Research at St George's

At St George's we want to ensure that our patients always have the best available treatments and access to the latest treatment therapies. St George's is one of the largest teaching hospitals in the UK and, as part of its work, is actively involved in medical research. During your hospital visit you may be approached with an invitation to take part in a research study. This leaflet offers more information on what research is and what will happen if you decide you would like to take part in a study.

What is research?

Research is searching for and gathering information to answer a particular question or problem. In medicine, research is used to:

- improve understanding of medical conditions
- reduce the number of people affected
- improve the treatment of illness and the quality of life of people affected by such illnesses
- develop new interventions and medicines.

Whether you say 'yes' or 'no' to taking part in a research study you will still receive the best available treatment. Saying 'no' will not affect your care in any way.

What if I would like to find out more about a particular study?

If you are interested in taking part in a research study and would like to know more, you will be given a patient information sheet to read. The purpose of the patient information sheet is to help you decide whether you would like to be involved in the research. It describes the study in further detail and tells you what you can expect if you take part. This may include information about the number and frequency of visits, as well as the potential risks and benefits. Please read the leaflet and ask about anything you do not understand. You may also wish to discuss the study with your family or GP before making a decision. We ask everyone to consider carefully the study requirements before agreeing to participate.

What are the benefits of taking part in research?

Depending on the particular study you are involved in, you may experience direct or indirect benefits. Some of the benefits of taking part in research include:

- access to the newest medicines and treatments
- access to health screening, additional tests and support for your condition
- satisfaction and pride – knowing you are helping others, influencing the future of medicine and improving the quality of research
- compensation for taking part (in some cases) – this will be detailed in the patient information sheet if it applies to you.

What are the risks?

All treatments and investigations that influence the body to produce a desired effect could also cause an undesirable effect (a side effect). Side effects of treatment may have been reported during previous research studies or by patients or healthcare professionals when the treatment was used routinely. Researchers will be aware of any reported side effects and these will have been described for you in the patient information sheet. Any side effects listed are only potential

side effects – they are listed only to make you aware of the possibility that you may experience them.

The research team will look after you. You will be carefully monitored throughout the study and asked about any changes (good or bad) that you experience.

I would like to take part. What next?

If you have expressed an interest in participating in research, the researcher will invite you back to answer any further questions you may have. You will be asked to sign an **informed consent form** to confirm in writing you have understood the information about the research and that you want to participate. You can withdraw your consent at any time, even if you have said 'yes' previously. The researcher will then ask you for some further details (sometimes called **screening questions**) to ensure you are eligible for participation in the study. If you cannot be included you will be told why.

If you are accepted onto the study, you will be given a **unique identification number** to be used in place of your name on all trial-related documents – this helps to protect your identity and ensures that your results are anonymous.

As a participant, we ask that you:

- attend all scheduled study visits and complete any requested paperwork
- tell the research team if you feel unwell, if your medical status changes or if any changes are made to the medication you are taking
- tell the team about any holidays you are taking to ensure that you have enough study medication (if relevant) to last you until your next visit. If you are travelling abroad you may require a letter to show at customs to avoid any potential problems.

What should I do if I have any concerns whilst participating in the research?

The patient information sheet will contain contact details for the research team, which you can use if you have any questions or concerns. You may also be given a **24-hour contact card**, which you should keep on you at all times. This will include important details about the study which could be vital in a medical emergency.

Can I still receive the treatment when the research study finishes?

This will depend on the study, and such details will be explained in the patient information sheet. Even if you have benefitted from the treatment, it may not be approved for use outside of the research study – there may not yet be sufficient proof of safety and further research studies may be needed. However, you will continue to be cared for at St George's with the best available approved treatment.

We are very grateful for your time and want to encourage you to keep asking about research.

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9am and 5pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk