NIHR | Research Delivery Network

Content for GP Website

Research page

This document is intended as a guide only for you to use as you see fit. It contains general information and reassurance for your patients regarding research activities happening at your practice. We developed this tool to help you inform the content of a research tab on your practice website. Please, feel free to copy, adapt or leave content according to your local needs.

While using this material is not mandatory, if your practice receives Research Site Initiative (RSI) funding from the Regional Research Delivery Network (RRDN), we would like to bring your attention to Appendix 1 of the funding agreement. This appendix requires the practice to "undertake research promotion activities to the patient population". Displaying research-specific information on your website is one of the ways of fulfilling this requirement. You may find this guide useful in this context.

Taking part in Research

Cropredy Surgery is involved in medical research and from time to time you may be approached to take part. Taking part in research is voluntary: you can freely accept or decline, and this will not affect the care that you receive in any way. Even if you agree to take part, you can still withdraw at any time, without having to provide justification. Withdrawing from a study will **NOT** affect the care we provide for you.

All research projects carried out at Cropredy Surgery have been thoroughly checked and approved by the relevant health authorities & ethical committees ensuring it is appropriate and safe to perform. You will always receive clear information about what taking part in a research study would involve and will have the opportunity to ask questions and obtain further details about a study. All projects are fully compliant with all UK laws (incl. GDPR).

- You may receive a text message, NHS App notification, email or a letter in the post offering you the opportunity to take part in a study (the letter will include some information about the project).
- Your doctor or nurse may also discuss research opportunities during your usual appointment.
- You may also be approached by a member of the study team in the waiting area; be assured that this person and their activity will have been approved by the practice.

What you will be asked to do as part of the research will vary from study to study. The Patient Information Sheet for each project will detail what is expected of you. The study team is also there to answer all questions you may have.

Things you may want to know

- Participation in research is entirely voluntary and you have the right to say ‘No’. Nobody will put pressure on you to take part in research if you do not wish to. You do not have to give us a reason if you decide not to take part.
- Your care and your relationship with your doctor or nurse will not be affected in any way if you decide not to take part in a research study.
- You will always receive clear information about what taking part in a research study would involve. The practice will usually provide you with a patient information sheet; then, if you agree to take part, the study team will explain the study to you in more detail and you will have the opportunity to ask questions about it.
- Nobody from outside this practice will be given your contact details or have access to your medical records without your prior consent. If you do agree to take part in a study, you will be asked to sign a consent form – this will clearly state which parts of your notes (if any) may be looked at for the purposes of the research.
- You will not be asked to take part in a large number of studies. Most researchers are very specific about the criteria that people need to meet in order to enter their study. Usually this means that only a relatively small number of patients at the practice will be suitable for any one study.

Your data for research (GDPR guidelines and Anonymous data)

If you do agree to take part in a study, you will be asked to sign a consent form. This will clearly state which parts of your medical notes (if any) may be looked at for the purposes of the research study. Nobody from outside your practice organisation will be given your contact details or have access to your medical records without your prior consent.

This practice is also participating in 3 national database project(s) which collects anonymised electronic medical records from GP surgeries throughout the UK. Through the electronic clinical system, we use to record medical notes, a completely anonymous (i.e. no identifiable patient details are shared at all) extract is taken which is used for medical research. This clinical data is then catalogued and provides continuous monitoring of infection and disease around the UK.

What if I don’t want to get involved in research?

We recognise that some people may not want to receive information about research studies by post or text message. If you do not want to be contacted about research studies that we may run at the practice in the future, please let us know. If you change your mind at a later date, you can still opt back in at any time.

To opt out of participating in any research studies visit the NHS Your Data Matters website to set your preferences.

APPENDIX: Optional Additional information to include if required

Research in the NHS in collaboration with the National Institute for Health and Care Research

The NHS is committed to the innovation, and to the promotion, conduct and use of research to improve the current and future health and care of the population

Clinical Research is a major driver of innovation and central to NHS practice for maintaining and developing high standards of patient care. Participating in Clinical research allows patients to get access to new interventions, treatments and medicines. Ultimately, investment in research means better and more cost-effective care for patients.

