One on One Interview and GDPR Clinic

Introduction

You are being invited to participate in a research study involving a number of one-on-one meetings. You've been invited because you are known to the research team or because you responded to an advertisement or have previously helped with this research. This information sheet will provide you with information to help you decide whether or not you wish to take part, before you sign our consent form. Please read carefully and discuss with others if you wish before making your decision. Even if you agree to take part, you will be free to withdraw at any time, even without stating a reason.

The study will involve two main parts, of which this information sheet describes the first part:
1. **One on One Interview/GDPR Clinic: This is to understand a little about your digital life and to help you to request copies of your own data using GDPR (1-2 hrs)**
2. One on One Explore your data session: Exploring your own data (1-2 hrs)

What is the purpose of this study?

My name is XXX, and I am XXXXX. For this study I want to meet individuals like you to understand how you use data in your everyday life, and to explore how your life could be improved with better access and better interfaces to your own data.

The first part of this study, the interview and clinic, has two main goals:
a) to discuss your digital life, the apps and digital services you use, the ways you use data, in order to select which companies to send GDPR requests to
b) to help and guide you the process of making a GDPR request with approximately three digital service providers of your choice.

What will I be asked to do?

You will be invited to meet me for a one-on-one interview and clinic session, where you will be asked about the different devices, applications, software platforms, services and the sorts of data that you use in your everyday life. You will be free to choose what information you share. You may be given cards to select different topics from, and you can choose the topics you are happy to talk about. As part of these discussions we will also be using sketching on a shared notepad to explore the topic, and you may be asked to write down or illustrate aspects of your answers. If you are, no drawing skill is required - think of spider diagrams, boxes, labels and arrows not works of art! This part will take no more than 40 minutes.

Having chosen some companies we want to target to we go into "clinic" mode where I will help you to request copies of your data, using your GDPR data access rights, from a small number of service providers that you use. This will take less one hour in total, but may involve meeting more than once, depending how service providers respond. The idea is that we will provide follow up support dealing with emails or contacts from the service provider. You will choose which services to approach and you will deal with the service provider directly, the research team will not receive or handle your personal data.

How much time will it take?

The interview and clinic should take no more than 2 hours, including any follow up support dealing with emails or contacts from the service provider. The total amount of your time taken across the entire study engagement will be less than 4 hours, spread over a two-month period. Times will be arranged at your convenience, to fit your availability. If you have busy periods, we can avoid them!

What are the benefits of taking part?

You will be helping with important research in the highly topical area of personal data access, which could identify ways in which digital service providers can give more power to users by giving them better abilities to interact with their data. Additionally, you will learn how to retrieve your own data using your GDPR rights, and you will get to explore what data is stored about you by some of the companies and organisations you use. We will aim for the sessions to be interesting, light-hearted and fun! Participants will be reimbursed for their time with Amazon gift vouchers worth £10 for each part of the study completed, so that is £20 if you take part in both parts of the study described here. Alternatives are available.

How will risks be minimised?

In this interview/clinic session, the research team will not be handling your personal data, so there are no risks associated with that. However, in the second part, you will receive personal data from companies, and therefore it is important that you are careful with any data you receive back. We will advise you on how best to do this, depending on the provider and the nature of the contact. As with the whole of this study, there are no physical risks, and we do not anticipate any emotional risks. You are free to refuse to answer any question or to ask us to stop a discussion or activity. In all cases you do not have to give a reason. The only other risks from participation would be the same as you would encounter in everyday life or being in a public place. We will try to make your participation stress-free and safe.

Will my taking part in this study be kept confidential?

Yes. All information that is collected about you during the course of this research, which might include our notes, things you write down or make during our meetings, and audio recordings of our interactions, will be kept strictly confidential. This data – only what you say, not the data you get back from companies – will only be shared with the minimal number of researchers in XXXXX required for the completion of the research. Any information or quotes that are published in our research output will be anonymised before sharing, so that you cannot be identified. All data will be kept on our secure servers at XXXXXXX. Metadata describing data from this research, including metadata about your personal data, will be made publicly available. You will not be identifiable through this metadata, and your data will only be shared with others where they agree to the conditions of this consent. For this purpose, your research metadata and will be stored for a minimum of 10 years from last request for access under public funding regulations.

What will happen to the results of the study?

The ideas, insights and designs arising from your participation will be used in academic papers and potential future software designs. Should you wish to learn more about any findings from the study has finished, you can contact us at any time.

Can I leave the study?

You are free to leave the study at any time, without giving a reason. If you do, we will ask you if you would like all your research data (recordings and transcripts of what you have said) to be deleted. We will follow your instruction and only use your research data if you do not instruct us to delete it.

Contacts for further information

If you have any questions, please contact XXXXX.