

Medical Research Council Prion Unit at UCL

Institute of Prion Diseases

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We are writing to let you know that UCL and the Institute of Prion Diseases have recently updated their Privacy Notices in light of the General Data Protection Regulation (GDPR), which came into force on 25 May 2018.

Transparency is a key element of the GDPR and this update is to inform you:

- How and why we use your personal data for business continuity activities
- What your rights are under GDPR and
- How to contact us if you have questions or concerns about the use of your personal data

1. What type of data do we hold?

The Institute of Prion Diseases, Faculty of Brain Sciences, UCL holds and processes personal data such as your name, your work (and/or personal telephone number, if agreed), and your work address email address as part of its Business Continuity Plan (BCP). The legal basis of processing your personal data is "Public task". The Data Controller for the personal data we hold is UCL. This means UCL determines the purpose(s) and means of processing personal data.

2. Why are we collecting and processing your personal data?

We collect personal data for administrative and internal business purposes. We undertake biomedical and clinical research and in the event of a major incident our BCP will be activated. As such key individuals within and outside of UCL will be notified of a major incident affecting the Institute of Prion Diseases or action that requires their input. We only collect and process information that is essential for our BCP and recovery measures.

3. Who do we share your data with?

The privacy of your personal data is paramount and your personal data will not be disclosed unless there is a justified purpose for doing so as part of our BCP or recovery measures. Those who have access to your personal data include designated staff at the Institute of Prion Diseases including the Business Continuity Co-ordinator, Head of IT, Unit Administrator and staff on the Institute of Prion Diseases Crisis Management Team.

Names and telephone numbers are also registered with BulkSMS, a trusted SMS service provider. BulkSMS will only be used to send a bulk text message(s) if a major incident has occurred that the Institute of Prion Diseases needs to inform key individuals about. BulkSMS undertake systems back-ups in their head office in South Africa and have a server located in Ireland and an office in the UK, which further supports the provision of their SMS messaging services. Your personal data will not be disclosed by BulkSMS to any 3rd party without written permission - unless BulkSMS is compelled to do so by a court of law. The BulkSMS privacy policy can be accessed on the following link: <https://www.bulkSMS.com/company/data-protection-and-privacy-policy.htm> Access to the BulkSMS account is restricted to the Unit Administrator, Head of IT and the Business Continuity Co-ordinator. If you would like your name and telephone removed from BulkSMS please contact GDPR@prion.ucl.ac.uk. Personal data is never sold to third parties.

4. How will my personal data be stored and secured?

The Institute of Prion Diseases takes a robust approach to protecting the information it holds with dedicated and locked storage areas, secure network servers and encrypted devices. UCL also has in place information security policies and procedures to ensure personal data is kept safe and secure and accessed only by authorised users in order to perform their duties. Your name and telephone number are also held securely by BulkSMS.

5. How long will my personal data be retained for?

Your personal data will not be kept for longer than is necessary. The length of time for which we keep your personal data will depend on a number of factors including how long you are involved in the Institute of Prion Diseases' BCP, and UCL's Records Retention Policy and Schedule, which states how long certain documents should be retained for.

6. Your rights under the GDPR

One of the aims of the GDPR is to empower individuals and give them control over their personal data. The GDPR gives you the following rights:

- The right to be **informed**
- The right of **access**
- The right to **rectification**
- The right to **erase**
- The right to **restrict** processing
- The right to **data portability**
- The right to **object**
- Rights in relation to **automated decision making and profiling**

7. Updating or withdrawing the processing of your personal data

If you (i) no longer wish for the Institute of Prion Diseases to use your data (ii) would like your personal data removed from BulkSMS or (iii) would like to update your contact details, please contact GDPR@prion.ucl.ac.uk

8. Who to contact if you have any questions or concerns

If you have any questions or concerns about your personal data you can contact the UCL Data Protection Officer at l.shailer@ucl.ac.uk or data-protection@ucl.ac.uk Tel: 0207 679 8726. You can also contact the MRC Prion Unit at UCL, Institute of Prion Diseases: GDPR@prion.ucl.ac.uk

The Information Commissioner is the regulator for GDPR and you have the right to raise concerns with the Commissioner. The Information Commissioner's Office (ICO) has a website with information and guidance:

<https://ico.org.uk/for-the-public/>