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Interdisciplinary Network for Dementia Using Current Technology

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INDUCT NEWSLETTER

Spring 2018

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WELCOME!

Welcome to the fifth 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. In this issue, we look back on the Third INDUCT School. This was a slightly different school from usual as it incorporated the mid-term review, which we are pleased to say was a success all round. We also hear from our new training manager, Fania Dassen, who we are very happy to welcome to the INDUCT team. Joeke (ESR 7) and Yvette (ESR 1) describe their experiences of involving people with dementia in their research, and finally Sara (ESR 9) and Hannah (ESR 10) from Maastricht University update us on their projects. We hope you enjoy reading this issue and we welcome any feedback via the contact information at the end of the last page.

Kate Shiells (ESR 13)

THE MID-TERM REVIEW AND THE THIRD INDUCT SCHOOL. WITTEN, GERMANY

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Half way there!

From 28 January- 2 February, the INDUCT ESRs, supervisors and second level partners met in Witten, Germany for the Third INDUCT School, organised in collaboration with Professor Martina Roes and colleagues from the DZNE (German Center for Neurodegenerative Diseases), and the INTERDEM Academy.



The first two days of the school focused on the mid-term review of the INDUCT project. ESRs presented their work to an external evaluator from the EU, and discussed the ways in which

their experiences acquired during INDUCT have influenced their future career plans. The meeting also allowed ESRs to come together to discuss preliminary recommendations in relation to usability, effectiveness and implementation of technology; the full list of which will be published at the end of the three years, giving guidance on human interaction with technology and dementia.

The second half of the week provided a valuable opportunity for members of the INTERDEM Academy to join together once again and learn from a range of experts in the field. Professor Paul Higgs added a new dimension to many of our projects by encouraging us to consider how the types of technologies we are researching will support agency amongst people with dementia. This was followed by a unique session led by Professor Louise Nygård and Helga Rohra from the European Working Group of People with Dementia, which enabled participants to hear the perspectives of both a researcher and a person with dementia on facilitating and participating in qualitative interviews.



During the remainder of the school, participants heard from a number of professors, including Professor Martina Roes and Professor Frans Verhey, on their career journeys, with some useful tips on how to balance busy schedules. Sessions on implementation frameworks and ethics in dementia research provided more in depth knowledge on these important topics relevant for all of our projects. Furthermore, participants were able to learn about the advances in Artificial Intelligence for supporting people with dementia. Finally, Michael Hagedorn, founder and photographer from the German organisation 'Konfetti im Kopf', explained how they are working to promote a more positive image of dementia through art and public actions.



We very much enjoyed the Third INDUCT School and would like to thank all those who were involved in organising and running sessions during the week. We are also pleased to announce that the next INDUCT school will take place in Prague from the 10-14 September.

Unfortunately, we said goodbye to Dr Inge Klinkenberg during the week, who has left INDUCT and the INTERDEM Academy to take up a clinical position. Inge played an integral role in both projects, as well as providing lots of support to early stage researchers. We will miss her but wish her well in her new position!

We are, however, pleased to announce that we have a new training Manager, Fania Dassen, now in post. Like Inge, Fania is based at Maastricht University. Read on to find out more about her and her recent visit to Nottingham University to meet the INDUCT management team!



INTRODUCING OUR NEW TRAINING MANAGER

Fania Dassen (INDUCT Training Manager). Maastricht University, The Netherlands

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Getting to know the INDUCT Team

Hello everyone. On April 1st, I started as the new Training Manager for INDUCT and also for the INTERDEM Academy. I would like to introduce myself and give you a quick update about my first month in INDUCT. Before I started working as a training manager, I was working on my PhD project exploring the role and trainability of cognitive control in obesity. I am currently busy finalising everything, as I will defend my thesis this summer.



