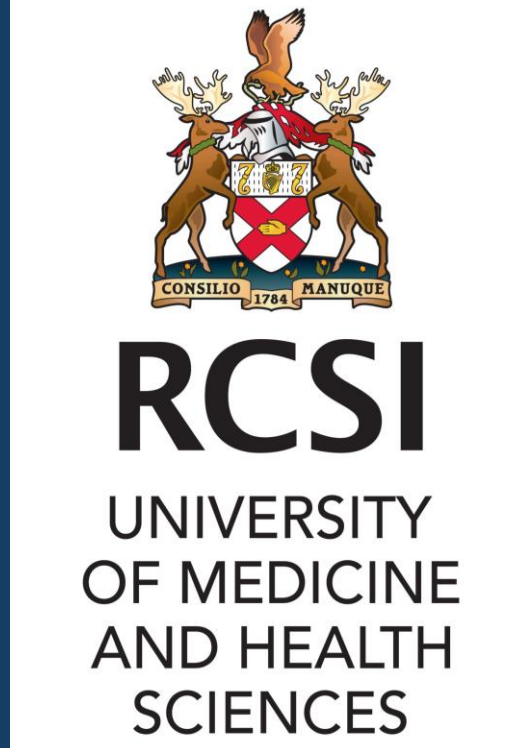


Empowering Voices, Enhancing Outcomes: Co-creating an Open-Source Health Economic Model for National Decisions on Care in Alzheimer's Disease and Dementia in Ireland

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24/PATH-A/12670

INTRODUCTION

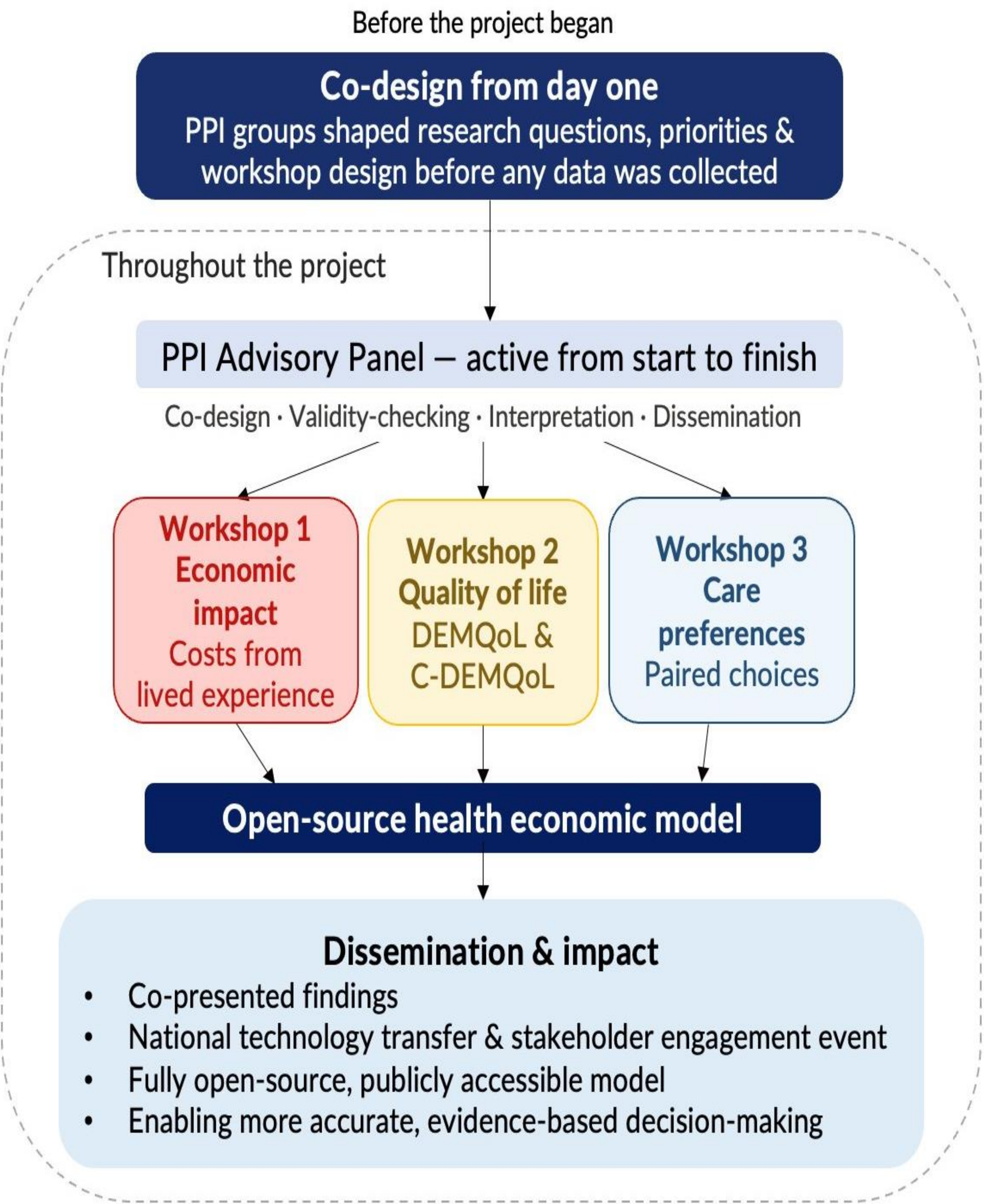
- Dementia is a major societal and economic challenge in Ireland, with estimated **annual costs of €2 billion**.
- **Around 50%** of these costs are provided through unpaid care by family members and carers.
- Current health-economic models often not accurately capture informal caregiving **costs, lived experiences** of people with **dementia** and **care preferences** of patients and carers
- As a result, healthcare decision-making may be based on evidence that does not fully represent the impact of dementia.
- This project aims to develop Ireland's first open-source, lived-experience-driven health-economic model. The model will be co-produced with people living with dementia and their carers to ensure it reflects real-world experiences, priorities, and outcomes.

