

Health in the West Midlands (The Hill Study) Participant Information Sheet

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IRAS No: 233714 Sponsor code: RG-0255-17

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

It is important that we ask people about their health to make sure that we are providing the right types of services. With improvements in health care, people are living longer with long-term health conditions (such as osteoarthritis, asthma and angina). There is a need to provide better ways to improve quality of life and reduce the effect of long term health conditions on the growing number of people with them. There is also a need to prevent these conditions, and build more public health activities into the healthcare system. In this research we are trying to find out about the impact of health conditions and their symptoms on daily life and identify factors that can be either prevented or managed by health care to improve quality of life for the population of the West Midlands.

Why have I been chosen?

A random sample of patients aged 35 years and over who are registered at this practice are being invited to take part. We are interested in your views about your health. If you could spare the time to fill in the enclosed questionnaire you would provide information that will be valuable for this study. We are interested in your responses **even if you have not had any health problems recently.**

Do I have to take part?

Whether or not you take part in this questionnaire is **voluntary**. If you decide to take part, you are free to withdraw at any time without giving a reason. A decision to withdraw, or a decision not to take part **will not affect your right to access health services at the practice or elsewhere.**

How long will it take?

It should take you approximately 15-20 minutes to complete the enclosed questionnaire on paper.

What are the possible benefits of taking part?

Although any direct benefit to you is unlikely, we hope this research will benefit everyone as we will learn about people's health and the ways in which it affects people's everyday activities. We hope this will allow better planning of health care services.

Will my taking part in this study be kept confidential?

The answers you give in the questionnaire will be dealt with in **strictest confidence**. Each person who responds to the questionnaire will be given a code number so the questionnaire will be stored without identifiable names and addresses. This means that the data are anonymous and on this basis may be used in other research studies in the future. Questionnaires will be stored without identifiable names and addresses for at least 5 years

in accordance with Keele Clinical Trials Unit (CTU) standard procedures. Beyond this date records will only be maintained if the study is still ongoing. The questionnaires will be stored in a secure lockable storage facility. Members of staff from regulatory departments may require access to your data to check that the research is being carried out to a high standard.

What will happen to the results of the research study?

At the end of the study we will publish the findings. In addition, the main findings from the study will be displayed on a poster in your GP practice in early 2019 and on the study website at keele.ac.uk/hillstudy. If you would like any other information then the research team will be happy to provide this. You will not be identified individually in any report or publication.

Who is funding and organising the research?

Arthritis Research UK are funding the research. It is organised by the Research Institute for Primary Care & Health Sciences and Keele CTU at Keele University.

Who has reviewed the study?

London Queens Square Research Ethics Committee has reviewed this study. The study has also been reviewed by scientific experts, who assessed it before awarding funding.

Giving us permission for medical record review

We would also like to look at your information on consultations, prescriptions and associated aspects in your medical record. We can do this by reviewing your medical records held by your GP, and we ask your permission to do this on the consent form. If you are happy for us to do this, please complete and sign the consent form on the last page of the questionnaire. When reviewing medical records, your name will not be used so you cannot be identified personally. All information will be held in the strictest confidence. We are still interested in your response to the questionnaire even if you do not wish us to review your medical records.

What will happen if I don't want to carry on with this study?

You can withdraw from the study by telephoning us on 01782 734721. You do not need to provide a reason. Withdrawing means that we would no longer contact you directly, but we would still keep and use the information you provided up to the point of your withdrawal, unless you expressly tell us not to. If you contact us to withdraw from the study, and you have consented to medical record review, we will check whether you also want us to stop reviewing your records.

Contact for further information

If you have any questions, or would like further information about this study, please contact The Hill Study Co-ordinator at Keele University on **01782 734721**.

If you have any questions or concerns about taking part in research you can also contact NHS England on: Tel: 0300 3112233, email: england.contactus@nhs.net or Keele University's Head of Research Integrity, on Tel: 01782 733371, email: research.governance@keele.ac.uk.

Thank you for taking the time to read this participant information sheet