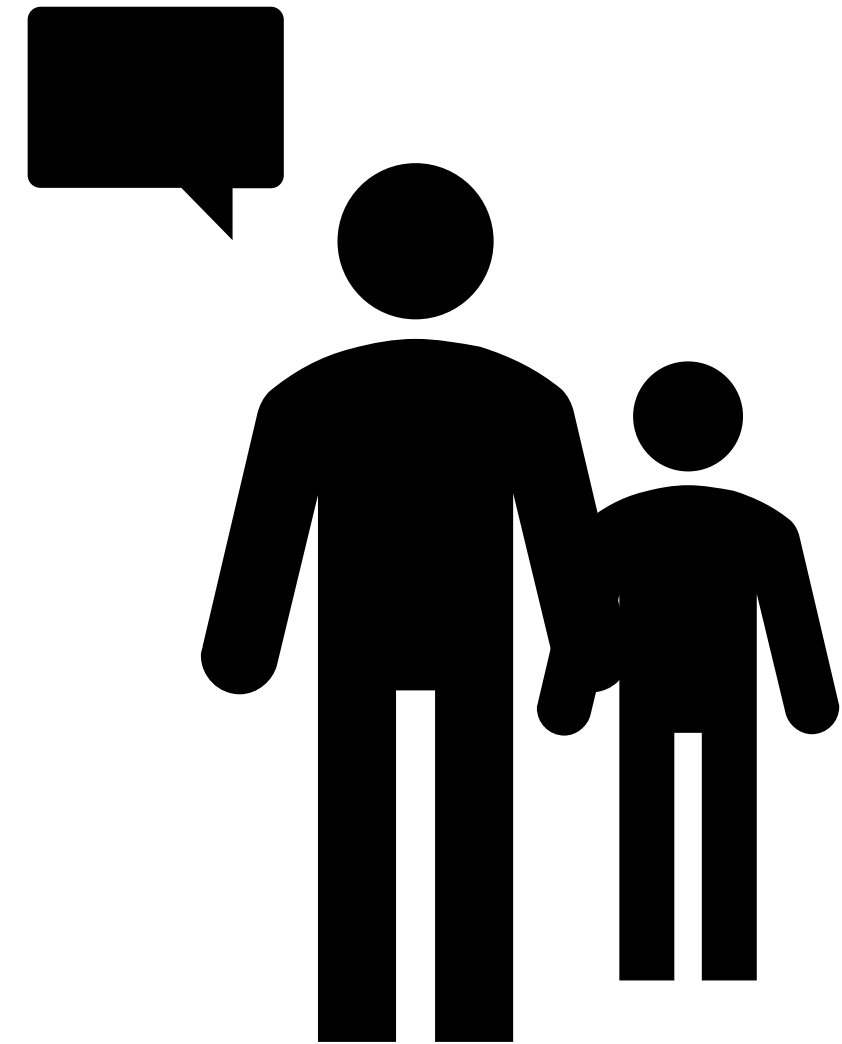
Level of involvement



independent



Supported / partly involved



substitute

“Stereotypes hinder a lot of people in their decision making, because they read the diagnosis or whatever on a piece of paper and automatically assume something about that person.”

- *Person living with a disability*

“...is a big issue in an institution like you, you’re butting heads all the time even on, you know, the rights when, the resident’s rights are supposed to be that they make any of their decisions but in reality that’s not the case.

- *long term care worker*

Barriers: System

- Lack of information/understanding on tools and legislation
- Lack of understanding of dementia and rights
- Stigma, paternalism, and assumptions
- Structure of care: process barriers, rushed pace
- Confusion on legislation
- Language and cultural barriers

Barriers: Personal



- Anxiety about further decline
- Doubting own capacity to make decisions
- Lack of support in decision making
- Lack of insight into decline
- Feeling left out of decisions

“My lady friend that passed away, she always went to the, to my doctor’s with me and the two of them talked together as if I wasn’t even there and they discussed everything. So I got to the point I wouldn’t take her anymore.”

- person living with dementia

Barriers: Other

“The old school legislation we have to work with is not really consistent with a lot of the First Nation’s values around who the decision maker should be, right, like I don’t care about Section 16...it should be the chief or it should be so and so, the elder, you know, so that sometimes [laughing] causes some tension, right.”

