

**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

**Authors:** Wilcock<sup>i</sup>, Poole<sup>ii</sup>, Robinson<sup>ii</sup>, Rait<sup>i</sup> on behalf of the COGNISNACE consortium<sup>iii-vii</sup>.

University College London<sup>i</sup>, Newcastle University, University of New South Wales<sup>iii</sup>,  
University of Sydney<sup>iv</sup>, McGill University<sup>v</sup>, Maastricht University<sup>vi</sup>, Wroclaw Medical University<sup>vii</sup>.

**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

**Authors:** Isabelle Vedel<sup>1</sup>, Shelley Doucet<sup>2</sup>, Alison Luke<sup>2</sup>, Carrie McAiney<sup>3</sup>, Pam Jarrett<sup>4</sup>, Laura Rojas-Rozo<sup>1</sup>, Amy E. Reid<sup>2</sup>, Emma Conway<sup>3</sup>, Ana Saavedra<sup>1</sup>, Luke MacNeill<sup>2</sup>, Julia Besner<sup>5</sup>, Rachel Thombs<sup>5</sup>, and The COGNISANCE Consortium.

**Authors if the 4 presenters also count for the authors :** Isabelle Vedel, Shelley Doucet, Alison Luke, Carrie McAiney, on behalf of the The COGNISANCE Consortium

1: Department of Family Medicine, McGill University; 2: Centre for Research in Integrated Care, University of New Brunswick Saint John; 3: University of Waterloo; 4: Horizon Health Network; 5: University of New Brunswick Saint John

Word Count: 317/350

**Objective:** The Forward with Dementia (FWD) project is a dementia awareness campaign that was implemented across five countries. The campaign included components such as websites (in four languages – [www.forwardwithdementia.org](http://www.forwardwithdementia.org)), webinars, newsletters, and social media posts. This campaign is the fourth phase of a three-year longitudinal mixed methods study with five phases in five countries: Canada (New Brunswick, Ontario, Quebec), Australia, the Netherlands, United Kingdom, and Poland. The purpose of this study is to evaluate the implementation and perceived impact of the FWD websites and campaign in the five participating countries.

**Methods:** The RE-AIM framework (Reach, Effectiveness, Adoption, Implementation, Maintenance) was used to guide the campaign evaluation. The evaluation was drawn from Google Analytics, surveys, individual interviews, and report cards. Data collection occurred between September 2021 and May 2022.

**Results:** There were approximately 124,945 page views across all FWD websites during the campaign. Participants of the surveys and interviews reported engaging in a range of campaign activities. They read information about receiving a diagnosis, stories from persons with lived experience in dementia, news, and attended webinars (or watched recording). Most participants rated the information that they read on the website moderately, very, or extremely helpful. In addition, the majority of respondents said that they plan to visit the website again. During the interviews, participants shared that the website was easy to navigate, practical, and that it maintains a positive tone related to dementia. The co-design aspect of the campaign was considered a strength.

**Conclusion:** The findings indicate that the FWD campaign can provide support for people who have recently received a dementia diagnosis and their family or friends. In addition, the campaign may provide health and social care providers with a new source of information and tools to use and share with their clients. These results informed the development of a playbook to guide regions and countries beyond those involved in this project to implement similar initiatives.

## **S6: Adapting and implementing WHO iSupport among dementia caregivers worldwide: users' perspectives and future development (Session I)**

### *Symposium Overview:*

The WHO Global Action Plan against Dementia calls for “at least 75% of member states providing carer support and training by 2025”. In response to the global target, WHO has developed iSupport aiming to provide support for caregivers of people living with dementia. The generic WHO iSupport has been translated and adapted in 39 countries and 37 languages so far. The adapted versions of WHO iSupport are now being implemented worldwide, usually as an online program for caregivers. The feasibility, accessibility, effectiveness and sustainability of the iSupport program in different cultural context is now being explored extensively. This symposium aims to share the up-to-date research findings and lessons learned on the adaptation and implementation process and users’ perspectives from diverse cultural background. It will include seven presentation and be divided into sessions: 3 presentations on Session I and 4 presentations on Session II.