



# Interdisciplinary Network for Dementia Using Current Technology

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INDUCT NEWSLETTER

Autumn 2018

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## WELCOME!

Welcome to the sixth 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, you can read about INDUCT's participation at the Alzheimer Europe Conference in Barcelona last month, which is just one example of how ESRs and Professors have been busy disseminating results. Two of our Professors, Professor Rose-Marie Dröes and Professor Lieve Van den Block, have also received prestigious awards for their work, a brief overview of which is provided on pages 3-4. We hear from a number of ESRs with updates on their projects, as well as Hannah Christie (ESR 10) with an account of the policy events she has recently attended, and Kate Shiells (ESR 13) with news of her secondments in Belgium and Spain. Finally, in September, INDUCT members came together for the penultimate school in Prague, and you can find out more about this productive week at the end of the newsletter. 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)

## INDUCT PARTICIPATES AT THE 28<sup>TH</sup> ALZHEIMER EUROPE CONFERENCE

### ***Sharing our research with the academic community & beyond***

The 28<sup>th</sup> Alzheimer Europe Conference in Barcelona provided the ideal platform for many of the INDUCT ESRs and their supervisors to present preliminary results of their research to the academic community and beyond. The conference was opened by **Professor Iva Holmerová**, Chairperson of Alzheimer Europe and supervisor of ESR 13, who emphasised the importance of being 'more mindful about the individual needs and preferences of people with dementia'.



Sébastien Libert (ESR 2)

As one of this year's 'Researchers of tomorrow' **Sébastien Libert** (ESR 2) delivered a lecture on the cultural anxiety around thinking about decline and dementia in Western societies and its impact on the use and development of assistive technologies. Alongside Sébastien presenting during this plenary session on 'Dementia care as a priority' was also **Professor Marjolein de Vugt** (supervisor of ESRs 9 & 10) and **Professor Martina Roes** from INDUCT's second level partner, the DZNE.



considering long term implementation from the start, for instance by involving health care organizations and insurers in cocreation.

On behalf of **Sarah Wallcock** (ESR 4), **Professor Louise Nygård** from the Karolinska Institutet spoke about how two groups of older adults with and without dementia already use technology in daily life. The varying levels of challenge encountered by participants in using information communication technologies, e.g. web-surfing on a tablet, were presented. In light of the results and differences shown between the two groups, Louise closed the presentation with a number of implications for practice, encouraging people to take into account routinely used technologies. As a modern problem for modern times, it is important to consider whether technology use is the solution to a problem, or is it the problem to be solved?



**Professor Louise Nygård & Sarah Wallcock (ESR 4)**

**Professor Rose-Marie Dröes** (supervisor of ESRs 7 & 8) also organised a parallel session on social health in dementia, which included a presentation by former INDUCT member **Antonio Garcia-Casal** on his review of technologies to promote social health in people with dementia, written with **Ángel Pinto Bruno** (ESR 14) and **Professor Manuel Franco** as co-authors.



**Sara Bartels (ESR 9)**

Also presenting at the conference was **Dr Georgina Charlesworth** (supervisor of ESRs 1 & 2) who spoke about 'Co-research with people living with dementia: the challenges for participation and collaboration', and **Professor Justine Schneider** (supervisor of ESRs 5 & 6) who presented a poster on 'Winston's world: Research-based cartoon opens up dementia home care for reflection and learning'. In addition, **Sara Bartels** (ESR 9) delivered two posters. One poster presented the study design and preliminary results of the 'Monitor-Mi' study, a feasibility and validity project of digital self-monitoring in people with MCI, and the other on the collaboration study between Maastricht University and Karolinska Institutet focusing on correlations between a self-report and an observational tool measuring the ability of people with MCI and mild dementia to use everyday technology.

Finally, **Professor Frans Verhey** (supervisor of ESRs 9 & 10), **Professor Marjolein de Vugt**, **Professor Lieve Van den Block** (supervisor of ESRs 11 & 12) and **Dr Fania Dassen** (Training manager) were all involved in delivering an INTERDEM Academy Masterclass on tips and tricks for academic writing.

