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SSE Spine Tango: a European Spine Registry promoted by the Spine Society of Europe (SSE)

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It is increasingly understood that, in any technology-driven surgical discipline, patients should be documented and registered in a standardized way if they are recipients of novel inventions and implants. This is to have a common language for reporting outcomes, complications and unforeseen incidents which can be better recognized in a large, common data pool serving as an early warning system. There is a call for such registries, since we know about their value in the fields of hip and knee arthroplasty. It is obvious that these endeavors are not only of benefit for the industry producing such technology but also even more so for surgeons when dealing with insurance and governmental regulatory bodies.

Such a project is, therefore, in the very best interest of surgeons and physicians who make use of rapidly changing technologies to accomplish their treatment strategies, and it cannot be sufficiently emphasized that we have to drive this agenda if we do not want to risk being driven by third parties.

It is for these reasons that some proponents of the SSE have initiated a European Spine Registry, called Spine Tango, and have convinced the Society to form a Spine Tango Committee, which was assigned with the implementation of such a registry.

Looking back, the development of Spine Tango has taken several years. During that time, a comprehensive

know-how regarding content and the technological implementation of such a system has been gathered. The Spine Tango 2004 represents the essence of our experiences, which have had a major influence on the way this registry is constructed today. The primary ambitious goal, to include all pathologies of the spine, including all levels, approaches and procedures, resulted in an extremely complex electronic questionnaire, which could be navigated with an “intelligent” Internet application. The system only displayed the relevant questions to the users, whereas content not applying to the respective case remained hidden in the background. This first version of Spine Tango required users with an advanced knowledge of web applications and many of our colleagues failed with it because of the complexity and time constraints. Unfortunately, we doctors quickly condemn things without really having understood them.

Nevertheless, since 2002 data sets of more than 2,500 surgical interventions and more than 1,000 follow-up examinations have been collected with the first version of Spine Tango and by that the feasibility of the system was clearly proven. The profile of the participating pilot clinics showed, however, that this project was mainly suitable for academic centers with a corresponding infrastructure and staff support, and less

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appropriate for poorly equipped pioneers and believers in documentation.

Besides the problems with content and technology, an additional issue arose, which was taken very seriously by the committee: though mandatory demographic data for the creation of an online patient chart was minimal, electronically transferring this data across regional or national borders conflicted with regulations about patient privacy in some countries, if written informed consent was not given by patients or their families.

These are important aspects for a European registry with a multitude of different legislations and they initiated and stimulated research and development of a completely new technology for the Spine Tango in order to address the legal concerns and make it usable for everybody.

The Institute for Evaluative Research in Orthopaedic Surgery at the University of Bern has introduced the concept of so-called documentation modules, which are little PC web-servers that are placed inside a country or a participating institution and act as filters for all data identifying users and patients. The respective data sets are stored in the database of the local module, whilst the anonymized medical questionnaires are passed on to the central European database labeled with a key (see *JBJS*, 86A(9):2077–2080, 2004). In addition, each module has its own Internet address and serves as entrance gate to the documentation network for all institutions belonging

to a specific country (e.g. <http://www.spinetango.austria.com>, <http://www.spinetango.finland.com>, etc.). Hence, only “raw” medical data sets leave national boundaries.

This allows two things: an individual institution can either directly join the central database of the Spine Society of Europe through its web page, or it joins the national module of its country, which will be administered by an academic institution or a national spine organization. As currently planned, those who want to use the SSE Spine Registry can go to the society web page and follow a link to Spine Tango or directly go to <http://www.spinetango.com>. In cases where a national module was installed, users can go to the web address of this module or follow a link on the web page of their national society. The first countries to be equipped with modules are Austria, England, and Finland. For Swiss users, the SSE module is the national module.

In long discussions, statistical evaluations and test runs, a core dataset has been worked-out from the original pool of questions still fulfilling the goal of covering the wide spectrum of pathologies and surgeries of the spine. In addition, a *paper-based version* of the questionnaire was designed for all those, who prefer this mode of data capture over the *online questionnaire*.

The double-sided A4 *primary questionnaire* and the single-sided A4 *follow-up questionnaire* can be completed with a no. 2 pencil and transferred to the central database by means of an optical mark reader (OMR scanner) connected to a PC and operated using the web interface.

Therefore, data collection in a spine unit or a hospital can either be conducted online or offline (paper-based). The physician-administered forms are completed by surgeons and medical staff; administration of the questionnaires should be done by secretaries, research nurses or other non-medical persons, either in the department or in a centralized office (e.g., that of a national society).

It is obvious that those centers using the paper-based solution either need their own scanner or the possibility of sending their questionnaires by regular mail to a facility offering scanning services (for a small fee). Depending on how many users are interested in such a set-up, the Spine Society of Europe is going to establish its own central scanning service.

The registry *manual* can be found on <http://www.eurospine.org> (link to Spine Tango Registry) or directly under <http://www.spinetango.com>

In conclusion, a sophisticated and user-friendly technology has been developed to centrally host the first official and comprehensive European Spine Registry, taking into account the heterogeneity of needs and regulations. It will enable us to establish and use the same language and data structure for the assessment of treatments and outcomes and to create European benchmarks for state of the art spine surgery. We encourage all readers and SSE members to join this ambitious and challenging project, either directly through the SSE web page or through one of the hopefully increasingly installed national modules.