**Participant Information Sheet for *the Generation Scotland (GS) STRADL cohort***

**Title: Validation of the Consortium Against Pain InEquality Adverse Childhood Questionnaire (CAPE-ACEQ).**

**University of Dundee School Research Ethics Committee Application/Approval Number: *UOD-SMED-SLS-Staff-2024-24-45***

You are invited to take part in a research project. Before you decide whether you would like to participate it is important that you read the information provided below. This will help you to understand why and how the research is being carried out and what participation will involve. Please let us know if anything is unclear or you have any questions by contacting Dr. Aikaterini Christogianni: [achristogianni001@dundee.ac.uk. Do not disclose your GS ID if you contact the researcher with queries, via email.](mailto:achristogianni001@dundee.ac.uk)

**Who is conducting the research?**

Researchers from the Consortium Against Pain InEquality (CAPE), a project that aims to identify why a large percentage of people suffer with chronic pain, have collaborated with patient partners to identify its link with highly stressful experiences in childhood. At the moment, there is a lack of assessment questionnaires that capture key aspects of traumatic childhood experiences and chronic pain together, that are meaningful to people with lived experience. For this reason, the CAPE-ACEQ was created that combines chronic pain and childhood trauma questions.

This study is conducted by University of Dundee as part of the CAPE funding led by Professor Tim Hales. Other researchers working on the project are Professor Lesley Colvin and Dr. Aikaterini Christogianni from University of Dundee, and Dr. Line Caes from the University of Stirling.

**Who is funding the research?**

The CAPE project has been peer reviewed through the funding processes of UK Research and Innovation (Medical Research Council (MRC) – UKRI).

**What is the purpose of the study?**

The aim of the study is to validate our newly developed questionnaire, CAPE-ACEQ, and to increase the understanding of how stressful childhood experiences are related to chronic pain in adults. We want to make sure that people find the questionnaire straightforward to complete and that the questionnaire is measuring what it has been designed to measure.

**Why have I been invited to take part?**

You have been invited to take part because you are a participant in the GS cohort study.

**Do I have to take part?**

Taking part in the study is voluntary and all your data will remain anonymous. You may decide to withdraw from the study at any time without explanation and decide not to submit your answers to the online survey. After you submit your answers and data collection is complete it may not be possible for you to withdraw from the study. However, your answers will not include any personal information and identifiers.

**What will happen if I take part?**

You will be contacted by GS either in your portal account or by email to complete the confidential online survey in the secure Gorilla platform. As soon as you open the web link you will find information about the study and a request to fill in the Consent Form with your initials before you move into the questionnaire. The online survey takes around 15 minutes to complete.

**Are there any risks in taking part?**

There is no risk for you in filling in the online questionnaire. In case any of the questions in the questionnaire bring back traumatic memories, you may decide not to continue and submit your answers. Also, we provide details of organizations such as Wellbeing Scotland and HAVOCA at the end of the online survey to seek support in case you need to talk to qualified staff about your trauma.

**What are the possible benefits of taking part?**

If you take part in the study, you will help validating the CAPE ACEQ and increase the understanding about the link between chronic pain and adverse childhood experiences. An early detection of this relationship may aid in early intervention and prevention measures. Also, it may assist clinicians in supporting management of chronic pain in an effective manner and tailor treatments according to patient cases.

**Will my taking part in this project be kept confidential?**

Your answers in the survey will remain anonymous, confidential and they will not be linked to any personal details.

**What will happen to the information I provide?**

The data will be password protested and stored in OneDrive at University of Dundee. Data will be shared with GS and Alleviate Pain Data Hub with secure OneDrive transfer. The data will not be shared with other third parties, and it will be kept in the University of Dundee secure servers for 10 years. The results of the online survey will be reported and communicated within the CAPE team, and they will be available in public, via journal publications, conference abstracts etc.

**Data Protection**

There will be no personal data collection in this study. The University asserts that it is lawful for it to process your answers in this project as the processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller. The University of Dundee is the data controller for your submitted answers processed in this project. Please contact Information Governance by emailing [dataprotection@dundee.ac.uk](mailto:dataprotection@dundee.ac.uk) if you are unsure about the University’s policies on data protection.

The University respects your rights and preferences in relation to your data and if you wish to update, erase, or limit the use of your information, please let us know by emailing Dr. Aikaterini Christogianni, [achristogianni001@dundee.ac.uk](mailto:achristogianni001@dundee.ac.uk)*.* Please note that some of your rights may be limited where personal data is processed for research, but we are happy to discuss that with you. If you wish to complain about the use of your information, please contact the University’s Data Protection Officer in the first instance (email: [dataprotection@dundee.ac.uk](mailto:dataprotection@dundee.ac.uk)). You may also wish to contact the Information Commissioner’s Office (<https://ico.org.uk/>).

You can find more information about the ways that personal data is used at the University at: [https://www.dundee.ac.uk/information-governance/data-protection](https://eur02.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.dundee.ac.uk%2Finformation-governance%2Fdata-protection&data=05%7C01%7Cn.x.millar%40dundee.ac.uk%7Cdc587888e29f44529f8508dbd54833d7%7Cae323139093a4d2a81a65d334bcd9019%7C0%7C0%7C638338278313110235%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=FZR8FRevZxibDNNZoAU9SPhxZHfWp9jAKOQGbZ%2BgVCk%3D&reserved=0).

**Is there someone else I can complain to?**

If you wish to complain about the way the research has been conducted please contact the Convener of the University Research Ethics Committee ([https://www.dundee.ac.uk/research-governance-policy/non-clinical-research-ethics-contacts](https://eur02.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.dundee.ac.uk%2Fresearch-governance-policy%2Fnon-clinical-research-ethics-contacts&data=05%7C01%7Cn.x.millar%40dundee.ac.uk%7Cdc587888e29f44529f8508dbd54833d7%7Cae323139093a4d2a81a65d334bcd9019%7C0%7C0%7C638338278313110235%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=zxZxynhTGlsVXAKLX6RzmPCosmtT1fYXgGwZa5BXXDE%3D&reserved=0)). You have the option to email the Convener or leave a voicemail.