Writing to patients from rheumatology

Brief participant information leaflet - Patients - Workshops

This study is about the letters rheumatology healthcare professionals (HCPs) write after an outpatient appointment. These are called clinic letters. They include a summary of the outpatient appointment. Clinic letters are different from appointment letters and results letters.

We have studied peoples' experiences of writing and receiving clinic letters and their views on who these letters are written to. We now want to run workshops with rheumatology patients and healthcare professionals. Our aim is to develop a set of resources to encourage and support rheumatology healthcare professionals to write directly to patients.

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish. Please ask if anything is not clear or if you would like more information. Thank you for taking the time to read this.

ABOUT THE RESEARCH

National guidance advises healthcare professionals to write clinic letters directly to patients, but not everyone does. Instead, some healthcare professionals write clinic letters to their patients' GPs. A copy may also be sent to the patients. We want to develop resources to encourage and support rheumatology healthcare professionals to write directly to patients. You can help us do this by joining our workshops and sharing your views on our study findings, what resources might be needed and draft versions. Resources could include, a best practice guide, example clinic letters and a glossary of terms with plain English explanations.

➢ Am I able to take part?

We want to hear from people who:

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

We would like to hear from a wide range of people. As such, everyone who expresses an interest in taking part will be asked to share some information about themselves.

The research is being carried out by a team from the Division of Musculoskeletal and Dermatological Sciences at The University of Manchester, led by Dr Charlotte Sharp and supported by Dr Rebecca Goulding. Our contact details are at the end of this leaflet.

Dr Charlotte Sharp

Dr Rebecca Goulding

- **What would I be asked to do if I took part?**

1) Contact us and/or visit the study website

If you are interested in taking part, the first step is to contact a member of the research team or visit the study website: https://bit.ly/W2Pworkshopspt We can discuss the study with you and answer any questions you may have. You can also complete the screening survey to help us select who to invite to take part.

2) Take part in one or more online workshops

If we invite you to take part, this will be in one or more online workshops. With your permission, these will be audio-recorded. We may also take notes. Each workshop will take between 60-120 minutes. We are planning four workshops in total, with both patients and HCPs. More information will be provided before each workshop. At the end of the first workshop you take part in, you will be asked to complete a short demographics form.

- **Will I be compensated for taking part?**

You will be offered a one-off gift voucher worth £15, plus an additional £5 per workshop to cover internet expenses.

- **What happens if I do not want to take part or if I change my mind?**

This study is voluntary and it is up to you to decide whether or not to take part. If you decide to take part, you can opt out at any time, up to two weeks after the final workshop.

- **Will the outcomes of the research be shared?**

We will write up the findings for publication and present the findings at seminars, conferences and events. Summaries of study outputs will be shared online via the study website, and can be shared directly with you.

This study has been reviewed and approved by the Health and Social Care (HSC) Research Ethics Committee B (Ref: 24/NI/0063, 07/05/24).

DATA PROTECTION AND CONFIDENTIALITY

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

In order to take part in this research project we will need to collect information that could identify you, called “personal identifiable information”. Specifically, we will need to collect:

- Your contact details, including your name, email address and/or telephone number
- Your written consent, or an audio-recording of your verbal consent
- An audio-recording of your voice during the workshop(s)

We will also request information about you, such as your age (in age groups) and ethnicity via the screening survey and demographics form. Questions will be multiple choice (tick box). Collecting this information will help us ensure we involve a range of different people in our study and help us understand how things may differ for different people.

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means we are 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. All researchers are trained with this in mind.

Further information is available in the full participant information sheet https://documents.manchester.ac.uk/display.aspx?DocID=75971.

CONTACT DETAILS AND COMPLAINTS

If you have any questions or queries about the study, or if you are interested in taking part 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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