Planning Health Services for Persons with Dementia In Ontario: Current Challenges and Opportunities

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Disclosures

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- Consulting: Cancer Care Ontario, Dementia Capacity Planning

- No disclosures related directly to my presentation

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Confessions

- Planning person centred services for people with dementia is complicated
- Resource constrained environment, how to do "better" with our resources
- Services are interconnected, need multiple services working in coordinated fashion for optimal outcomes
- Need solutions yesterday, but no quick fixes
- Data for decision making is not always complete

Objectives

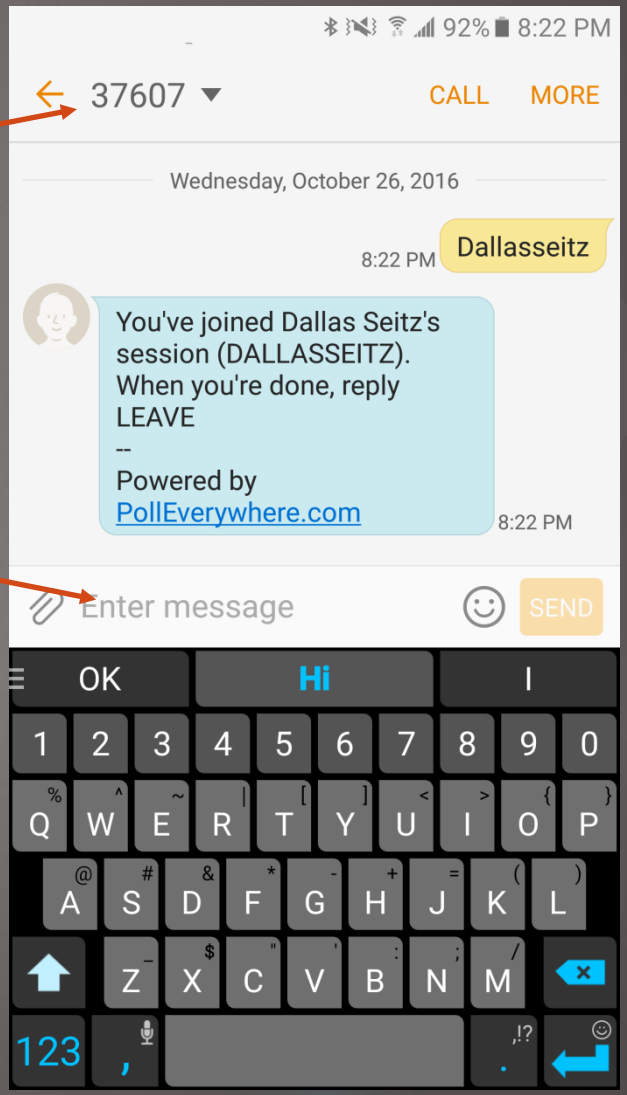
1.) To understand the importance of health service planning for persons with dementia;

2.) Examine promising evidence-based models of care for persons with dementia;

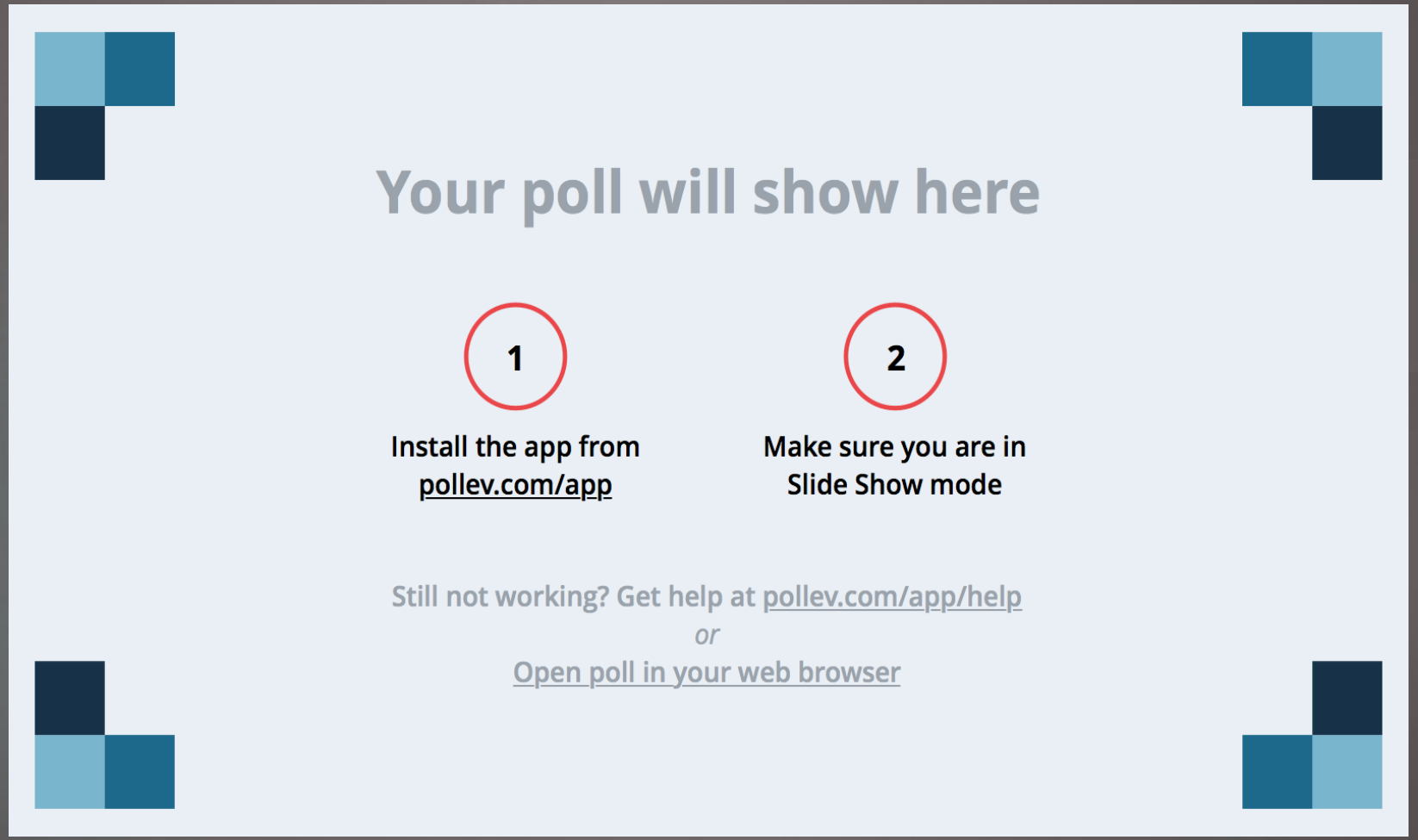
3.) Review the Dementia Capacity Planning model for Ontario

Capacity Planning in Action!

- Take out your phones!
- #37607
- Text: dallasseitz
- Response indicating you have been registered



About you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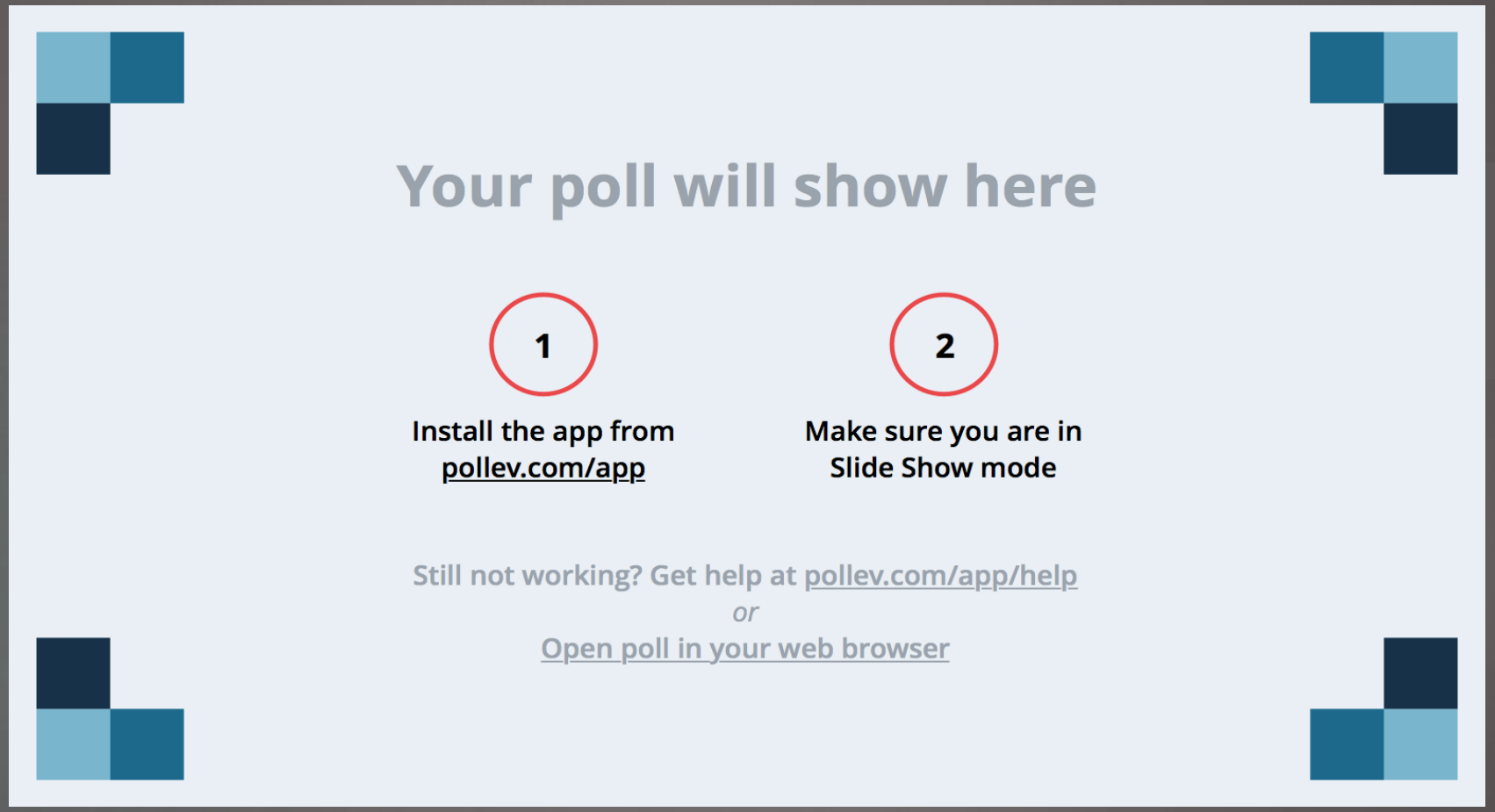
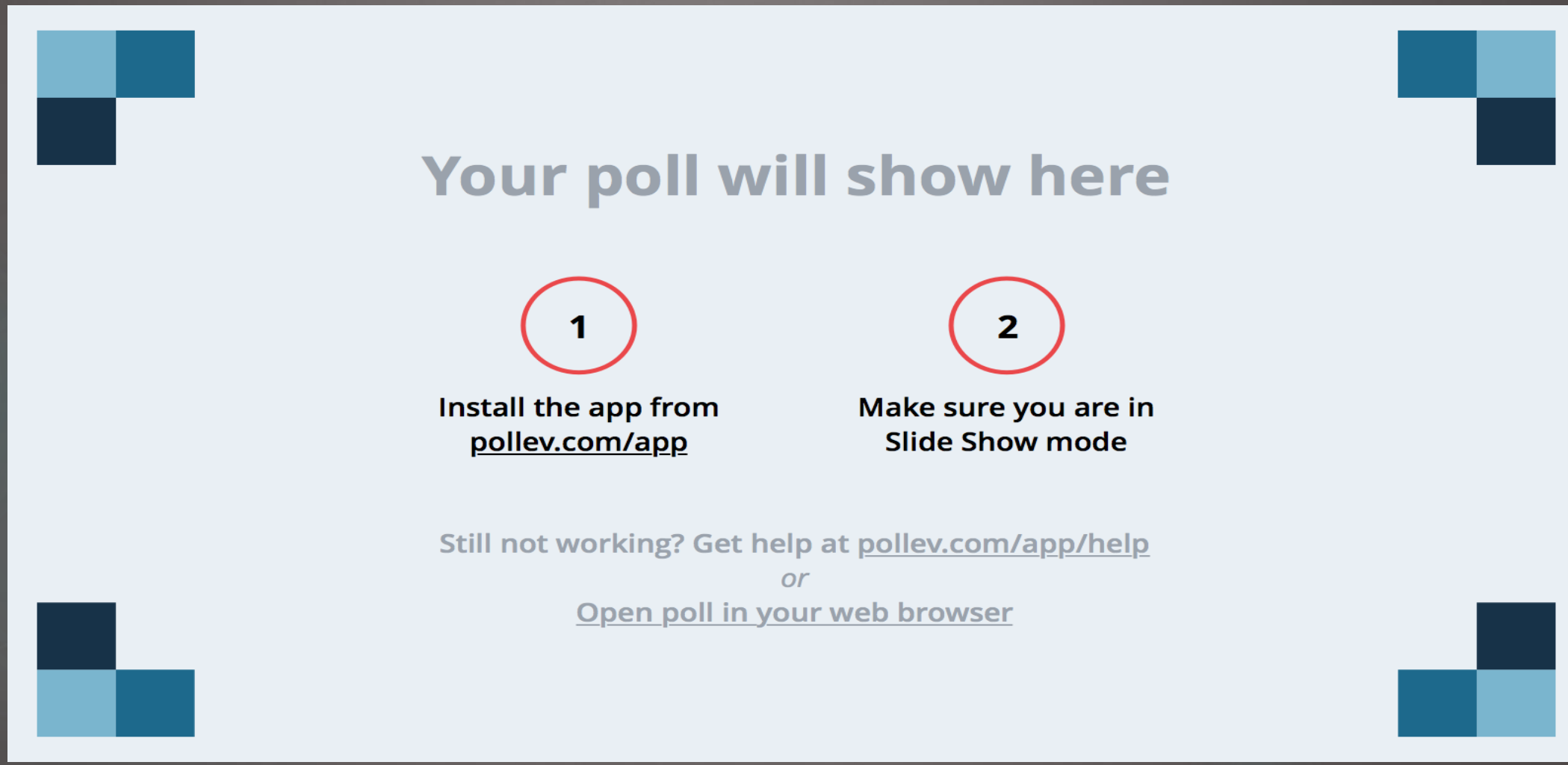
Dementia Services



Challenges in Dementia Services



Vignette

Mrs. S. has been living with mild symptoms of dementia for 3 years and has a MMSE = 23/30. She is happy and content with her life. Mrs. S does not have any significant limitations in her basic activities of daily living. She is medically stable and has no significant behavioural changes. She can use the phone, has some difficulties with preparing meals, needs reminders about her medications, and is not able to drive. She lives in a basement suite at her adult daughters home, her daughter works.

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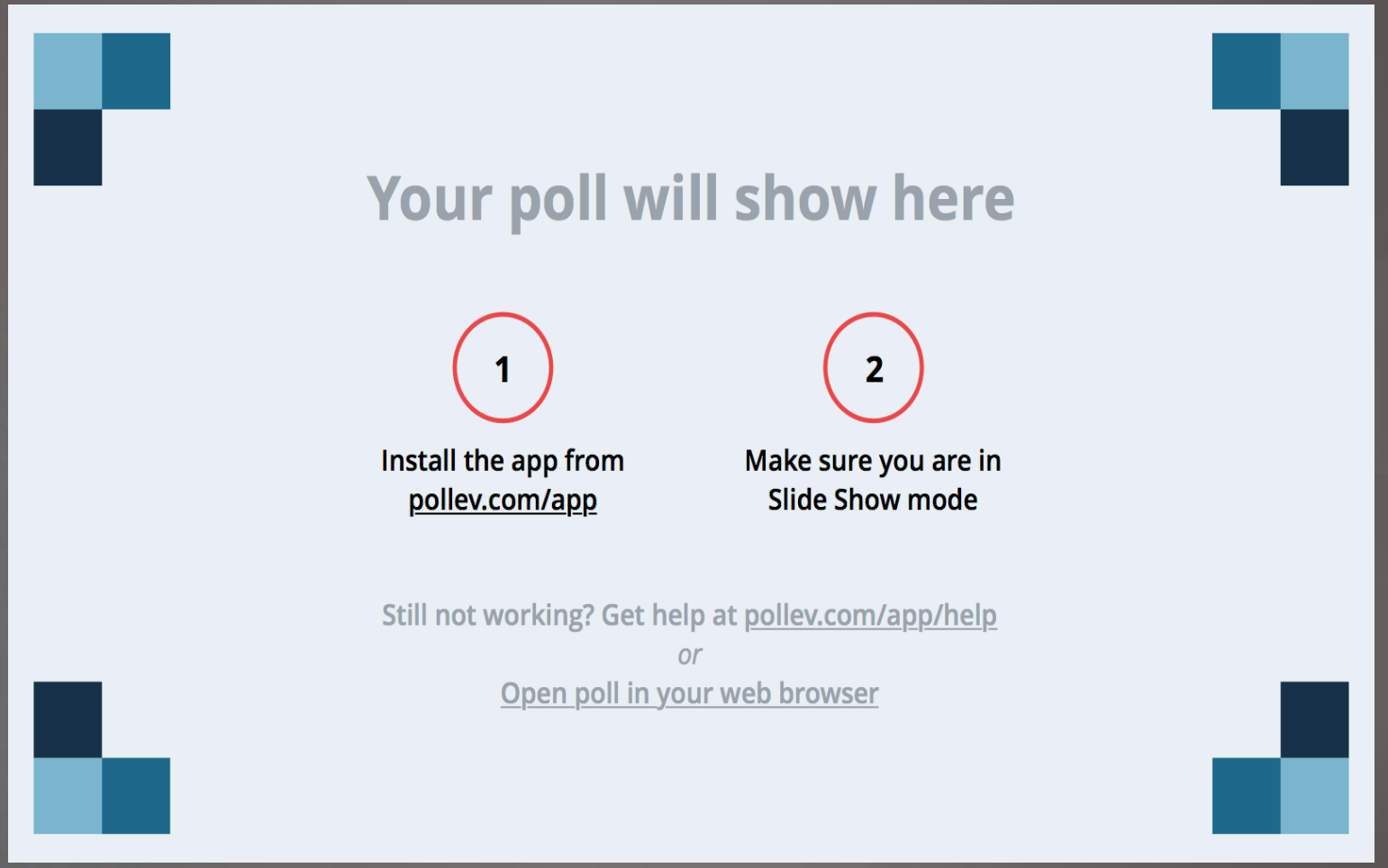

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What is your background?

