

# Information about research





## **Welcome to Papworth Hospital – a focus on research**

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**As a specialist centre we pride ourselves on the quality of care that we provide for our patients. Knowledge in health care is continually changing and we cannot afford to stand still if we are to maintain and improve these standards.**

We therefore have a very active research programme at Papworth – evaluating new ways of diagnosing and treating disease and new methods of delivery and organisation of care.

This is why we ask all patients who come to Papworth to be aware of the research ethos of the hospital and to take some time to consider any requests to participate in our studies.

## How could I get involved in research at Papworth?

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- You may be asked to take part in one of our research studies, either while you are waiting to come into hospital, while you are in Papworth or after you have returned home. If so, you will be given detailed information about the study and time to decide whether or not to take part. There is no obligation to do so and your treatment will not be affected in any way if you say 'No' or if you say 'Yes' but change your mind at some later date and withdraw.
- We may need to access your medical records to carry out research. Before doing so, we would present a plan of investigation to the Research Ethics Committee for their approval so you can be assured that the research will be conducted to high standards, and that your personal details will be kept confidential.

## Why should I get involved in research?

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- The modern NHS aims to provide the best possible care for its patients and the only way to decide which methods of care are best, is through research.
- Clinical research is entirely dependent on the assistance offered by patients.
- The results of the research are not only used at Papworth. Because of the specialist nature of our work, the results of our research are often of national and international significance and are made freely available through conference presentations and publications in medical and nursing journals.
- Many patients are very pleased for the opportunity to give something back to the NHS.

## What could I be asked to do?

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- Most research studies are designed so that patients are asked to do only one or two things in addition to having their routine treatment.

For example we might ask you to fill out some questionnaires, provide a blood or tissue sample or have an additional test.

- If we ask you to return to Papworth for any additional research visits we will pay your travel expenses.
- If we need a sample of your blood or tissue for future research we will ask you to sign a separate form consenting to this. Any information about you will be held anonymously on a computer.

## How will I understand what the research is all about and what it might mean for me?

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- A member of the research team will explain the study and give you a leaflet containing further details. You will be asked to take time to discuss it with your family, friends and GP if you so wish. The leaflet will have details that enable you to contact the research team should you need further information or advice at any stage.
- When you return to hospital a member of the research team will be available to discuss the study further and answer any questions.
- If you are happy to participate you will be asked to sign a consent form. You can withdraw your consent at any time without giving a reason and this will not affect your treatment, either now or in the future.

## How will I know that the study is properly designed, is ethical and safe and will be properly managed?

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- The Papworth Research and Development Unit oversees the general management of all studies at Papworth Hospital. Early in 2002 the R&D Unit was subject to independent scrutiny as part of a Commission for Health Improvement (CHI) review of the entire hospital. In an unprecedented move CHI awarded the highest possible score to Research and Effectiveness at Papworth. You can find the report at <http://www.chi.nhs.uk>
- Studies at Papworth go through a process known as 'peer review'. This means that experts in their field scrutinise the proposed study to ensure that it is asking a worthwhile question and that the design of the study will produce an answer. We can therefore assure you that becoming a research participant is a worthwhile thing to do.
- No study can start until it is approved by a Research Ethics Committee. These Committees look at a study from the point of view of the patient; they ensure that the research is worthwhile and that patients are not being exposed to unnecessary inconvenience or risk. They will also approve the information being provided to patients about the study and ensure that time is taken over the important process of informed consent.
- The NHS Research Governance Framework specifies the standards by which research is conducted, including the monitoring of protocols and procedures to ensure that these are followed. Papworth is accountable directly to the Department of Health for compliance with these standards.

## How can I find out about the results of the research?

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- Generally, patients participating in major research studies will be informed about the results personally.
- All research participants are very welcome to contact the research team and request any published or other material that may interest them.
- Research participants will be welcome to attend future Research Open Days.
- Research results are posted on the Papworth Hospital website [www.papworth-hospital.org.uk](http://www.papworth-hospital.org.uk).

## Fine, but what has research ever done for me?

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- All doctors and clinical staff are obliged to base their decisions about the best care for their patients on their experience and on the latest evidence. This evidence comes from research done within Papworth and at other hospitals in the UK or throughout the world.
- Any new procedures or drugs at Papworth have to go through a process which includes an assessment of the evidence of their effectiveness.

So, even if you do not participate in a research study while you are at Papworth you cannot fail to benefit from the results of previous research!

## MORE INFORMATION ABOUT.....

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### RESEARCH ETHICS COMMITTEES

- All research conducted in the hospital is scrutinised by a Research Ethics Committee whose duty it is to protect the welfare of the patients being asked to take part.
- The network of UK Research Ethics Committees was set up by the Department of Health. Each Committee provides independent advice to participants, researchers, funders, sponsors, employers, care organisations and professionals on the extent to which proposals for research studies comply with recognised ethical standards.
- The purpose of a Research Ethics Committee is to protect the dignity, rights, safety and well-being of all actual or potential research participants. To do this the Committee must satisfy itself that the study is asking a worthwhile question, that it has been designed well enough to provide an answer and that patients are fully informed of any inconvenience, risks or benefits.
- Research Ethics Committees meet regularly and consist of people with relevant interests eg doctors, other health professionals, lawyers and interested members of the public.
- All Committees operate according to strict standards and principles laid down by the Central Office of Research Ethics Committees (website: [www.corec.org.uk](http://www.corec.org.uk) )



## DONATING TO PAPWORTH'S RESEARCH WORK

- Much of Papworth's Research and Development Programme would not be possible without the generosity of our supporters. Any donations that are made specifically for research are placed in a Research Fund.

- These Research Funds are administered by the Papworth Research and Development Planning Group, which meets monthly. Any substantial expenditure from these funds is also reviewed by the Trust Board of the hospital

- Allocation of support from these Research Funds is by open competition and involves submission of a research proposal for discussion by the Group. Some funds are used to 'pump prime' projects at an early stage. This step enables researchers to carry out a preliminary feasibility study before applying for larger funds from an external agency.

- If you would like to make a donation to research at the hospital, please make your cheque payable to "Papworth Hospital Charitable Funds" and send it to:

Corporate Affairs Department  
Papworth Hospital NHS Trust  
Papworth Everard  
Cambridge  
CB3 8RE  
Tel: 01480 364240

indicating you would like your donation to be used for research purposes

- If you wish, we can inform you exactly how your donation was used.

## Further sources of information

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### CLINICAL LIBRARY AT PAPWORTH

All staff at Papworth Hospital have access to a very specialised Clinical Library Service that helps them keep informed about the very latest research evidence.

The Clinical Library Service plays an important role in the research programme at Papworth. All staff can use the Library's resources and training programmes to help them with their research work.

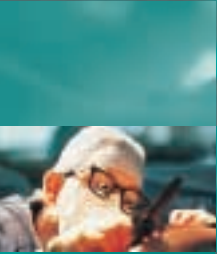
The Library provides a proactive awareness service by alerting staff to items of interest in the current literature. Details of research group interests are held and appropriate material is supplied.

Research information is also disseminated to staff via the Knowledge Zone and via the production of a quarterly newsletter. This is available on the hospital's intranet site and on the hospital's website ([www.papworth-hospital.org.uk](http://www.papworth-hospital.org.uk)).

A website we would recommend as a source of high quality health information is the National electronic Library for Health – [www.nelh.nhs.co.uk](http://www.nelh.nhs.co.uk).



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Produced by Infinite Design, July 2003