

newsletter

The Newsletter of the Patient Empowerment through Predictive
Personalised
Decision Support (PEPPER) Project

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Project Coordinator



Welcome to the sixth issue of the PEPPER Project newsletter. We have had an exciting few months since the last issue. You will find news about clinical trial advancements. Also, you can also read our experience at ATTD2019 and the informal event in London to raise awareness of the potential impact of the PEPPER project on the lives of people with type 1 diabetes. And finally, the interview with Joan Josep Vendrell I Ortega, the president of the Catalan Association of Diabetes.

If you would like to offer us any feedback please contact contact_pepper@googlegroups.com

Clinical trial advancements

Since February 2019, IDIBGI has not involved new participants. The numbers of total participant involved are 26 participants (14 MDI participants and 12 CSII participants). However, IDIBGI has had 3 dropped outs, all of them are pump's users. IDIBGI has fully completed the study in the MDI cohort of 14 participants (the last participant finished on July 29th, 2019). Completed data from the pump patients are approximately 95.4% at IDIBGI (the last participant finished on July 29th, 2019). In total, the results are 98.2% at IDIBGI complete. We have implemented a crossover study. The starting of the CBR stage for the first intervention group was January 9th, 2019 and for the second intervention group was April 1st, 2019.

Imperial College London (ICL) started recruitment for Phase 3 of the PEPPER Clinical Trials on 7th January 2019. A total of 34 participants were recruited (15 MDI and 19 pump participants), with 32 formally enrolled on the study. Due to unfortunate circumstances with Cellnovo (our pump manufacturer and collaborator) in administration, the participants on insulin pumps are currently on hold. We hope to be able to fully complete the crossover study.



II. ATTD2019

The PEPPER project was on display at the 12th International Conference on Advanced Technologies & Treatments for Diabetes (ATTD 2019) which took place in Berlin, Germany from 20-23 February 2019. Bedour Alshaigy (Oxford **Brookes** University) presented a poster titled (Application of Usability Engineering to the Development of a Personalised Decision Support System for Type 1 Diabetes Self-Management). The poster was collaboration between (Oxford Brookes University, Imperial College London, Institut d'Investigació Biomèdica de Girona and University of Girona). Visitors of the

conference were impressed with the PEPPER system.





III. Interview: Joan Josep Vendrell I Ortega, MD, PhD



Dr. Joan Josep Vendrell i Ortega, president of the Catalan Association of Diabetes, is an endocrinologist at the Joan XXIII University Hospital in Tarragona, and a member of the management team at the Pere Virgili Health Research Institute, a pillar of the biomedical research in the province of Tarragona (Catalonia, Spain). He is also a professor of medicine at the Rovira i Virgili University also in Tarragona and co-director of the research group on diabetes and metabolic diseases of this university.

What does the Catalan Association of diabetes do?

The association welcomes professionals working in diabetes, such as doctors and nursing staff. It is a professional-based association, as most health associations that exist throughout Catalonia, and its main objective is to promote social and scientific interaction tasks between professionals, helping them in training and dissemination activities that are done in the field of diabetes to reach out to society.

What are the most important concerns of the partners?

Our associates are worried about training and their incorporation in the public and private workforce systems. They want to be up-to-date on new knowledge and new technologies, and they are also worried about precariousness in the workplace in the medical professional field. We also hear and voice concerns of future professionals, or those who are training in this specialty. The Catalan association of Diabetes is a sort of meeting point to get together and share our concerns.

And do you also gather patient's concerns?

Patients have their own association, and we interact with them to know their concerns. In fact, I have a pending meeting with the patient association to understand first-hand their concerns. Patients are the ultimate goal of all professional activity, the improvement of their quality of life, and therefore this is something our association addresses on a daily basis.

What are the main objectives of the web?

Besides scheduling meetings, timetables and scientific activities that may be of interest to our partners, we also want to give a somewhat educational vision, and in fact we are talking with other associations to include training activities for younger professionals on the web, and so, we are trying to work on a training program for medical residents. Some recommendations, articles, etc. are also published. As a project for the immediate future on the web, we plan to publish societal points of view and currents of opinion on different ways of treating the disease.

