



DEMENTIA: INTERSECTORIAL STRATEGY FOR TRAINING AND INNOVATION NETWORK FOR CURRENT TECHNOLOGY



Welcome to the winter newsletter!

Time flies and we are in our third DISTINCT year already. So much has happened since our last update. In spite of difficult times and the COVID-19 still ongoing, we have been working hard on our projects. Our enthusiasm for our projects and being able to be involved in dementia care has certainly been fruitful. This newsletter is filled with lots of exciting information on things that have happened in the last months to the DISTINCT projects and the ESRs.

Grab a cup of coffee or tea, sit back and relax, and enjoy the third DISTINCT newsletter.

Warmest greetings from the editors – Gianna (ESR10) and Aysan (ESR13)

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Updates from the ESRs

The COVID-19 pandemic is still ongoing, but we have been working hard to keep our projects moving forward. Read how the ESRs are doing and what they have been working on these past two(ish) years.



Lesley Garcia (ESR1)

I have remained in my home country of Trinidad and Tobago for all of 2021 since relocating back there at the start of the pandemic in March 2020. Closed borders and national lockdowns due to COVID-19 have hindered my return to the UK. It has been a challenge to maintain real-time communication with colleagues as I am five hours behind the UK. However, this has meant that I am in the same time zone as my software development partner MPower Me who are based in Virginia, USA. I have taken advantage of this for training and taking part in clinical working groups meetings which has facilitated my understanding of the web-based technology that will be used in my intervention ROAD MAP.

Esther Gerritzen (ESR2)

Whereas the first year of DISTINCT was mainly about designing my project and preparing the studies, the second year was more about starting the individual studies. I started a focus group study to learn more about how people with Young Onset Dementia experience having peer support meetings in online videoconferencing platforms. For this study I collaborated with fellow DISTINCT ESR Gianna Kohl. The second study I started is an online survey for people with Young Onset Dementia about their experiences with and ideas about online peer support. The survey is still open for people to take part. In parallel with those two studies, I continued working on my systematic review on online peer support for people with chronic neurodegenerative conditions, which will cover three individual papers. Furthermore, during the second year I completed my secondment with the Rare Dementia Support Impact Study at UCL. I'm currently still working with some members of the team on a survey study on the impact of the Covid-19 pandemic on people with a rare type of dementia and their carers. For the final year I will complete the ongoing and remaining studies of my project, complete a secondment with Maastricht University, and write my PhD thesis.





Fanny Monnet (ESR3)

My project focuses on developing an advance care planning (ACP) website for people with dementia and their families. ACP is a process that enables individuals to identify personal values, to define goals and preferences for future care and medical treatment, and to discuss these with family and healthcare providers.

During the last few months, I have been working on the development of our ACP website for, and with, people with dementia and their families. We tested all our prototypes with people with dementia and family caregivers. We first focused on the layout and overall design of the website, then went on to test the information part of the website, and are now testing the communication part of the website. In our next step, we will test the website as a whole with our participants. All throughout this development process, we are also regularly consulting an advisory group composed of people with dementia, family caregivers and regional stakeholders.

Furthermore, some other projects are still ongoing such as the analysis of dementia associations' websites and the ACP content they provide, qualitative work on the European Working Group of People with Dementia's perspectives on ACP, and an overview of theories that could be applicable to ACP for people with dementia.

Simone Anna Felding (ESR4)

2021 has been an eventful year. Unfortunately, I started the year with a bike accident that resulted in a longer sick leave. But I was lucky and got back on working on my project, not least thanks to my supervisor Prof. Dr. Martina Roes, who has been incredibly supportive throughout this process! Getting back, I started off by finishing my scoping review resulting in our submission of the review this fall. I was also able to present the review findings at the 31st Alzheimer Europe Conference and based on the findings I have written a recommendation for the DISTINCT best practice guideline. I also started making the final



arrangements for my ethnographic fieldwork including a PPI session with the European Working Group of People with Dementia together with a group of ESRs. This was a great help in getting ready for doing fieldwork and for working closely, empathetically and consciously with people with dementia. In September I packed my bags and went to my hometown of Copenhagen to start the fieldwork in Danish nursing homes using pet robots. Here I got the position as guest researcher at the Department of Anthropology, University of Copenhagen. This has given me the opportunity to reconnect with old colleagues, participate in research meetings and seminars and provided me an office to write my field notes. The fieldwork is a great time to really get close to the people whom my work is all about – the people with dementia living in nursing homes as well as the staff and family members. I have become an accepted part of everyday and really enjoy spending time and building relations with these incredible people. COVID-19 makes this a challenging time to do this research, but also an important time and I am grateful to have been accepted as a researcher in the nursing home. Soon the fieldwork is coming to an end, and I will go back to Germany and look forward to seeing all my colleagues and friends again and to an exciting 2022. I also started my secondment with Alzheimer Europe on 1 February 2022.



Golnaz Atefi (ESR5)

My project is mainly about informal caregivers. During the last few months, I have: 1) Received the ethical approval of the ACT-IC feasibility study protocol; 2) Completed a quick oral presentation in Alzheimer Europe; 3) Organised a hiking fundraising for Alzheimer centrum Limburg; 4) Published as a second author in collaboration with Beliz (ESR 15); 5) Completed my secondment; 6) Presented in a workshop on “barriers of E-health interventions and suggested solutions” in my secondment institute; 7) Started writing a paper on “emotional inertia and its association with the future course of depression in informal caregivers”; 8) Planned my second secondment in Nottingham.

David Neal (ESR6)

Since the last newsletter my team and I have hit some a couple of milestones in our research with the FindMyApps intervention.

By November 2021 we had recruited more than 100 people with dementia to participate. This is fantastic news, which means we’re well on the way to our target of 150 people. Size matters with our research: the more people who take part, the more reliable the conclusions we’ll be able to draw about the effectiveness of the FindMyApps intervention.

In October, I completed a productive secondment at Saxion University of Applied Sciences. We gained some media attention and presented as part of a symposium at the GSA 2021 Congress, for our work on the cognitive accessibility of online privacy information. We hope that this will result in a publication next year.

Before the next newsletter I’m also expecting to hit an important personal milestone. My wife and I are expecting our first child, sometime around the end of December or beginning of January. This means that I’ll be away from the project for six weeks - a sort of mini-secondment to teach me how to change nappies, look after my wife and function without sleep! Photo updates to follow...



Mauricio Molinari Ulate (ESR7)

The last months have been very exciting! My project has been progressing and I had the opportunity to experience some adventures abroad. I spent three months (Sept. to Nov, 2021) at the Psychiatry Department of Amsterdam University Medical Centres at VUmc where I worked on the project of developing an *Online Introductory Course for the Implementation of Meeting Centres* in different languages with Prof. Rose-Marie Dröes. During this period, I had the opportunity to visit four Meeting Centres (MC) around the Netherlands and experience their friendly environment and philosophy. Also, we surveyed potential facilitators and barriers of implementing MC in Ecuador and Spain through interviews with stakeholders in these countries. With the end of this project, I have already completed my two secondments and am ready to incorporate both experiences and results into my main project. For the following months, I expect to disseminate the results from the systematic reviews of my project and the projects of my secondments; additionally, I am excited to start with the field studies with the prototype of the platform. 2022 is going to be busy and challenging but happy to start this last stage of the project!

Jaroslav Cibulka (ESR8)

I was mainly busy with practical development work in the lab, especially upgrading PetBot to make it into a minimum viable product to be used in acceptability studies. I have focused on hedonistic features as a path to increase user acceptance. I have made multiple units for parallel and longitudinal co-creation experiments.

**Viktoria Hoel (ESR9)**

Our feasibility trial evaluating I-CARE is coming to an end, and although it has been an incredibly frustrating challenge to recruit participants, those who have enrolled in our study have provided feedback on I-CARE. This is truly encouraging. And through the trial, we have had some great discussions with our participants. Not about how they liked I-CARE and what they need to use the system independently at home, but also about how the dyads have coped together through the pandemic, and how it has affected their social health and relationship with each other. This project has really sparked my interest in positive experiences in caregiving, and how caregiving dyads find enrichment in their relationship together. I am looking forward to completing the quantitative and qualitative analyses and sharing our results! Before that, I will (hopefully, if possible in these crazy times) go on my second three-month secondment to NUI Galway in February. Together with Wei Qi, I will work more on operationalizing the concept of “Enrichment” in dementia caregiving, as well as assisting Wei in her upcoming Delphi study. I am really excited to be working on something new for a while, in a new environment and with such an eminent colleague!

