



If you have questions about this study, please contact:  
Professor Nick Midgley: [nick.midgley@annafreud.org](mailto:nick.midgley@annafreud.org)

If you have concerns about how your data will be used in this study, you can contact the Anna Freud Centre data protection officer: Susan Henry, [DPO@annafreud.org](mailto:DPO@annafreud.org)

# Depression: Online Therapy Study (D:OTS)

## Participant Information Sheet

UCL Ethics Project ID number: 19095/001

We would like to invite you to participate in this research project. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what participation will involve. You can ask any questions you wish before deciding whether to take part.

### ***What is the purpose of this project?***

Research suggests that internet-based treatment can provide good and long-lasting effects for many, and this study will be testing a relatively new treatment package, which has been developed and tested in Sweden, but not used in the UK until now. The treatment we use in this research study is called I-PDT, which stands for Internet-Based Psychotherapy. We are carrying out this study to try and develop more effective and accessible treatments for young people aged 16-18 who are feeling depressed.

### ***Is this suitable for me?***

If you are interested to take part and meet the study criteria (see below) you will be able to access a self-guided treatment package via a website and will also be offered support via e-mail and a weekly chat session with a therapeutic support worker. One requirement for taking part is that you have access to a computer / smartphone / tablet with an internet connection and the ability to send and receive e-mail.

### ***What is internet-based psychotherapy?***

The treatment consists of 8 "chapters" that you will get sent weekly, with text, video and exercises that you do on your smartphone or computer. The treatment lasts for 10 weeks so you have a little extra time if needed. You also have your own therapeutic support worker who provides feedback and who you can

text-chat with online for up to 30 minutes every week through the treatment's website. Your therapeutic support worker will receive supervision from a licensed psychologist.

### ***For whom is the internet-based treatment suitable?***

The treatment was developed for young people aged 16-18 suffering from depression. However, the format is not for everyone. There is limited opportunity for personal support in addition to the contact you have within the framework of the treatment's structure. Internet-administered treatment is not suitable for people with complex needs, more severe depression or other mental health problems. For those who suffer from bipolar illness, psychosis or if you have thought of taking your life or previously tried to take your life this is not an appropriate treatment. If that situation applies to you, we recommend that you book an appointment with your GP to discuss a possible referral to a specialist service, or if the situation is urgent, go directly to your local A&E department. The treatment might also not be suitable for people with a diagnosis of autism spectrum disorder, or if you are suffering from alcohol or drug addiction.

### ***What happens if I'm interested to take part?***

To begin with, we will ask you to fill in a questionnaire to help see whether I-PDT is something that seems suitable for you. This is done via an online form. You do not have to experience all the problems we ask for to be able to participate in the study! If the assessment shows that the treatment may suit you, you will be contacted by one of the therapeutic support workers to arrange a personal interview by phone. We will not call and stress you and demand that you answer questions immediately – it needs to be a time that suits you. The phone call is to help us all decide whether this treatment is suitable for you and to answer any questions you may have before deciding whether to participate. This usually takes about 30-60 minutes. The caller is used to all kinds of answers and you do not have to worry about your answers being wrong, weird, or embarrassing. In fact, there are no wrong answers and whatever your responses are no one will be angry, disappointed, or think you are weird.

If we feel that this programme isn't right for you and that you need a more specialist support service, we will give you advice on how you can access such services. All the data you have provided up to that point will be securely destroyed. If this study is right for you, and you do want to take part, we'll ask you to sign an online consent form. We will then explain how you can access the online platform and start treatment by completing a couple of baseline questionnaires.

Participating in a program like this requires time and commitment. Your therapeutic support worker will give you support and advice, but we expect you to engage with the programme online and complete weekly exercises. This is required because we want you to learn strategies and techniques that are useful even after the study is over. If you do not have time for this in your life right now, it may be better to wait to sign up, as completing the programme will take some commitment on your part. If you really want to give it a try, we believe that I-PDT can help you to feel better by giving you tools that can help you now and in the future.

### ***What does my participation in this study involve?***

Each of the chapters of the I-PDT programme will be available on a weekly basis and you will have access to chat with your therapeutic support worker every week for the duration of the treatment. They will contact you at the beginning of the treatment to arrange a regular time that works for you both.

You will be asked to fill in some questionnaires about yourself and how you're feeling before starting treatment, and there are also a smaller number of questionnaires that you'll be asked to fill in each week, so we can keep track of how you're doing. After completion of the treatment, you will be asked to fill in the questionnaires again, to help us to estimate the results of the treatment. These questionnaires will also be filled in 3 months after the end of treatment to evaluate any long-term improvement. As you can see, there are quite a lot of questionnaires to fill in, but most young people have told us that the questionnaires are quite interesting as they help you to reflect on yourself and how you're feeling. The information you provide will also help you to get the most from your online chat sessions with your therapeutic support worker.

