

Privacy Notice - Patient & Public Contributors

(Adapted from Privacy Notice for Research participants by kind permission from Research Governance Office)

Your expectations of us under this notice:

We will ensure that personal data held about you is processed in accordance with data protection law. The law requires that any information held is accurate and has been processed fairly and lawfully. Where it is necessary to collect sensitive information about you - we will only share this information with colleagues who have a legitimate reason for the details.

You also have the right to access any personal information we hold about you, and to correct it if necessary.

Our expectations of you under this policy:

Please help us to ensure that your personal information is up to date, by letting us know of any changes.

The University of Manchester conducts Patient and Public Involvement and Engagement (PPIE) to the highest possible standards to maximise benefit to our research, teaching and wider contribution to society.

Your privacy is very important to us. We follow the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018 (DPA). This document sets out how we will collect, store, process and protect your personal data.

What is personal data?

‘Personal data’ means any information which can identify you. We promise to respect the confidentiality and sensitivity of the personal information that you provide to us. We will tell you how we will use your information, how we will keep it safe and who it

will be shared with. We commit to keeping your personal information secure and will not use it to contact you for any other purpose unless you have agreed to this.

Information about you

It can include information such as your name, gender, date of birth, address/postcode or other information such as your opinions or thoughts. It can also include information which makes it possible to identify you, even if your name has been removed (such as quotes or social media postings).

We will only ever collect information that is appropriate and necessary. Sometimes we are required to collect information to report to research or education funding bodies on whether we are using their funding effectively. Generally, these reports will not contain personal information but will provide statistics. Depending on your volunteer role, we may also need to collect, store and use personal data on:

1. Personal contact details: name, addresses, telephone numbers and email, emergency contact
2. National Insurance number and bank account details where required for payment of fees and expenses
3. Recruitment information (relevant experience and where required, information regarding Disclosure and Barring Service enquiry)

We will only keep your personal information for as long as necessary. However, some personal information (including signed records of consent, where required) will be kept for a minimum of 5 years as required by external funders or our policies and procedures.

Your involvement may also include speaking to our students as part of the teaching programme. With your consent, the session may be recorded as a 'podcast' for students to view online. You

are under no obligation to be recorded and can refuse consent without providing a reason.

The Legal Part

Data protection law requires us to have a valid legal reason to process and use personal data about you, known as a 'legal basis'. GDPR requires us to be explicit with you about the legal basis upon which we rely in order to process information about you. Most commonly, we will use your personal information in the following circumstances where it is:

1. Necessary for the performance of tasks that we carry out in the public interest (e.g. teaching and research)
2. Necessary for the pursuit of the legitimate interests of the University (i.e. PPIE)

We may also use your personal information in the following situation, which is likely to be rare:

3. Where we need to protect your vital interests (or someone else's interests)

If we require your consent for any additional uses of your personal information, including your image and more sensitive personal information (e.g. 'Special Category Data' we will obtain it (see below).

What is 'Special Category Data?'

In rare cases, we may collect some information about you that is considered to be 'sensitive' and this is called 'special category' personal data. This includes, but is not limited to, information such as your ethnicity, sexual orientation, gender identity, religious beliefs, details about your health or past criminal convictions. These types of personal information require additional special safeguards, particularly in relation to sharing, which the University ensures are in place. Your consent will be obtained before we collect any such information.

Special safeguards include policies, training, security standards, confidentiality clauses with third parties, ethics committees (where appropriate) and data protection impact assessments.

Sharing your information

Your personal information will be kept confidential at all times. The University as Data Controller, we will always remain responsible for keeping your information safe throughout. We would not share information with other people or organisations about you or pass on your contact details without your permission.

Your rights

By law you have rights in relation to the personal information we hold about you. These include the right to:

- See the information/receive a copy;
- Correct and inaccurate information;
- Have any information deleted;
- Limit or raise concerns to our processing of the information;
- Move your information ('portability');

The above would be granted unless it is legally prohibited and/or would put you or another person at serious risk of harm.

For questions please contact:

Alex Daybank
The Data Protection Officer
Information Governance Office,
Christie Building
University of Manchester, Oxford Rd
Manchester, M13 9PL
Tel: 0161 275 7789
dataprotection@manchester.ac.uk

[University's Data Protection
webpages](#)

If you are not happy with the way your information is being handled, you have the right to lodge a complaint with the Information Commissioner's Office:

Information Commissioner Office
Wycliffe House
Wilmslow
SK9 5AF

<https://ico.org.uk>