INovative Midlife INtervention for Dementia Deterrence (IN MINDD)

Dublin, Ireland
Kate Irving

Project Stage:
Idea
Website:
http://www.inmindd.eu/

- Aging
- Health care
- Health education
- Wellness

Project Summary

Elevator Pitch

Concise Summary: Help us pitch this solution! Provide an explanation within 3-4 short sentences.

Our innovative online dementia risk profiler can be used by a clinician to design & support personalised strategies for modifiable risk reduction.

About Project

Problem: What problem is this project trying to address?

Dementia is a serious loss of cognitive ability beyond what might be expected in normal aging. The experience of dementia can be a frightening ordeal resulting in loss of self-esteem and personhood. Providing support and care for those affected by dementia can cause considerable emotional and financial burden for carers. The impact of dementia resides not only at the levels of the individual, their families and friends, but also at a global level. Europe's population is ageing and, as old age is the biggest risk factor for dementia, we face a dementia epidemic in the coming decades. Currently, the global costs for people with dementia amount to more than 1% of GDP. Dementia is incurable and its complex etiology and pathogenesis make the likelihood of a cure a remote possibility. While some medications such as memantine and galantamine have been found to slow the progression of the condition for some patients, they do not reverse it or stop its progress. Therefore prevention is an issue of considerable importance. The presence of elevated risk factors is associated with an increased chance that a given disease will develop or will develop earlier. In the case of dementia, certain risk factors are non-modifiable such as age and genetic make-up. However, there is a large body of compelling evidence that measurable and modifiable risk factors in midlife have a profound impact on the risk and/or onset of dementia in the over-70s. Such modifiable risk factors include cardiovascular markers, mood and depression, social networks and diet. Lack of awareness of dementia and its prevention is a global problem. Due to the debilitation associated with dementia, it is the most feared condition related to ageing with many adults attending GPs with memory concerns. These patients are receptive to information about dementia risk reduction, but unfortunately, general negative attitudes towards interventions to prevent dementia are common among both GPs and the general public. Significantly, research has shown that most GPs and their nurses consider their dementia knowledge to be inadequate. Testing for memory problems or discussing dementia with their patients is rare. Strategies for reducing dementia risk are well established but are not widely known in the general public or well addressed among primary care providers.

Solution: What is the proposed solution? Please be specific!

The social innovation challenge addressed by In-MINDD is to raise awareness that it is possible to profoundly influence future dementia risk for at-risk individuals aged between 50 and 60 years and to provide personalised support through individual risk profiling. In-MINDD will develop a

highly accurate and complete model that predicts risk as it relates to a broad multidisciplinary set of modifiable risk factors. Scalable online tools for doctors and patients to work together on risk identification and reduction will be embedded into existing healthcare systems. The solution combines peer enthusiasm, expert knowledge and personalised progress assessment. Additionally, In-MINDD innovatively combines personalised medicine with social networks and “crowd-powered” social networking via the internet and mutual social support to address this need. The In-MINDD solution is as follows: • An individualized risk factor profile and a quantitative, evidence-based measure of future dementia risk will be produced using a series of simple routine tests suitable for the primary care environment (e.g. a GP clinic). • Based on an individual’s risk factor profile a personalized strategy for risk reduction can be generated. Working closely with the primary care clinician, a personalized action plan for reducing dementia risk can be tailored for each individual. • Support from clinical experts and other patients, delivered via an interactive and supportive online environment, will help reinforce adherence to the risk reduction strategy • Communication and awareness that dementia risk can be modified will have a major impact In-MINDD represents a radical step forward – not only will we communicate the fact that many dementia risk factors can be modified, we will empower primary care providers to advise and support their patients in adhering to a personalized risk reduction strategy. Old-age dementia is an important issue for both the elderly and society as a whole. It impacts the quality of life of elderly citizens and the sustainability of health care systems. The prevention or delay of the onset of old-age dementia is a crucial societal need. In-MINDD addresses this need using socially innovative solutions that combine information technology, social networking and mutual social support.

