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Alzheimer's disease biomarker testing: Learning from persons with lived experience

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Acknowledgements

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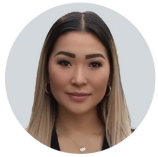

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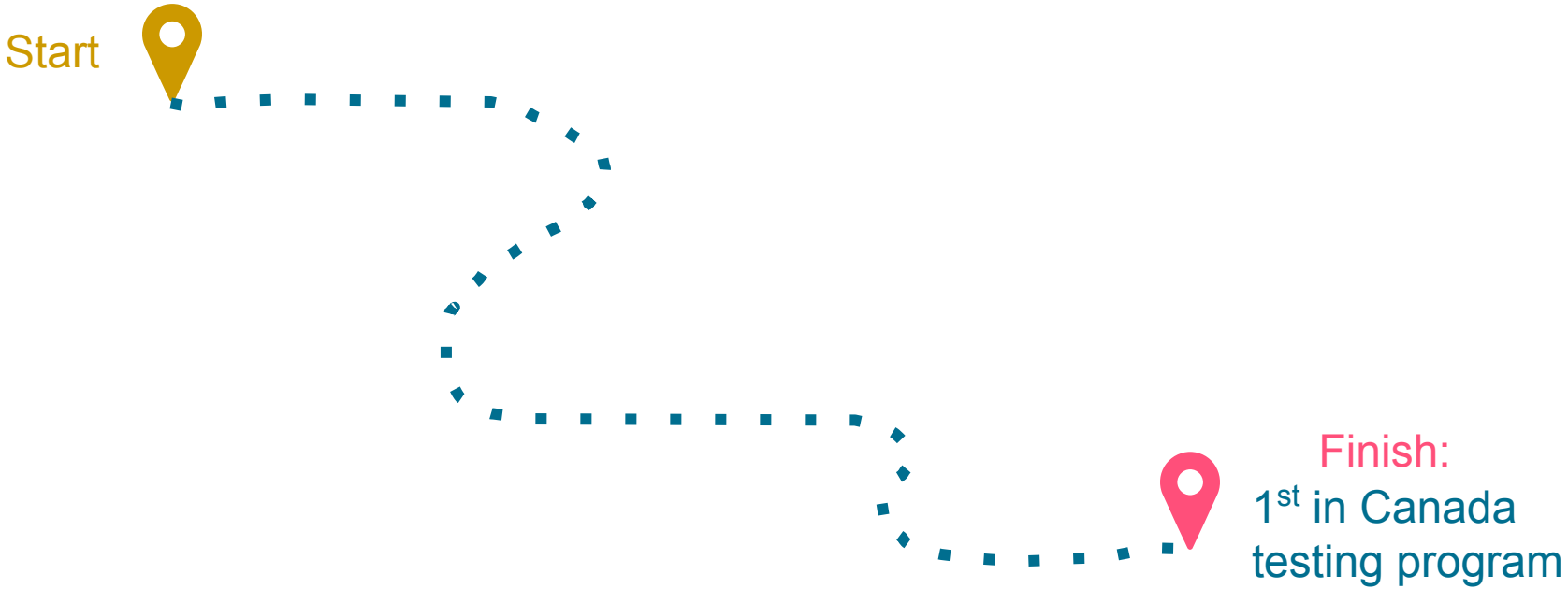
Alzheimer Society Canada
CCNV Consortium canadien en neurodégénérescence associée au vieillissement
CCNA Canadian Consortium on Neurodegeneration in Aging
The University of British Columbia
Women's Brain Health Initiative
Pathology and Laboratory Medicine, Providence Health Care
Djavad Mowafaghian Centre for Brain Health

Learning objectives

1. Describe the change in diagnostic confidence as a result of the use of Alzheimer's disease biomarkers.
2. Describe common personal motivations of persons deciding to undergo Alzheimer's disease biomarker testing.

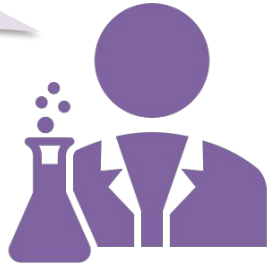
Our path to a national biomarker testing program for Alzheimer's disease



Our path to a national biomarker testing program for Alzheimer's disease

We want access to Alzheimer's disease CSF biomarker testing.

