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Abstract

THEME 3 - VARIABLES INCLUDED IN A SPINE REGISTRY

FinSpine - Experiences from building a registry today

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In 2014, Finnish Society of Spine Surgery (FSSS) internal survey revealed a broad consensus inside the society to establish a national spine surgery quality registry. In 2015 the FSSS registry task force was founded involving neuro- and orthopedic surgeons from every major hospital. Also members of FSSS were involved in shaping the content of the registry, which increased later the acceptance of the registry. FinSpine was developed with the help of a commercial IT-provider paid by participating hospitals. In 2017, FinSpine was finally integrated with first hospital IT-systems marking the start of spinal registry data collection in Finland. First, the commercial IT-provider collected the registry data on their servers. However, in January 2023 the registry keeping was transferred to the Finnish Institute for Health and Welfare by a decree issued by the Finnish Ministry of Social Affairs and Health, which made FinSpine a statutory registry partly financed by the government.

During the whole development process one of the main goals was to include most common and meaningful variables in the registry. We also took other Scandinavian spine registries into account in the choice of the variables in FinSpine. At the same time we wanted to keep the registry as simple as possible in order to make the completion of the questionnaires as easy as possible for both the surgeons and the patients.

We have included following minimal data set with spine specific outcome measurements in FinSpine:

Patient identifier, Hospital, Age, Gender, Height, Weight, ASA-classification, Method of communication with patients (email/phone), Smoking (no/yes), Neurological deficiencies (affecting ambulation, myelopathy), Diagnosis (with definitions!), Type of surgery (primary, secondary, revision and their definitions!), Procedure (with definitions!), Operation level and number of levels, Complications (at least perioperative), Operation and complication dates, VAS/NRS, ODI/NDI, Global Rating Scale and EQ-5D.

FinSpine was not originally developed as implant registry. However, the Medical Device Regulation of the EU has sparked a vivid international cooperation between worldwide spinal registries and different stakeholders in order to find ways to integrate spinal implant data into existing and future registries. Even though FinSpine does not include implant data yet, we now suggest to collect also implant and graft data as part of minimal data set.