



The British Spine Registry

End of Year Annual Report

(2016 – 2017)

British Spine Registry - a strategic approach to:

- Improving spinal care throughout the UK by encouraging research, audit and good clinical practice.
- Educating patients about spinal problems, the available treatments, expectations and quality of life.

Executive Summary

The British Spinal Registry (BSR) set out to provide a strategic solution to meet the objectives of BASS. Its initial remit was to develop a mechanism, using 21st Century technology, to monitor the outcomes of spinal procedures, collecting valuable and insightful data to better understand procedures, techniques and a patient's experience and quality of life.

Since it was established in May 2012, the success of the BSR strategy is evident:

- It has made huge progress in recruiting members with a common aim towards improving patient safety and monitoring the results of spinal surgery.
- The Registry now captures and tracks all types of spinal surgery, in the UK. It provides a platform to monitor patient recovery both from a clinical perspective and one that is cognisant of the patient's experience.
- The Registry, which is strongly supported and respected by The British Association of Spine Surgeons (BASS), British Scoliosis Society (BSS) and the Society of British Neurological Surgeons (SBNS).
- It has gathered significant momentum since its inception and now has 1182 users registered, which includes Consultants (pathway owners) and delegates.
- The number of patients added to the Registry has increased by 63% since the end of 2016 and currently stands at an impressive 71390.

BSR Chairman, Mike Hutton, has been working closely with the development team at Amplitude, the Registry software provider, to deliver the simplest, clinically valid, patient experience data capture system on the market. The BSR is now the largest medical Registry dedicated to spinal surgery in the UK.

Goals and aims

This is an exciting year for the BSR. Its stated aim remains to be to improve patient safety and monitor the results of spinal surgery through effective and meaningful data capture.

To achieve meaningful data, it is essential that the information collected includes clinical data comprising of diagnosis, comorbidities and clinical outcomes, as well as, patient experience scores, procedure details and any complications. To this end, clinicians, support staff and patients must be actively engaged.

Data is available to BASS members contributing to the registry to help facilitate important research and development, audit and national comparisons.

Each Registry member has a part to play in order to ensure that patient compliance is optimum. It is imperative, in the field of spinal surgery, for patients to input their own PROMs and consultants and their delegates to collect accurate contact information, in order for the Registry to be as clinically valid and meaningful as possible.

Clinical aims

The Registry Steering Group, on behalf of the parent spinal societies have agreed a minimum, mandatory dataset pertaining to the core procedures in spinal surgery.

We have entered an age where proven value based health care is seen as a very high priority.

Achievements and areas for improvement

In 2016/17 the Registry has achieved a lot:

- The total number of registered users has reached 1182
- The Registry has reached over 71000 patients, which is a 63% increase on the prior year.

The steering group have decided over the next 12 months to focus on:

- Introduction of groups allowing comparative data share within and between units for comparison.
- Real-time reporting for pathways of patient outcomes.
- Historical Data upload from other data sets (e.g. Spine tango & Sprint).
- An emergency referral system with a virtual patient whiteboard that feeds patient demographics and symptoms into the British Spine Registry.
- Comparative Funnel Plots for common procedures such as single level discectomy and decompression.
- A live feed web based tool for industry to check their implants appear correctly with a change request.

Functionality Update February 2017

In February 2017, the registry underwent a number of functional upgrades. These are summarised here: -

General Upgrades

National ID

The national ID default is set at NHS number. This is now mandatory so that we can reduce duplicate patient records on the system. National ID default can be changed in settings with the new addition of Northern Ireland H&C number. We encourage wherever possible that private patients NHS number is recorded, but in the case of overseas patients and channel island patients the GEN number can be used and we recommend that passport number is stored here.

Finding Patients:

It is now possible to see all patients on the system and add to their patient record. The system has a fully auditable trail. When searching for patients, users can either search all patients or “My Patients Only”

Patient Portal

The patient portal (iPads/kiosks and email response) has new functionality. A new consent process allows the patient to consent and this is recorded on the system.

The patient is asked to verify system information held on them including email address. The patient can change incorrect information accordingly.

Body Mass Index is now patient reported and calculated appearing on a patient record.

Notifications

The notification icon now pulsates if unread notifications have arrived. These notifications are broken down by **subtypes**, **unread notices**, **consent rejections** and **expiring delegates**.

New Mandatory Fields

In order to improve data capture through the patient portal, we have made postcode a mandatory field allowing patient identification.

Implant and consumable costs are now a mandatory field.

All mandatory fields across all pathways are now mandatory (you can't save without filling them in).

As the system is fully auditable deletion of patients and pathways is now possible (BE CAREFUL).

Procedure/Pathway Changes: -

Logbook roles of supervising surgeon and surgeons are now available.

The procedure 'free text box' for operation notes is now much bigger.

Navigation options for pedicle screws are now available across all pathways.

Deformity Pathway

'Patient Age' now triggers different outcome scores:

Less Than 10	<u>Early Onset Scoliosis Score</u>
10-18	<u>SRS 22</u>
Over 18	<u>EQ5D, VAS Back & Leg & SRS22</u>

The GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM (GMFCS) is now an option available on non-idiopathic deformity pathways.

Tumour & Trauma Pathways now trigger EQ5D & Performance Status outcomes only

Sacro-Iliac Joint Fusion now appears as an option in Lumbar Degenerative Pathway.

Reporting Tool

The dashboard for Instant reports is now customisable. New instant reports are available comparing user data with the whole of the registry and calculating PROMs by pathway.

User Settings

Users can customise visible complications per pathway e.g. remove dysphagia from lumbar degenerative pathway by clicking on a pathway cogwheel.

The **Data Exchange** functionality is now enabled, giving users the ability to push data to relevant *pro one™* or *pro enterprise™* systems.

We have introduced a **new consent process**. This means if data is being uploaded via the **Data Exchange** process, the patient will be presented with consent messages for the registry as well as the system in which the data is being captured i.e. the *pro one™* or *pro enterprise™* system consent. Full audit trails are available on all consents.

Clinical forms grouping functionality has now been updated. Within each patient's pathway, all clinical forms are now grouped together, cleaning up the dashboard and making it clearer which tasks are outstanding and which are complete/future tasks.

The '**Date Confirmed**' checkbox has been made configurable for each form rather than being mandatory across all forms. You can decide whether or not you'd like the date confirmed checkbox to be a mandatory field in each separate form.

On the settings page, the word 'Settings' has been changed to '**User Settings**'.

The '**age of patient**' widget has been expanded to include the age categories of 50-60, 60-70 and 70+.

The widgets displaying as line graphs now display a '**coloured legend**'

There is no longer a '**save anyway**' option when completing the procedure forms.

The '**date confirmed**' tick box will only appear on procedure forms and no longer on any other type of form.

Implant fields have been updated.

Planned Future upgrades 2017

Quarter 1:

- Improvements to the print preview functionality – increasing the size of the title and highlighting the post-operative instructions
- General widget changes and addition of new widgets

Quarter 2:

- The separate Add and Search for patient buttons are being merged together to create an add/search patient button
- The ability to have groups of Consultants across the registry who can compare their results with consent

Quarter 3:

- The national identifier is becoming mandatory which will eradicate the creation of duplicate patients
- Creation of the revalidation report

Quarter 4:

- Creation of funnel graphs

Pathway Specific Upgrades

Quarter 1:

Pathways will read as one historical record. When patients are transferred to an alternate Consultant or are added to another pathway, all details will remain in a single record rather than appearing in multiple pathways.

Pathway specific widget changes. For example, whether patients have consented or not.

