

## **Information for patients and other non-professional visitors, using the “Dialogue support”.**

Dear Visitor,

The program called “Dialogue Support”, which is currently exposed on your screen (see illustration below), has been developed to be an aid when discussing and deciding on surgery for common diseases/disorders of the low back and neck.

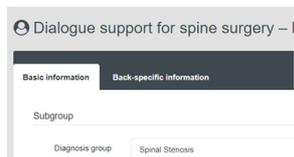
It tool is based on, today October 2020, approximately 140 000 Swedish patients (increasing with approximately 10 000 every year) having gone through a surgical procedure for those diseases. Patients are registered in the Swedish National Quality Register (Swespine), where they have answered questionnaires before the operation and 1 year after (so called PROMs = patient reported outcome measures), providing data to document outcome of the operation, i.e. if pain and function were improved or not.

No individuals are completely alike, nor are patients going through surgery for back or neck problems. We are of different age, height, and weight. We have varying mental state, social state, and physical capacity. Some of us smoke. As patients with back or neck problems we have different intensity of both back and leg pain, and/or neck and arm pain, and we have had pain for varying periods of time. We may also have other diseases that could influence quality of life.

This means that not only the diagnosis as such, for example a disc herniation or a spinal stenosis, and the surgical removal of it, determine the outcome of an operation. Many individual factors also influence the degree of improvement. This is the reason why it can be difficult for a surgeon to state with certainty how much an operation will benefit you or not. And, which is important to consider, all surgical procedures include a possible risk of not getting better, and of complications.

Swespine includes data on the individual aspects mentioned above, and many more. By statistical analysis of the whole database it is possible to weight the importance of the individual aspects for the outcome after surgery. This knowledge reduces the uncertainty in predicting outcome and serves as the basis and function of the Dialogue Support that you are about to enter.

One important consideration before you continue: the outcome presented in the Dialogue Support is still a prediction based on statistics. It is NOT a certain fact! The actual outcome may differ from the prediction, why it is important that you discuss with your spine surgeon before deciding on surgery.



So, let us get started. Once you press the icon, the rest is hopefully rather intuitive. First you will see information to the profession including a PowerPoint presentation (if press two red arrow heads).

Press the square icon at the bottom left and you will open the tool

The important thing is that you enter all your personal characteristics correctly in the left column. Start with “Basic information” which appears automatically. Begin with “Diagnosis group”. There are four alternatives: Disc herniation (Lumbar disc herniation), Spinal stenosis (Lumbar spinal stenosis = narrowing of the spinal canal), Degenerative disc disease (Chronic low back pain), and Rhizopathy neck (Cervical disc herniation).

Then continue downwards and fill in all questions on this side (the last question is Comorbidity). Quality of life (EQ-5D) may be difficult, but you can leave that question if you do not know. For example, use 0,3.

When you have done this, press “Back-specific information” at the top of the page and fill in those data. For functional impairment, if you do not know this, you could use for example 45.

That is all you must do.

Now you can concentrate on the right side of your screen, where you will find the circular “pie diagram” in different colors, the “Results”. At the top you find two percentage numbers: “Proportions of satisfied patients” and “Proportion with successful outcome”, and “Expected length of stay”.

The percentage number to the left is the proportion of patients in Swespine having approximately the same characteristics as you at the time of surgery, and who are **satisfied** with the outcome of the operation.

The percentage number in the middle is the proportion of patients in Swespine having approximately the same characteristics as you, who consider the outcome **successful**. Successful means that pain has disappeared or is much improved.

The number to the right is the expected length of stay in hospital (in Sweden, these figures may differ from country to country) after surgery, under the same conditions as above.

When you look at the circular “pie diagram” you see a more detailed description of the outcome for the whole group of patients in Swespine with the same characteristics as you. Dark green and light green added = “success”. You will find that a small “piece” shows the proportion of the patients whose pain was unchanged (orange) and another small “piece” showing those who report worse pain after surgery (red). The yellow piece reflects those who have answered “somewhat better”, which is considered to be too uncertain to be included in the “success”-group.

The results presented in the Dialogue Support give you an idea of what you can expect if you are to be operated on.

But you must keep in mind that the results are PREDICTIONS, PROBABILITIES, NOT FACTS!

You must also consider that the results are based on analysis of Swedish citizens in Sweden. General conditions in your own country may be different, and this could influence the results. However, taking all into account, these predictions are based on very many patients from a country in Europe, and you can find the actual numbers by choosing the little circular symbol at the far-right bottom end of the screen;



Finally, we again strongly advise you to discuss the demonstrated results with your physician, so you know you have not misunderstood anything.

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Eurospine steering board/ Everard Munting and Tim Piggott

Swespine steering group for the Swespine society of spinal surgeons

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