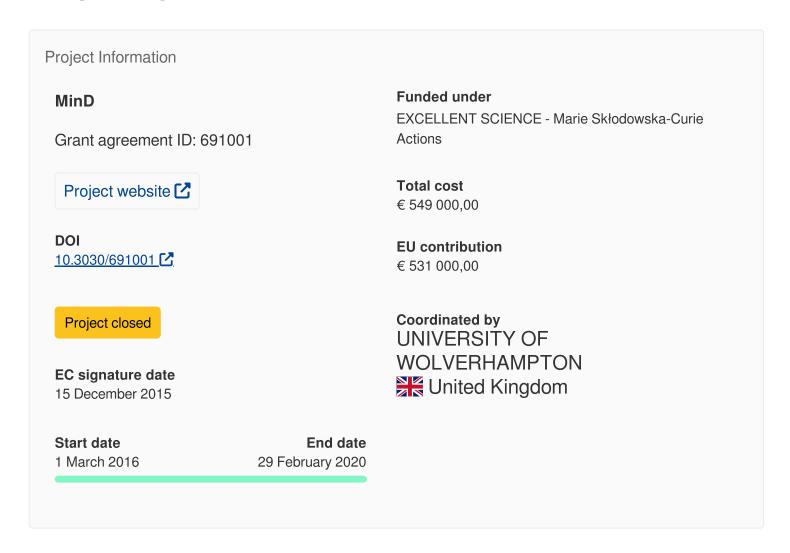
Designing for People with Dementia: designing for mindful self-empowerment and social engagement



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Reporting



Periodic Reporting for period 2 - MinD (Designing for People with Dementia: designing for mindful self-empowerment and social engagement)

Reporting period: 2018-03-01 to 2020-02-29

Summary of the context and overall objectives of the project

MinD aims to help people living with dementia (PwD) engage in social contexts to improve psychosocial wellbeing. PwD often face cognitive, behavioural and psychosocial difficulties, including memory impairment/degeneration and perceived loss of identity. This can cause difficulties recognizing, relating to and empathising with other people, which affects social engagement and quality of life.

MinD investigated how design can complement existing care approaches in novel ways, using mindfulness to empower PwD in everyday social situations. It focused on personal difficulties with, and environmental influences on social engagement. We explored how mindful design can help develop innovative solutions that help PwD enhance perceptions of identity, confidence and agency through meaningful social engagement, mindful reflection and decision-making.

Objectives:

- 1) investigate challenges/opportunities to increase PwDs' subjective wellbeing and social engagement through mindful design;
- 2) develop mindful co-design approaches to empower PwD to express their needs and challenges during the design process;
- 3) develop a mindful design approach to developing product solutions to empower PwD to engage socially;
- 4) investigate/test the conceptual and technical development of tangible mindful design solutions (personal/environmental), supportive of personal wellbeing and social inclusion within dementia care;
- 5) develop a holistic model of mindful design-integrated dementia care re social engagement challenges/opportunities.

Outcomes:

- 1) new design uses to help PwD engage socially and improve subjective wellbeing;
- 2) robust methodological co-design framework for design development and evaluation with PwD;
- 3) holistic mindful model of designing for mindful care for PwD;
- 4) policy recommendations to include design in dementia care.

Work performed from the beginning of the project to the end of the period covered by the report and main results achieved so far

MinD comprises 5 scientific WPs (2-6), in 3 overlapping phases, underpinned by organisational WPs.

Mindful Design Framework (WP2)

This provided the project's theoretical backbone: the conceptual framework and values that underpin all practical aspects of the research. It included a review of the theoretical position and approaches of mindfulness, and identification of core mindfulness values, and synthesised into a guiding framework. It created a set of policy recommendations for using design to support people with mental health

issues, specifically PwD.

Dementia Framework and Data Collection (WP3)

WP3 core tasks were the theoretical review of relevant dementia care areas, data collection and analysis with PwD and their carers. Information was collected about daily living, leisure and social activities, decision making involvement in these 3 areas, times/situations of wellbeing (or not), changes over time, and any supporting objects or devices used.