When I started my new job, to begin with I went through all the documents that Inge left behind. I learned a lot from Frans and Marjolein about the network, and I had interesting chats with Sara and Hannah, the ESRs based in Maastricht. In the second week of May, I flew to Nottingham to meet with the management team there. Thank you, Déborah, Ann, Martin, Justine and Harleen for your warm welcome and helpful meetings discussing INDUCT. I am impressed Déborah, so many things to oversee, but you are so

organised and you seem to know everything! You even found the time to give me a quick city tour, including the castle, Robin Hood statue, the oldest pub in Europe and the cat café. We had sunny lunches at the University and a nice Caribbean dinner at Turtle Bay with Harleen.



In addition to my role as training manager, one day a week I will be responsible for outreach activities for the Alzheimer Center Limburg. I will be the coordinator of the adoption project, in which children from primary schools visit people with dementia in their care home. During these weekly visits, the children participate in daily activities such as serving coffee and tea, playing board games or going for a walk; a rewarding experience for both. Just send me an email if you want to know more about it.

The next big thing on the agenda is the fourth INDUCT school in Prague, 10-14 September. In the past weeks, we have finalised the programme and I am certain that we will have an inspiring week with great speakers and topics. We will send out the programme and registration options soon.

For now, a big thank you to all of you. Everyone from INDUCT has been so welcoming and helpful and I am looking forward to meeting everyone in Prague!



ESR 7 VOLUNTEERS AT A DAY CENTRE FOR PEOPLE WITH DEMENTIA

Joeke Van Der Molen-Van Santen (ESR 7).VU University Medical Center,
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Exergaming in daycare centres: diving into daily practice

In the exergaming project, we investigate the effects of interactive cycling* in people living with dementia and their informal carers. Our research includes a systematic literature review, an evaluation of effectiveness and cost-effectiveness and a process (implementation) analysis. The RCT has been running in several daycare centres for people living with dementia since February 2017, and data-collection will be ongoing until March 2019.

I have visited each daycare centre involved several times to talk about the research project or to conduct baseline interviews with participants. However, I never really had a clear idea of what a day at a daycare centre looks like. So, on Tuesday the 27th of February I joined as volunteer at the daycare centre Overspaarne (part of the care organisation Kennemerhart) in Haarlem, a city near Amsterdam.

At 8.30 a.m., the staff had a meeting to discuss any issues and prepare for the day ahead. From around 9.30 a.m. the visitors start to arrive, some are dropped off by taxi, others by their informal carers. When everyone has settled with a cup of coffee and a biscuit, one of the volunteers reads the newspaper together with the group; a nice moment with plenty of social interaction, without any pressure of having to participate (one visitor is drawing in his sketch book).



Then it is time for some physical exercise, and of course, I am in charge of the exergaming activity! An employee of the daycare centre explains the equipment and how long each participant is supposed to cycle for. The participants are very motivated and enjoy talking about the route they see on the screen while taking turns to cycle. After this, it is time for chair ballet with lovely classical music. Everyone is hungry after exercising, and luckily, it is time for lunch.

In the afternoon, we play a game with dice at the

table in the living room of the daycare centre, and some visitors have a little rest. Before I know it, it is 4 p.m., the visitors are picked up to go home and the day is over.

It has been an inspiring day for me, seeing and experiencing the different aspects of working in a daycare centre. I found it especially touching to see the people working and volunteering there doing their best to meet the needs of each individual visitor. The general ambiance was very relaxed and amiable, and the visitors responded very well to





this.

This will definitely help me create an even better and deeper understanding of the context for our research findings. I would like to thank the incredibly friendly and helpful staff, the volunteers, and of course, the wonderful group of visitors of the daycare centre for an informative and fun day!

*Interactive cycling = cycling on a stationary bicycle while a movie of an outside route is played on a screen, creating the experience of a regular bike ride; also called exergaming.

PATIENT AND PUBLIC INVOLVEMENT IN INDUCT

Yvette Vermeer (ESR 1). University College London, United Kingdom

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First UCL-SURP meeting with research advisors was a success

In March, the first UCL-SURP meeting was held. UCL-SURP is a new group where experts by experience are involved as research advisors. The involvement of research advisors is often seen as complex, expensive, and time-consuming. Consequently, people with dementia might be excluded in research or attempts to involve them may be tokenistic. That is why Yvette Vermeer, Jem Bhatt and Georgina Charlesworth created the UCL-SURP; a sustainable group where experts by experience can be meaningfully involved in research projects for a longer period of time.