Impact: How does it Work

Example: Walk us through a specific example(s) of how this solution makes a difference; include its primary activities.

In primary care many non-demented individuals within the general public express significant concerns about their memory. Additionally, awareness of early intervention/disease prevention is increasing the number of people reporting subjective memory complaints to their general practitioners and/or attending memory clinics. Typically, these individuals are not diagnosed with a clinical condition, and it is at this point that a person is very receptive to dementia risk reduction. Our solution can be implemented at this crucial juncture, and this will involve the GP completing an In-MINDD risk profile (a decision support system) which will suggest a bespoke risk reduction plan, which can then be modified by the GP as appropriate. Our scalable on-line support environment for doctors and patients to work together on risk identification and reduction brings together evidence-based measures to support lifestyle modification (such as on-line smoking cessation programmes, weight loss or exercise advice)

Sustainability

Marketplace: Who else is addressing the problem outlined here? How does the proposed project differ from these approaches?

Existing models of risk are based on 8-10 factors, some of which are not modifiable. These models also lack factors such as depression and physical activity. There is a need to use a broader portfolio of risks, particularly modifiable risks. In-MINDD presents a more complete model that predicts risk as it relates to a broad, multi-disciplinary set of risk factors which are appropriate for routine measurement in general practice. Current online supports for dementia prevention (e.g. brainyapp.com.au) only give generic advice. Some relatively small trials into cognitive health promotion have been conducted (Passport Study, Hansen et al. 2010; FINGER Study, Kivipelto et al, 2010; MAPT Study, Gillette et al, 2009), however these are not scalable. There is a need for low cost and scalable resources which can have a real impact on population health. A solution which combines scalability with personalisation and which places the patient in control is required. In-MINDD will deliver this system and embed it into existing healthcare systems. The solution combines peer enthusiasm, expert knowledge and personalised progress assessment.

About You

Visit website

About You

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Implementer(s) and cooperation partners

Name

In-MINDD

Type

Network

Country where main implementer is located

, DB, Dublin

How long has the main implementer been operating?

Less than a year

Please provide a short description of the main implementer.

In-MINDD is a three-year project, funded by the European Union Seventh Framework Programme (FP7/2007-2013). The project commenced in November 2012. The In-MINDD technical concept is to develop and rigorously validate online tools that enable personalised dementia risk to be modelled, generate personal risk reduction strategies and facilitate adherence to these strategies. This technical work is enhanced by extensive communications and awareness raising. Project partners are based in Ireland, the Netherlands, Scotland and France.

The information you provide here will be used to fill in any parts of your profile that have been left blank, such as interests, organization information, and website. No contact information will be made public. Please uncheck here if you do not want this to happen..

Cooperation partner

Name

Dublin City University (DCU) (Coordinator)

Type

University

Website

http://www.dcu.ie/info/staff_member.php?id_no=2639

How does this cooperation partner support the initiative? What competencies and resources does this partner bring to the initiative?

Dr. Kate Irving (DCU) is principal investigator and also lead on two workpackages - Dementia risk profiler and Online Support Environment; overall Project Management. DCU's team includes clinicians who work day-to-day with dementia patients, cognitive psychologists and information technology experts

Cooperation partner

Name

University of Glasgow (GU)

Type

University

Website

http://www.gla.ac.uk/researchinstitutes/healthwellbeing/staff/kateodonnell/

How does this cooperation partner support the initiative? Which competencies and resources does this partner bring to the initiative?

Prof. Catherine O'Donnell, Institute of Health & Wellbeing GU, will lead the Validation study of the dementia risk profiler & support environment. GU will provide supports relating to primary care access and will have key input into future planning and long-term use of the project results.

Cooperation partner

Name

Maastricht University (MU)

Type

University

Website

http://www.maastrichtuniversity.nl/web/Faculties/FHML.htm

How does this cooperation partner support the initiative? Which competencies and resources does this partner bring to the initiative?

Prof. Verhey & Dr. van Boxtel (MU) will lead the development of the Dementia Risk Prediction Algorithm based on a longitudinal ageing dataset. MU expertise includes psychiatry of old age and dementia risk modelling.

