

## Privacy Notice for Patients

### BSGE Endometriosis Database

Last Updated: 6 March 2020

#### Introduction

The British Society for Gynaecological Endoscopy (“BSGE”/“we”/“our”) is committed to protecting your privacy and meeting our legal obligations when;

- Agreeing to provide your medical information to the [BSGE Endometriosis Centre Database](#) (the “Database”),
- Agreeing to provide follow up medical information concerning your post-surgery experiences.

This privacy notice explains what personal data BSGE collects from individuals who agree to take part as a patient in the BSGE Endometriosis Database (“you”/“your”).

As an information led organisation, we place great importance in ensuring the quality, confidentiality, integrity and availability of the data we hold, and in meeting our data protection obligations where we process personal data. BSGE is committed to protecting the security of your personal data. We use a variety of technical and organisational measures to help protect your personal data from unauthorised access, use or disclosure.

We update this privacy notice from time to time in response to changes in applicable laws and regulations, to our processing practices and to products and services we offer. When changes are made, we will update the ‘Last Updated’ date at the top of this page. Please review this privacy notice periodically to check for updates.

#### Personal data we collect when you provide personal medical data to the BSGE Database

The BSGE exists to improve standards, promote training and encourage the exchange of information in minimal access surgery techniques. The BSGE Database provides a rich and valuable source of medical information to help improve the post-surgical outcomes for patients by enabling medical staff to access information, education and training as well as sharing knowledge and experiences with other Endometriosis centre members who provide minimally invasive surgery in gynaecology.

When you first agree to provide your medical data to the Database we may collect, store and use the following kinds of information: personal contact information (your name, email address, home address, signature, date of birth, NHS number, NHS hospital and consultant details) and personal medical information, including lifestyle questions (smoking, height, weight) and gynaecological information, including menstrual pain, bowel function, medical therapies, fertility data, pain medication, Endometriosis treatment history and general health). This information will be collected in consultation with specialist nurse and recorded on a pelvic pain questionnaire.

After the Endometriosis Centre staff have entered your data on the Database, you may agree to disclose further personal data relating to follow up consultations at 6, 12 and 24 months after surgery.

Only Endometriosis centres (lead and deputy consultants) will have access to your data. Other Database users will only be able to review aggregated patient data and training resources.

## Cookies & social media links

There are no cookies or social media links connected with Endometriosis Database.

## How we use your personal data when you provide your data to the Database

Personal information submitted to us will be used for the purposes specified in this policy. We may use your personal information to:

- a) Improve the administration of the Database,
- b) improve your user experience when adding or updating your medical records,
- c) send you general advice regarding better treatment of Endometriosis,
- d) send you email notifications which you have specifically requested,
- e) deal with enquiries and complaints made by or about the Database,
- f) verify and keep the Database secure and prevent fraud and ensure compliance with data protection regulations.

We will not provide your personal information to any third parties other than BSGE accredited Endometriosis Centres that support and use the Database.

## Basis for using your personal data

When we use your personal information we are required to have a lawful basis for doing so. There are various different legal bases upon which we may rely, depending on what personal information we process and why. The legal bases we may rely on include:

- consent: where you have given us clear consent for us to process your personal information for a specific purpose,
- legal obligation: where our use of your personal information is necessary for us to comply with the law (not including contractual obligations),
- vital interests: where our use of your personal information is necessary to protect you or someone else's life,
- public task: where our use of your personal information is necessary for us to perform a task in the public interest or for our official functions, and the task or function has a clear basis in law
- contract: where our use of your personal information is necessary for a contract (e.g. out of hours service agreement with a GP surgery) we have with you, or because you have asked us to take specific steps before entering into a contract,
- legitimate interests: where our use of your personal information is necessary for our legitimate interests or the legitimate interests of a third party (unless there is a good reason to protect your personal information, which overrides our legitimate interests).

For further details on when we collect personal information, what we collect as well as how we use it, please read the following sections.

| When information is collected   | What information we ask for   | How and why we use your information   |
|---|---|---|
| When your Endometriosis centre consultant shares your completed Pelvic Pain Questionnaire with us and at 6, 12 and 24 | Personal contact information (your name, email address, home address, signature, date of birth, NHS number, NHS hospital and consultant). | We ask for this information in order to populate the database with enough information with which to create a valuable resource of information about successful treatments and post-surgery data.<br><br>We rely on your consent as the lawful basis for collecting and using your personal information to |

| When information is collected  | What information we ask for   | How and why we use your information  |
|--------------------------------|---|--|
| month follow up consultations. | Personal medical information, including lifestyle questions (smoking, height, weight) and gynaecological information, including menstrual pain, bowel function, medical therapies, fertility data, pain medication, Endometriosis treatment history and general health. | <p>identify areas for developing better surgical techniques.</p> <p>For future patient advisory services we rely upon consent from patients to be contacted by email in the future to complete follow up questionnaires.</p> <p>For archiving purposes in the public interest or scientific purposes [Article 9(2)(j)] if it could be shown that the data informs the medical profession of good practice, leading to improved medical interventions we rely upon your consent to retain you medical records to the database in aggregated form.</p> |

## Sharing your data

We do not and will not share your personal information with any third parties other than BSGE accredited Endometriosis Centres that support and use the Database. There are no centres outside the UK.

It is possible that we may be required to share your data to comply with applicable laws or with valid legal processes, such as in response to a court order or with government or law enforcement agencies.

## Security of your information

We will take reasonable technical and organisational precautions to prevent the loss, misuse or alteration of your personal information. We will store all the personal information you provide on our secure (password and firewall protected) servers.

While we use SSL encryption to protect data in transit, transmission of information over the internet is inherently insecure, and we cannot guarantee the security of data sent over the internet.

Access to the Database by Endometriosis Centre staff is strictly controlled using two factor authentication. Only your consultant and a deputy (if any) are authorised with your consent to access your personal medical records.

## How long we keep your data

We will retain your personal data for as long as it necessary for the purpose of our relationship or until you withdraw your consent.

## Your Rights

Individuals whose personal data we hold, and process have the following rights:

- You have the right of access to your personal data and can request copies of it and information about our processing of it.
- If the personal data we hold about you is incorrect or incomplete, you can ask us to rectify or add to it.

- Where we are using your personal data with your consent, you can withdraw your consent at any time.
- Where we are using your personal because it is in our legitimate interests to do so, you can object to us using it this way.
- In some circumstances, you can restrict our processing of your data, request a machine-readable copy of your personal data to transfer to another service provider and compel us to erase your personal data

If you wish to exercise your rights, please contact us at [bsge@rcog.org.uk](mailto:bsge@rcog.org.uk).

You will not have to pay a fee to access your personal data (or to exercise any of the other rights). However, we may charge a reasonable fee if your request for access is clearly unfounded or excessive. Alternatively, we may refuse to comply with the request in such circumstances.

In addition to the above, please note that you have the right to make a complaint at any time to the [Information Commissioner's Office](#) if you are concerned about the way in which we are handling your personal data.

## How to contact us

You can contact BSGE in relation to data protection and this privacy notice by writing to:

Vice President,  
BSGE,  
10-18 Union Street,  
London  
SE1 1SZ

Alternatively, you can email us at [bsge@rcog.org.uk](mailto:bsge@rcog.org.uk).