## NEWS FROM OUR PROFESSORS

### **Yvette Vermeer (ESR 1). University College London, UK**

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#### **Royal Award for Professor Rose-Marie Dröes**

We would like to congratulate one of our INDUCT supervisors, Prof. Dr. Rose-Marie Dröes for receiving a Dutch Royal Award. Professor Dröes supervises ESRs 7 and 8 in their research projects on technology to promote meaningful activities. The award honours those who have contributed to society, the state, and the Royal House for many years in the Netherlands. Alderman Simone Kukenheim appointed Dröes as Officer of the Order of Orange-Nassau in recognition of her important contribution to research and society.

Rose-Marie Dröes worked from 1983 to 1992 as a researcher at the Faculty of Human Movement Sciences, and carried out her PhD on psychosocial support for older adults living with dementia. Dröes also researched the effectiveness of Meeting Centres, where people with dementia and family caregivers can come together and share their experiences. Currently, 146 of such centres are established in the Netherlands. Professor Dröes has continually focused on societally relevant research with an impact on daily living, in particular improving the quality of care and the quality of life of people living with dementia and their family carers. One quote from the ceremony:

*'Dröes received her well-deserved Royal Award because of her commitment to the scientific and societal field. She is transforming both national and international research to a higher level and inspires people in the field of healthcare for older adults with dementia.'*

Huge congratulations to Professor Dröes on this outstanding award!



### **Annelien Van Dael (ESR 12). VUB, Belgium**

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#### **Excellent PhD Supervision Award for Professor Lieve Van den Block**

We would like to congratulate one of our INDUCT supervisors, Prof. Dr. Lieve Van den Block for receiving the first Excellent PhD Supervision Award of the Vrije Universiteit Brussel (VUB). Lieve supervises ESRs 11 and 12 in their research projects on complex health technologies in dementia, in particular advance care planning and palliative care interventions.

The award was initiated by the three VUB Doctoral Schools 'to promote styles of good supervision and support towards doctoral candidates'. PhD candidates of all doctoral schools were called upon to nominate their supervisor for this prestigious prize. They all had to write a 500-1000 word essay on why they believed their PhD supervisor was worthy of the award. The jury, comprising of the VUB vice-rector, 3 doctoral school directors, coordinator of the Research Training & Development Office and 3 PhD representatives, were said to have been moved by the nomination



essays and were very happy to award Prof. Van den Block with this prize. Some elements from the nomination essays:

*'In my opinion, Prof. Van den Block deserves praise for the way in which she stimulates collegiality.'*

*'Lieve sets the bar high and expects the same from her students. Yet there is still room to make mistakes and to learn from them; Lieve hands out compliments, not only when things are going well, but also when she notices that you are putting in hard work and giving it your best shot.'*

We would like to congratulate Lieve on this outstanding achievement!

## RECENT EVENTS ATTENDED BY ESRS

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

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#### **A snapshot of the policy world**

Many systematic reviews have shown eHealth interventions for caregivers of people with dementia to be effective on a variety of outcomes. However, very few of these interventions manage to find their way into practice and remain unavailable to the caregivers that need them. This is why I decided to do my PhD on the implementation of eHealth interventions for caregivers of people with dementia. In my research, I am combining perspectives from academic research, industry and policy. This past month I have been submerging myself in the field of policy.

First, on 25 September my supervisor Professor Frans Verhey and I attended a European Alzheimer's Roundtable meeting, organized by the International Centre for Parliamentary Studies. I was happy to see the familiar faces of INDUCT members Professor Justine Schneider, Professor Martina Roes, and ESR Rose Miranda there as well. During the meeting, experts from across Europe discussed the current policy framework of Alzheimer's disease in the EU: improving earlier diagnosis, new treatments, quality of care, fostering research, innovation (including eHealth!), drug development, the future of Alzheimer's, and shared recommendations. It was very exciting to look at my research from a new perspective and hear opinions from people working on dementia in different fields. There were also presentations by two representatives from the European Commission and from the European Parliament. I learned a lot about potential new outcomes for measuring treatment effect using big data, like sleeping or eating habits. Happily, a recurring theme was the need for more implementation research.



