

Writing to patients from rheumatology

Participant information - Patient survey

➤ **About the research**

This study is about the letters rheumatology healthcare professionals write after an outpatient appointment. These are called clinic letters. National guidance advises healthcare professionals to write clinic letters directly to patients, but not everyone does. Instead, some healthcare professionals write these letters to their patients' GPs. A copy may also be sent to the patients.

We are carrying out this survey as part of a wider project. Our aim is to develop a set of resources to encourage and support rheumatology healthcare professionals to write directly to patients. To help us do this, we need to know more about people's experiences of receiving clinic letters (or not), and their views on these letters and who they are written to.

➤ **Who can take part?**

We want to hear from people who:

- Are currently a patient of an NHS / HSC rheumatology outpatient department in the UK
- Are aged 18+, and
- Have attended two or more NHS / HSC rheumatology outpatient clinic appointments in the UK

➤ **What information will you collect about me?**

We want to find out who has answered the survey and see what things are similar or different for various groups of people. As such, we will request some information about you, such as your age (in age groups) and ethnicity. These questions are optional - you can select 'prefer not to say'.

If you would like to be sent information about the results of this survey or be sent information about other related research, you can provide your name and contact details. This information will be collected through a separate survey and will only be used for the purpose(s) you agree to. We will not be able to connect your name to the responses you provide in the main survey.

All data will be stored on The University of Manchester's secure server. The University of Manchester is responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used.

➤ **Will the outcomes of the research and/or the collected data be shared?**

We will write up the findings for publication and present the findings at seminars, conferences and events. Summaries of key study outputs, including the findings, will be shared online via the study website: <https://bit.ly/W2P>. Links to and/or copies of these summaries can be shared directly with you if you agree to this.

The fully anonymised dataset, collected for this study, may be used to support other, future healthcare research carried out at The University of Manchester, in accordance with the UK Policy Framework for Health and Social Care Research (<https://bit.ly/HSCRframework>). It may also be made available to researchers at other institutions through the British Society for Rheumatology research registers. Researchers who want to access and use the fully anonymised dataset will need to apply to the British Society for Rheumatology Registers & Research Committee, providing information on the questions their research is designed to answer and explaining what they will do

to answer those questions. If the application is approved, the fully anonymised dataset will be shared using secure research drives. You will be asked to provide your consent for this as and when you agree to take part in the study.

➤ **Who can I contact if I have questions?**

If you have any questions or queries about the study, then please contact a member of the research team. You can also contact us if you have any worries, concerns or complaints.

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