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DIAdIC Internal Newsletter, issue #4: DIAdIC consortium updates

Dear DIAdIC Partners,

Hereby, we are happy to present this new edition of the Internal DIAdIC Newsletter to you. Enjoy the reading and have a nice weekend!

Kind regards,

DIAdIC Coordination Team

DIAdIC Trial

- **IMPORTANT! ALL PARTICIPANTS OF DIADIC TRIAL:** Please carefully read an email from Joachim specially dedicated to the important materials related to the Trial (instructions, manuals, checklists, tips&tricks). Please see the [DIAdIC Trial Practical Documentation Overview \(Trial Documents Chart\) attached](#) with links to the useful documents that were placed on OneDrive. Keep this document as a guide through the folders.
- Trial status updates:
 1. [Belgium \(VUB&UGent\)](#): recruitment has started and 9 dyads have already been enrolled to the study across the 2 participating hospitals. They will fill in their baseline questionnaire in the nearest future.
 2. [The Netherlands \(EMC\)](#): approval has been granted by the ethical committee. The intervention nurses have completed the online training course. Recruitment can start.
 3. [Denmark \(KU\)](#): The start of the Trial is anticipated on 15 March. Data collectors are hired and team Denmark is currently in the process of hiring the intervention nurse. One of the two hospitals is ready to start recruitment as of March.
 4. [Italy \(AUSL RE\)](#): Four intervention nurses have been selected and will be employed part-time on the project. On March 4th team AUSL RE will have a meeting with the nurses and afterwards they will be ready to start the

iFOCUS needed to be fixed first.

5. The UK (Belfast and London): Teams QUB and KCL have received their full ethical approval for the UK and governance approval is pending. In Belfast a study nurse (Margot Creighton – see introduction of the new staff below) is hired and she cannot wait to start. In London Lydia Tutt (the Research Fellow) and Joanna Bate (the study nurse) have joined the project. The training has been introduced to the nurses.
6. Ireland (UCD): Ethics approval is secured, FOCUS+ manuals have been printed, consent packs being prepared, and the nurses completed training. One more barrier to commencement of recruitment: the ability of the hospital system to accommodate the trial at the moment due to the spike in Covid cases after Christmas. Therefore, start of recruitment is anticipated in March. Confirmation from a second recruitment site is pending.

Introducing the new staff

Intervention nurses from the Netherlands:



Janita de Koeijer

My name is Janita de Koeijer, 42 years old, born and raised in Rotterdam. After I graduated I started a career in retail. After ten years I realised it didn't make me happy anymore, quit my job and went to England and worked as an aupair for six months. Working there I realised I wanted to do something in healthcare and I went back to school to become a nurse at 26. When I graduated I began my nursing career in the Erasmus Medical Center at the palliative care unit.



Erika van Wijk

I live in the Netherlands. I was born in 1983, happily married and mother of 2 beautiful children (12 and 10 years old). I am an oncology nurse. I've worked for 14 years in het Erasmus MC Cancerinstitute (Rotterdam). After a change in my residence in 2018, I started to work in the hospital 'Amphia' in Breda. Since 2013 I work as a consultant by Care for Cancer, part of Allertzorg. In this job, I accompany patients at home with cancer and their caregivers. This

years I kept myself busy with studying to get some more degrees and now I am an oncology nurse with a specialism in palliative care on the oncology ward. Within my job I also keep myself busy as a coordinator of palliative care within our hospital and organize presentations for palliative care nurses to keep them educated. Every three months I write a newsletter to make as many colleagues as possible aware of the importance of palliative care. On my days off, I love to spend my time with my 4 year old son Ian and reading really scary books.

Being a member of this international DIAdIC study team makes me really proud and I am really looking forward to starting.

Intervention nurses from the UK:



London: Joanna Bate

I currently work as a clinical nurse specialist in Guys and St Thomas Community Palliative care team but also have extensive inpatient palliative care experience too over the last 7 years. I am keen to be part of this

do my work as an oncology nurse, both in the hospital and at the home of the people. I think it is great to use my knowledge and experience in the international research project DIAdIC. I'm curious how I will experience the project and what the results of the research will be. In my spare time, I like to walk in nature, to work in the garden, to read a book, to play with the children, to meet family and friends, to cook and enjoy a delicious meal.



Belfast: Margot Creighton

My name is Margot Creighton. I qualified in nursing in 2005 and since then I have worked in Oncology in both an inpatient and outpatient setting. I completed my Postgraduate Certificate in Palliative Care Nursing in 2008. I have recently taken up post as a Cancer Clinical Research Nurse within the Northern Ireland Cancer

frontline clinical work. Prior to this I worked in oncology and haematology including chemotherapy and the acute setting where I developed a special interest in palliative Care. I am a mother of 2 young children and enjoy cooking, running, dancing and pilates in my spare time. I also have a special interest in complementary therapies and a “Namaste Care” approach having trained as a message therapist prior to becoming a nurse.

working on the DIAdIC study involving psychoeducational intervention in advanced cancer. I am keen to get started, and feel privileged to be involved in this exciting international study.

Please kindly share with us the profiles and contact details of the intervention nurses working with your team.

Postdoctoral researcher in the UK (KCL):



Dr Lydia Tutt

Lydia has joined the KCL team as a Research Associate. She started off her career as a community pharmacist and soon developed a passion for supporting patients and their families through cancer. Subsequently, Lydia undertook her PhD exploring the role of the community pharmacist in supporting breast cancer survivors. Since then, she has also been involved in research on improving health and social care services for older people. In her spare time, Lydia enjoys socialising, going for walks and reading. For Lydia, the DIAdIC project provides an exciting opportunity to combine her research interests with her passion for supporting patients and families.

Extending the duration of the project

As decided earlier, DIAdIC coordination team has initiated an “amendment procedure” and requested a 6-months extension of the duration of the project. Please note that the 6-months extension has been applied to the last reporting period of the project – now it is 12 months long. The duration of the remaining periods (P2 and P3) have not changed (18months). This means that the current reporting period ends on December 31, 2021 and the next periodic report is due

Next Management Board Meeting (1.5 h)

According to the preferences submitted in Doodle it has been decided that the next Management Board meeting will take place on March 4, 13.00–14.30 (CET) in ZOOM: please see the details in the email/calendar invitation sent earlier.

Reminder on the next digital consortium meeting

As decided during our last consortium meeting, the next one will take place on April 29–30, 2021 in ZOOM.

Dissemination

DIAdIC Dissemination team is inviting everyone to think about the involvement of DIAdIC in the digital EAPC Congress in October (suggest the format and the content of the participation). Also those who haven't done it yet, please update the website with your photos and bio's by sending them to Paulina Gono <paulina.gono@ecpc.org> from the ECPC team.

Did you know that...?

Did you know that during her student years DIAdIC Project Manager, Yuliana, had a chance to work on the Hollywood movie production?

In summer 2003 she assisted [Patrick Swayze](#), the star of "Dirty Dancing" and "Ghost", and the Hallmark Entertainment crew in shooting [the ICON movie](#) in Moscow. Being a member of the Moscow coordination team Yuliana dealt with the daily management of the production on site and helped the crew and the main actors with English–Russian translation as well.

The movie was also shot in Sofia, Bulgaria, where Sofia played the role of Moscow (being cheaper for the production purposes). But who cares when they all look same, right?!

But if you are not a fan of substituting geographical locations, the endless undercover fights between the Russian and the American secret services and the cultural cliches in general, you might want to skip this movie. 😊



3 years after the release of the *Icon* movie, in 2008, [Patrick Swayze](#) was diagnosed with pancreatic cancer. He fought the illness for well over a year, enrolled in a clinical trial at Stanford University for experimental chemotherapy and was even able to continue working, but died on September 14, 2009 at home under a home hospice program. Between the time of his diagnosis and the time of his death, he tried to raise awareness about this form of cancer by detailing his symptoms during television appearances and interviews. In April 2008, his longtime friend and "Ghost" co-star Whoopi Goldberg told Britain's GMTV that Swayze was not living as if he had "an expiration date on his backside." Instead, the actor and his loved ones, "just know at some point it's going to happen, and that's how he's looking at it."

The story of Patrick Swayze's terminal pancreatic cancer has been told by his widow, actress Lisa Niemi Swayze, in a book, "Worth Fighting For: Love, Loss and Moving Forward."

Barron H. Lerner, Professor of Medicine and Public Health at Columbia University Medical Center, [writes about it](#): "There is one other issue that "Worth Fighting For" teaches about serious illness. A patient dying of cancer once told me that while she appreciated the attention from solicitous friends and family, no one ever asked how her primary caretaker, her husband, was doing. I have never forgotten that comment and always make a point to inquire. Lisa Niemi Swayze was a typical caretaker, sharing in the joys of small victories, mourning her dying spouse and, mostly, bearing an enormous emotional toll. Her new book not only has important lessons for cancer patients, but also for those who love them."

... And we felt like sharing this as a part of our "DIAdIC story".



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