Cooperation partner

Name

Universite de Nice Sophia Antipolis (UNSA)

Type

University

Website

http://www.inmindd.eu/

How does this cooperation partner support the initiative? Which competencies and resources does this partner bring to the initiative?

Prof. Robert (UNSA) will contribute to all workpackages. Their Cognition and Behavioural Technology Unit (CoBTeK) will contribute to the technical (ICT) aspects of the project as well as providing clinical expertise and establishing and managing the support environment in France.

Problem and solution

Which of these fields of Active and Healthy Ageing are addressed by your initiative?

Health literacy and patient empowerment, Personalized health management, Prevention and early diagnosis of functional and cognitive decline.

If none of the above, answer here:
Please describe if and how your stakeholders (cooperation partners, funders, users, etc.) have been participating in defining the problem and developing the solution.

It is widely agreed that a multidisciplinary approach to dementia deterrence is required. While there is some agreement over the broad areas that impact on dementia risk, less is known about how these factors interact. In-MINDD has gathered together leading experts in dementia prevention in a Delphi exercise to rank a spectrum of risk factors and agree a combinatorial model to predict dementia risk. Our cooperation partners in MU are currently validating several iterations of this model against an existing population sample (n=1200) to identify a model that combines the expertise of the Delphi team with the documented outcomes from this dataset. Next steps in developing the solution will include (i) translating this risk model into a user friendly tool that provides a personalized risk quotient and (ii) feasibility testing of the In-MINDD system. These activities will be conducted by partners in DCU, MU, GU, and UNSA, with each having clearly defined roles at various stages. Input will also be sought from selected general practices in the partner countries to co-design, develop and test the In-MINDD system in order to understand how both practitioners and patients use the tool.

Has your solution been tested in trials, experimentations, or pilot projects? If yes, please describe the process and outcome.

In the coming months our risk profiler and supportive online environment will be implemented in a random group of 600 individuals from the general public in up to 20 general practices from the 4 countries involved in this project. The feasability study will enable the team to evaluate the effectiveness of In-MINDD in relation to risk factor reduction, as well as test its usability in both routine practice and in the lives of those who use it.

How long has your solution been in operation?

for less than a year

Please select the relationship between your solution and related solutions currently established in our society. Is your solution…

complementary (your solution is complementing existing solutions and compensating their weaknesses while not intending to substitute them)

What barriers might hinder the success of your initiative? How do you plan to overcome them?

1) In-MINDD aims to incorporate new technology into the everyday lives of primary care staff and individuals deemed at risk of developing dementia. Such routine embedding is not guaranteed. In order to address this, we will attend to the inherent workability and routinisation of the tool into the person's life and primary care provider's work, using a recognized social theory, Normalisation Process Theory (NPT). In-MINDD will apply NPT and extensive consultation to ensure that new dementia prevention tools are actually usable and valuable in a clinical setting.
2) Failure to recruit sufficient numbers of doctors and patients. We address this potential low risk barrier by leveraging the strong existing relationships our partners have with doctors who have access to large patient groups to ensure adequate numbers. Additionally, we have planned a robust education framework for GPs to engage them in the importance of dementia risk reduction.

Organization and funding

Regularly paid employees

15

Volunteers

0

Trainees

0

External advisers and experts

20

Others (please specify)

0

What are the specific professional backgrounds and competencies your team brings to the initiative?

The team unites dementia specialists, frontline clinicians, mathematical model specialists, information technology experts, leaders in social networks and social innovation to validate the hypothesis that lifestyle adjustment in midlife can reduce dementia risk in later life. Each partner is suited to the tasks allocated and collectively the team has the capability to deliver the project. The consortium has been recruited to assemble all the expertise and resources needed to achieve the project's scientific and social innovation objectives and to maximize social value and long-term impact.

Please describe your management or coordination structure in the initiative.

