



Study title: EMERALD: Exploring mental illness and diabetes

**Research Team: Dr Najma Siddiqi (lead researcher) and Dr Sue Bellass (study manager),
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of York, Heslington, York YO10 5DD**

You are being invited to take part in a study about people who have diabetes as well as a mental illness. This leaflet provides further information about the study and what your involvement will be if you decide to take part. Please read the information carefully and, if there is anything that is not clear, please contact the study manager **Sue Bellass** at the address above or by telephone (**01904 321679**) or email (**sue.bellass@york.ac.uk**).

What is the purpose of the study?

People with a mental illness such as schizophrenia or bipolar disorder are almost three times as likely as the general population to have diabetes, and to experience poorer health and healthcare. Currently, we know little about what it is like to live with a mental illness and diabetes or how people with mental illness experience diabetes healthcare. For this study, we are interviewing patients who have a mental illness and diabetes, their family members and healthcare professionals. We are aiming to develop understandings of what it is like to live with mental illness and diabetes and how we might improve diabetes care in the future.

Why have I been chosen, and do I have to take part?

You have been identified as someone who provides support to a close family member or friend who lives with a mental illness and diabetes.

Participation in the study is entirely voluntary. No-one outside the research team will be informed if you decide not to participate and your decision would **not** affect any services or benefits you or the person you support receive. If you decide to participate you will be asked to sign a consent form.

What will happen if I decide to take part?

A researcher will contact you to arrange an interview to talk about your experiences of supporting your relative or friend. During the interview you would be asked to talk about your experiences of supporting someone who lives with a mental illness and diabetes. For example, you would be asked

about how diabetes and mental illness impact on their life, what you think of the healthcare they have received and what kinds of support you provide.

You can choose when and where the interview takes place. It can be face-to-face or over the telephone, and will last no longer than 90 minutes. If it is easier for you, the interview can take place over two shorter sessions. We would like to audio-record the interview so we don't miss anything you say but it is up to you whether the interview is recorded.

What are the possible benefits and risks of taking part?

The research findings will be used by the research team to improve health services for people with co-existing diabetes and mental illness. There are no direct benefits associated with taking part in the study. It is important that you know that the study may not change your relative or friend's circumstances but that it could help other people in the future.

Are there any expenses or payment for taking part in this study?

You will not receive any payment for taking part in this study, but we will reimburse any out of pocket expenses such as paying for a substitute carer for dependents for the duration of the interview or any travel costs associated with taking part.

If I want to take part, what do I do next?

If you would like to take part in the study, please complete and return the enclosed form in the envelope provided.

Alternatively, please contact the study manager **Dr Sue Bellass**, who can answer any questions about the study and can arrange an interview. A friend or relative may speak to us on your behalf if you wish.

Tel: 01904 321679

Email: sue.bellass@york.ac.uk

Address: Mental Health and Addiction Research Group, Department of Health Sciences, University of York, Heslington, York YO10 5DD

What if I change my mind during the study?

If you agree to an interview and then change your mind, you can contact Sue Bellass to cancel the interview and we will not contact you about this study again. Even if the interview has started you can change your mind and we will stop the interview. After the interview you can withdraw your information as long as it has not already been used in the study. You do not have to give us any reason for changing your mind.

What will you do with the information I provide?

We will use the information you provide to understand more about the experience of caring for someone who has diabetes as well as a mental illness. The information will be anonymised so that your name, address or any other contact details will not appear in any reports, publications or presentations. We will share anonymised findings with study participants, researchers, care providers, service users and commissioners.

Only the research team will have access to the information that we collect about you during the study. This information will be stored securely in password-protected files or locked cabinets at the University of York.

Will you tell my relative / friend what I have said? What about other people?

We will not tell your relative or friend anything that you tell us, but we may need to tell someone if something you said makes us concerned that you or someone else is at risk of harm. We would talk to you first about the best thing to do.

Only our research team has access to the information that we collect from participants. There are very strict rules about confidentiality that the team follow. All information is stored in locked filing cabinets and in password-protected folders on computers. When we write reports, we do not include names or other information that could identify individual people.

How long will you keep my information?

Your personal details will be kept for up to three years from the interview (until 2021) so that we are able to contact you about the study findings if you decide to receive details of the study findings.

The anonymised data will be kept for ten years following the end of the study (from 2019 until 2029) so that we are able to publish the findings and carry out additional analysis.

All participants will be asked if they would like to be contacted about future related research at York University. If you agree to this, your details will be retained until the research has finished. If you initially agree but later change your mind you can contact Sue Bellass on 01904 321679 or at sue.bellass@york.ac.uk to have your contact details removed from the database.

Who has reviewed this study?

All research involving NHS patients is reviewed by an independent Research Ethics Committee. This research was reviewed and approved by Greater Manchester West Research Ethics Committee (reference no. 18/NW/0005).

What will happen if the study stops earlier than expected?

Should the research stop earlier than planned and you are affected in any way we will tell you and explain why.

Who is organising and paying for the research?

The study has been funded by the National Institute for Health Research (study reference number 15/70/26) and is being carried out by the Department of Health Sciences, University of York. The study is part of a large research project called **DIAMONDS (Diabetes and Mental Illness: Improving Outcomes and Services)** that is led by the University of York and Bradford District Care NHS Foundation Trust.

For more information, please visit our website: www.diamonds.nihr.ac.uk

If I have a complaint, who can I contact?

If you have any complaints about the study you can contact the lead researcher **Dr Najma Siddiqi**, Lead Researcher, Mental Health and Addiction Research Group, Department of Health Sciences, University of York, Heslington, York YO10 5DD. Email: najma.siddiqi@york.ac.uk Tel: **01904 321681**.



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The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health