Ok! To start, let's see what the evidence is for implementation in patient care…



AD changes in the brain

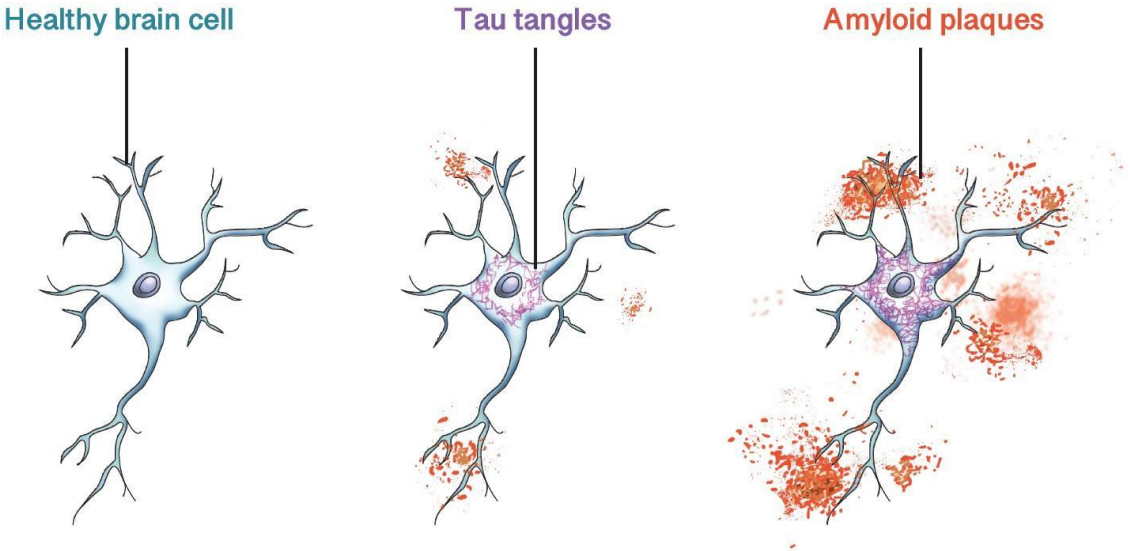
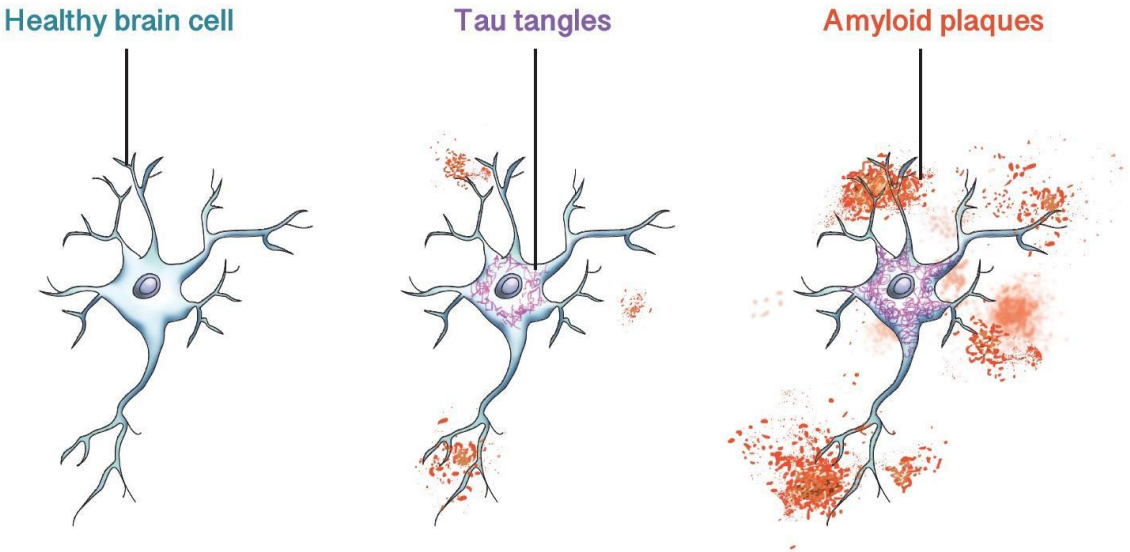
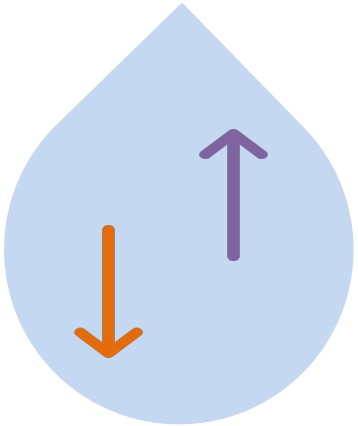