Second, on 5 October I attended the Standing up for Science EU meeting, organized by Sense about Science. It was also a very stimulating day, with sessions on 'Researchers Communicating', 'What policy makers are looking for' and 'What journalists are looking for'. We also discussed how researchers should take responsibility for the public discussion of science evidence, from the beginning of their careers. The main point I took away was that my research is interesting for a wider audience than I would have originally identified, and to not be afraid to be a part of the discussion.

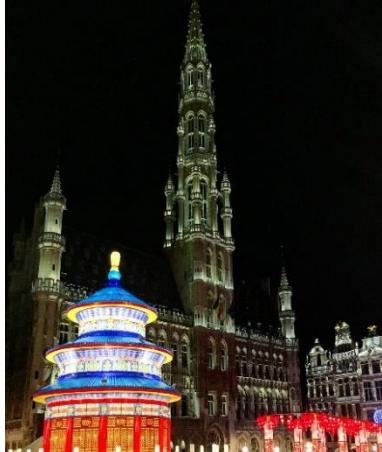
Finally, on World Dementia Day I attended the Dutch municipality of Roermond's symposium about their path to becoming a Dementia Friendly Municipality and learned that the most important thing when it comes to policy is to just *do*. Dementia policies should be sustainable, but to be successful they also need to be flexible and frequently adapted to the changing needs of a community. By making dementia a long-term priority, and implementing flexible and constantly evaluated strategies, Roermond has set a great example.

## AN UPDATE FROM THE SECONDMENTS

Kate Shiells (ESR 13). Univerzita Karlova, Czech Republic [Kate.Shiells@fhs.cuni.cz](mailto:Kate.Shiells@fhs.cuni.cz)

### ***From Brussels to Zamora: The importance of international collaboration***

2018 has been an extremely busy year of travelling and collecting data. In January, I moved to Brussels, a place which was familiar to me having worked as an intern in the city back in 2012. This time, however, I was based at the End-of-Life Care Research Group at VUB where I was supervised by Professor Lieve Van den Block and Dr Lara Pivodic. It was reassuring to see two familiar faces on the first day: Rose Miranda (ESR 11) and Annelien Van Dael (ESR 12) who helped me settle into the team.



Together with Lieve and Lara, I began working on a scoping review of the literature on the self-reported needs of people with dementia in nursing homes. Previous reviews exploring the needs of people with dementia have primarily focused on those living in the community, and furthermore, have almost always relied on proxy accounts. The review is now near-completion and I plan to submit the paper for publication by the end of the month. We hope that the findings will guide evidence-based care in nursing homes.



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In addition to this review, my other main task whilst in Belgium was to collect data in one nursing home on the experiences of care staff with electronic patient record systems. This was my first experience of collecting data outside of the UK, and an interesting experience it was, with interviews often merging between English, French and Flemish- a language I do not speak! Overall, this secondment in an academic environment allowed me to participate in a day-to-day research environment, including opportunities to attend workshops, and even deliver my own workshop on electronic patient records and methods of usability testing.

In the spring, I travelled to Zamora, Spain, to work at Fundación Intras, supervised by Professor Manuel Franco. I enjoyed speaking daily with many of the individuals who attend the day centre, and observed the GRADIO Trial in action. I also worked with INTRAS researcher Andrea



Lettieri on his article on employment opportunities for people with mental health problems, which enabled me to develop my skills

in reviewing and editing papers. I was extremely pleased to meet the new ESR 15, Alejandra Angie Diaz, who joined in May. With my limited Spanish, Angie was invaluable in helping me collect data in the nursing home in Zamora.



Perhaps the most valuable message I have taken away from my secondments is the importance of international collaboration: linguistically, but also through the sharing of skills and experiences obtained from diverse professional, academic, and cultural backgrounds. It is only through such international collaboration that we can produce the highest standards of research, which as researchers we are optimistic will translate into policy action and have a positive impact on the lives of people with dementia.