The expression of interest for this group was overwhelming with people writing in from various places and backgrounds. At the first meeting, the research advisors were asked to comment on two research projects. For project 1, the advisors discussed empowerment and surveillance, a discussion which was proven to be fruitful, insightful and fun. The advisors were so enthusiastic that the researchers sometimes had to ask to move on to the next topic as time was running out. Advisors also commented on another project that seeks to develop an intervention to support disclosure decision making in dementia. This group exemplifies that people are willing to become involved and that a lot can be learned. A little extra work should not stop us from involving people in research.

Interested in more information about UCL-SURP? Or want to become involved as a research advisor in London? Please email y.vermeer@ucl.ac.uk or Jem Bhatt jemini.bhatt.15@ucl.ac.uk.

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AN UPDATE ON OUR PROJECTS: ESR 9 & ESR 10

Sara Bartels (ESR 9). Maastricht University, The Netherlands

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Secondment of ESR 9 facilitates a sustainable collaboration between Maastricht University and Karolinska Institutet

In the period between August and November 2017, Sara Laureen Bartels, ESR 9 based at the Alzheimer Center Limburg, Maastricht University, performed her secondment at the Division of Occupational Therapy, which is part of the Karolinska Institutet (KI) Stockholm.

Prof. Louise Nygård supervised her during that time and gave Sara the opportunity to present INDUCT and her research project to delegations from Belgium and New Zealand as well as the CACTUS and HELD group, resulting in brain storm meetings with Prof. Eric Asaba and Dr. Ann-Helen Patomella to discuss common research interests. Consequently, the idea to start a project together focusing on the experience sampling method used in older adults to improve health arose, leading to a collaboration and article. This literature review is currently in process and is expected to be finished by the end of 2018. Additionally, Dr. Camilla Malinowsky from KI is now a co-supervisor of ESR 9 and together with three other researchers from the division and Jenny Jamnadas-Khoda from the University of Nottingham, a publication on the relationship



between self-reports and observations to understand technology use in people with mild cognitive impairment and dementia is expected to be finished by July this year. This article will also be integrated into the doctoral thesis of Sara Laureen Bartels. ESR 9 visits the host institute every two months for a couple of days to discuss the progress in person. The INDUCT secondment resulted in a fruitful and sustainable collaboration between the Netherlands and Sweden and is enjoyed very much by the ESR.



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

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Exploring the implementation of eHealth interventions

Systematic reviews have shown eHealth interventions for caregivers of people with dementia to be effective for a variety of outcomes, but these interventions have had trouble making their way into the daily lives of the caregivers that need them. An important reason for this is that little is known about the organizational and contextual factors that determine their successful implementation.

Within the INDUCT project, ESR 10, Hannah Christie (hannah.christie@maastrichtuniversity.nl; @HChristie_) is currently meeting with 10 municipalities in the EU-Region Maas-Rhine and developing strategies to implement two eHealth interventions developed by the Alzheimer Center Limburg (Myinlife and Partner in Balance) in their communities. These communities are participants in the INTERREG EuPrevent



Senior Friendly Communities (SFC) Project, where 30 municipalities have signed up to make their communities more 'senior-friendly' by choosing to implement a number of initiatives focusing on dementia and depression in the elderly.

By interviewing the involved municipality personnel and other implementing staff, Hannah hopes to gain insight into how municipalities can develop personalized implementation strategies and bring the E-health interventions out of a more artificial RCT (randomized controlled trial) context, into the real world. It will allow us to pay special attention to mapping determinants associated with the implementing organization and wider context, which is essential in formulating a sustainable and effective strategy for long-term implementation.

The first paper resulting from this study will examine the views of municipality officials on eHealth in general and detail their implementation plans for Inlife and/or Partner in balance in their communities. This paper is expected early 2019, with later papers evaluating the implementation of the interventions at the municipal level expected in early 2020.

MORE INFORMATION

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



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Articles for the Autumn 2019 newsletter to be submitted by 10 November 2018 to:
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