Image: Li & DeMarco, 2020

AD changes in CSF



Cerebrospinal fluid



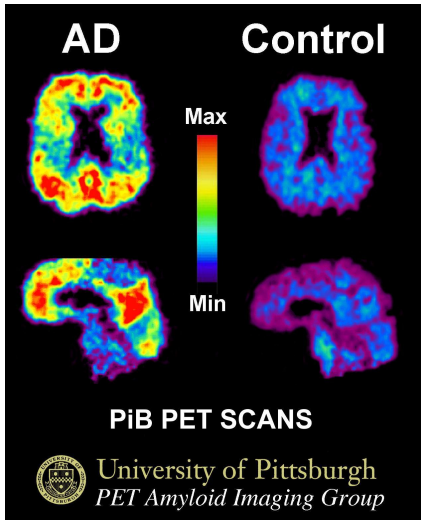
<u>Core AD biomarkers</u>

Amyloid-β 1-42

Phospho-tau

Total-tau

Diagnostic Accuracy



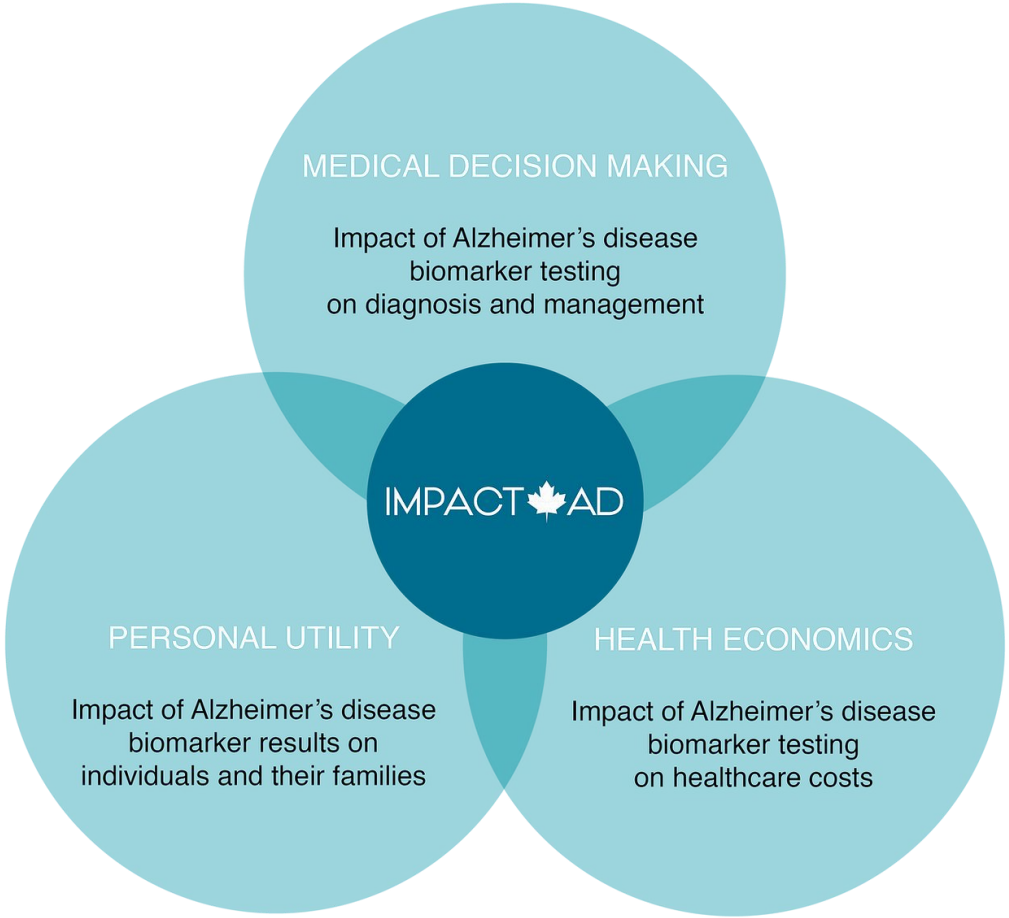
- Total-tau/Aβ42 & phospho-tau/Aβ42 ratios improve diagnostic accuracy
  - mean sensitivity of 92% to identify brain amyloidosis
  - mean specificity of 88% to exclude brain amyloidosis
  - ROC area under the curve of 0.95–0.96
- Contemporary comparator: PET positivity
- Gold standard: autopsy

Shaw L. et al. **Appropriate use criteria for lumbar puncture and CSF testing in the diagnosis of Alzheimer's disease**. *Alzh & Dem. 2018*

Evidence for implementation of in medical care

- ✔ High diagnostic accuracy
- ✔ Expert consensus opinion on appropriate use scenarios
- ✔ Use results in changes in diagnosis

- Evidence for changing medical care
- Knowledge in the context of the Canadian health care system
- Perspectives from patients & care partners



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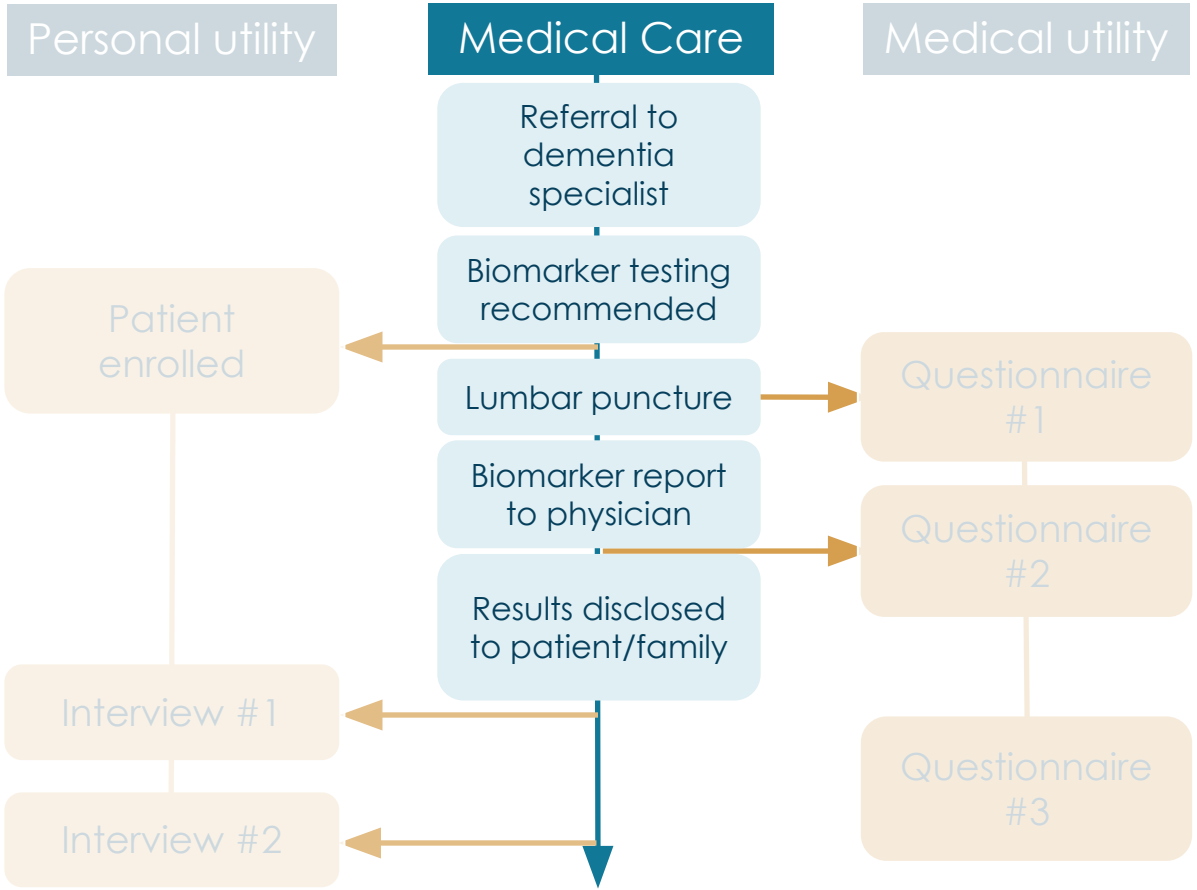
Translating research into practice: Investigating the impact of Alzheimer's disease diagnostics in Canada

