

Extra Information for Parents

The University of Bristol is the sponsor for this study and is based in the United Kingdom. We will be using information from your child's medical records as well some information about you (the parent/legal guardian) including you and your child's name, address and contact details in order to undertake this study.

The University of Bristol will act as the data controller for this study. This means that we are responsible for looking after you and your child's information and using it properly. The University of Bristol will keep identifiable information about your child for 5 years after the study has finished.

As a University we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

You and your child's rights to access change or move your child's information are limited, as we need to manage your child's information in specific ways for the research to be reliable and accurate. If you withdraw your child from the study, we will keep the information about him/her that we have already obtained. To safeguard your child's rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your child's information by contacting bee-study@bristol.ac.uk or data-protection@bristol.ac.uk.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer is Henry Stuart and you can contact them at data-protection@bristol.ac.uk.

Your GP will collect information from your child's medical records for this research in accordance with our instructions.

Your child's GP surgery will use your child's name, NHS number and your contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your child's care, and to oversee the quality of the study. Individuals from The University of Bristol and regulatory organisations may look at your child's medical and research records to check the accuracy of the research study. Your child's GP surgery will pass these details to The University of Bristol along with the information collected from your child's medical records together with your (the parents) contact details. The only people in The University of Bristol who will have access to information that identifies your child and you will be people who need to contact you (the parent) to complete the follow up, audit the data collection process and who do the analysis.

The University of Bristol will collect information about your child for the purpose of the BEE study from his/her medical records. This information will include your child's name, NHS number, Date of Birth, address and health information, which is regarded as a special category of information. We will use this information to contact you during the follow up stage of the study and for qualitative interviews.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](#)

Your information could be used for research in any aspect of health or care and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance. Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.