



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

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CCNV

Consortium canadien en
neurodégénérescence
associée au vieillissement



CCNA

Canadian Consortium
on Neurodegeneration
in Aging



Women's Brain
Health Initiative



PATHOLOGY
AND LABORATORY
MEDICINE
PROVIDENCE HEALTH CARE



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PATHOLOGY AND
LABORATORY MEDICINE
PROVIDENCE HEALTH CARE



Pathology &
Laboratory Medicine

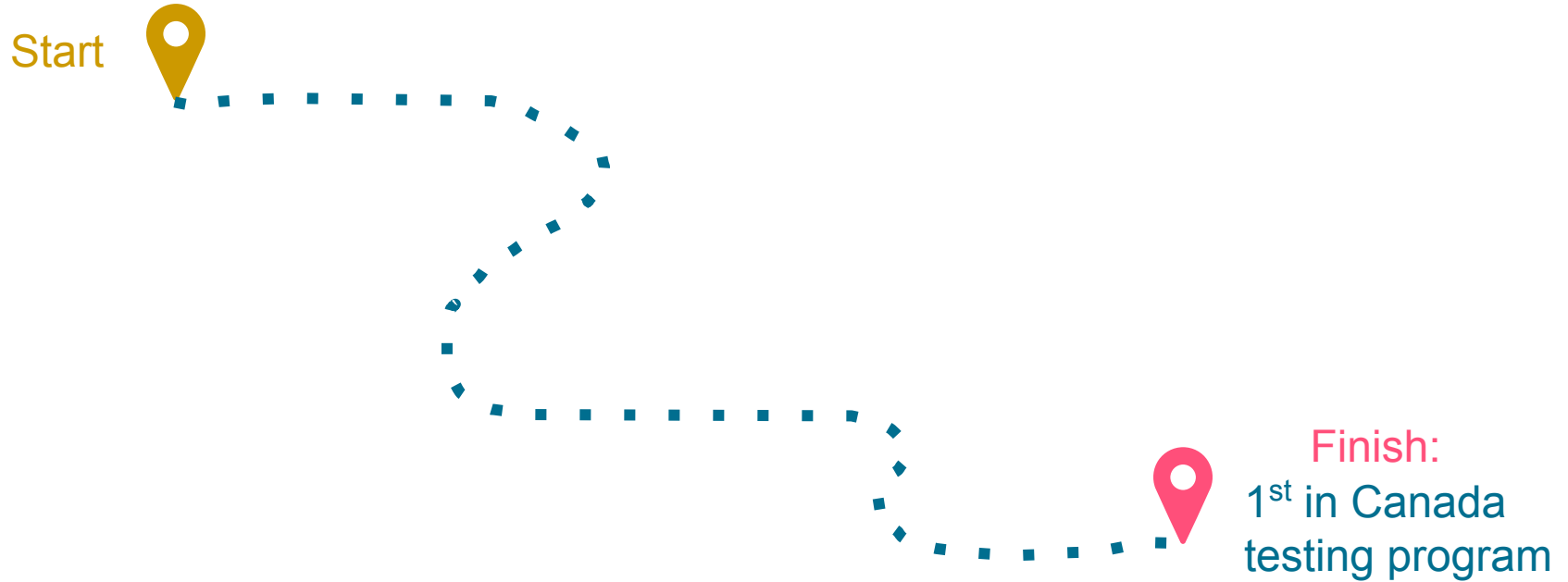
Learning objectives



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

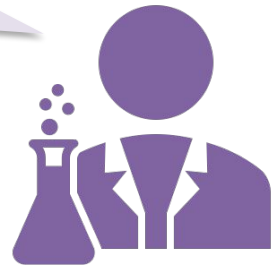


Our path to a national biomarker testing program for Alzheimer's disease



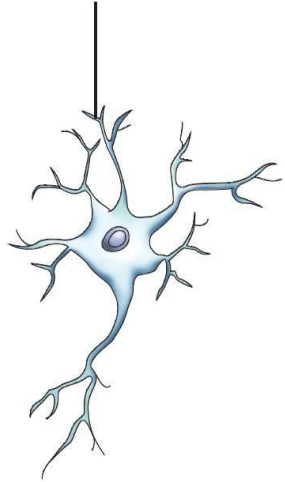
We want access to Alzheimer's disease CSF biomarker testing.