ESR-10: Gianna Kohl

During the last months, I have been working on preparing two of my studies for recruitment. One study is an interview study and the other one is an (international) online survey. Both studies revolve around how people with dementia and family carers decide to share the dementia diagnosis with other people and which factors play a role in that. I am currently recruiting participants for both studies and have had a lot of interest from people with dementia and carers who would like to take part. I am very happy that it has been going smoothly so far and am eager to share the findings once they have been analysed. I finished my first secondment with the University of Hertfordshire in May 2021, and have just started my second one with Alzheimer’s Disease International and Alzheimer’s Society UK. I’m very excited about this secondment, because I will get a chance to learn more about the development of online content for people living with dementia as well as get a chance to work with people affected by dementia to adapt the existing “Who to tell, how and when” intervention. I think 2022 will be an exciting and challenging year, and I am looking forward to spending some more time with the other ESRs in our final year.





Pascale Heins (ESR11)

During the past months, I worked on a qualitative interview study on the experiences of community-dwelling people with dementia regarding their social out-of-home participation. I conducted dyadic interviews with people with dementia and their informal caregivers. In collaboration with Gianna (ESR10), I am currently analysing the interview data. Furthermore, I conducted my virtual secondment at Karolinska Institutet (Stockholm, Sweden) and visited the secondment institution for two weeks in October 2021. Right now, I am working on a paper resulting from this secondment. The paper is related to the concerns of community-dwelling people with dementia when participating in social out-of-home activities. Besides, I am working in collaboration with the ESRs with an Occupational Therapy background on a position paper on the role of occupational therapists in the design and implementation of emerging technologies for people living with dementia. At the same time, I am working on a protocol and ethics application for my feasibility trial that will evaluate the potential effects of the mobile application 'Viamigo' on the social participation of people with dementia (see: <https://www.viamigo.be>).

Wei Qi Koh (ESR12)

The overall purpose of my project is to identify strategies for implementing pet robots in nursing homes for residents with dementia (pet robots are a technology-based substitute for live animals). The first steps are to gain a thorough understanding of the barriers and facilitators that influence their uptake in real world practice. To achieve this, we synthesised literature in the field, and also conducted a qualitative study. The latter involved in-depth, one-to-one interviews with key stakeholders in several nursing homes in Ireland. We are in the process of analysing the data, and expect to be able to share our findings by spring 2022. Moving forward, these findings will also inform the development of our subsequent modified Delphi study, which is expected to commence in spring 2022. On a more personal basis – after nearly 2 years of living with the pandemic, work-from-home somewhat feels more normalised. But I look forward to a (hopefully) less virtual 2022, and seeing more of the lovely fellow ESRs in person 😊



Aysan Mahmoudi (ESR13)

Recently I submitted my scoping review article and got the ethical approval for the feasibility and efficacy study of MINI. We are designing a living lab for the robot deployment. This lab will be one of the sites for our first trial study. Also, I'm running my secondment plan at VUmc, Amsterdam, and am so excited to work with Professor Rose-Marie and her nice team. The plan is to identify the potential facilitators and barriers to implementing the MINI robot in the meeting center in the Netherlands. The recruitment for the first trial of the MINI robot will start as soon as I get back to Spain."

Josephine Rose Tan (ESR 14)

2021 was a challenging year! I started my recruitment in February 2021 (while I was working remotely from New Zealand!), and from the first 4 residents that we had then, we finished with a total number of 23 residents recruited for the year. Despite the difficulties of the current global pandemic, I will be forever grateful to the residents, families, and the professional carers especially, for continuing to work with us despite it all! There is a lot of work in store for us in 2022, especially in recruitment, but I remain hopeful.



On the other hand, I completed my online secondment with the University of Nottingham, and I enjoyed being able to present and talk about our app, the Fotoscope to different audiences. I gathered feedback from academic members of the Centre for Dementia, and I presented to the Dementia, Frail Older People and Palliative Care PPI group.

A highlight of the year was having my oral presentation accepted for the 2021 Alzheimer Europe conference, and also presenting during the INTERDEM annual meeting. I am also happy to say that my first article has been accepted and is currently in preparation, so stay tuned! Finally, I would have to say that this year has been memorable because finally, the ESR's got to meet up in person in the mini Prague school, and the formal school in Nottingham!

**Beliz Budak (ESR15)**

I had some delays when getting ethical approval for my PhD, which led to some stressful times and some lengthy discussions on changing some steps. Also, I am preparing for my secondment in Silverfit in February. I am planning on deploying my survey in January on Ambient Assisted Living technology in nursing homes in Europe and the UK.

The mini and the 4th DISTINCT school: A recap

The global pandemic meant that we had not been able to meet in person for almost two years. We were all eager to meet up and are very grateful that we had our first meet-up at the mini school in Prague in September 2021, followed by the official fourth DISTINCT school in Nottingham. Read on to find out more about the schools.

Prague

Our first meet-up took place in Prague from 16-18 September 2021. We were warmly greeted by the local coordinators from Czech Technical University Olga Štěpánková, Jaroslav Cibulka, and Milena Zeithamlova on Thursday morning and learned more about dementia care in the Czech Republic and the exciting work that is being done at the university. We ended the day slightly wet from the rain with a visit to the Gerontology Day Centre that is being led by Iva Holmerová, where some lovely snacks and drinks waited for us.



Friday started off with a visit to the Tech Lab where we were able to try out some exciting technological innovations that are being developed there: the aging suit and virtual reality games for memory training. This fun experience was followed by presentations from fellow PhD students presenting their current research projects, and a hackathon where we discussed current technology promoting social health during COVID-19.



We were all very excited for Friday afternoon where we had the opportunity to experience Prague by boat while cruising on the Vltava river. Some of us had never been to Prague and this was a lovely way to see and hear more of the city and its history. We finished the day off with a great celebratory dinner at the Obecní dům restaurant where we were all admiring the Art Nouveau interior and chandeliers.

A big thank you to the local coordinators and Jaroslav, and to Viktoria and Mauricio for having made this trip possible. This mini school was a great way to meet each other in person and to experience beautiful Prague.



Nottingham

The 4th DISTINCT school took place from 11-15 October 2021 and brought out nearly 25 people into the De Vere Jubilee Conference Centre at Nottingham University, where people found a great opportunity to attend management meetings, get training sessions, and do social networking. The ESRs got involved in several management and networking meetings in the first



three days, and discussed their current progress and future plans as well as the presentations of the local team. The fourth and fifth day were devoted to the INTERDEM masterclass sessions where members took away a lot of knowledge on implementation science, the future in dementia as well as innovations.



On Tuesday in the late afternoon, we met Robin Hood himself who guided us through the city centre to teach us

about the world-famous legend and to show us the best that Nottingham has to offer. This was followed by the celebratory dinner, which was organized to take place at the Lace Market Hotel in central Nottingham. The dining room was abuzz with excitement as Professor Martin Orrell raised a toast to DISTINCT, and David received some gifts for his upcoming arrival: little baby Robert!



There was another great dinner gathering at Ye Olde Trip to Jerusalem, said to be the oldest pub in England. We all found the place very ancient and quirky and a warm environment to stay together until late at night. The ESRs and consortium hope to meet again at the 5th DISTINCT school in Spain!

Stress, the PhD and 2021

We all know that doing a PhD, especially during a global pandemic, can be very challenging and stressful. We asked the ESRs what they find especially stressful and how they tackle stress. We also wanted to know how they would describe 2021 to have a short recap of the previous year.



Question 1:

What stresses you or worries you when it comes to your work?





Question 2:

What are your stress buster tips and tricks?

Question 3:

In one word, how would you describe the last year?



