

**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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