



Interdisciplinary Network for Dementia Using Current Technology

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INDUCT NEWSLETTER

Spring 2017

@INDUCT_MSC

WELCOME!

Welcome to the third INDUCT newsletter. This bi-annual document is to inform project collaborators, stakeholders and interested members of the community about the content and development of INDUCT. The fifteen Early Stage Researchers (ESRs) are now well into their first year of the project, and this newsletter focuses on the progress they have made in their research, their initial experiences on secondments, as well as recent exciting events in the field of dementia and technology which they have attended. We hope you enjoy reading this issue and welcome any feedback via the contact information at the end of the last page.

Kate Shiells (ESR 13)

INTRODUCING OUR EARLY STAGE RESEARCHERS

Joeke van der Molen-van Santen (ESR 7). VU University Medical Center, Amsterdam, The Netherlands.

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Time flies!

The interview event is roughly one year ago now, I cannot believe how time flies. I lived for several years in the UK and was an MSc-student at University College London (MSc Clinical Mental Health Sciences). In September 2016, I finished this course and started my work as a PhD-student and Early Stage Researcher for INDUCT at the VU University Medical Center in Amsterdam, the Netherlands. I feel incredibly lucky to be able to return to my hometown on a Marie Curie appointment.



The INDUCT Network offers unique opportunities in many ways, such as networking and training. How would I describe my first months as an INDUCT ESR? Busy, useful, interesting, inspiring, informative, sometimes a bit stressful, yet also lots of fun. I have already learned a lot, not only by formal training courses, but also from my INDUCT- and Amsterdam-colleagues.

My job is to investigate the (cost-)effectiveness of exergaming for people living with dementia visiting day care centers and their informal caregivers. Currently I am writing up the results of the systematic literature review. And although recruitment of day care centers is still ongoing, data-collection for our RCT has started last March. If you would like to know more about the exergaming research project, please do not hesitate to contact me. I am looking forward to seeing everyone again at the INDUCT Summer School in Salamanca or perhaps at the Alzheimer Europe 2017 conference in Berlin!

THE SECONDMENTS BEGIN!

Floriana Mangiaracina (ESR 8). VU University Medical Center, Amsterdam, The Netherlands.

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Exploring a new workplace and culture, can't expect anything better!

It is with a feeling of thrill that I left my home institution at VU Medical Center, Amsterdam to start my secondment at MindTech – Institute of Mental Health, University of Nottingham. Even more exciting was that I am the first ESR to do the secondment.



Upon my arrival at MindTech, I felt immediately welcomed by my local supervisor Jennifer Martin and the whole MindTech team, as well as by my INDUCT buddy Aline Cavalcanti Barroso and people from the Institute of Mental Health of the University of Nottingham. The aim of my secondment at MindTech is to compose a plan for the process evaluation of the Randomized Controlled Trial – in which we will evaluate the effectiveness of a personalized tablet programme which will help people with dementia and their carers to select apps for self-management and meaningful activities.

With the collaboration and supervision of the MindTech team, I will consider which aspects of the process evaluation can be collected using analytics or other methods (i.e. experience sampling method). And needless to say, the expertise of MindTech is of great help in this. I consider this experience a very precious opportunity and I could not be more delighted to explore and work in a new environment and culture!

RECENT EVENTS ATTENDED BY ESRS

Hannah Christie (ESR 10). Maastricht University, The Netherlands.

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Alzheimer's Disease International Conference, Japan.

The annual Alzheimer's Disease International (ADI) Conference took place 26-29 April in Kyoto, Japan. It was attended by over 4000 delegates from more than 100 countries. Four INDUCT ESRs (Harleen Rai, Aline Cavalcanti Barroso, Sara Bartels and Hannah Christie) and Project Manager Dr Deborah de Oliveira were in attendance. On 27 April, they gave a presentation on INDUCT at the *World Young Leader in Dementia Symposium*, chaired by ADI executive director Marc Wortmann. The presentation described the INDUCT project organization and aims, and short pitches from the ESRs about their own research projects. Each researcher also presented a poster during the poster exhibition.