Resources and information on stress while doing a PhD:

- Chris Woolston for Nature Career feature: [PhDs: the tortuous truth](#)
- Marta Oliveira & Laura Breimann for "The Cancer Researcher": [7 reasons why we get stressed during our PhD](#)
- Ryan Raver for "The Grad Student Way": [Dealing with PhD stress the right way: Advice from 3 PhD graduates](#)
- Dr Max Lempriere for "The PhD proofreaders": [39 PhD Mindfulness Exercises To De-Stress Your PhD](#)

Commentary on ISO app quality standard

DISTINCT network protests potentially stigmatizing eHealth quality standard

By David Neal (ESR6)
Amsterdam University Medical Center, VUmc



The DISTINCT network's biggest collaboration to date resulted in an article published in *Lancet Digital Health* in February 2022 (click [here](#) to access the article). More than 40 researchers supported a commentary, raising concerns about the International Organization for Standardization (ISO) standard for health app quality assessment.

DISTINCT ESR David Neal first raised concerns that the new quality assessment tool may stigmatize or exclude certain groups from using health apps. The ISO standard aims to assess which health apps are 'easy to use'. However, the assessment and labelling of apps as 'easy to use' doesn't account for factors like cognitive impairment, age and culture, which may make an app harder to use for some people than for others.

From the results of our research within DISTINCT, previous Marie Skłodowska-Curie network INDUCT, and many other sources, we know that stigma is a problem: people make negative assumptions about the ability of people with dementia to use technology.

If apps are designed well, they have great potential to help people with dementia maintain and improve health. However, if people are offered apps which are labelled 'easy to use' but aren't designed to meet their needs, they are likely to struggle. If they conclude that they can't even use 'easy' apps, it could harm self-confidence and lead to people giving up on eHealth altogether. This would reinforce negative stereotypes and make eHealth less accessible for people with dementia.

Quality assessment and clear labelling of apps are absolutely necessary. COVID-19 is driving availability of and reliance on eHealth. We need to know we're investing in things which work, so quality assessment is important to help policymakers, doctors and the public choose the best apps.

Collectively we're calling on the ISO to urgently review and revise the quality assessment standard. In particular, one thing has to be made clear in any 'easy to use' labelling: who has an app been tested with? In other words, has it been tested with people with cognitive impairment and refined to meet their needs, or not?

In the meantime, we think doctors, healthcare leaders and the public shouldn't rely on these quality labels. We have to review the quality of health apps on a case-by-case basis.



Working in times of COVID-19: My secondment in Brussels

By Golnaz Atefi (ESR5)
Maastricht University

As part of my secondment project, I have been collaborating with “Vrije Universiteit Brussel” (VUB) over the past few months.

Despite this difficult time of the pandemic, “End-Of-Life Care Research Group” managed to remain creative, structured, and safe. We were advised to work in small groups of colleagues called “bubbles” and we had to register our bubble for our selected “office day”. Thus, we could still maintain our social contact while adhering to the COVID regulations. My bubble (+ Fanny) became my circle of friends in Brussels!



Learning more about advanced care planning and palliative care

During online "staff meetings," I was able to connect with the rest of the colleagues in VUB. The research group actively provided interactive meetings and workshops where junior and senior employees could discuss their requests, scientific updates, plans and future perspectives at the individual and team level. Informal discussions and outside-the-box thinking made dissemination research to this group very interesting and informative.

I gained a better understanding of advance care planning, and palliative care where you can approach the topic from clinical, philosophical as well as ethical points of view. (As a side note the book “A Matter of Death and Life”, written by one of the foremost existential psychiatrists and his writer wife “Irvin and Marilyn Yalom” might interest you).

Little recommendation regarding in-person secondment for my ESR fellows: during the time of COVID when in-person meetings even with your own team are limited, in case of possibility, try to arrange regular joint online meetings with the host as well as the secondment partners. Stepwise planning and clarifying the detail of the project together with both teams (especially before arrival) might accelerate the speed of your project at the later stage.

Finally, I’m grateful to my incredible secondment supervisor Prof. Lieve Van den Block whose wisdom and expertise gave me better and deeper insight toward work as well as life. Thanks to the end-of-life care research group and its inclusive and dynamic work environment, I will leave Brussels with inspiring experiences.



Cycling through the Netherlands... Developing the road to the Spanish version of the Meeting Centres Support Programme

By Mauricio Molinari Ulate (ESR7)
IDES



In September 2021, I got on my “*Oma Fiets*” (Dutch for “Granny bike”) to start my secondment journey at the department of Psychiatry of Amsterdam University Medical Centres, location VUmc. My bike took me all over Amsterdam to visit the *Meeting Centres (MCs)*, friendly community centres dedicated to supporting people living with dementia and their carers through psychosocial, psychomotor, and emotion-oriented care interventions. Crossing Amsterdam, through its bicycle paths and canals, I could taste, feel, and learn about the philosophy and methodology of the Meeting Centres Support Programme (MCSP). This brought me back to the essence of doing research for the people and the community. I understood that “*the MCSP is something you have to experience, not just learn*”.

Experiencing the methodology in the MCs, and hearing about the road that led to it, provided me with the necessary knowledge to start a new ‘cycle path’ to transfer this methodology to other international communities. With the support of Prof. Rose Marie Dröes, Prof. Manuel Franco Martín, and Brigitte Bélanger, the idea of developing an *Online Introductory Course for the Implementation of Meeting Centres* in different languages gradually became a reality. The online course is intended to inform pioneers around the world who wish to set up a MC in their own country about the vision and methods of the MCSP and its step-by-step implementation. In addition to the translation into Spanish, it was important to identify potential facilitators and barriers to implementing MCs in Spanish speaking countries in order to improve the adaptative implementation of the programme. Therefore, we interviewed stakeholders from Ecuador and Spain. We are now close to putting the Online Course into the basket of my “*Oma Fiets*” and travelling with it to Spanish-speaking countries. We expect to arrive in Spring 2022.

Letter from the field

By Simone Anna Felding (ESR4)
German Center for Neurodegenerative Disease

I sit down next to a resident. I put the cat on the table. She asks me, what it is. I explain, that it is a mechanical cat. I ask her, if she wants to sit with it for a little while. She tells me, that she's allergic to cats, so unfortunately it's not possible. I take the cat in my lap. I tell her, that I am also allergic to cats, but that it's different with this one. This cat is mechanical. Hanne replies: "It's not a real cat, is it?" I tell her that it isn't. That it has batteries and everything. She laughs loudly. "Don't try to fool me!" I laugh with her. "No, no", I say, "you are no one's fool". We laugh. I ask her, if she wants to try it, since it is not allergenic. She nods. I give it to her. "Ahhh", she screams. "It itches, it itches", she yells out loud. I quickly remove the cat from her and put it on the table (Field note excerpt, 25.10.2021, translated from Danish).

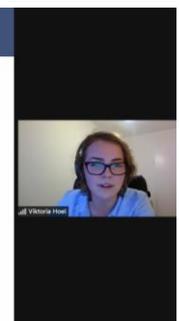
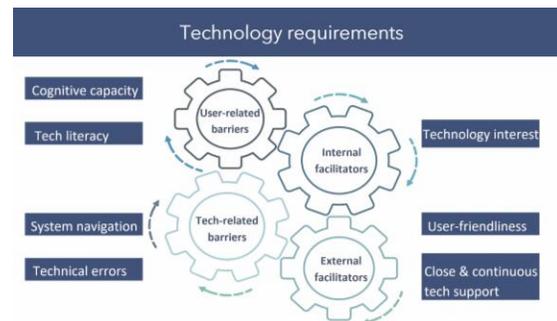
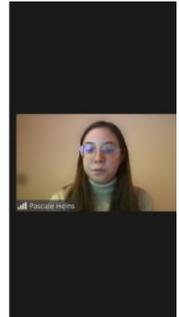
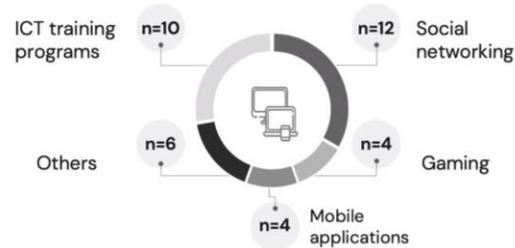


I have had the privilege of doing ethnographic fieldwork in a Danish nursing home for the last 5 months. During this time, I and the robotic cats and dogs, that I am researching, have become part of everyday life. I am a conversation partner for many of the residents, regardless of whether the conversations are verbalized or purely nonverbal. The robotic cats and dogs are a part of these conversations and interactions and I bring them around with me, something which has earned me a reputation as the cat lady. The pet robots are surprising and unstable beings. As we can see in the field note excerpt above, the robots can change from being mechanical to real animals in a matter of seconds and their existence and potential is ever-changing. As my fieldwork is coming to an end, I look forward to going through my many pages of field notes and interview transcriptions, pictures and drawings, and start to gain a better understanding of how and when these robots work in practice. For now, I am preparing to say goodbye to the people who have become an important part of my life in this period and embark on the next chapter of my research!