Study Design



Medical utility: Outcomes

Primary outcome

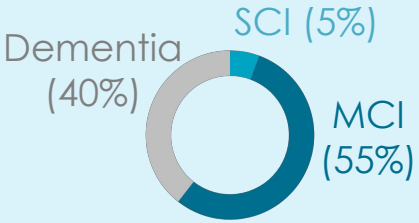
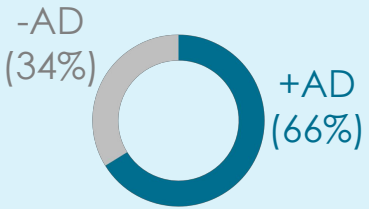
Change in management (pre- v. post-biomarker results) in a composite measure including:

- AD drug therapy
- Other dementia-relevant drug therapy
- Diagnostic procedures
- Referrals and counselling

Secondary outcomes:

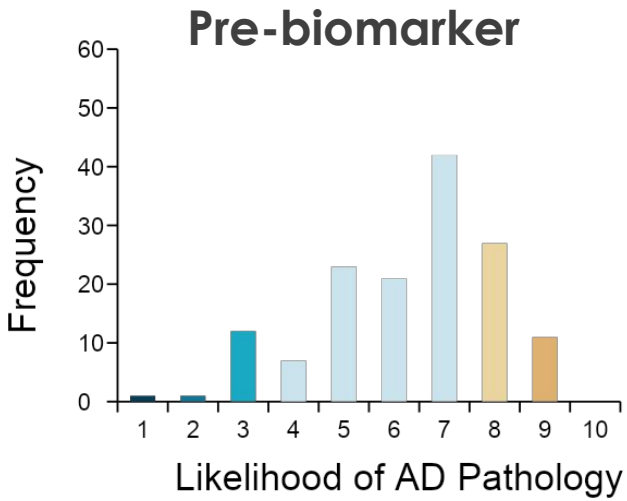
Changes in diagnosis and diagnostic confidence

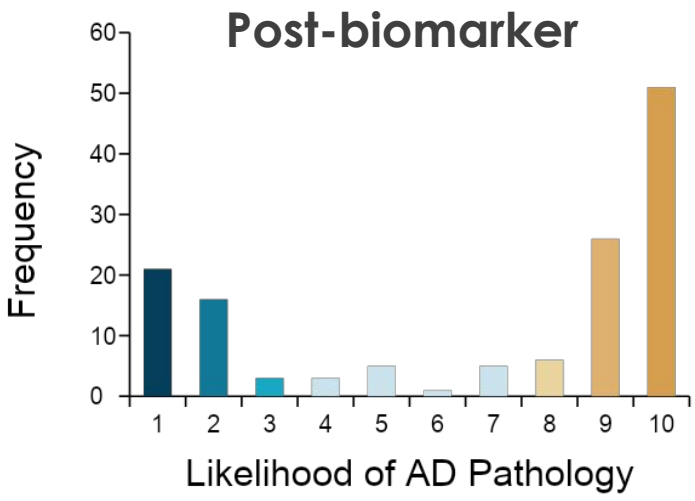
Demographics

			Cognitive impairment at baseline	Biomarker interpretation
142	52%	64 years (IQR: 59-69)		

Yang … DeMarco. Changes in clinical management as a result of Alzheimer's disease biomarker testing. *Manuscript in prep.*