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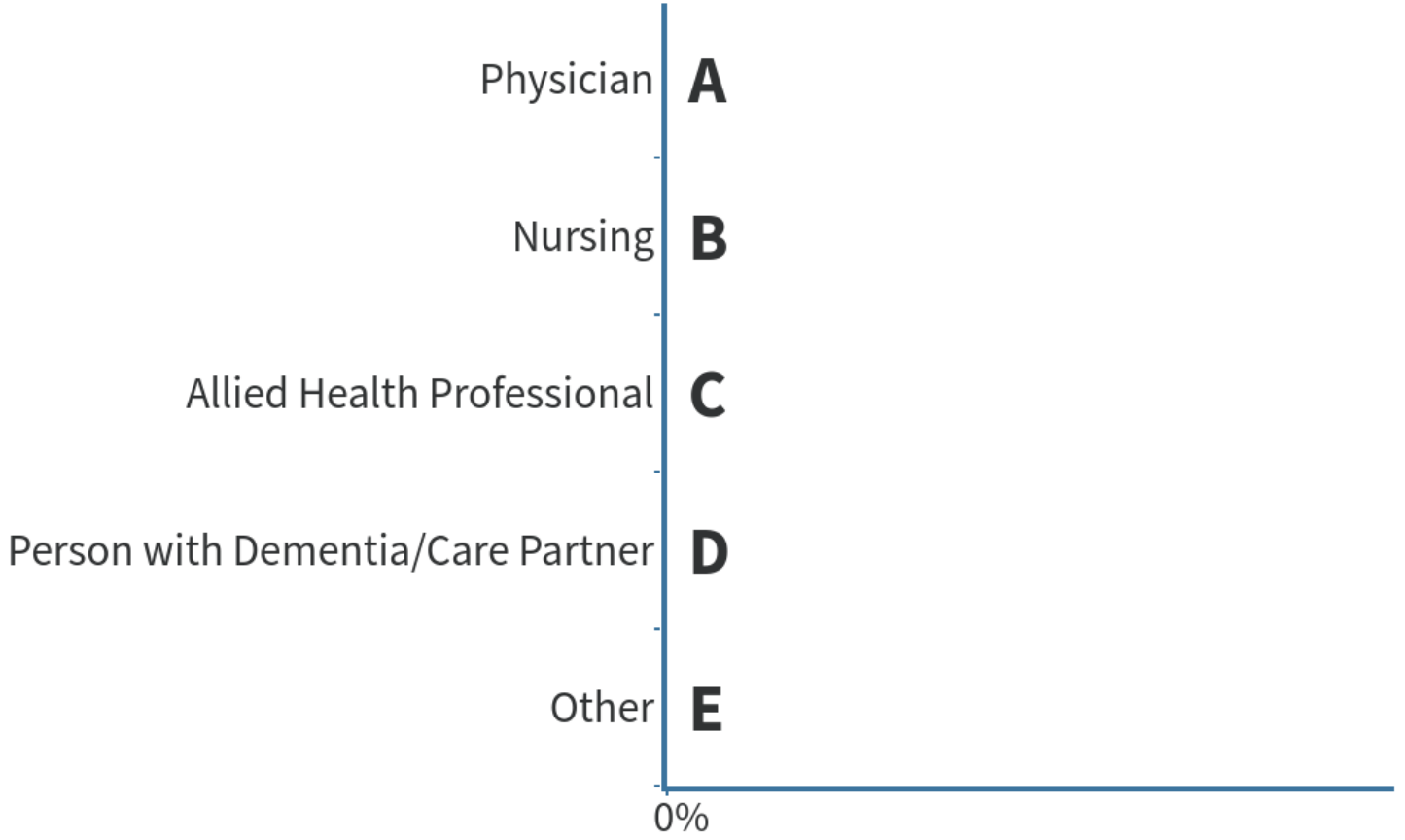

Which of the following services are most helpful for supporting community dwelling persons with dementia?

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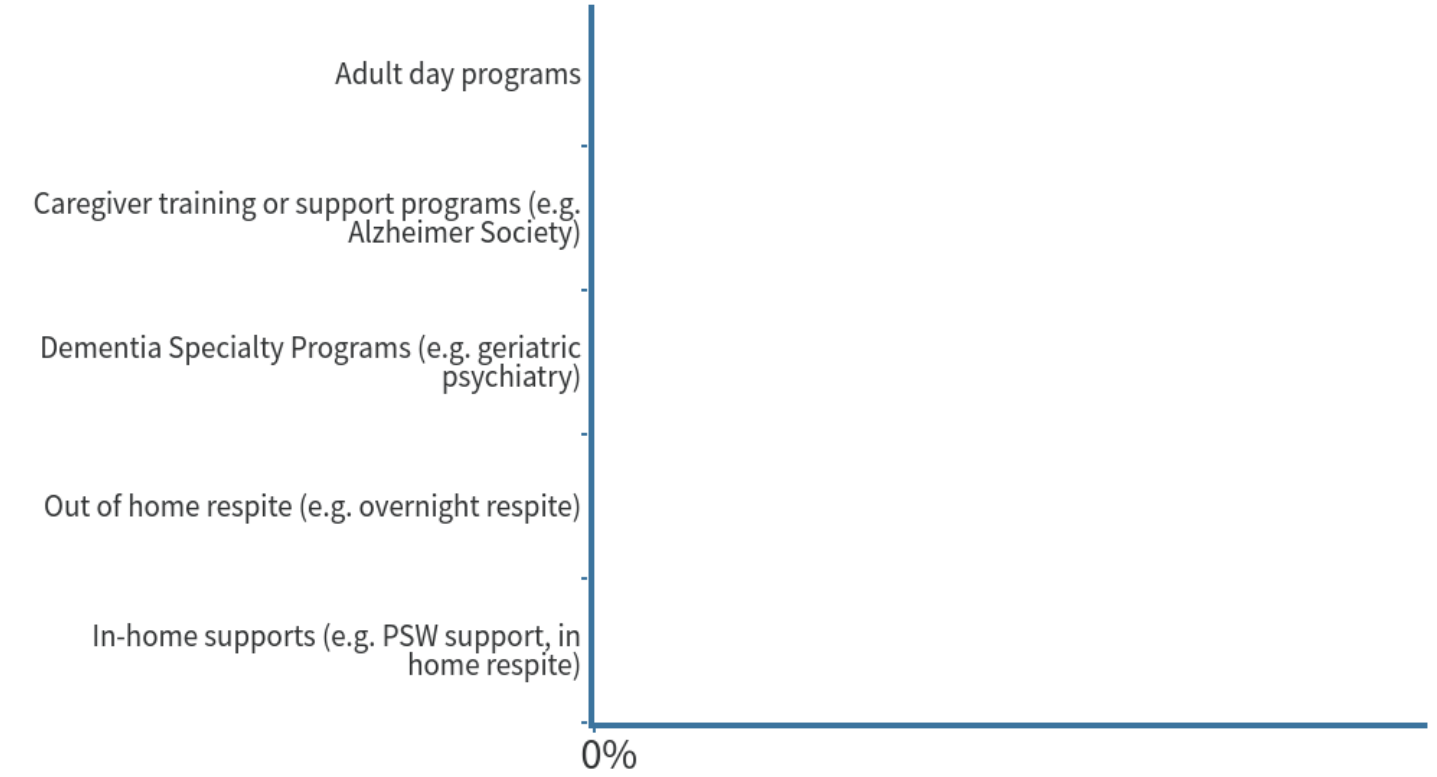

What are the biggest gaps you see right now related to in home supports for persons with dementia in Ontario?

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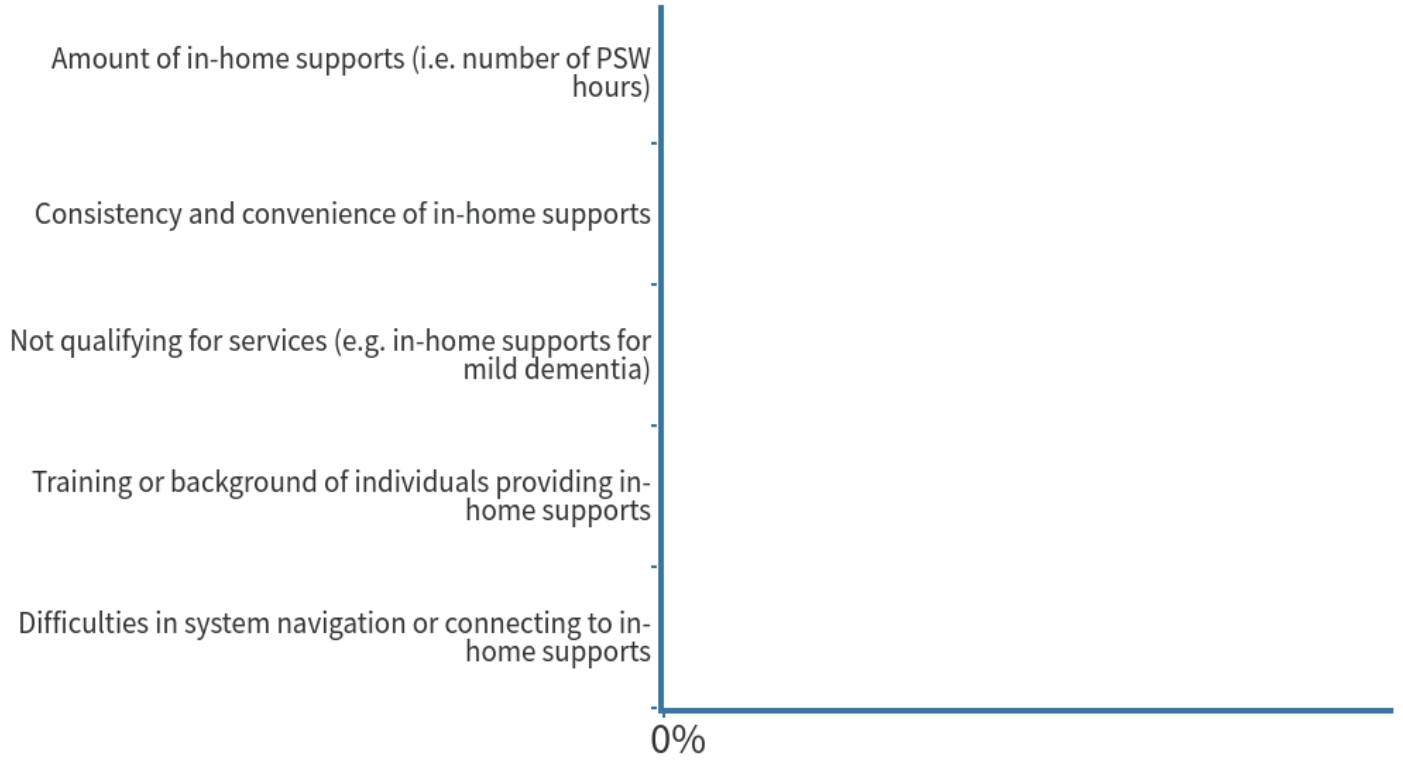

Vignette

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How many PSW hours each do you feel would be needed for Mr. S. to be able to continue to live at home safely and with a good quality of life for her and her daughter?

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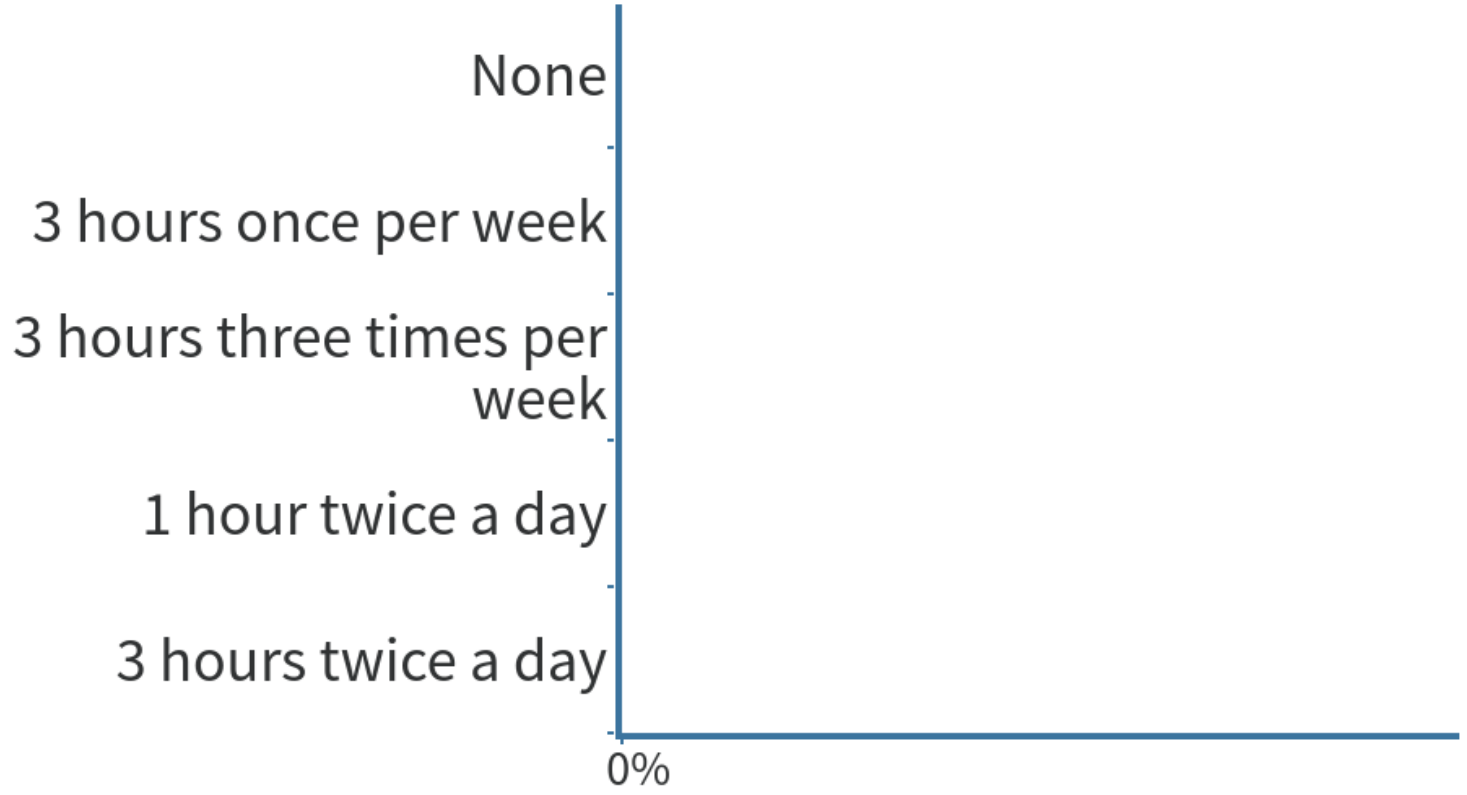

What if Mrs. S. lived alone?

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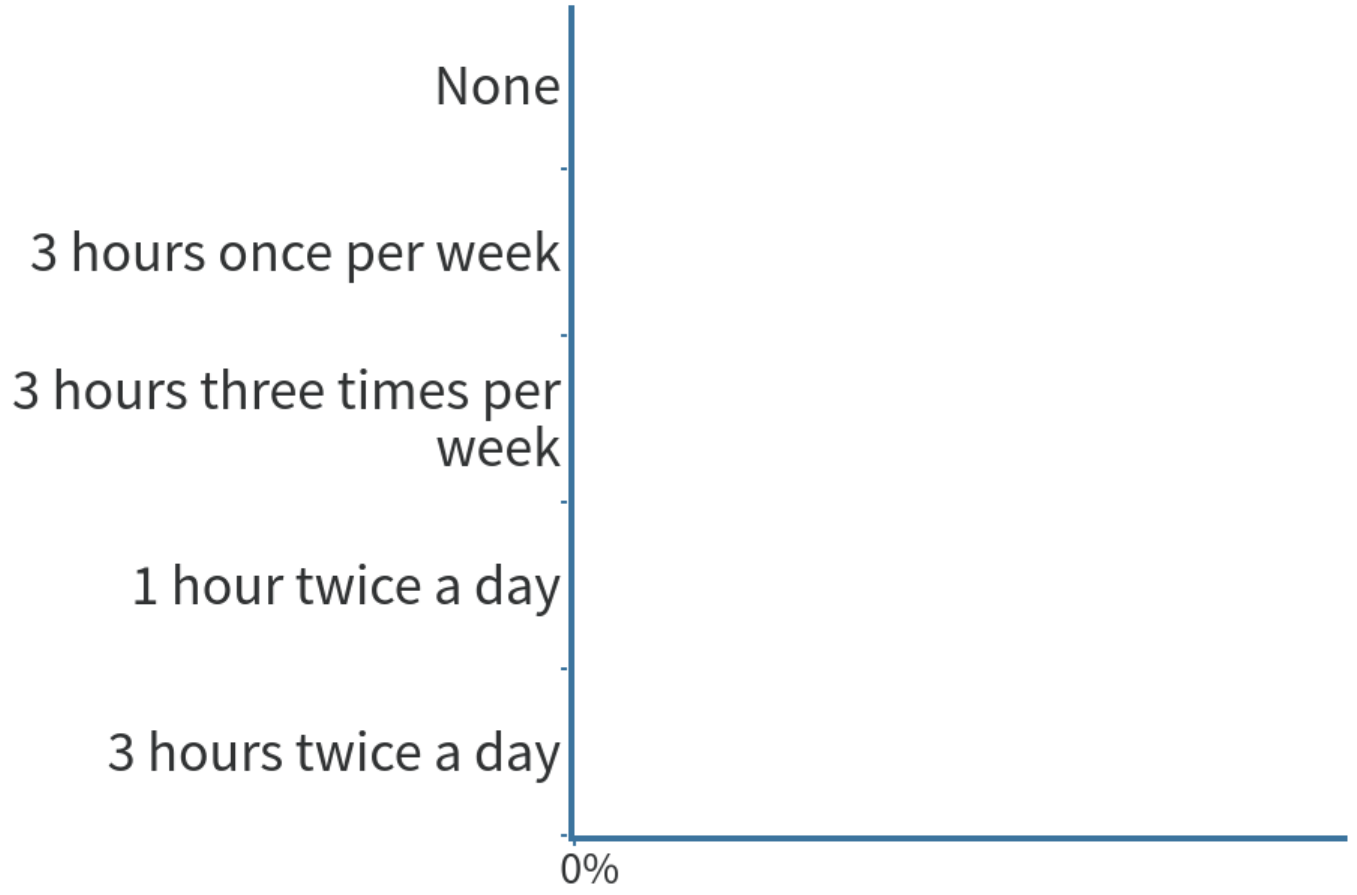

Which of the following characteristics of persons with dementia has the greatest impact on remaining at home?

