

Scottish Mental Health Research Register



Information Sheet

You are invited to put your name onto a register of people who are interested in taking part in mental health research. Before you decide, it is important for you to understand why this is being done and what it will involve. Please take your time to read the following information carefully and to discuss it if you wish to do so. Please ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the register?

The purpose of the register is to keep an up-to-date list of contact details for people who may be interested in taking part in future research studies on mental health. We intend to contact people on the register to invite them to participate in research studies as the studies come up.

What studies will I be taking part in?

You may be contacted in the future to be asked if you would like to take part in a research study. If this happens, information about the study will be sent to you and you can decide at that time whether you would like to take part or not. You are not agreeing to take part in any studies just now, only that we may keep your contact details to send you information in the future.

Why have I been chosen?

We have approached you because we think you may be interested in supporting research on mental health. We are contacting people who have experienced mental illness, people who know someone who has, and also people who have never had any experience of mental illness. We are looking for all kinds of people to join the register.

What will happen to me if I take part?

If you agree to take part, we will ask you to sign a consent form and complete a contact details sheet. We will then send you a newsletter about updates in mental health research once a year. We may also occasionally contact you to ask if you would like to take part in an upcoming research study.

What are the possible disadvantages and risks?

There are no substantial disadvantages to taking part and we will not ask you to undergo any medical treatment or do anything else that you have not agreed to do. If you decide not to join the register or take part in any studies this will not affect your access to any medical treatment.

What are the possible benefits of taking part?

Adding your name to the register will not benefit you directly. However, the information we obtain in future research studies may help us to better understand the causes of mental health problems. We will also write to you about the results of research projects that we support. We hope that you will find this information interesting and that it will keep you informed about the reasons for doing mental health research and ways that it can contribute to medical knowledge.

Will my agreeing to join the research register be kept confidential?

The details you give us will be kept securely and confidentially in an electronic database by the University of Edinburgh. This information will be held in accordance with the Data Protection Act 1998. The database will be password protected and encrypted and only researchers working for the register team will be able to access it. Under the Freedom of Information (Scotland) Act 2002, you are entitled to see any details we hold about you at any time.

Who will have access to my details?

Access to your details will be maintained by the Scottish Mental Health Research Register team. Other responsible researchers may also be allowed to contact you or send you information about their research studies. They will only be allowed to do this if their research is of high merit and has been approved by an ethics committee. They also have to agree to follow certain important procedures and guidelines, such as the Data Protection Act 1998. We will never share your details with anyone else other than for the purpose of the research register.

What if something goes wrong?

If you wish to complain, or if you have any concerns about the way you or your information has been treated, you are able to follow the normal NHS complaints procedure or make a complaint directly to the University of Edinburgh, College of Medicine and Veterinary Medicine.

How do I withdraw my details?

You are free to withdraw your details from the register at any time without giving a reason. If you wish to withdraw from the register, contact us using the details below and we will permanently delete any information we hold about you.

Contact details for Scottish Mental Health Research Register:

Please do not hesitate to contact the research register team by phone or email if you have any questions about the register or if you would like further information.

Lothian Area:

Scottish Mental Health Research Network, University of Edinburgh

Research Register Database Administrator

Phone: 0131 537 6673

Email: smhrr@ed.ac.uk

To download electronic versions of the register forms from a website go to www.smhrn.org.uk/register

If you would like independent professional advice from someone who is not part of the register team you can contact Dr Elizabeth Hare, NHS Consultant Psychiatrist, phone 0131 537 6000.

Please return the Consent Form and Contact Details Sheet to:

**Research Register
2nd Floor, Kennedy Tower
Royal Edinburgh Hospital
Edinburgh EH10 5HF**