

# NASS Spine Registry



## For Patients...

Your healthcare provider wants you to have the best possible spine care. To help reach this goal, they and other spine care providers across the country are participating in the NASS Spine Registry to collect information and measure the care they provide and how treatments work.

### *What is a registry?*

A registry is a collection of information about individuals, usually focused around a specific diagnosis or condition. Many registries collect information about people who have a specific disease or condition, while others seek participants of varying health status who may be willing to participate in research about a particular disease. Individuals provide information about themselves to these registries on a voluntary basis.<sup>i</sup>

### *What is the NASS Spine Registry?*

The NASS Spine Registry is a diagnosis-based clinical data registry that tracks patient care and outcomes related to spine care. The registry is owned by the North American Spine Society (NASS), a 501(c)(3) not-for-profit organization. NASS is a multidisciplinary medical organization for spine care providers dedicated to fostering the highest quality, ethical, value-based and evidence-based spine care through education, research and advocacy. The purpose of the registry is to collect data to enhance understanding of spine care treatments, their outcomes and examine the natural history of spine disorders.

### *How will I benefit from participating?*

The information you contribute helps provide a fuller picture of spine care that can help physicians and patients make treatment decisions and lead to improved outcomes.<sup>ii</sup> Participation also helps increase clinical knowledge about spine disorders to help improve care.<sup>i</sup> This is an important opportunity for patients and spine care providers to work together on the study of the spine care.

You will receive feedback on your health condition in the form of Oswestry Disability Index scores each time you enter data. This is a common measure that shows how you are progressing over time with your back problem. Links to patient education will also be available to you.

### *How do I participate? Why is it important that I provide follow-up information?*

Your care provider will invite you to participate if your condition meets the inclusion criteria for the registry. If you participate, completing your follow-up surveys at the request intervals is very important. These follow-up surveys help develop information about what treatments work both over the long- and short-term and make the registry complete.

### *Will my personal information be disclosed? Who will know if I participate in the registry?*

Personal health information will only be available to your care provider, just as any other time you visit a healthcare provider. Any information entered in the registry will be de-identified and no personal identifiable information is being stored. No one but your provider will see your personal health information. NASS can only see a de-identified data pool.

### *Who owns the data in the registry?*

Healthcare providers own their own data. NASS owns the de-identified, aggregate pool.

### *Can I withdraw from participating in the registry?*

Participation in the registry is voluntary and patients are free to choose not to participate. You may withdraw at any time.

*Who should I contact if I have questions about the registry?*

If you have any questions, please contact your spine care provider and they will be happy to assist you.

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<sup>1</sup> National Institutes of Health. List of Registries-Frequently Asked Questions. Available at: <https://www.nih.gov/health-information/nih-clinical-research-trials-you/list-registries>. Accessed: 5/8/18.

<sup>2</sup> NQRN. Participating in a Clinical Registry. Available at: <http://c.vmcndn.com/sites/www.theccpi.org/resource/resmgr/nqrn-participating-in-clinic.pdf>. Accessed: 5/9/18.