

240000

People on the SHARE Register

SHARE

## Newsletter

February 2019

## So far...



Over **80,000** leftover blood samples have been collected throughout Scotland.



**240,000** people have joined the SHARE register.



SHARE has been involved in around **80** research studies with over **50,000** people having been contacted as potential participants.

According to the World Health Organisation (WHO)

*"The number of people living with diabetes has nearly quadrupled since 1980 to 422 million adults."*

## SHARE Celebrated 200,000 Registrants!



The Lord Provost of Dundee, Ian Borthwick became the 200,000th signatory of the SHARE register on

the 12th of March 2018. The Provost welcomed the world-renowned diabetologist Dr. V Mohan to the city to discuss his role in the new Scotland-India partnership.

By joining the register Mr Borthwick, who is the longest serving councillor in Scotland, is joining over 240,000 others who are willing to be contacted by the SHARE team about relevant research projects that are recruiting volunteers. He then has the opportunity to agree or decline the invitation to take part. Mr Borthwick has also

given permission for any of his spare blood samples to be used for anonymised genetic research. Scotland is the first country in the world to utilise leftover blood samples for anonymised genetic research. The research carried out using this blood will help design the treatments and medicines of the future. An example of this is SHARE's involvement in the INSPIRED project (see page 2).

2018 has been a great year for the SHARE team and they would like to send out a big thank you to all of the registered SHARE participants who have willingly expressed their interest to be involved in research.

Thank You!!!



Pictured left to right: Dr V Mohan, Lord Provost Ian Borthwick and Prof. Colin Palmer

## Register now from age 11!

One of the biggest changes to SHARE in 2017 was lowering the age you can register from 16 to the legal age of consent, which is 11 years. Why have we lowered the age? This will allow researchers to investigate disease processes in teenage and young adults, and explore new treatments. SHARE volunteers can choose to be contacted if relevant research opportunities arise and give permission for spare blood to be utilised.

Children aged 11 and over can sign up themselves with parental guidance.

For registrants that are aged below 16, we will also take contact details and permission from a parent or guardian to ensure they are happy for their child to be on the SHARE register. SHARE will always contact the parent or guardian about any relevant research projects that come along and as always, there is never any obligation to take part.



**So if you have any children or wards, who would be interested in hearing about research please register for SHARE today at:**

[www.registerforshare.org](http://www.registerforshare.org)

Keep up to date with all of our news by following us on social media  
SHARE's goal is to reach 1,000,000 registered Scots, please help us achieve this by spreading the word about SHARE today!



# SHARE Gets INSPIRED!



Professor Colin Palmer,  
NIHR Director/Chief  
Investigator for the  
NIHR INSPIRED project.

SHARE is excited to announce the launch of the INSPIRED (INdia-Scotland Partnership for pRecision mEdicine in Diabetes) project. The University of Dundee has been awarded £7m from the National Institute of Health Research (NIHR) programme to establish a major new clinical partnership between Scotland and India to combat disease.

INSPIRED is a collaboration between the University of Dundee and the Madras Diabetes Research Foundation.

This NIHR funded project will see Dundee's world leading expertise in the use of medical records to deliver improved care in diabetes matched with the large patient data set (over 400,000 Indian diabetic patients) collected by Dr Mohan's Diabetes Specialities Centres.

The aim of the project is to compare and contrast diabetes in India and Scotland to determine common and specific problems in both countries, with the objective to improve health and reduce health

inequalities in both countries. The blood samples from SHARE volunteers have been used to compare disease progression in these populations and SHARE will be working closely with the INSPIRED team in the future.

**If you would like to be involved in research projects such as INSPIRED please register for SHARE today at [www.registerforshare.org](http://www.registerforshare.org)**



Please visit our website for further information.  
[www.registerforshare.org](http://www.registerforshare.org)

## Current Studies

### CELO (Obesity)

This study examines how brown fat (which generates heat production) activation is controlled. Location: Lothian.

### EPIC (COPD)

Studying genes and lung inflammation to understand individual susceptibility to tobacco smoke. Location: Tayside, Fife and Glasgow.

**Generation (Alzheimer's Disease)** Investigating two new drugs for the prevention of Alzheimer's Disease. Location: Tayside.

**EPAD(Dementia)** European Prevention of Alzheimer's Dementia Longitudinal Cohort Study. Location: Tayside and Lothian.

### INCOGNITO (COPD)

Investigating COPD Lung Infections With Two Different Inhalers. Location: Tayside and Glasgow.

**The INTERVENTION Factory** Does taking up a new activity benefit our thinking skills? Location: Lothian (EH1-17).



As part of the MRC funded Mental Health Data Pathfinder award, researchers from the University of Glasgow and University of St Andrews are establishing a new Scottish Schools Health and Wellbeing Improvement Research Network (SHINE) and are inviting schools to take part in the pilot study.

website: [www.gla.ac.uk/shine](http://www.gla.ac.uk/shine).

## GDPR and Your Privacy

From May 25th 2018, the new European General Data Protection Regulations have been enforced to strengthen the already robust data management systems within the NHS. We have updated our Privacy Policy on our website to reflect this, which you can access [here](#).

## SHARE study success stories

### EYE TRACKING



"We used the SHARE database to assist with the recruitment of control participants for our Visual Fields Study. The SHARE team did a great job of identifying the correct individuals required for the study. The tailored database, which was provided, has all the information we required in order for us to contact and track the individuals who agreed to take part and we were pleased with the resulting numbers. Without the use of the SHARE database we would not have been able to meet the target number of control subjects required. As a research coordinator with the University I would definitely use SHARE to assist with other projects I am involved in."

Jane Andrews, University of Edinburgh

### AICOPD

### PHARMATICS

"We needed SHARE to distribute a questionnaire to people with COPD. The questionnaire sought patients' views on an artificial intelligence APP for managing COPD. Given the demography of people with COPD we did not expect a great response to a request involving smartphones and AI. We had hoped for between 30 and 50 responses. SHARE turned around the request in around two weeks and delivered 187 responses! I would advise everyone doing research with patients in Scotland to use SHARE and will certainly use it again."

Felix Agakov, Chief Executive Pharmatics

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