

The Princess Grace Hospital

part of **HCA**Healthcare UK

PATIENT CONSENT TO ENTER DATA IN THE BRITISH SOCIETY OF UROGYNAECOLOGY DATABASE

Dear patient,

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. BSUG has developed a database of clinical and surgical data for the purposes of publishing *anonymous* statistical information for research purposes and to enable individual NHS Trusts and consultants to audit information about operations to ensure that the procedures performed at their hospitals are as safe and effective as possible.

Before reading on, please indicate that you have read and understood the patient information sheet relating to the BSUG database by ticking this box:

The patient information held in the BSUG database comprises name, hospital number and date of birth, together with clinical and surgical information (“**Patient Identifiable Data**”). Because this information is confidential to each patient and is that patient’s personal data within the meaning of the Data Protection Act 1998, we do not disclose Patient Identifiable Data to BSUG without written consent.

If you agree to allow us to enter your Patient Identifiable Data into the BSUG database, please sign at the end of this document. This will signify your consent to the following:

Consent

I consent to the disclosure of my Patient Identifiable Data to BSUG Database Limited (“BSUGDL”) on the condition that BSUGDL undertakes not to use or disclosure my Patient Identifiable Data except in accordance with the next section.

Consents to BSUGDL

I consent to:

- 1. the processing of my Patient Identifiable Data for the research and auditing purposes described in this letter.**
- 2. the disclosure by BSUGDL of my Patient Identifiable Data to its IT Service Provider or any future IT Service Provider, where such IT Service Provider has:**
 - (a) agreed to adopt appropriate technical and organisation measures to protect the security of my Patient Identifiable Data and only to process it in accordance with BSUGDL’s instructions;**

- (b) been instructed NOT to store my Patient Identifiable Data on a server which is located outside of the United Kingdom; and
 - (c) been informed of the existence of my legal right to confidence in respect of my Patient Identifiable Data.
3. the disclosure of my Patient Identifiable Data to the consultant team (and the NHS Trust employing that consultant team) who disclosed it to BSUG.
 4. the disclosure of my Patient Identifiable Data to BSUG or any legal entity which is wholly owned by BSUG, for processing in accordance with the consents in this section.

Please note that you can request access to view your entry on the BSUG database from your consultant team and can request that this is deleted at any time by sending a written notice to your consultant OR to the following address:

BSUG Database Limited
 c/o BSUG, Royal College of Obstetricians & Gynaecologists
 27 Sussex Place
 Regents Park
 London
 NW1 4RG

Signed... ..	Date...../...../.....
Print Name.....	
Name of person obtaining consent:	

If you would like to keep a copy of this form, please ask the person who has asked you to complete it to provide you with a copy

Please affix patient ID sticker here

Initial number

ICIQ-UI Short Form

CONFIDENTIAL

DAY MONTH YEAR

Today's date

Many people leak urine some of the time. We are trying to find out how many people leak urine, and how much this bothers them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

1 Please write in your date of birth:

DAY MONTH YEAR

2 Are you (tick one):

Female Male

3 How often do you leak urine? (Tick one box)

- never 0
- about once a week or less often 1
- two or three times a week 2
- about once a day 3
- several times a day 4
- all the time 5

4 We would like to know how much urine you think leaks.

How much urine do you usually leak (whether you wear protection or not)?
(Tick one box)

- none 0
- a small amount 2
- a moderate amount 4
- a large amount 6

5 Overall, how much does leaking urine interfere with your everyday life?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

ICIQ score: sum scores 3+4+5

6 When does urine leak? (Please tick all that apply to you)

- never – urine does not leak
- leaks before you can get to the toilet
- leaks when you cough or sneeze
- leaks when you are asleep
- leaks when you are physically active/exercising
- leaks when you have finished urinating and are dressed
- leaks for no obvious reason
- leaks all the time

Thank you very much for answering these questions.

ICIQ-VS 10/05

Initial number

CONFIDENTIAL

VAGINAL SYMPTOMS QUESTIONNAIRE

Many people experience vaginal symptoms some of the time. We are trying to find out how many people experience vaginal symptoms, and how much they bother them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

Please write in today's date:

<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
DAY	MONTH	YEAR

Please write in your date of birth:

<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
DAY	MONTH	YEAR

Vaginal symptoms

1a. Are you aware of dragging pain in your lower abdomen?

