



The Diabetes Reference Panel [DRP] & Diabetes Online Review Group [DORG] NEWSLETTER

Nr. 2 - October, 2017

Towards Patient-led Clinical Care



Welcome to the second edition of our Newsletter.

The Reference Panel [DRP] and the Online Group [DORG] have met twice since our last update. Here we report on the 2nd BRC-sponsored meeting held on the 3rd of October 2017 with researchers and clinicians and on the following meeting, held in January 2018 at OCDEM, to discuss a wider patient-led event (Research Design Day) originally planned for Saturday the 3rd of March and eventually postponed to **Saturday the 28th of April 2018**.

Dr. Marco Pontecorvi

Pears and Apples [F. Karpe]



Prof. F. Karpe explaining the importance of fat distribution for diabetes and cardiovascular risk.

funding to examine links between social factors such as poverty and social mobility and molecular factors affecting fat distribution. This is a really exciting new way of linking environmental and biological influences and could suggest new ways in which we can target the poor health outcomes seen in social deprivation.

The way we store fat in our body is a key factor for increased Diabetes and Cardiovascular risk. We already know that it is more beneficial to be “pear-shaped”, with a typical female distribution of fat in the bottom and thighs, than “apple-shaped”, with a more fat around the waist.

In the meeting, Prof Karpe talked about a new research grant application that will investigate further some of the associations with different body shapes. With teams from Bristol and Cambridge, he is applying for



Fat distribution is a key factor for increased Diabetes and Cardiovascular risk

Your views matter *[Dr. I. Spiliotis]*



Dr. I. Spiliotis illustrating his project timeline

A clinical research project requires on a number of carefully thought-through components, and patient involvement in the early stages of planning can greatly enhance the quality and likelihood of success. We ran a pilot clinical trial entitled LEGEND-A, which looked at whether low doses of glibenclamide (a type of anti-diabetic medication which is used to increase the amount of insulin released by the pancreas) could be used to improve the release of another pancreatic hormone called glucagon in people

with type 2 diabetes. Glucagon is important in response to hypos and is known to have abnormal levels in diabetes.

As part of the trial set-up, we ran a Patient Involvement Project to get some feedback about various components of the study from the type 2 diabetes community. Their responses challenged some of our preconceptions and helped us design a study that was more efficient to run, had no dropouts, and ultimately led to a statistically significant result.

We are now designing a new trial entitled DEPTH, which will look at whether it is possible to prevent exercise-induced hypoglycaemia using a medication called dapagliflozin in people with type 1 diabetes. We used a similar Patient Involvement Project, which demonstrated the enthusiasm of the community for research into this condition, and helped us secure funding for the trial.

NAFLD and Diabetes: links and answers in genetics *[Dr. R. Koivoula]*

Accumulation of fat in the liver is a very common but less well-known manifestations of type 2 diabetes. This is known as “NAFLD” which stands for "Non-alcoholic fatty liver disease". NAFLD is also linked to obesity: about a quarter of obese people and half of those with type 2 diabetes are affected with NAFLD.

I am working with a team in OCDEM investigating the genetic links to both Type 2 and NAFLD. We have found that some genetic changes increase risk for both type 2 diabetes and NAFLD, while other genetic changes seem to cause NAFLD but actually protect against type 2. Understanding these mechanisms is important because they could be targets for new treatment for NAFLD and type 2, and so it is important not to design a treatment that could raise risk for one disease while treating the other.



Dr. R. Koivula discussing his project with the panel and the other guests.

The overarching aim of my study is to understand better the relationship between NAFLD and type 2. I will aim to characterise this relationship by using what we know about the genetics mentioned above as ‘molecular tweezers’ to tease out what the underlying mechanisms are. Initially I will use existing data from studies in humans that have been carried out already. One study, based in Oxford, will be entirely new, where participants from the Oxford Biobank will be invited to take part in the study based on their genetics. Funding is currently being sought to carry out this work.

Research Design Day *[Prof. K. Owen and Dr. M. Pontecorvi]*

We have planned an exciting day of Research Design which due to adverse weather conditions has been postponed to **Saturday April 28th 2018 at the Oxford Spire Hotel, Abingdon Rd, Oxford**. The aim of this day is to gain patient and lay view on the way we use routine clinical data in research. At the moment, as part of the Digital advances taking place in the Oxford Hospitals Trust, there is an ongoing project to link up the data sources within the Trust such as blood tests and other investigation results and details on hospital admissions and link them to GP systems that hold prescribing information and to other data such as retinal screening results. This will provide a very rich source of data for describing the whole patient journey and linking to future events.

It may be a surprise to some that this kind of data linkage is not already in place, and in fact arrangements like this are up and running some locations, with the system across Scotland being the most developed. This allows many research questions on things like treatment response and diabetes outcomes to be examined anonymously in populations without ever having to see a patient. With appropriate consent, it is also a powerful tool for finding individuals who meet criteria for recruitment into studies and for those who want to take part to find studies.

We would like to set up a system which uses routine clinical data for research (with patients' consent) and can link eligible patients to research studies.

We feel it is important to involve patients with diabetes in this project from the start and are planning this design workshop to consider views of patients', researchers', IT experts' and healthcare professionals'. The day will be professionally facilitated.

The day is now fully booked, but contact Marco if you are particularly keen to come and we'll see if we can find a space.

Registration for the event is available at: bit.ly/DiabetesDesign

More News

Final remarks *[Prof. K. Owen]*

Thanks to all for another interesting and interactive patient panel meeting. I very much enjoyed hearing from our young researchers Jon and Robert as well as from Professor Karpe. Thanks for all the feedback from the panel members.

We hope that the panel members and online group will be keen to take part in our Research Design Day on the 28th of April. This will be our first event of this kind and I am really looking forward to spending more time with panel members on a project that should make a difference to how we do research in Oxfordshire.



Prof. J. Todd and
Prof. K. Owen.

SAVE THE DATES! Calendar and dates for 2018-2019 meetings

Saturday 3rd March, 2018: Research Design Day - see details above

Tuesday, 12th of June, 2018: Diabetes Panel Meeting #3 [postponed from 08/05/2018!]

Tuesday 9th October 2018 - Meeting #4

Tuesday 29th of January 2019 - Meeting #5

Tuesday 18th of June 2019 Meeting #6

All Panel meetings are still planned to run from **1:00pm to about 3:30pm**, but we are also investigating other possible times during the day (i.e., late afternoon/evening) in order to facilitate member still in full time employment, as well as video-conference for members with limited mobility or availability to travel during the day. You will be kept informed on any development on the matter.

FROM PATIENTS' EYES *[Dr. M. Pontecorvi]*

All patients in the group are welcome to submit a short comment they may want to share about their experience in the group, the meeting, other involvements they may have across the numerous and different PPI bodies and organizations.

If interested, please contact Marco Pontecorvi (marco.pontecorvi@ocdem.ox.ac.uk), thanks.

Feedback Request *[Dr. M. Pontecorvi]*

If you have any feedback on the meeting (if you attended), this newsletter or the recently launched NIHR/BRC website, please do feel free to contact me at marco.pontecorvi@ocdem.ox.ac.uk and discuss any suggestion you may have. Also, if you wish to participate to the next edition of the Newsletter you are very welcome to contact me as well. Thanks!