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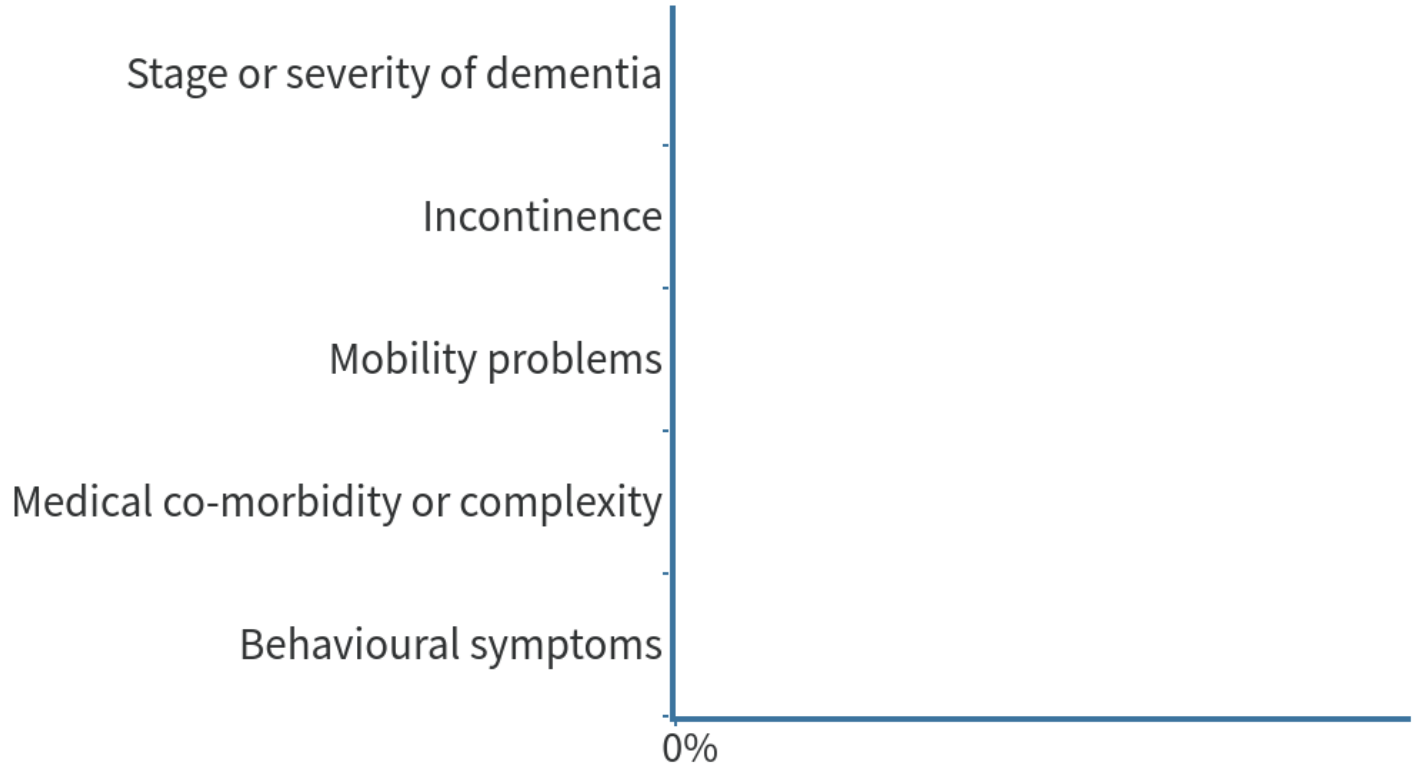

What is the anticipated growth in the number of people with dementia in Champlain LHIN between 2015 and 2020?

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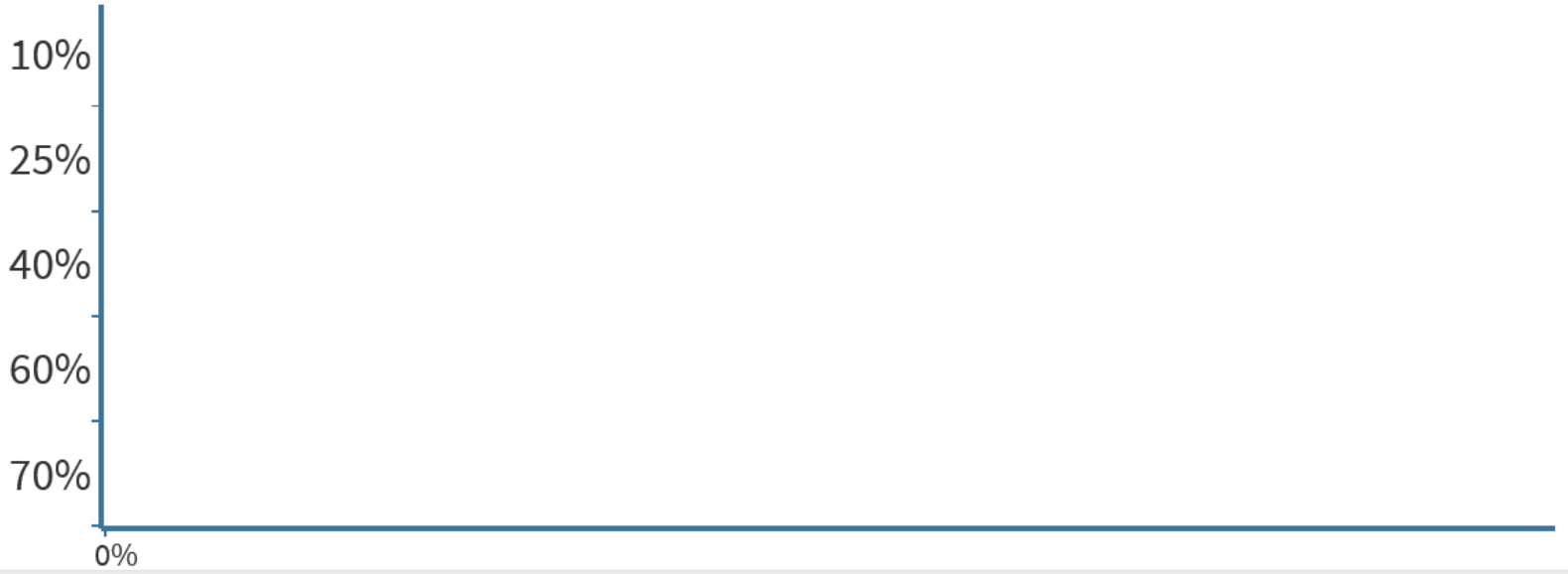

What is the anticipated growth in the number of community-dwelling persons living with dementia who will be on a LTC waitlist between 2015 and 2020 in the Champlain LHIN?

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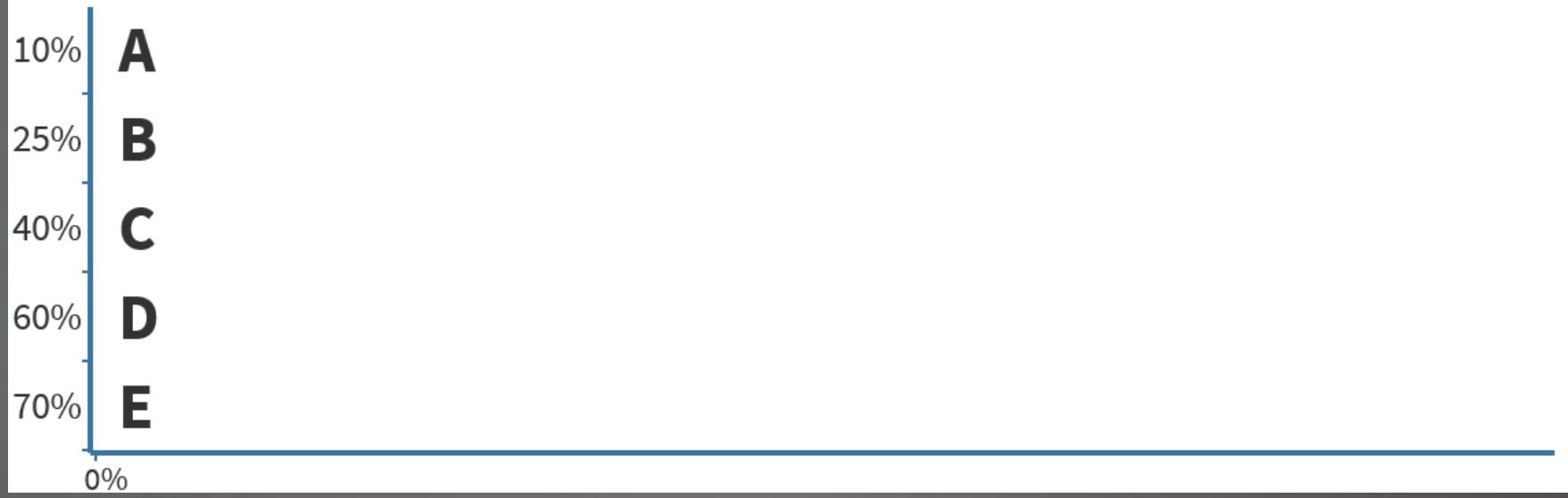
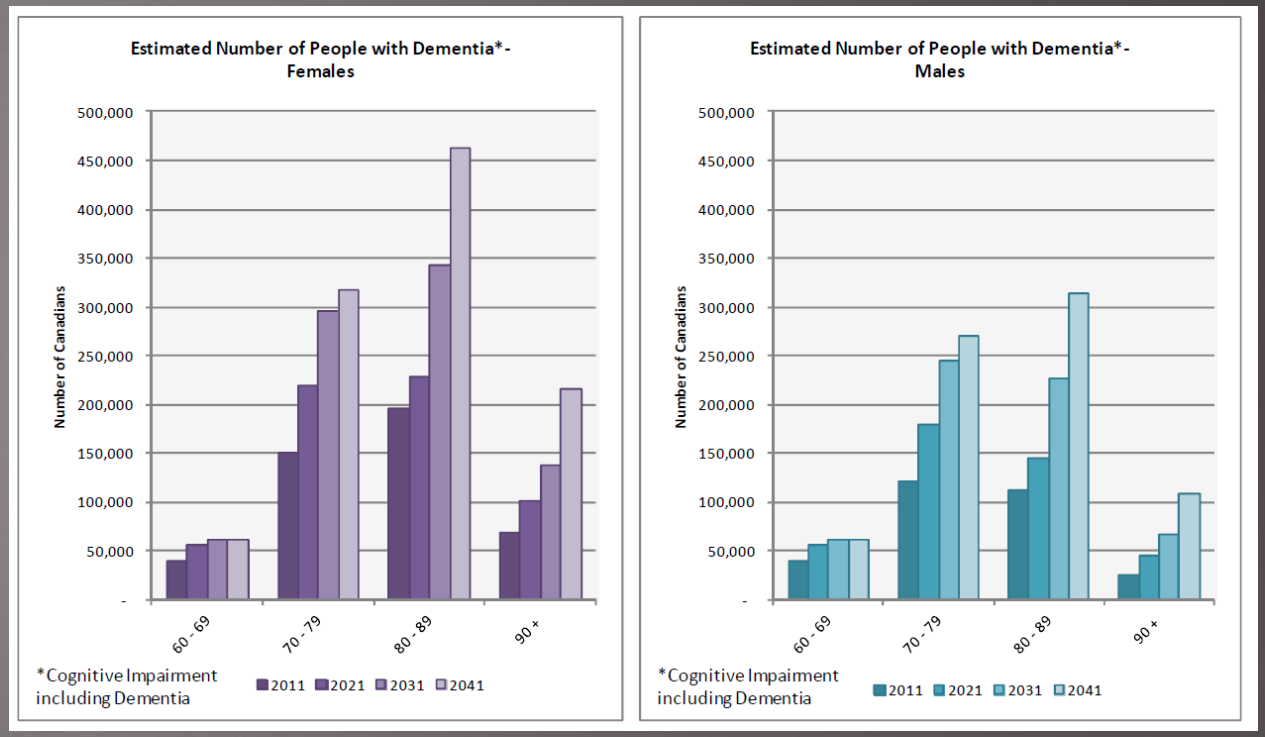


Dementia in Canada

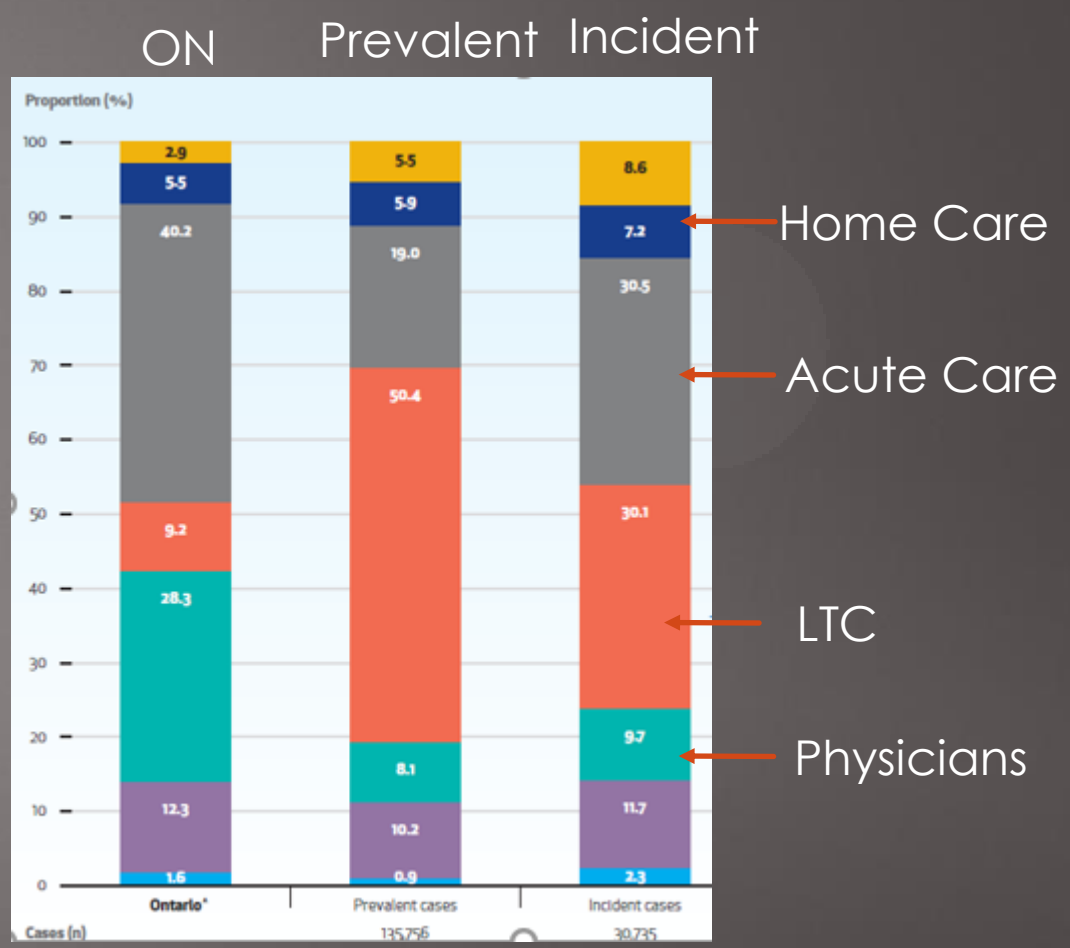
- Populations in Canada are aging
- ~500,000[1,2,3] individuals diagnosed with dementia in Canada
  - 7% of all adults over age 65
- ↑ prevalence to 1.4 million by 2031, 1.8 million by 2041
- Majority of people with dementia live in community



1. Mapping Connections, Health Canada, 2014
2. Alzheimer Society of Canada, 2010
2. RiskAnalytica, 2012

Dementia and Health Services

- Majority of costs associated with dementia related to LTC (50%) and acute care (30%)[1]
- Acute care use by older adults with dementia[2]:
  - ER visits: 40% dementia vs 24%
  - Admissions: 22% dementia vs 10%
- Dementia and alternative level of care[3]:
  - ¼ of all ALC hospitalizations, 1/3 ALC days
  - Median ALC LOS 23 days vs. 10 days



1. Ng, Brain Disorders in Ontario, 2015
2. Bronskill, ICES, 2011
3. Walker, Healthcare Quart, 2009

Economic Impact of Dementia

- Cumulative costs of dementia over next generation in Canada: $872 billion[1]
- Canada, annual total costs: $15 billion → $153 billion by 2031
  - $8 billion direct costs, $5 billion indirect (caregiver) costs
- Informal care in Canada: 230 million hours, 50% in is community settings
- U.S. 17.9 billion hours of unpaid caregiver time (average 20 hours per week) = $217 billion

1. Rising Tide, Alz Soc Canada, 2010
2. Alzheimer Dement, 2015

Health System Costs Associated with Dementia

- Globally: $645 billion annually
- Most developed countries spend 3 to 5% of total health care budget on dementia care
- U.S. direct health care costs (excluding caregiver costs) $226 billion per year[1]
- Total direct healthcare costs in Canada: $8 billion
- Mean and median direct annual costs of services for person with dementia: $29,000, $21,000[2]
  - ~ double that age matched population

OECD, Addressing Dementia

1. Hurd, NEJM, 2013
2. Ng, Brain disorders in Ontario, 2015

‘I shouldn’t have had to push and fight’: health care experiences of persons with dementia and their caregivers in primary care

Jeanette C. Prorok[a,b], Maria Hussain[a,b], Salinda Horgan[a,b] and Dallas P. Seitz[a,b]

