

Privacy Notice

Your Personal Data

Swansea Bay University Health Board (SBUHB) will be what's known as the 'Data Controller' of your personal data processed in relation to the Genital Oedema Education Needs of Health Professionals project. This privacy notice will explain how the research team will process your personal data.

Why we need it

We are collecting the minimum of personal data that enables us to conduct this project. For the survey we will only be collecting the country in which you live/work, whether you are a health professional or patient/carer/related industry worker and whether you are male/female or otherwise identified. We will not require your basic personal data such as your name, contact information, nationality, appointment. If you opt to participate in the focus group, then your name and contact details are also collected. This is collected in order for you to receive further information about the focus group, a consent form and receive details of how to join the focus group. We will only collect data that we need in order to provide and oversee this project.

Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is consent.

What we do with it and who we share it with

The survey data is anonymous and is initially held by Survey Monkey and is managed in a fully secure online environment (as per the Participant Information). Only the research team and anyone who has legal duty to oversee the governance of this study has access to that data. That data will then be held on SBUHB computers under the security requirements of NHS Wales. All the personal data you submit in relation to the focus group will be processed by the research team in SBUHB, Wales, UK.

How long do we keep it for?

Personal contact data for the focus group will be held only for as long as is needed to hold the focus group event, contact details will then be securely destroyed as per SBUHB procedure. The anonymous research data will be held for 5 years as is a requirement of the governance of the project.

What are your rights?*

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or erased. You may also have the right to object to the processing of data and the right to data portability.

Where we have relied upon your consent to process your data, you also have the right to withdraw your consent at any time.

If you wish to exercise any of these rights, please contact the Data Protection Office.

*Please note that the ability to exercise these rights will vary and depend on the legal basis on which the processing is being carried out.

Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the SBUHB Data Protection Officer who will investigate the matter.

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO), UK.

Swansea Bay University Health Board Research and Development

As a research active University Teaching Health Board, also act as a non-commercial Sponsor (Organisation responsible for the design, oversight and conduct) of Health care research for studies led by our local clinicians. We use personally-identifiable information to conduct research to improve health, care and services. As a publically 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. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

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. <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/> If you wish to find out more about how we manage your information or 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 can be contacted at ABM.DPO@wales.nhs.uk