PIFU (Patient-Initiated Follow-Up) Study

Chief investigator: Professor Gareth Jones

Participant Information Sheet (Patient)

Introduction:

You are being invited to complete a survey as part of the Patient-Initiated Follow-Up (PIFU) study. Before you decide whether you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and, if you wish, discuss it with others. You can ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

What is the purpose of the study?

Clinicians within the NHS Grampian Rheumatology service and researchers at the University of Aberdeen are working on a research study to understand patients' experiences of patient-initiated follow-up. PIFU is an approach that allows patients to initiate their own follow-up appointments, rather than having them scheduled automatically (e.g., annually). We would like to invite people who are on patient-initiated follow-up within NHS Grampian Rheumatology to complete a survey.

Why have I been invited to complete this questionnaire?

You have been invited because you are on patient-initiated follow-up within NHS Grampian Rheumatology. We are inviting approximately 3600 patients to take part in the study.

Do I have to complete the survey?

No. It is up to you to decide whether to take part. If you decide to take part, you are still free to withdraw at any time and without giving a reason by contacting the research team using

the details below. With your consent data you have already provided will still be retained. Deciding to withdraw at any time, or deciding not to take part, will not affect the care you receive.

What will taking part involve?

You are asked to complete a survey – either online or on paper. This will ask about your experience of patient-initiated follow-up with NHS Grampian Rheumatology. Even if you haven't accessed care through patient-initiated follow-up, we are still interested to know this. You will also be asked some questions about yourself and about your condition so that we can better understand the characteristics of patients and health outcomes in relation to experiences of patient-initiated follow-up.

There are two additional parts to the study:

1. You will be asked whether we can link your survey data to existing NHS health data. This will allow us to look at whether patient-initiated follow-up is related to different health outcomes. Even if you don't wish us to do this, we would still value your survey responses. The survey contains a tick box question where you can opt in to the data linkage (or not). Data will be linked by authorised personnel with the Grampian Data Safe Haven (DaSH).

2. We are looking for a small number of participants who would be willing to discuss their experiences and perspectives of patient-initiated follow-up within a focus group. Again, there is a question in the survey where you can opt in, if you're willing to do so. If so, the research team may email you further information about the focus groups and you can decide whether you definitely want to take part after you have read this extra information. If we have a lot of interest, we will not be able to invite everybody.

If you have been invited to complete the survey online, you can find the link to access it in your study invitation. If you would prefer to complete a paper copy of the survey, you can request this from the study team using the contact details at the end of this document. If you have been asked to complete a paper copy, please return this to the research team in the provided pre-paid envelope. If we don't hear from you, you may receive up to two reminders.

What are the possible disadvantages and risks of taking part?

There are no risks involved in completing this survey. Completing the survey will take approximately 30-45 minutes. No additional time is required if you opt in to the data linkage. Information about focus groups will be provided to interested participants in a separate Participant Information Sheet.

What are the possible benefits of taking part?

We do not anticipate that there will be any direct benefit to you if you decide to take part. However, we hope that the findings from this study will help us understand more about patient-initiated follow-up and whether there are key factors that help or hinder successful delivery of the service.

How will we use information about you?

Please see the included GDPR statement for information about how we will use information about you and for information on your choices about how your information is used.

What will happen to the results of the research study?

Results from the study will be used to shape the delivery of patient-initiated follow-up in the future. They will also be published in academic conferences and journals and in summary format on our website. Anonymised comments from participants may be used in these publications. When this happens, it will be impossible to identify individuals who participated. If you would like to receive them, we will send you a summary of our findings after the study has been completed. If you are interested to do so, you can also provide consent to be contacted about a workshop where we will share the findings of the study, and discuss implications of the research and recommendations for PIFU services. Depending on interest, we may not be able to invite everyone who is interested in this may be invited to participate.

Who is organising and funding the research?

The study is sponsored by the University of Aberdeen and is funded by the NHS Grampian Charity.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by South Central – Hampshire A Research Ethics Committee.

Who can I talk to about the study?

You can contact the researchers using the contact details at the end of this information.

What if there is a problem?

If you have a complaint or concern about any aspect of the research, in the first instance you should ask to speak to the study team who will their best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this by contacting the NHS Grampian Feedback Service:

NHS Grampian Feedback Service
Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Tel: 0345 337 6338
Email: gram.nhsgrampianfeedback@nhs.scot

Contact information:

For further information and to contact us, please use these details: pifu@abdn.ac.uk; 01224437863

If you would like to contact NHS Grampian Rheumatology to ask about patient-initiated follow-up, please email: gram.rheumadvice@nhs.scot