Communication

Care Partner as Manager

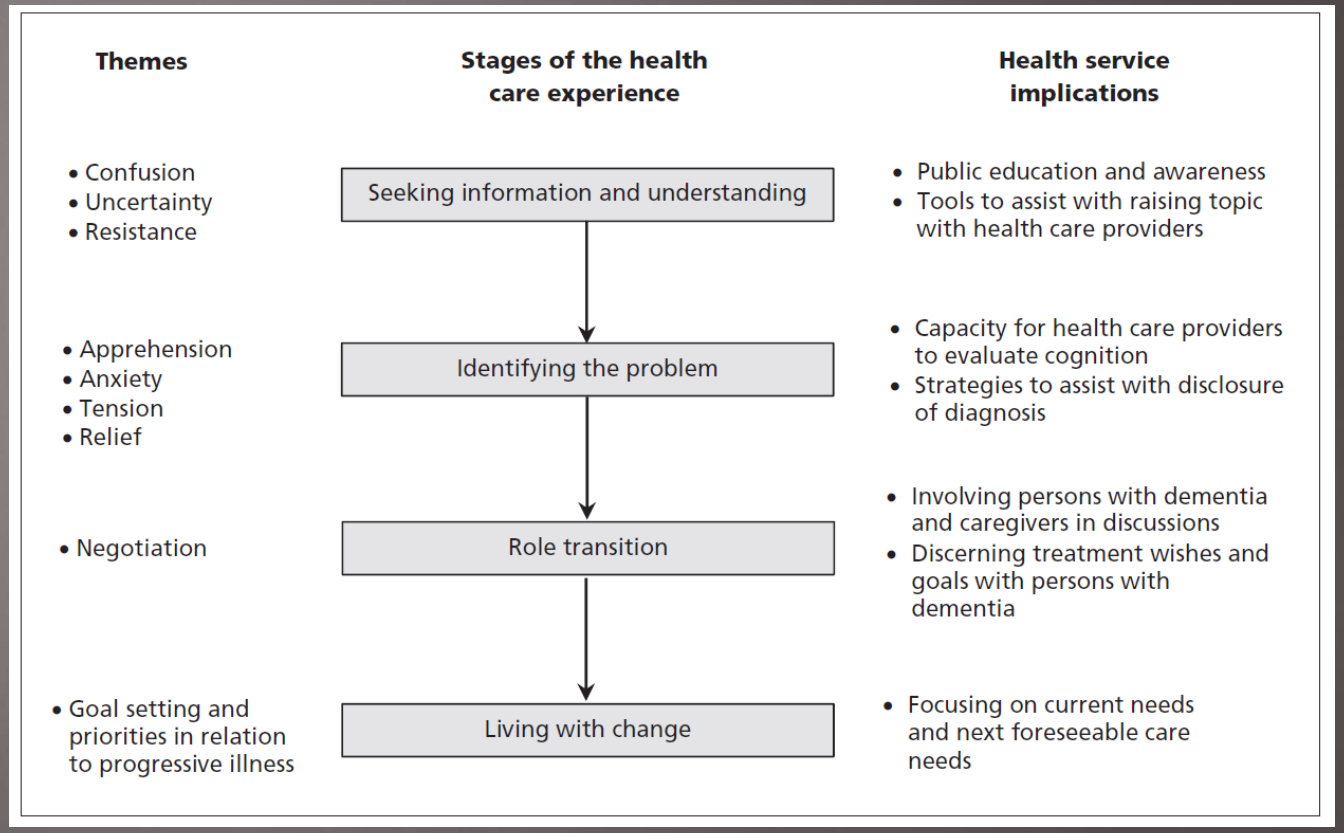
System Navigation

Ease of Access

Theme	Illustrative quotations
Communication	
Manner of communication	*Person with dementia*: ‘It was not really so much the fact of having that diagnosis, it was the way that diagnosis, the information was delivered to me…I felt like I was a criminal in the dark…like I had done something terribly wrong and that’s one of the worst things that I’ve encountered since my diagnosis. It felt punitive.’
Content communicated	*Caregiver*: ‘After we got the test and I find out that she had fourteen out of thirty…That’s it; what does fourteen mean?’ *Caregiver*: ‘They know the information so well themselves. They do it every day but they don’t realize that you don’t know.’ *Caregiver*: ‘I didn’t even know what dementia was.’
Caregiver as manager	
Day-to-day management	*Caregiver*: ‘We put green tape around the telephone handle, the receiver, so he saw the green and he could pick up the receiver and answer the phone. Just little easy marks.’ *Caregiver*: ‘It’s the caregiver group that we come to and say…this is what’s going on and somebody will say, oh this is what’s going for me or worked for me or not worked for me. This is our connection; my lifeline.’
Long-term management	*Caregiver*: ‘It’s not just the caring and nurturing and all that, it’s like where’s the money coming from if he has to go in somewhere.’ *Caregiver*: ‘I really feel like I’ve been jerked by the (LTC) administration. I really feel like they’ve bled me dry. There’s nothing left now so I don’t know what the future’s going to bring.’
Managing self	*Caregiver*: ‘Dealing with the guilt of what I’ve done and I haven’t done anything but you know, I put her in a nursing home. I sold her home…It almost destroyed me.’ *Caregiver*: ‘We’re standing here rapping on the doctor’s door saying, I need help! I cannot give this up but I cannot do this by myself.’ *Caregiver*: ‘I’m not doing right and I’m not good enough and I’ll never be able to do this because I can’t manage all of this. It’s too much.’
System navigation	
‘Point person’ necessary	*Caregiver*: ‘It’s almost as if once a diagnosis is made, if it’s communicated, there should be a person, it may not be the physician because of time, there should be a person to sit down with the diagnosed person and the family and has those resource list and just says “We’re going to bridge the gap and you need to go.” You know that little step is missing.’ *Caregiver*: ‘I’m dying for somebody to say to me, some sort of mechanism where we can get into the system.’
Prolonged path to resources and supports	*Person with dementia*: ‘I’ve yet to be even put on a list.’ *Caregiver*: ‘It was 9 months to a year before my mom was actually seen.’ *Caregiver*: ‘Getting the assessment took a long time until we went through a back door, which annoyed our doctor, which then we had a bad relationship with him after that.’
Ease of access	
Necessary push by persons with dementia and caregivers	*Person with dementia*: ‘I really had to push and push and push for that referral…I shouldn’t have had to push and fight for that.’
Timing	*Caregiver*: ‘I think an earlier diagnosis would have probably been helpful.’ *Caregiver*: ‘You can tell that there’s a bit of quickness that has to happen and I don’t think that’s the best environment for communication for someone who’s got dementia or Alzheimer’s.’ *Caregiver*: ‘She made it very clear you know, you have this half hour.’ *Caregiver*: ‘He (family physician) may not be seeing the symptoms with the five, ten minute time slot that he’s got with this particular patient.’
Provider knowledge	*Person with dementia*: ‘She didn’t know what to do; how to deal with me. She didn’t have the knowledge.’ *Person with dementia*: ‘We’re barking up the wrong tree here.’ (Referring to physician focusing on physical symptoms) *Caregiver*: ‘The doctor really just said when he (spouse) said “Do you think maybe I’m getting Alzheimer’s or something?” He said, “Oh, no no, you’re too young.”’

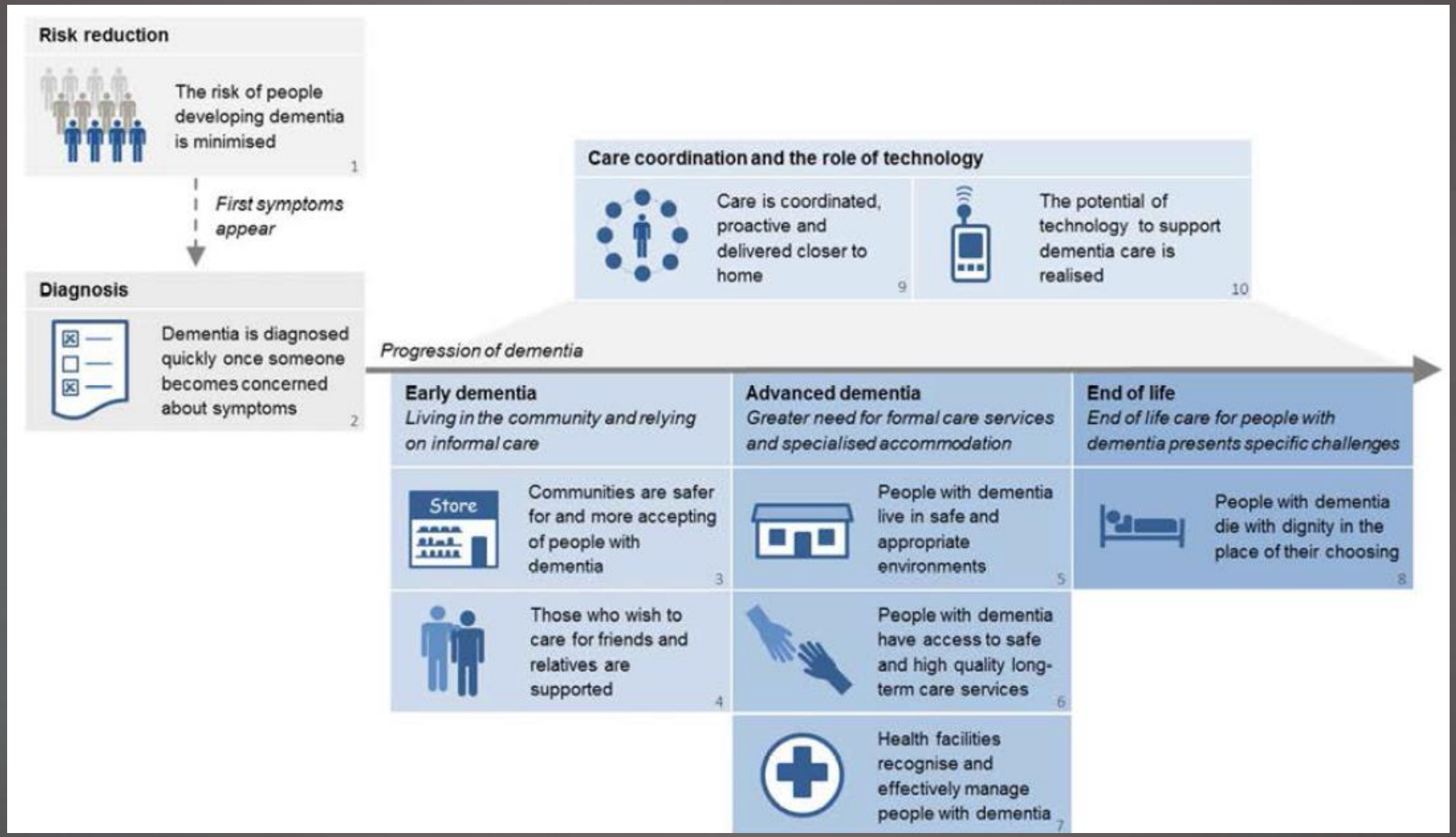
Health Care Experiences of Persons with Dementia

- Meta-ethnography of qualitative studies evaluating health care experience of persons with dementia and care providers
- Themes:
  - Seeking a diagnosis
  - Accessing supports and services
  - Addressing information needs
  - Disease management
  - Communication and attitudes



Prorok et al., CMAJ, 2013

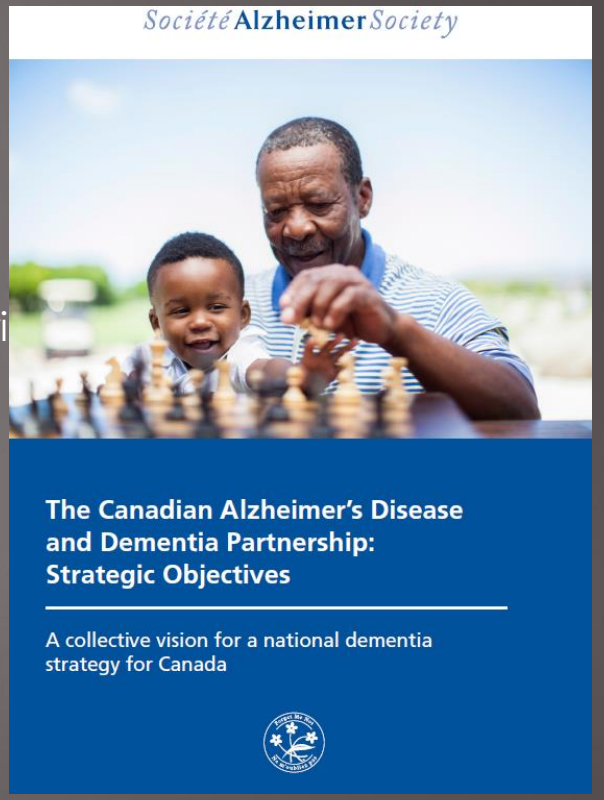
Framework for Dementia Policy



OECD, 2015

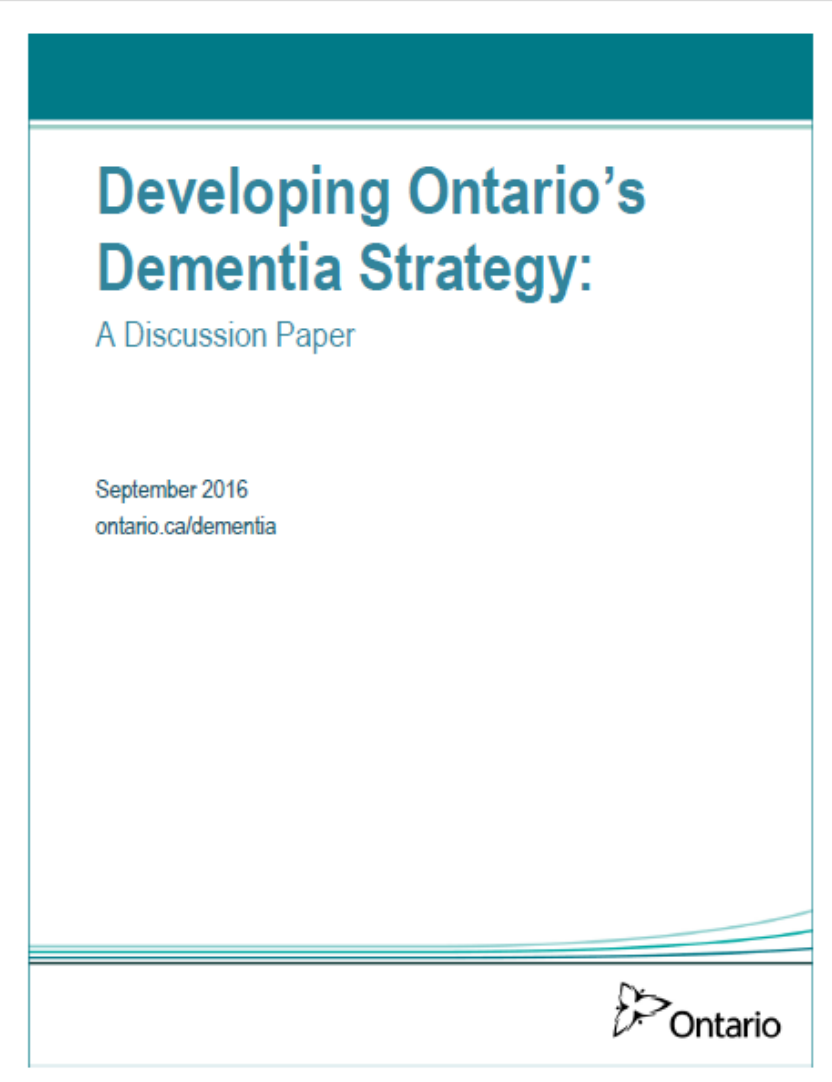
Canadian Alzheimer's Disease and Dementia Partnership

- 1. Research:
  - Support key research initiatives (CCNA, SPOR)
  - Develop national standards for care based on evidence
- 2. Prevention
  - Develop and adopt targets for dementia screening (75% screening at ri
  - Support "Dementia Friends" – businesses and employers
  - Public awareness campaign to promote prevention, reduce stigma
- 3. Living well with Dementia
  - Improve caregiver leave benefits
  - CME programs for dementia care
  - Curriculums for health care professional training programs
  - First Link programs
  - Go to hubs for evidence based practice and virtual collaborations



Alzheimer Society Canada, 2015

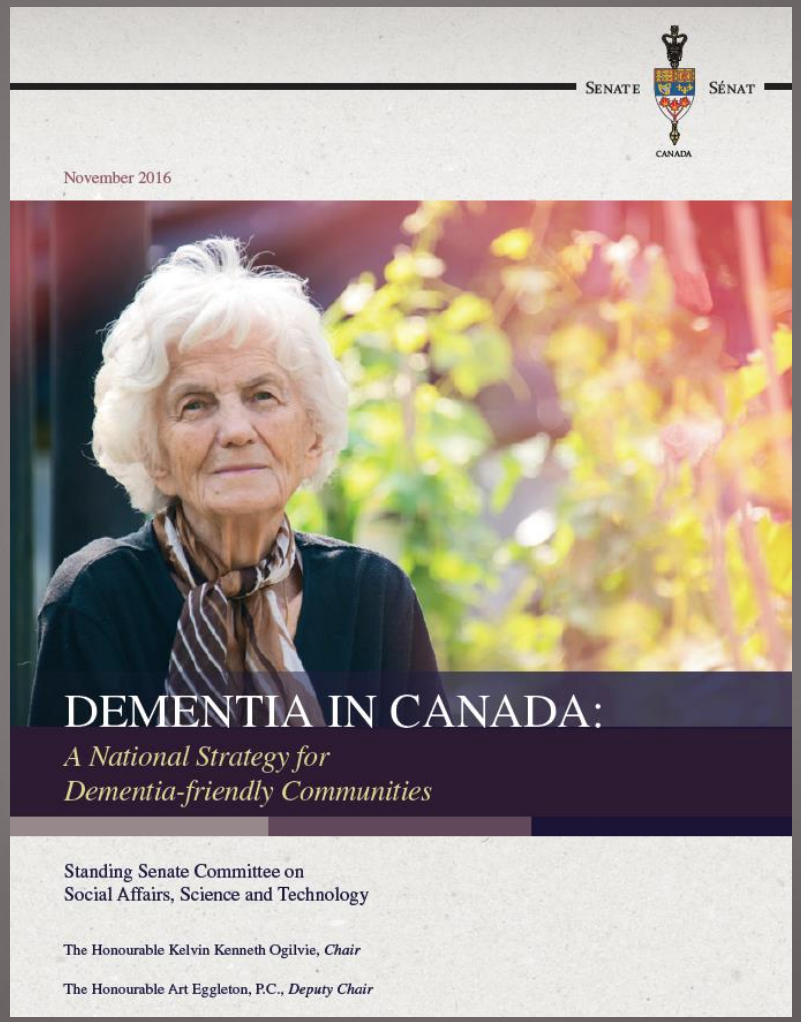
Ontario Dementia Strategy



1. Supports for People Living with Dementia
2. Accessing Dementia Services
3. Coordinated Care
4. Supports for Care Partners
5. Well Trained Dementia Workforce
6. Awareness Stigma and Brain Health

https://www.ontario.ca/page/developing-ontarios-dementia-strategy-discussion-paper

Senate Committee Report



Dementia Capacity Planning Project

Partnership between Cancer Care Ontario, MOHLTC, Institute for Clinical Evaluative Sciences, Ontario Brain Institute (September 2015 – March 2017)

Vision: Support persons living with dementia at home and in the community safely, as long as possible