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

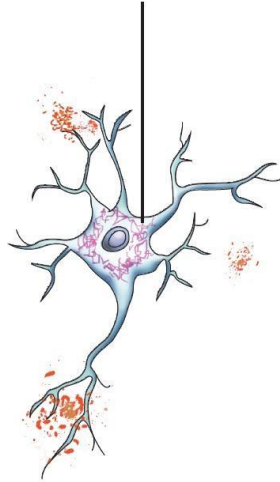


AD changes in the brain

Healthy brain cell



Tau tangles

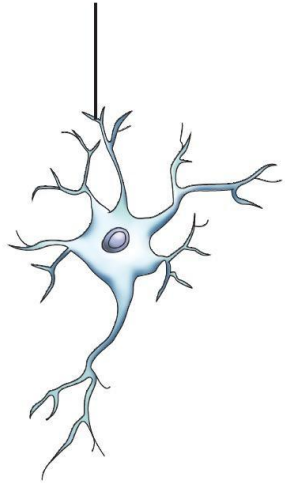


Amyloid plaques

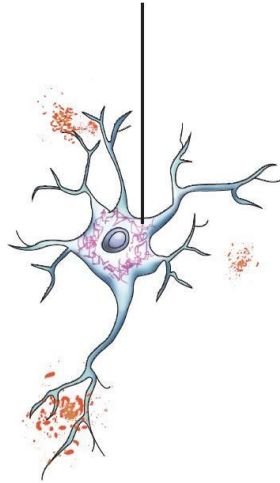


AD changes in CSF

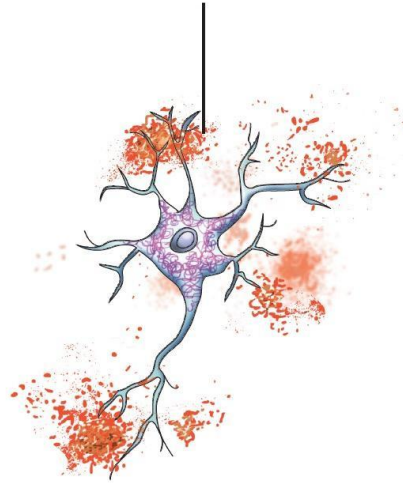
Healthy brain cell



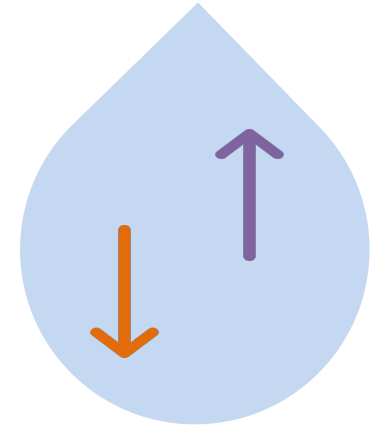
Tau tangles



Amyloid plaques



Cerebrospinal fluid



Core AD biomarkers