METHODS

We are developing **three** dementia-inclusive workshops to inform the model:
(1) **Economic Impact**, examining the financial consequences of living with AD;
(2) **Quality of Life**, assessing well-being using AD-specific instruments; and
(3) **Care Preferences**, applying a dementia-adapted Analytic Hierarchy Process (AHP) to elicit and rank care priorities.

Workshops will be conducted across three sites (Dublin, Cork, and Galway) to ensure regional diversity.
We will recruit a total of 120 participants (60 people living with dementia and 60 family carers)

A six-member PPI Advisory Group co-designs all aspects of the study, including materials, topic guides, recruitment strategies, and accessibility adaptations, supported by a multi-disciplinary steering group.



RESULTS

Early co-production findings from our first PPI workshop, June 2026

- **Partnership established**
 - The PPI Advisory Group held its first meeting in June 2026, with members drawn from the Dementia Research Network Ireland, Global Brain Health Institute, Lewy Body Society, Dementia Research Advisory Team, and lived-experience advocates from rural Ireland and Dublin, across different genders and ages.
 - Members agreed a collaborative working model centred on co-design, with the research team committing to accessible communications and iterative input at each study stage

► Priorities raised by members

Members highlighted the importance of capturing informal carer burden and care preferences alongside clinical outcomes, directly informing the HRQoL and utility inputs of the model. Accessibility of materials and plain-language summaries were identified as essential for meaningful ongoing engagement

► Shaping next steps

The group will co-review recruitment materials and workshop topic guides ahead of the July 2026 participant recruitment launch, with workshop delivery beginning August 2026 across Dublin, Cork, and Galway.

CONCLUSIONS

- This work will provide a framework and a more accurate health-economic modelling tool that incorporates lived experiences and supports more person-centred national decision-making in dementia care.
- The resulting open-source Markov model, co-produced with people living with dementia and their carers, will be Ireland's first publicly accessible health-economic model for Alzheimer's disease.
- By embedding multi-level PPI throughout, this study aims to ensure the model is shaped by outcomes that matter most to those living with dementia and their carers.

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