There is no payment for taking part, however, the treatment itself is free of charge.

### ***Is it possible to keep my participation confidential?***

You will have to fill in a questionnaire about how you are feeling before the treatment begins, where you will provide your name and phone number before we conduct the interview. The document with this personal data will then be stored in a secure manner and be separated from the other information that you provide to us during the treatment by filling in the questionnaires.

During treatment your data will be kept confidential through automatically generated study codes that are given to each participant. The identification key that connects the participant's study code to the actual personal identifiable information (full name, mobile number, and email address) is stored in an encrypted USB that only the research team can access. All your personal information stays between you and the research team. Your information is confidential. That means we cannot share your information with anyone unauthorized. Although this study has received ethics approval from University College London, if any UCL students choose to participate in this study, this information will not be shared with the university and students' participation will not impact their studies in any way.

By law, there are certain exceptions where we need to contact a parent or carer. Read about it under "What happens if my depression becomes worse".

You will receive reminders from the online treatment if you need to log on and complete activities. These notifications will be sent by email or SMS to the address and number you provide us with. Therefore, it's important to make sure that no one else can access your emails or messages, otherwise they might be able to read these notifications.

### ***Do I need to tell my parents or carers?***

We recommend everyone to tell their guardians (usually parents), but as you are 16 or above, it is not a requirement to be able to be included in the study. What is said during the treatment will not reach your

parents, unless we are worried about your safety. (See the section below, 'What happens if my depression becomes worse?').

### ***Do I have to take part?***

It is up to you to decide whether or not to take part in the study. If you do decide to take part and the study is suitable for you, you will be asked to sign an online consent form that we will keep as a record. You will have an opportunity to ask any questions by email or during the phone interview. We want to make sure you understand what your participation involves. It is completely voluntary to participate and you can end your participation in the program and the study whenever you want. Although it is helpful for us to know why anyone decides to stop taking part in the study, you can do so without giving any reason.

You can also stop the treatment whenever you want. We hope of course that you can be part of the whole treatment, as continuing until the end is usually associated with a greater positive effect. If you decide to stop, you can let us know via the platform where you communicate with your therapeutic support worker. If you do not say anything, as part of the programme your therapeutic support worker will try to contact you and ask you to continue with the intervention.

### ***What happens if my depression becomes worse?***

There is no indication that taking part in I-PDT will make your depression worse, but for all kinds of reasons, this can sometimes happen. Your assigned therapeutic support worker will keep track of your well-being by looking at the questionnaires you fill in every week and paying attention to what you say in the chat sessions. If your depression becomes worse while you are part of the project, the clinical team will think about this with you, and if necessary, think together about what other kinds of support you may need to access. If we are concerned that your mood has worsened so much that it is a danger to your life or that of others, then we will need to think about how we can keep you safe. This may involve us sharing essential information with others, such as your parents or the safeguarding team at the Anna Freud Centre. To be able to participate it will be compulsory for participants under 18 to provide contact details to a legal guardian after they have provided informed electronic consent. Participants aged 18 will be advised, but not obliged to do the same. Our priority is always to keep you safe, but we also want to respect your confidentiality and work collaboratively with you.

### ***How will communication work and is it secure?***

We will send notifications and reminders to fill in questionnaires through text messages or email. Should there be any more sensitive information, such as feedback on your answers to the questionnaires and exercises, you will have to log into the platform to be able to read them. You may receive a message by email saying that you have a pending message in the platform, but not what the message says. You can use your regular email address to register and log into the platform.

Contact with the therapeutic support worker and those responsible for the study will take place via the I-PDT website and notifications will be sent by email or text message. You will be assigned a username that you will use for the treatment.

To ensure your participation in the study, and all correspondence, remains confidential, please use an email account and phone number that only you have access to. Please also be careful to log out of the platform if you are using a shared device.

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

We do not know of any risks that are specific to the Internet-based psychological treatment and the study has been approved by UCL ethics committee. Some may experience it as challenging and at first uncomfortable to reflect on one's mood and start exploring emotions which have previously been avoided. However, this usually leads to feeling better in the long run. Your therapeutic support worker will keep track of your progress. Should there be a deterioration in your mood, your therapeutic support worker and the clinical team in the study will think with you what other steps might need to be taken.

### ***What do you do with my data?***

Your information will not be used for commercial purposes. No unauthorized person will know that you have participated or be able to see your responses. All information – including your questionnaire responses and transcripts of your 'chat' with your therapeutic support worker - is stored securely and only in unidentifiable form using a study code, which you are assigned at the beginning of the project. The questionnaires will be analysed statistically using the participants' code and presented only as an average of all participants so that individuals' responses cannot be traced. The reason we ask you to fill in information about yourself and your mood is that we want to evaluate how effective the treatment is. In this way, we can further develop the treatment so that it can help more adolescents with depression.