Joint symposium at the Gerontological Society of America's 2021 Annual Meeting

By Pascale Heins (ESR11)
Maastricht University

On the 5th of March, I got an e-mail from Viktoria (ESR9). She asked if someone would be interested in collaborating on a joint symposium at the Gerontological Society of America's (GSA) Annual Scientific Meeting, which was planned to take place in Phoenix, Arizona. I was lucky to be one of the ESRs that replied fast enough to be part of this conference submission – together with David (ESR6), Gianna (ESR10), and Viktoria. As the submission deadline was less than one week later, we started to work immediately on a symposium theme and our individual abstracts.



CONCEALING & DISCLOSING

Why disclose?

- Get access to resources and services
- Increase well-being and quality of life
- Get support from others

(Birkun et al., 2012; Pachanki, 2007)

Why conceal?

- "How does dementia kill you?" **DAILY EXPRESS**
- "Alzheimer's: A living death both for the patient and their loved ones" **Daily Mail**

#GSA2021
GSA2021.org



PRIVACY INFORMATION

In the European Union, the General Data Protection Regulation has created a form of 'mandated disclosure' with respect to data privacy. All apps and websites must provide users with information about privacy. But this can lead to problems (see Ben Shahrar & Schneider 2014). It would take 244 hours a year to read all this information (McDonald & Cranor 2008).

Problems with privacy information

- Too long (>1500 words)
- Too complicated (Common European Framework of Reference level C1)
- Design does not promote attention

#GSA2021
GSA2021.org



Three months later we got the good news: our symposium abstract has been accepted! We were looking forward to being part of this American conference that brings together experts in the field of aging from various countries and backgrounds. Unfortunately, the conference had to take place online due to COVID-19. Since the conference was supposed to be held in Phoenix (with a time difference of 8 hours), our presentations were scheduled on a Saturday night. Even we were a bit tired, we enjoyed being part of this big conference network and sharing our research insights related to "Strategies to Design Technology Promoting Social Participation of People With Dementia and Their Caregivers".

We would like to give a special thanks to Dr. Jane Flanagan for leading the session and discussion in such an enthusiast way and Prof. Dr. Karin Wolf-Ostermann for supporting us during the conference submission.

Technology used in DISTINCT

We all know DISTINCT has something to do with technology, and some ESRs are even developing and/or testing some kind of technological innovations. But have you ever wondered what kind of technology some ESRs are actually working on or with? So did we! Read on to find out more.



Example photo representing the ACP website

Fanny Monnet (ESR3) – Vrije Universiteit Brussel

As part of my DISTINCT project, we are developing an advance care planning (ACP) website for people with dementia and their families. We are working with an IT partner and are using an agile development approach, meaning that we are building the website in several iterations, before testing it as a whole. We are currently mid-way through the development process.

Gianna Kohl (ESR10)- University College London

I am working on the adaptation of an existing group-based face-to-face intervention called “Who to tell, how and when” into a web-based intervention. The original intervention has been developed at University College London and is aimed at people affected by dementia who are fearful or worried about disclosing the dementia diagnosis to their social networks. The intervention exists of three sessions that participants go through. The overall aim is to be confident in deciding whether or not to tell other people about the diagnosis.



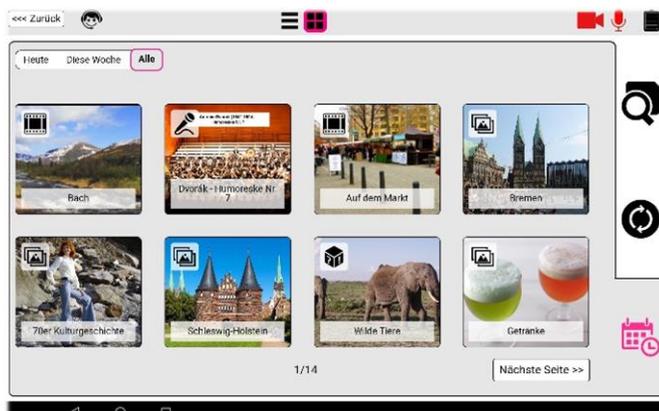
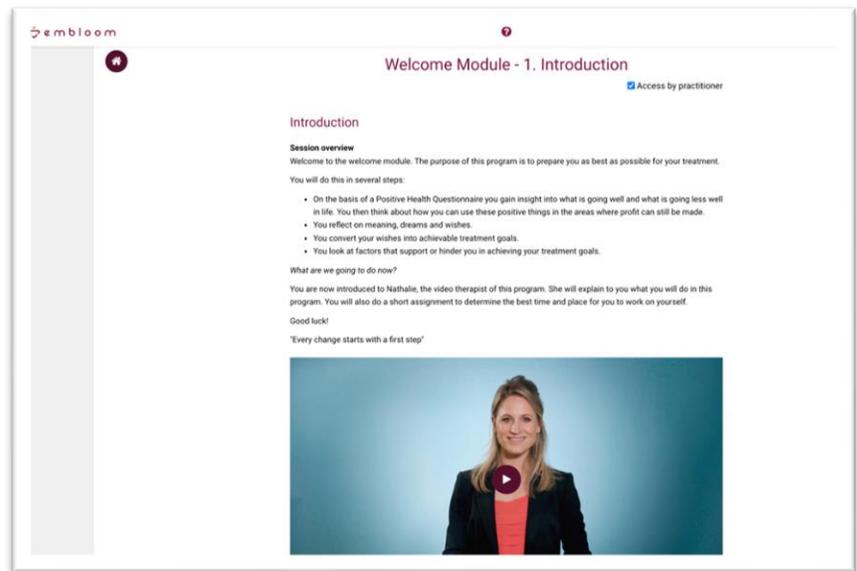
TALKING ABOUT DEMENTIA

A resource for people living with dementia who are worried about sharing the diagnosis with other people.

[Learn more](#)

GoInaz Atefi (ESR5) – University of Maastricht

I am working on a psychological intervention that will be delivered via an internet-administered, self-help program called 'Embloom' which offers modules consisting of written material, videos, and assignments. This program will mainly focus on enhancing psychological flexibility and a sense of acceptance while facing unpleasant thoughts and feelings. Participants are anticipated to engage with the intervention from their own computers/tablets. Participants will also be receiving weekly motivational voice/video calls from a coach located at Maastricht University.

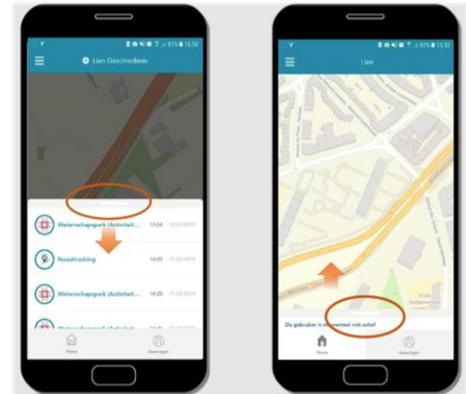


Vikoria Hoel (ESR9) – University of Bremen

I-CARE is a tablet-based activity system specifically designed for people with dementia to do in tandem together with a partner. In our project, we are evaluating the system with community-dwelling people with dementia and their family caregiver in a dyadic relationship. The system contains a wide array of different activities, with different difficulty levels, making I-CARE suitable for any age, as well as most stages and types of dementia. Through machine learning methods, the system learns about the preferences of the user, and can thereby recommend activities that suit the users' preferences. The vision of I-CARE, as stated by the developers, is that the system can promote joint activities that are meaningful in themselves.