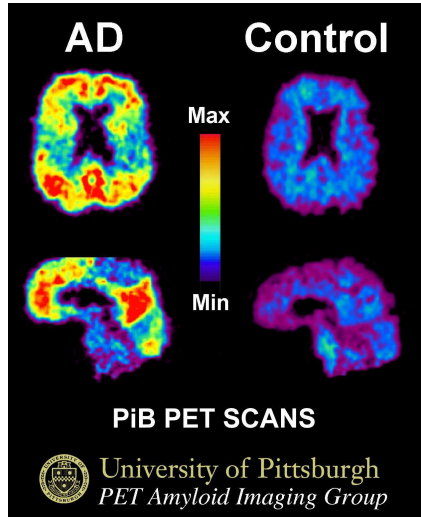
Amyloid- β 1-42

Phospho-tau

Total-tau



Diagnostic Accuracy



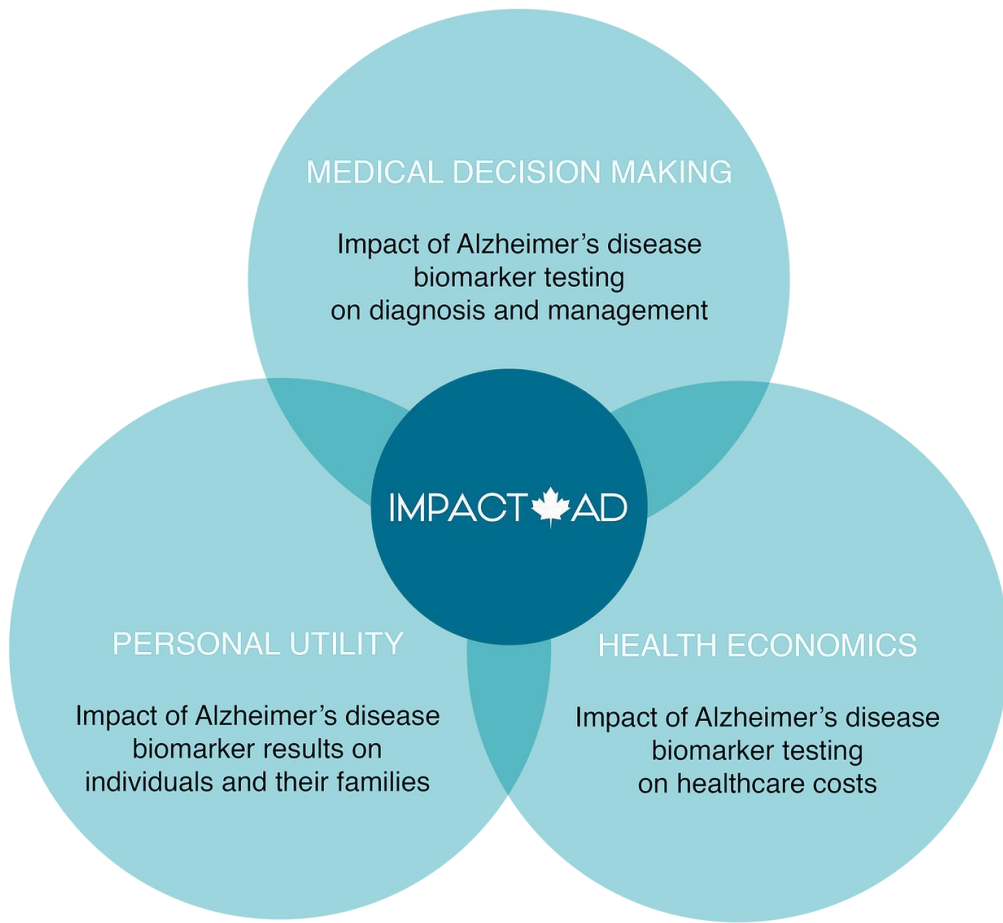
- Total-tau/A β 42 & phospho-tau/A β 42 ratios improve diagnostic accuracy
 - mean sensitivity of 92% to identify brain amyloidosis
 - mean specificity of 88% to exclude brain amyloidosis
 - ROC area under the curve of 0.95–0.96
- Contemporary comparator: PET positivity
- Gold standard: autopsy



