Get involved - FAQs

- **Is it safe?**
  All our research is approved by the Health Research Authority and the NHS Research Ethics Committee. They look at everything that will take place in the study and how it will be done, with a focus on the interests of patients.

- **What do I need to do?**
  Involvement will be different for every study and could include:
  - Filling in a questionnaire
  - Being interviewed by a researcher
  - Take part in Talking Therapy
  - Giving a blood or saliva sample
  - Trying out a new piece of equipment
  - Taking a new medication
  - Sharing information from your medical record

  You'll get a chance to discuss this in detail with our researchers before you decide whether or not to take part. If you're not comfortable with it, you can choose not to take part.

- **What is informed consent?**
  A doctor, nurse or other researcher should get your permission (your 'informed consent') before entering you into a research study. They cannot enter you if you do not give your informed consent.

  However, there are a few exceptional circumstances when people might be entered into a study without their informed consent (for example, in a trial of the treatment of head injuries or dementia, when the individual may not be able to give consent). In these cases the permission may be given by a relative or other legal representative.

  If a study involves children, the process of getting informed consent is different and will be fully explained to you by our researchers.
  It is important that you are satisfied that you have enough information to make an informed decision and to give your informed consent.

- **What are the benefits of the study?**
  Researchers cannot guarantee that you will receive any benefit. They might believe that a new treatment they are testing will be better than the existing treatment, but they can only tell you that you may benefit.

  The biggest benefit of research is often not directly to you, but is the increase in knowledge which may help future patients. If you are currently receiving treatment it is likely that you are benefiting from research which has already been carried out with the help of patients in the past.

While you are on a study, your general health may be monitored closely by the researchers. You may find this extra monitoring reassuring.

- **Is it confidential?**
  All researchers must follow our confidentiality policy. They will not share any of your medical information outside of the study.

- **Can I refuse?**
  Taking part in research is always voluntary. You may be asked by the researcher why you don't want to take part in case there is something that can be changed or improved in the future, but you don't have to give a reason.

- **Can I change my mind once I am in a study?**
  You can leave a study at any time without giving a reason, even if you have already given your consent to be part of it. If you are part way through a study the researchers may want to see you one last time to give you a medical exam just for your safety.

- **Will my care be affected if I refuse or withdraw from the study?**
  No, your treatment will continue as normal if you decide not to take part in the research or if you withdraw.

- **Where will the study take place?**
  Due to the busy lives people lead, researchers will attempt to meet at a time and place convenient to you, where possible. However, at times this may be at your local clinic or hospital. All appointments will be made in advance giving you time to plan ahead.

- **Will I get paid to participate?**
  Some studies provide compensation for time and travel. Each study is different and the compensation offered will be included in the project information and discussed with you.

- **What if I have concerns about the study?**
  If you have any questions or concerns about the research, you should contact either the:
  - researcher;
  - principal investigator;
  - research team: email – epunft.research@nhs.net
  - PALs - 0800 0857935
    e-mail: epunft.pals@nhs.net