

PATIENT INFORMATION SHEET

Last Updated: 25th July 2024

The British Society for Urogynaecology (“BSUG”) Database

The British Society of Urogynaecology (“BSUG”) is a national group of gynaecologists with a special interest and expertise in the treatment of incontinence and prolapse. We would like to seek your permission to include your personal data and important information about your operation in the audit database developed by BSUG and support the ongoing national audit. We have invited you to take part in our database as you are due to have, or have recently undergone a surgical procedure, and we believe that the information about this procedure could help us to improve patient care in the future. We are intending to involve as many individuals that have undergone surgical treatment for prolapse, incontinence and mesh procedures (all pelvic floor surgeries) in our database as possible.

Before you decide, it is important that you understand why this project is being undertaken and what it would involve for you. Please take time to read this information, and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask us.

What is the purpose of the Database?

BSUG has developed a database of clinical and surgical information which we hope will make future procedures as safe and effective as possible. Hospital Trusts and individual Consultants can use this information to look at their practice and make any necessary changes for the improvement of patient care.

Do I have to take part?

- No. Taking part is entirely voluntary.
- You can withdraw from the database at any point and you will not be required to give a reason for doing so. Your withdrawal will not affect your clinical care in any way.

What will happen to me if I decide to take part?

- You will not need to do anything from your end and will receive clinical care as usual.
- Your consultant and their team will include some of your personal information like date of birth, NHS number and hospital number, and clinical information about your condition and operation into the database.
- Your consultant team may also collect information about the outcome of your operation so that it is possible to look at success rates and potential complications associated with individual procedures.

Will my information within the Database be kept confidential?

- BSUG has made the necessary arrangements to ensure that all information collected is de-identified and kept safe and secure.
- No-one apart from your consultant and/or their team will have access to any identifying information about you.
- Patients will be identified within the database by episode number only, with all direct identifiers removed.
- Responsible members of The British Society for Urogynaecology and/or NHS Foundation Trust may also be given access to the data to assist them in maintaining the compliance with applicable statutory obligations and/or regulations.

How will BSUG use my data?

- We will only be using the information provided by your clinician (from your medical records) for clinical audit purposes.
- The British Society for Urogynaecology is the data controller which means that we are responsible for looking after your information and using it properly. When collecting your personal data, we will use the minimum amount of personally identifiable information possible.
- An online copy of the main database is also available to BSUG members on the public network (<https://www.bsug.net/>). However, this database is available for reporting purposes only, with all information being de-identified, and patient data remaining anonymous. Although this website is on a public network, the data is not available to the general public, and is only available to your consultant team and the BSUG administrator.
- Any personal data processed for audit purposes shall be retained for 5 years after the period of clinical audit (10 years) has been completed, or for 5 years after the expiration of your clinician's BSUG membership (whichever is earlier).
- Any personal data collected and processed within our database will be managed in line with the Records Management Code of Practice for Health and Social Care 2021 (Updated October 2023). More details of which can be found by visiting the link below:
<https://transform.england.nhs.uk/information-governance/guidance/records-management-code/>.
- You can find out more about how we use your information by contacting bsug@rcog.org.uk.
- All personal data is processed and stored within the UK and therefore, BSUG does not transfer personal data internationally.

What will happen to the data collected as part of the Database?

- The data collected will be used by BSUG members to audit their own practice, their centre's practice, and to compare it to national practice and outcomes. It will also be used by BSUG to produce national reports on a regular basis to audit national practice, and the outcomes of urogynaecological operations.
- There may be occasions where a BSUG member would like to use the database for research purposes. In such cases, the BSUG member will need to obtain permission from the BSUG Research Committee. If permission is granted, the data shall be provided to the researcher in an anonymous form, so that patients cannot be identified. The research being undertaken may also contribute to the fulfilment of an educational requirement (e.g. a doctoral thesis).
- Patients will not be identified from any report or publication placed in the public domain. This would also apply to any information used when presenting our findings at a conference for example.
- Special category data and any documents containing personal information, such as consent forms, will be stored securely by your consultant within the NHS Health and Social Care Network (HSCN), which is hosted by ISO 27001, ISO 9001 and Cyber Essentials certified suppliers.

What will happen if I no longer want to be part of the Database?

- Inclusion is voluntary and patients may change their minds at any stage.
- Withdrawal will not affect the care you receive from any relevant service (e.g. if you are a patient from the NHS).
- You can withdraw your consent at any time by contacting your consultant or BSUG directly at bsug@rcog.org.uk.
- If you withdraw from the database, we will destroy all your personally identifiable information, but may continue to use the anonymous data collected up to your withdrawal for analytical and statistical purposes.

What if there is a problem?

If you wish to complain, or have any concerns about how your personal data has been handled as part of this project, you should contact bsug@rcog.org.uk.

Who is organising and funding the project?

Our BSUG database is funded directly through our BSUG membership subscriptions.

Who has reviewed the project?

All medical research is looked at by an independent group of people, called a Research Ethics Committee, to protect patient's interests. However, as the main purpose of this project is clinical audit, ethics approval is not required. Although ethical approval is not applicable to this project, our database has been designed and developed to ensure that we align our processes to their guidelines and evidence-based recommendations.

Further information and contact details:

You can contact BSUG in relation to data protection and this information sheet by writing to:

The British Society for Urogynaecology
c/o Royal College of Obstetricians & Gynaecologists
10-18 Union Street
London
SE1 1SZ

Alternatively, you can email us at bsug@rcog.org.uk.

We have also appointed a Data protection Officer ("DPO"). Our DPO is Evalian Limited and can be contacted by using the above email or postal address.

Please send your communication clearly indicating 'FAO the 'Data Protection Officer', your message will be passed directly to Evalian Limited for attention.