Dementia Capacity Planning Project

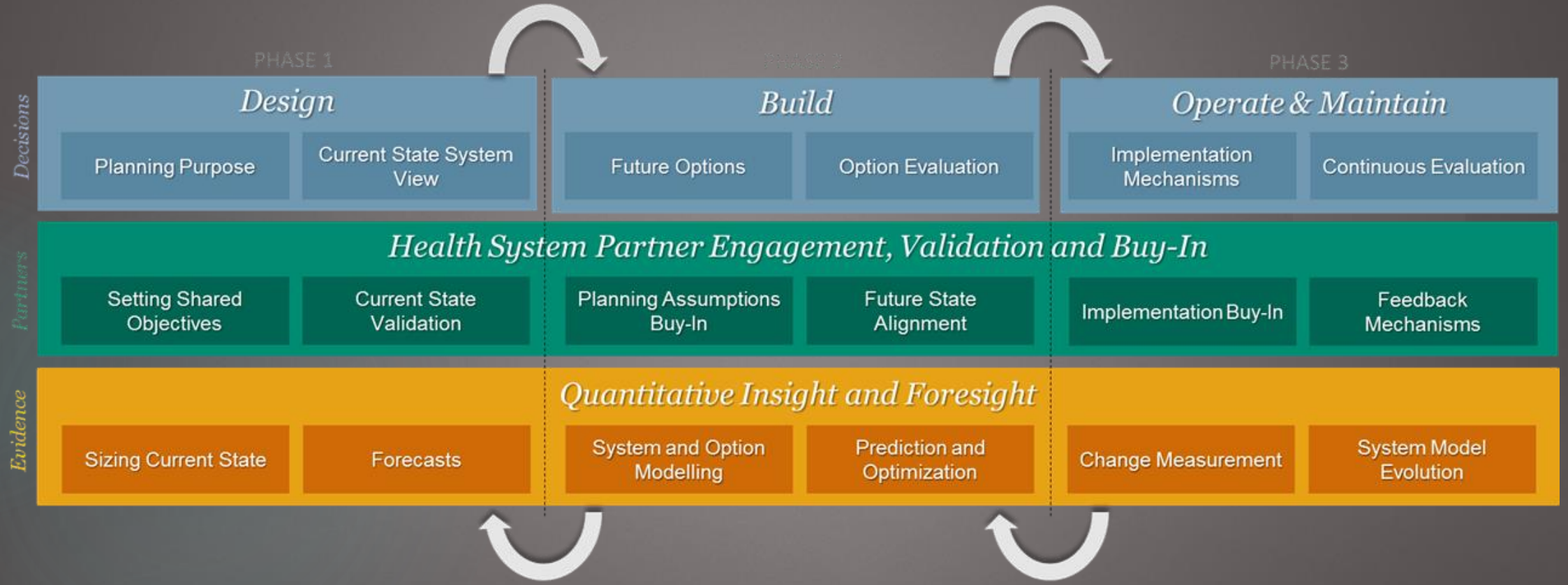
Purpose:

- To establish a planning framework, processes and tools to address the needs of persons living with dementia and care partners
- Capacity planning implications for the Dementia Strategy

Ou

1. Scenario analysis informed by quantitative and qualitative research and ongoing engagement with health system partners with system and lived experience (What are some of the best ways to help?)
2. Knowledge transfer and exchange plan to inform future population-based planning activities within the MOHLTC (How can this be used in Ontario?)

Framework for Dementia Capacity Planning

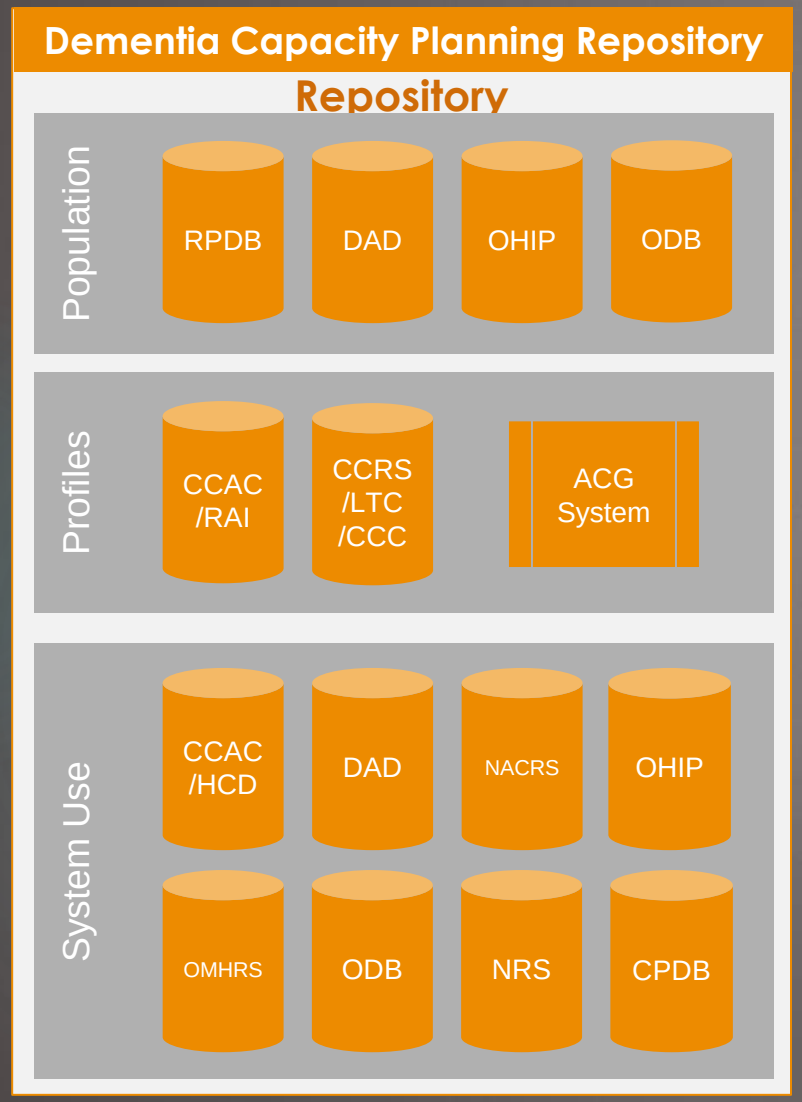


Dementia Capacity Planning Model

- Understanding the current state of persons with dementia and caregivers using administrative data and qualitative data
- Develop model to simulate future state
- Identify current actual needs of persons with dementia, care partners from multiple perspectives
- Develop "what if" scenarios – changes to supports and services based on evidence
- Evaluate the impact of possible scenarios on outcomes
  - E.g. Time able to remain in community, caregiver stress, costs, use of community services

Establishing the Current State

What does our current population look like?

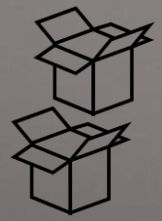


Population

- Who are the persons living with dementia?
- Where are they?
- How long since they were physician diagnosed?

Profiles

- What are the cognitive, functional and clinical characteristics of persons living with dementia?
- Are there subgroups that require attention?



System Use

- What is the current resource utilization patterns?
- What are health system transition trends?

Identifying Persons with Dementia

Approach:

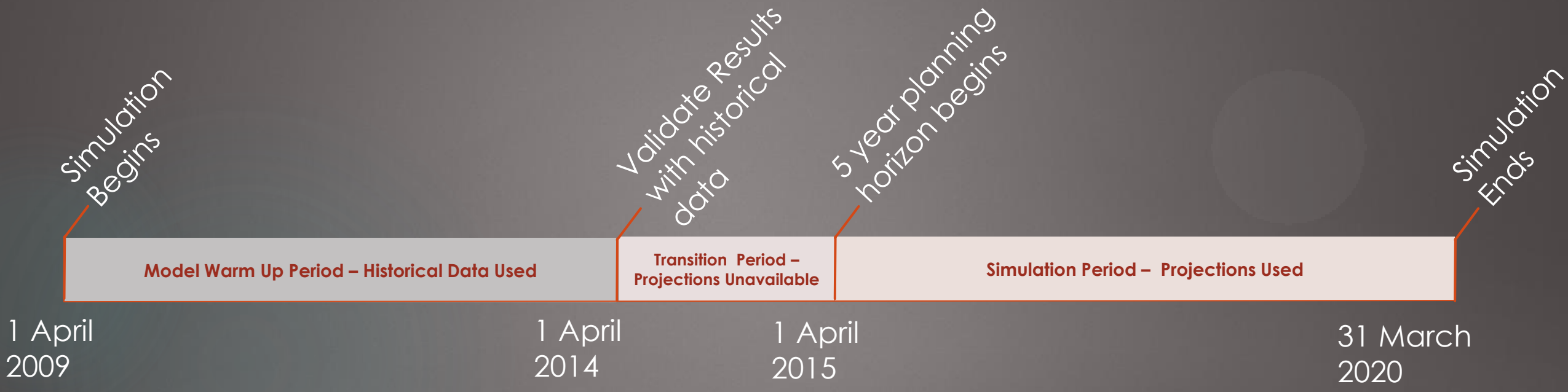
This number is based on meeting the following criteria from clinical/administrative datasets:

i. 1 hospitalization record from DAD or
ii. 3 physician claim records at least 30 days apart in a 2-year period from OHIP or
iii. 1 prescription drug reimbursement record from ODB for cholinesterase inhibitor

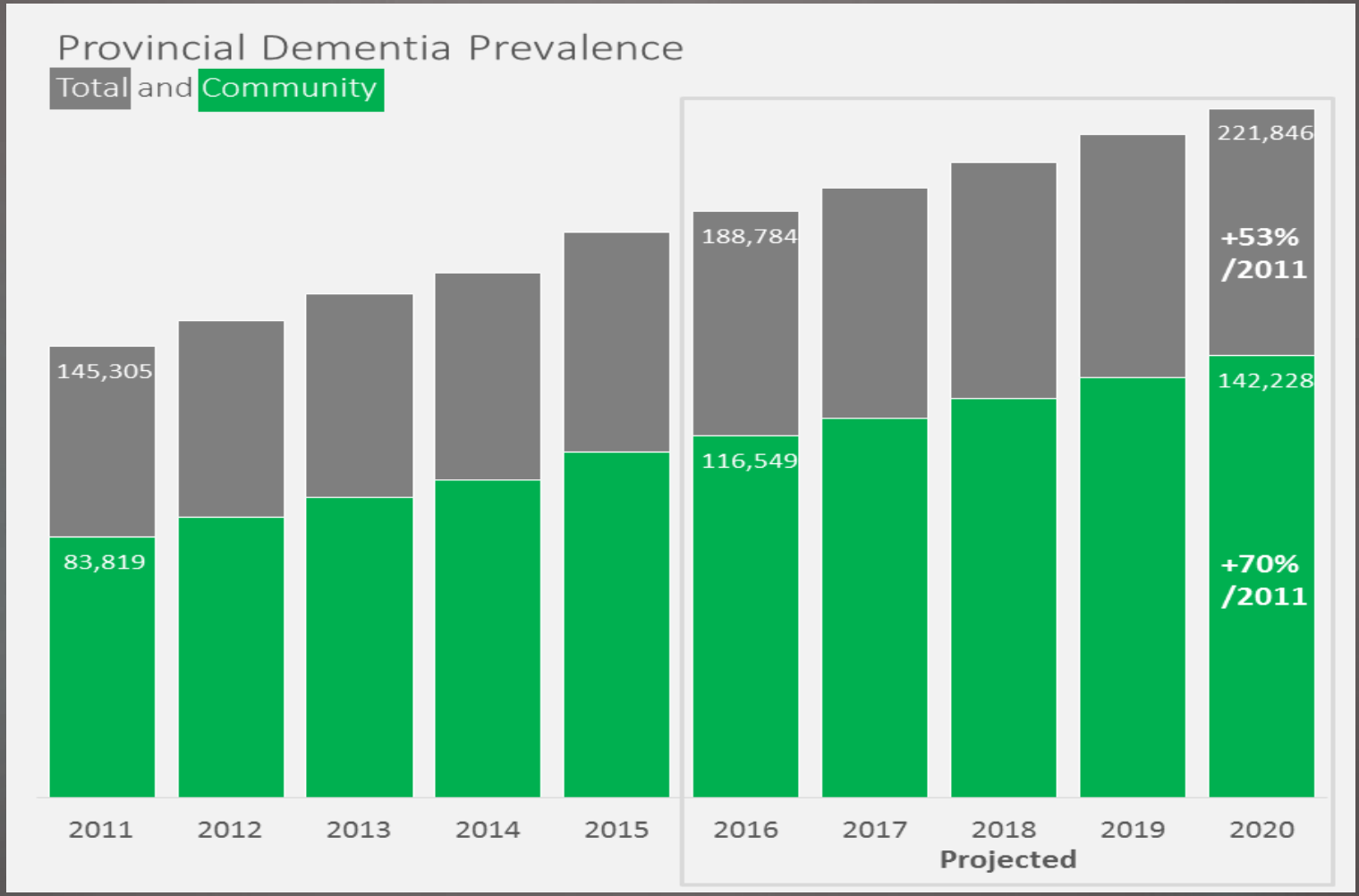
Performance:

Measure	Value (with 95% Confidence Intervals)	Meaning
Sensitivity	79.3 (72.9 – 85.8)	Algorithm will correctly flag dementia for 79.3 of the 100 individuals who have dementia
Specificity	99.1 (98.8 – 99.4)	Algorithm will correctly avoid flagging dementia for 99.1 of the 100 individuals who don't have dementia
Positive Predictive Value	80.4 (74.0 – 86.8)	For every 100 people flagged with dementia, 80 truly have dementia
Negative Predictive Value	99.0 (98.7 – 99.4)	For every 100 people not flagged with dementia, 99 truly don't have dementia

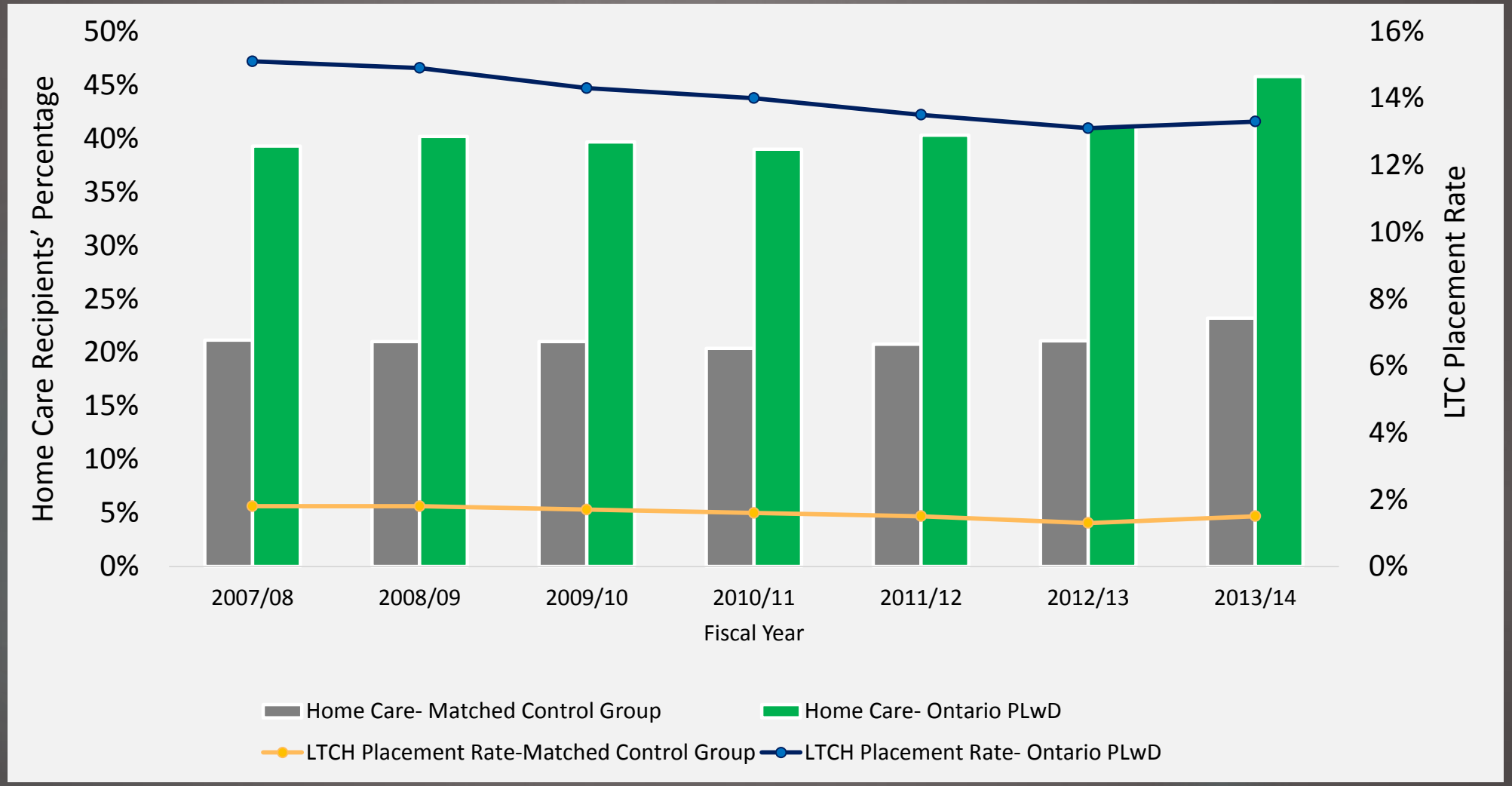
Modelling Changes to Dementia Care



How many people are living with dementia in Ontario?