The treatment includes contact with your therapeutic support worker via chat and messages. Quotes or sentences from chats and messages may be presented in research presentations and in scientific publications, and in the future we may want to go back and study what has happened in the chat sessions, to help us improve the way the treatment works. This will only be done with your consent. We always delete names and any other personal information that can be traced to an individual. No one will be able to see who wrote a message. The reason why we may come to analyse chats and messages are to describe to other researchers how the treatment is done and evaluate the effectiveness of text messages in the treatment.

If you have given consent, we will ask if we can interview you by telephone after you have been in the treatment. It is entirely voluntary, and you have the right to say no without it affecting your participation in the study in any way. This is to help us understand more about your experience of IPDT and your involvement in the study. Quotations from these interviews may be presented in research, but all personal information, such as names, will be changed so you cannot be identifiable.

### ***How long will the data be kept before being securely destroyed?***

We process personal data following the General Data Protection Regulation (GDPR). All data containing personal information (full name, address, mobile number), your responses to the questionnaires, and transcripts (written copies) of your weekly chat sessions will be kept in the iterapi platform, and in a password-protected file on the Anna Freud Centre server and will only be looked at by the research team. You can request that information about you be deleted and that the processing of your personal data is limited (applies to data that can link you to the study code) at any point during the intervention or after you have completed the treatment. At the end of the study, we will securely destroy all

identifiable information about you. However, anonymised data (i.e. data that does not include any identifiable information about you) is stored for ten years after the study has ended. During this time, anonymised copies of data that cannot be linked to you may be used by researchers in the future, who want to continue to understand the results of this project or develop future research studies. These future researchers will not know who you are or that you participated in the study.

### **What will happen to the results of the research project?**

The information you provide will be used to write a research paper which will be submitted for publication in an academic journal, your data will remain unidentifiable if this happens. We will also write a summary of what we found in the study and all participants will get a summary of the study results if they wish so. If you have any questions about the study, or if any questions arise after you have participated, you are welcome to contact us.

### **An Ethics Committee has checked the research project**

All research projects are looked at by an independent group of people, called a Research Ethics Committee, to protect your rights. This research has been reviewed and agreed by the UCL Research Ethics Committee (Project ID Number: 19095/001).

### **What happens if something goes wrong?**

If you wish to complain, or have any concerns about any aspect of the way that you have been approached or treated by members of staff, please contact Nick Midgley -the Principal Researcher on this project – at [Nick.Midgley@annafreud.org](mailto:Nick.Midgley@annafreud.org). If you then feel that your complaint has not been handled to your satisfaction, you can also contact the Chair of the UCL Research Ethics Committee at [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk).

### **What happens next?**

Please feel free to discuss the information above with others, if that would help you to decide whether to take part. You can keep this information sheet to look at whenever you need to. If you decide to take part, you will need to give consent (on the online form) before you can start filling in the introductory questionnaires. Once you have completed the questionnaires a member from the research team will contact you over email to arrange a time for the interview and then decide whether the treatment might be suitable for you. After this enrolment process has been finished you will be assigned a username and a participant code so you can register in the platform and begin the treatment.

### **Researcher contact details**

Professor Nick Midgley

Principal investigator

Tel.: +44 (0)20 7794 2313

Email: [Nick.Midgley@annafreud.org](mailto:Nick.Midgley@annafreud.org)

**Thank you for reading this information sheet and for considering taking part in this research project.**

# Privacy Notice

## Privacy Notice for D:OTS (Depression: Online Therapy Study)

### 1. Who we are:

The Anna Freud Centre, also known as the Anna Freud National Centre for Children and Families, is a registered mental health charity, and is the data Controller for this data processing. The D:OTS study aims to explore the feasibility of implementing an adapted version of internet-based psychodynamic therapy (I-PDT), as developed by Stockholm University, in a UK setting. The interventions is for adolescents (16 – 18) with mild to moderate depression. The study will use an English-language version of this I-PDT programme.

This notice informs you how we may use the personal data we collect young people who participate in this study and receive the online therapy for Depression. If you have any questions about the content of this notice you can contact us at:

- Nick Midgley: [nick.midgley@annafreud.org](mailto:nick.midgley@annafreud.org)
- [Write to us](#): Anna Freud National Centre for Children and Families, 4-8 Rodney Street, London N1 9JH.

Our Data Protection Officer is Susan Henry, [DPO@annafreud.org](mailto:DPO@annafreud.org) 020 7794 2313

We are working with an additional organisation: Linköping University, in Sweden. Linköping University is a data Processor for this project. They provide the Iterapi platform used to collect and manage your data.

