



WELCOME TO THE FIRST NEWSLETTER FOR THE EU PROJECT **IN-MINDD**



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IN-MINDD

Innovative,
Midlife
Intervention for
Dementia
Deterrence

For further information on
the project please visit the

Project website
www.inmindd.eu

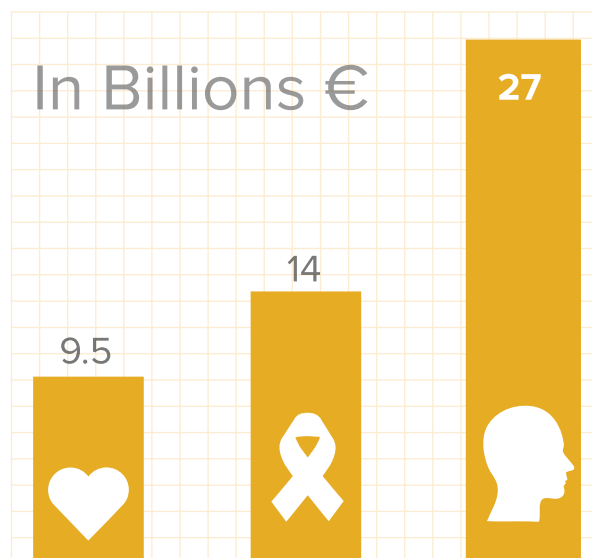
or

Twitter
[@fp7InMindd](https://twitter.com/fp7InMindd)

ALL ABOUT IN-MINDD

DEMENTIA - THE PROBLEM

DEMENTIA is a serious loss of cognitive ability beyond what might be expected from normal ageing. The condition has a profound personal impact on patients themselves and on their family and friends. There are also significant social and economic costs. 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. Globally, costs for people with dementia amount to more than 1% of gross domestic product (GDP) - if dementia care were a country, it would be the world's 18th largest economy. In Europe, the total cost of dementia was estimated in 2005 at €130 billion.¹ Dementia costs the UK economy 27 billion Euro a year - this is more than cancer (€14 billion) and heart disease (€9.5 billion) combined. It is clear that preventing and/or delaying the onset of dementia would result in significant personal benefits for individuals and substantial health care savings.²



IN THE UK, DEMENTIA COSTS MORE THAN HEART DISEASE & CANCER COMBINED

While dementia is incurable, there is increasing evidence that it can be prevented or delayed by following a healthy lifestyle in middle age. **In-MINDD** seeks to contribute to the battle against dementia in a number of ways.

THE IN-MINDD CONTRIBUTION

In-MINDD's focus is on dementia risk assessment, prevention and delay. We aim to reach potential future patients when they are in mid-life and help them adopt lifestyle changes that will reduce their risk of developing dementia, or delay its onset.

Our first task (already underway) is to confirm risk factors for dementia that are modifiable by undertaking an innovative combination of literature review and collaboration with established experts in a Delphi consultation. From this work we will build a dementia risk model, which will be validated against existing population samples (established longitudinal datasets).

We will use our risk model to build an online knowledge base and rules engine ("the In-MINDD system") which will accept a patient's risk factor profile and generate a quantitative dementia risk quotient and a personalised risk reduction strategy.

1) Wimo and Prince, 2011 World Alzheimer Report 2010 The Global Economic Impact of Dementia. Alzheimer's Disease International. September 2010.

2) Alzheimer's research Trust 2010 Alzheimer's & Dementia: The Journal of the Alzheimer's Association Volume 5, Issue 4, Supplement, Page P145, July 2009

THE IN-MINDD PROJECT AT A GLANCE

IN-MINDD (Innovative, Midlife Intervention for Dementia Deterrence) is an EU-funded project that aims to:

- Identify and validate modifiable risk factors for dementia.
- Develop online tools that can be used by doctors to determine the dementia risk of individual patients in midlife and to devise personalised strategies to reduce their risk.
- Provide supportive, socially driven online environments to help patients follow their risk reduction programme.
- Promote the message that action can be taken in midlife to prevent and/or delay dementia onset in future years.

