

Centre for Healthy Brain Ageing (CHeBA)

Co-designing Dementia Diagnosis and Post-diagnostic Care (COGNISANCE)

NEWSLETTER | December 2020

Greetings from the Australian COGNISANCE Research Team. We wish you a peaceful festive season and a happy and healthy 2021.

The end of year is usually a time of reflection perhaps more so in 2020 which has been challenging for us all.

COGNISANCE aims to improve the way in which a diagnosis of dementia is communicated and the support that people with dementia and care partners receive following that diagnosis. COVID-19 meant that many of our research plans had to be re-imagined at short notice. Our arrangements for interviews and focus groups had to move online, we learnt to work and collaborate remotely, and we conducted a small sub-study to learn about your experiences during COVID.

We are proud of what you have helped us achieve this year in overcoming these challenges. We finished the first phase of our project, consisting of surveys and focus groups or interviews that aimed to understand better your experience of dementia diagnosis and post-diagnostic support.

Thank you to all who participated. Your frankness in sharing your experience was invaluable.

We are now "full speed ahead" towards a fully functional, online or printable toolkit which will empower people living with dementia and their care partners with information and plans to help acquire the support they need.

During 2020, we established co-design groups across the five countries involved in our research in collaboration with Spencer DuBois (an UK based marketing company). The people living with dementia, care partners and health and social care professionals who make up the co-design group have a breadth and depth of knowledge that is humbling!

Those involved in this group are currently working hard to bring these toolkit plans to life, and we can't wait to share this with everyone next year.

In September we farewelled our research assistant Lauren

King, who has moved back to the UK to pursue her PhD in clinical psychology. We welcomed Nora Wong, our new Research Officer who some of you may have the pleasure of meeting in this coming year.

We are looking forward to the year ahead. Around the middle of 2021 will see the launch of the toolkits and a social marketing campaign across select regions in Australia, Canada, United Kingdom, The Netherlands and Poland. We anticipate that this campaign will encourage a 'call to action' to improve support provided by health care practitioners as well as support seeking by people with dementia and their care partners and families.

Lastly, we want to thank you again for your participation and ongoing support for COGNISANCE. Without you, we would not be able to continue this work towards our aim of improving the communication of dementia diagnosis and post diagnostic support.

Scientia Professor Henry Brodaty AO, Chief Investigator and the Australian COGNISANCE team



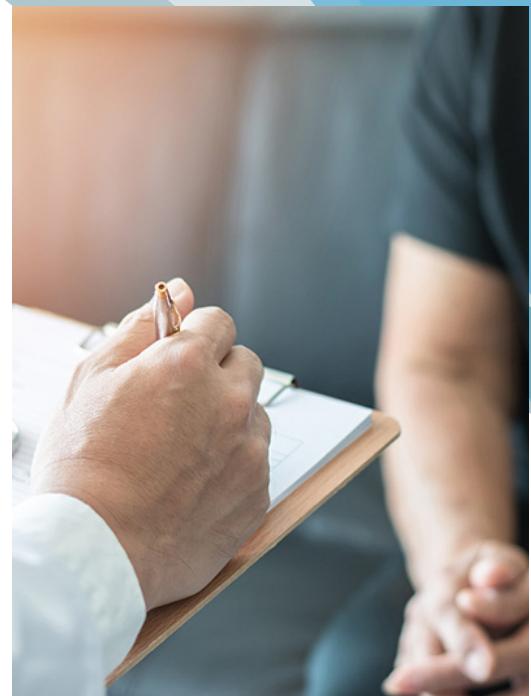
How your participation has helped us so far

At the end of our first round of survey data collection across the five participating countries, we received 92 completed surveys from people living with dementia, 300 from care partners, and 316 from health and social care professionals. In Australia, we also completed a range of interviews and focus groups, which some of you would have been a part of. In total 10 people living with dementia, 17 care partners and 19 health and social care practitioners participated.

While data analysis is still underway, it is evident from the interviews and focus group that many of you felt there was an 'information vacuum', with some participants describing a lack of support, feelings of loss, and isolation. Health and social care practitioners found the communication of diagnosis difficult, often feeling they needed to 'soften the impact'.

