

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

NEWSLETTER

Nr. 1 - June, 2017

From 2017 to 2022: the new BRC3/NIHR



The new BRC Diabetes and Metabolism Theme logo

based, at the [Wellcome Trust Center for Human Genetics](#). After a short break, [Dr. Rustam Rea](#), Diabetes consultant, outlined the many different local and national patient databases and discussed with the panel about possible future steps in merging and organising these multiple datasets and how this may impact on local research. [Professor Katharine Owen](#), diabetes consultant and chair of the meeting, closed the meeting with a few words about future directions for the NIHR/BRC and the Diabetes Theme leadership and thanked the speakers and all those present for the invaluable feedback.

On the 1st of April 2017, the management of the Diabetes Reference Panel (DRP) and the Diabetes Online Review Group (DORG), has officially been transferred from the [CRN \(Clinical Research Network\)](#) to the [Oxford NIHR BRC - Diabetes and Metabolism Theme](#), led by Prof. Anna Gloyn and based at [OCDEM](#) (Oxford Centre for Diabetes, Endocrinology and Metabolism).

During the last meeting, on the 6th of June 2017, Polly Kerr, talked about the BRC plans for PPI under the lead of [Professor Trish Greenhalgh](#) and [Professor John Todd](#) passionately discussed his long and successful research experience in Diabetes, between the Universities of Cambridge, Stanford and Oxford, where is currently

Dr. Marco Pontecorvi

Introduction to BRC3 and PPI [P. Kerr]



Polly Kerr addressing the panel

The [Oxford BRC](#) is a collaboration between the [University of Oxford](#) and the [Oxford University Hospitals Trust](#), and is funded by the [National Institute for Health Research](#).

Oxford BRC has just received its third wave of five-year funding of £113 million for research across 20 specialist areas, called Themes. There are 20 Themes covering specific disease areas, of which Diabetes is one. In addition there are 3 ‘cross-cutting’ themes: Informatics, Imaging and the [Partnerships for Health, Wealth and Innovation](#) Theme in

which PPI sits. This emphasises that PPI is an integral part of the research process rather than something separate.

This partnership with patients and the public is key to ensuring that the research being done by the BRC addresses the areas that are important to them when considering new research projects. We would like your help with trying out a new way of setting priorities for research by taking part in a Research Priorities Event. This will bring together patients, researchers and clinicians to pitch research ideas to each other in a creative, informal way, facilitated by an independent researcher. It is a new concept and Diabetes will be the first to try it out. So watch this space for more details of the BRC Design Pilot.

We’ll be providing more information over the next few months and in the meantime if you have any questions, please get in touch via email: polly.kerr@phc.ox.ac.uk or tel: **01865 617765**.

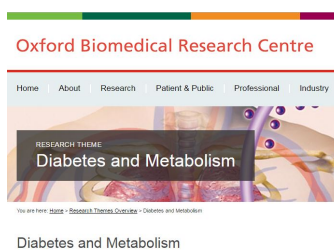
A message from Prof. Trish Greenhalgh [BRC PPI LEAD]

I’m excited to be leading the Partnerships theme with the many opportunities it offers to collaborate. Patient and public involvement is advancing all the time and I look forward to working with you in innovative ways to embed it in both research and service design and delivery, ensuring patients’ priorities are addressed.



Professor Trish Greenhalgh is the Leader for the Partnerships for Health, Wealth and Innovation Theme of the NIHR Oxford Biomedical Research Centre.

The new BRC/NIHR website *[Dr. M. Pontecorvi]*



The new website has been just launched (<https://oxfordbrc.nihr.ac.uk/>) and any feedback on it is very welcome. A small team of patients will start shortly to provide the input necessary to design a proper dedicated page for the Diabetes Patients Panel and Online group within the BRC/Diabetes pages. (mail to marco.pontecorvi@ocdem.ox.ac.uk)

Treatment and prevention of type 1 diabetes *[Prof. J. Todd]*



[Prof. John Todd](#) is internationally renowned for his work on the genetics of autoimmune disease, particularly Type 1 diabetes. His career has taken him from Oxford to Stanford to Cambridge and recently back to Oxford again. He is now Professor of Precision Medicine at the [Wellcome Trust Centre for Human Genetics](#). Over the past 10-15 years, John

and his team have been at the forefront of work to describe the genes involved in increasing risk of Type 1 diabetes and they are now moving into the next step of developing this work into a treatment to modify the immune response that destroys the insulin producing beta-cells in Type 1 diabetes. Even if a very small amount of insulin production is preserved, we know it leads to a positive impact on diabetes control and the frequency of low blood sugars. John is about to start a UK-wide study hoping to recruit 40 children recently diagnosed with Type 1. John gave a fascinating account of his career and the importance of the involvement of patients (and parents) in research.

Online patient consent: the situation *[Dr. R. Rea]*

[Dr. Rustam Rea](#) is a Consultant in Diabetes and Acute General Medicine. He is interested in the development of integrated working between primary and secondary care to improve the whole pathway for people with diabetes. In the meeting, he presented ideas for sharing of the data held in GP, hospital and other databases to make communication better and improve clinical care. Sharing of data could also assist research considerably by allowing us to search efficiently for those fitting the criteria for studies. We could also look at the changes which occur over time to evaluate things like response to different diabetes treatments in Type 2 diabetes and the amount of natural insulin production over the years since diagnosis. Rustam presented an overview about how sharing of data might occur and discussed how we could use new technologies to enable patients to consent for research. The panel gave some useful feedback on this area.



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.



More News

Patient and Public Involvement project *[Dr. I. Spiliotis]*

Dear patient, the OCDEM is planning a new clinical trial into type 1 diabetes, exercise and hypoglycaemia and we'd like to hear your opinions about it. We would really appreciate your input at this early stage, whether you have diabetes or not. This is an opportunity for you to help us develop and design our study. Please follow this link [CLICK HERE](#) to get some background information, followed by a short survey and thank you in advance for your great help!

Note: For manual input, the link is www.surveymonkey.co.uk/r/HBX3W8B



Dr. Ioannis Spiliotis (centre) who is collecting data for the trial with part of the research group.

Final remarks *[Prof. K. Owen]*

I'd like to thank all the speakers and panel members who attended the meeting and to Alison Monk for all her hard work in organising panel meetings over the last few years. I came away from the meeting feeling really positive about the future of patient involvement in local Diabetes Research. We have been passing this positivity on at our regular OCDEM BRC meetings. It will be very exciting to work with Polly Kerr on the Research Priorities event. Please put the dates of the next 3 meetings in your diary and let us know if there are any particular subjects that you would be interested in hearing about :

Tuesday, 3rd of October 2017

Tuesday, 29th of January, 2018

Tuesday, 8th of May, 2018

All 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.



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

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!