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

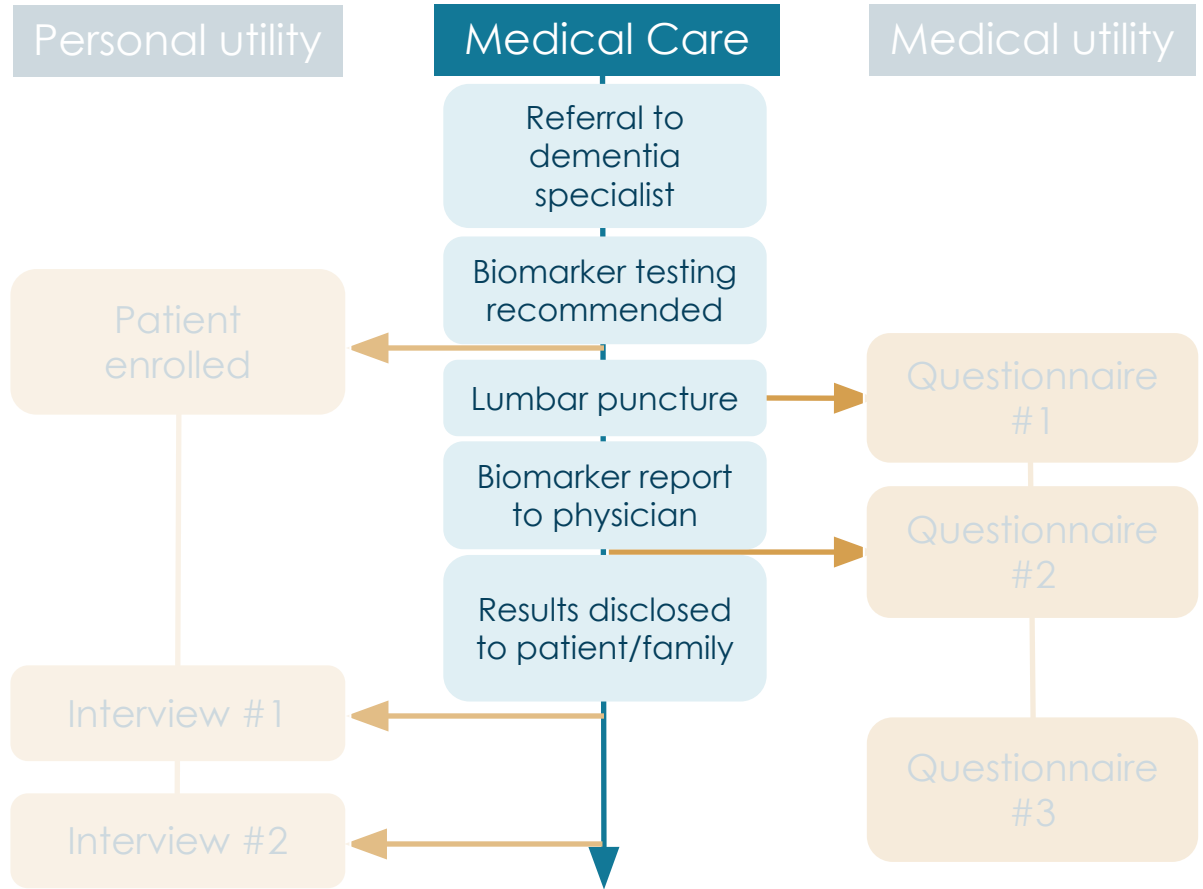


IMPACT AD

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



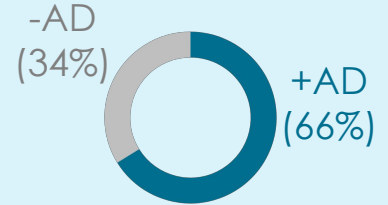
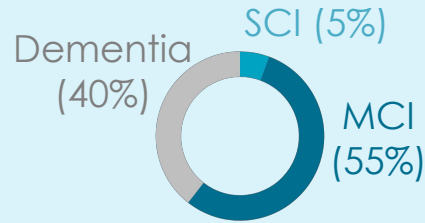
Cognitive
impairment at
baseline

Biomarker
interpretation

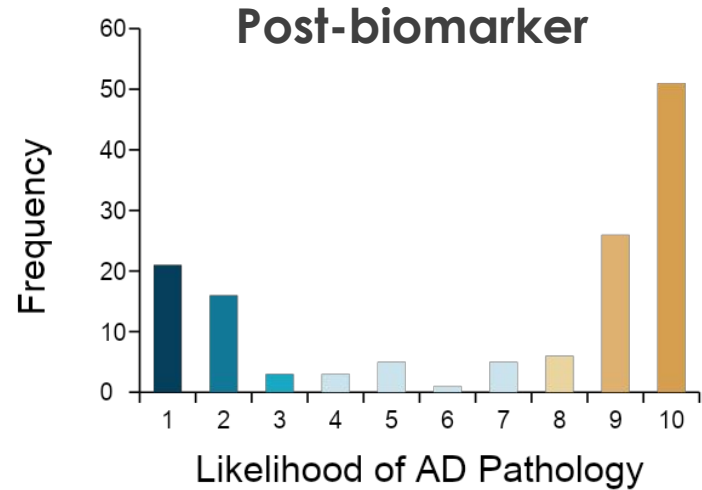
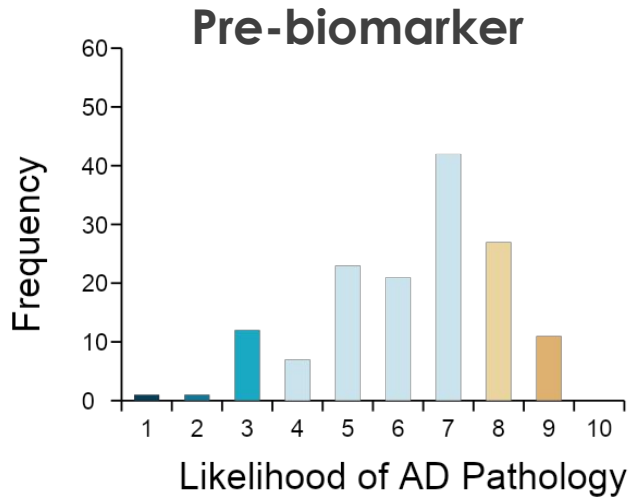
142

