



# Interdisciplinary Network for Dementia Using Current Technology

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INDUCT NEWSLETTER

Autumn 2017

@INDUCT\_MSC

#### **WELCOME!**

Welcome to the fourth 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 newsletter, we look back on a productive INDUCT summer school in Salamanca, and also hear from Chris Roberts, Vice Chair of the European Working Group of People with Dementia, on his experiences of being involved with INDUCT. On pages 4-6, two of our ESRs explain how involving people with dementia has been invaluable in informing their research projects so far. And finally, Martina (ESR 15) and Harleen (ESR 5) share their memories of two very enjoyable secondments. 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)

### INTRODUCING OUR EARLY STAGE RESEARCHERS

Aline Cavalcanti Barroso (ESR 6). University of Nottingham, United

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# It's a long way to the top (if you wanna rock 'n' roll)...and we are already half way through!

Time goes by so fast! Seems like yesterday we were all together in London for the interview event. I cannot believe it was a year and a half ago! Perhaps you have already met me in one of the INDUCT Schools or at a conference, but I will introduce myself. My name is Aline and I am originally from Brazil. I am based at the University of Nottingham (UK) and I am supervised by Professor Justine Schneider and Professor Martin Orrell. I graduated in Psychology from the Universidade de Brasília, Brazil and I have an MSc degree in Neuropsychology from Maastricht University, Netherlands. At the moment, I am back in the Netherlands for my secondment with my buddy Floriana Mangiaracina and Professor Rose-Marie Dröes at the VU Medical Center, and my next secondment will be at the Karolinska Institute in Sweden.



During my secondments, I will conduct an online survey to check which art apps are more popular and used in care settings in the United Kingdom, Sweden and the Netherlands. This survey will also identify barriers and incentives towards adopting touch-screen technology to create arts and crafts in care settings. At a later stage, people living with dementia will be invited to join the study and will be using the most promising art apps found through the survey.

If you have any queries, suggestions or comments about my project, please send me an email! aline.cavalcantibarroso@nottingham.ac.uk

Looking forward to seeing you all at the next INDUCT School in Witten!

#### REUNITED! THE SECOND INDUCT SCHOOL IN SALAMANCA

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From the 25-29 September, the participants of the INDUCT project attended the Second INDUCT School in Salamanca, organised by IDES/INTRAS, CREA, the University of Salamanca, and with the support of the INTERDEM and INTERDEM Academy Networks. Early Stage Researchers, supervisors and second level partners had the opportunity to bring together their expertise, discuss current developments and future plans, and obtain insight into new advances and perspectives on technologies for dementia care.

During the first two days, the school took place in the CREA (Spanish Centre of Reference for Alzheimer's Disease). CREA is the most advanced Alzheimer's research centre in Spain and the cornerstone of intervention research in dementia. CREA also offers temporary



accommodation for people with dementia alongside three residential modules. The two days spent there not only provided participants with an opportunity to learn about CREA's facilities, but also to prepare for next steps within the INDUCT projects, and vitally, involving EWGPWD members.



On Wednesday, the team moved to Zamora to visit the facilities of INTRAS foundation. INTRAS foundation has worked effectively in several European projects developing and using technology as a facilitator in older adults with and without dementia in activities of daily living. The participants of the school could try out all the technologies currently used in the INTRAS Memory Clinic, learning about the implementation of technology in a community where the aged ratio is one of the highest around Europe, especially in rural areas.

On Thursday and Friday, the Symposium of new technologies in dementia care organised by the University of Salamanca was a great opportunity to learn about the newest advances in dementia interventions. Participants also had the chance to experience the Research and Development building of the University of Salamanca, where many PhD students and researchers are working to

make the translation of academic knowledge into society possible. We also heard from both Floriana Mangiaracina (ESR 8) and Martina Vanova (ESR 15) who presented updates on their projects so far.

Finally, congratulations to Sara Bartels (ESR 9) for winning the prize for 'Best Poster', and to Rose Miranda (ESR 11), and Annelien van Dael (ESR 12) as runners-up. A fantastic start to your research careers!

And of course, thank you to all those who made this very productive week possible, which has enabled us to keep learning and building networks to improve dementia care from a multi-professional perspective!



