

psychiatric disorders, MBI was associated with a significantly higher psychopathology severity, especially in the apathy and negative symptoms domain.

Preliminary longitudinal analyses were also performed on a subsample of 83 patients followed-up for at least 3 months (on average for one year): at baseline 44 patients had been diagnosed with primary mood disorders including 23 patients in remission and 21 patients with current mood episodes; 22 patients had MBI and 17 were diagnosed with dementia. While at follow-up patients with mood episodes showed a significant decrease in psychopathology severity and increase in global functioning, those with MBI had no significant improvements.

In conclusion, MBI is a common condition in psychogeriatric settings and shows distinctive clinical features that may help differential diagnosis. Moreover, the presence of MBI in patients with late-life psychiatric disorders may affect both clinical and functional outcomes. The recognition of patients with MBI symptoms, including apathy, might be useful for the early detection of individuals with poor prognosis.

## **S5: COGNISANCE: Co-Designing Dementia Diagnosis And Post Diagnostic Care**

### *Symposium Overview*

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People with dementia can live full and meaningful lives after diagnosis, but still many people with dementia and their family care partners are dissatisfied with the process of getting a diagnosis and may also receive limited, if any, post-diagnostic support. The international COGNISANCE project aims to improve the communication of dementia diagnosis and post-diagnostic support. It is a 3-year project supported by the EU Joint Program for Neurodegenerative Disease Research (JPND), with partners in Australia (lead), Canada, Netherlands, UK, and Poland.

Based on the experiences of people with dementia, family care partners and health care professionals, and in partnership with them, we codesigned a website that provides structured information, resources and tools tailored to empower people with dementia and their family care partners. Effects of the campaign was evaluated using the RE-AIM framework. From our collective experiences, a 'playbook' was produced outlining how to deliver similar campaigns in other countries. Through these activities we aimed to improve health care practitioner's diagnostic habits and provision of support, as well as increase help seeking by people with dementia and care partners.

In this symposium, you will hear about the latest results of four workpackages of this COGNISANCE project:

1. A general overview of the rationale, goals, and design of the project will be presented by the principal investigator
2. Data of a qualitative study will be presented on the experiences of receiving a diagnosis, and the barriers and facilitators towards post-diagnostic support, as well as on the differences and similarities between countries.
3. The development of an online actionable guide Forward with dementia ([www.forwardwithdementia.org](http://www.forwardwithdementia.org)) using a person-centered approach with target audience groups. The aim of this online guide was to support decision making and to help people find their way forward from a diagnosis of dementia.
4. Data will be presented of the evaluation of the implementation and perceived impact of the Forward With Dementia websites and campaign in the five participating countries

### **Co-Designing Dementia Diagnosis And Post Diagnostic Care, The Cognisance Project: Forward with Dementia (FWD)**

COGNISANCE Team\*

Despite many national guidelines for diagnosis and management of dementia, persons diagnosed with dementia and their family carer partners are often dissatisfied with the diagnostic process and receive limited post-diagnostic support.

Teams from Australia, Canada, the Netherlands, the UK and Poland co-designed and delivered, in partnership with people living with dementia, family care partners and health care professionals, online packages, toolkits and campaigns to improve the dementia diagnostic process and post-diagnostic support.

Our website [www.forwardwithdementia.org](http://www.forwardwithdementia.org) (FWD) offers information in English, Dutch, French and Polish for people living with dementia, carers and health care practitioners developed based on published evidence, national dementia guidelines and, across five countries, from surveys focus groups and input from each target group; and refined after field testing. FWD uses engaging language and graphics to provide personal stories, tips, advice and local contacts for assistance. The FWD website, and in two countries an online tool-kit for curating the information, was promoted with social media, regionally-specific targeted campaigns, webinars, local events, television coverage and presentations to the public and to health care providers. The effectiveness of the internationally varied campaigns, evaluated using RE-AIM framework, demonstrated variable Reach and Engagement; Adoption, Implementation and Maintenance are still being assessed. In collaboration with the World Health Organisation, Alzheimer's Disease International and Dementia Alliance International we have developed a playbook that facilitates FWD to be adapted and implemented internationally.

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## **Experiences in coping with dementia and the role of support; a qualitative study of the COGNISANCE project.**

**Objective:** People with dementia and informal caregivers utilize a variety of coping strategies to deal with the consequences of a dementia diagnosis. In the beginning they often rely on informal support, but research shows that they could benefit from formal support. The societal and cultural context may also influence how people deal with dementia. Yet, most research that takes place across countries or cultures provides little detail about cross-country differences or similarities. The purpose of this qualitative study is firstly to describe experiences of receiving a diagnosis and experiences, barriers and facilitators towards post-diagnostic support and secondly, and to examine differences and similarities between countries

**Methods:** A cross-country qualitative study with people with dementia recently diagnosed and their informal caregivers was carried out in Australia, Canada, the Netherlands and Poland between March 2020 and September 2020. A wide range of recruitment strategies and methods was adopted to aid recruitment and participation during the covid pandemic. Participants could participate in (online) Individual and dyadic interviews as well as online focus groups. To examine experiences after diagnosis and support, methods utilized 'projective techniques' whereby participants could project their experiences onto two fictional characters (a person with dementia, and her informal caregiver). A multi-step iterative inductive qualitative content analysis was carried out.