

# Patient and Public involvement Forum

## Privacy Statement

This privacy statement is an adjunct to King's College London's general privacy statement, which can be found [here](#). In this privacy statement we will highlight how we are dealing specifically with data related to Patient and Public involvement (PPI) Forum activities.

### **Who we are**

We are the PPI Forum team part of the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation at King's College London. If you need to contact us about this privacy notice, please write to:

Cicely Saunders Institute  
PPI Forum team  
Bessemer Road  
London SE5 9PJ  
United Kingdom

**Email:** [support@csipublicinvolvement.co.uk](mailto:support@csipublicinvolvement.co.uk)

### **What is the legal/ lawful basis for processing your personal information?**

We can only process (collect, use, store etc) your personal information if one of the following applies:

- We process your data as described in this statement because we have a legitimate need to do so to deliver the PPI Forum services and research ambitions.
- We need your personal information to provide a service as part of a contract. Note that in English law 'contracts' are not limited to those in writing, so this justification may also cover less formal agreements between you and the university/ PPI Forum.
- We need your personal information to perform our official functions as a teaching and research institution, and those functions are in the public interest. Our official functions may derive from legislation or our Charter. This justification also covers situations where we need to share information with other organisations in order for them to carry out their official functions (for example, taxation, reporting crimes, preventive)

- We need your personal information for a legitimate interest of the university or a third party, provided that interest is not overridden by your interests and rights (for example, we may need to process your information to protect our network and information security). Note this justification cannot be used when we are carrying out our official functions.
- You provide consent for us to process your personal information, based on clear and specific information, with a genuine choice (without any pressure), and the ability to change your mind at any time.

### **How do we use your personal information?**

We will generally use your personal information to provide you with the services, products or information you have requested from us. We may need to share your information with our service providers for these purposes, but we will ensure that appropriate contracts with these parties are in place and they only process your information in accordance with our instructions and data protection legislation. If we need to transfer any information to a country not recognised as providing equivalent protection, we will use additional safeguards approved by UK or EU regulators.

To ensure we fully understand when it is appropriate to rely on consent and when it is a legitimate interest of ours to process your data we routinely carry out impact assessments to ensure the way in which we use your data is fair does not personally impact you

The data we collect may be used for research purposes. All our analyses are carried using anonymised datasets, which do not identify individuals and where identification is very unlikely to take place. We follow the UK Office for National Statistics recommendations related to analysing and reporting anonymised data.

This privacy statement tells you what to expect when we collect personal information related specifically to PPI Forum activities.

This privacy Statement applies to

- 1/ Information we collect when you use the PPI Forum website
- 2/ Information you give us when you sign up to the PPI Forum website
- 3/ Retention and security of your personal data
- 4/ Changes to the terms of this privacy statement
- 5/ Use of children's personal information
- 6/ Your information rights and responsibilities
- 7/ How can you contact us or make a complaint to the regulator?

## **1/ Information we collect when you use PPI Forum website**

We use reputable third party providers in order to be able to run and administer the PPI Forum website. This includes hosting providers, data storage providers and web analytics providers. All the research activities we undertake with your data are carried out in house.

### **Web statistics/ analytics for PPI Forum website use for research**

When someone visits the PPI Forum website, we use a reputable third party service to collect standard internet log information and details of visitor behaviour patterns. We do not use cookies for this and we do not attempt to track or correlate your use of other sites or vice-versa.

The data we collect includes IP address (which may imply geographical location), browser type, browser language, referral source, length of visit and number of page views. The data collected as part of our analytics never includes names, usernames, or email addresses. The data we collect may be used for research purposes. All our analyses are carried using anonymised datasets which do not identify individuals and where identification is very unlikely to take place. All the research activities we undertake with your data are carried out in house.

### **Use of cookies by PPI Forum website**

We do not set any cookies unless you log in to the website.

We use the cookie "MoodleSession" to record your status as logged in and this expires after two hours or when you close your browser. The cookie "MOODLEID\_" is used to remind you of your username on future visits and has a lifetime of six months.

### **Security and performance of PPI Forum website**

The PPI Forum website uses a reputable third party service to host and help maintain the security and performance of the website. The site is hosted on a server in the UK. To deliver this service it processes the IP addresses of visitors to the PPI Forum website.

By visiting our site, your IP address will be recorded by our servers and stored in log files. These log files are used for record keeping, tracking referring websites, inferring your general location, and for security purposes to avoid SPAM, abuse and DDOS attacks.

## **2/ Information you give us when you sign up to the PPI Forum website**

When you sign up to the PPI Forum website you provide us with data for the purpose of registering with us on the website and subscribing to our website services and email notifications. We collect first and last name, email address, username, city/ town, country, reasons for signing up, palliative care descriptor, previous PPI experience and specific interests

If you wish you can also provide us with the optional information: gender; age; ethnicity;

## **3/ Retention and security of your personal data**

We store data about you in line with King's College London retention and disposal schedule, which can be found [here](#). We do not aim to keep any data for longer than necessary.

All data you hold with us is backed up in separate physical premises with technical and organizational security measures. This is to ensure that your data is not lost or destroyed should the original be destroyed without your instructions.

## **4/ Changes to the terms of this privacy statement**

PPI Forum website privacy statement will be occasionally updated over time. If we believe that the updates are significant, we will notify you by posting the updates on the PPI Forum website or sending you an email, or both.

## **5/ Use of children's personal information**

We do not knowingly collect or store any personal information about children under the age of 16. If you are aged under 16 please get your parent or guardian's permission before you provide any personal information to us.

## **6/ Your information rights and responsibilities**

By law, you have certain rights over your personal information:

- To receive a copy of your information
- To ask us to correct any errors
- To delete it once we no longer need it

- To ask us to stop using your information in a certain way
- To ask for certain information in a portable, electronic format
- To object to certain uses of your information (for example, marketing and automatic profiling or decision making)

To make a request for any of the above, please see our [Data Subject Rights](#) page.

## **7/ How can you contact us or make a complaint to the regulator?**

To contact us about our privacy notice or information we hold about you, please write to [support@csipublicinvolvement.co.uk](mailto:support@csipublicinvolvement.co.uk)

You can also contact the university's Data Protection Officer, Albert Chan:

- by email – [info-compliance@kcl.ac.uk](mailto:info-compliance@kcl.ac.uk)
- or by post – Information Compliance team, King's College London, Room 5.20 JCMB, 57 Waterloo Road, London SE1 8WA

If you don't feel we have dealt with your request appropriately, you can complain to the Information Commissioner's Office.