

16.01.2019

Patient information letter for QRNS quality registration

Dear Sir/Madam,

Neurosurgeons in the Netherlands are always looking for the best possible treatment methods. They do this not alone, but together. The Dutch Association for Neurosurgery continuously strives for further improvement of care.

This is only possible if there is good insight into the effects of existing treatments. What works well, what works better? In order to gain this insight, treatment data are needed that are compared with each other. The Foundation for Neurosurgery Quality has established for that purpose.

We would like to ask your permission to register and analyse your data, including the medical data related to the condition for which you are being treated neurosurgically. All data collected about you and your condition will be kept strictly confidential. These are covered by medical professional secrecy and the legal privacy rules. The organizations involved in the registration have made agreements with each other about the careful handling of your personal data.

Why this registration?

By recording treatments and their effects in a registration system, it is easier to see what the effect is on you as an individual patient, and on groups of people with the same condition. Registration of data makes comparison possible, resulting in better insight into the quality of care. Participation in this registration can therefore also contribute to achieving better treatment, for yourself and for other patients.

Your personal and medical data

It is important that your name, gender, date of birth and e-mail address are registered in order to process your medical data correctly and to provide feedback to your practitioner. This data is encrypted before it is recorded in the database, so that it is not visible who it concerns.

Registering your e-mail address is important in order to be able to approach you with a request to complete a short questionnaire that will be fed back to your treating physician (neurosurgeon). The data is stored for a maximum period of 15 years after the last consult. That is as long as your medical file is kept at the hospital.

Your data is compared with the treatment data of other patients with the same condition and that comparison is fed back to your practitioner. Only your treating neurosurgeon therefore has access to your personal data. The comparison made by the computer takes place with so-called pseudonymised data. This means that personal data is processed in such a way that it is not visible during the processing who it concerns (pseudonym), but that when it is returned to the practitioner it can be indicated that it concerns his or her patient.

Confidentiality and your rights

The Foundation for Neurosurgery Quality has engaged a data processing organization to manage the data of the quality registration. Everyone who participates in the quality registration is bound to secrecy.

Your data is stored securely. Storage and processing of the data meet the legal safety and due care requirements and compliance is strictly monitored.

If necessary for the purpose of registration, the encryption can be removed so that the data can be traced back to a specific person. This is only allowed in exceptional cases and by a few specifically designated persons. If a security incident occurs (also referred to as a 'data leak'), this will have to be reported to the Dutch Data Protection Authority by law.

You always have the right to know what data is being processed about you and to view it. You also always have the right to withdraw from the registration at any time without giving any reason and to have your data destroyed/removed from the database.

A report is drawn up annually that shows the general results of the registration and analysis. That annual report does not contain any patient data. This general report can be made available to the National Health Care Institute (part of the Ministry of Health, Welfare and Sport) and other bodies involved in improving Dutch neurosurgery.

Participation in this registration is voluntary. You will not receive any compensation. This also does not apply to the neurosurgeon and the other care providers, such as the physician assistant, nurse practitioner or nurse, who are involved in your treatment. Further explanation can of course be provided by your neurosurgeon.

* Appendix: Patient consent form