

Staring into the void...

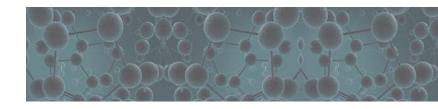
Co-Designing Dementia Diagnosis and

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"







### **Contributing factors**

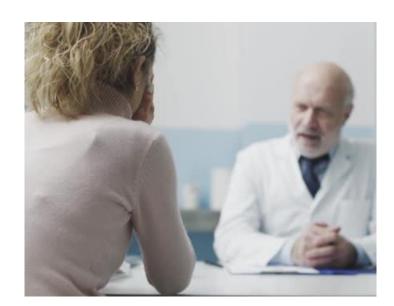
- Practitioner behaviours are influenced by personal, patient, health system related and societal factors
- GP's report they lack time, knowledge and skills in diagnosis, its communication and post diagnostic care
- Limited availability of post-diagnostic services is likely also a contributing factor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



for Healthy Brain Ageing



#### 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 (lan 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

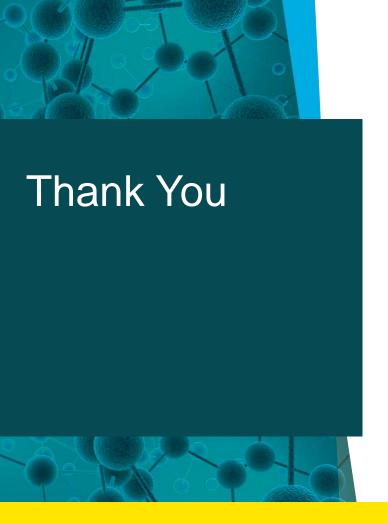




### **Questions**

- 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?





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