Understanding the need for spinal registries: Lee Breakwell reviews the importance of registries in spinal research and explains why the British Association of Spinal Surgeons (BASS) has decided to set up its own registry

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A registry is an organised collection of data that allows interrogation and analysis of that information. Information regarding operations has always been collected and interpreted for patient care purposes, and advances in computing and data storage have significantly aided this process.

The Swedish Hip Register, begun in 1979, has shown that prospective, disciplined data collection can offer huge benefits in improving patient care through identifying trends and early problems [1]. It has also led the way with a lumbar spine database, which was followed by Spine Tango—the first multinational European registry.

With the advent of surgeon league tables, and the drive towards Value Based Health Care, individuals, and the healthcare system has a duty to collect, store and interpret data, to facilitate an uplift in quality whilst maintaining appropriate downwards pressure on the increasing costs [2].

Therefore, BASS resolved to institute a British Spine Registry (BSR), both in terms of clinical expediency and the availability of secure yet accessible web-based technology. The registry was conceived as a surgeon-driven database, with patient-centred information, to enable assessments of certain procedure types, and their outcome.

A subcommittee was formed, led by Ashley Cole, consultant spinal surgeon, Northern General Hospital, Sheffield, UK, to define the dataset and to create a tender process. Bluespier International was the successful company, and has worked with the BASS registry committee to design and launch the BSR on the Amplitude platform.

The main aims of the BSR design were to create a secure, comprehensive database, to allow individual surgeons and their teams to collect prospective data in a convenient and timely manner. To achieve this, a web-based solution was developed, ensuring that all users could access the BSR wherever, and whenever they wished.

In order that patient data security issues were appropriately addressed, the BSR has been registered with the UK bodies the Information Commissioners Office, the Healthcare Quality Improvement Partnership, and the Record of Central Returns. In addition, NHS IT experts have reviewed the security policies, and data storage technology.

From a design perspective the BSR has been built around the concept of patient pathways. All patients' data can be collected with options for lumbar and cervical degenerative, trauma, tumour, infection, deformity and intradural surgery.

Details of the presenting clinical symptoms, and signs, plus the resulting operative data, including the use of spinal implants, can then be added to define a treatment episode.

The Association of British Healthcare Industries (ABHI) has enabled listing of a majority of the available spinal implants, such that an overview of usage, and ultimately outcomes on a national scale can be achieved for the very first time.

A major feature of the BSR is patient reported outcome measures (PROM). Each patient pathway allows collection of data, using validated scores such as the Oswestry Disability Index, and EuroQOL 5D. This data can be collected in a multitude of ways dependent upon local practice, but use of the associated Amplitude Patient Portal for direct electronic input is recommended.

BASS launched the BSR at Britspine 2012 (2–4 May, Newcastle Upon Tyne, UK) and the registry is now

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available to all registered users. The British Scoliosis Society (BSS) is now supporting the project, ensuring the BSR is available to any surgeon who is a member of either organisation.

Once online surgeon registration is complete, individuals can nominate co-workers who can obtain access for improved data collection.

Currently there are over 200 registered surgeons, and over 3,000 patients enrolled in the registry. Individuals will be able to interrogate their data, with surgical outcomes, including complication rates by procedure type. The societies will be for the first time able to create real-time accurate population data on spinal surgery in the UK. This simply has to be the way forward.

For registration, downloads, assistance or more information, see: <http://www.bscentre.org.uk>.

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Conflict of interest None.

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