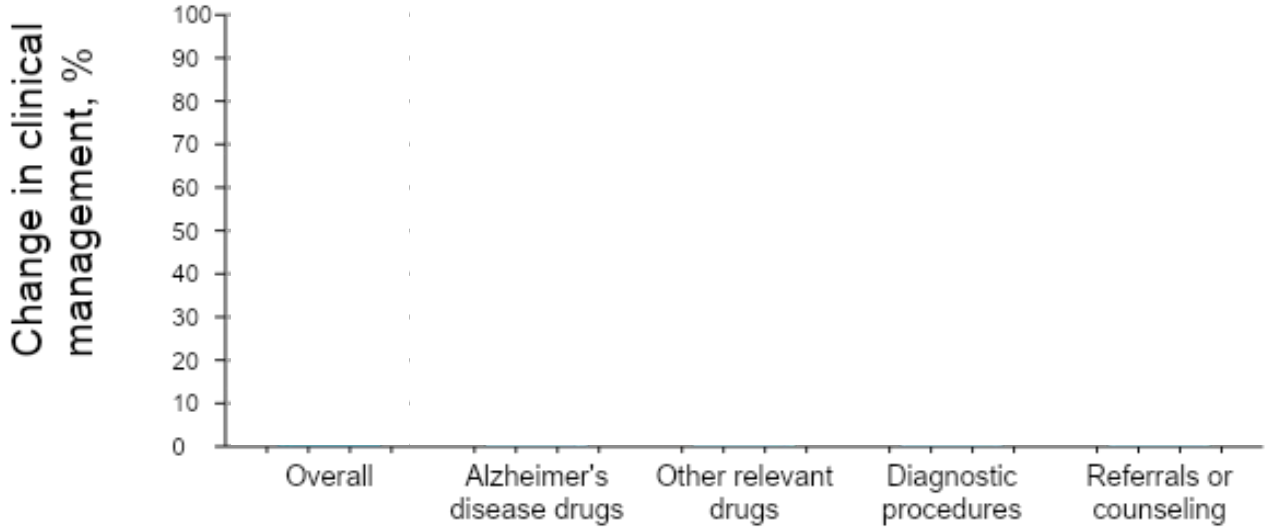
Secondary outcomes:
Change in diagnostic confidence





Diagnostic gray zone reduced from 65.5% to 9.9%

Primary outcome: Changes in management



Summary: Medical management

Changes in clinical management
as a result of biomarker testing

↓ **Costly diagnostic procedures**

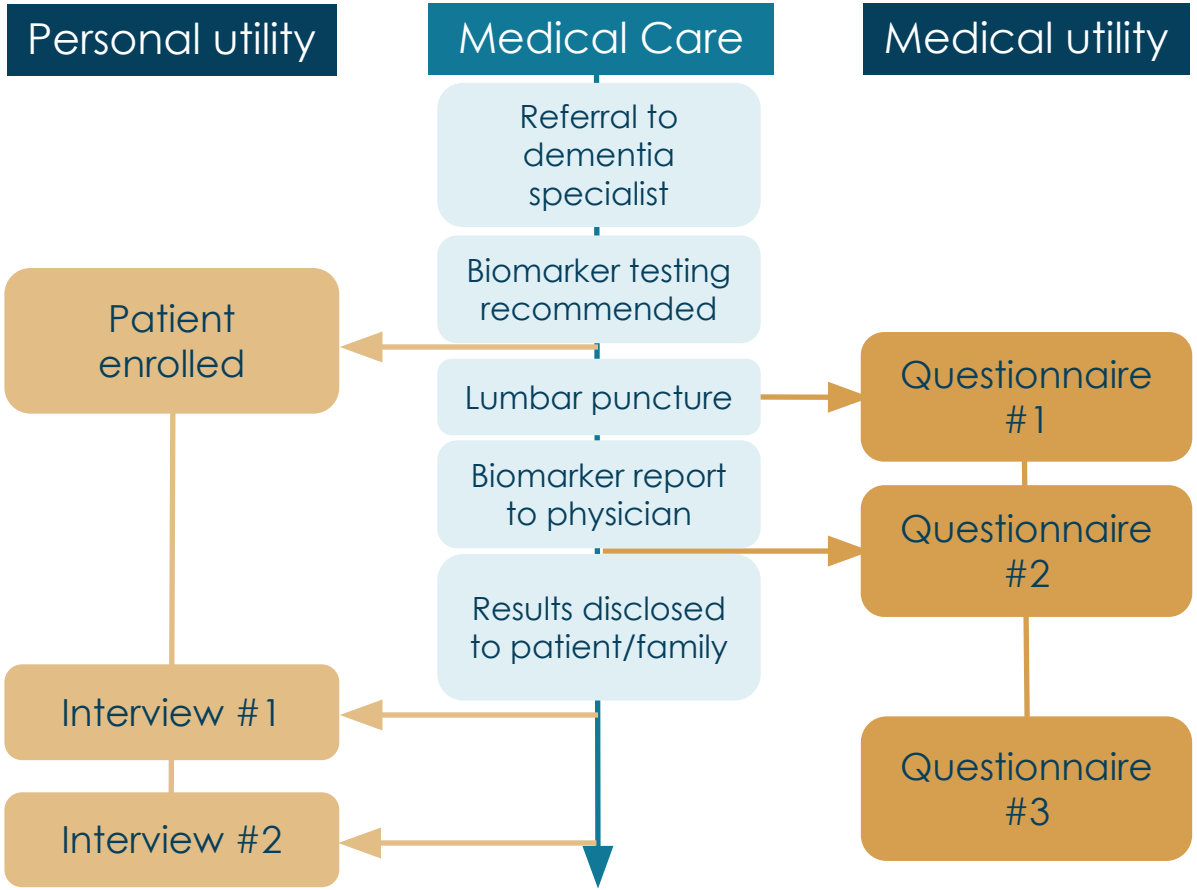
Changes in AD drug use
↑ AD+ biomarker profile
↓ AD- biomarker profile