We use the Iterapi platform to manage the participant screening process. After screening, if you don't go ahead with participation in the study, your information will be removed from the iterapi platform.

### **Purpose of the processing and the lawful basis for the processing**

We are collecting your personal data to enable us to conduct a research study, which evaluates online therapy for depression. This will help us to understand whether the therapy works to improve young people's symptoms of depression and help us to improve the therapy in the

future. We collect data about you at the start, to ensure that the therapy is appropriate for you. The information you provide during the study will be used to understand more about whether and how your depression symptoms change whilst you are receiving the online therapy.

We also ask you to provide the name and contact details of your parent/guardian, which we would use only in case of an emergency when we were unable to contact you directly or we had safeguarding concerns about you. This contact data will be held securely and will only be used to contact them if necessary. Their details will be securely disposed of at the end of the study. We use Art 6(1)(f), Legitimate Interest, to process this data and do not share their contact details outside of the Anna Freud Centre.

Our lawful bases for processing this data are specified in the General Data Protection Regulation:

Article 6(1)(f): Legitimate Interest. We collect your data to administrate the research study and we ensure our use does not infringe your rights and freedoms by only collecting the minimum required for the study.

Where we collect special category data, we rely on Article 9(2)(j) Research purposes and DPA 2018 condition Schedule 1(Part 1)(4).

## **2. How we get information**

We use information collected directly from you via the various questionnaires that you complete during screening and when participating in the online therapy. The second screening questionnaire is collected through a phone call with a member of the research team, and this data is processed using an online platform provided by a company called NView – we use this platform to assist our interpretation of the data, but all data stored on the platform is anonymous. You will be assigned a participant code, and your real name and details will not be entered into the NView platform. All of the other questionnaires are completed on the Itherapi platform, provided by Linköping University.

## **3. Who we share your data with**

The identifiable data we process is only shared with the data processor (the research team at Linköping University). This sharing is conducted with a contract in place governing they must manage your data, including keeping it secure.

Anonymised and aggregate data (data that does not identify you individually) may also be used by other researchers at the Anna Freud Centre, including students, for the purposes of continued research.

Otherwise we do not use third parties to process the data and we do not share it with third parties for other purposes, including direct marketing.



Generally, we will ask your permission before we share your data, but in some circumstances, we are legally obliged to share information, for example under a court order. Where we do share, we satisfy ourselves that we have a lawful basis on which to share the information and document our decision making.

#### **4. How long we retain your data**

Your data will be held securely until the end of the research study, December 2021, after which it will be anonymised and kept for up to 10 years for research purposes. Then we review it before secure disposal.

#### **5. Your data rights**

Under data protection law, you have rights we want to make you aware of. The rights available to you depend on our reason for processing your information and may only apply in certain circumstances. You can check the [Information Commissioners website](#) for more detail or contact the DPO.

- **Your right to be informed** – this notice informs you what data we collect and how we use it.
- **Your right of access** – You have the right to ask us for a copy of your personal information.
- **Your right to rectification** - You have the right to ask us to correct information which you think is inaccurate or incomplete.
- **Your right to erasure** - This is known as the ‘right to be forgotten’ and you have the right to ask us to erase your personal information in certain circumstances, such as where it is no longer required.
- **Your right to restriction of processing** - You have the right to ask us to limit the processing of your information in certain circumstances.
- **Your right to object to processing** - You have the right to request we stop processing some or all of your data.
- **Your right to data portability** - This only applies to information you have given us and where we rely upon your consent to process the data but we can provide a copy of your data if desired.

You are not required to pay a charge for exercising your rights. We generally have one month within which to respond to your request.

Please contact us at [DPO@annafreud.org](mailto:DPO@annafreud.org) if you wish to make a request with regard to any of your rights.

#### **6. Ethics Consent**

In addition to these data protection rights we also consider your ethical rights. This evaluation has been approved by the UCL Research Ethics Committee and as part of that approval process we are required to have your consent for your participation in this evaluation.

If you, at any time, want to withdraw from the evaluation we will respect that decision and cease to use your data. You can contact us using the contact details included at the top of this notice to make such a request. The only exception to this is where we have already included your data in our analysis – at this point your data would have been combined with all the other data, and it wouldn't be possible for us to remove yours from the analysis.

### **7. Making a complaint**

If you feel we may not be handling your data appropriately or if you have any queries or concerns about this you can contact us, [dpo@annafreud.org](mailto:dpo@annafreud.org)

You can also, at any time, make a complaint about our processing of your data to the Information Commissioner, <https://ico.org.uk/global/contact-us>

### **8. Obligation to provide data and automated decision making**

You can choose to participate in the study, in which case we do require your data. We do not use profiling or automated decision making when processing your data for any purpose.

This notice was last updated on 9/11/2020