The National Institute for Health and Care Research is the nation's largest funder of health and care research and provides the people, facilities and technology that enables research to thrive. Working in partnership with the NHS, universities, local government, other research funders, patients and the public, they deliver and enable world-class research that transforms people's lives, promotes economic growth and advances science.

Cropredy Surgery is part of a network of local practices participating in research activities under the banner of National Institute for Health and Care Research South Central Regional Research Delivery Network (NIHR SCRRDN). The SCRRDN is hosted by Southampton University Hospital NHS Foundation Trust and covers Buckinghamshire, Oxfordshire, West Berkshire, Frimley, Hampshire, and Isle of Wight

Click here to find out more about the work of the National Institute for Health and Care Research.

Support for Primary Care Research

The National Institute for Health Research works with researchers and primary care practitioners such as GPs, practice nurses, pharmacists and dentists to promote the successful delivery of research studies in the NHS. We support a wide range of research including studies which look at:

- Promoting a healthier lifestyle
- Disease diagnosis and prevention
- Management of long-term illnesses such as diabetes or hypertension
- Prevention of future ill-health
- Treating common conditions such as influenza

Following GDPR guidelines and ensuring your data is protected

Use of third-party document outsource processors (mailing companies)

Researchers regularly use document outsource processors such as Docmail to send study information to people who might be interested in taking part in clinical research. Only companies that are confirmed as being fully compliant with the laws surrounding data protection and data sharing, such as GDPR, are used. In addition to this, providers will be reviewed and permitted by the regulatory bodies that ethically approve, govern, and oversee clinical research taking place in the UK, such as the NHS Health Research Authority and Research Ethics Committees.

We would like to reassure you that, should you receive an invite to participate in a research study:

- The letter will have come directly from the practice. We do not share identifiable information with researchers without patient consent.
- It is our practice staff who perform research mailouts using the document outsource processor. Your contact details will not be shared outside of the system and will be deleted after 28 days.

Practice collaboration with research data registries

We are part of **Clinical Practice Research Datalink** which means that we contribute de-identified data to CPRD (Clinical Practice Research Datalink) for public health research. CPRD is a real-world research service supporting retrospective and prospective public health and clinical studies and is jointly sponsored by the Medicines and Healthcare products Regulatory Agency and the National Institute for Health Research (National Institute for Health and Care Research), as part of the Department of Health and Social Care.

Individual patients **cannot** be identified from this information, but you are able to opt out if you prefer. **Protecting the confidentiality of patient data is paramount, and only anonymised patient data is provided to researchers**

Royal College of General Practitioners

We are part of the **Royal College of General Practitioners (RCGP) Research Surveillance Centre (RSC)** which means that we contribute de-identified data to the RSC for public health research. The RSC is an active research and surveillance unit that collects and monitors data, in particular Influenza, from practices across England.

Individual patients **cannot** be identified from this information.

What are the benefits of your practice being active in research?

Evidence suggests that patients who receive care in research-active institutions have better health outcomes than those who are treated in a non-research environment.

By joining the research community, we are actively helping to improve the standard of healthcare for our patients.

Research provides an opportunity for you, the patient, to better understand your health conditions as well as give something back to the NHS and wider community.

Sometimes it can provide patients with access to new treatments, as well as bringing a new dimension to practice and added skills to those involved.

The practice will receive funding to cover any additional costs of taking part in research (it does not come out of our own budget and so routine patient services will not be affected).

PATIENT PERSPECTIVE: Is research right for me & what do patients taking part in research really think?

Ultimately, our research helps people to access and take part in studies which could potentially make a real difference to their health conditions and quality of life. Click on the links below to hear more from patients who have taken part in research.

Click on the links to find out more information:

Health talk: Patient and public involvement in research

NIHR – Participant in Research Experience Survey (PRES)

Here are a few quotes from patients who have taken part in research:

"I felt being part of the research helped my case, maybe got treatments that I would not have had otherwise"

"I do feel as though I'm contributing to the improved care for future generations"

"With the close monitoring / treatments from everyone, I now feel a lot healthier"

"The process has made me much more aware of my condition and that advice and care was immediately available"