

PARTICIPANT (Patient & Parent/Carer) INFORMATION SHEET

(Version 2; 02/07/2019 IRAS number: 246433)

Study looking at the factors that are most important when transitioning (moving) from Child and Adolescent Mental Health Services (CAMHS) to Adult services for eating disorders**We invite you to take part in a research study**

The research is examining what factors are important when moving from CAMHS services to adult services (we call this transition) for the treatment of eating disorders.

This is a project being conducted by the Leicestershire Adult Eating Disorders Service and Leicestershire CAMHS Eating Disorders Services.

Please read this information sheet carefully. It is important for you to understand why the research is being done and what it would involve if you agree to take part. If you have any questions please contact the study coordinator (contact details are at the end of this sheet). Please take time to consider whether or not you wish to take part and discuss it with friends and relatives if you wish.

What is the study about?

We are looking at how to improve the transition process from CAMHS to adult services for the treatment of eating disorders. There is currently little research in this field, and this study will be the first to examine the priorities for transition from the perspectives of clinicians, patients and parents/carers in the UK.

What does the study involve?

Taking part in the study would involve a sorting task. We have already conducted a service evaluation with patients, parents/carers and clinicians and have generated a list of 40 statements about the transition process from this. We would like you to rank these statements based on your strength of agreement/disagreement with its content. This will take approximately 45 minutes to one hour. In order to receive the sorting task pack you need to email the study team your name and address so we can send this to you. We enclose a pre-paid envelope so you can send the information back to us without any cost to you. We will not be discussing personal eating problems; it's just about the process of transition. If you wish you can go into a prize draw where you have the chance to win a £50 voucher for your participation.

Why have I been chosen?

You are being invited to take part if you meet the recruitment criteria for our study project which is:

- People over the age of 18
- Patients who have been offered transition from children's and young people's services to adult services (whether or not they actually made the transition)
- Parents/carers of young people who have been offered transition from children's and young people's services to adult services (whether or not they actually made the transition)

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you are asked to keep this information sheet and sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

I am interested in taking part, what do I do next?

If you would like to take part, please contact the study coordinator by email: ResearchED@leicspart.nhs.uk

What if I agree to take part and then change my mind?

You are free to withdraw from the study at any time, without giving a reason. Although as all data is collected anonymously it may not be possible to remove your data once it has been posted back to the study team.

What are the possible disadvantages of taking part?

Taking part in the study should not cause you any discomfort or distress, however if you have any concerns about eating disorders you should contact your GP or Beat (eating disorders charity).

Beat contact details: www.beateatingdisorders.org.uk

Unit 1 Chalk Hill House, 19 Rosary Road, Norwich, Norfolk NR1 1SZ

Young people helpline: 08088010711 fyp@beateatingdisorders.org.uk

Adult helpline: 08088010677 help@beateatingdisorders.org.uk

What are the possible benefits of taking part?

Whilst there are no individual benefits to the participants taking part in the study you will help us understand how we can improve the transition process for young people and their families in the future. By seeking participants from a wider geographical area we hope our results will be transferrable to other services.

What if something goes wrong? / Who can I complain to?

If you have a concern or complaint regarding anything to do with this study, you can initially approach the study investigator. If you remain unhappy and wish to complain formally you can do this through the NHS complaints procedure: Complaints Team, Leicestershire Partnership NHS Trust, FREEPOST, LPT PATIENT EXPERIENCE. Telephone: 0116 2950831

Will my taking part in this study be kept confidential?

Yes. Leicestershire Partnership NHS Trust is the sponsor for this study based in the UK. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information that we have already obtained from you as it will be returned anonymously so it will not be possible to identify the data to an individual. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at www.leicspart.nhs.uk/Library/LPTPrivacyNoticeFeb2019v15.pdf

The study team, part of Leicestershire Partnership NHS Trust, will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded to oversee the quality of the study. Individuals from Leicestershire Partnership NHS Trust and regulatory organisations may look at the research records to check the accuracy of the research study. The study team will hold these details along with the information collected from you. The only people in Leicestershire Partnership NHS Trust who will have access to information that identifies you will be people who need to contact you to take part in the study or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, or contact details. Leicestershire Partnership NHS Trust will keep the information you return, which will not identify you, for a maximum of 3 years after the study has finished.

Should you wish to be included in the prize draw for your participation you will be asked to put your details in a separate sealed envelope on returning the study information. This will be held separately until the draw is made and not linked to the information you send.

What will happen to the results of the research study?

We will analyse all of the information we receive from patients, parents/carers and clinicians to examine how we can improve the transition process for patients with eating disorders and their families. We will write up the results of the study for publication in a peer-reviewed journal to disseminate our findings widely. Details of this publication will be made available on the website of the Leicestershire Eating Disorders Service and the Beat website.

Who is organising and funding the research?

The research is organised by the Leicestershire Eating Disorders Services and is funded by Leicestershire Partnership NHS Trust.

Who has reviewed the study?

This study has been reviewed by the Health Research Authority.

Contact for Further Information

If you have any questions or concerns about this study, please contact the researcher:

Jackie Wales (Study Coordinator)

Leicestershire Eating Disorders Service

Bennion Centre, Forest Grange

Glenfield Hospital

Leicester LE3 9DZ

Tel 0116 225 2583 Email ResearchED@leicspart.nhs.uk

Thank you for taking the time to read this information sheet and considering taking part in the study.

Please retain this information sheet for future reference