Data were collected from Sep 2016-Apr 2017 in Germany, Netherlands and Spain with both PwD and carers, using focus group interviews, individual interviews, and visual diaries for richer data about people's emotions, values, and visual information on supportive/challenging design objects or devices. Data analysis reviewed 9 themes that were of importance to PwD with regard to social wellbeing and empowerment. Findings were presented for validation/feedback in LU in May 2017 to PwD and carers from the Europe Working Group for PwD.

Mindful Design process and Solutions (WP4 and WP5)

From Sept 2016 for 6 months, WP teams worked together to develop data collection materials (visual cards and visual diaries) to support data collection activities in WP3. Cards functioned as memory/discussion aids. Diaries, completed at home with more time and reflection, added understanding participants' wishes, values and challenges in everyday life.

The design development and co-design process included:

- Review of existing design products/services available to support PwD re personal wellbeing, self-empowerment and meaningful social engagement.
- Framework development for mindful scenario task analysis to identify opportunities for mindful design interventions related to improving subjective wellbeing, self-empowerment and meaningful social engagement.
- Development of a persona tool to enable designers better to understand PwDs' views, concerns and preferences.
- Brainstorming and ideation sessions to develop initial design ideas and concepts from WP3 results.
- Consultation sessions with care professionals, carers and PwD in UK, ES and DE to develop concepts and gain feedback for selection of design ideas to develop into prototypes.
- cCncept and prototype development co-design sessions with PwD in UK, DE and ES to develop selected design ideas appropriately for PwD.

WP4 and 5 developed 4 design solutions:

- 'This is Me' board game to support people following the dementia diagnosis with a forward-looking positive attitude and social engagement through focusing on what they can/want to do.
- 'Living the Life' reflective booklet to support post-diagnosis in developing a positive attitude to everyday challenges through simple suggestions and mindful exercises.
- 'You and Me' discussion tool to aid PwD to take charge in discussing issues and changes resulting from their illness with carers (responding to perceived challenges).

• 'Let's meet Up!' hybrid electronic board game responds to PwDs' need to stay socially active, by supporting them to make arrangements for social and physical activities.

Implementation and User Evaluation (WP6)

WP6 developed the strategy and tools to evaluate the design prototypes with PwD and carers, through interviews, focus groups and public and patient involvement (PPI) workshops. Questionnaires ascertained the user experience, including design usability, enjoyment and potential impact. 'This is Me' was evaluated with PwD in UK, DE, NL and ES, with excellent results. Further work after evaluation led to a new version of 'Living the Life' available online. The UK PPI group evaluated a 'Let's Meet Up!' experiential prototype (full evaluation planned through follow-on grant). WP6 collated the design guidelines including tools and co-design processes with/for PwD.

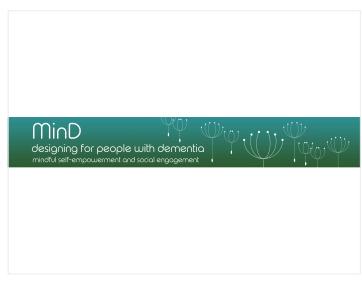
Training, dissemination and outreach (WP7 and WP8)

MinD was delivered through numerous events and training activities during project exchanges, including presentations, site visits, training workshops, co-research and more.

Dissemination and outreach through academic and public publications and events included 3 public symposia, an international conference, and several presentations, focus groups and workshops with stakeholders, including the European Working Group of PwD and PPI groups in UK, DE and ES.

Progress beyond the state of the art and expected potential impact (including the socio-economic impact and the wider societal implications of the project so far)

- Contribute to dementia care research (core EC priority) through a unique focus on social engagement, joining dementia care, mindfulness and design, improving the human dimension.
- Aid human-focused use and integration of new technologies within health (EC recommendation). It addresses current issues of insufficient user involvement in innovation development, highlighted by leading Alzheimer organisations.
- further design innovation potential by expanding/applying healthcare design interventions ('Design for Europe'): improving peoples' experiences, public services, and recognition of design's importance in health research.
- Further design research: provides growth capacity for EU design research and contribution to healthcare improvement, by providing new skills/training in design research.



MinD logo

Last update: 15 December 2020

Permalink: https://cordis.europa.eu/project/id/691001/reporting

European Union, 2025