52%

64 years
(IQR: 59-69)

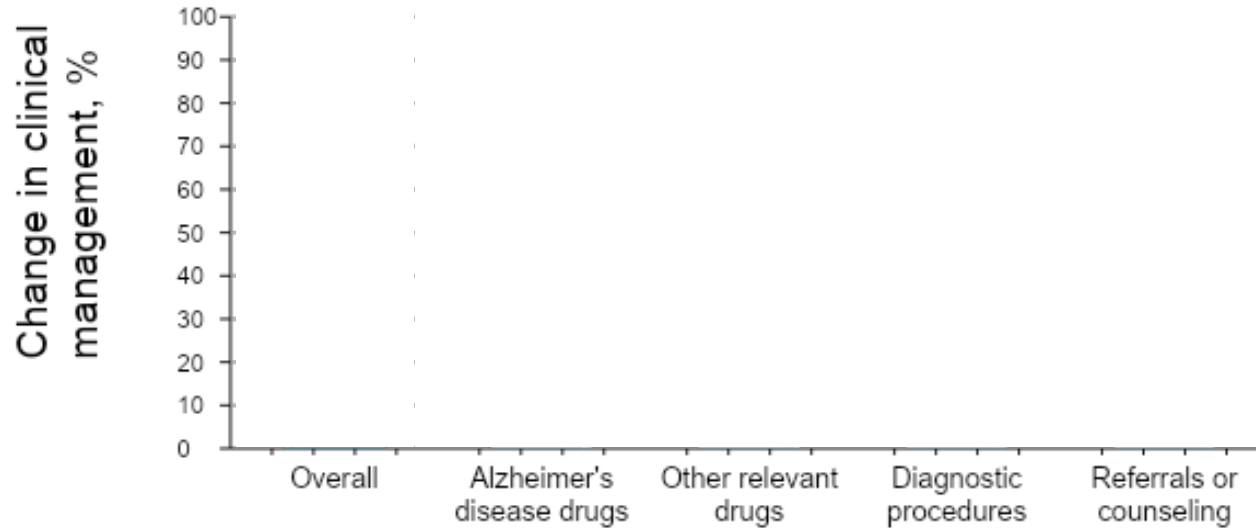


Secondary outcomes: Change in diagnostic confidence



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

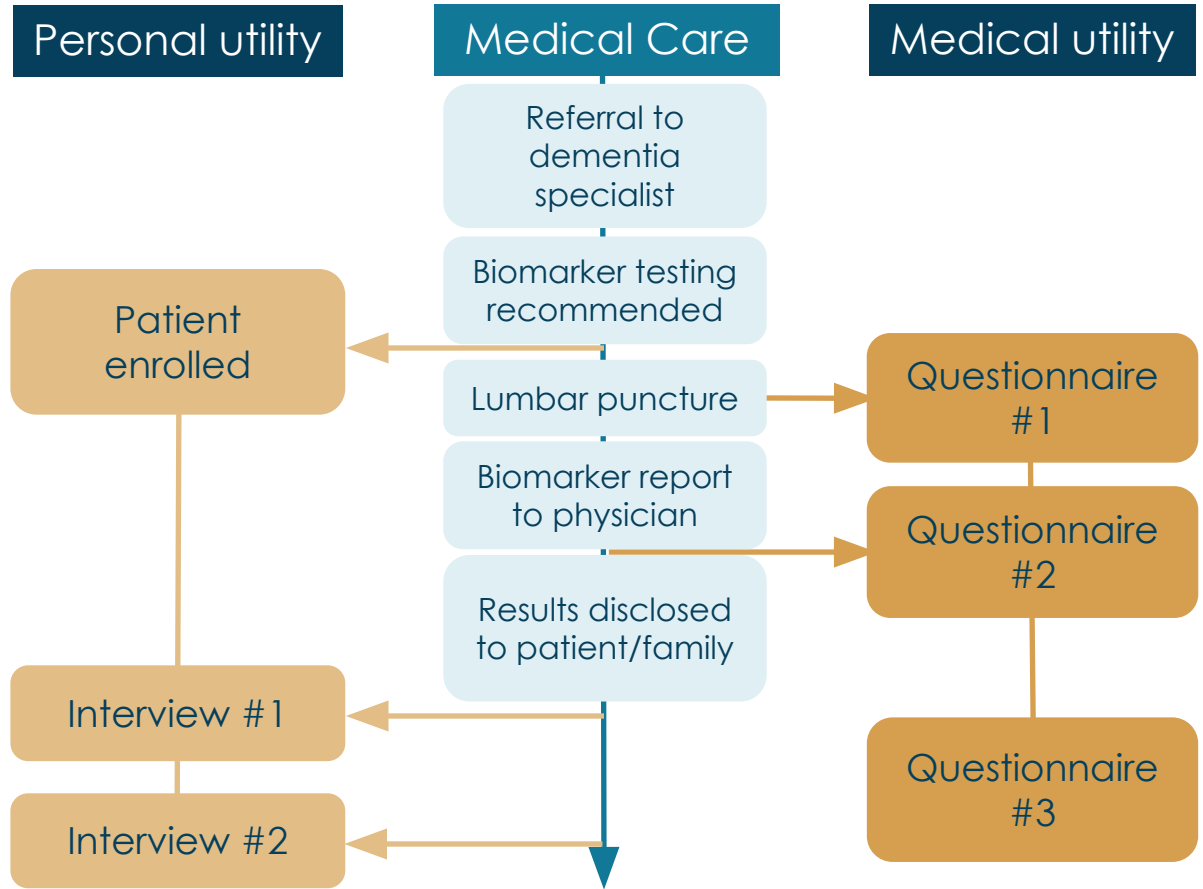


Physicians reported **higher confidence**

Findings demonstrate value of early diagnosis in guiding medical care



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

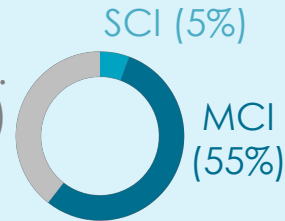
Medical
utility

142

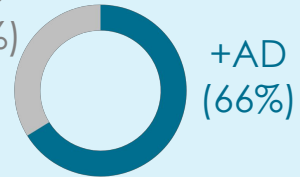
52%

64 years
(IQR: 59-69)

Dem.
(40%)



-AD
(34%)



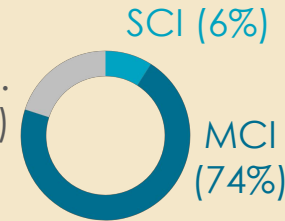
Personal
utility

34

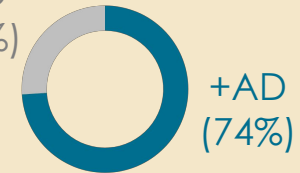
41%

63 years
(IQR: 56-68)

Dem.
(20%)



-AD
(26%)



Semi-structure phone interview

Decision to
have testing

What factors were important to you in **making your decision to have the lumbar puncture and testing done?**

Wellness &
lifestyle

After learning the test results, did you plan to **add or increase the amount you exercise?**

Long-term
planning

Since learning the test results, have you thought about **planning for future home care assistance?**

Effect on patient & their
family/friends

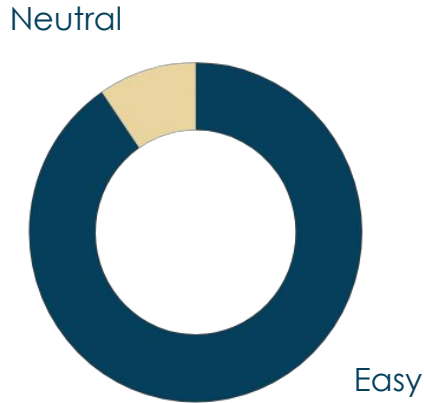
How do you think learning your results has **affected you?**

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

- Need for a diagnosis
- Clear communication & trust
- Source of reassurance
- Plan ahead
- Help with research
- No reason to dissuade from testing