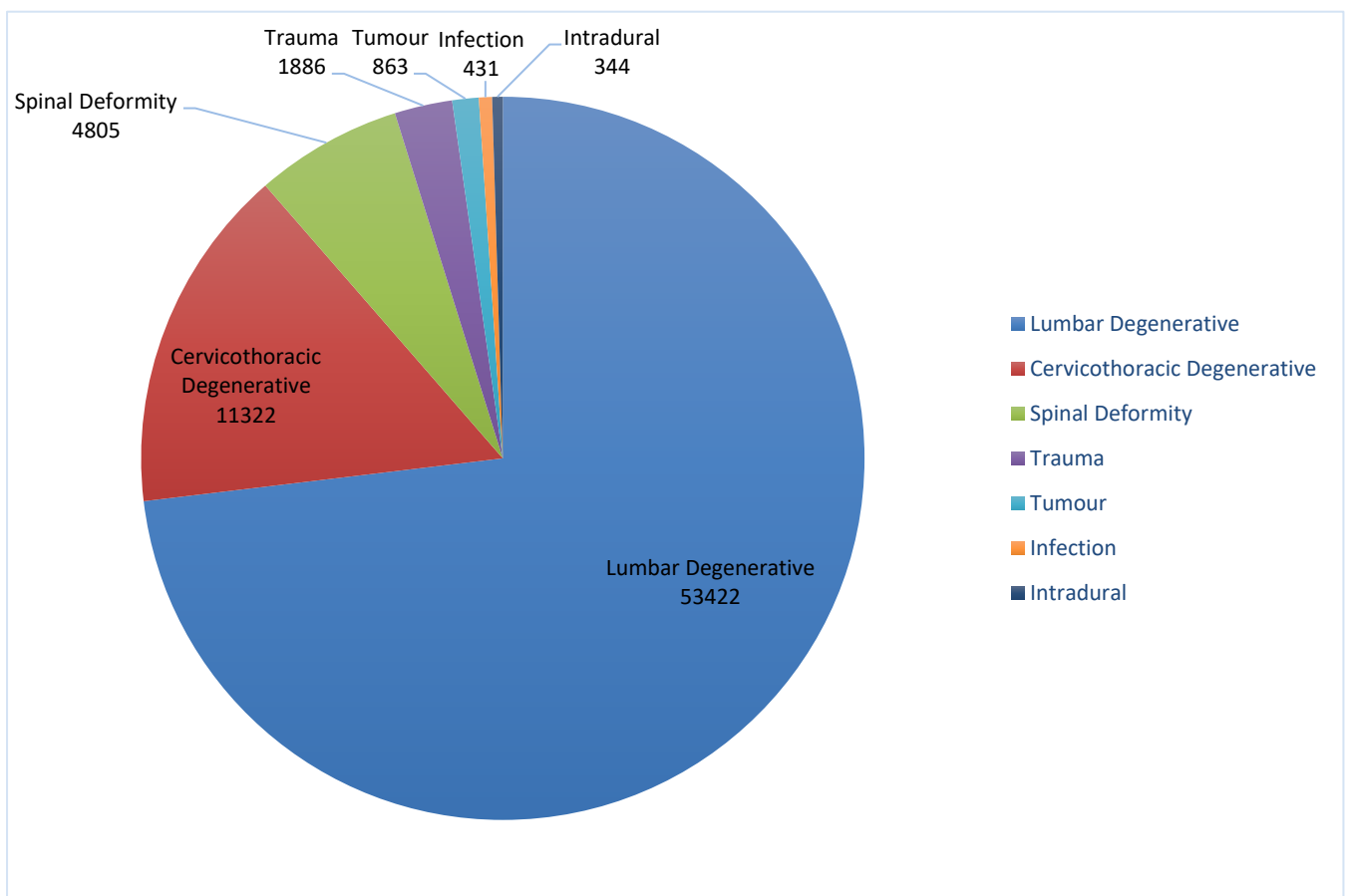
Registry usage data

Total number of users: 1,182 (**42% increase** from 2015-16)

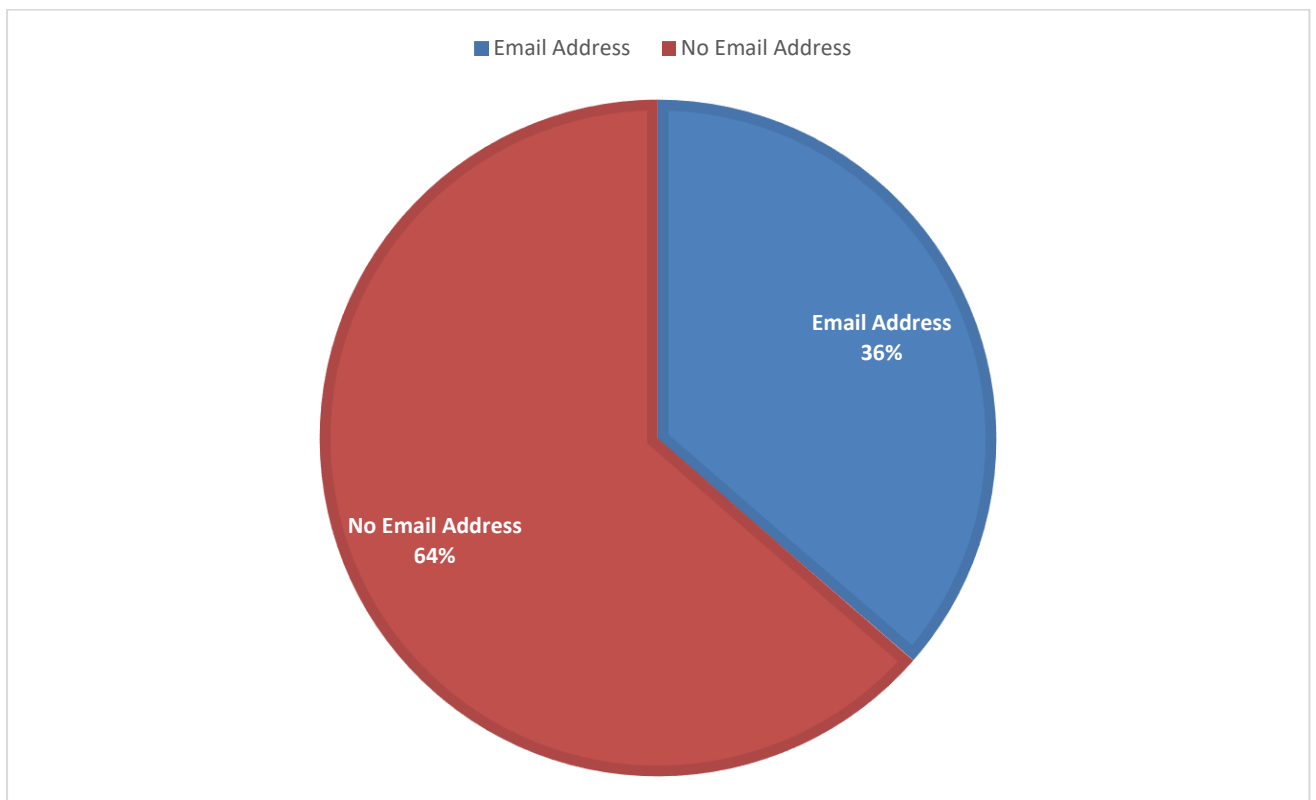
Total number of patients: 71,390 (**63% increase** from 2015-16)

There are currently 812 consultants (pathway owners) actively adding data into the BSR.