Physicians reported **higher confidence**

Findings demonstrate value of early diagnosis in guiding medical care

Yang … DeMarco. Changes in clinical management as a result of Alzheimer's disease biomarker testing. *Manuscript in prep.*

Study Design

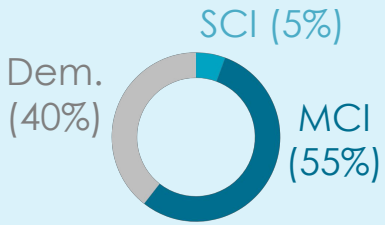
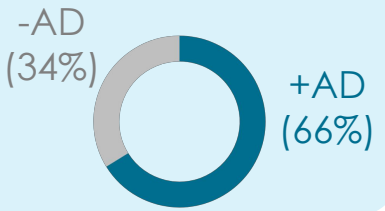
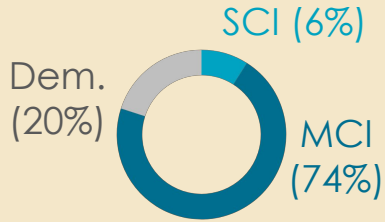
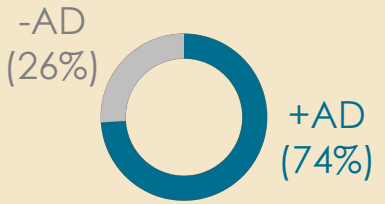


Personal Utility: Outcomes

Describe patients and care partners' experience with Alzheimer's disease CSF biomarker testing

Evaluate impact of Alzheimer's disease CSF biomarker testing on patients and care partners' planning and decision-making

Demographics

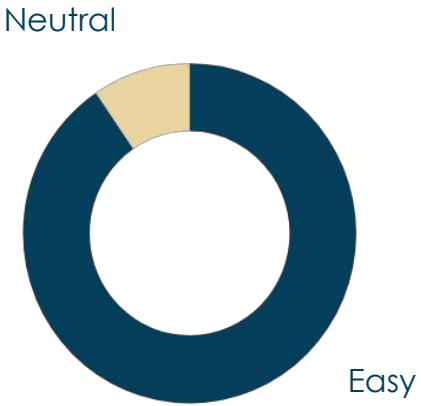
		♂		Cognitive impairment at baseline	Biomarker interpretation
Medical utility	142	52%	64 years (IQR: 59-69)		
Personal utility	34	41%	63 years (IQR: 56-68)		

Semi-structure phone interview

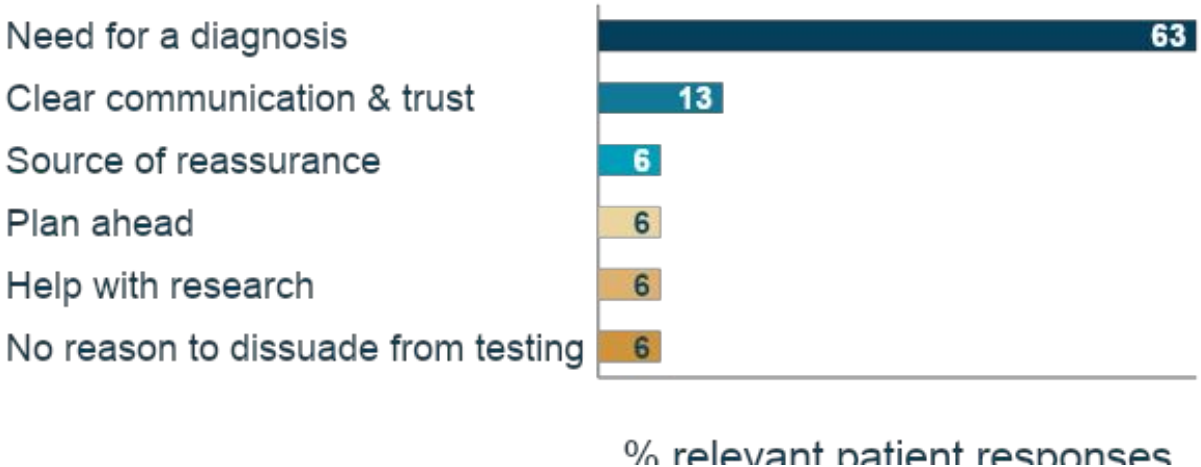
Decision to have testing	Wellness & lifestyle	Long-term planning	Effect on patient & their family/friends
What factors were important to you in **making your decision to have the lumbar puncture and testing done**?	After learning the test results, did you plan to **add or increase the amount you exercise**?	Since learning the test results, have you thought about **planning for future home care assistance**?	How do you think learning your results has **affected you**? How do you think learning your results has **affected the people in your life**?

