

Welcome to the 9th issue of the NIHR Exeter Clinical Research Facility (CRF) newsletter

The aim of this newsletter is to highlight the achievements of our facility and provide an overview of our current projects, and show how you can become involved, or continue to be involved, in improving healthcare through research.

Exeter 10,000 Update

Exeter 10,000 (EXTEND) goes from strength to strength, and the good news is that we can continue for at least another 5 years! Our recent application to the Health Research Authority (HRA) for an extension of the EXTEND/Peninsula Research Bank ethics approval was successful. This means we can keep doing what we do best – facilitating local clinical research. We can also invite people who have already participated in EXTEND for a valuable return visit to replace samples that have been used up, update the health data that we recorded when they joined, and give participants the opportunity to join the NIHR BioResource (<https://bioresource.nihr.ac.uk/>). This is like a national version of EXTEND and the Exeter CRF is one of 13 local recruiting centres across the UK. If you are interested in this, you can join directly by going online, or when you have your return EXTEND visit.



A very big thank you to all the wonderful people who have volunteered to participate in the Exeter 10,000 and the NIHR BioResource tissue bank studies. Between forty and fifty people volunteer each month for both of these studies that play a crucial role in improving healthcare. Throughout the year, we attended events, local shows and wellness festivals to talk about research to as many people as possible. We have developed a set of games for all ages around health and wellbeing designed to promote discussion about getting involved in health research. The Halloween season saw us get spooky when we supported the Four of Swords immersion theatre group's play Doctor Dracula in the beautiful grounds of National Trust's Knightshayes, near Tiverton. We were on hand before and after the play along with members of the Haemochromatosis Society and the NHS Give Blood programme to talk to the audience.

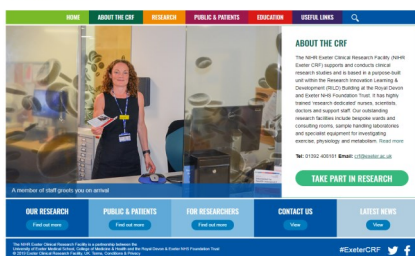


We really love getting out and talking to the public because we are very passionate about improving healthcare by being involved in research so if you have any suggestions of events coming up that might be suitable please do let us know!

For more information about the Exeter 10,000, the NIHR Bioresource and all the other research projects on the go at Exeter please visit our website <https://exetercrfnihr.org/about/exeter-10000/> or email crf@exeter.ac.uk

New NIHR Exeter CRF Website Launched

NIHR | Exeter Clinical
Research Facility



We launched our new CRF website <https://exetercrfnihr.org/> in Spring 2019. It has been designed to be easier to navigate and more engaging for those interested in getting involved in research. It now includes clear tabs to click on which take you directly to the information you are looking for, including the CRF team and facilities, or information about our research studies and patient and public involvement (PPI) activities. We welcome your feedback about our new website, so please send us any comments, observations or suggestions to: crf@exeter.ac.uk

You can now also follow us on Facebook, Twitter and Instagram to keep up to date on our latest activities and new studies starting.

Get Involved in Diabetes Research at the University of Exeter!

The **Exeter Diabetes Patient and Public Involvement Group** is seeking volunteers with Type 1 or Type 2 diabetes to join a group dedicated to improving diabetes research. The group informs and provides feedback to researchers and study coordinators in order to help diabetes research become more relevant and accessible for people with diabetes.

If you are interested in joining the group, please contact Louisa on:

01392 408182 or L.Bolt@exeter.ac.uk

Study Volunteers Needed!



You could take part in this research study if you are:

- Diagnosed with Type 1 diabetes in the last 100 days
- Aged 18 years or over at the time of diabetes diagnosis
- Receiving Insulin Treatment



You could take part in this research study if you were:

- Diagnosed with diabetes in the last 12 months
- Over 50 at diagnosis
- Receiving Insulin Treatment

For more information about **DROPLET** or **StartRight** contact:

Telephone: 01392 408181

Email: rde-tr.DiabetesResearch@nhs.net

Research Highlights

• The CRF's dementia study portfolio is rapidly growing. The **Deep and Frequent Phenotyping (DFP) Study** has recently opened to recruitment in Exeter and is being sponsored by Oxford University. This is a repeated measures observational study in prodromal Alzheimer's disease which is using both established and novel markers to identify a marker set for measuring outcomes in prodromal disease. Measurements will include PET imaging, biochemistry tests and measures of gait and retinal pathology.



• **Respiratory Research** has been an expanding area for the Exeter CRF and we have had participants successfully recruited to and complete the **PTI-808** study into Cystic Fibrosis, an inherited condition that causes sticky mucus build up in the respiratory and digestive systems. The **Astraeus study** is currently recruiting patients who have Alpha 1 antitrypsin deficiency, a genetic disorder that causes lung and/or liver disease. We have also opened the **ATLAS study** for patients with idiopathic pulmonary fibrosis. This study is looking at the benefits of an inhaled drug rather than tablets taken by mouth.

For more information regarding our respiratory research, please contact: Julie.wollaston@nhs.net

• We are delighted with the success of the **PROTECT study** since launching the



study website in Exeter in January 2019. Over 2,400 new participants signed up from around the UK; approximately 300 of these are Exeter 10,000 members.

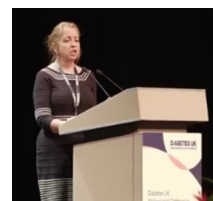
Participants have been completing cognitive tests of memory and reasoning and completing questionnaires about themselves on topics, such as medical history and lifestyle, to contribute to our research into how our brains age and what we can do to help prevent dementia. If you are interested in joining or would like more information, please visit our website: www.protectstudy.org.uk

• **Huntington's Disease Research** - Huntington's Disease is caused by a genetic disorder which causes an abnormal protein (called Huntingtin) to be made. It causes nerve cells in the brain to deteriorate over time and those affected to have problems with movement, emotions and the ability to think. Two patients have been recruited into studies sponsored by Wave Life Sciences looking at a new treatment that will hopefully show it is possible to 'switch off' the genetic fault that causes this protein to be made, thereby potentially treating the symptoms of this disease.

Awards for our Researchers

Exeter nurse awarded prestigious Arnold Bloom lecture at Diabetes UK annual conference 2019

Professor Maggie Shepherd, Lead Nurse for Research at the RD&E NHS Foundation Trust, Honorary Clinical Professor at the University of Exeter Medical School and NIHR 70@70 Senior Nurse Research Leader received the award for her contributions to clinical care in monogenic diabetes. She was the first nurse ever awarded this lecture which recognised her role in improving awareness of monogenic diabetes and leading the national Genetic Diabetes Nurse project.



Funding Boost to Expand Diabetes Research Excellence

A £6 million Government award to the University of Exeter, working in partnership with the Royal Devon & Exeter NHS Foundation Trust, will enable Exeter's globally renowned diabetes research to expand, providing even more benefit to patient care. The award is part of the Government's modern Industrial Strategy and is designed to increase the excellent diabetes research being conducted in Exeter. It will further develop our research by supporting recruitment of additional established experts and promising young researchers, plus investment in the latest genomic and imaging equipment.

Please contact us if you have recently moved house, changed your telephone number, or have received this by post but would be happy to provide us with an email address : **01392 408181** or crf@exeter.ac.uk



The **DARE** Study continues as planned to follow up participants already taking part. Fair processing information which clarifies what we do with your data can be found at <https://www.diabetesgenes.org/current-research/dare/>

The NIHR Exeter Clinical Research Facility is a partnership between the University of Exeter Medical School College of Medicine and Health, and Royal Devon and Exeter NHS Foundation Trust.