

## **NIHR PRU in Addictions PPIE Privacy Statement.**

### **Privacy Statement**

#### **Introduction**

We are the Policy Research Unit (PRU) in Addictions which is funded by the National Institute of Health and Care Research (NIHR). We conduct research into alcohol, illicit drugs, gambling, and nicotine and tobacco to help inform the Department of Health and Social Care's policies in these areas. This privacy notice is for people who wish to become involved in our Patient and Public Involvement and Engagement (PPIE) network hosted by King's College London. It tells you what we will do with your personal data.

We are committed to protecting and respecting your privacy. We will treat your data in accordance with the EU General Data Protection Regulation (GDPR) and Data Protection Act 2018.

When we collect or use your data, King's College London is the 'data controller' and the 'data processor'. This means that King's College London decides how and why your data is processed as well as being responsible for its safety.

We strongly recommend that you take some time to read this policy carefully to understand how we treat your personal data. Contact details for the data controller can be found at the bottom of this notice.

More information can be found on the King's College London Statement on Use of Personal Data in Research at: [King's College London Statement on Use of Personal Data in Research - King's College London \(kcl.ac.uk\)](https://www.kcl.ac.uk/nihr/pru/addictions/privacy-statement)

#### **What personal information do we collect?**

We collect information directly from you in two ways:

1. During sign up to the patient and public involvement and engagement network.
2. During your involvement with the patient and public involvement and engagement network (e.g. if any of your details change).

You have a choice about the data we collect. We will need to collect some information via an Expression of Interest form when you sign up to ensure your experiences are matched to the research we are conducting and to maintain principles of equality, diversity and inclusion. The information we collect is outlined below:

- Name (mandatory)
- Contact details – either email or telephone (mandatory)
- Age (mandatory)
- Gender (mandatory)
- Ethnicity (mandatory)
- Nearest town or city (optional)
- Country of residence (mandatory)
- Current or previous use of addictive products and/or engagement in addictive behaviours (mandatory)
- Whether you are a carer or family member to someone who is living with addiction (optional)
- Your interest in taking part in patient and public involvement and engagement activities (optional)
- Whether you are a member of the public with an interest in addiction research (optional)

We will also ask you to disclose information which might lead to a conflict of interest. For example, we will ask you to disclose if you are receiving project funding or support from an organisation which is funded by companies or lobbying groups connected to the alcohol, tobacco, gambling or pharmaceutical industry. Please contact us if you are unsure about this.

## **Networks and Devices**

We do not collect or store your internet address (IP address).

## **How do we use this information?**

### **Communication with you**

We can use the data you provide to help tailor patient and public involvement and engagement opportunities to your interests. We want to make sure we are offering opportunities to people who can make the biggest difference to research (especially people with lived/living experience).

We will also use your information to respond to you if you contact us. Communications will only relate to addiction research and activities conducted by the PRU in Addictions PPIE team. We will not share your data for marketing purposes.

### **Promote security**

Should you be offered payment for taking part in patient and public involvement and engagement activities, we use the information you have provided to verify your bank account

details. We also use it to promote safety and security by investigating suspicious activity or violations to our meeting guidelines in our terms of reference.

## **Improvement and development**

From time to time, we may conduct surveys or correspond with you to better understand how to improve the features of patient and public involvement and engagement. This is part of how we measure whether our work is having an impact.

## **Is my information confidential?**

We will securely store information from the Expression of Interest form on a SharePoint drive in a password protected file. Any information you volunteer to researchers will be treated as strictly confidential unless it violates our terms and conditions or safeguarding policies.

## **How is your information shared?**

We will not share your data with other organisations without your consent unless the law permits us to do so. We will share data only with our authorised data processors, who must act at all times on our instructions as the data controllers under the GDPR and Data Protection Act 2018. Before you submit any information, it will be made clear to you why we are asking for specific information, and it is up to you whether you provide it. We do not and will never sell any data.