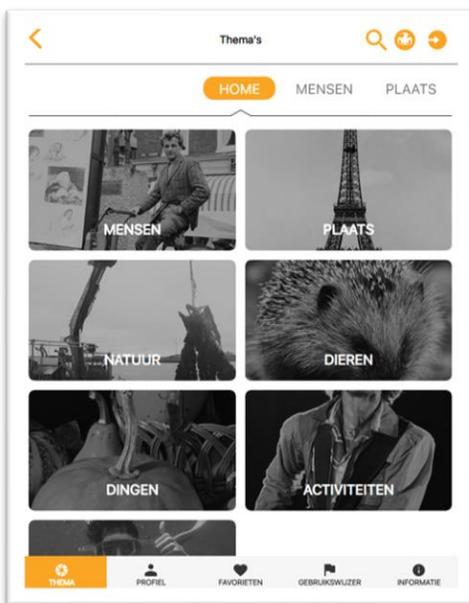
Pascale Heins (ESR11) – University of Maastricht

Viamigo is a Geographic-Information-System-based mobile application for people with intellectual disabilities that is developed by the Transportation Research Institute (IMOB) of Hasselt University. The application helps to accomplish a known individual route, so that people with intellectual disabilities can independently participate in outdoor activities while a personal coach (e.g. informal caregiver) monitors the person in real-time at a distance, using the Viamigo web-based or mobile application. In my research project, I will evaluate the feasibility and acceptability of using Viamigo to enhance the (social) out-of-home participation of people living with dementia.

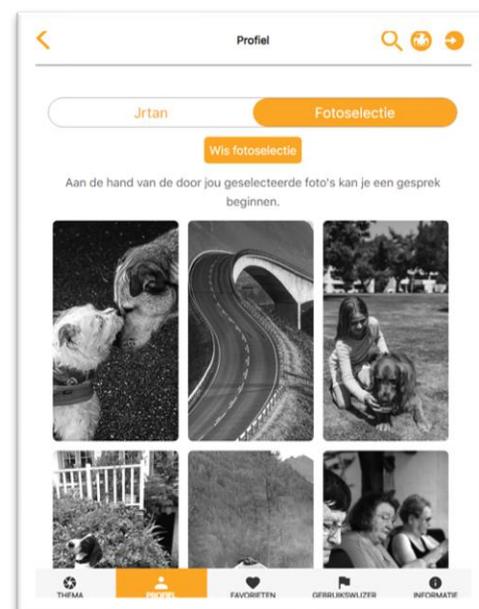


Josephine Rose Tan (ESR14) – University of Amsterdam, VUmc

The Fotoscope web-app: digital tablet version of the Photo-Activity intervention for residents with dementia in the nursing home and their carers, developed in collaboration with researchers in the field of dementia, experts in ICT, a visual artist, carers and residents living with dementia.



Themes page



Fotoselectie (photo-basket page)

David Neal (ESR6) – University of Amsterdam, VUmc

FindMyApps addresses three important barriers to people with dementia in using or learning to use a tablet:

1) Learnability challenges → Tailored training and support

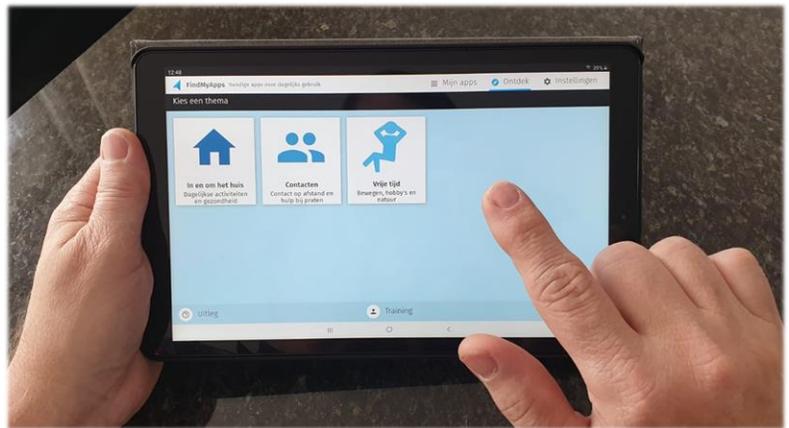
FindMyApps provides multi-modal tailored training in tablet use, and for informal caregivers training in how to support a person with dementia to (learn to) use a tablet.

2) Too many choices → App selection tool

Amongst millions of apps in the app stores, FindMyApps helps people easily find suitable apps, which can support independence and engagement in social and other meaningful activities. People use a selection tool, personalized based on their own needs and interests.

3) Generic approach → Person-centred implementation

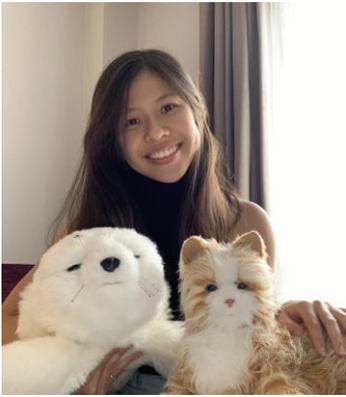
The personalized training and user-profile optimize the enabling experience of the tool. FindMyApps allows for new possibilities, rather than focusing on limitations of the person with dementia.



Beliz Budak (ESR15) – German Center for Neurodegenerative Diseases

I am working with the Silverfit Mile. The interactive bike SilverFit Mile projects a film so that the indoor experience resembles reality. The aim is to increase the duration of individual sessions and improve therapy adherence. Find out more about the bike by clicking [here](#). My project is interested in finding out more about the experiences of professional caregivers with regards to implementing the

Silverfit Mile in long-term care. I am also exploring the experiences of people living with dementia from the Turkish immigrant community with Silverfit products in regards to culture and loneliness.



Wei Qi Koh (ESR12) – National University of Ireland Galway

I am looking into the implementation of pet robots, and here are two of the robots: PARO (left), a baby harp seal, and the Joy for All cat (right).

Aysan Mahmoudi (ESR13)- IDES

“My name is Mini Maggie, but normally everyone calls me Mini as Mickey Mouse's girlfriend!! Hahaha! I'm here to have a fun time with you. I'm 5 years old, so I'm tiny, but cute.” Says Mini.

Mini is designed for psychosocial and cognitive stimulation and to provide entertainment for people with dementia.



Simone Anna Felding (ESR4) – German Center for Neurodegenerative Diseases

I am studying social robots in my PhD. In my ethnographic fieldwork I am focusing on pet robots and especially the JoyForAll cats and dogs.

Jaroslav Cibulka (ESR8) – Czech Technical University

I am working on the design, development and testing of PetBot, a pet-like care-bot to help people with dementia in their daily routine. A picture of the “PetBot squad” is shown on the right.





Induction into Hall of Excellence

- What an honour! -

By Lesley Garcia (ESR1)
University of Nottingham

On December 1st 2021, St. Joseph's Convent, Port of Spain of Trinidad and Tobago held its 10th biennial induction ceremony into its Hall of Excellence. The celebration in this year was significant as it was against the backdrop of the 185th Anniversary Celebration of the School, the oldest secondary school for girls in the country, and in the year the Cluny Sisters have dedicated to praying for the Canonisation of foundress Blessed Ann Marie Javouhey.



Sr. Maureen Alexander, Dr. Lesley Garcia, Archbishop Dr. Charles Jason Gordon (from left to right)

DISTINCT ESR 1, Lesley Garcia (alumna '82), was inducted into the Hall of Excellence for her contribution to the development of the profession of occupational therapy nationally. In 2004 she co-founded the Trinidad and Tobago Occupational Therapy Association and in 2016 she led the establishment of the only Master of Science in Occupational Therapy programme in the English-speaking Caribbean.

The Hall of Excellence, established in October 2001 by the St. Joseph's Convent, Port of Spain Past Pupils' Association, has a dual objective of recognizing the outstanding achievements of past pupils and providing role models for current students. Eleven alumnae who have made outstanding contributions in the categories of Academia, the Arts, Sports, Social/ Charitable Works, Religion, Professional, Pioneering, Business and Public Service received awards from Sister Maureen Alexander and The Most Reverend Dr. Charles Jason Gordon, Archbishop of Port of Spain.