- | | | |
|------------------|----------------------|---|
| never | <input type="text"/> | 0 |
| occasionally | <input type="text"/> | 1 |
| sometimes | <input type="text"/> | 2 |
| most of the time | <input type="text"/> | 3 |
| all of the time | <input type="text"/> | 4 |

1b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

2a. Are you aware of soreness in your vagina?

- | | | |
|------------------|----------------------|---|
| never | <input type="text"/> | 0 |
| occasionally | <input type="text"/> | 1 |
| sometimes | <input type="text"/> | 2 |
| most of the time | <input type="text"/> | 3 |
| all of the time | <input type="text"/> | 4 |

2b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

Pre-operative

3a. Do you feel that you have reduced sensation or feeling in or around your vagina?

not at all 0
a little 1
somewhat 2
a lot 3

3b. How much does this bother you?
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all a great deal

Prolapse is a common condition affecting the normal support of the pelvic organs, which results in descent or 'dropping down' of the vaginal walls and/or the pelvic organs themselves. This can include the bladder, the bowel and the womb. Symptoms are usually worse on standing up and straining (e.g. lifting, coughing or exercising) and usually better when lying down and relaxing.

Prolapse may cause a variety of problems. We are trying to find out how many people experience prolapse, and how much this bothers them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

4a. Do you feel that your vagina is too loose or lax?

not at all 0
a little 1
somewhat 2
a lot 3

4b. How much does this bother you?
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all a great deal

5a. Are you aware of a lump or bulge coming down in your vagina?

never 0
occasionally 1
sometimes 2
most of the time 3
all of the time 4

5b. How much does this bother you?
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all a great deal

6a. Do you feel a lump or bulge come out of your vagina, so that you can feel it on the outside or see it on the outside?

- never 0
- occasionally 1
- sometimes 2
- most of the time 3
- all of the time 4

6b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

7a. Do you feel that your vagina is too dry?

- never 0
- occasionally 1
- sometimes 2
- most of the time 3
- all of the time 4

7b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

8a. Do you have to insert a finger into your vagina to help empty your bowels?

- never 0
- occasionally 1
- sometimes 2
- most of the time 3
- all of the time 4

8b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

9a. Do you feel that your vagina is too tight?

-
- never
- occasionally
- sometimes
- most of the time
- all of the time

9b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

Sexual matters

We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

10. Do you have a sex life at present?

- yes 1
no, because of my vaginal symptoms 0
no, because of other reasons 2

If NO, please go to question 14

11a. Do worries about your vagina interfere with your sex life?

- not at all 0
a little 1
somewhat 2
a lot 3

11b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

12a. Do you feel that your relationship with your partner is affected by vaginal symptoms?

- not at all 0
a little 1
somewhat 2
a lot 3

12b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

13. How much do you feel that your sex life has been spoiled by vaginal symptoms?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

Quality of life

We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

14. Overall, how much do vaginal symptoms interfere with your everyday life?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

Thank you very much for answering these questions.

VAGINAL SYMPTOMS QUESTIONNAIRE

SCORING

(This section is for administrative use only)

Patient number

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NOT FOR PATIENT USE

Vaginal symptoms score

Vaginal symptom score = 2×(dragging pain) + 2×(soreness in vagina) + (reduced sensation) + 2×(vagina too loose) + 2×(lump felt inside) + 2×(lump seen outside) + 2×(vagina too dry) + (faecal evacuation)

symptom*	score	weighted score
Q1. 'dragging pain'		x 2 =
Q2. 'soreness in vagina'		x 2 =
Q3. 'reduced sensation'		x 1 =
Q4. 'vagina too loose'		x 2 =
Q5. 'lump felt inside'		x 2 =
Q6. 'lump seen outside'		x 2 =
Q7. 'vagina too dry'		x 2 =
Q8. 'faecal evacuation'		x 1 =
Total vaginal symptoms score		

*(Note: Q9, 'vagina too tight', is primarily for detecting a potential post-treatment complication and is therefore not included in the scoring)

Sexual matters score

Sexual matters score = (sex-life spoilt) + 8×(worries about vagina interfere with sex-life) + 8×(relationship affected)

sexual matter	score	weighted score
Q11. 'worries about vagina interfere with sex-life'		x 8 =
Q12. 'relationship affected'		x 8 =
Q13. 'sex life spoilt'		x 1 =
Total sexual matters score		

Quality of life score

quality of life	score
Q14. 'quality of life affected'	