

Information for Patients about the Spine Tango Registry

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Dear Patient,

The number and complexity of treatments for spine conditions is growing rapidly. It is therefore very important that we track the quality and effectiveness of treatments and devices (such as implants) to recommend the best care for patients. We do this by recording each treatment and its outcome in a registry. The registry is like a notebook where we write down each medical diagnosis, the treatment performed, spinal implants used and the outcome for each patient. We can then use the information to compare treatments and implants to understand which is most effective.

Your consent to having your treatment information entered in the Spine Tango Registry is a vital step in improving care for future spine patients everywhere.

Spine Tango registry

Spine Tango is the European patient registry for spinal treatments and has been providing quality assurance and research since 2002. This registry is used for data collection in many different countries within Europe and beyond. So far, Spine Tango has been used to write over 70 original research publications and multiple scientific reports – all with the goal of improving quality and effectiveness in the delivery of spinal treatments.

What data are collected?

With your explicit consent, the hospital can register all relevant medical data on your treatment.

Personal data: Your name, date of birth, and gender will be registered by your treating physician.

Medical data: The medical data includes information on admission, diagnosis, details of treatment, and follow-up examinations.

Who has access to your data?

The hospital collects your personal and medical data. In addition, other organisations including the registry provider (a UK-based company called NEC Software Solutions UK Ltd) as well as registry owner, EUROSPINE, the Spine Society of Europe (based in Switzerland) require access to administrate the registry. No other organisation has access to your personal data.

Your personal data (name, gender and date of birth) will only be used by your treating physician to identify you in the registry. Some treating physicians don't document patient names at all.

NEC and EUROSPINE produce regular reports on treatment quality and publish the results (you can view an example here: <https://www.eurospinepatientline.org/>). Your medical data – without your name but including the year of your birth to provide an age range – will be presented in reports combined with large numbers of other patients to make tables, graphs and other representations of groups of patients. Spine Tango does not report on the information of single individuals.

Hospitals can request access to data from the registry to use in their own research. If the request is granted, the hospitals will only receive access to anonymised medical data. The requesting hospitals will not be able to use the data to identify individual patients. Suppliers of spinal implants can request access to data stored in the registry for quality assurance purposes. If the request is granted, the implant suppliers will only receive access to data in the form of graphs, tables, charts, figures and other representations of groups of patients. The implant suppliers will not be able to use the data to identify individual patients.

How are your data secured?

The transferred data are encrypted and stored in a secure data centre, subject to strict security controls, and are protected from being accessed by unauthorised persons as required by law. Also, the data transmission to the database is encrypted according to the current standards for healthcare data. In addition, the NEC and EUROSPINE staff are bound by strict confidentiality obligations. The registry provider adopts information security best practice standards, undertakes other physical and procedural methods to protect data. The provider also requires its staff to participate in annual data protection training and ensures all staff fully understand the need for patient confidentiality.

What are your rights and how can you exercise them?

To exercise your legal rights regarding the protection of your personal data, please contact our Spine Tango Team at spinetango@eurospine.org.

According to European data protection law, you have rights in relation to the use and storage of your data by EUROSPINE, NEC and your hospital. These rights are related to:

- (1) Access to your personal data
- (2) Rectification of your personal data
- (3) Erasure of your personal data
- (4) Restriction of processing of your personal data
- (5) Portability of your personal data
- (6) Objection to the processing of your personal data
- (7) Objection to automated decision-making

Your personal consent

To allow your treating physician to register your data in the Spine Tango registry you need to sign a consent form.

If you do not give your consent, your treating physician will not transfer your personal data to the registry, and it will not be processed or evaluated.

If consent is withdrawn, NEC and EUROSPINE will cease to process your data and irreversibly anonymise it in the registry. This way, an identification of you as a patient will no longer be possible.

What if I change my mind?

You may withdraw your consent at any time with no influence on the contract governing your medical treatment by contacting your treating physician in your hospital or by contacting health_servicedesk@necsws.com. Please be aware that the withdrawal of your consent does not affect the lawfulness of any previous data processing that took place before your withdrawal. You may exercise these rights by contacting the appointed contact person. If we are unable to provide the requested data or information or make the changes you requested, we will provide the reasons for such decisions.

Further information

For further information please contact your treating physician or our Spine Tango team (spinetango@eurospine.org) from EUROSPINE.

Your Spine Tango registry team