The In-MINDD project commenced in November 2012 and is led by Dr Kate Irving of DCU.

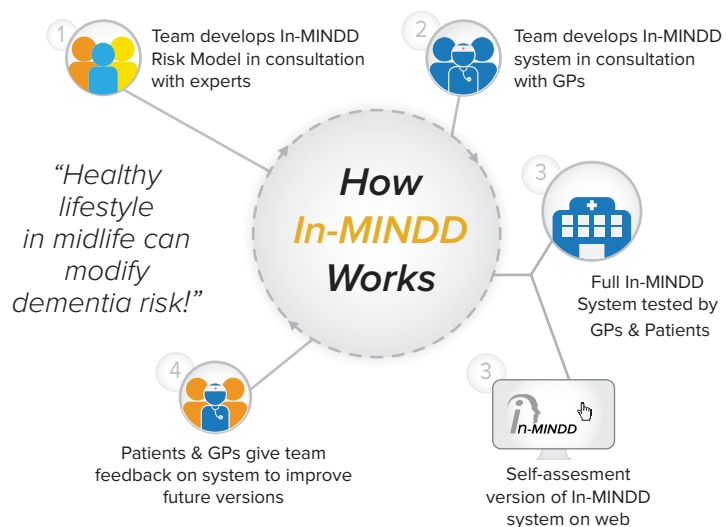
The project involves experts from Ireland, the UK, France and the Netherlands and has secured funding of €2.95m from the EU.



The design of the on-line system will be informed by consultation with general practices in each of the partner countries to ensure suitability for use in primary care settings. A “lite” version, aimed at users with no medical expertise (patients) will be made available through the project website and will offer a general assessment of risk (with a recommendation to visit a doctor for a fuller assessment as appropriate). The In-MINDD system will also deliver supportive online environments in which In-MINDD participants can interact with one another and with clinician specialists to encourage adherence to their risk reduction plan, track progress and drive success.

Finally, we will test the In-MINDD system in a feasibility study that (1) evaluates how the In-MINDD profiler tool is used in general practice, (2) measures the use of the support environment by patients and (3) compares the impact of the In-MINDD programme on patients’ modifiable risk factors (e.g. level of physical activity, weight, cognitive function) with a group of patients who do not access the In-MINDD tailored programme. This will enable us to understand how patients have used the In-MINDD programme and to identify barriers and facilitators to its use.

In-MINDD’s contribution will be to further knowledge and understanding about the risk factors for dementia that can be modified, to provide a validated on-line dementia risk assessment and risk reduction tool, to develop a supportive on-line environment for programme participants and to spread the message that old-age dementia can be prevented or delayed by adopting a healthy lifestyle in middle-age.



MODIFIABLE RISK FACTORS FOR DEMENTIA

The starting point for the development of effective prevention strategies for dementia is the identification of major midlife risk factors that can be modified. Much of the work carried out in the early months of the project has been dedicated to this task. A recent project report (28 April 2013) prepared by the University of Maastricht, summaries the work in this area undertaken to date.

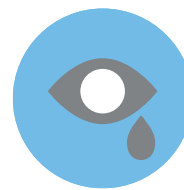
Two complementary approaches were taken by the In-MINDD team in Maastricht to summarize the best evidence on risk and preventive factors: a systematic literature review and a Delphi expert study. In the literature review the team succeeded in spotting some novel risk factors that were not included in previous risk factor reviews (e.g. renal dysfunction, heart disease) by adopting a broad search strategy. In the In-MINDD Delphi study, leading experts in dementia epidemiology were asked for their opinion regarding important risk factors. Their responses were then synthesized with information from the systematic review. There was considerable agreement between the Delphi expert panel and the systematic literature findings. All top-10 risk factors named by experts were among the best-documented risk factors based on the In-MINDD review.