- *Health care provider*

- Cultural/language barriers
- Challenges in communication and understanding
- Fluctuation of dementia
- Care partner burnout

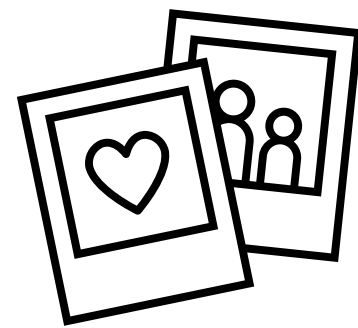
Communication Strategies

“So what we’ve
chosen to do is I
make sure we get a
menu beforehand
and we go through
it and we talk about
it.”

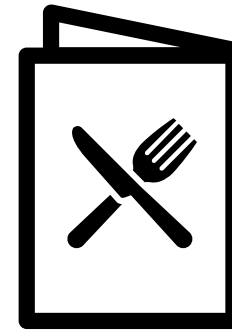
– care partner



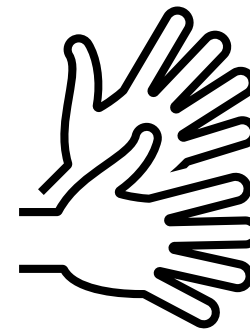
Communication
& support



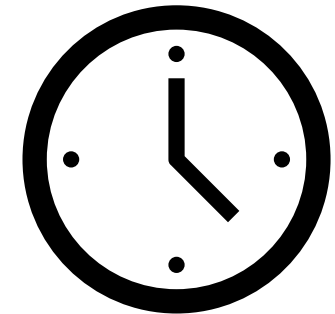
Visuals



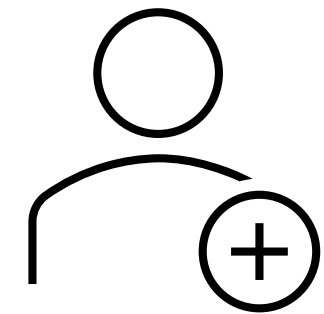
Options



Non-verbal



Enough time



Trust / rapport

Person-centered strategies

- Best interest
- Prioritizing decisions
- Values & context
- Culture and beliefs
- Positive self-talk

“As long as they are still capable, focusing on them as the centre point of decision-making. If they want to involve family, that’s up to them.”

– geriatric psychiatrist

“It’s their place. And It’s their life, right. It’s their home. We try to make it their home, most of us, and let them make the decision. But not everybody does that... That’s what we’re trying to do, that it’s their home and it’s their choice.”

– care aid

Other strategies

- System navigation
- Finding information
- Understanding legal tools
- Advocacy
- Boundaries
- Involving others
- Planning ahead

“I have a daughter who wants to control everything. So I have to tell her, manage the investments. You are the beneficiaries of this. I will not even think about what you will decide... but my house, I will take care of my house... You have to put it in compartments... Just focus on the things I am giving you... I have to be so careful about that, because some people can be so pressing.”

- person living with MCI



Solutions

- Advocacy
- Systems change
 - Information access
 - Legislation
 - Oversight / accountability
- Training
- Context of care
 - Clarity on assessments / risk
 - More time

“What we also must have is a change in attitude. That is done one on one at an individual level and also at an institutional level. [We] also need a greater understanding of different communication needs and styles and not to stereotype people as a result of that.”

- *Person living with a disability*

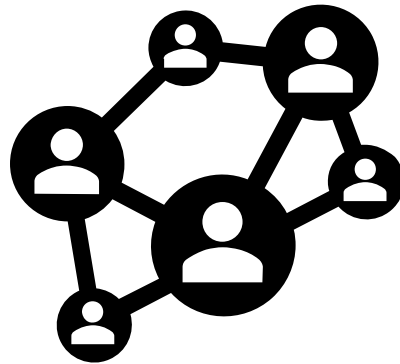
Tool development: components

- Stories/scenarios
- Process of assessing incapacity
- Explaining misconceptions
- Stages of dementia
- Communication strategies
- Values: person-centred / respect
- Cultural considerations
- Navigating risk and liability

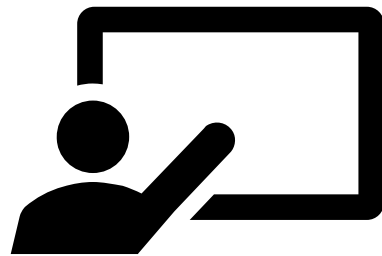
“People assume that you have the right to intervene if there’s risk but still don’t have a great understanding that the risk has to be grave enough to impact somebody’s life. So you can’t really intervene until the risk is to their life or their assets, you know, that’s where emergency powers lay is the right to intervene to be somebody’s face if they’re at risk of losing their assets or if they’re at risk of serious harm.”

