



Would you be happy to be contacted about research?

PARTICIPANT INFORMATION LEAFLET

You are being invited to take part in a research study called The Who. Thank you for taking the time to read the following information. This leaflet explains why the research is being carried out, what is involved and how you can take part. You can also find this information on your general practice website.

What is the purpose of the research?

The purpose of this research is to find out whether people would be happy to be contacted by their general practice, about research that is of relevance to them, to improve care for patients in the NHS. With an increase in the use of technology, as a result of the COVID-19 pandemic, this research will also investigate if text messages (SMS) and online questionnaires can make it easier for patients to get involved in research.

The research team have worked with patients and the public to ensure that this research is acceptable and that the information being provided is understandable. Being involved in research can help to improve healthcare and patient choice.

Who is funding and organising the research?

This research is being organised and funded by Keele Clinical Trials Unit (CTU), Primary Care Centre Versus Arthritis, Keele University and the NIHR Clinical Research Network: West Midlands.

Why have I been asked to take part?

Several general practices across the West Midlands are taking part in this research. You have been invited to take part because you are 18 years of age or older and you have an active mobile phone number recorded on your general practice's clinical system.

What will I need to do if I take part?

If you are aged 18 years or over and your general practice have an active mobile number for you recorded on their clinical system, you may receive a text message (SMS) from them, inviting you to take part in The Who. The text message (SMS) contains a link, to a very brief online questionnaire, for completion by you. By completing the online questionnaire and submitting your response, you are providing us with your informed consent to participate.

As many people as possible are needed to complete the brief online questionnaire over the next 3 weeks, in order that we can collect the brief research data. The questionnaire will take less than 5 minutes of your time to complete.

It's up to you, whether you take part or not. If you do choose to take part and complete the online questionnaire, your responses will go straight to Keele University and will be managed in accordance with the Data Protection Act 2018. Data will be stored on Keele University storage services within the UK and protected by industry standard security tools. You can't be identified from your responses. Your responses will not be shared with your GP. You are also free to withdraw or amend your response at any time, without giving a reason.

What are the possible benefits of taking part?

Although there are no direct benefits from taking part, you will be helping us to understand the best ways to engage with patients in research. Some people find it rewarding to take part in health research.

What should I do if I do not want to take part?

If you do not wish to answer the research questions on the questionnaire, ignore the text message you receive, or exit the online questionnaire without completing it or submitting it. If you do complete the online questionnaire and then wish to amend your answers, please contact the research team on **Telephone:** 01782 732950 or **Email:** ctu.operations@keele.ac.uk.

If you choose not to take part, this will not affect your current or future health care you receive.

What are the risks of taking part?

There are no risks involved in taking part in this research.

Our commitment to protecting your information (data)

If you do decide to take part in this research, the information collected about you will be treated in strict confidence and in accordance with the Data Protection Act 2018.

You can find out more about how we use your information at:

<https://www.keele.ac.uk/informationgovernance/informationgovernanceforthepublic/>

What happens at the end of the research?

The results of this research will be shared at national and international conferences and within publications in academic journals which are read by a large number of health professionals. You will not be identified individually in any poster, report or publication.

Has the research been reviewed?

To protect your interests, all research in the NHS is looked at by an independent group of people, called a Research Ethics Committee who are part of the Health Research Authority (HRA). This research has been reviewed and given favourable opinion by the London - Surrey Research Ethics Committee 21/PR/1292.

What if I have a query?

If you have a concern about any aspect of this research, you can discuss this with the research team on, **Telephone:** 01782 732950 or **Email:** ctu.operations@keele.ac.uk

Alternatively, you can contact NHS England;

Telephone: 0300 311 2233 or **Email:** england.contactus@nhs.net