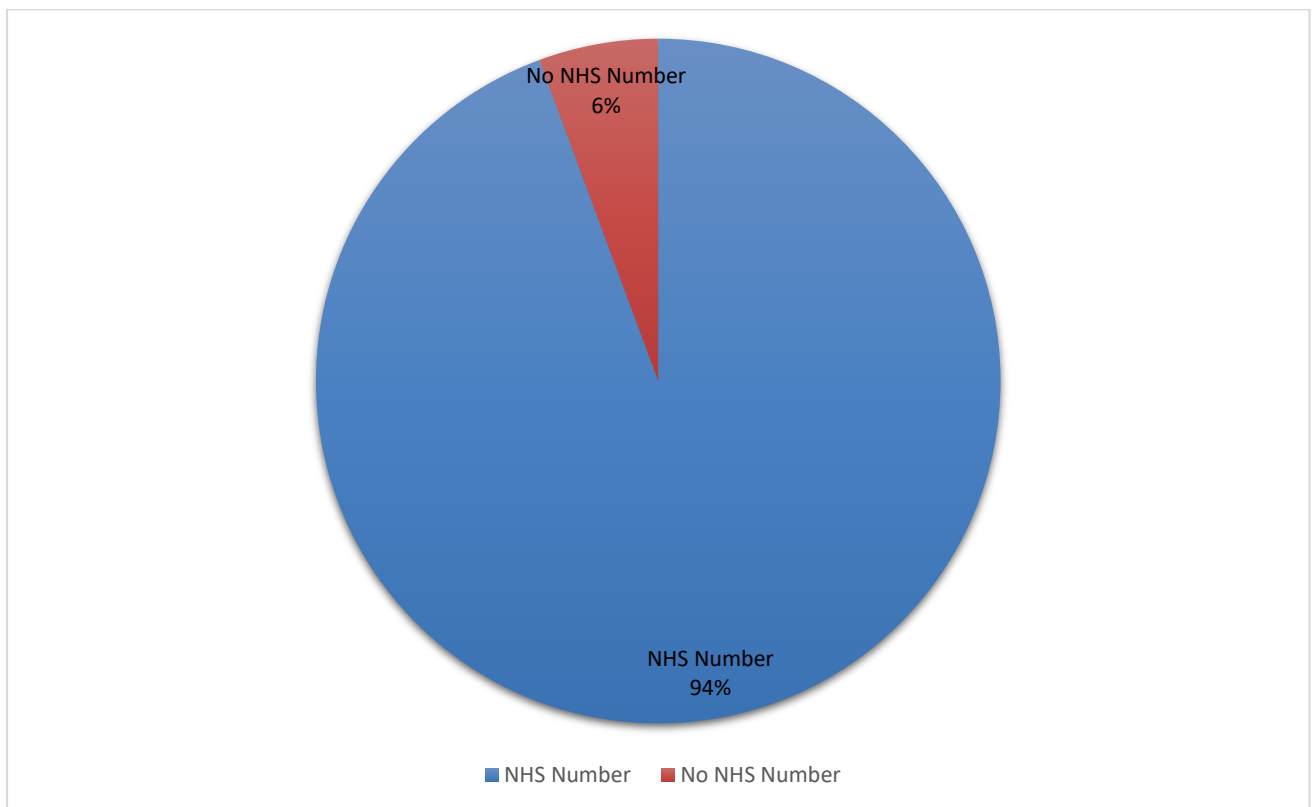
Number of patients added up to 2015/16 broken down by pathway:



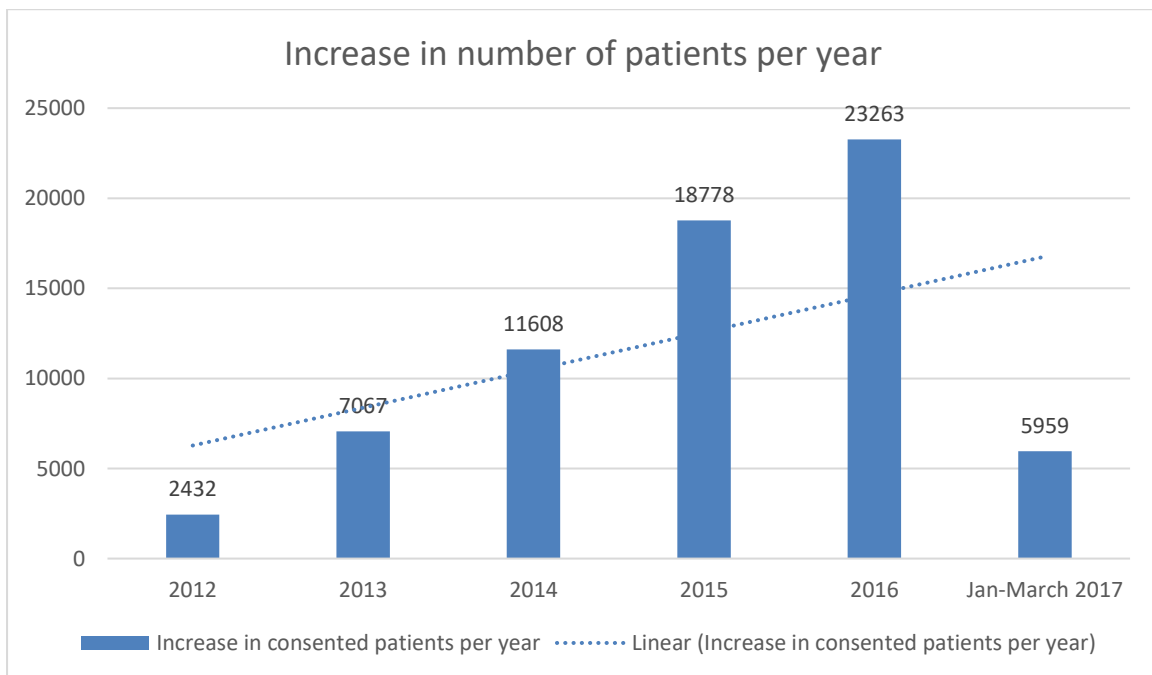
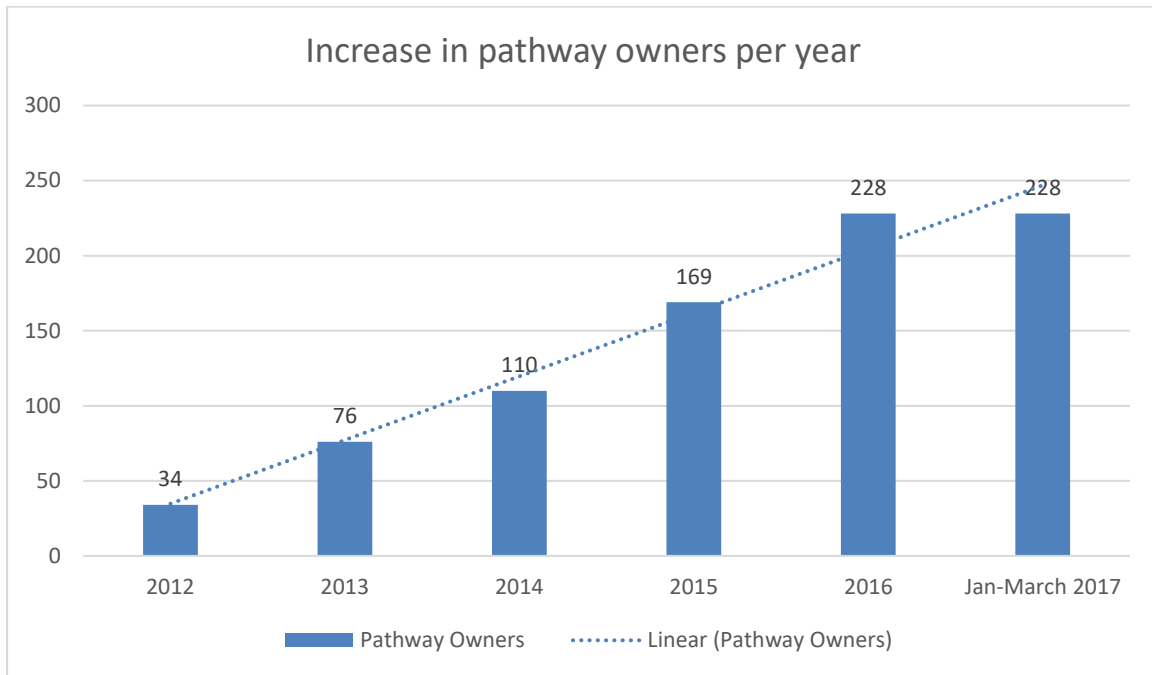
Patients with e-mail addresses:



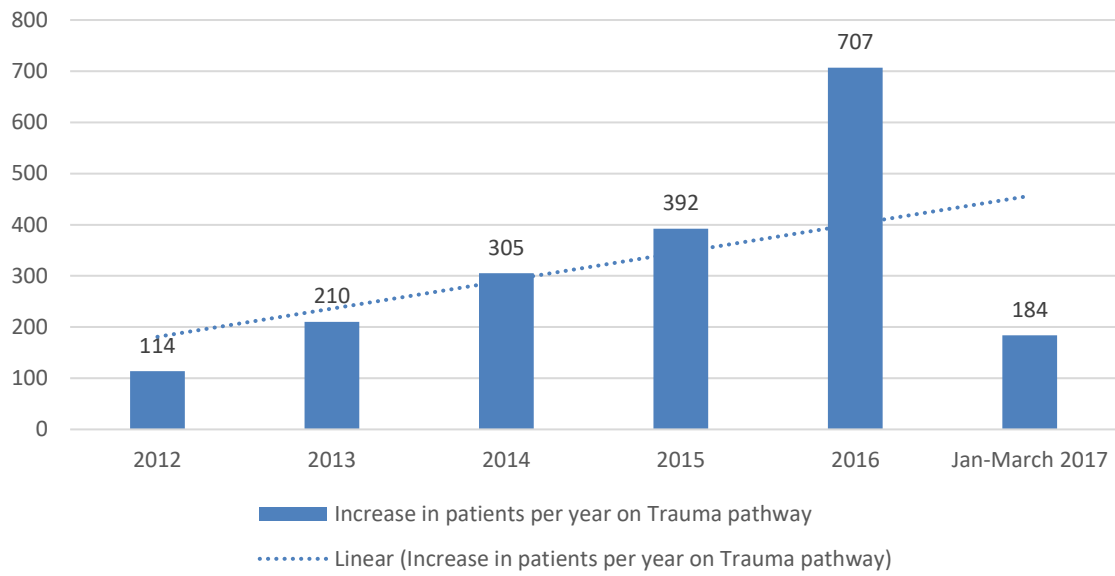
Patients with NHS Number:



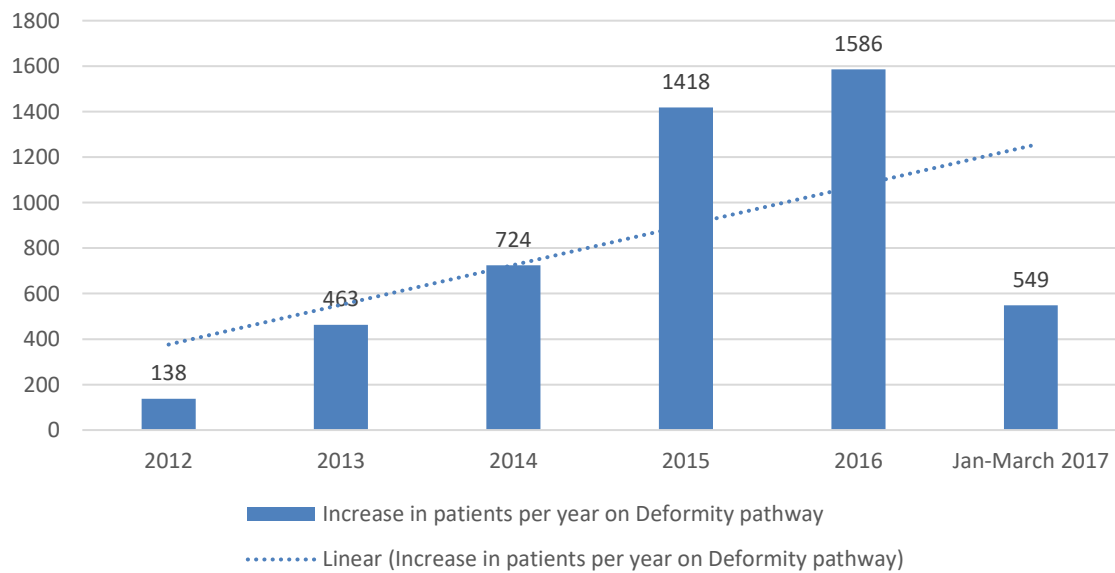
Since its inception, the BSR has had a significant increase in pathway owners per year, number of consented patients per year and number of patients per pathway per year, broken down below:

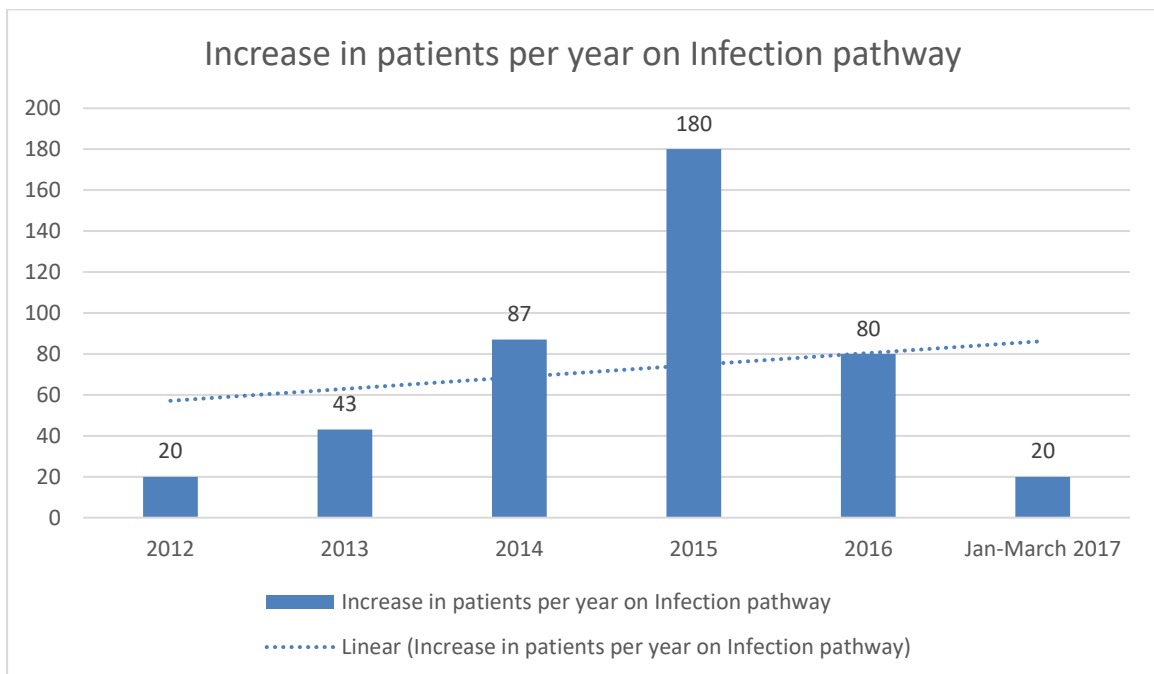
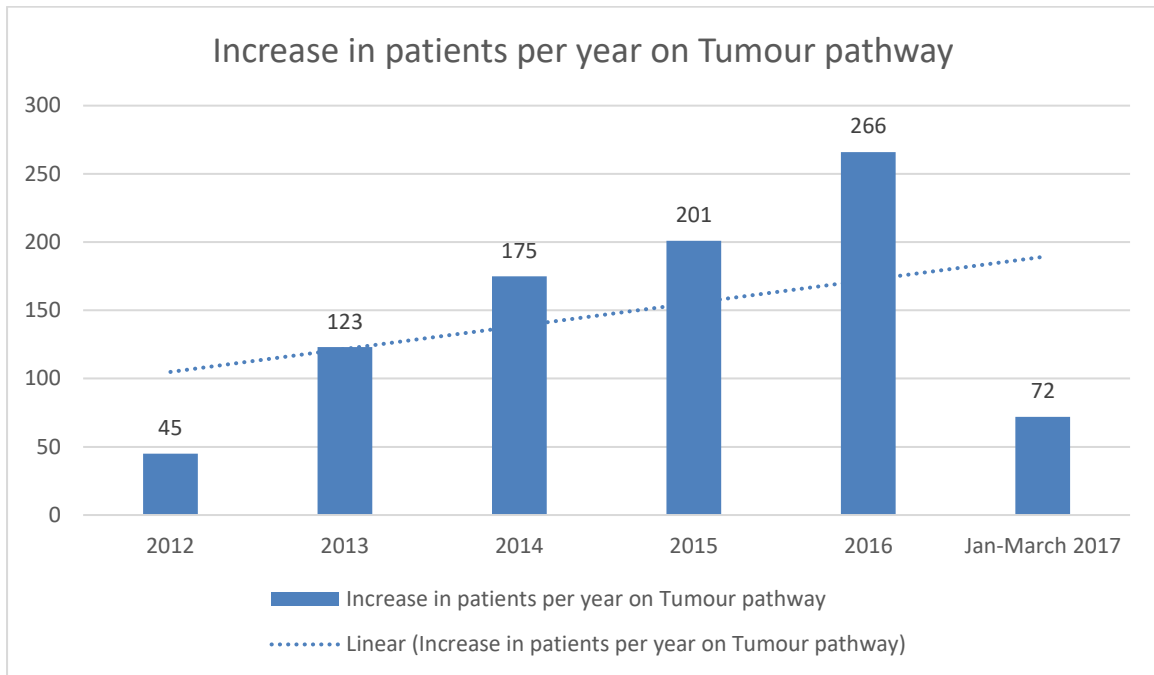


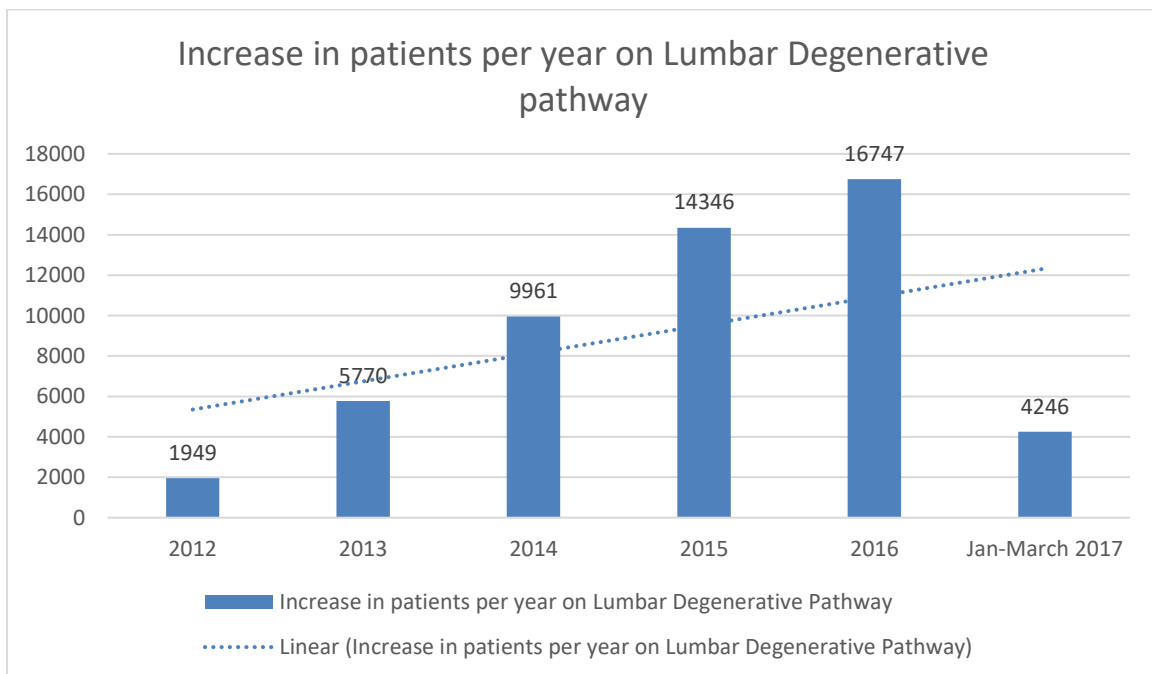
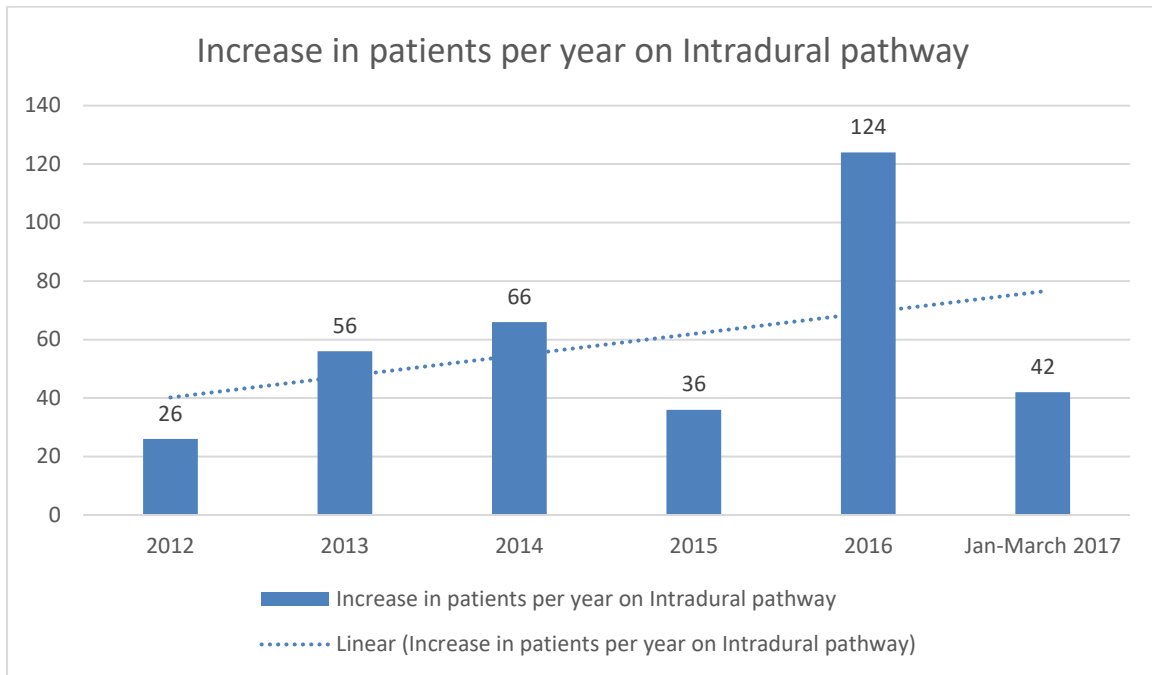
Increase in patients per year on Trauma pathway