## NEWS FROM OUR ESRS

### Sophie Gaber (ESR 3). Karolinska Institutet, Sweden

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#### **Sophie Gaber is elected Chair of the Doctoral Student Council**

Congratulations to our ESR 3, Sophie Gaber, who has been elected as Chair of the Doctoral Student Council for the Department of Neurobiology, Care Sciences and Society (NVS) at the Karolinska Institutet. Sophie looks forward to building on her experiences with the INDUC Network to promote a healthy and inspiring work and study environment - starting with 'The Dialogue'. 'The Dialogue' has been developed by Doctoral students, for Doctoral students to support communication in supervisory meetings between students and supervisors. All INDUC members are invited to try using and sharing 'The Dialogue'.



For more information: [https://ki.se/sites/default/files/2018/10/11/nvs\\_doctoral\\_student\\_dialogue\\_final\\_version\\_oct.\\_2018.pdf](https://ki.se/sites/default/files/2018/10/11/nvs_doctoral_student_dialogue_final_version_oct._2018.pdf)

### Annelien Van Dael (ESR 12). VUB, Belgium

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#### **Training of staff is complete!**

Exciting times coming up for ESR 12, Annelien van Dael. Her project, an educational intervention for nursing home staff, is coming to a close. In the past eight months the staff of 7 nursing homes in Flanders, Belgium received training, educational seminars and one-on-one coaching to implement an intervention about Advance Care Planning (ACP). Staff was trained in conducting ACP conversations with all their residents, including those living with dementia, and their families. Sustainability of the intervention is the last step in the implementation-phase, after which T1 measures will be collected, to measure effectiveness of the intervention. In the upcoming months both effectiveness measures, as well as process measures will be taken. After that, ESR 12 is really looking forward to be able to share results of this project!



### Sébastien Libert (ESR 2). University College London, UK

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#### **ESR 2, Sébastien Libert sends some updates from his fieldwork**

Throughout the first part of his PhD research, Sébastien contacted potential partners for his research looking at cultural understandings of ageing and dementia within technologies from an anthropological perspective. It resulted in the establishment of 4 research collaborations: 1) with the PROTECT Study, at King's College, London; 2) with Alzheimer Europe and the European Working Group of People with Dementia; 3) with the PRIDE project at University College, London; and 4) with the INTRAS Foundation in Spain. Thanks to these collaborations, he could already set up: observation periods with the European Working Group of People With Dementia leading to a consultation with the group next December 2018; in-depth interviews with 27 participants in research on brain training for dementia (The PROTECT Study) and with 7 developers of an intervention



to promote independence in dementia (PRIDE). Additionally, Sébastien is currently conducting observations with researchers and clinical staff in a health centre in Spain who use a cognitive rehabilitation app for people with dementia and cognitive decline (INTRAS) until the end of December 2018. Starting from January 2019, he will dedicate most of his time to analysing the data collected and writing up his thesis. He hopes that his work will enable us to know more about the dominant cultural understanding of ageing within western societies today, its influence on the fear of dementia, and manifestation in new technologies for dementia, as well as its impact on people living with the condition.

## Harleen Rai (ESR 5). University of Nottingham, UK

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### **Feasibility trial in the UK open for recruitment!**

In the past year we have developed a computerized version of individual Cognitive Stimulation Therapy (iCST) together with our INDUC partner Eumedianet. A first version was taken forward in focus

groups and interviews including 26 people with dementia and their family carers. Participants bench-tested the App and shared their thoughts and opinions with the researchers. After collecting their valuable feedback, a second version was developed which currently includes more content and adaptations to existing activities. The second version is now ready to be tested in a feasibility trial where people with dementia and their family carers will be able to use it for several weeks. We are interested to know if there are any potential signs of effectiveness in terms of cognition for the person with dementia, and quality of life for both the person with dementia and family carer. We will also assess the usability of this second version of the App and make any adaptations where necessary after the trial has concluded. If you are interested in participating in this UK-based study or have any questions, please do get in touch!



