

Staring into the void...

*Co-Designing Dementia Diagnosis and
Post Diagnostic Care*

Dr Meredith Gresham

on behalf of the COGNISANCE Team



Dementia



Context

- Improvements needed for making and communicating a dementia diagnosis
- While guidelines exist, diagnostic process and post diagnostic support is lacking
- Families often dissatisfied and experience “prescribed disengagement”

“I was told to give up work, give up study, and to go home and live for the time I had left”
– *Kate Swaffer*

Contributing factors

- Practitioner behaviours are influenced by personal, patient, health system related and societal factors
- GP's report they lack time, knowledge and skills in diagnosis, its communication and post diagnostic care
- Limited availability of post-diagnostic services is likely also a contributing factor
- Patients experience fear, stigma and self-stigma

Lessons from other health conditions

- In cancer research, practitioner training has been found to improve communication of results and reduce patient anxiety
- Our interviewees have said “it would be better to have breast cancer”
- Stigma reduction campaigns have been successfully conducted in the past



The COGNISANCE Project

Co-Designing Dementia Diagnosis and Post Diagnostic Care
A 5-country, 3-year project that aims:

- To co-design and deliver in partnership with people with dementia, family care partners, health and social care professionals, social marketing campaigns and toolkits that will
- improve communication of dementia diagnosis and post-diagnostic support in Australia, Canada, the Netherlands, the UK and Poland
- To evaluate the campaigns
- To design a “playbook” of how to best navigate the process of diagnosis and offer post-diagnostic support that is able to adapted and implemented globally.

Campaign and Toolkits

- A **social marketing** campaign will be co-designed with health professionals social care professionals, care partners and people living with dementia to promote behaviour change
Part of the campaign will be two toolkits:
- Toolkits will empower people living with dementia and their carers to ask for support
- Toolkits will equip health and social care practitioners to deliver effective support plans



How will we do this?

Collecting data on experiences, barriers and supports available...

- Participants complete survey, are then invited to participate in a focus group, interview or asked if they would like to be involved in the toolkit design
- Systematic review and scoping review on care planning in dementia

How will we do this?

Then using this data to develop internationally applicable toolkits for the public and health care professionals

- Through co-design with people living with dementia, their care partners, and health care professionals
- Ensure sustainability through our external partners ADI, DAI and WHO as well as national Alzheimer's associations

PHN Involvement

How will we work with the PHN?

- Distribute and promote the survey to your network of GP's
- Participate in focus groups and/or contribute to toolkit relevance through user testing
- Provide representation on the co-design group (Ian and Maria) to
 - » Bring PHN perspective on toolkits, campaign activities
 - » To provide information to ensure toolkits that integrate with existing systems with ease
 - » to leverage from research activities to assist the PHN in its work

Questions

- What is the most effective way PHN's have influenced change in GP practices?
- How can existing chronic care plan software be adapted for dementia?
- What are the must-haves for the toolkit to be practical, effective and user friendly?



Thank You

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<https://cheba.unsw.edu.au/consortia/cognisance>



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