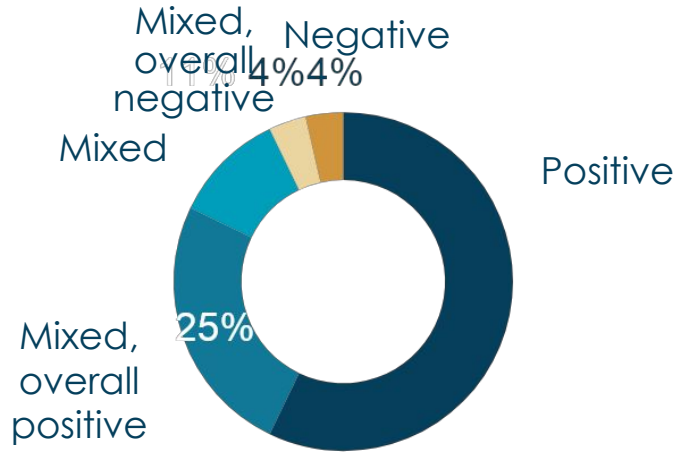


% relevant patient responses

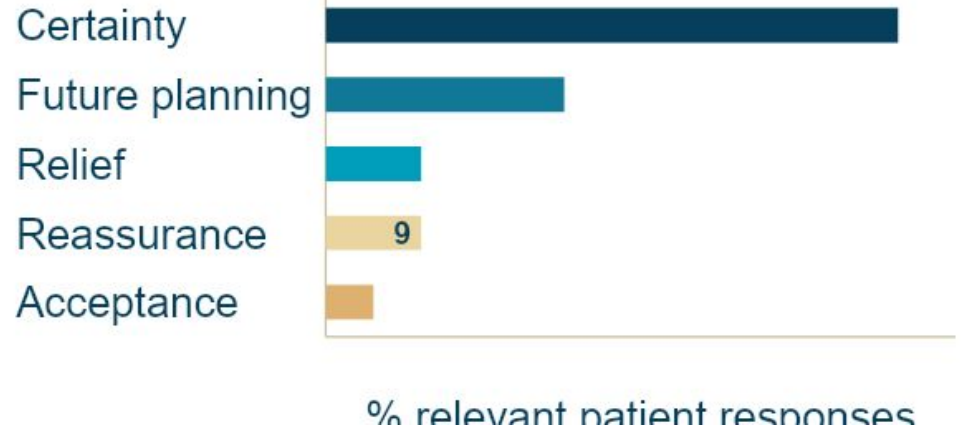


Post-disclosure feelings

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

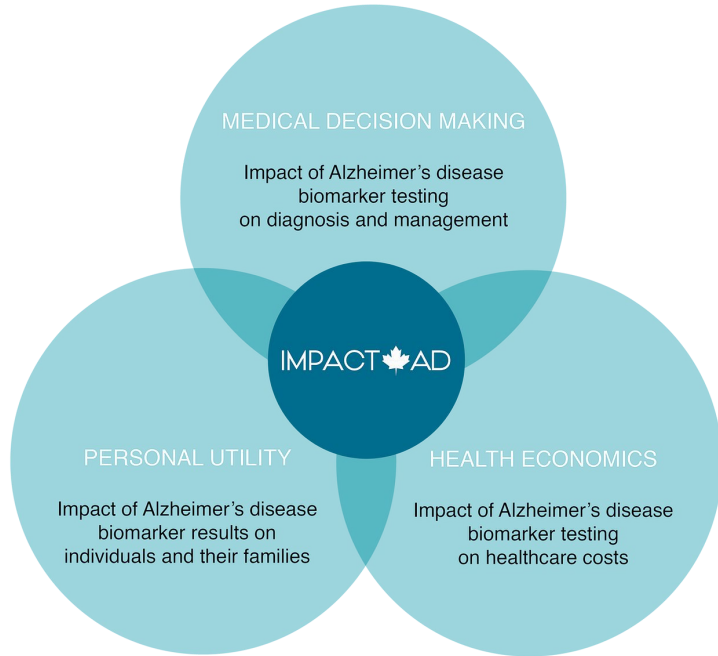


Value for care partners

Information for planning
+
recognition of caregiving



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

Brain Health Resources in BC

Alzheimer Society of British Columbia

Phone: 1-800-667-3742
Email: info@alzheimerbc.org

Minds in Motion® A fitness and stage dementia program

Support Groups Information and support for individuals living with dementia and their families