Decision to undergo biomarker testing

Rating for ease/difficulty of decision-making

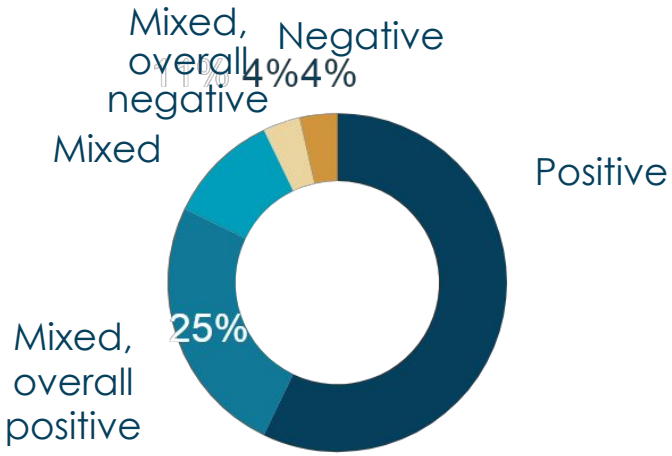


Primary reason for 'easy' decision-making

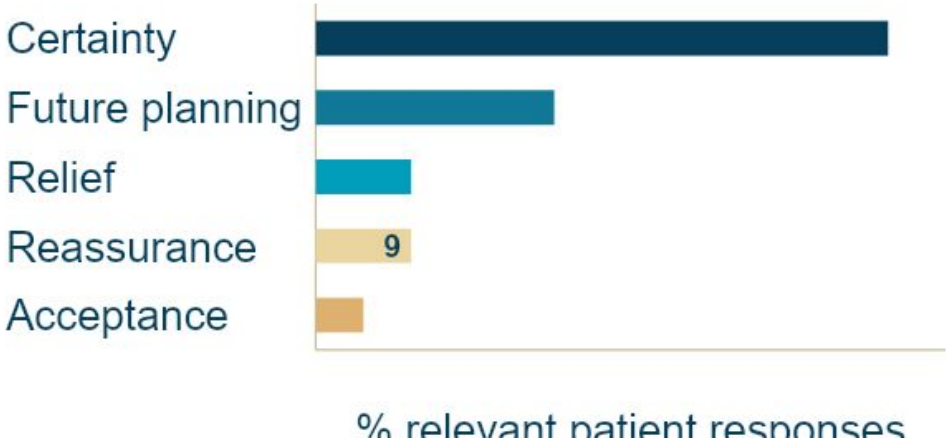


Post-disclosure feelings

Feelings after learning results



Primary reason for positive feelings



Major themes from patient responses

Diagnostic clarity (44%)

"**Makes me know that I'm not crazy**. It's a potential medical condition."

Living with the diagnosis (41%)

"I say to myself, this is **my new normal**. I have learned how to cope with what has happened in my brain, and so I keep things very positive."

Impact of diagnosis on family (22%)

"I am **worried that my children will insist that I go into care**. I value my independence."

Themes: Effect on care partner

Clarity on the patients' diagnosis (63%)

"… being able to put a **definitive label** to it […] probably makes it a little bit easier"

Concern about disease progression (30%)

"A little bit frightened because at this point, we **don't know if it is going to be months or years..** before he has severe difficulties or death."

Themes: Effect on care partner

⇧ awareness of future caregiving & desire for resources (37%)

"I have a little **more responsibility for her**, like paying her bills. I do call her every day … so it definitely has brought on more responsibility into my life"

More information to plan for future (26%)

"It **motivated me to really get on top of things financially**, where he needs, he still needs to be cognitively healthy enough to make certain decisions."

Summary: Personal utility

Diagnostic clarity

Major motivation for testing
+
primary reason for positive emotions

Decision-making and planning

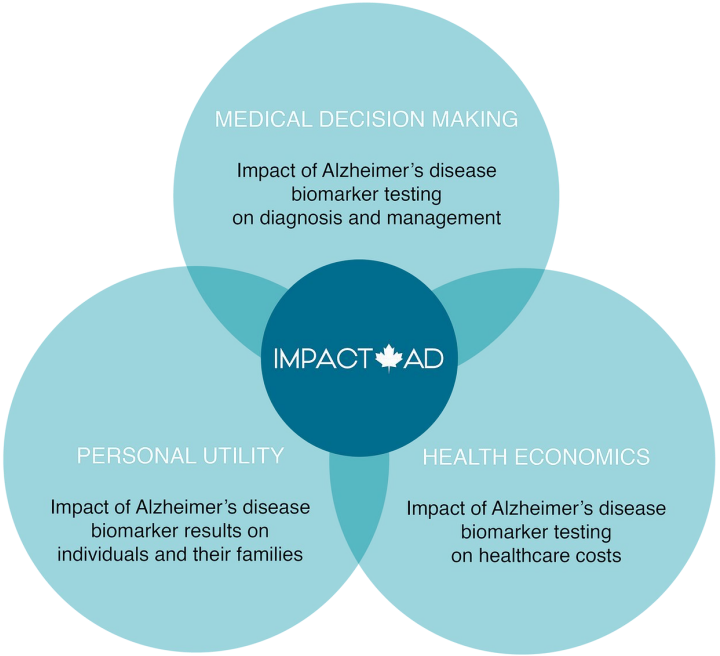
Positive lifestyle changes
+
future planning