- nurse

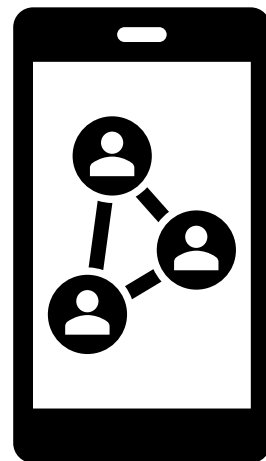
Tool development: place



Community organizations
Health care system



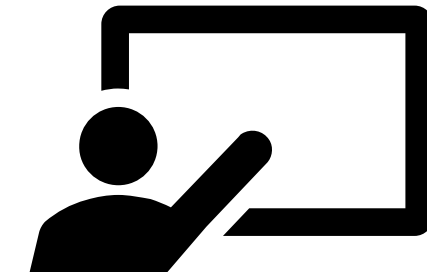
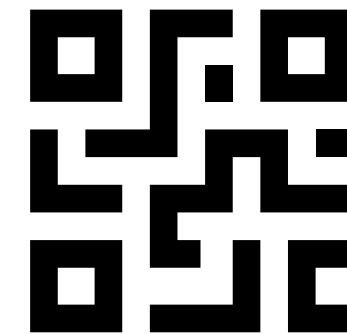
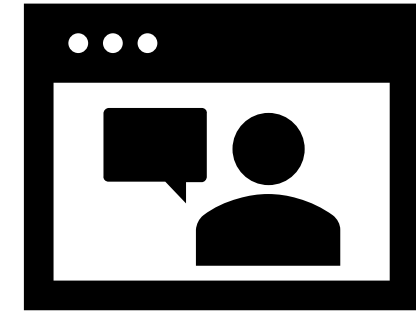
Trainings
Live Workshops



Social media
Online videos

Tool development: method

- Print: newsletters, brochures, booklets
- Audio: public service announcements
- Short videos / interactive modules
- App with modules / scenarios
- Check-lists, infographics with QR code
- Webinars, trainings, grand rounds
 - Point of contact for follow up
 - Physician to physician



Thank you to our funder

vancouver
foundation

Thanks to:

- [Alzheimer Society of BC](#)
- [Family Caregivers of BC](#)
- [Centre for Research on Personhood in Dementia](#)
- [Inclusion Langley](#)
- [Inclusion BC](#)
- [DIVERSEcity Community Resources Society](#)
- [Richmond Society for Community Living](#)
- [Burnaby Access Advocacy Committee](#)
- [Plan BC](#)
- [PosAbilities](#)
- [The Disability Alliance](#)
- [The Bloom Group](#)
- [Dementia Advocacy Canada](#)
- [Burnaby Seniors Outreach Society](#)
- [Alzheimer's Café: BC Chapter](#)
- [Council of Senior Citizens Organizations of BC \(COSCO\)](#)
- [Canadian Hard of Hearing Association \(Chha-BC\)](#)
- And more!

Resources

- [My Life, My Decisions](#) – Guide on decision-making with developmental disabilities by Iris Institute
- Health care decision-making rights of people living with dementia: [CCEL video and booklet](#)
- CCEL [Engaging People Living with Dementia in Decision Making Project Page](#)
- Advance Care Planning: [BC Centre for Palliative Care](#)
- Learn about dementia stigma: [Flippingstigma.com](#)

Let's stay in touch!

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PROJECT WEBPAGE:

www.bcli.org/project/engaging-people-living-with-dementia-in-decision-making

CCEL RESOURCES ON DECISION MAKING RIGHTS:

<https://www.bcli.org/project/health-care-decision-making-legal-rights-of-people-living-with-dementia>