The surveys revealed that only 22% of people living with dementia and 34.7% of care partners received a plan of support. Support was very variable across Australia: some of you found that the support following diagnosis was somewhat or very helpful, however others found that it didn't help or made it worse.

The information you shared will be used (anonymously) to guide the creation of the toolkits and to understand what is lacking and where help is needed. Full analysis of the results will be published, hopefully later next year, and we will share this with you too.



How to stay involved in the project

In 2021 we will begin "user testing" of the toolkits. This means we will be sending them to those of you who indicated a wish to be involved in this process. In the online survey we sent you we asked if you would like to be involved in user testing of the toolkits. If you haven't signed up yet, please let us know.



We will ask you for feedback on the contents of the toolkit and how well it works. This is an important step in our co-design process, to make sure that what we have created will be able to help those who are facing a new diagnosis of dementia, and their families and care partners.

Introducing COGNISANCE Study Coordinator, Meredith Gresham

What is the ultimate hope you have for your research?

That the outcomes of this research are implemented. We are developing practical toolkits through a codesign process. That is, we are bringing together everyone involved in dementia: people with dementia, care partners, health, and social care professionals. By working together, toolkits should be relevant and practical. Toolkits will 'speak' to the people who need them.

"My biggest hope for our research is that it is widely accepted and widely implemented - not only throughout Australia but because it is an international project - throughout the world."

My greatest wish is that it provides a sense of hope for people diagnosed with dementia and their care partners. It provides health and social care practitioners with new tools and new ways of thinking about approaching and supporting people with dementia.

Read Meredith's full interview here:

<https://cheba.unsw.edu.au/blog/dr-meredith-gresham-meet-our-researcher-series>



Dr Meredith Gresham, PhD
Study Coordinator, COGNISANCE

Student Projects with COGNISANCE

ISSRA ALLAM, Honours Student

My Honours research project aims to try to better understand the experiences of dementia diagnosis and post-diagnostic care in the Australian Lebanese community. There is currently no research into the types of dementia supports needed in this community. Therefore, Australian healthcare practises may not be suitable, which could negatively affect their quality of life and health outcomes. If you are a Lebanese person who has been diagnosed with dementia within the last two years, their carer or a health care practitioner whom attends in their care, please email cognisance@unsw.edu.au.



PAULINE BEARD, ILP Student

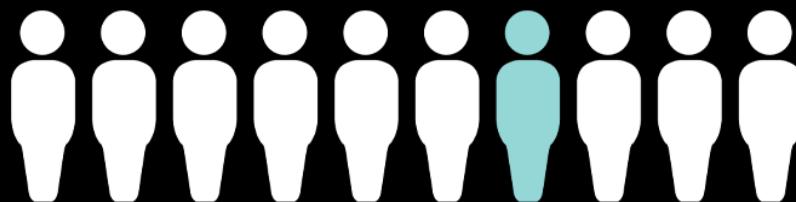
My study explored how COVID-19 restrictions impacted people with dementia and their carers over a two-month period. While I found that physical distancing and restrictions negatively impacted their lifestyles and routine and showed their vulnerability to social isolation, most people with dementia and carers were able to adapt and accept the restrictions that were put in place.

About CHeBA

The Centre for Healthy Brain Ageing (CHeBA) is a premier research institution at UNSW Sydney, investigating brain ageing. CHeBA was established in October 2012 and headed by internationally acclaimed leaders in the field, Professor Henry Brodaty and Professor Perminder Sachdev. Our vision is to achieve, through research, healthier brain ageing and better clinical care of age-related brain diseases. The COGNISANCE project is one of the international consortia which CHeBA leads. It is a multi-organisation, international collaboration. In Australia the team comprises: Professor Henry Brodaty; Dr Meredith Gresham, Ms Nora Wong and Ms Ashley Stevens at the University of NSW; Professors Lee-Fay Low, and Yun-Hee Jeon, Ms Tanya Duckworth Ms Pauline Beard and Ms Issra Allam at the University of Sydney; Associate Professor Lyn Phillipson at the University of Wollongong and Ms Kate Swaffer, founder of Dementia Alliance International.

For any enquiries regarding the COGNISANCE Project, please get in touch with us via cognisance@unsw.edu.au.

1 in 10 Appeal



Let's reduce the risk

www.bit.ly/CHeBA1in10Appeal

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