Lesley is humbled by the award and hopes to embody the spirit of Blessed Anne Marie Javouhey and the school's motto, "Sapientia et Scientia: Wisdom and Knowledge" through her work in the DISTINCT programme. She hopes to encourage future learners to enter the field of social science practice and research.

Publications, conferences and other dissemination activities

Let's have a look at how the ESRs have shared their research findings with others.



Lesley Garcia (ESR1)

Presentations:

- Garcia, L., Schneider, J., & Orrell, M. (2021, October 30). *The recovery approach in dementia care; theory and practice: A systematic review and narrative synthesis*. 15th Biennial Scientific Conference, Association of Caribbean Occupational Therapists, Virtual, Cayman Islands
- Garcia, L., Schneider, J., & Orrell, M. (2021, March 10). "Development of a ROAD MAP (digital) Recovery-Oriented Approach to Dementia through Meaningful Activity and Participation". Centre for Dementia lunchtime seminars (online), Institute of Mental Health, University of Nottingham, UK
- Garcia, L., Schneider, J., & Orrell, M. (2020, October 23). *Promoting occupational justice through the development of a ROAD MAP for people living with dementia: Exploring the relationships between critical occupational therapy and occupational science, the recovery approach and dementia care intervention development* [Online Workshop]. End of Life Care Research Group, Vrije Universiteit Brussel, Belgium



Esther Gerritzen (ESR2)

Presentations:

- Gerritzen, E.V., Kohl, G., McDermott, O., & Orrell, M. (2021, Nov 29 – Dec 1). *Peer support through Zoom: experiences of people with Young Onset Dementia* [Oral presentation]. 31st Alzheimer Europe Conference.
- Gerritzen, E.V., McDermott, O., & Orrell, M. (2021, March 10). *Online peer support for people with Young Onset Dementia*. Centre for Dementia lunchtime seminars, Institute of Mental Health, University of Nottingham

Publications:

- Lee A.R., Gerritzen E.V., McDermott O., Orrell M. (2021). Exploring the Role of Web-Based Interventions in the Self-management of Dementia: Systematic Review and Narrative Synthesis. *Journal of Medical Internet Research*, 23(7).



Fanny Monnet (ESR3)

Presentations:

- Monnet, F., Pivodic, L., Dupont, C., Dröes, R.M., Diaz, A., Gove, D., & Van den Block, L. (2021, Nov 29 – Dec 1). *Information provided to people with dementia and their carers on advance care planning: a content analysis of dementia associations' websites in Europe* [Quick oral presentation]. 31st Alzheimer Europe Conference.



Simone Anna Felding (ESR4)

Presentations:

- Felding, S.A., Koh, W.Q., Teupen, S., Budak, K.B., Laporte-Urbe, F. & Roes, M. (2021, Nov 29 – Dec 1). "At first, "At first, I thought it makes no sense. But then I began to like him" – Results from a scoping review on acceptance of social robots in nursing homes [Quick oral presentation]. 31st Alzheimer Europe Conference.
- Koh, W.Q*, Felding, S.A., Budak, K.B., Toomey, E., & Casey, D. (2021, July 15-16). *What are the barriers and facilitators affecting the implementation of social robots for older adults and people with dementia: A scoping review* [Rapid oral-poster presentation]. 4th UK Implementation Science Conference. (*presenting author)

Publications:

- Koh, W.Q., Felding, S.A., Toomey, E., & Casey, D. (2021). Barriers and facilitators to the implementation of social robots for older adults and people with dementia: a scoping review protocol. *Systematic Reviews*, 10(1), 1-6.
- Koh, W.Q., Felding, S.A., Budak, K.B., Toomey, E., & Casey, D. (2021). Barriers and facilitators to the implementation of social robots for older adults and people with dementia: a scoping review. *BMC Geriatrics*, 21(1), 1-17.

Other:

- Recommendation in the best practice guideline based on scoping review



Golnaz Atefi (ESR5)

Presentations:

- Atefi, G., Bartels, S.L., van Knippenberg, R.J.M., Levin, M.E., Kilkens, T.O.C., Verhey, F.R.J., & de Vugt, M.E. (2021, Nov 29 – Dec 1). *The potential utility of Acceptance and Commitment Therapy for informal caregivers: a systematic review* [Quick oral presentation]. 31st Alzheimer Europe conference.
- Atefi, G., Bartels, S.L., Van Knippenberg, R.J.M., Levin, M.E., Kilkens, T.O.C., Verhey, F.R.J., & De Vugt, M.E. (2020, Oct 20-22). *The potential utility of Acceptance and Commitment Therapy for informal caregivers of people with dementia: A systematic review* [Poster presentation]. 30th Alzheimer Europe Conference.

Publications:

- Budak, K.B., Atefi, G., Hoel, V., Laporte Uribe, F., Meiland F., Teupen S., et al. (2021). Can technology impact loneliness in dementia? A scoping review on the role of assistive technologies in delivering psychosocial interventions in long-term care. *Disability and Rehabilitation: Assistive Technology*, 1-13.
- Golnaz Atefi, Sara Laureen Bartels, Tessa O.C. Kilkens, Frans R.J. Verhey, Marjolein E. de Vugt. *How do Acceptance and Commitment Therapy interventions work for informal caregivers? A Systematic Review*. PROSPERO 2020, CRD42020186450.



David Neal (ESR6)

Presentations:

- Presented at internal research seminar of Saxion University of Applied Sciences Faculty of Nursing (31st August): "Read & understood? User-centered design of a cognitively accessible privacy policy for the FindMyApps intervention"
- Presented about ongoing research at Hogeschool Zuyd event for care organization in Limburg (29th September)
- Chaired and presented during DISTINCT symposium at GSA 2021 congress (online) 13th November: "Read & understood? User-centered design of a cognitively accessible privacy policy for the FindMyApps intervention"
- Presented via Amsterdam UMC Alzheimer Centrum Online Lunch & Learn Event 18th November: "Digitale hulpmiddelen en dementie: randvoorwaarden"
- Presented about ongoing research to national network of EDOMAH (dementia specialist) occupational therapists, 23rd November
- Presented at INTERDEM event prior to Alzheimer Europe, 29th November: *COVID-19: A Catch-22 for providing tablet training?*
- Interview on radio 1Twente 6th December as follow-up to Saxion article: *Ouderen zijn bang voor privacy-voorwaarden en worden zo buitengesloten - YouTube*

Publications:

- Article about secondment activities published on Saxion University of Applied Sciences website 30th November: *Niet op 'ja' durven klikken: hoe los je onzekerheid bij ouderen over privacy-info in gezondheids-apps op?*
- Neal, D.P., Engelsma, T., Tan, J.R., Craven, M.P., Marcilly, R., Peute, L., Dening, T., Jaspers, M., & Dröes R.M. (2022). Limitations of the new ISO standard for health and wellness apps. *The Lancet Digital Health*, 4, 2.
- Neal, D.P.; van den Berg, F.; Planting, C.; Ettema, T.; Dijkstra, K.; Finnema, E.; Dröes, R.M. (2021) Can Use of Digital Technologies by People with Dementia Improve Self-Management and Social Participation? A Systematic Review of Effect Studies. *Journal of Clinical Medicine*, 10, 604.
- Neal, D.P., Kerkhof, Y.J.F., Ettema, T.P. et al. (2021). Evaluation of FindMyApps: protocol for a randomized controlled trial of the effectiveness and cost-effectiveness of a tablet-based intervention to improve self-management and social participation of community-dwelling people with mild dementia, compared to usual tablet use. *BMC Geriatrics*, 21, 138.



Mauricio Molnari Ulate (ESR7)

Presentations:

- Oral presentation "Technology and Mental Health" at Costa Rica Pint of Science 2021 on May 17 2021.
- Poster presentation "Comprehensive Geriatric Assessments for long-term and home care settings and digital platforms available to support their applicability: A Systematic Review" at Alzheimer's Association International Conference 2021
- Seminar presentation on "ePPI and Dementia" at Centre of Dementia, Institute of Mental Health, University of Nottingham, July 14th, 2021.
- Oral Presentation "Psychometric features of Comprehensive Geriatric Assessments (CGAs) in long-term and home care settings: A Systematic Review" at 2021 International Psychogeriatric Association Virtual Congress.
- Oral Presentation "A Systematic Review on Digital Health Interventions (DHIs) supporting the administration of Comprehensive Geriatric Assessments (CGAs) use in long-term and home care settings" at 2021 International Psychogeriatric Association Virtual Congress.
- Oral presentation "Have you been listening online? Moving to digital co-production for dementia" at MindTech Symposium 2021.



