

MASTERPLANS Data Protection Privacy Notice for Patient Collaborators

You are a MASTERPLANS patient collaborator as soon as you have returned the MASTERPLANS Confidentiality Undertaking to the Project Manager. The purpose of this document is to describe the personal data we hold about you in your role of patient collaborator, why we hold it, what we do with it, how long we will keep it and what your rights are. The controller for your personal information is the University of Manchester.

When changes are made to this privacy notice, we will email you.

Your personal data – what we hold and why we need it

The University of Manchester will record and process the following information about you:

1. The MASTERPLANS project management team will keep your name, address, email and phone number secure and will use it for contacting you in your role as a MASTERPLANS patient collaborator.
2. Your name and email address, may be shared with MASTERPLANS collaborators in the UK, Europe and worldwide as necessary for MASTERPLANS research and your role as a patient collaborator. A list of MASTERPLANS collaborators is available at: www.lupusmasterplans.org/aboutus.html.
3. We will use and keep on record information for administering your attendance at any MASTERPLANS project meetings, including dietary and any additional requirements you may have. We may need to pass these details on to the venue, or other attendees (e.g. presenters) to ensure your needs are catered for.
4. The University of Manchester will process and store information for authorising and paying fees and expenses to you.
5. The University of Manchester may provide details of your fees and expenses to the Medical Research Council (the MASTERPLANS funding body) for administering our funding.
6. The MASTERPLANS project management team will retain a copy of your Confidentiality Undertaking, as this is the agreement between us regarding confidentiality of project information;
7. Subject to your specific agreement on each occasion, we may use your photo and information that you have provided to us on the MASTERPLANS website, MASTERPLANS Facebook or Twitter pages. Our normal practice is not to include your name, though on the rare occasion that we might wish to do so, we will agree this with you as well. We will always check with you whether you are happy for your photo and other information to appear on these media.

Your information will only be used for the above purposes. Your personal information will be maintained in accordance with the UK Data Protection Act and other applicable laws, and the

University of Manchester's policies on handling and storage of personal data. All University staff undergo compulsory training and periodic refreshers on Data Protection.

We are required to tell you the legal basis for processing your personal information. Our normal legal basis for processing your data is that we believe it is in our legitimate interests to do so, in order for MASTERPLANS to run effectively and efficiently. The legal basis for using your information on the MASTERPLANS website, MASTERPLANS Facebook or Twitter pages is consent.

We will not share your personal information unless it is completely necessary to do so for the purposes above, or you have given your consent.

How long we will keep your personal data

We will keep your data for the length of time described in the University of Manchester Records Retention Schedule, a copy of which can be obtained at <http://documents.manchester.ac.uk/DocuInfo.aspx?DocID=6514> or by googling 'university of Manchester data retention policy' or by contacting the MASTERPLANS Project Manager. The length of time varies according to the type of information held. Your Confidentiality Undertaking and email address will be kept for ten years from the date of agreement.

What are your rights?

If at any point you believe that the information we hold on you is incorrect, you can request to see this information and have it corrected and where feasible, deleted (there are some documents such as your Confidentiality Undertaking and fees and expenses that cannot be deleted within the retention period).

Because we need your specific agreement to include your photo and information on the MASTERPLANS website, Facebook or Twitter, you can withdraw your consent at any time and we will remove your information.

If you wish, you can raise a complaint on how we have handled your personal data, by contacting the MASTERPLANS Project Manager or the Principal Investigator. If s/he is unable to address your concerns, or you wish to make a formal complaint, you can contact the University of Manchester's Data Protection Officer. You also have a right to lodge a complaint to the Information Commissioner's Office, if you feel that your information has been processed illegally or insecurely.

See overleaf for key contacts.

Key contacts

MASTERPLANS Project Manager: <name, email, phone>

MASTERPLANS Principal Investigator: <name, email, phone>

University of Manchester Data Protection Officer: <name, email, phone>

The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow SK9 5AF, tel. 0303 123 1113 (<https://ico.org.uk/concerns>).