

*Making it easy
to take part in
research*

Reach West:

- is a list of people like you, who are interested in improving healthcare through research
- provides a safe and secure way for you to find out about NHS and University approved health research projects
- allows you to decide which research projects to take part in

Sign up today at www.reachwest.org.uk



Reach West at a glance....

We are inviting you to participate in a project called Reach West which aims to improve health and healthcare in the west. Reach West provides opportunities for patients and members of the public to take part in research projects relevant for them.

The concept of Reach West is a simple one and so we have designed this first page to provide you with all the core information you need to know. In the booklet is the more detailed information.

Reach West provides opportunities for individuals to take part in health research projects relevant for them. It is often difficult for researchers to find suitable people for research studies, even for common conditions. Reach West matches interested people to high quality NHS and University approved research projects that are likely to be relevant to them. It is hoped that this will improve patient care for all areas of disease.

In order to identify the projects that would be relevant, Reach West will ask you for permission to link together the information held in various NHS computer records. When an individual is identified as being suitable for a study, the Reach West team will contact them to ask if they would be interested in taking part. Only if an individual is interested in taking part in a study will their contact details be passed to the study researcher. Details of the research studies would be explained, and participation is completely voluntary, for any and all studies

You are under no obligation to join Reach West. If you would like to join, you will need to sign a consent form or you can also sign up to Reach West online at www.reachwest.org.uk. By signing up you are agreeing that Reach West staff may contact you to ask if you would like to take part in relevant research projects.

Before you decide whether to take part, please take some time to read the information below which explains why Reach West has been set up and what will be involved if you decide to join. Please feel free to contact us if there is anything that is not clear or if you would like more information.

What we do

Reach West aims to increase the number and range of people taking part in research to improve health and healthcare. Reach West is part of NIHR CLAHRC West which ensures collaboration between Universities and NHS organisations across the west.

Working together

Reach West is a list of people living in the west country who are interested in taking part in health research. There is evidence that people who take part in research projects do better than those who do not. We also know that many people would like to take part in research projects, but it is often difficult to find out what studies are available. Reach West will provide a safe and secure way for people interested in research to find out about NHS and University approved health research projects that are relevant to them. They will then be asked if they would like to take part in particular projects. You will be under no obligation to take part in the research – you will be able to make an informed choice to take part or not in each project you are invited to participate in.

So we can identify the relevant projects, we will ask for your permission to link together the information held in various NHS computer records. This will mean that:

1. Reach West will only invite you to take part in research projects that are relevant to you. Your identifiable information will only be used to decide whether to contact you. The research itself will not use identifiable information.

2. NHS- and University-approved researchers will be able to carry out research using health-related data from large numbers of people or patients. We will only use your data anonymously (you will not be identifiable).

Frequently asked questions

Who is being asked to join Reach West?

Anyone over the age of 18 years can join Reach West. You do not need to have a medical condition or specific medical diagnosis. Healthy people are important too.



Do I have to take part?

You do not have to join Reach West. This information sheet explains what Reach West is and its purpose. If you would like to join, you will need to sign a consent form to show your agreement or you can also sign up to Reach West online at www.reachwest.org.uk. By signing up you are agreeing that Reach West staff may contact you to ask if you would like to take part in relevant research project's, and that your anonymised data can be used in approved research projects. Each time you are invited to take part in a research study, you will be free to decline if you wish.

What information do we need from you?

NHS records routinely store information including contact details, hospital admissions, treatments and outpatient appointments. If you wish to join Reach West, you will be asked to provide your consent to link together your NHS records to provide anonymised data for researchers and to work out which research projects you are suitable for. We will store information about any health conditions and NHS treatments you have received. Access to your information will be strictly controlled and limited to Reach West staff. As part of Reach West, some of your information may be used in NHS

or University approved research. Strict NHS and University confidentiality rules apply to all data involved in Reach West.

What does “anonymised data” mean?

Anonymised data items have had identifiable details about you (such as name, address and date of birth) removed and replaced by a unique participant number. Researchers who work on anonymised data do not have access to any personal data. Identifiable information is kept in a secure password protected database, which is only accessible to authorised members of the Reach West team.

Keeping your information safe

Your participation in Reach West will remain completely confidential. All information and communication will be held securely at all times. It will be managed by Reach West staff who are strictly regulated.

How will Reach West work?

If you join Reach West, we will send you information about opportunities for you to take part in research projects. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. Research projects will first have to be approved by an ethics committee. Reach West staff will search through the database to find people with appropriate characteristics and then contact them with an information sheet about the research project. If you receive this invitation, you will be able to decide whether or not you are interested. If you are interested, the Reach West team will then allow the researcher to contact you directly to explain in more detail about the research. You can then decide whether or not to take part.



What sort of research would Reach West invite me to join?

There are many different types of health-related research. You may be approached to take part in studies of a specific medical condition that you have, or medication that you are taking, or in relation to public health issues such as healthy eating. For example, if you have diabetes or arthritis, you might be asked to take part in a study to find out whether a new service being set up in your local area might improve care and outcomes. You might be asked to take part in some studies as a 'healthy volunteer', possibly because of your age, or simply because you live near the site of the research. You may also be asked to take part in research studies asking for your opinions and views on healthcare issues.

Working together in the future

We will try not to contact you too often, probably about 3-4 times a year. If you feel you are being asked too often, we can reduce the frequency of contact in future. You are always free to say no to any invitation.

How will I be contacted?

You can choose to be contacted by email or letter. We will use your preferred option to contact you.

Who will be able to see my information?

Researchers wishing to work with Reach West will be required to provide evidence that the research has been approved by an NHS or University ethics committee.

All projects will be checked to ensure they meet with all regulations and that they aim to improve health and health services. Only research projects meeting these criteria will be allowed to use Reach West. It is expected that the vast majority of research projects will be funded by the NHS, University or government funding bodies. Commercial companies based in Universities or the private sector will have to provide evidence that they are fully compliant with all regulations and that they aim to improve health and

health services. We will make it clear to you who funds the research so you can decide whether to take part.

Looking into Reach West

This study has been reviewed and given a favorable opinion by the South Central – Oxford Research Ethics Committee.



Things to think about...

There are no obvious disadvantages or risks associated with joining Reach West. If you are contacted to take part in a study, all risks associated with that study will be clearly presented to you so that you can decide whether or not to take part. You can withdraw from a study or from Reach West at any time, without giving a reason.

Some people are concerned about the risks of being identified, or that their personal information might be lost or misused. Reach West is committed to ensuring your confidentiality in accordance with the Data Protection Act 1998 and works to the same standards of privacy as in your existing relationship with the NHS. Your information will be held securely at all times.

Taking part

If you would like to take part in Reach West, please complete the consent process online at www.reachwest.org.uk. If you would rather complete the paper consent, please complete **both** consent forms and send **one** back in the pre-paid envelope provided. Please keep the information sheet and second consent form for your future reference.

What if I have other concerns or want more information?

Thank you considering joining Reach West. If you need more information please contact the Reach West team using the contact details overleaf.

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