First version of our App logo

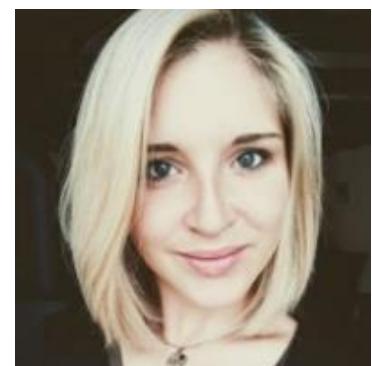


## Sara Bartels (ESR 9). Maastricht University, The Netherlands

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### **Special issue in Psychology and Aging-Manuscript in preparation**

After receiving reinforcing feedback from the editor on the manuscript proposal for a special issue in *Psychology and Aging*, ESR 9, Sara Bartels, is currently preparing the manuscript for submission. The special issue focusses on the role of psychological factors in the well-being and adaptation of individuals with cognitive impairment and their caregivers using innovative methods and perspectives. Therefore, the planned article evaluating the behavioural change in dementia carers in relation to affect and sense of competence over the course of the 'Partner in Sight' intervention based on the experience sampling method will be a valuable contribution. The deadline is the 1<sup>st</sup> of December 2018.



## FOURTH INDUCT SCHOOL TAKES PLACE IN PRAGUE

Kate Shiells (ESR 13). Univerzita Karlova, Czech Republic [Kate.Shiells@fhs.cuni.cz](mailto:Kate.Shiells@fhs.cuni.cz)

### **Developing knowledge and skills for the future**

ESRs, supervisors and second level partners met once again from 10-14 September for the penultimate INDUCT School in Prague. The School began with a visit to CIIRC- the Czech Institute of Informatics, Robotics and Cybernetics. Following an introduction by Professor Olga Štěpánková of the Czech Technical University in Prague, ESRs had the chance to visit the laboratories where researchers showcased their latest technologies, including a Tai Chi performing robot.

The next part of the summer school was dedicated to ESRs presenting updates on their projects. ESRs have come a long way in the last two years, which was evidenced by the number of articles published, conferences attended and data collection completed.



*'As a PhD student who is still on the fence about continuing a career in academia, or branching out into policy and other non-academic fields, I found this session extremely helpful. It was interesting to learn about our strengths and weaknesses as researchers when talking policy. By attempting to draft our own policy brief, we learned a lot about the many nuances of evidence-based policy, which will definitely be useful in the future.'*

On Wednesday, ESRs were joined by researchers from the INTERDEM Academy, which began with a policy workshop led by Professor Anne Margriet Pot from the WHO, and Wendy Weidner from Alzheimer's Disease International. Hannah Christie (ESR 10) said:



INTERDEM Academy members were then transported back into the world of technology, with an informative session by Professor Maurice Mulvenna from Ulster University on event logging, ecological momentary assessment and machine learning.



The second day of the Academy opened with a captivating lecture by Professor Martin Prince on dementia demographics around the world, which concluded with the important message that dementia is preventable if we place more emphasis on factors such as education and literacy in early life, smoking cessation and the reduction of hypertension throughout the life course. Professor Frans Verhey and Professor Marjolein de Vugt then encouraged us to consider the importance of the psychosocial model in dementia research, and the importance of social health in dementia.

Several sessions during the week allowed ESRs to build key skills for their future careers. These included two very useful sessions from Professor Lieve Van den Block and Dr Aline de Vleminck from VUB on grant proposal writing and the delivery of oral presentations. And on the final day, the school took a slightly different format, beginning with an interactive session exploring 'who we are as leaders', facilitated by Ilona Schumacher. Judita Matáyšová, a journalist from Prague, then co-facilitated a session with Professor Iva Holmerová on interaction with the media. ESRs were encouraged to present a brief snapshot of their research, whilst being filmed. Important preparation for any future contact with the media!



The final INDUCT school will take place from **13-17 May 2019** at the University of Hertfordshire.



## MORE INFORMATION



For more information, please access our website: [www.dementiainduct.eu](http://www.dementiainduct.eu)

Follow us on Twitter: @INDUCT\_MSC

Articles for the Spring 2019 newsletter to be submitted by 22 May 2019 to  
[Kate.Shiells@fhs.cuni.cz](mailto:Kate.Shiells@fhs.cuni.cz)