



STERLING Patient Reply Slip Privacy Notice

This Patient Invitation letter has been created by the STERLING-PMR team at the Clinical Trials Research Unit, University of Leeds.

What data about me is the STERLING-PMR Reply Slip collecting?

We (the STERLING-PMR team at the University of Leeds) are leading this study, called STERLING-PMR. This is an ethically approved research study being carried out in the public interest. If you are interested in taking part in this research, we would like to collect your name, address, contact telephone number(s), email address (if you use one), your contact preferences and your GP's name and address. This is so that you can be contacted to discuss the study further. We will only collect data that we need for STERLING-PMR. We will only use it for this research and not for any other purpose.

Collection of this data has been approved by the Research Ethics committee, Health Research Authority.

Who is responsible for your data?

The University of Leeds is responsible for what data is collected, what it is used for and making sure it is used correctly and legally. This means they are called the "data controller".

Who is my data shared with?

Several NHS hospitals around the UK are participating in this research. We will ask someone from the STERLING-PMR team at one these hospitals to contact you to discuss the study further. To do this, we will need to share your information securely with them. A full list of the hospitals taking part in the STERLING study can be found on our website (<https://ctr.u.leeds.ac.uk/sterling-pmr-uk/>).

Will my data be kept securely?

The data we collect will be stored securely at the hospital and at the Clinical Trials Research Unit, University of Leeds (CTRU). Only the teams responsible for running the study at the hospital and at CTRU will have access to this data. If you tell us at any point before joining the study that you no longer want to be contacted about it, both CTRU and the hospital will securely destroy your data. After 6 months, if the hospital team have not been able to reach you, we will assume you are no longer interested in the study and your data will be securely destroyed at both CTRU and the hospital. If you agree to take part in the research, we will keep your information for longer. You will get more information about this later with the rest of the information about the research.

CTRU and the hospital will securely destroy your personal information once it is no longer needed for the study. It will also be destroyed by the hospital team at that point if they have been unable to reach you or if you have confirmed you are no longer interested in taking part in the study. If you do agree to take part in the research, we will keep your information for

longer. You will get more information about this later with the rest of the information about the research.

What are my rights once this data has been collected?

Once you have sent us your data you have rights about the way we handle it. You can ask us to amend or update it, change how it is used or even delete it. Making these changes might mean that you would no longer be able to join the study. If you would like to talk to us about any of these, please contact us using the following details:

Tel: 0113 343 4781 or 0113 343 0281

Email: sterling-pmr-ukpatients@leeds.ac.uk

Who do I contact with questions or complaints about my personal data?

If you have any questions about how your data is used, or would like to report a problem, please contact the University of Leeds Data Protection Officer:

Email: DPO@leeds.ac.uk

General Postal Address: University of Leeds, Leeds LS2 9JT, UK

Postal address for data protection issues: University of Leeds, Room 11.72 EC Stoner Building, Leeds, LS2 9JT

Telephone number: +44 (0) 113 343 7641

For more about how data is used at the Leeds Institute of Clinical Trials Research and who to contact if you are having any difficulties, go to <https://ctrul.leeds.ac.uk/privacy/>.