Jaroslav Cibulka (ESR8)

Reports:

- Doctoral Study Report and successful defence, which allows to proceed to PhD state exams

Presentations:

- Abstract submitted: "Acceptability and usability test of a PetBot, an affordable care system for people with dementia". Conference IUPESM WC2022 - World congress on medical physics and biomedical engineering.

Publications:

- Ozdemir, D., Cibulka, J., Stepankova, O. et al. (2021). Design and implementation framework of social assistive robotics for people with dementia – a scoping review. *Health and Technology*, 11, 367–378.



Viktoria Hoel (ESR9)

Presentations:

- Hoel, V. et al. (2022). Social Health among German Nursing Home Residents with Dementia during the COVID-19 Pandemic, and the Role of Technology to Promote Social Participation. *International Journal of Environmental Research and Public Health*, 19(4).
- Hoel, V. et al (2022). Social Isolation and the Use of Technology in Caregiving Dyads Living with Dementia During COVID-19 Restrictions. *Frontiers in Public Health*, 10.
- Hoel, V. et al. (Dec 2021). *Dyadic coping through COVID-19 with and without social technology: Experiences from community-dwelling people with dementia and their spouse* [Quick oral presentation]. 31st Alzheimer Europe Conference.
- Hoel, V. et al. (Dec 2021). *Social health among German care recipients with dementia during COVID-19, and the role of technology to promote social participation* [Quick oral presentation]. 31st Alzheimer Europe Conference.

- Hoel, V. et al. (2021, Nov 10-13). *Technology-Driven Dyadic Interaction Support for Community-Dwelling People with Dementia and Family Caregivers*. In K. Wolf-Ostermann (Chair), *Strategies to design technology promoting social participation of people with dementia and their caregivers*. [Symposium]. The Gerontological Society of America Annual Scientific Meeting, Phoenix, AZ, USA.
- Hoel, V. et al. (Sept 2021, virtual webinar). *Was a global pandemic needed to adopt the use of telehealth in occupational therapy? Results of a global survey assessing the impact of Covid-19 for occupational therapy*. WORK: A Journal of Prevention, Assessment & Rehabilitation.
- Hoel, V. et al. (Sept 2021). Social isolation and the use of technology in caregiving dyads living with dementia during COVID-19 restrictions. In K. Wolf-Ostermann (Chair), *Häusliche Pflege und Versorgung während einer Pandemie – Ergebnisse quantitativer und qualitativer Forschung* [Symposium]. Gemeinsame Fachtagung der Deutschen Gesellschaft für Gerontologie und Geriatrie (virtual).
- Hoel, V. et al. (2021, July 26-30). *Technology-driven dyadic interaction in caregiving* [Poster presentation]. Alzheimer's Association International Conference.
- Hoel, V. et al. (Dec 2020). *Technology-driven dyadic interaction enhancement for community-dwelling people with dementia and their family members* [Poster presentation]. MindTech2020: Digital Mental Health in the Age of COVID-19.

Publications:

- Budak, KB., Atefi, G., Hoel, V., et al. (2021). Can technology impact loneliness in dementia? A scoping review on the role of assistive technologies in delivering psychosocial interventions in long-term care. *Disability and Rehabilitation: Assistive Technology*, 1-13.
- Hoel, V. et al. (2021). Technology-driven solutions to prompt conversation, aid communication and support interaction for people with dementia and their caregivers: a systematic literature review. *BMC Geriatrics*, 21(1), 157.
- Hoel, V., von Zweck, C., Ledgerd, R., & World Federation of Occupational Therapists. (2021). The Impact of Covid-19 for Occupational Therapy: Findings and recommendations of a global survey. *World Federation of Occupational Therapists Bulletin*, 1-8.
- Hoel, V., von Zweck, C., Ledgerd, R., & World Federation of Occupational Therapists. (2020) Was a global pandemic needed to adopt the use of telehealth in occupational therapy? WORK: A Journal of Prevention, Assessment & Rehabilitation.



Gianna Kohl (ESR10)

Presentations:

- Bhatt, J., Kohl, G*, Dröes, R.M., Muller, M., Scior, K., & Charlesworth, G. (2021, 29 November-1 December). *Predictors of discomfort with diagnostic disclosure by people with dementia: A cross-country comparison between the UK and the Netherlands* [Quick oral presentation]. 31st Alzheimer Europe Conference (virtual, *presenting author)
- Gerritzen, E.*, Kohl, G., McDermott, O., & Orrell, M. (2021, November 29 – December 1). *Peer support through Zoom: experiences of people with Young Onset Dementia* [Oral presentation]. 31st Alzheimer Europe Conference (virtual, *presenting author)
- Kohl, G., Molinari Ulate, M., Bhatt, J., Lynch, J., Scior, K., & Charlesworth, G. (2021, November 10-13). *Individuals' decision to disclose a diagnosis of dementia and the development of an online empowerment intervention* [Oral presentation]. In K. Wollf-Ostermann (Chair), *Strategies to design technology promoting social participation of people with dementia and their caregivers* [Symposium]. The Gerontological Society of America Annual Meeting (virtual), Phoenix, AZ, United States.
- Kohl, G., Molinari Ulate, M., Bhatt, J., Scior, K., & Charlesworth, G. (2021, July 26-30). *Factors associated with disclosing a diagnosis of dementia to one's social network: A systematic review* [Poster presentation]. Alzheimer's Association International Conference (virtual), Denver, CO, United States.
- Neal, D.P.*, Kerkhof, Y.J.F., Beentjes, K., Kohl, G., Bergsma, A., Muller, M., Zwan, M., Graff, M., & Dröes, R.M. (2020, October 20-22). *Proven feasibility of the FindMyApps tablet-based intervention to promote social health in dementia* [Oral presentation]. 30th Alzheimer Europe Conference (virtual), Bucharest, Romania (*presenting author)

Publications:

- Kohl, G., Molinari Ulate, M., Bhatt, J., Scior, K., & Charlesworth, G. (2021). Factors associated with disclosing a diagnosis of dementia to one's social network: A systematic review. *Alzheimer's & Dementia*, 17(S7), e056146.
- Kohl, G., Molinari Ulate, M., Bhatt, J., Lynch, J., Scior, K., & Charlesworth, G. (2021). Individuals' decision to disclose a diagnosis of dementia and the development of an online empowerment intervention. *Innovation in Aging*, 5(1, Suppl.), 589-590
- Kohl, G., Molinari Ulate, M., Bhatt, J., Scior, K., & Charlesworth, G. *Factors associated with self-disclosure among people diagnosed with a neurological disorder*. PROSPERO 2020, CRD42020192495.

Other:

- Two meetings with PPI groups consisting of people with dementia and carers to discuss findings of the systematic review at the University of Hertfordshire
- Manager of DISTINCT social media account and website, May-December 2020



Pascale Heins (ESR11)

Presentations:

- Koh, W.Q.*, Whelan, S.A., Heins, P. et al. (2021, Nov 10-13). *Experiences and perceptions of using a low-cost pet robot for older adults and people with dementia* [Poster presentation]. The Gerontological Society of America's 2021 Annual Scientific Meeting. (*presenting author)
- Heins, P., Boots, L.M.M., Koh, W.Q. et al. (2021, Nov 10-13). Technological interventions and social participation in community-dwelling older adults with or without dementia. In K. Wolf-Ostermann (Chair), *Strategies to design technology promoting social participation of people with dementia and their caregivers*. [Symposium]. The Gerontological Society of America Annual Meeting (virtual), Phoenix, AZ, United States.
- Heins, P.*, Malinowsky, C., Nygård, L., & Brorsson, A. (2021, Nov 17). *What factors can influence the out-of-home participation of older adults with dementia?* [Panel session]. 2021 Occupational Science Europe Conference. Virtual.

