





# D3.2 Network of researchers and stakeholders working for the mitigation of loneliness, isolation and dementia

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## D3.2

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## **Executive Summary**

#### Subject matter

This report describes the creation of the MARIO network of researchers and stakeholders working for the mitigation of loneliness, isolation and dementia, the programme of activities that are planned to engage the network, and the development of a Delphi questionnaire to explore the role of social robots in the mitigation of loneliness and isolation experienced by people with dementia.

#### How does the deliverable fit into MARIO?

This deliverable is designed to extend the reach of MARIO by setting up a sustainable network to continue the work of MARIO beyond the life of the project.

#### Methods of analysis

- A network of researchers and stakeholders, MARIONet, was created whose members were identified through internet searches and "snowballing"
- Levels of interest were ascertained by email
- A programme of activities to engage the network members was developed
- A Delphi questionnaire was created and validated by expert review

#### Findings

The MARIO network of researchers and stakeholders currently has 411 members. This network will continue to be added to over the lifetime of the project.

#### Conclusions

- A network of researchers and stakeholders has been created
- Levels of interest have been ascertained
- A programme of activities to engage the network members has been developed
- A Delphi questionnaire has been developed

#### Recommendations

A Delphi survey of MARIONet members should be undertaken using the questionnaire developed in this work package for the purpose of seeking consensus in relation to the role of service robots in the mitigation of loneliness of people with dementia.



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## 1. Introduction

## 1.1 Work Package Objectives

This work package has three objectives:

- Establish a network of researchers and stakeholders working in the fields of robotics and dementia.
- Create a programme of relevant activities for network engagement.
- Develop a Delphi questionnaire in order to explore the role of service robots in facilitating connectedness.

#### **1.2 Purpose, Target Group and Outcomes**

This purpose of this deliverable is the creation of a network of researchers and stakeholders to try to reach a consensus on the best ways for service robots to facilitate the connectedness of people with dementia and to advance knowledge about ways of fostering social inclusion.

It will do this by connecting and engaging with network members, ultimately to establish best practices across European countries. This network is called MARIONet.

This deliverable targets those with an interest in MARIO. These include robotic experts, dementia researchers, psychosocial dementia researchers, health agencies, advocacy groups and people with dementia and carers.

The key outcome is the creation of MARIONet. Once created, an agreed programme of engagement activities with MARIONet will be put in place. A further outcome will be the development and validation of a Delphi questionnaire to be used in a future Delphi survey.

#### **1.3 Relations to other Activities in the Project**

This deliverable is related to a number of other deliverables. It extends the work undertaken for deliverable 10.3, which provided some of the original email addresses that were later expanded for MARIONet to include, name, address, contact number and interest level. Its outputs, MARIONet and the Delphi questionnaire, are prerequisites of deliverable 3.5.

The deliverable also is linked to a number of tasks. Task 3.3 of WP3 required a literature review to be undertaken to explore the factors that impact on the connectedness of people with dementia. The findings of this



review provided the core information required for the Delphi questionnaire developed for this deliverable.

Task 3.4 of WP3 requires the creation of a network to agree ways of facilitating connectedness with service robots and to advance knowledge about ways of fostering social inclusion by connecting researchers and stakeholders in order to establish best practices across European countries. Deliverable 3.2 created the network required by Task 3.4 – MARIONet.

This deliverable also relates to work started in WP1 on the identification of dementia-friendly communities. This work continued in WP3 and will be developed further in WP8 as part of the engagement with dementia-friendly communities.

MARIONet will be used extensively in the dissemination activities to be undertaken for WP10.

#### **1.4 Document Outline**

Section 1: Introduction

Section 2: MARIONet

- Section 3: External Advisory Board and its Role in MARIONet
- Section 4: MARIONet Activities to Date
- Section 5: Planned Activities
- Section 6: Development of the Delphi Questionnaire

Section 7: MARIO Publications

Annex 1: List of MARIONet stakeholders

#### **1.5 About MARIO**

MARIO addresses the difficult challenges of loneliness, isolation and dementia in older persons through innovative and multifaceted inventions delivered by service robots. The effects of these conditions are severe and life-limiting. They burden individuals and societal support systems. Human intervention is costly but the severity can be prevented and/or mitigated by simple changes in self-perception and brain stimulation mediated by robots.



From this unique combination, clear advances are made in the use of semantic computing techniques, personal interaction, and applications tailored to better connect older persons to their care providers, community, own social circle and also to their personal interests. Each objective is developed with a focus on loneliness, isolation and dementia. The impact centres on progress toward EU scientific and market leadership in service robots and a user driven solution for this major societal challenge. The competitive advantage is the ability to treat tough challenges appropriately. In addition, a clear path has been developed on how to bring MARIO solutions to the end users through market deployment.



