

## **Breast Cancer Surgery Priority Setting Partnership - FAQs:**

### **What is a PSP?**

Priority Setting Partnerships focus on a particular condition or healthcare issue – in this case, surgery for breast cancer. PSPs are made up of organisations and people affected by the condition, their carers, and the healthcare professionals who treat them.

### **What does a PSP do?**

PSPs work to find and then prioritise unanswered questions about the condition that can be answered by research. These are decided by people living with the condition (in this case, having undergone surgery to treat or prevent breast cancer), together with the healthcare professionals working in this field. The PSP will first ask people to complete a survey, highlighting the questions that they would like to see answered by research.

These questions are then prioritised into a final list of Top 10 Priorities, which will be available to both researchers and research funders. This process is overseen by an organisation called the James Lind Alliance.

### **What is the James Lind Alliance?**

The [James Lind Alliance](#) (JLA) is a non-profit-making initiative that was set up in 2004. It brings patients, carers and healthcare professionals together to find and prioritise the unanswered questions about different health conditions. The [National Institute for Health Research](#) (NIHR) funds the JLA infrastructure, to oversee the processes for PSPs.

### **Who is involved in the Breast Cancer Surgery PSP?**

The [Association for Breast Surgery](#) is funding the PSP. The PSP is guided and overseen by a Steering Group, which includes people who have had surgery for breast cancer, healthcare professionals, ABS staff and the James Lind Alliance. The breast cancer research and care charity [Breast Cancer Now](#) is also represented on the Steering Group. You can find more information about the Steering Group members [here](#)

### **What does the Breast Cancer Surgery PSP cover?**

Breast cancer remains one of the most common cancers in the UK. Everyone diagnosed with breast cancer will see a surgeon at some stage in their treatment journey, and breast cancer surgeons are responsible for much more than carrying out operations for women diagnosed with breast cancer, including

- Seeing people with breast symptoms in the out-patient clinic to make a diagnosis
- Looking after women who are at high risk of getting breast cancer. This may be because of a strong family history of breast cancer, for example.
- Working in a multidisciplinary team with other healthcare professionals to deliver a full range of breast cancer treatments – such as oncologists to deliver radiotherapy and chemotherapy, for example.

- Looking after people who have had previous breast cancer surgery, in order to reduce the risk of long-term problems or complications after surgery, and improving the quality of life for such patients.

The Breast Cancer Surgery PSP aims to identify unanswered questions which could be addressed by research in all of these areas.

### **What sort of areas are included in the PSP?**

The questions in the PSP survey cover three broad areas, and some examples of the sort of questions that you *might* think of are:

#### Question 1:

What questions for research do you have about the diagnosis and initial treatment of people with breast cancer, or the care of people at high risk of developing breast cancer?

Some examples might be:

- What are the best methods of counselling for people diagnosed with breast cancer?
- What is the best information to provide at the time of diagnosis?
- How can we best support people at the time of their breast cancer diagnosis?
- What is the best order of treatments for people diagnosed with breast cancer?

#### Question 2:

What questions for research do you have about the choice and timing of breast cancer surgery?

Some examples might be:

- What are the advantages and disadvantages of different types of operations for breast cancer?
- What is the best type of breast reconstruction to have?
- When should chemotherapy be given before breast cancer surgery?
- Should radiotherapy be given before breast cancer surgery?

#### Question 3:

What questions for research do you have about the experiences around breast cancer surgery?

Some examples might be:

- What are the best treatments for pain after breast cancer surgery?
- What are the best dressings to use after breast cancer surgery?
- What is the risk of complications after breast cancer surgery?

These are only examples of the sorts of questions that you might want to see answered. Please write in any question in each of these areas that you may have, whether or not you feel that someone else may ask them or whether they may have already been answered.

### **What happens after the survey?**

The Steering Group will look at all the questions that have been asked in the survey and will check that they fit with the aims of the PSP and that they have not already been answered by research. We will then bring a list of unanswered questions forward to be placed into an order of priority. If you want to be involved in doing this then please give us your contact detail in Section 3 of the Questionnaire.

### **Why are PSPs important and why is the Association of Breast Surgery investing in one?**

As the professional organisation representing breast surgeons and other professionals working in this area, it's important that we make sure that breast cancer surgical research aims to answer the questions that surgeons and people with breast cancer feel are important. A great deal of money is spent funding breast cancer research in the UK every year – but only a small proportion of that is spent on research relating to surgery, although almost every breast cancer patient will have surgical treatment.

This process will allow us to involve people having breast cancer surgery and their healthcare professionals in decision about what research is important for them, and to influence researchers and research funders.

### **The results and their impact**

#### **What will happen to the final Top 10 research priorities?**

Once these have been agreed, the ABS will publicise the final Top 10 research priorities widely to researchers, and organisations that fund surgical and breast cancer research. The priorities could influence those who work in universities and academic institutions, government agency or in industry.

#### **What happens to questions that are not prioritised or put in the final Top 10?**

These questions will not be lost – they will be published on the James Lind Alliance website, and can still be looked at by the Association of Breast Surgery, researchers, and other organisations that fund research.

#### **What difference does this process make?**

Many areas of research have seen a benefit as a result of carrying out PSPs, and some of the funded research going on as a result of PSPs can be seen [here](#).

#### **If I take part in this survey, what will happen to my information?**

You can complete the questionnaire anonymously. By completing the survey, you have given consent for us to analyse your responses and use these anonymised responses in our project report (no individuals or organisations that have taken part will be identifiable).

However, if you would like to take part in placing the research topics in order of importance, we will need your contact details, which you can provide in Section 3 of the questionnaire. We'll only contact you if you provide these. More detailed information about how we use look after your data can be found [here](#).