

## Uplift website for depression feasibility study

### Participant Information sheet

#### **Invitation to participate**

You are invited to take part in this research study to find whether the Uplift website is acceptable to people with symptoms of depression. You should only agree to take part if you want to. If you choose not to take part this will not affect the medical care you receive.

Please read this information carefully before you decide to take part; this will tell you why the research is being done and what you will be asked to do if you take part. Please ask if there is anything that is not clear or if you would like more information. If you decide to take part you will be asked to give your consent to say that you agree. You are free to withdraw at any time and without giving a reason. However, the research study will keep any information that has already been collected from you.

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

The purpose of this study is to find out how acceptable the Uplift website is to people with depression. The Uplift website offers different activities that may be helpful for depression. These activities are a different approach to treating depression because they do not focus on symptoms and problems but focus on building strengths, enjoying day-to-day experiences and connecting with your friends, family and community. The Uplift website is designed for people with depression to use independently. However, support will be available for any practical or technical issues. The Uplift website is also designed to be used alongside other treatments for depression. It is not a substitute for other treatments for depression; it does not replace medical advice or treatment.

#### **What would taking part involve?**

##### Eligibility check (up to ten minutes):

First of all, a researcher will speak with you to check that you are eligible to take part in the study, at this time you will also be invited to ask any questions you have about the research. If you are eligible you will be invited to provide your informed consent online, this is your agreement to take part in the study.

Participation in the study is for a total of between 7 and 9 weeks, depending on how soon you complete the final activity.

The study is then in three parts, you will be invited to:

##### 1) Complete an online questionnaire

Week 1: This online questionnaire will take up to twenty minutes to complete. You will answer some demographic questions about your age, gender etc. and some questions about your health.

##### 2) Use the Uplift website for six weeks

Weeks 1 to 6: You can then try the Uplift website for six weeks. We would recommend that you try and use at least one activity per week, which is about an hour per week. We will automatically collect some data on how many times you use the website including how many times you log in and how many times you use the

different activities. However, we will not be able to see the information that you put onto the website for each activity. The activities are personal to you and will be seen only by you.

During this time you will receive up to six email reminders about using the website. If you wish to you can opt out of receiving these reminders.

3) Complete an online follow up questionnaire

Week 7: In week seven of the study, you will be invited to complete an online questionnaire taking up to 20 minutes to complete. You will answer some questions about your health and your views on the Uplift website.

Optional face-to-face interview:

Some participants will be invited to an optional face-to-face interview taking up to an hour to discuss their views on using the website. This interview will be audio recorded.

**Will I be compensated for my time?**

To reimburse you for the twenty minutes it takes to complete the questionnaire at the beginning and end of the study, you will receive an electronic £10 gift voucher for Amazon for each completed questionnaire. If you are invited to take part in the face-to-face interview this will take up to one hour of your time, for which you will be reimbursed £20 cash, plus local travel expenses.

**Will information collected about me be kept confidential?**

Yes, all of the information we collect about you will be kept confidential. We will ensure this by giving you a unique identification (ID) number and using this on all of the data we collect about you, instead of your name. Your personal details will be stored separately and only the people in charge of the research study will have a list of ID numbers matched to names. This list will be kept in a secure folder on an NHS computer. This means that your name or other personal details will not be seen by others. Your email address will be stored on the Uplift website during the study so that you can log in and use the website. The Uplift website is secure and uses the latest encryption technology to keep your details safe. After six weeks of using the website, your email address will be deleted from the Uplift website as you will no longer be able to use the site. If you are invited to take part in the face to face interviews, this will be audio-recorded and then sent to a transcription company to type up. You will not be able to be identified from your interview, it will just have your unique identification number. Once your interview is typed up, the audio recording will be securely deleted.

We will keep your personal contact details until the end of the study, after this we will securely destroy these.

Data you provide during the study will be stored in encrypted databases, or in secure folders on NHS computers which only the researchers have access to.

This information will be archived at the end of the study and will be kept for 20 years in accordance with Research Governance Framework, 2005, the Data Protection Act, 1998 and East London NHS Foundation Trust's record management policy after which it will be securely destroyed.

Regulatory authorities or by persons from the Trust may access the data collected for this study as part of monitoring and auditing procedures designed to ensure that the study is complying with relevant laws and regulations. Regulators would check that your data is being stored confidentially and securely.

If you agree to take part we will write to your GP to let them know.

It may be necessary to break this confidentiality agreement if you tell us anything that may put yourself or others at risk of harm. If this happens, we will explain why we will need to break the confidentiality and who we will inform.

### **What are the possible disadvantages of taking part?**

We believe that this study is safe and do not expect you to suffer any harm or injury because of taking part. The questionnaire will ask for details about your health and your views on the website. However, your answers will be kept confidential. Taking part will take some time but you will be compensated for this.

### **What will happen once the research study ends?**

Once the study is over the Uplift website will not be available to use because we are still testing it. You will still have access to any treatment that you may have been receiving for your depression from your local health services.

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

You may find doing some of the activities on the Uplift website helpful or interesting. In future, we hope this research may lead more treatment choice for people with depression.

### **What will happen to the results of the study?**

The results of this research will be used in a doctoral thesis submitted to the Queen Mary University of London. We hope to publish the results in scientific journals. Please be assured that you will not be identified in any report or publication. We will send you a summary of the results of the research once the report has been written up unless you ask us not to.

### **Who is funding and organising the research?**

The study is being done as part of an educational qualification for a PhD, the researcher is Sophie Walsh who is supervised by Professor Stefan Priebe. East London NHS Foundation Trust are sponsoring and funding this research study.

### **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by REC: 16/NW/0447

### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of the study, you should ask to speak to the researcher (Sophie Walsh) who will do her best to answer your questions (020 7540 4380 extension 2309). If

you are still unhappy and wish to complain formally, you can do this by contacting the Patient Advisory Liaison Service (PALS):

**Freephone:** 0800 783 4839 **By email:** PALSandComplaints@elft.nhs.uk

**Write to:** Patient Advice and Liaison Service, Trust Headquarters, 9 Alie Street, London, E1 8DE

**To find out more or if you have any questions you can contact Sophie Walsh on:**

**Email:** sophie.walsh@elft.nhs.uk **Tel.:** 020 7540 4380 **Extn:** 2309 **Mob.:** 07706 678176

**Thank you for taking the time to read this Information Sheet**