The conference was an excellent opportunity for the ESRs to experience an international scientific conference, work on their presentation skills, and build connections with researchers working on related topics. The ESRs also acquired many useful insights for their own projects.



The involvement of so many international researchers, as well as people with dementia and their carers, was very inspirational. ESR 9, Sara Bartels, says: "Reflecting on the ADI conference, I got the impression that we are well on the way to a dementia-friendly world".



Another opportunity that the ESRs had as part of their trip to Japan was a visit to a care home which currently uses robotics and other technologies as part of their day-to-day care, for people living with early to advanced stages of dementia. Project Manager Dr Oliveira says: "The ESRs had the opportunity to discuss with the care home staff about the benefits of using technology on their day-to-day care, about how technology was implemented in their service, as well as their challenges and barriers to implementation. The ESRs attended one of the day-care activities where they used robotics to stimulate people with dementia to dance, sing and play quizzes. People with advanced dementia enjoyed stroking the fur of a fluffy electronic seal and we were told by the care home staff that these activities reduced pain and distress for these individuals. These also helped improve

communication and allowed residents to sleep better."

The ESRs were very pleased to have been given this opportunity and look forward to sharing their stories with the other ESRs at the upcoming INDUCT School in Salamanca, Spain.



Harleen Rai (ESR 5). University of Nottingham, UK. harleen.rai@nottingham.ac.uk

'Breadcrumbs, burgers and bugs'

You might wonder why one might talk about hamburgers and breadcrumbs when one is trying to design software for older people with dementia? A while ago, I had the pleasure of attending an interview event for software companies who are hoping to take on the project of developing a digitalized version of the PRIDE manual. Promoting Independence in Dementia (PRIDE) is a five-year research programme and the aim of this particular work package within the PRIDE project is to



develop a social intervention to enhance independence and quality of life for people with mild dementia and their carers.

The paper-based manual for the intervention will be adapted and delivered via a website. The companies proposed wonderful solutions and presented us with software options which we were unfamiliar with. We realized that the field of software development is relatively unknown to us and that there is a lot to be explored. The use of specific jargon referred to as 'user interface metaphors' sparked our curiosity. An example is the term 'breadcrumbs' which is used to keep track of the user journey as users navigate through different parts of a website. Another term is the 'hamburger menu' which is used to describe the lay-out of a specific menu which only shows three horizontal lines instead of the full menu.

Thinking about 'slices of pie' instead of 'layers of pie' made us understand things from the business value perspective. Non-food related jargon proved to be more difficult to grasp e.g. '2-factor identification', 'posting back bugs' and the Japanese term 'kano'. Since some of us have a focus on dementia friendly technology within our work, we will get acquainted with the field of software development in due time. I have learned that it is a good idea to get familiar with the field at an early stage since software development is a very dynamic and ever-changing field which makes it even more exciting to be a part of.

Martina Vanova (ESR 15). IDES, Spain.

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Keep Calm and Curie on.

On Saturday 25th of March, researchers, PhD candidates, post-docs and representatives from all around the world involved in Marie Skłodowska-Curie actions met in the historical city of Salamanca, Spain, on an annual Marie-Curie Alumni Association conference. Lectures and presentations covered topics on the role of science in society, entrepreneurship and start-ups, and mobility programmes for scientists.

I had an opportunity to speak with other Marie Curie academics about our projects and possible collaboration. The event also offered many networking opportunities for researchers from different backgrounds. Personally, what caught me most was a motivational talk from the president of Erasmus Mundus saying: "As a researcher, always keep on the move" and I could not have agreed more. For a researcher, knowing the world from different perspectives and discovering new cultural backgrounds can be important to influence their work and help in developing new ideas. Such outcomes can become even more universal and influential for the wider public. I believe that INDUCT is a good example of such practice.