The project management structure consists of (i) the Project Management team, within (ii) the Project Board; (iii) Sub-Committees; (iv) Work Package Leaders and (v) a specific clinical validation function. A relatively lightweight management model emphasising communication and integration is most appropriate. The project is coordinated by Dr Kate Irving of DCU. Her role is to provide scientific leadership ensuring that all work packages progress as planned and that all partners are aware of their roles. Dr Irving is supported by a specialist EU project administrator from Pintail Ltd.

Please provide the total yearly budget in Euro that your initiative spends on implementing the solution.
National public funding

%

European Union public funding

100%

Economic return from own products/services

%

Foundations and philanthropy capital

%

Single donations from private individuals

%

Donations from private companies

%

Crowdfunding platforms

%

Participation fees

%

Other (please specify)

%

Target group, scale and impact

Which target group(s) do you want to reach with your solution?

There are two end-users our solution is targeting – the primary care staff and the individuals deemed at risk. Both groups will be required to incorporate new technology into their everyday working or private life. In-MINDD is raising awareness that it is possible to influence future dementia risk and will support individual responses to this awareness through personalized risk profiling and risk reduction strategies. Primary care providers will be empowered to advise their patients and also support each individual in adhering to a personalized risk reduction strategy.

Please estimate the number of persons within your target group (users, clients, etc.) that you currently reach directly with your solution.

During the feasibility phase of our initiative, we will reach 600 individuals (including at risk) in up to 20 general practices

In which local/regional/national area(s) is the solution currently implemented?

Within the year, the solution will be implemented in selected GP practices in Ireland, Scotland, France and the Netherlands.

What is the impact on your target group (users, clients) you want to generate?

Patients will be equipped to manage their own health by adhering to the personalized risk reduction strategy which can make a profound difference to their health in later life. The project also exploits peer-powered social networks to support prescription adherence. Impact in terms of additional healthy years will be extrapolated from risk factor changes. In-MINDD will enable primary care professionals to accurately assess dementia risk and prescribe a strategy for reducing such risk thus improving the quality of care which doctors can offer their patients.

What is the wider impact on society you want to generate?

Awareness and reduction of the risk factors for dementia has a potential impact on a similar scale to the linking of smoking to lung cancer. In-MINDD attempts to prevent or delay the onset of old-age dementia thereby reducing the burden placed on EU healthcare systems. The healthy lifestyle promoted will also reduce the healthcare system burden from illnesses with related risk factors (e.g. cardiovascular disease and depression). The team will deliver the In-MINDD solution for several years after project end in order to “mainstream” results into clinical practice and public health awareness.

What are the impacts on your target group you already achieved?

To date, In-MINDD has combined the opinions of leading dementia experts in a Delphi study to identify the most accurate model of interrelated risk factors which can yield a personalised dementia risk quotient and profile. Communication of the message that dementia risk can and should be modified has been conducted using a suite of dissemination material (e.g. waiting room brochures; conference presentations) as well as media interviews and public talks. There is ongoing shared design and specification work on the risk profiler and online support environment to be rolled out in primary care.

How has the impact of your initiative been assessed?

Feedback-based self-assessment (you assessed the impacts based on feedback from the target group without using specific methods), Self-evaluation (you used qualitative and/or quantitative methods to assess impacts), External evaluation of impacts based on qualitative methods (interviews, focus groups, etc.), External evaluation of impacts based on quantitative methods (quantitative measurement of impact indicators).

Public information and strategy

What information on your initiative is publicly available?

Mission and strategy, Organisational structure, Information on team members, Working method and 'theory of change'.

Please indicate webpage or contact for obtaining the respective information.

www.inmindd.eu

What are your milestones for further developing, implementing, and establishing your initiative in the next three years? Please describe 1-3 milestones.

1. Validate a model to predict personalized risk of developing dementia over time using longitudinal ageing study datasets and test this model in primary care setting (next 9 months)
2. Implement the online risk analysis system and the In-MINDD supportive online environment and work closely with selected GP practices in the partner countries to co-design, develop and test the In-MINDD system. Develop a final version for feasibility testing (next 12 months)
3. Evaluate the use of the In-MINDD profiler and online support environment with practitioners and patients (next 24 months)

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