



## **Information Sheet**

### **What is the Project about?**

We have developed an online resource which aims to support, inform, upskill and provide a sense of hope for parents and carers caring for a young person with an eating disorder within the first few weeks of diagnosis. As part of this project we hope to review whether the website is helpful by collecting information when you log onto the website for the first time and four weeks later. We want to see if the resource reduces distress in parents & carers or improves knowledge in anyway.

### **Who is the Website for?**

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

### **Data Collection?**

When entering the website, we will ask you to complete a demographic questionnaire. This will be used by NHS Lothian to assess who has accessed the resource.

In order to evaluate how beneficial the website is, we will also ask you to complete two self reported outcome measures (The Brief COPE and the Eating Disorder Symptom Impact Scale; EDSIS) which ask questions about carer burden, coping and the impact caring has on you as an individual.

The self reported outcome measures will then be repeated in order to assess if the resource has had any impact. The email address you leave will be used to email you a link, which once clicked on, will take you to a webpage to complete the self reported outcome measures approximately 4 weeks after completing the first outcome measures. If you do not wish to be emailed you do not have to complete the outcome measures (EDSIS & BREF COPE). You can still access the website even if you do not wish to complete the outcome measures. You can also leave general feedback about the website within a link on the website or from the link that will be emailed to you.

### **Why do we require this information?**

The demographic information, outcome measures and feedback will be analysed by a Research Nurse who works for NHS Lothian.

#### This feedback and data will go towards:

- Evaluating if the website meets its aims.
- 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 evaluation of the website will be treated confidentially.

Any data collected as a part of evaluation will be stored and transmitted as per NHS Lothian's Research Data Management policy and security standards. Personally identifiable information gathered through the website 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 may be used to inform future respective service delivery,

### **Consent:**

We would like to ask you to confirm your agreement for your information to be used in this way whilst participating in the evaluation of this website.

If you would like more information please contact the following:

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CAMHS Research Nurse

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*Thank you for taking the time to help with this project. Please sign and return the sheet and keep a copy for your information.*

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