Value for care partners

Information for planning
+
recognition of caregiving

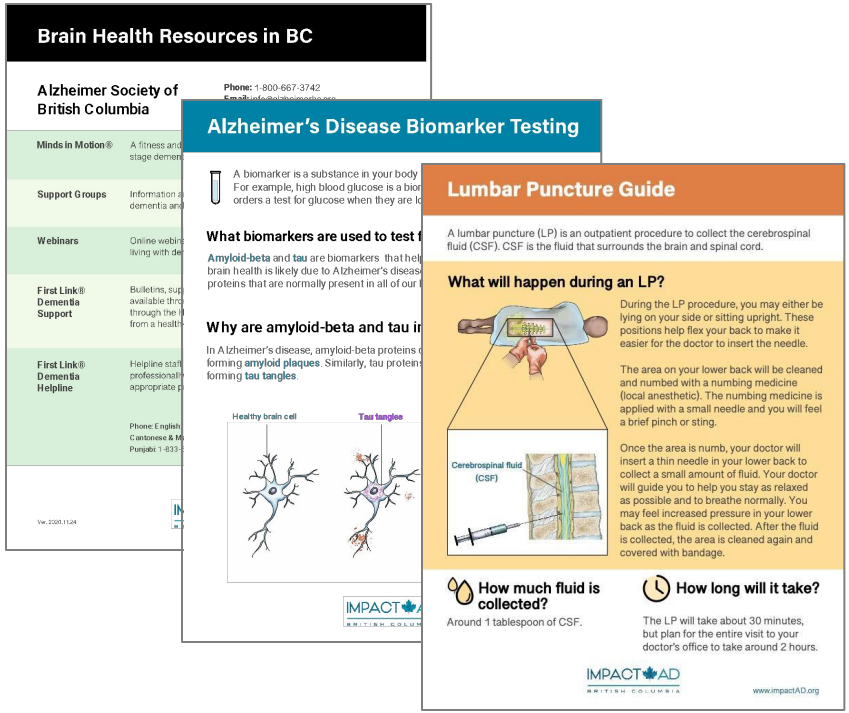
Patel… DeMarco. Personal value of Alzheimer's disease biomarker testing and result disclosure from the patient and care partner perspective. *Manuscript in prep.*

New knowledge and tools



- ✔ Evidence for implementation in medical care
- ✔ Knowledge in the context of the Canadian health care system
- ✔ New understanding of value of testing from individuals with lived experience
- ✔ New resources for patients and care partners

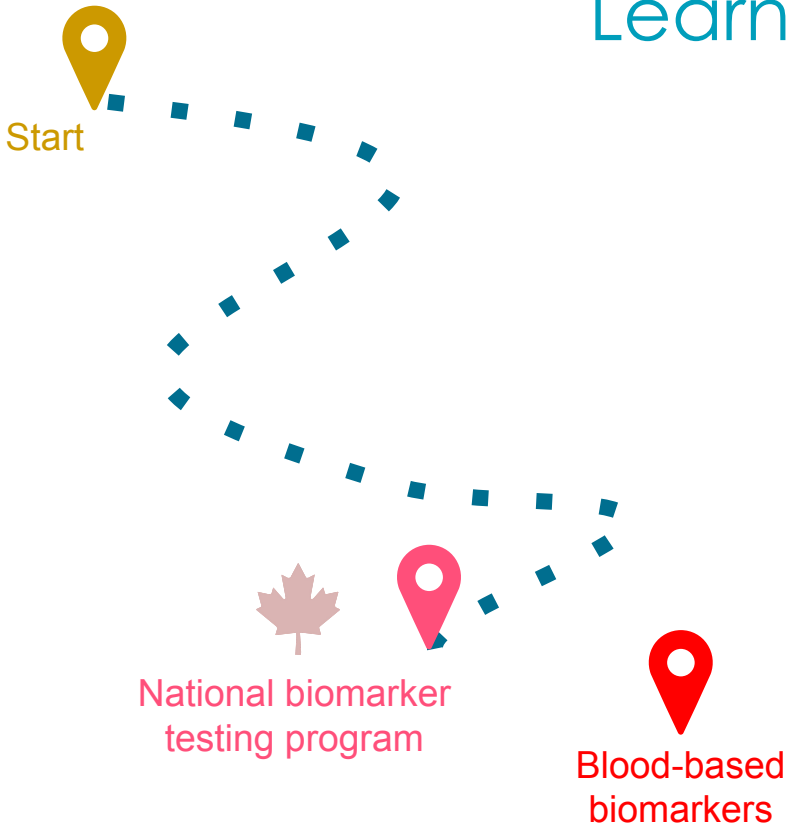
IMPACT AD



Suite of resources for individuals and families living with dementia @ impactAD.org

Available in multiple languages

Learning objectives



1. Describe the change in diagnostic confidence as a result of the use of Alzheimer's disease biomarkers.

2. Describe common personal motivations of persons deciding to undergo Alzheimer's disease biomarker testing.

In their own words…

"I am just leaving a meeting with a 58 year-old patient who was told by multiple physicians that her cognitive symptoms were due to stress. She found the relief of having a proper diagnosis of Alzheimer's disease through biomarkers to be of immense relief and this allowed her to seek out clinical trial opportunities and get access to disability."