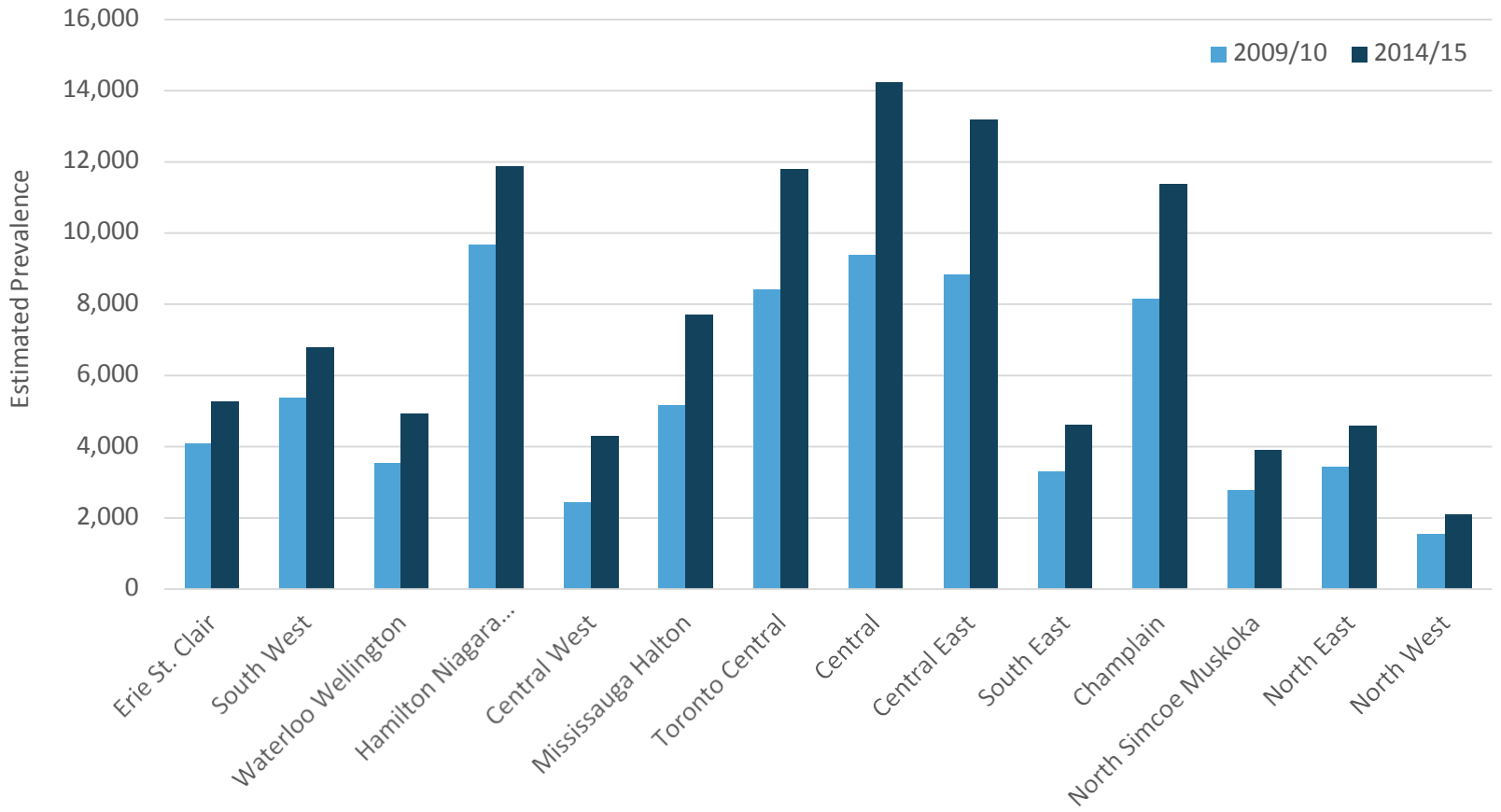


What supports and services do people with dementia currently use?



How many people in the community need support?

Change in Number of Community Dwelling PLwD (2009/10 and 2014/15)



Provincially, the community dwelling population has grown from 76,416 to 106,940 from 09/10 to 14/15 (+40%).

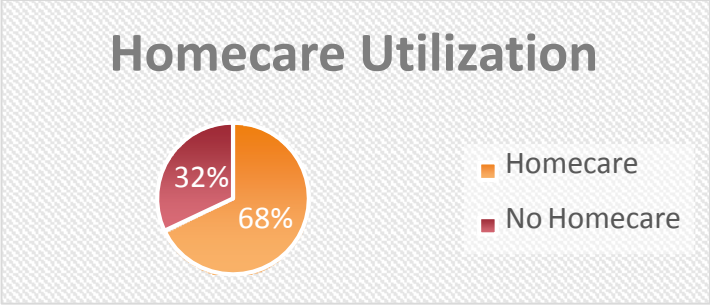
North West LHIN has the smallest community dwelling population (2,094) and Central LHIN has the largest community dwelling population (14,219).

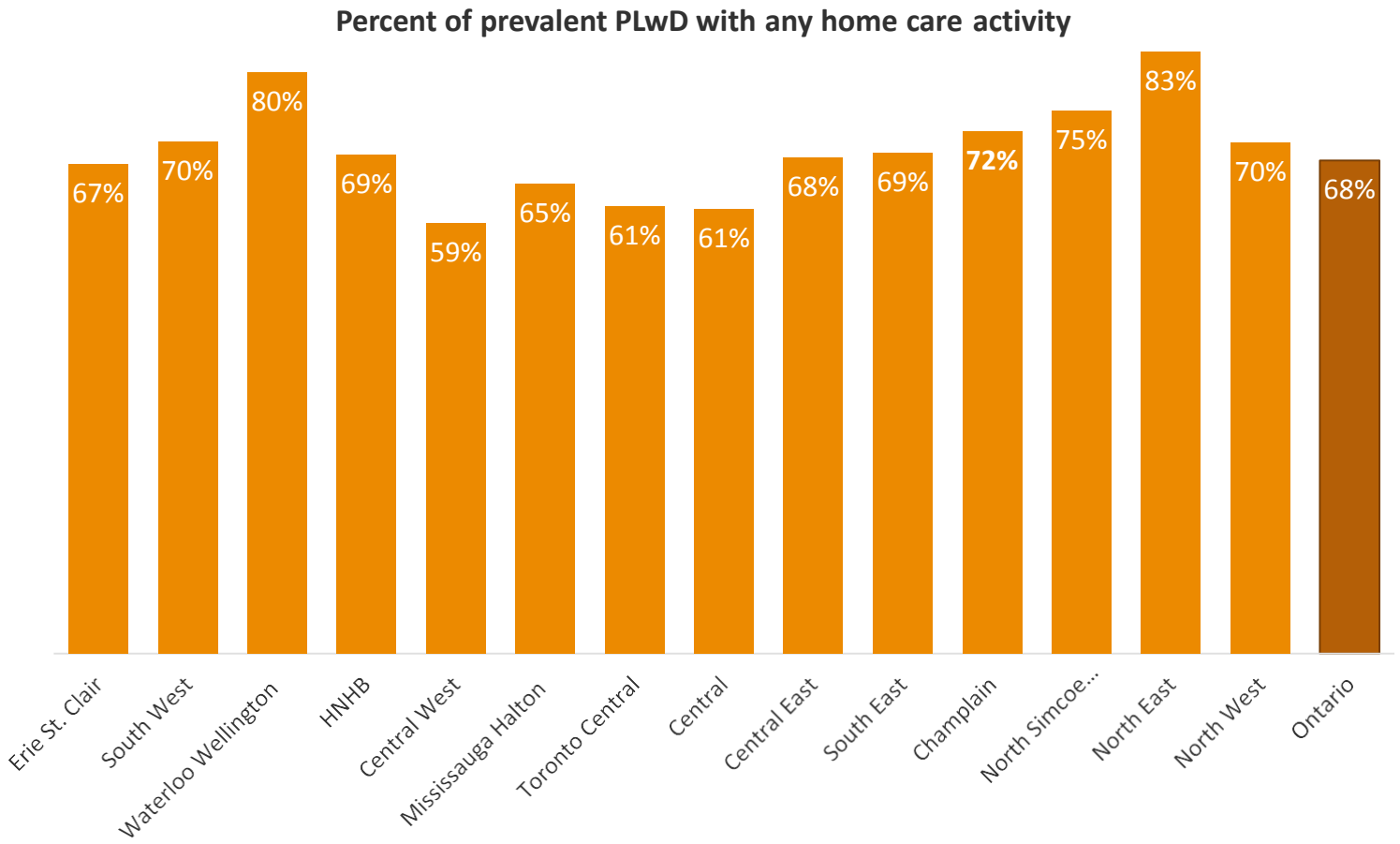
The highest growth was seen in Central West LHIN (+77%) and lowest growth was seen in HNHB (+23%).

Note: All results are preliminary, and should not be used for decision-making.

Who is receiving any support?

Homecare Utilization by Community Dwelling PLwD





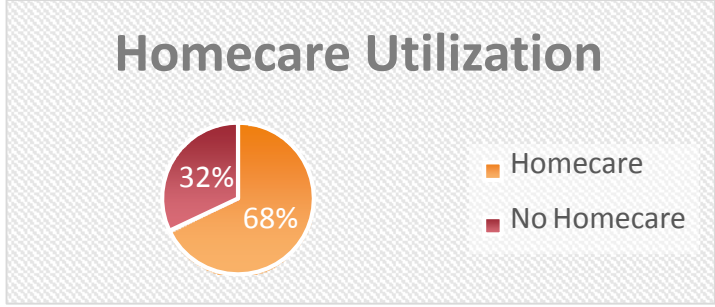
In 14/15, 68% (71,990 PLwD) of the community dwelling dementia population received homecare. This varies across regions.

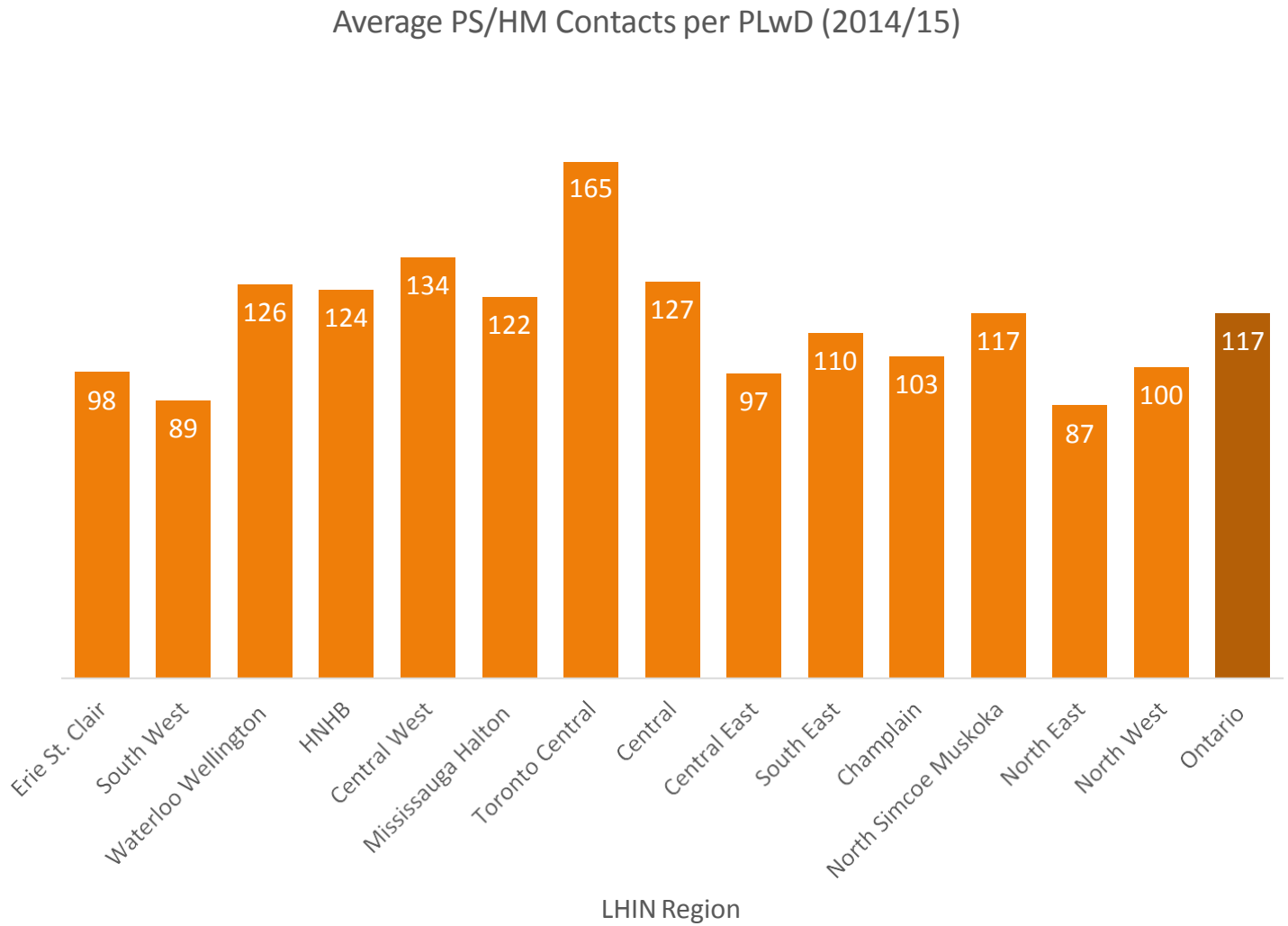
The highest homecare utilization occurs in the North East LHIN (83%) and the lowest homecare utilization occurs in Central West LHIN (59%).

Note: All results are preliminary, and should not be used for decision-making.

How much support is currently provided?

Use of Personal Services by PLwD in the Community



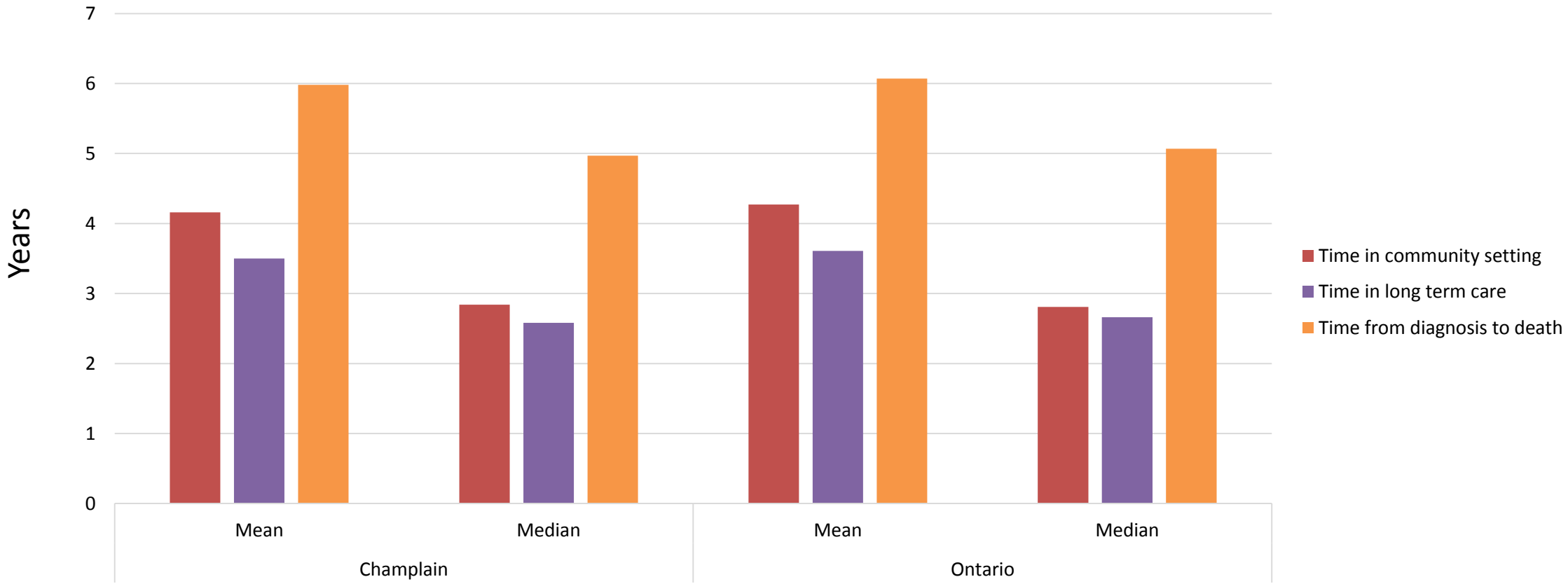


Of the 71,900 community dwelling PLwD receiving homecare provincially, on average they received 117 PS/HM contacts per PLwD in 2014/15 (or ~2 contacts per week).

The highest number of contacts per PLwD were delivered in the Toronto Central LHIN (165) and the fewest number were delivered in the North East LHIN (87).

Note: All results are preliminary, and should not be used for decision-making.

How much time do persons living with dementia spend in the community?



SIMULATION MODELLING TO UNDERSTAND THE FUTURE

CHAMPLAIN LHIN CASE STUDY

Future State

What does dementia in Ontario look like in five years according to status quo scenario?

Status quo scenario projects how the dementia cohort and associated system use may change to 2020/21 given:

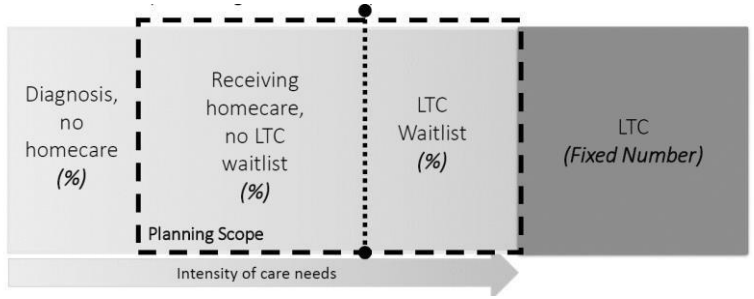
Physician Diagnosed Population: Incidence trends at the sub-LHIN level observed from 2009/10 to 2014/15 continue into the future, allowing for 10% and 20% uncertainty in case ascertainment

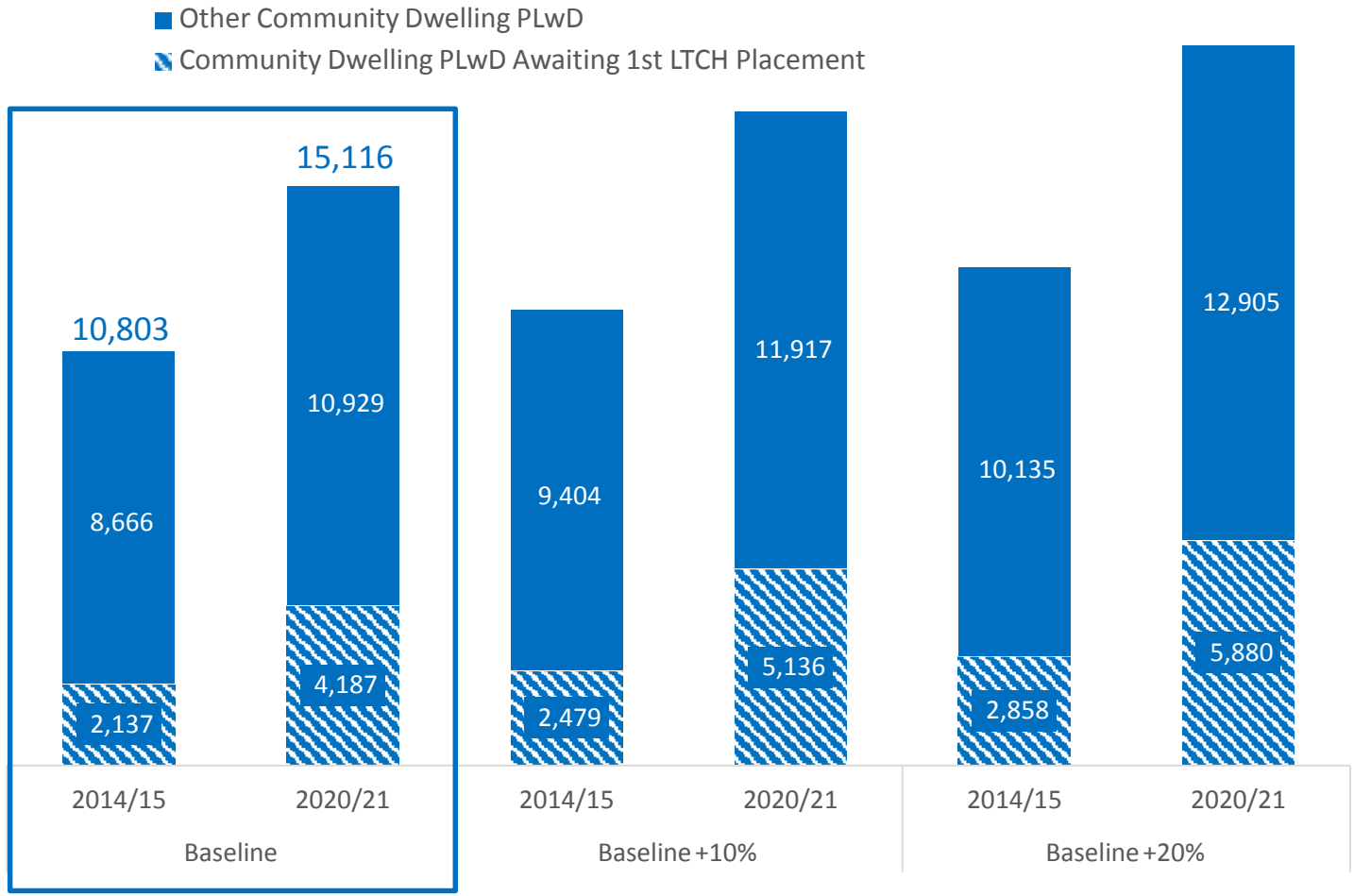
Transitions: Healthcare status transitions follow historical rates and LTCH capacity remains fixed at the 2014/15 level

Utilization: Health service consumption rates at 2014/15 levels

Status Quo Scenario | Champlain

How many people will be living with dementia?