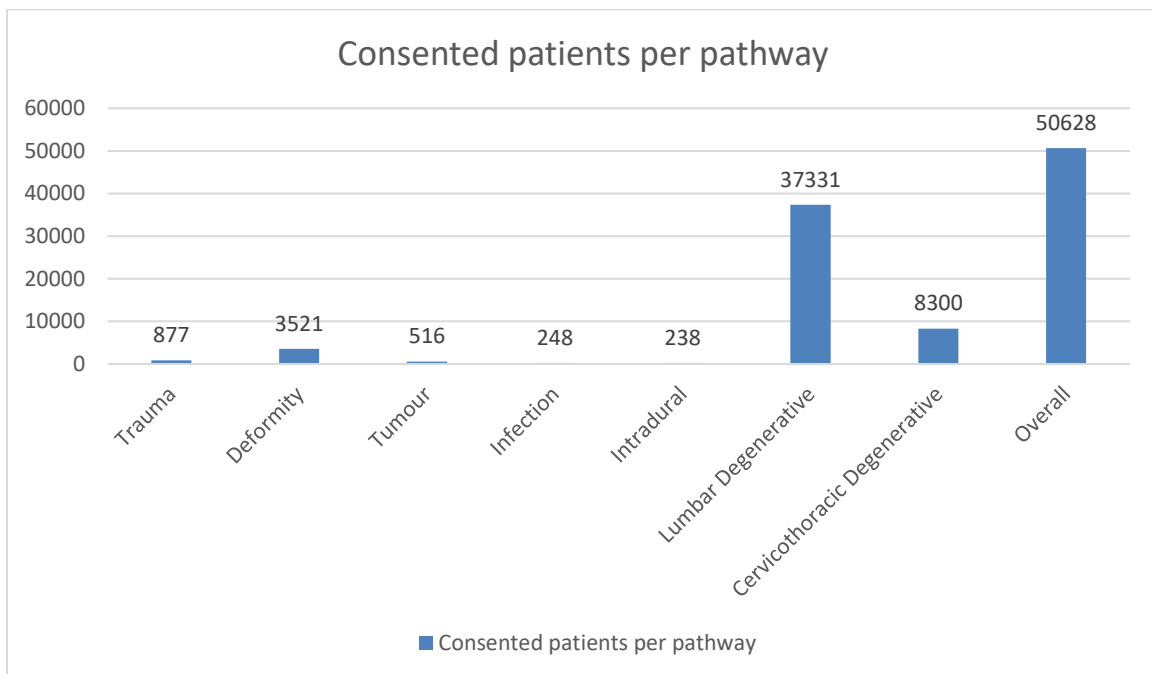
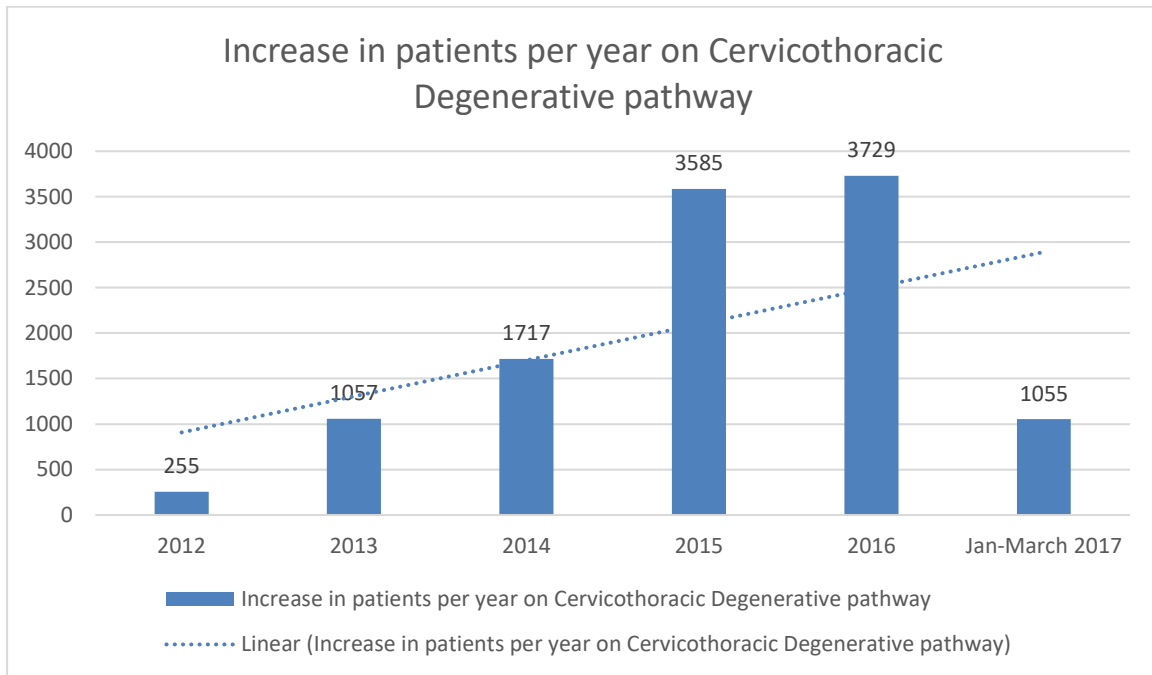