## 2. MARIONet

This section describes MARIONet, its aims, and how it was created.

#### 2.1 MARIONet and its Aims

MARIONet is a human network for the mitigation of loneliness and isolation of people with dementia. It consists of a group of varied researchers and stakeholders who share an interest in exploring the role and potential of social robots in the care for people with dementia. This group includes researchers, industry partners, health agencies, older people groups and people with dementia.

MARIONet has three aims. These are to:

- bring together people interested in exploring the extent to which social robots have a role in the daily living activities for people with dementia
- disseminate information and generate discussion about social robots and dementia
- identify people with an interest in participating in future research in social robots and dementia

#### 2.2 MARIONet Creation

MARIONet was created by first deciding upon the categories of potential members that should form the network. Then individuals within these categories were contacted to determine their interest in network participation.

In December 2015, an initial email list of potential network members that was created by deliverable 10.1 was expanded through internet searches and snowballing. An internet search on keywords such as 'dementia', 'robotics', 'robotics and dementia', 'companion robots', 'service robots', 'engineers and robotics', 'robotics and ethics' was undertaken to identify relevant individuals or groups. Snowballing techniques were used whereby individuals identified as having a possible interest in network participation were asked if they knew others who might also be interested. At key European conferences, International Psychogeriatric Association (Berlin, 2015), 25<sup>th</sup> Alzheimer's Europe Conference (Ljubljana, 2015), International Conference on Social Robotics (Paris, 2015), Extended Semantic Web



Conference (Slovenia, 2015) interest was solicited from attendees, and these individuals, if interested, were also added to the network.

Additionally, a search was conducted to identify national dementia-friendly groups in Ireland and dementia advocacy groups in Galway. The national dementia-friendly groups comprise researchers, carer groups, age-related groups, and health boards. In order to conduct this search a varied search strategy was employed which included word of mouth, social media (Twitter (Researchgate, and Facebook), academic social sites LinkedIn), conference publications and listed speakers, and combination keyword searches in Google. Individuals who were part of the InterDEM network, a major European network for psychosocial dementia research, were also invited to join following a presentation on MARIO given at the InterDEM annual meeting in Ljubljana on 1st September 2015.

The research and public engagement activities taking place at the current stage project are most likely to interest researchers, dementia-friendly advocacy groups and health agencies. For this reason these are the majority in the current version of MARIONet. In the later stages of the project, industry and broader older aging groups are likely to be interested in the project's findings. Therefore MARIONet will be expanded in Deliverable 3.5 to include industry and active aging stakeholders.

Currently MARIONet has 411 members. These fall into three broad categories: researchers, advocacy groups and health agencies. Researchers include dementia psychosocial researchers, companion robot researchers, engineers with an interest in robotics, and technologists. Advocacy groups include dementia groups and dementia-friendly groups. Health agencies include health boards and nursing home associations.

MARIONet details are available in an Excel file with separate worksheets used to partition the network by member category. Each row of a worksheet records information for an individual within the associated member category: name, title, organisation, address, email address, salutation and level of interest in MARIO. For the purpose of creating this deliverable, the MARIONet is listed in Annex 1.

To elicit level of interest an email was then sent to all on the list in December 2015 to solicit their level of interest in the MARIONet. Level 1 was information about MARIO only, level 2 was information about MARIO and an interest in engaging in network activities and level 3 was all of two



and an interest in participating in future research activities. In total, 61 responded that they were interested in MARIONet at level 3.



## 3. External Advisory Board and its Role in MARIONet

The External Advisory Board (EAB) is a subset of MARIONet members that includes specialists in robotics, dementia specialists, policy makers, people with dementia, and advocacy group representatives. Its purpose is to provide a source of expert advice to the project team, which has included validation of the Delphi questionnaire developed for this work package.

There are 13 people on the EAB, one of whose members is also a member of the Galway Dementia Network. The EAB meets twice per year. So far two meetings have been held, the first in November 2015 and the second in June 2016. A further meeting is scheduled for February 2017.



## 4. MARIONet Activities to Date

### 4.1 TEDxFullbright Talk

In February 2016, Professor Dympna Casey and Professor Kathy Murphy from NUIG gave a TEDxFullbright talk in Dublin that addressed the role of social robots in the lives of people with dementia. This talk was filmed and released on-line as a YouTube video. The video has been viewed by over 1,400 people across the world and continues to be viewed. Once it became available on-line an email was sent to MARIONet members updating them on the progress of the MARIO project and providing a link to the TEDx video.

