

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 (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.

Results: 23 people with dementia and 53 informal caregivers participated. The following themes were identified; 'getting a diagnosis, 'coming to terms with dementia', 'support from friends and family', 'formal support', 'adapting to the role of informal caregiver' and 'living well with dementia'. 'Formal support' and 'support from friends and family' could serve as a barrier, facilitator or both in relation to 'coming to terms with dementia' and 'adapting to the role of informal caregiver'. Coming to terms was a necessity for living well with dementia. 'Adapting to the role of informal caregiver' was an ongoing adaptation process that was part of 'coming to terms with dementia' and extended into 'living well with dementia'. Similarities of the themes across countries were larger than the differences.

Conclusion: Support should enable the process of coming to terms with dementia in a culturally appropriate manner.

"FORWARD WITH DEMENTIA" CO-DESIGN OF AN ONLINE GUIDE FOR DEMENTIA PATIENTS AND FAMILIES

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Objective: Through a co-design process we set out to improve post diagnostic dementia support as part of a wider international programme. A partnership approach was taken with people living with dementia, carers and healthcare professionals.

Methods: A scoping review and thematic analysis of existing national and international dementia policies guidelines and campaigns were undertaken to identify gaps and to create a core evidence base. We established co-design local working groups in each of the five partner countries. A series of 20 objective led iterative workshops, four in each country over a period of six months were held. In this way a prototype website was designed, built, populated, and refined. Evidence based English language content was generated and edited collaboratively, core themes were derived from operationalising national Dementia Clinical Guidelines, utilising current evidence, responding to co-designers' requests and formative research findings. The website was then adapted regionally through translation, links to local information, and including culturally appropriate images, stories and news items. These adapted sites were then user tested and further refined ahead of awareness raising campaigns.

Results: We co-designed a dementia friendly accessible resource to support people living with dementia, carers and healthcare professionals for the first 12 months following diagnosis. The workshops determined that the resource should be available online, current, practical, and relevant at a regional and individual level. The need for a practical, empathetic and individually tailored resource was identified. Language, tone, and online accessibility were essential, particularly for people living with dementia. It was important that the content be written and presented specifically and discretely for people recently diagnosed with dementia, for care partners and for healthcare professionals.

Conclusion: We set out to improve the dialogue around dementia diagnosis. To empower patients and practitioners through providing information, practical tools, improving awareness of and access to available local supports. Through a person-centred approach with target audience groups together we have developed an online actionable guide [Forward with dementia](https://www.forwardwithdementia.org) (<https://www.forwardwithdementia.org>) which supports decision making and to help people find their way forward from a diagnosis of dementia.

Evaluating the Forward with Dementia Campaign in Five Countries

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