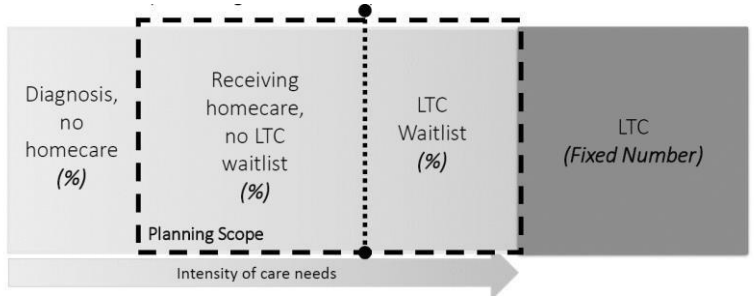


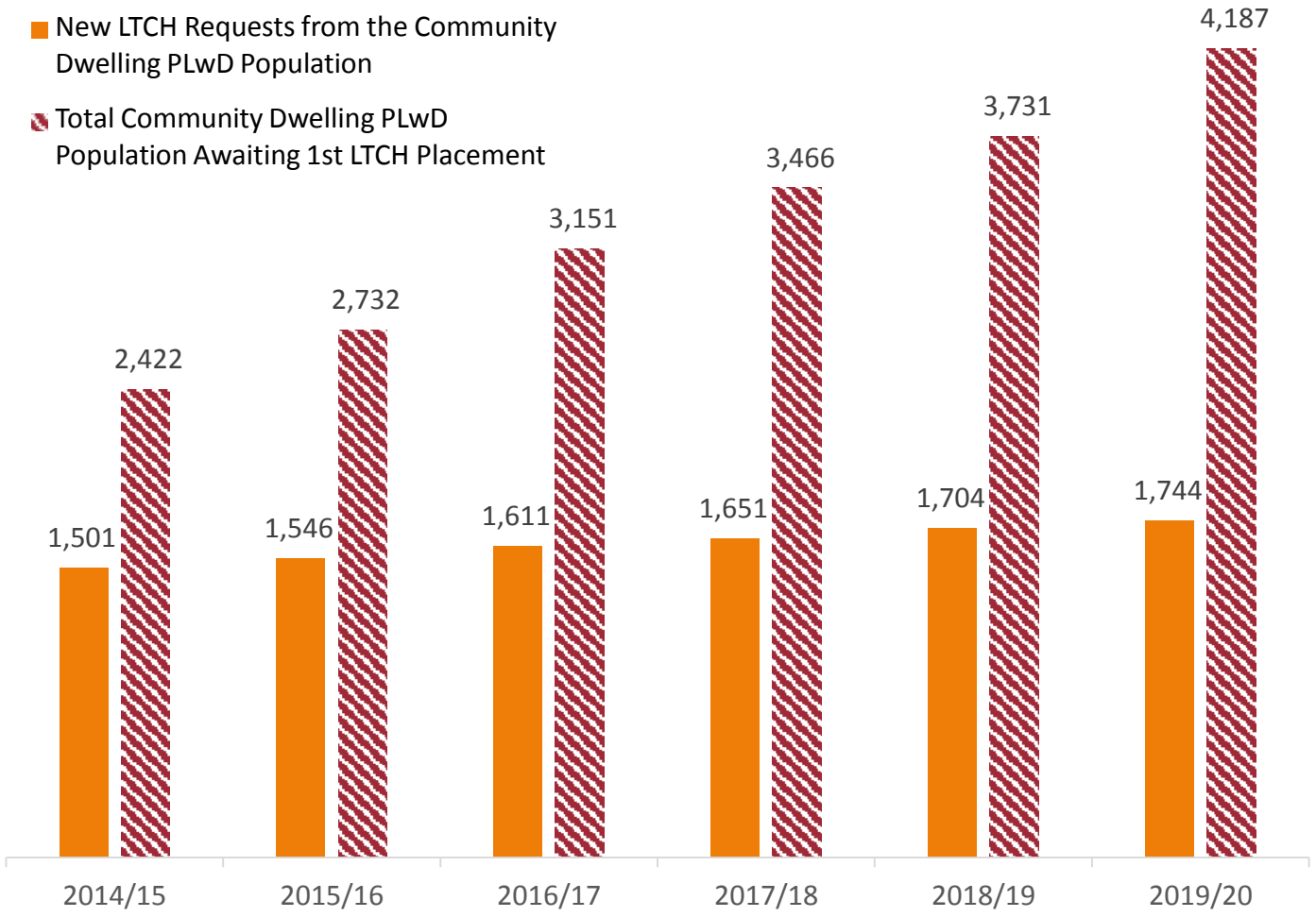
Baseline projections indicate that from 2015 to 2020, total community dwelling population may increase from 10,803 to 15,116 (+40%)

Note: All results are preliminary, and should not be used for decision-making.

Status Quo Scenario | Champlain

Long-Term Care Requests and Waitlists





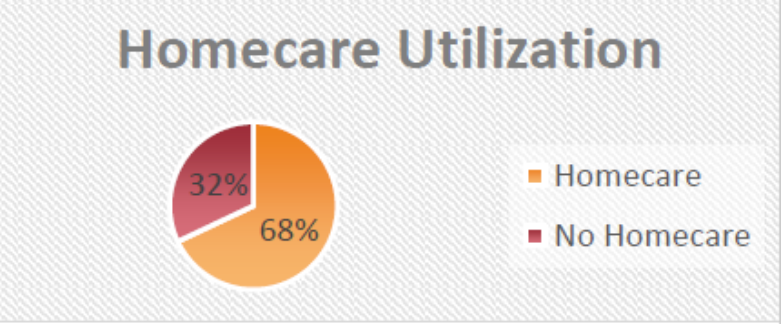
PLwD LTCH requests in Champlain will increase only by 16% over the projection horizon, however, fixed LTCH bed capacity and transitions out of LTCH will cause those **waiting for first LTC placement to increase by 73%**

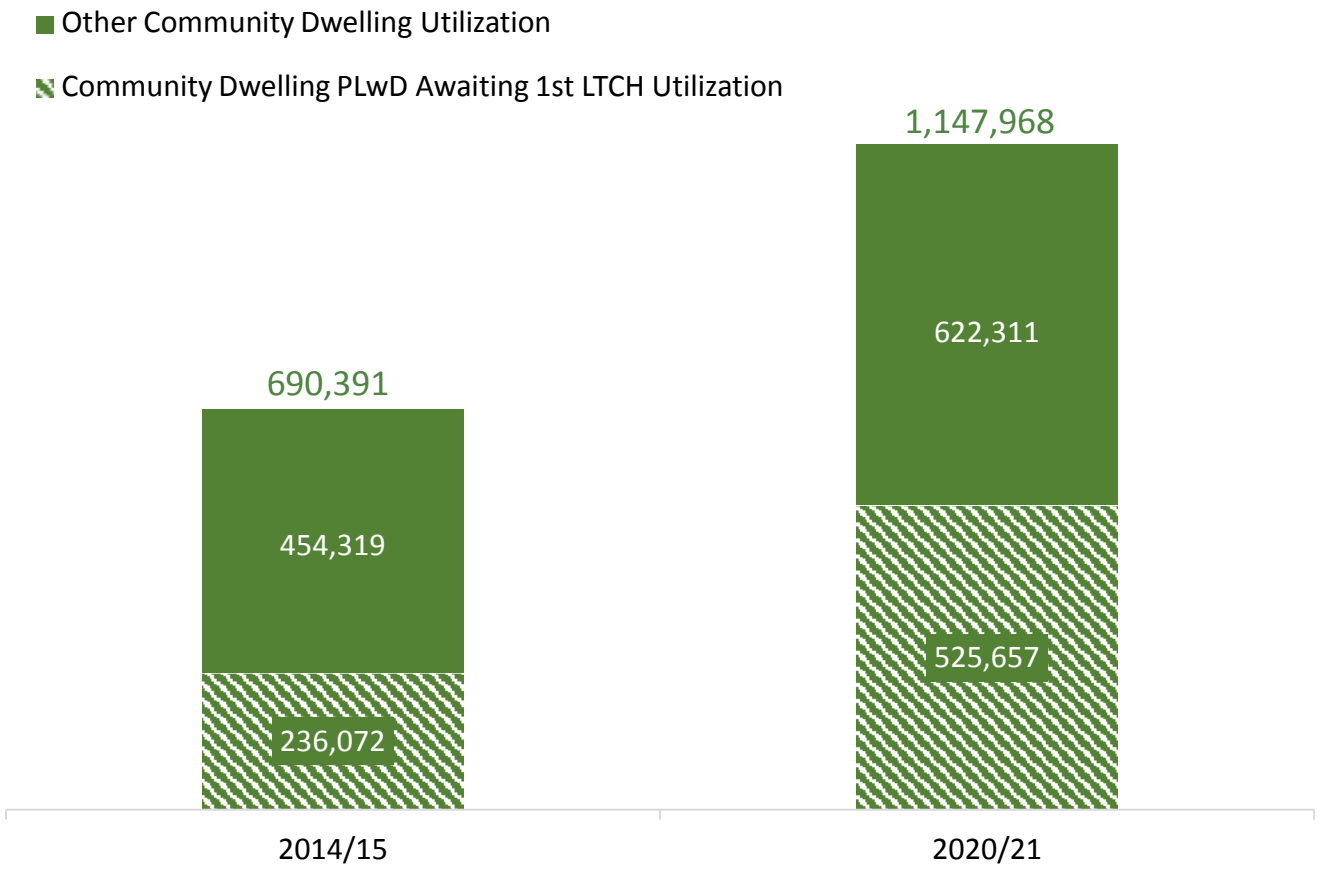
*The analysis on this slide assumes baseline population projections.

Note: All results are preliminary, and should not be used for decision-making.

Status Quo Scenario | Champlain

What is the expected increase in CCAC supports required?





If Champlain's 2015 CCAC utilization rates continue to 2020, Champlain LHIN can expect a 66% increase in the use of CCAC services by 2020 for persons living with dementia.

*The analysis on this slide assumes baseline population projections.

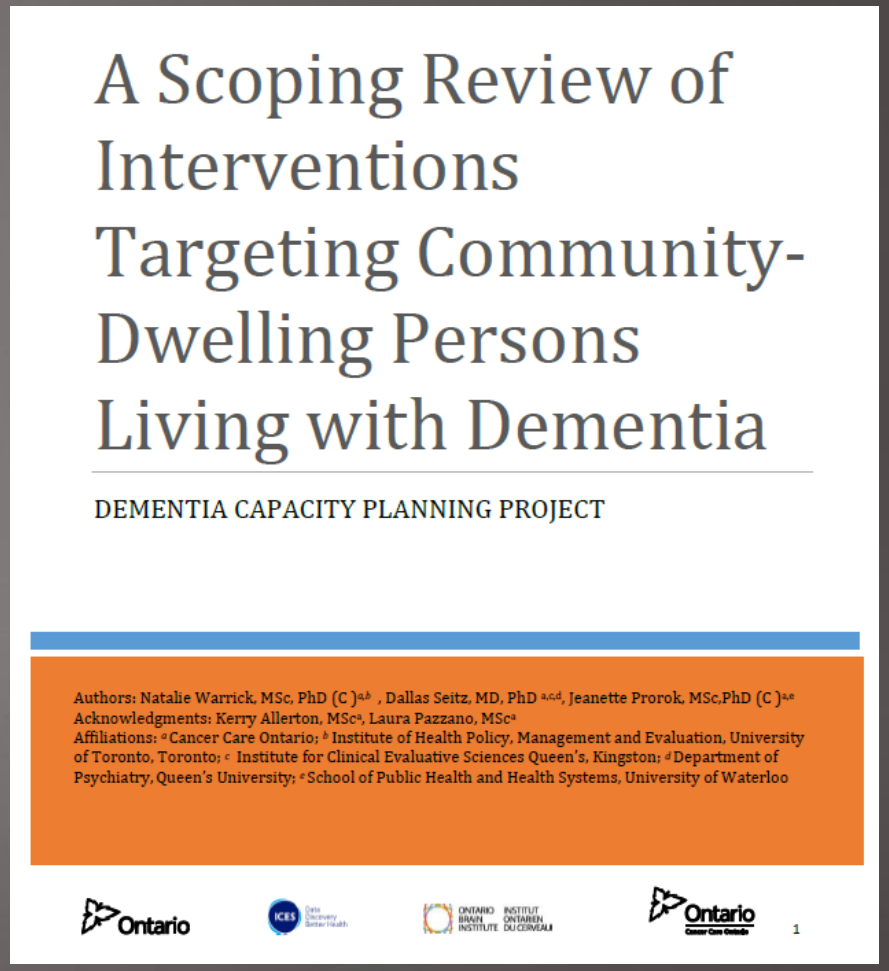
Note: All results are preliminary, and should not be used for decision-making.

Identifying Strategies to Help Support Living in the Community

- Evidence from health partner engagement, clinical advisory committee
- Scoping literature review to identify priority areas
- Setting: Individuals with dementia living in the community
- Context: current availability and potential for scaling up, alignment with relevant MOHLTC (e.g. Patients First, Dementia Strategy)

What might help better support people at home?

- Scoping review of interventions to support persons with dementia
- Outcomes:
  - Impact on supporting people at home longer
  - Benefits for persons living with dementia (functioning, behaviours)
  - Impact on care partners (stress, burden)
  - Economic evaluation
  - Other health system outcomes (e.g. hospitalization)



A Scoping Review of Interventions Targeting Community-Dwelling Persons Living with Dementia

DEMENTIA CAPACITY PLANNING PROJECT

Authors: Natalie Warrick, MSc, PhD (C)[a,b] , Dallas Seitz, MD, PhD [a,c,d], Jeanette Prorok, MSc,PhD (C)[a,e]
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Affiliations: [a] Cancer Care Ontario; [b] Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto; [c] Institute for Clinical Evaluative Sciences Queen's, Kingston; [d] Department of Psychiatry, Queen's University; [e] School of Public Health and Health Systems, University of Waterloo

Ontario ICES Ontario Brain Institute Institut ontarien du cerveau Ontario

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Capacity Planning Modelling Scenarios Initial Priority Areas

- Programs currently funded by MOHLTC
  - Care Partner Education and Support
  - In-Home Respite
  - Adult Day Programs
  - Institutional Respite
  - Comprehensive Community Supports (combinations of the above)
- Optimization of current resources, reducing variation in home care utilization in province

Evidence for Dementia Services

Service	*Support People at Home Longer*	*Improved Caregiver/Patient QoL*	*Costs*	*Hospitalizations*
Care Partner Education and Supports	Strong evidence in favor (1A)	Strong evidence in favor (1A)	Strong evidence in favor (1A)	NA
Day Programs	Weak evidence in favor (2B)	Strong evidence in favor (1B/1C)	Weak evidence in favor (2B/2C)	NA
In-home Respite	Weak evidence in favor (2C)	Strong Evidence in favor (1B/1C)	Weak evidence in favor (2B/2C)	NA
Institutional Respite	Weak evidence against (2A)	Weak evidence against (2B)	Weak evidence in favor (2B/2C)	NA
Comprehensive In Home Support	Strong evidence in favor (1A)	Weak evidence in favor (2B)	Weak evidence in favor (2B)	Weak evidence in favor (2B)

Future Scenario Planning

- Other scenarios for literature and evidence review:
  - Specialty services (e.g. geriatric psychiatry, geriatric medicine, neurology)
  - Primary Care, Care Provider Education
  - Care Management or Care Coordination
  - Rehabilitation
  - Pharmacological and Nonpharmacological Treatments (e.g. cognitive training)
- Impact of changes to dementia detection and diagnosis (e.g. earlier diagnosis)
- In-hospital services and acute care utilization