This talk, entitled 'Fighting ageing with companion robots', can be viewed using this link. https://www.youtube.com/watch?v=eq0FJyYexnQ&t=4s

#### 4.2 MARIO Webinars

The MARIO Webinars were inaugurated on October 26th, 2016 with a live, on-line presentation by Professor Dympna Casey and Professor Kathleen Murphy from NUIG. The presentation was titled 'What do you think people with dementia want from companion robots? Sharing findings from the MARIO Project.' and was followed by a discussion. Twenty six people attended the live webinar, and two weeks after the event the webinar video was viewed 130 times.

#### 4.3 MARIO Symposium

During the European AAL Forum, Ageing well with Technology, held in St Gallen (Switzerland) on the 27th of September 2016, Dr. Antonio Greco organised a symposium, *Domotics and Robotics for Alzheimer Disease*. The issues discussed ranged from the personal such as the usefulness of robotics and domotics to face dementia, isolation and loneliness, to the societal such as the economic impact of new technologies. Approximately 50 people directly attended the event, including academics, business leaders, politicians, and engaged members of society. Recordings of the symposium were shared with AAL members, prompting positive feedback about the MARIO project and the necessity to further develop solutions addressing the problems faced by people with dementia.



## 5. Planned Activities

#### 5.1. MARIO Webinars

A schedule of regular webinars tailored for the MARIONet audience was developed to maximize the visibility of the project among researchers in the areas of 'Companion Robots', 'Companion Robots for People with Dementia' and 'Semantic Robotics'. The current frequency of webinars is one every 45 days. Each consists of a presentation by the project partners lasting between 30 and 40 minutes; these are followed by a discussion during which the webinar audience has an opportunity to ask questions. The webinars are delivered through the YouTube Live platform, which supports live streaming of video as well as facilitating interaction with a remote audience. Afterwards, webinars are posted on YouTube. Webinars are advertised in advance within MARIONet, on MARIO's social media channels, and through the Robotics Worldwide mailing list.

The MARIO Webinars were inaugurated on October 26th, 2016 as described in section 4.2 above. Future webinars are as follows (presenting partner in brackets):

- People with Dementia and staff perception and experience on the different pilot sites (Stockport, IRCCS).
- I know what you mean: semantic representation for companion robots (CNR).
- Ensuring robust and flexible communication for companion robots (University of Passau).
- Apps for companion robots for People with Dementia (Caretta-Net).
- Market for companion robots for elderly care (R2M Solution).

#### 5.2 Delphi Survey

An invitation to participate in a Delphi survey will be emailed to members of MARIONet. The survey's aim is to seek consensus amongst members on the role of social robots in the mitigation of loneliness and isolation in people with dementia. The results of the survey will be presented in Deliverable 3.5. It is also intended to publish the results in an academic journal as part the project's dissemination activities. The development of



the questionnaire to be used in the conduct of the survey is described in the following section.



## 6. Development of the Delphi Questionnaire

A Delphi questionnaire was developed as part of this work package. The questions were designed to seek the opinions of MARIONet members and to try to reach a consensus on the best ways for service robots to facilitate the connectedness of people with dementia.

#### **6.1 Literature Review**

To help construct the questionnaire, a literature review was first undertaken (WP3, Task 3.3) on social connectedness, focusing on ways of fostering connectedness utilising service robots. This involved a comprehensive search in the following databases for literature published between 2009 and 2015:

- Cochrane Library
- PubMed
- Scopus
- CINAHL Complete
- EMBASE
- Web of Science Core Collection
- PsychINFO
- Compendex

The titles of 420 identified papers were scanned for relevance, and duplicates discarded. The abstracts of 140 papers were then read and included in the review if they met all of the following criteria: a) written in English, b) involved older adults with or without a diagnosis of dementia, c) referred to robotic or non-robotic technological interventions aiming to promote social connectedness, independence and reduce isolation. The references contained in each included paper were also followed up, and these too were included in the review if they met the criteria.

The final review included 85 original research papers, 23 literature reviews, 17 systematic literature reviews, ten opinion pieces and five study protocols. The literature revealed reciprocity, creativity, mobility (particularly outdoors), communication, autonomy, and engaged participation were enhancers of social connectedness for people with dementia, while music therapy, singing, reminiscence, and physical exercise can be effective interventions. It also revealed that understanding the robot user's perspective and attention to context are key to realising the potential of

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social robots. However, many of the studies completed to date were observational, involving small samples and short durations of human-robot contact. In conclusion, the review endorsed the need for the Delphi survey and suggested that future research needs to involve larger, longitudinal studies.

## 6.2 Establishing the Focus of the Delphi Questionnaire

From the literature review key aspects of service robots and connectedness were identified and used to divide the questionnaire into six main areas:

- defining social connectedness
- social health and its relation to connectedness
- factors that impact on social connectedness
- strategies for connectedness and building resilience
- role of robots and connectedness
- role of robots in mitigation of isolation and loneliness and prerequisites for acceptance of social robots

The questionnaire contained thirteen questions focused on the above areas.