Increase in patients per year on Deformity pathway





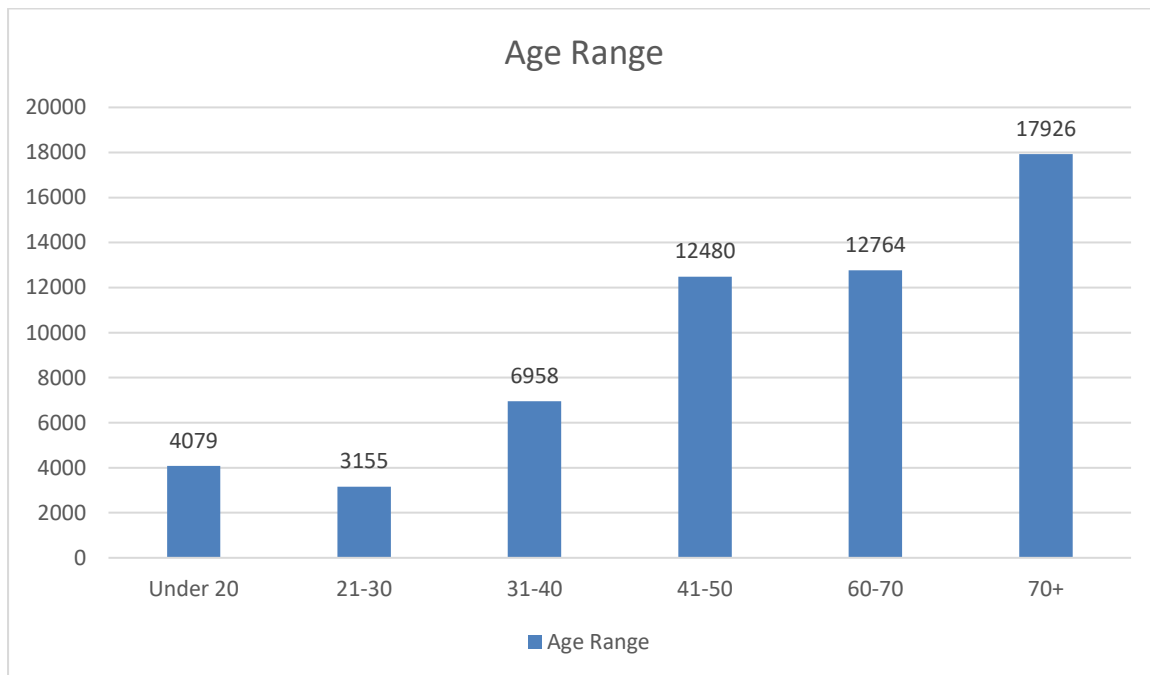




Clinical analysis

To date the British Spine Registry includes information on 15,839 Primary Lumbar Decompressions, which include 8653 discectomies. The total complication rate for these procedures, including immediate and post-operative problems was 15%.

The patient age range is as below:

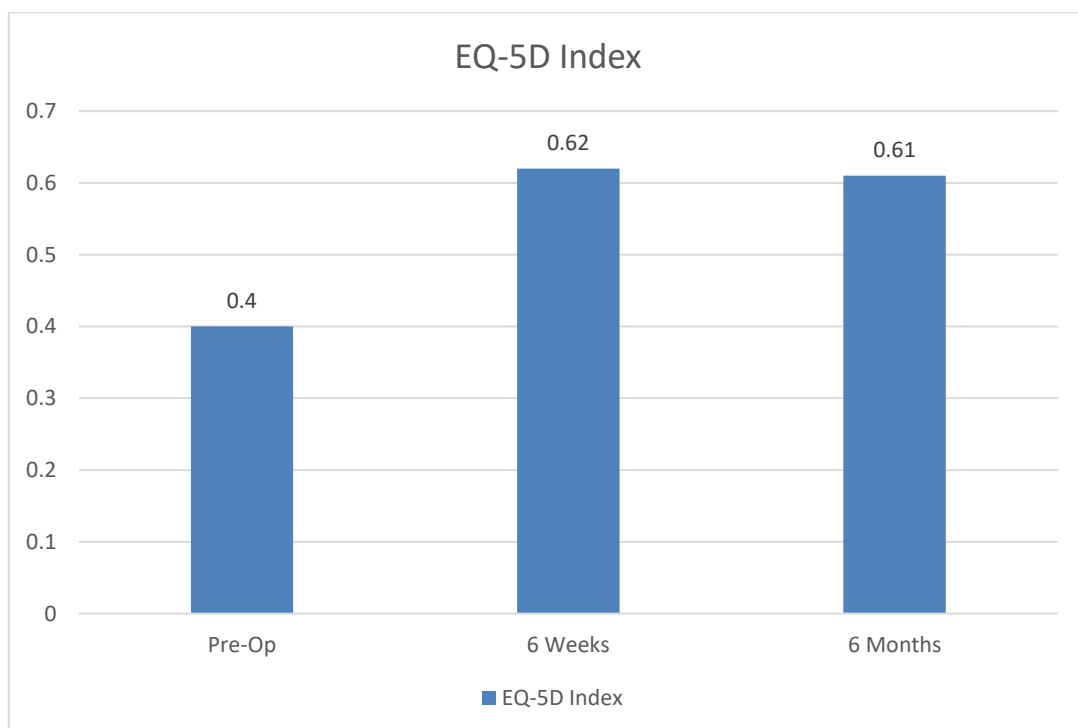
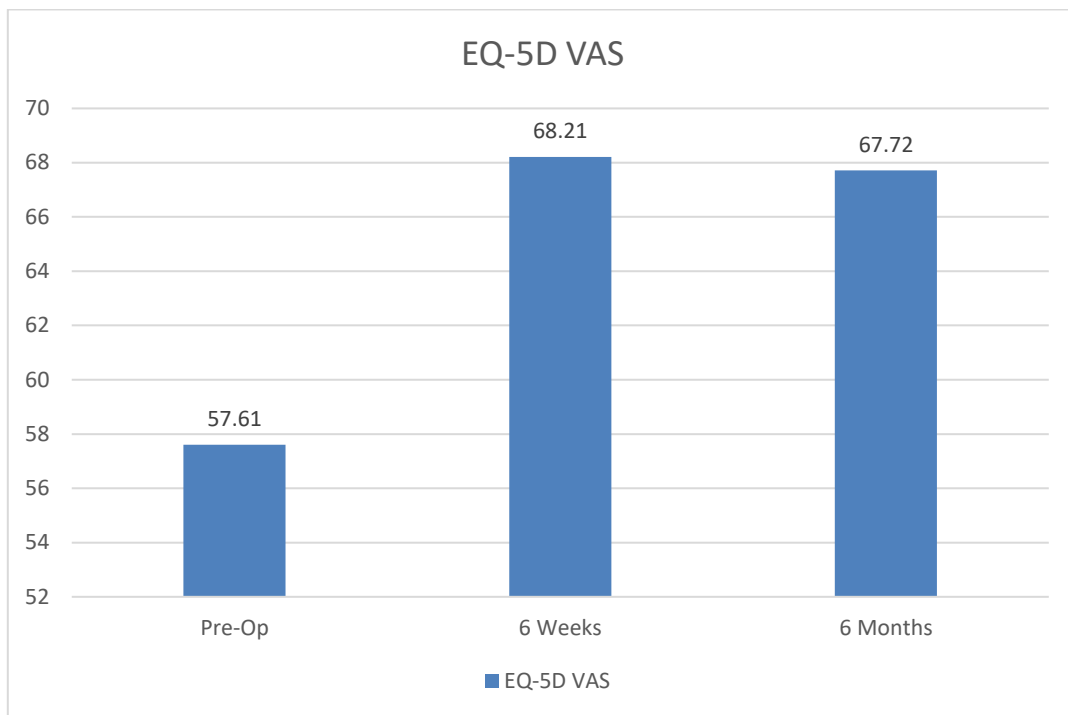