# Chris Roberts (Vice Chair of the European Working Group of People with Dementia)

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We, three members of the European Working Group for People with Dementia (EWGPWD) and supporters, along with the student members and facilitators, got together in Salamanca, Spain, to present updates on the research progress of the 15 Early Stage Researchers (ESRs) and to exchange knowledge and skills including our own knowledge as experts by experience in our dementia.

During lectures, workshops and interactive group meetings, various topics concerning current technology for people affected by dementia were discussed. The topics ranged from recruitment to research to publishing tips to patenting. The involvement of us members



of the EWGPWD after listening to the conversations and feedback was a real asset to the Summer School, all the ESRs were greatly inspired by our input and by our supporters' knowledge. All said it was an invaluable source of first-hand information and experience which helps bring their textual knowledge to a practical level of understanding, proving yet again the value of collaboration and involvement of experts by experience in all things usually done "for us" instead of "with us".

It was invaluable for us too. We learn so much which helps us to live better lives and was an excellent experience finding out about all the work and research being conducted on our behalf which is so appreciated. Being involved also allows our needs and wants to be heard now, and what we may want or need in the future when we might not be listened to in the same way as now.

Research work and collaboration like this gives us hope where before there might have been little or none. People living with, and affected by, dementia become experts by experience in their own right. They bring their own unique contribution which can only add to the expert knowledge of all. It is refreshing to see that INDUCT, with the help and assistance of Alzheimer Europe and INTERDEM, has acknowledged this, and fully involves people living with, and affected by, dementia. Thank you INDUCT and especially the ESRs and facilitators that made this event happen. Myself (Chris Roberts, Vice Chair), Idalina Aguiar and Nina Balackova, with our supporters, Jayne Goodrick, Nelida Aguiar and Iva Coelho, attended the event.

### PATIENT AND PUBLIC INVOLVEMENT IN INDUCT

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

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# What do people living with dementia need in surveillance technologies?

The Early Stage Researcher, Yvette Vermeer (ESR1), researches surveillance technologies for the Interdisciplinary Network for Dementia Using Current Technology (**INDUCT**). Surveillance can be a technological product used on and by people with dementia to track their location. Recently, Yvette presented at the 'DO NOT GO GENTLE – GERONTOLOGY AND A GOOD OLD AGE' 2017 conference from the British Society of Gerontology, where she discussed the growing awareness of the role that surveillance has on addressing the needs of people with dementia and their caregivers. For example, how people with dementia are portrayed by marketing messages as 'wanderers' who need to be tracked.



You can watch Yvette's presentation on the Aging Bites Youtube channel.

A key point in this research project is to understand what people with dementia think about these surveillance technologies. The second INDUCT school, which took place in Salamanca (Spain), was a great opportunity to discuss some of these issues with several project partners. The European Working Group of People with Dementia (EWGPWD) was one of these partners and provided an insightful and rich contribution to the project. One of these contributions was that the group highlighted their individual preferences and experiences with surveillance. This started a discussion where some individuals like the idea of being chipped with a tracker, but argued that current trackers on the market often do not work properly. Whilst other individuals were immediately opposed to the idea of their location being tracked. Thus, an interesting starting point for discussing what someone would or would not need in surveillance.

We are currently looking for people living with dementia to give their opinion about surveillance technologies and about whether they can become empowered through using these products. If you are living with dementia and would you like to know more about this research, please send an e-mail to v.vermeer@ucl.ac.uk.

### Sarah Wallcook (ESR 4). Karolinska Institutet, Stockholm, Sweden

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#### Local Links for Consultation

People living with dementia in Cumbria, a rural part of the Northwest UK, have been consulting on the INDUCT research project with Sarah Wallcook, ESR4.

Cumbria is home to the Lake District, a UNESCO world heritage site of outstanding natural beauty and an international tourist destination. It also has pockets of high deprivation and a super ageing population. For the people that live there, travel times are long with little public transport, and the sparse population and geographical terrain present challenges to accessing services.

This is really important to consider in developing sustainable opportunities for people to participate in all kinds of activities. It takes



time to get the word out, build trust and make it worthwhile for people investing the effort to come together. Connecting with existing local groups and networks to add value and offer complementary opportunities for research consultation has been vital.