## 6.3 Reviewing the Questionnaire to Establish Validity and Clarity

The MARIO Expert Advisory Board (EAB) was asked to provide an expert review of the questionnaire in order to establish content validity. Five EAB members agreed to participate in this review.

For each of the 13 questions in the questionnaire, the five EAB reviewers were asked if they felt the question was valid and clearly phrased, and to suggest any changes to the question that they felt might enhance its clarity.

The reviewers were all female from varied occupational backgrounds: three were academic researchers, one was an international consultancy worker and one was an operations director. Their experience of working with people with dementia ranged from less than 5 years to greater than 20 years. They rated their level of expertise of working with people with dementia from 'some' to 'recognised expert'. These variations are important as it is aimed to make the final Delphi questionnaire relevant to a range of occupational backgrounds and levels of experience of working with people with dementia.



#### 6.4 Results of Review

The majority of EAB reviewers deemed all 13 questions valid; however, they proposed amendments to the phrasing of a number of the questions.

Three questions were deemed valid and clear by all five reviewers and no changes were suggested: question 5 (examining if social connectedness and resilience are related), question 11 (examining the importance of context) and question 12 (the importance of context for social robots working with people with dementia).

A synopsis of the other ten questions and an overview of reviewer feedback for each is given below.

<u>Question 1</u> provides a definition of social connectedness and is designed to examine survey respondent's agreement with this definition. All reviewers agreed that the question was valid. However, three provided a recommendation to reword a phrase to make it less scientific and easier for a lay person to understand.

<u>Question 2</u> provides a synopsis of how social health is related to social connectedness and asks whether survey respondents agree with the synopsis. All reviewers agreed that the question was valid. However, two advised that the statement was too long and needed to be made more concise.

<u>Question 3</u> examines opinions regarding the potential factors that influence social health. All reviewers agreed that the question was valid. However, two highlighted that subsections should be added to allow for survey respondents to comment on their answer about each individual factor, rather than commenting on all factors together. An additional factor that was not listed in the question was identified by one reviewer for inclusion.

<u>Question 4</u> provides a definition of resilience and is designed to examine if survey respondents agree with it. Four of the reviewers agreed that this question was valid. However, two did not see the definition as relevant to people with dementia. Specifically, they suggested that the definition needed to be widened to make it more relevant for people with dementia.

<u>Question 6</u> lists the factors deemed relevant for social connectedness and asks survey respondents to state if they agree that these factors are important. All reviewers agreed that this question was valid. One suggested



adding an additional factor that she deemed important, while another suggested that the question should be divided into subsections.

<u>Question 7</u> asks survey respondents to comment on the strategies used by companion robots when interacting with people with dementia. All reviewers agreed that the question was valid and clear, though one suggested grammatical corrections.

<u>Question 8</u> is an open-ended question that asks survey respondents to identify other strategies whereby companion robots could improve social connectedness. All reviewers agreed that the question was valid, while four agreed that the question was clear. To improve question clarity, one reviewer offered a rewording.

<u>Question 9</u> asks survey respondents to consider the essential features of psychosocial interventions for increasing resilience in people with dementia. Three reviewers reported the question to be valid. However, two found it difficult to understand and felt it was directed towards academics rather than lay people. One reviewer commented that not all people with dementia would respond to the same intervention and therefore one should not generalise.

<u>Question 10</u> examines survey respondent's beliefs regarding the potential mechanisms by which companion robots might improve social connectedness. All reviewers agreed that the question was clear and valid. One made a suggestion to improve the question's wording and clarity.

<u>Question 13</u> asks survey respondents about the appropriate time interval between the introduction of the robot and the evaluation of its acceptability and impact. All reviewers agreed that this question was clear and valid. One reviewer suggested that time interval options should be provided for the respondents to choose between. One reviewer commented that a sensible answer could only be obtained from those experienced in working either with robots or with people with dementia.

#### 6.4 Future Plans

These amendments have been made, and at present the questionnaire is being prepared to be distributed to MARIONet members. The results will be reported in Deliverable 3.5.



## 7. MARIO Publications

A listing of MARIO publications is provided on the project website and updated monthly. Links to these publications are made available on the Open Access Institutional Repository, OpenAir, where they can be accessed by the wider public. In future, links to MARIO publications will be distributed by email to MARIONet members on a monthly basis.

There have been publications in several areas of interest to MARIONet members. These include the perceptions of people with dementia to service robots and the benefits they would hope to gain from them. Additionally, there have been publications in the technological field that may be of interest to those who work in robotics, e.g. sentiment analysis in service robots.



**Annex 1: List of MARIONet Stakeholders** 

Spreadsheet 1	Researchers	Spreadsheet 1: Researchers						
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