TEC: Car<u>ed</u>
Technology Enabled Care: Parent Support (PILOT)

<u>Information Sheet</u>

What is the Project about?

The project is funded by the Scottish Government's Technology Enabled Care Grant and aims to provide an online resource which will support, inform, up skill and provide a sense of hope for parents and carers caring for a young person with an eating disorder.

The part you are considering being involved in is the project "pilot". Our aim is to generate feedback on the content, layout and ease of use of the resource. We would also like to find out if the content impacts you in any way at all; reduces sense of guilt, carer burden or improves knowledge in anyway.

Who is the Support for?

The resource is aimed at any parents and carers of those who have a loved one with an eating disorder aged 12 to 25 and are in the early stages of treatment.

Data Collection?

When signing up for the online pilot, we will ask you to complete a demographic questionnaire. This will be used within the study for NHS Lothian to assess who has used the resource. We will also ask you to complete two self reported outcome measures (The Brief COPE and the Eating Disorder Symptom Impact Scale; EDSIS) around carer burden, coping and the impact carer has on you as an individual.

In order to evaluate how beneficial the resource is, we will ask you to complete short surveys questions after using the resource to gain feedback. The self reported outcome measures will then be repeated in order to assess if the resource has had

any impact.

You can still access the service even if you do not wish to complete the surveys or outcome measures.

Why do we require this information?

The feedback and survey information will be analysed by a Research Nurse who works for NHS Lothian.

This feedback and data will go towards:

- Helping to inform the content, layout and ease of use of the resources
- Measuring the impact of the resource
- Informing the TEC Project and Scottish Government about how their grant has helped people. Possible further publications of how the successful/acceptable the support was.

All of the data and feedback gathered by NHS Lothian will only be used for the purposes stated.

Privacy and Confidentiality?

All comments and responses related to the research project will be treated confidentially however, information you provide may be shared if you share anything that indicates that either you or another person is at significant risk of harm. In this situation we may pass this information to another person who can help to keep you safe, such as your GP. However, we would always discuss this with you beforehand.

Any data collected as a part of this project will be stored and transmitted as per NHS Lothian's Research Data Management policy and security standards. Personally identifiable information gathered through the website, registration and through the research project that is securely stored electronically and, will only be accessible to specific members of NHS Lothian who have been granted the necessary privileges.

The data collected will be used anonymously in publications/conferences by NHS Lothian and Beat, and may be used to inform future respective service delivery.