

POCKET INFORMATION SHEET

Study Title

Partnership for Assessment and Investigation of Neuropathic Pain: Studies Tracking Outcomes, Risks and Mechanisms (PAINSTORM).

PAINSTORM Dundee epidemiology study – investigating risk factors and possible causes of neuropathic pain.

Chief Investigator (Person with responsibility for the research)

Blair Smith, Professor of Population Health Science, University of Dundee.

Why are we doing this study?

Many people who have diabetes, or who get chemotherapy for cancer treatment, develop long-term or chronic neuropathic pain. This pain is caused by damage to nerves. Not everyone develops neuropathic pain and those that do may not respond to treatment. We don't fully understand why.

A previous study, DOLORisk, identified some of the key factors that cause neuropathic pain and that can treat it effectively. The PAINSTORM research aims to find out if these factors are important in people with diabetes and/or receiving chemotherapy for cancer treatment. We hope this will help us to provide better treatment and advice for these people in the future.

Why have I been contacted?

You are either a participant of GoDARTS and have previously taken part in DOLORisk or you have signed up to SHARE and you have been identified as possibly having diabetes or possibly receiving chemotherapy to treat cancer.

Do I have to take part?

No. Taking part in this study, or not, is entirely up to you. If you decide not to take part, we will not contact you again about this study. The medical care you get and your relationship with the medical or nursing staff looking after you won't be affected. This will not affect your future involvement with SHARE/GoDARTS.

What do I have to do if I take part?

There will be two questionnaire surveys to find out about any pain you might have. We plan to do the first in 2022 and the second approximately 18 months later. You can complete the questionnaires online or in paper format.

What will happen with the information I give you?

The information will go to the Health Informatics Centre (HIC), University of Dundee, (who sent your invitation) and stored securely and confidentially in an approved database. The research team will have access to your anonymised responses but will not have any details that will identify you.

We may share your anonymised study responses with other researchers, who may be from commercial companies or outside of the UK and EU.

Who is organising and funding this research?

The University of Dundee is conducting the research and the sponsor is NHS Tayside. The work is being funded through the Advanced Pain Discovery Platform.

What are the possible disadvantages and risks of taking part?

We do not think there will be any disadvantages or risks in taking part as you will only be completing questionnaires.

What are the possible benefits of taking part?

Our study might not bring any direct benefit to you personally, but we hope that the information from this large research project will improve the treatment of people receiving chemotherapy for cancer and people with diabetes and help to develop new ways to prevent or treat neuropathic pain.

Who has reviewed the study?

This study has been reviewed and approved by London - Brighton & Sussex Research Ethics Committee (ref: 22/PR/0803).

What if I am concerned about taking part in the study, need more information or help with the study?

Please email the study team at: painstorm-study@dundee.ac.uk.