**BASED ON FULL SYNTHESIS OF THE DATA,
THERE IS GOOD EVIDENCE FOR THE
FOLLOWING
MIDLIFE DEMENTIA**

RISK FACTORS



HIGH BLOOD PRESSURE



DEPRESSION



DIABETES



LACK OF EXERCISE



OBESITY



SMOKING / DRINKING

Other risk factors identified require further validation e.g.: hyperlipidemia/high cholesterol, coronary heart disease, low cognitive activity, renal dysfunction and functional impairment. The validation of these additional risk factors will take place in the second Delphi survey round.

The work undertaken to date by In-MINDD has produced an established list of modifiable risk factors for dementia and a further list of potential risk factors. All the risk factors identified will be subject to further fine-tuning and validation in established datasets/longitudinal studies. Our conclusions on modifiable risk for dementia will open the door to credible and effective risk reduction strategies. The final risk model developed will be used as the key building block for the assessment of risk and development of personalised risk reduction strategies within the In-MINDD system. Our findings also have the capacity to fuel risk reduction and public health education far beyond the In-MINDD project itself.

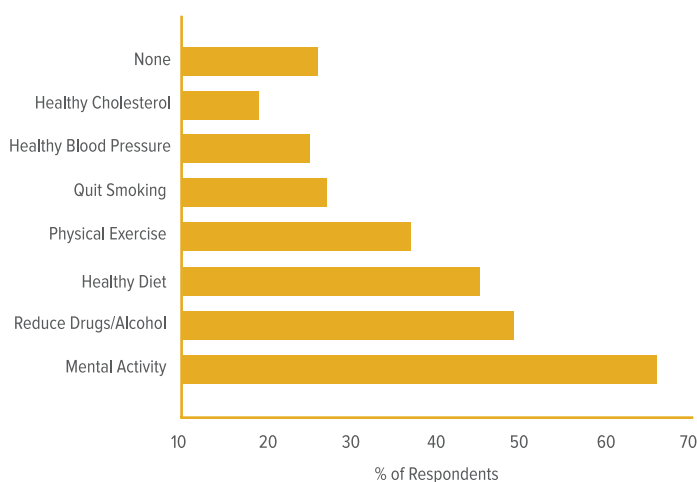
SPREADING THE WORD

There is a general lack of public awareness that dementia risk depends largely on factors that are modifiable. According to a survey among more than 5,000 Australians, only half of respondents believed that dementia can be prevented.³ Even when given specific risk factors, about one third still did not think that they influence someone's risk. For the rest, staying cognitively active was by far the most important factor, while giving up smoking, and keeping a healthy blood pressure and cholesterol were considered to be far less important.

Raising public awareness must play a fundamental role in any dementia risk reduction strategy and is a key aim for In-MINDD. In addition to publicising the In-MINDD system itself, we want to raise general public awareness that adopting a healthy lifestyle in middle age can reduce the risk of dementia or delay its onset. To date our work on dissemination has included:

- Online Presence: Project website - www.inmindd.eu / Twitter - @fp7InMindd / Facebook Account
- Press releases
- Media and Press coverage (e.g. RTE 19 Sept 2012, Irish Times 22 Oct 2012)
- Representation/presentation at Conferences (e.g. Tokyo Symposium on ageing societies in Europe and Japan 9 & 10 Oct 2012; 5th Annual Translational Medicine Conference (TMED 5) "Enabling Healthy Ageing" 2/3 May 2013)
- Links to other websites (e.g. featured on Alzheimer Nederland website 22 Nov 2012).
- Distribution of project materials (In-MINDD flyer and brochure)

As the project progresses our dissemination activities will intensify. In addition to targeting the general public, team members will also publish in peer reviewed journals and present findings at international conferences. Numerous dissemination activities and events are planned (e.g. distribution of In-MINDD public awareness brochures; engagement with GPs, primary carers, policy makers, public health promotion agencies and Alzheimers associations; hosting the In-MINDD closing conference etc.). Details of our dissemination activities and events will be included in future editions of our newsletter and will be advertised on our website.