Currently, as our first secondments are approaching, we are preparing not only to collaborate on an international level, but also to open our projects to international inputs. This will definitely enrich our work and I am looking forward to Harleen Rai (ESR 5) coming to Zamora to work on her iCST adaptation on which I can participate. Similarly, in September, I will be going to the University of Nottingham to learn more about RCTs and to work on my literature review, which I believe will enhance the RCT we are conducting here in Spain.

EXPERIENCES OF INVOLVING PEOPLE WITH DEMENTIA IN RESEARCH

Yvette Vermeer (ESR 1). UCL, UK.

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Research can be empowering!

At the start, I knew one thing for sure; it is essential to involve people with dementia and family caregivers in this research project. My project explores what people with dementia and family caregivers need in surveillance, how these products are designed, and how using these products could impact them. Surveillance products do not always support individual needs; yet, are often seen as the empowering solution.



Literature suggests that people with dementia are usually excluded from research, for ethical approval is complex and can be time consuming. Also, many people had warned me about the complexity of managing to involve people. With my previous experience of getting ethical approval in the Netherlands, I knew the amount of work it would take. Nevertheless, the project is about empowerment. Empowerment in my book means to have your voice heard, to be able to participate equally in society, and to receive transparent information to make informed decisions.

The initial plan was to conduct focus groups in different countries. What the literature did not prepare me for were all the different requirements and various forms to fill in, while having to send in many personal documents. Sometimes you even have to be a native citizen to conduct research in that country. Finally, the result was a simple 'No'.

This experience has taught me that there are other paths to follow. The advantages of being part of INDUCT is that there are many international professionals involved. The research team has fully supported me throughout this process. In addition, I have been included in newsletters and blogged about my experiences. Suddenly, I received all these wonderful e-mails from people living with dementia and family caregivers, sharing their experiences and offering to help. It does show people are willing to become involved, and that a little paperwork should not stop me.

Interested in more information about this research project? Please email me or have a look at my blog.

A WORD FROM THE MANAGEMENT & TRAINING TEAMS

Dr Déborah Oliveira (Project Manager)

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Dr Inge Klinkenberg (Training Manager)

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One year has passed!

One year has already passed since the INDUCT project first started in March 2016. All 15 ESRs have been appointed and are well on the way with their project development. So far, we have had great achievements with regards to ESRs' development and training activities, dissemination and collaboration with our second-level partners. ESRs have started publishing and presenting at local and international events, have started their secondment activities and have had several opportunities to involve people with dementia and their carers in their research. INDUCT had its first INDUCT School, in which ESRs had the opportunity to network, had their Fellow Board established and appointed representative ESRs, and took part in several training activities.



The ESRs have also taken some vital first steps towards their INDUCT doctoral training, which will ultimately help them maximise their employability across sectors as well as their career perspectives. They have drawn up their Personalized Career Development Plans (PCDPs) in order to select courses that are offered at their home universities, as well as abroad, which will benefit their individual projects. From November to December 2016, the ESRs also participated in the interactive online course "Living with Dementia: Personal Perspectives" offered by Maastricht University. This module enabled them to think about how individuals live with dementia, as well as the effect on their relationships and carer needs in an international and interdisciplinary context.



Through the 1st INDUCT School, taking place 9-13 January 2017 in Maastricht, the 15 ESRs have been able to meet the full INDUCT network, and have gained valuable training on dementia-care specific research skills as well as transferable skills. It was a week filled with informal discussions, interactive group work, project meetings, and in-depth classroom lectures on topics ranging from dementia technology practices and products, Patient Public Involvement, international dementia health care policies, to the MRC Framework, and how to maximise the impact of your research.

We are looking forward to the next two years!

MORE INFORMATION



For more information, please access our website: www.dementiainduct.eu

Follow us on Twitter: @INDUCT_MSC

Articles for the Autumn 2017 newsletter to be submitted by 10 November 2017 to:
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