Webinars Online webinars for individuals living with dementia

First Link® Dementia Support Bulletins, support groups, and other resources available through the First Link Helpline

First Link® Dementia Helpline Helpline staff provide professional support and information appropriate to your needs

Phone: English 604-683-8833, Cantonese 604-683-8833, Punjabi 1-833-833-8833

Vic: 2500.1124

Alzheimer's Disease Biomarker Testing

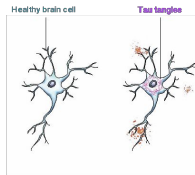
A biomarker is a substance in your body. For example, high blood glucose is a biomarker. Doctors order a test for glucose when they are looking for diabetes.

What biomarkers are used to test for Alzheimer's disease?

Amyloid-beta and tau are biomarkers that help brain health is likely due to Alzheimer's disease. These are proteins that are normally present in all of our brains.

Why are amyloid-beta and tau important in Alzheimer's disease?

In Alzheimer's disease, amyloid-beta proteins form amyloid plaques. Similarly, tau proteins form tau tangles.



Lumbar Puncture Guide

A lumbar puncture (LP) is an outpatient procedure to collect the cerebrospinal fluid (CSF). CSF is the fluid that surrounds the brain and spinal cord.

What will happen during an LP?

During the LP procedure, you may either be lying on your side or sitting upright. These positions help flex your back to make it easier for the doctor to insert the needle.

The area on your lower back will be cleaned and numbed with a numbing medicine (local anesthetic). The numbing medicine is applied with a small needle and you will feel a brief pinch or sting.


Once the area is numb, your doctor will insert a thin needle in your lower back to collect a small amount of fluid. Your doctor will guide you to help you stay as relaxed as possible and to breathe normally. You may feel increased pressure in your lower back as the fluid is collected. After the fluid is collected, the area is cleaned again and covered with bandage.

How much fluid is collected?

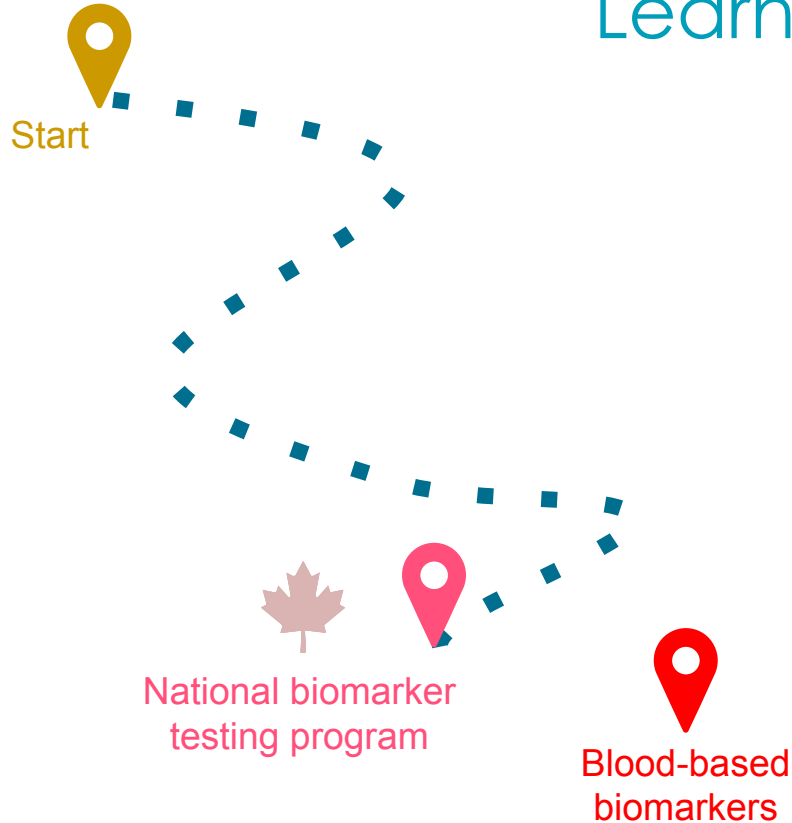
Around 1 tablespoon of CSF.

How long will it take?

The LP will take about 30 minutes, but plan for the entire visit to your doctor's office to take around 2 hours.

 www.impactAD.org

Learning objectives



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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.”