Our data processes (organisations which help us store and use your data securely) are:

**REDCap™** : REDCap is a secure web platform for building and managing online databases and surveys. Databases are password protected and access is restricted to members of the patient and public engagement and involvement team and management team of the PRU. It is hosted on 3<sup>rd</sup> party servers which are located in Liverpool, United Kingdom. REDCap will never sell or distribute your data.

**MS Forms, OneDrive, and SharePoint:** These applications and storage platforms are part of Microsoft 365 package which allows teams to work together on shared files. All data is stored in the United Kingdom. Where possible, all files containing identifiable data will be password protected and only accessible to the immediate PPIE team and Management Team of the PRU. De-identified data (information about you which is not linked to your name or contact details) will be available to PRU researchers so they can search for people who may be suitable for their research projects.

We will need to share your name and bank account details with finance teams within King's College London where applicable so that you can be reimbursed for patient and public

involvement and engagement activities. Your bank details are kept separate from other information about you to help keep your information confidential.

## **How long do we retain your personal data?**

Your personal data will be held and processed as long as you remain active within the patient and public involvement and engagement network. If you choose to leave the network or are inactive for an extended period of time (over five years), your data will be deleted immediately from our SharePoint drives and files.

King's College London will hold this data for five years in the first instance unless you ask for your details to be removed. After this point, you may be contacted again by the patient and public involvement and engagement team at King's College London to ask for your consent to continue using this data for the same purposes.

## **How will we notify you of changes to this policy?**

We may amend this policy in the future to ensure it is kept up to date with legal requirements. We will notify you when we make any changes to this policy and invite you to review and consent before continuing to use the service.

## **How to contact us with questions or concerns**

If you have any additional questions regarding this policy, please feel free to contact us using the details below.

## **Your rights**

To exercise these rights, please contact us using the details at the end of this policy.

### **Right to be informed**

This policy and information given to you by the patient and public involvement and engagement team at King's College London covers both how and why your data will be used. The legal basis for processing your data is by explicit consent. We are not able to offer patient and public involvement and engagement opportunities without your agreement to us collecting, processing, and storing this data. If you have any additional questions, please contact us.

### **Right to access**

You have the right to request access to your personal data which we hold. You can request a full set of data by submitting an information request, free of charge, and expect an answer within a month's time. You cannot access somebody else's personal data.

### **Right to rectification**

If you believe that any other part of your personal data is inaccurate or incomplete, you have the right to ask for this to be corrected. You can expect a formal reply within a month.

### **Right to erasure (right to be forgotten)**

In some circumstances you may ask us to erase your account and data which the account contains. However, there are some situations whereby we would be unable to erase your data, such as when we need to comply with regulatory requirements.

### **Right to restriction of processing**

If certain conditions apply, you have the right to restrict the processing of your information. Which includes:

- If you contest it as being inaccurate
- When processing your data has been unlawful but you decide against erasing your data
- If we no longer need your data for the original purpose it was obtained, but you require us to hold it to establish, exercise or defend a legal claim.

In these cases, we will retain your data for a period of 5 years, but we will not use it.

### **Right of portability**

In certain circumstances you have the right to move, copy or transfer your personal data to another organisation. This works slightly differently from your right of access, but you are still entitled to the same amount of information under the right of portability as you would be entitled to under the right of access.

### **Right to object**

You have the right to object to us processing your data unless we can demonstrate legitimate grounds for processing your data or if the processing of your data is for the establishment or defence of a legal claim.

### **How do we respond to legal requests?**

We may be required under law to share your information if there is a legal request with which we must comply such as a search warrant or court order.

### **How to contact us with questions or concerns**

If you have any additional questions regarding this policy, would like to exercise one of your rights under GDPR, or need more information, please feel free to contact us at: [info-compliance@kcl.ac.uk](mailto:info-compliance@kcl.ac.uk)

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