Publications:

- Koh, W. Q., Whelan, S., Heins, P., Casey, D., Toomey, E., & Dröes, R. M. (2022). The Usability and Impact of a Low-Cost Pet Robot for Older Adults and People With Dementia: Qualitative Content Analysis of User Experiences and Perceptions on Consumer Websites. *JMIR Aging*, 5(1), e29224.
- Koh, W.Q., Heins, P., Whelan, S., Toomey, E., Casey, D., & Dröes, R.M. (2021). Experiences and perceptions of using a low-cost pet robot for older adults and people with dementia, *Innovation in Aging*, 5(1, Suppl.), 945.
- Heins, P., Boots, L.M.M., Koh, W.Q., Neven, A., Verhey, F.R.J., & de Vugt, M.E. (2021). Technological Interventions and Social Participation in Community-Dwelling Older Adults With or Without Dementia. *Innovation in Aging*, 5(1, Suppl.), 590.
- Heins, P., Boots, L.M.M., Koh, W.Q., Neven, A., Verhey, F.R.J., & de Vugt, M.E. (2021). The Effects of Technological Interventions on Social Participation of Community-Dwelling Older Adults with and without Dementia: A Systematic Review. *Journal of Clinical Medicine*, 10, 2308.
- Heins, P., Boots, L.M.M., Koh, W.Q., Neven, A., Verhey, F.R.J., & de Vugt, M.E. *The effects of technology-based interventions on social participation of community-dwelling older adults with and without dementia: a systematic review*. PROSPERO 2020 CRD42020206654

Other:

- Manager of DISTINCT social media account and website, May-December 2020



Wei Qi Koh (ESR12)

Presentations:

- Koh, W.Q., Ang, X.H.F., & Casey, D. (2021) *Recommendations for Implementing Pet Robots for People with Dementia in Nursing Homes: A Mixed Methods Study Protocol* [Poster presentation]. 31st Alzheimer's Europe Conference 2021
- Koh, W.Q., Whelan, S.A., Heins, P., Casey, D., Toomey, E., & Dröes, R.M. (2021). *Experiences and perceptions of using a low-cost pet robot for older adults and people with dementia* [Poster presentation]. The Gerontological Society of America's 2021 Annual Scientific Meeting.
- Koh, W.Q., Felding, S.A., Budak, K.B., Toomey, E., & Casey, D. (2021). *What are the barriers and facilitators affecting the implementation of social robots for older adults and people with dementia: A scoping review*. 4th UK Implementation Science Conference. (Best rapid oral-poster presentation)

Publications:

- Koh, W.Q. et al. (2021). Exploring Barriers and Facilitators to the Implementation of Pet Robots for People with Dementia in Nursing Homes: A Qualitative Research Protocol. *International Journal of Qualitative Methods*, 20, 16094069211047059.
- Koh, W.Q., Felding, S.A., Budak, K.B. et al. (2021). Barriers and facilitators to the implementation of social robots for older adults and people with dementia: a scoping review. *BMC Geriatrics*, 21(1), 1-17.
- Heins, P., Boots, L.M., Koh, W.Q. et al. (2021). The Effects of Technological Interventions on Social Participation of Community-Dwelling Older Adults with and without Dementia: A Systematic Review. *Journal of Clinical Medicine*, 10(11).
- Koh, W.Q., Ang, F.X.H, & Casey, D. (2021). Impacts of Low-cost robotic pets for older adults and people with dementia: scoping review. *JMIR Rehabilitation and Assistive Technologies*, 8(1): e25340.
- Koh, W.Q., Felding, S.A., Toomey, E., & Casey, D. (2021). Barriers and facilitators to the implementation of social robots for older adults and people with dementia: a scoping review protocol. *Systematic Reviews*, 10(1), 1-6.

Other:

- Irish Farmers Journal. (2021). Social robots could address future skills shortage in care sector. 15 February 2021, Available [here](#)
- The Irish Times. (2021). Social robots could address future skills shortage in care sector. 21 January 2021, Available [here](#)
- Koh, W.Q. 'DISTINCT project researchers find that low-cost robots may have potential to improve the psychosocial health of people with dementia.' Alzheimer Europe Newsletter, 2021, issue 3. Available [here](#)

Aysan Mahamoudi
(ESR13)

Presentations:

- Mahmoudi et al. (2021, July 26-30). *Methodologies used to study the effectiveness of social robots in long-term and community care settings* [Poster presentation]. Alzheimer's Association International Conference, Denver, CO, United States.
- Molinari Ulate*, M., Mahmoudi, A. et al. (2021, July 26-30). *Comprehensive Geriatric Assessments for long-term and home care settings and digital platforms available to support their applicability: A systematic review* [Poster presentation]. Alzheimer's Association International Conference, Denver, CO, United States
- *The use of social robots in dementia care* [Oral presentation]. Neuropsychology module, University of Salamanca, Spain.
- *The use of social robots in dementia care and mental health* [Oral presentation]. Community care course, Provincial Hospital of Zamora, Spain.
- The use of social robots in dementia care [video clip]. SIDECAR project
- Project presentation at Trimbos-instituut, the Netherlands.

Publications:

- Submitted: *Methodologies Used to Study the Feasibility, Usability, Efficacy, and Effectiveness of the Social Robots in Clinical and Social Care Settings for Elderly Adults: A Scoping Review*.



Josephine Rose Tan
(ESR14)

Presentations:

- Presentation at CaRe Days (Netherlands School of Public Health and Care Research), "*The Fotoscope: A new app for dementia care*" – online, 26 May 2021
- Presentation at Centre for Dementia Seminar (Nottingham, UK), "*The Fotoscope: A new app for dementia care*" – online, 14 July 2021
- Presentation at the INTERDEM Annual Meeting annex to Alzheimer Europe conference (virtual meeting)- Development of the Fotoscope App: a tool for creating meaningful connections between nursing home residents with dementia and their carers"- online, 29 November 2021
- Tan et al. (2021, Nov 29 – Dec 1). *Development of the Fotoscope app: A tool for creating meaningful connections between nursing home residents with dementia and their carers* [Quick oral presentation]. 31st Alzheimer Europe conference.
- Presentation to Dementia, Frail Older People and Palliative Care PPI group in Nottingham via secondment, "*The Fotoscope: A new app for dementia care*" – online 19 Nov 2021

Publications:

- Tan, J.R.O. et al. (2022). Known in the nursing home: development and evaluation of a digital person-centered artistic photo-activity intervention to promote social interaction between residents with dementia, and their formal and informal carers. *BMC Geriatrics*, 22, 25.
- Neal, D.P., Engelsma, T., Tan, J.R. et al. (2022). Limitations of the new ISO standard for health and wellness apps. *The Lancet Digital Health*, 4(2).
- 3rd newsletter of the Photo-project sent out in Dec. 2021: Nieuwsbrief – Gekend in het verpleeghuis. Available [here](#).
- 2nd newsletter of the Photo-project sent out in Aug. 2021: Nieuwsbrief – Gekend in het verpleeghuis. Available [here](#).

Other:

- Raised funds (total of \$1,213 NZD) for Alzheimer's New Zealand, 'Move for Dementia' campaign – September 2021
- Currently managing DISTINCT social media account with fellow ESR Esther Gerritzen. DISTINCT Twitter account won as most influential Twitter Account during the AE Conference 2021



Beliz Budak (ESR15)

Presentations:

- Budak, K. B. (2020). *Loneliness and Technology: Can technology help reduce loneliness in dementia?* Paper presented at the 2020 IPA Virtual Congress, USA. doi: 10.1017/S1041610220001866

Publications:

- Budak, K.B., Atefi, G., Hoel, V., et al. (2021). Can technology impact loneliness in dementia? A scoping review on the role of assistive technologies in delivering psychosocial interventions in long-term care. *Disability and Rehabilitation: Assistive Technology*, 1-13.

Exciting news to finish off!



David Neal and his wife Sofie welcomed their son Robert at 11:45am on 7 January 2022. He was born happy and healthy, weighing 3.9kg. We are all very excited for the first DISTINCT baby and want to congratulate them on their new bundle of joy!



Wishing you all a lovely spring!

We would like to thank Fania Dassen and the whole team in Maastricht for organising the DISTINCT schools and the training activities. A special thanks also to Martin Orrell, Orii McDermott and Ann Gibbons for leading the DISTINCT project and their continuing support.

Thank you!



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