What are your most immediate interests /projects?

The association does not have a specific research program, nor it does promote research programs. Instead, it provides resources to researchers so that they can carry out research within their expertise. We promote research at the level of education, nursing, clinical or basic research, and in this sense the association does not favour particular research approaches. We try to promote scholarships, prizes, and grants so that quality research is carried out and that the groups present quality projects through conferences and congresses. Scholarships are awarded for projects in all areas that affect the overall treatment of the disease and that may be of interest to society. In this sense, we think it would be wrong to prioritize one area as opposed to another. The field of new technologies will be very important, and in fact we have awarded prizes or grants to groups that work in this line, and it is indeed an area that will have an important development in a specific group of patients. I think new technologies cannot be applied universally to everyone alike, then there will be a type of patient that will benefit more. In summary, from the association we reinforce this type of research, but we also support other types that are equally important for the improvement of the patient's life with diabetes.

What do you think of the PEPPER project proposal?

Each system has its advantages and disadvantages, and what I think is that all these technologies will be applicable to a very specific segment of patients, especially those that depend entirely on the use of exogenous insulin, that is, patients with Diabetes Mellitus type 1. However, we must not forget that it is necessary to have a certain ability in the use of new technologies so that the system is really useful, and there

are still many people, especially older people, who have diabetes since a long time, and who are a little reluctant to use this technology. These systems will be very useful when you find an algorithm that really works well in a specific sector of the population, so here is where projects such as PEEPER are relevant. Another thing is that this algorithm is integrated in the same machine that the patient carries, this is often hung in a cloud, they are very large databases, and of course, access to the cloud ... something else is that you can integrate it and that it is personalized to the patient needs, and that he can make use of the service without consulting external data of the device. Surely it can be applied in a section of the population that can really profit from it. It is also necessary that the patient is willing to do it, because there are people who do not want to check their status every day, or that are not fully aware of their illness. Those people need integrated systems that combine sensors and insulin infusors in a single device. People get tired of paying attention to food, sports etc. they may do it for a while but then they get tired. If everything was much easily integrated into a device that calculates everything, it would alleviate the burden of the disease itself. In the end, the issue is to avoid using complex systems.

What do you think should be done in order to be able to apply PEPPER devices to daily clinical practice?

Make it cheap and financed by the administration, because if it is expensive the range of beneficiaries will still be smaller. Do something that children can use. Type 1 diabetes appears in childhood. In children it becomes complicated to control what they eat or the exercise they do. In fact, it is almost impossible because they go through stages of growth and the adolescence is a complicated stage ... even though most of all are attracted to new technologies, it is a very

difficult stage of life and even more for people with diabetes. In summary, that device can be financed at affordable prices and may have its variant for the child population.

It seems that there are two factors that are very concerned with the application of new technologies: age and aspects adherence to the use of new technologies, is it true?

Yes. These are factors that must be taken into account when it comes to creating such a technology. The systems must be easy, accessible, economically bearable and must ready to be applied in different topologies of patients; for example, in different stages

of life. Everything that facilitates life to patients is the focus of the Catalan association of diabetes.

What do you think a project such as PEPPER can bring to society?

New technologies are inevitable. They are already there and they must be developed in order to make the patient's life easier. This will be the case, and there is nothing that can stop it. We are fully developing this technology, and over time we will be able to create technologies that will greatly improve the lives of patients in diabetes. These technologies will not only be for diabetic patients of type 1, but also for patients of type 2.



IV. Night event - AI: The Future of Diabetes Self-Management

On Tuesday, 12 March 2019, the PEPPER project team hosted an informal event in London to raise awareness of the potential impact of the PEPPER project on the lives of people with type 1 diabetes, among a general audience. The event was part of a broader educational campaign which includes the launch of the second PEPPER video, with a more in-depth, patient perspective than the previous one, providing more detailed information about the underpinning science. The meeting was sold out, and attended by a audience including varied patients, researchers, clinicians, industry and patient and members advocacy groups associations such as Input/JDRF. The timing of the event was chosen to coincide with the final PEPPER clinical study involving 50 participants in two clinical centres for eight months.

The meeting was themed around the broader topic of Artificial Intelligence (AI) for Diabetes Management. The evening began with an introduction to the system from both the patient and clinical perspective, which was followed by a screening of the new video (www.tinyurl.com/pepper2018) as

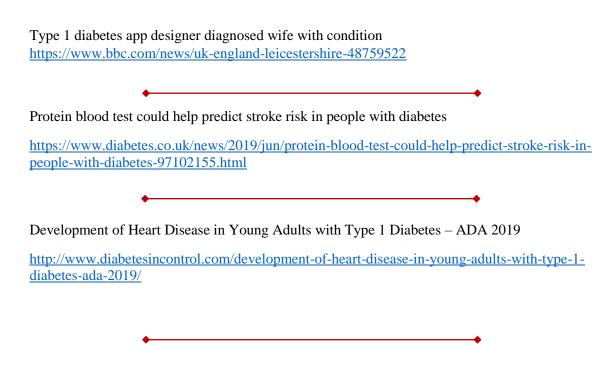
well as a short demo. The second part of the evening consisted of a panel discussion with members of the PEPPER team from Imperial College London, Cellnovo Ltd and Oxford Brookes University, as well as an expert on the ethics of AI. Emma Yapp, a researcher at Kings College London, said "This was a really inspiring event. It was great to see so many different viewpoints on the project, and to see so much space given to user and patient perspectives."

The speakers were:

- Dr. Parizad Avari, Imperial College Healthcare NHS Trust
- Dr. Monika Reddy, Imperial College Healthcare NHS Trust
- Dr. Clare Martin, Oxford Brookes University
- Mr. Ben Marshall, Cellnovo Ltd Dr. Matthias Rolf, Oxford Brookes University
- Patient Advocate



V. Other related news



VI. Profile



Mrs Marion Waite – Principal Lecturer

After a career in the NHS as a nurse, midwife and health visitor Marion joined Higher Education in 2002 to follow her interest in professional education. Since then Marion has developed her role as a teacher, staff developer and nurse and pedagogic researcher with a specialist focus on improving patient outcomes, student learning, and the student experience. Marion also collaborates with colleagues both from the Faculty of Technology, Design, and Engineering and institutions, patient groups and clinicians nationally and internationally on projects that aim to empower patients with long-term conditions by the development and use of health care technologies. This includes a successful EU Horizon 2020 research bid "Patient Empowerment through Predictive Personalised Decision Support" (PEPPER) http://www.pepper.eu.com/.

Marion has designed, implemented, cofacilitated and evaluated a range of courses for qualified nurses, allied health professionals, and educational practitioners by collaborating with both learners and colleagues locally, nationally and internationally This includes one of the first Massive Open Online Courses (MOOCs) to be delivered in the UK, #FSLT12 http://openbrookes.net/firststeps12/

Marion engages learners to adopt a variety of roles to transform their continuing professional development and has developed a novel model of the student as co-producer and research writer. This takes the form of a Faculty-based writing group for academic staff and students or alumni writing-in-dyads for peer-reviewed publication. Marion was awarded a University teaching fellowship in 2012 in order to lead and develop this project.

Marion's identity as a Digital Scholar has emerged from her own teaching practice and is focused on developing digital literacies for colleagues and learners. This is influenced by a philosophy of inclusiveness and access for all to the skills which are required for participation in healthcare practice, academic study and research in the 21st Century. Marion facilitates varied staff development activities for internal and external colleagues in order to promote this. She draws on sensitive communication skills developed during her healthcare career to facilitate change participants. Marion's research experience is further consolidated by reading for a D.Phil at the Department of Education, University of Oxford. She is exploring academic research writing development within nursing.

VII. Future events

23th-27th July 2019 <> Berlin 41st EMBConference 2019- Engineering in medicine and Biology https://embc.embs.org/2019/

Clare Martin Beatriz López Núria Estapé Sara Murlà

Editorial Team: cemartin@brookes.ac.uk beatriz.lopez@udg.edu nuria.estape@udg.edu s.murla@udg.edu



PEPPER Consortium





