

Taking part in research

WHY READ THIS LEAFLET?

We support various types of research in the practice, and we would like you to be aware of this. This leaflet tells you about the kind of research that we support and what is involved when taking part. We hope it will help you to decide whether you might want to take part.

What is research?

Research is an important part of healthcare. It is used to learn more about illness: how to prevent it and how to treat it.

Research involves patients like you taking part in interviews, postal questionnaires or being invited to take part in a clinical trial.

The quality of research is carefully checked by the people who fund the research and Research Ethics Committees.

This means that independent groups review the research to make sure it is worthwhile and that procedures are in place to safeguard your interests and well being.

What types of studies do we conduct?

• Clinical trials

These compare two or more treatments. Treatments are only compared in these trials if there is genuine uncertainty about which one is the best. Treatments which are known to be unhelpful or unsafe would never be used in such studies. The treatment you receive is decided at random. This helps us to compare the treatments fairly.

• Surveys

These are large postal studies. Many questionnaires are sent out and the replies are studied to identify how illness develops and affects daily life. These may be conducted over a period of time. Follow-up questionnaires after the main survey are used to track the changes taking place over time.

We sometimes invite people who have replied to attend a clinic for a more detailed assessment.

• Interviews

You are interviewed about your condition and experiences. The recorded interviews are analysed to give an in-depth impression of your experiences and condition.

Some studies may provide no direct benefit to you. However, we are interested in learning from your experience of health care and your medical condition. We hope that the research will help other people with similar problems in the future.

When might I be invited?

You will be invited to take part if your GP or nurse (or other healthcare professional you are seeing) thinks you will be able to help us with the research.

You will be given an information leaflet. This will tell you about the research and what it means for you. It is then up to you to decide if you want to take part.

What happens if I am invited to take part?

- You will have the opportunity to consider the research information.
- You will be encouraged to ask questions and can expect your questions to be answered to your satisfaction.
- You will then be asked if you are completely happy to be involved and sign a form to confirm this.
- If you decide not to take part or withdraw, your normal treatment will not be affected.
- Your voluntary participation and clear understanding of what taking part involves is very important to us.

Remember:

- Your right to medical care will not be affected in any way if you do not wish to take part.
- Your involvement is entirely voluntary.
- You can change your mind even have agreed to take part.
- Confidentiality is paramount. Any information you provide is treated in the strictest confidence, all researchers are bound by a code of confidentiality and the information is kept securely.



Use of records for research

For some studies the researchers are interested in what is recorded in the medical records, for example, how many people have diabetes or arthritis and what treatment they receive.

For these studies only anonymised records are needed. This means that all identifying information about you such as name, address and postcode has been completely removed.

When this has been approved by a NHS Research Ethics committee we can then make the records available without your written permissions as they do not contain any information which could identify who you are.

For further information regarding medical records please see "Use of your medical records for research" leaflet

How do I opt out of research?

If you do not wish to take part in the kind of studies described above, please talk to the practice staff. We can record this information so that you are not included in future projects.

What are Primary Care Networks?

Primary Care Research Networks (PCRN) have been set up to support high quality research in primary care. The network has a large support team to make sure the research runs smoothly.

Your practice is a member of Primary Care Research West Midlands North (PCR WMN), a network of GP Practices, in Staffordshire, Shropshire and Wolverhampton.

This practice is working with the network to research how to improve the care given in the NHS

How do I learn about the results of research?

The results are fed back through poster displays that appear from time-to-time in waiting rooms and as newsletters to your practice.

The people of Staffordshire, Shropshire and Wolverhampton contribute through their participation in our research projects to many articles in scientific and medical journals.



Primary Care Research WMN is a partnership of the six PCTs in West Midlands North and acts as the primary care delivery arm of WMN CLRN

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Primary Care Research West Midlands North