WHAT YOU CAN DO

Dissemination of the In-MINDD message is important and there are a number of ways you can help:

Make sure you are on the project mailing list and recommend colleagues also add their name to the list (you can join the mailing list by using the contact form on the project website www.inmindd.eu).

Contact us to arrange hosting a link to the In-MINDD website on your webpage.

Contact us to arrange free delivery of our public awareness brochure (which you can make available in your reception area or waiting room).

Contact us to arrange free delivery of our project poster for display.

3) Farrow M, Alzheimer's Australia. Dementia Risk Reduction: What Do Australians Know? Alzheimer's Australia, 2008.

WHAT'S NEXT?

It will be noted from “Modifiable Risk Factors for Dementia” above that our work on identifying reliable modifiable risk factors for dementia is well advanced. In the coming months the team in Maastricht University will lead fine-tuning of the risk prediction model and the validation of the risk factors selected in established datasets/longitudinal studies.

The team in DCU are already preparing the ground work for the In-MINDD system and Glasgow University are taking the lead on preparations for the feasibility study and securing the ethical approvals required. Université de Nice - Sophia Antipolis will have key input into the design of the In-MINDD system and the feasibility study.

Specifically, in the period from May 2013 to April 2014 (month 18 of the project) we envisage the following:

- The Delphi round on modifiable risk factors completed.
- Systemic review completed.
- Production of a provisional risk model based on the findings re risk factors, devised to detect individual risk of developing dementia.
- GP and Patient demonstrations re In-MINDD system completed.
- Data collection instruments and ethical protocols finalised.
- Validation of the risk model using the first established dataset (and adaptation of the model as necessary).
- Validation of the risk model using the second dataset.
- Final dementia risk model available.
- Prediction & analytics components for In-MINDD system finalised (Patient).
- Patient Demonstrator & GP portal, version 1.
- Recruitment of GP practices.
- Report on the ethics structures in each country and their impact on the research proposed.
- Ethical Approvals secured.
- Continued work on dissemination.

In our next newsletter we will provide updates about the progress of these key work streams.

NEWS

News related to the project and its aims will be posted on the project website as the project progresses. Recent news and developments include the following:

- In March 2013 In-MINDD partner UNS was involved in the IX Journée de la Fédération CMRR du Sud de la France and the Fragilité Think Tank.
- In-MINDD added to Innovatexchange health care innovation map <https://www.innovatexchange.ca/>
- In-MINDD featured at the Irish Gerontological Society's Gerontology and PhD Study Day on April 26th in Our Lady's Hospice, Harold's Cross.
- In-MINDD new media centre launched April 2013 on project website www.inmindd.eu.
- In-MINDD featured at the 5th Annual Translational Medicine Conference (TMED 5) “Enabling Healthy Ageing”, 2/3 May 2013 – presentation by Kate Irving, DCU.
- May 2013 designated European Month of the Brain by the EU – several conferences and events were organised across Europe.

THE IN-MINDD TEAM

In-MINDD brings together partners from across Europe, with the specific mix of expertise essential for delivering the project:

Dementia expertise:

Dublin City University, Universiteit Maastricht and Université de Nice - Sophia Antipolis

Decision support systems & modelling:

Dublin City University

Primary care, usability, implementation science & end user validation: University of Glasgow

Online supportive peer environments:

Dublin City University

Project management & administration:

Dublin City University & Pintail Limited

The project also benefits from the active input of a team of international leaders in dementia, who engage in a Delphi consultation and contribute to our advisory board.



UPCOMING EVENTS

Details of upcoming events will be available on the project website as the project progresses. In particular, watch out for:

- Publication of the In-MINDD public awareness brochure in Summer 2013.
- Publication of the In-MINDD poster in Summer 2013.
- The next edition of our newsletter in Spring 2014.
- Our closing Conference in September 2015.
- Our final reports and results due in October 2015.

THANK YOU FOR READING.
LEARN MORE ABOUT IN-MINDD AT
WWW.INMINDD.EU