Kizzy Pyne is the dementia support worker for the Alzheimer's Society in West Cumbria and is the catalyst for the newly formed Service User Review Panel (SURP). Primarily set up to consult on services and opportunities within the charity, Kizzy wondered if the group may welcome acting as consultants on wider issues, including the opportunity to advise on the unfolding INDUCT research. Kizzy said:

"This sounded like a genuine opportunity for the group to put forward their views with no hidden motives. This is a new group and it's essential that we start out as we mean to go on and make sure that the time people spend discussing topics leads to real action and change. Perhaps we will build more connections with people who share that focus."

Sarah met this fledgling group, together with Kizzy and volunteer Julie Barncroft, at their second ever meeting in October. Members thought they could feedback and help direct the research findings and results to appropriate audiences in Cumbria. In so doing, it is hoped that the SURP can use the research to positively affect change in daily life for people living in developing Dementia Friendly Communities. Sarah said:

"Hearing the SURP members' insights and perspectives on the agenda items was compelling. I am pleased to have this connection with the group and I look forward to discussing new and important ideas about why the research matters to their communities. If we collaborate on those ideas, we can make more impact with the study."



Photo 171030 SURP: The Cumbria Alzheimer's Society Service User Review Panel and INDUCT Member Sarah Wallcook

The SURP group have planned for future consultations to take place remotely via email and videoconferencing with Sarah based at the Karolinska Institutet in Stockholm. They hope that this will prove a successful, inclusive and engaging way to continue the conversation.

#### MEMORIES FROM THE SECONDMENTS

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

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Martina Vanova (ESR 15). IDES, Spain

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# Half a year together - that's meant to be...

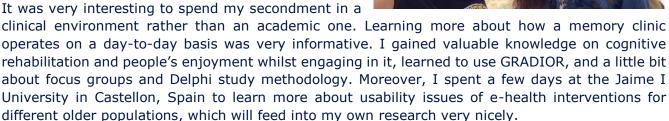
This year, ESRs 5 and 15 spent their secondments together. Harleen Rai (ESR 5) was on her secondment from June to August at the INTRAS Foundation in Zamora, Spain and Martina Vanova (ESR 15) is still on her secondment, which started in August at the Institute of Mental Health (IMH), University of Nottingham. How it all went and how the ESRs spent half a year together, you can read below.

#### MV: So Harleen, tell us about Spain...

Good weather, good people, good food, great trips we went for 4 days to Galicia in the North of Spain, and more... One of my very first social encounters was during a laser combat battle with Martina's friends, which was a lot of fun. Despite the language barrier, the group grew closer.

#### MV: How about work?

It was very interesting to spend my secondment in a



#### MV: What are you taking back from this experience?

To my surprise, I managed to fit in to Spanish culture and lifestyle very quickly. The sun, the siestas and the overall atmosphere were all right for me. I cannot wait to go back to my favourite spot at the Cathedral in Zamora and read my book and enjoy the sunshine again. Last but certainly not least, I met some great people who made my stay even more enjoyable.

#### HR: So Martina, let's start with the social life. How is it going in Nottingham?



Well, I do not even know where to start. On my second week, I established an IMH hiking group, going for walks to the Peak District nearly every weekend. We had a Halloween pumpkin carving evening and of course, the social evenings with other PhDs are great too. I also ran a marathon in Leicester in October, and what I will never forget is you shouting at me: 'You go, champ!'

#### - HR: Are you enjoying working at the IMH?

Definitely. For me it is a very nice change working in an academic environment so I can meet with other researchers, sharing thoughts and experiences. I am

attending some university short courses, working on my articles, and learning to analyse fMRI data, which is super exciting for me. I am also learning about RCT management. I went to the RCT unit in Sheffield and I am shadowing an RCT 'Journeying through dementia'. Overall, many exciting work activities.

#### HR: What will you always remember about your secondment?

The people, the hills, the life and our evenings cooking together. Moreover, I will also remember well your secondment in Spain. Luckily, there are still a few more weeks left for me in the UK.

#### HR: Any final thoughts?

I will be back...

In conclusion, these secondments were more than work experience for both of us. We supported each other in the good and bad, shared moments which we will not forget, and we could say that our secondments made not only our working relationship better but also made our friendship stronger.

## **MORE INFORMATION**





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

Follow us on Twitter: @INDUCT\_MSC

Articles for the Spring 2018 newsletter to be submitted by 10 May 2018 to: kate.shiells@fhs.cuni.cz