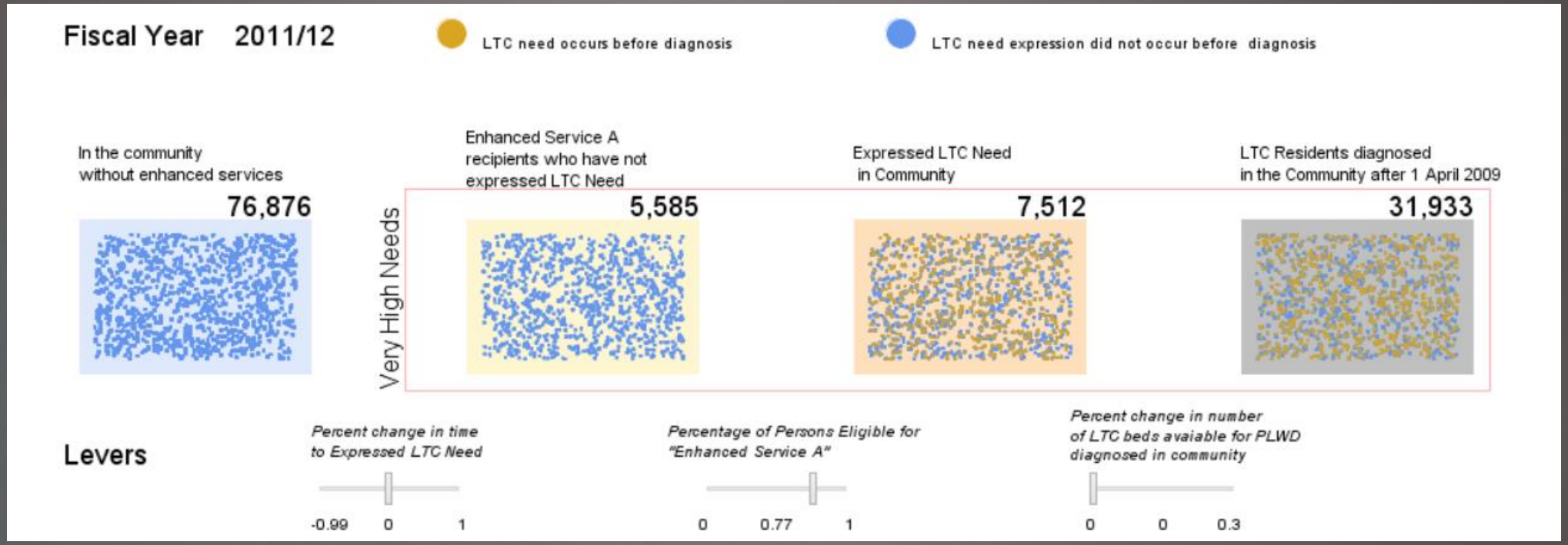
Using Model to Evaluate "What if"

Persons with Dementia Receiving Current Care

Persons Receiving Additional Services

Persons Awaiting LTC

Persons with Dementia Transitioned to LTC



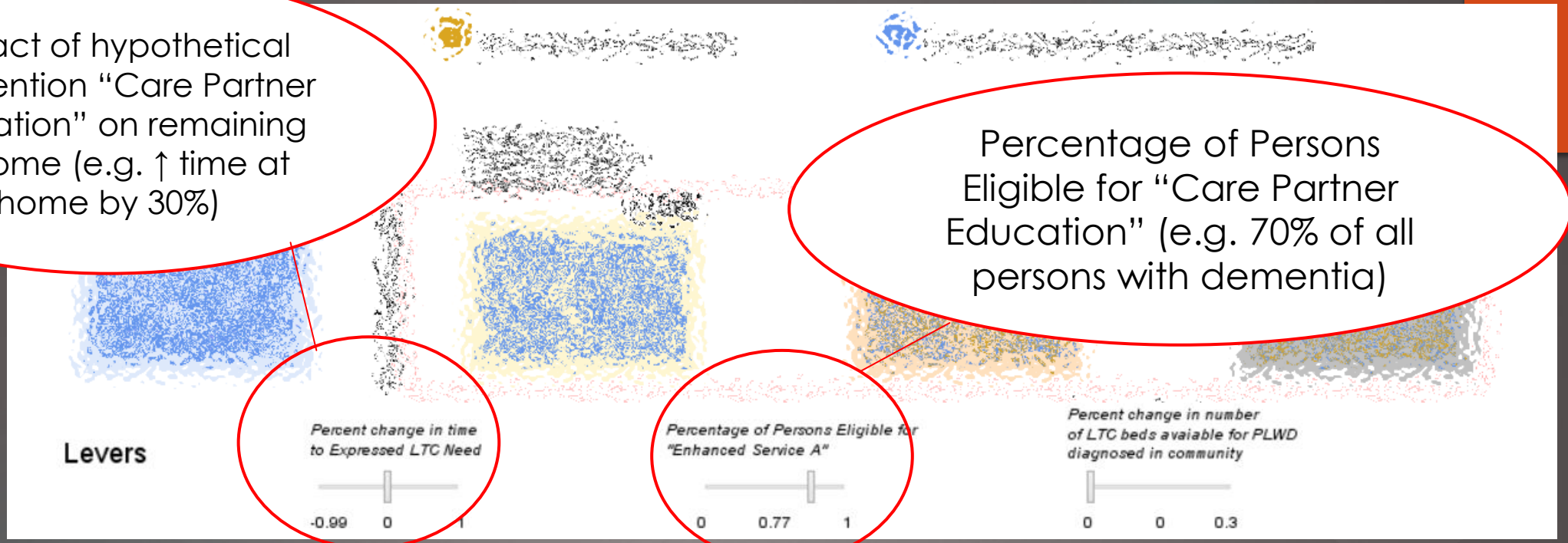
How well does this service support people with dementia?

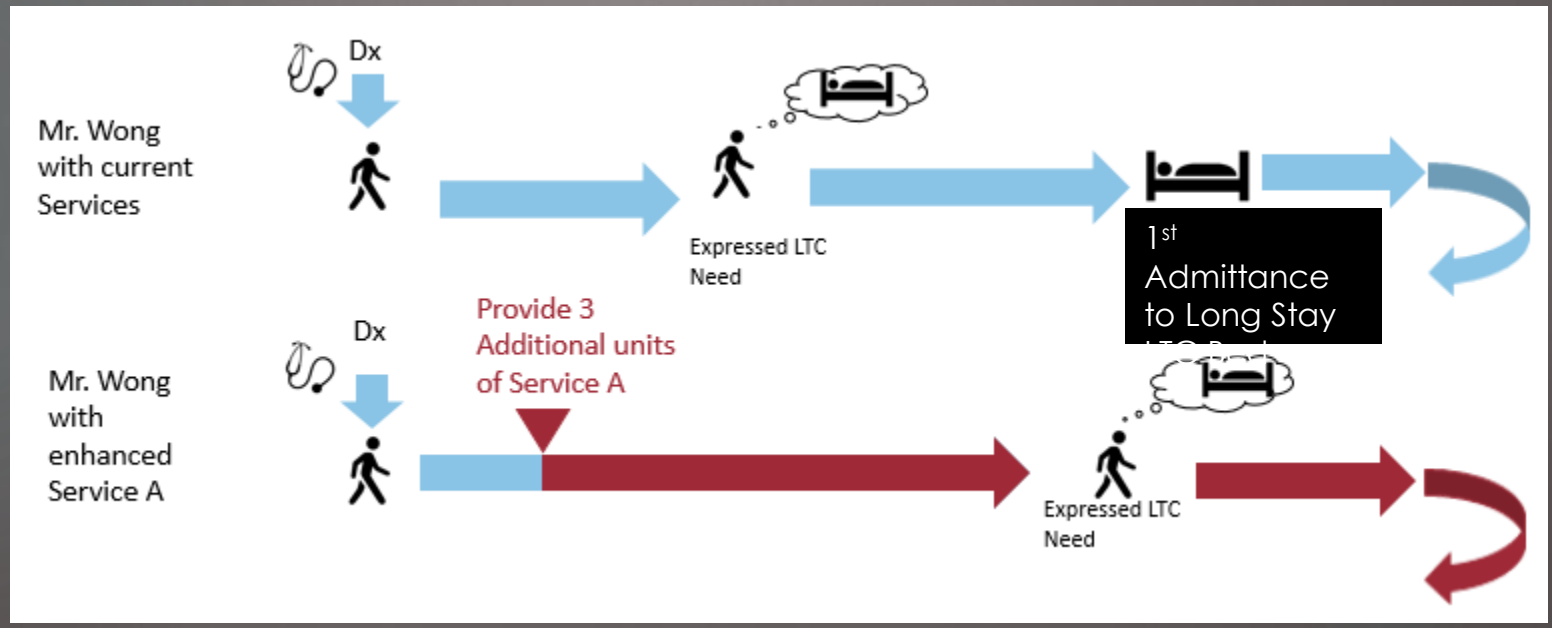
How many people can we provide this service to?

Are there any changes to LTC availability (i.e. more or less beds)?

Impact of hypothetical intervention "Care Partner Education" on remaining at home (e.g. ↑ time at home by 30%)

Percentage of Persons Eligible for "Care Partner Education" (e.g. 70% of all persons with dementia)





Care Partner Education and Support Program

Modelling Effective Community Based Interventions

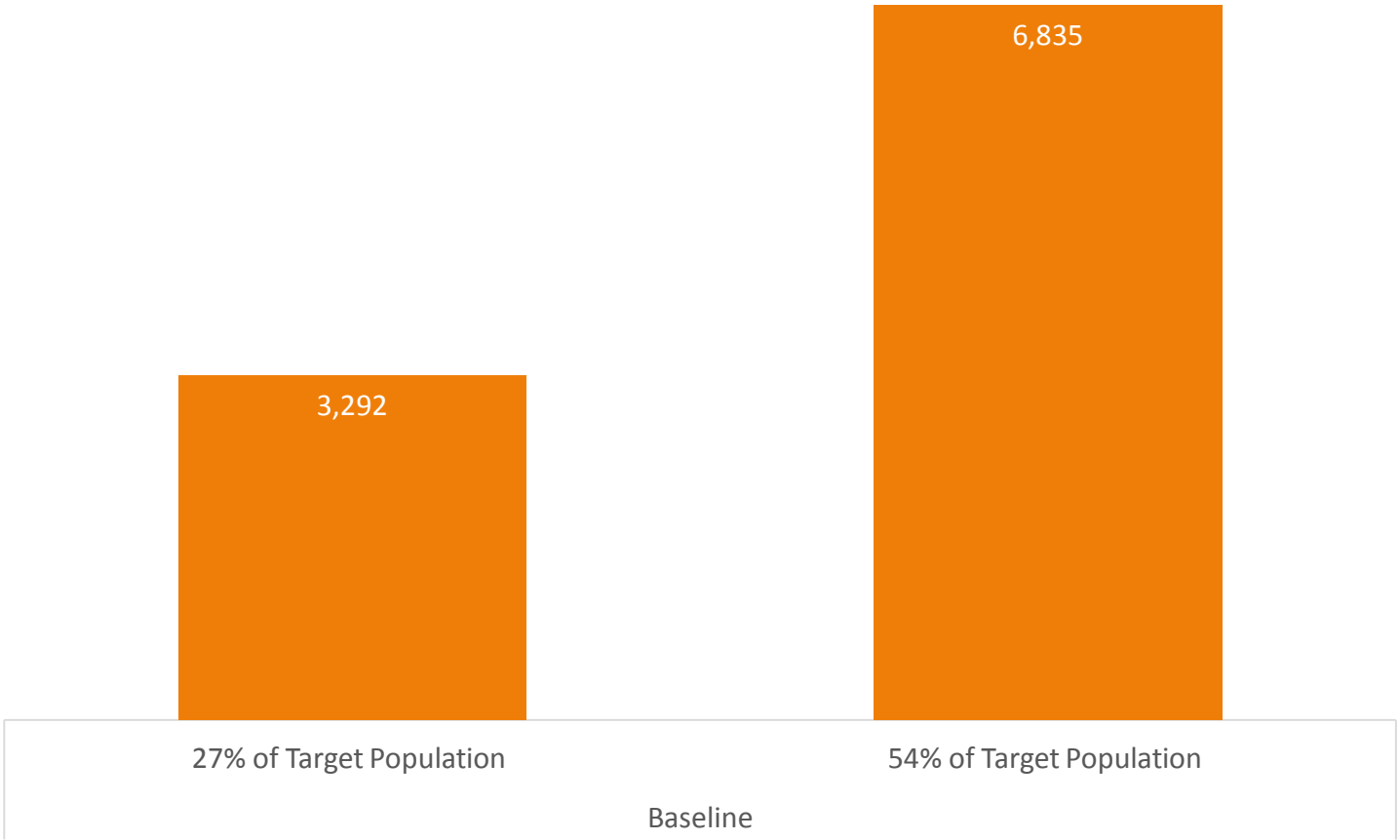
This scenario projects how the dementia cohort and associated system use may change to 2020/21 given:

Care Partner Education Key Specifications:

- Target population: Urban dwelling PLwD
- Retention rate: 92.2%
- Delay: 557 days with uncertainty between 239 and 647 days
- Percent of Target Population who will participate in program: 54% of urban dwelling PLwD (based upon historical percentage of RAI-assessed PLwD in urban areas with a live-in Care partner)
- Physician Diagnosed Population: Incidence and deaths are unchanged
- Utilization: Health service consumption rates at 2014/15 levels

Care Partner Education | Champlain

Capacity Requirements: Monthly Counselor Hours required by 2020



If Champlain were to implement a Care Partner Education program, by FY 2020 they could need up to 6,835 monthly counselor hours in order to serve up to 7,033 urban PLwD with a live-in care partner

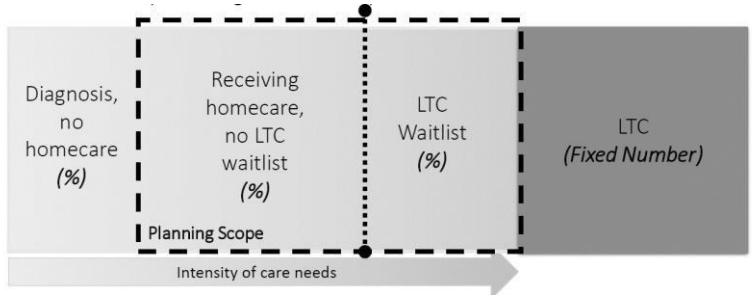
*The analysis on this slide assumes only urban individuals would be able to access the Education Services. Additional services would be required to serve rural and remote PLwD

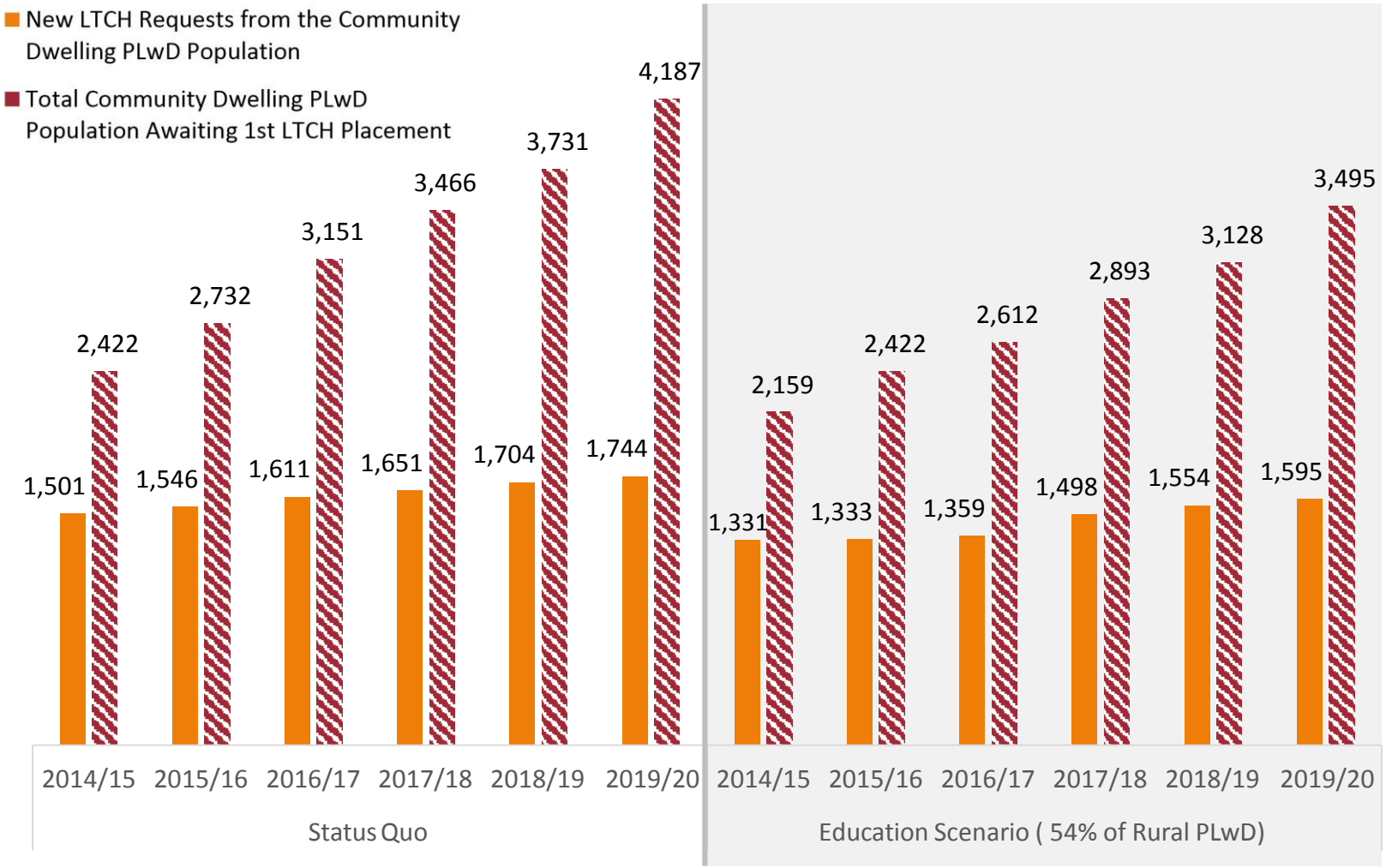
* The analysis on this slide assumes baseline population projections

Note: All results are preliminary, and should not be used for decision-making.

Care Partner Education | Champlain

Impact on Long-Term Care





If an effective Care Partner Education program were implemented, by FY **2019 the number of LTC requests could be reduced up to 8.5%**, and the number of persons waiting in the **Community for LTC could be reduced up to 17%**

This implies 692 more PLwD in Champlain could be living *well* in the community.

Note: All results are preliminary, and should not be used for decision-making.

Dementia Capacity Planning Future Steps

- Ongoing engagement with health systems partners and MOHLTC
- Evaluation of additional scenarios different potential service scenarios
- Detailed case studies with persons living with dementia and care partners, determine actual needs
- Evaluation of the impact of receipt of different services in current state on transitions (e.g. specialty services, home care)
- Evaluate other outcomes such as hospitalization, ER use, ALC

Conclusions

- There are increasing numbers of individuals with dementia in Ontario
- Helping people stay healthy in their homes requires careful planning and evidence
- Capacity planning methods can be useful in helping health system planners identify optimal strategies to support persons with dementia

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- Cancer Care Ontario
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