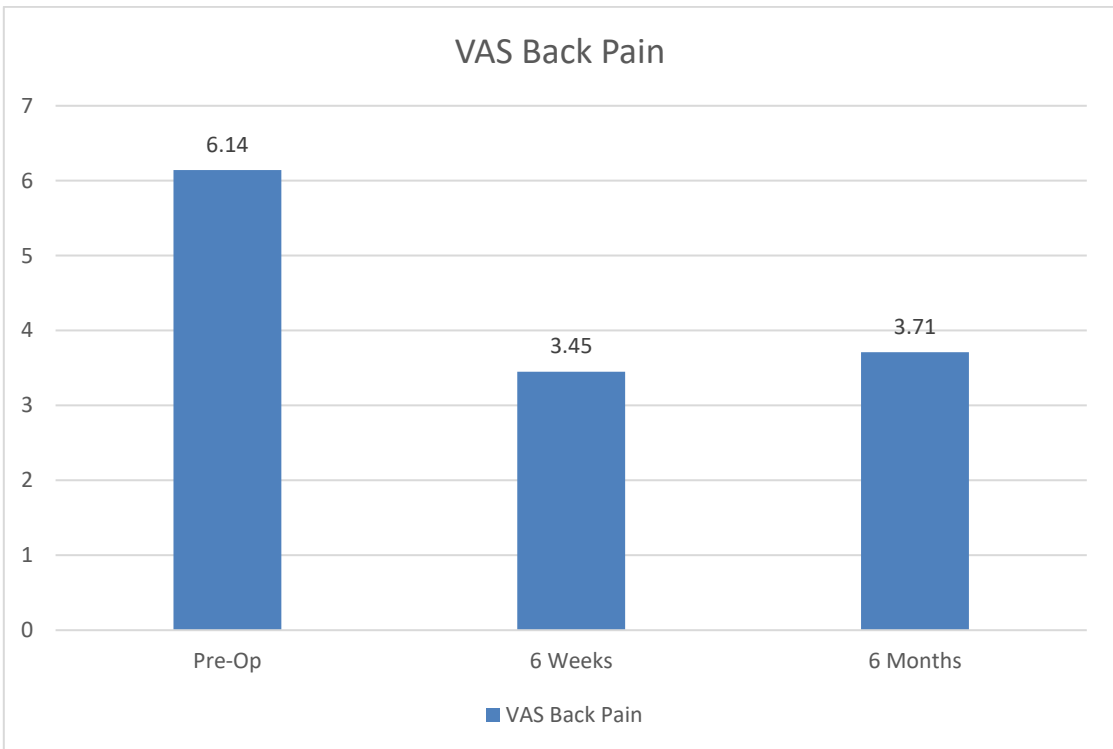
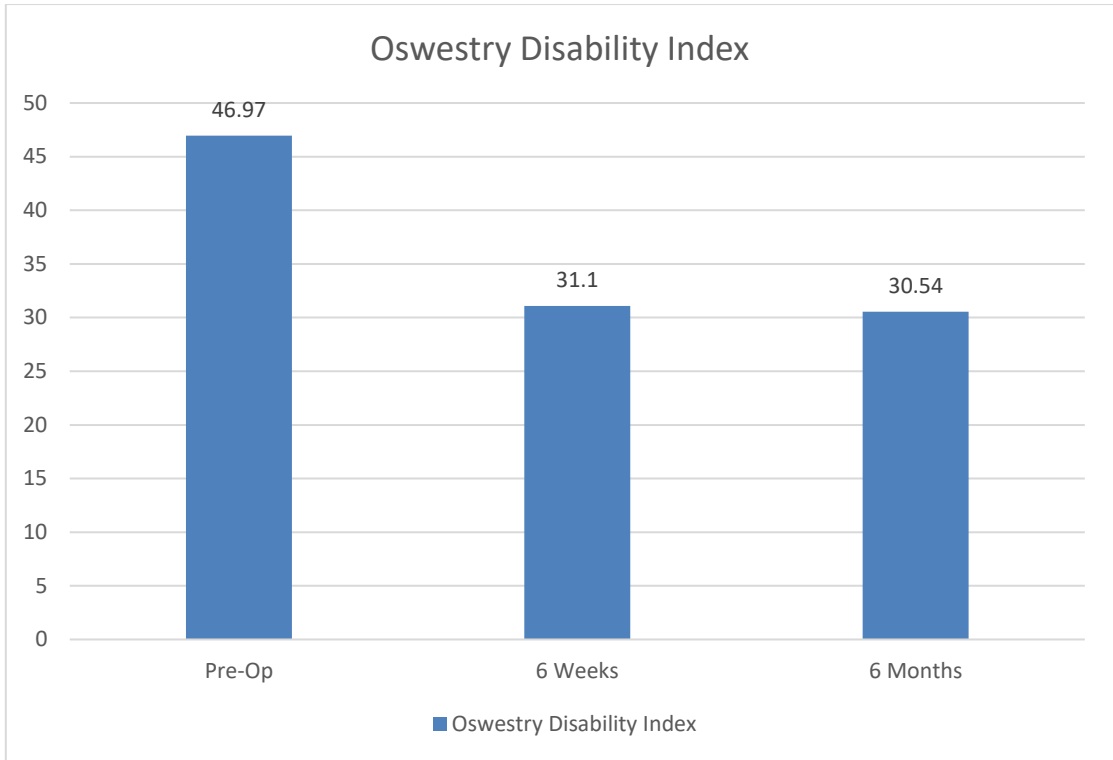
These statistics demonstrate that 25% of all patients on the BSR are currently 70+ years of age, whilst the patients aged between 21-30 make up just 4% of the Registry.

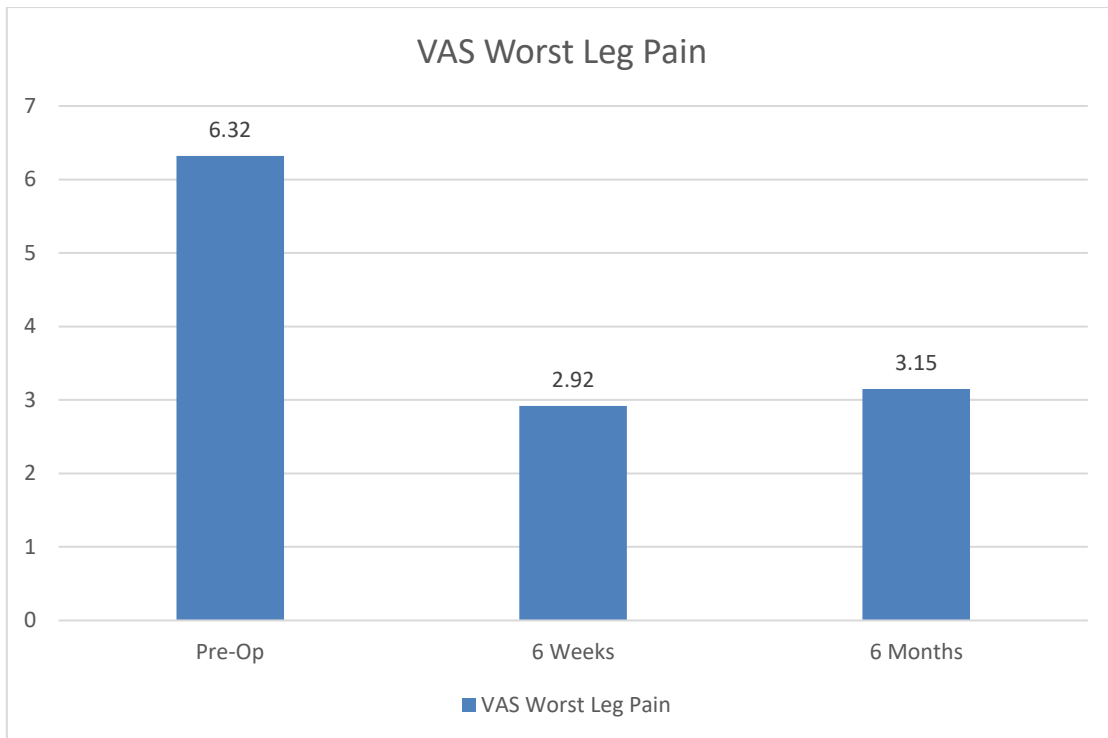
The recorded Patient Reported Outcome Measures (PROMs) are measured as follows:

- Pre-Op from 360 days before the intervention to 14 days after the operation
- 6 weeks from 15 to 70 days after the intervention
- 6 months from 71 to 270 days after the intervention

The PROMs outcome score averages are as below, representing averages across all pathways:

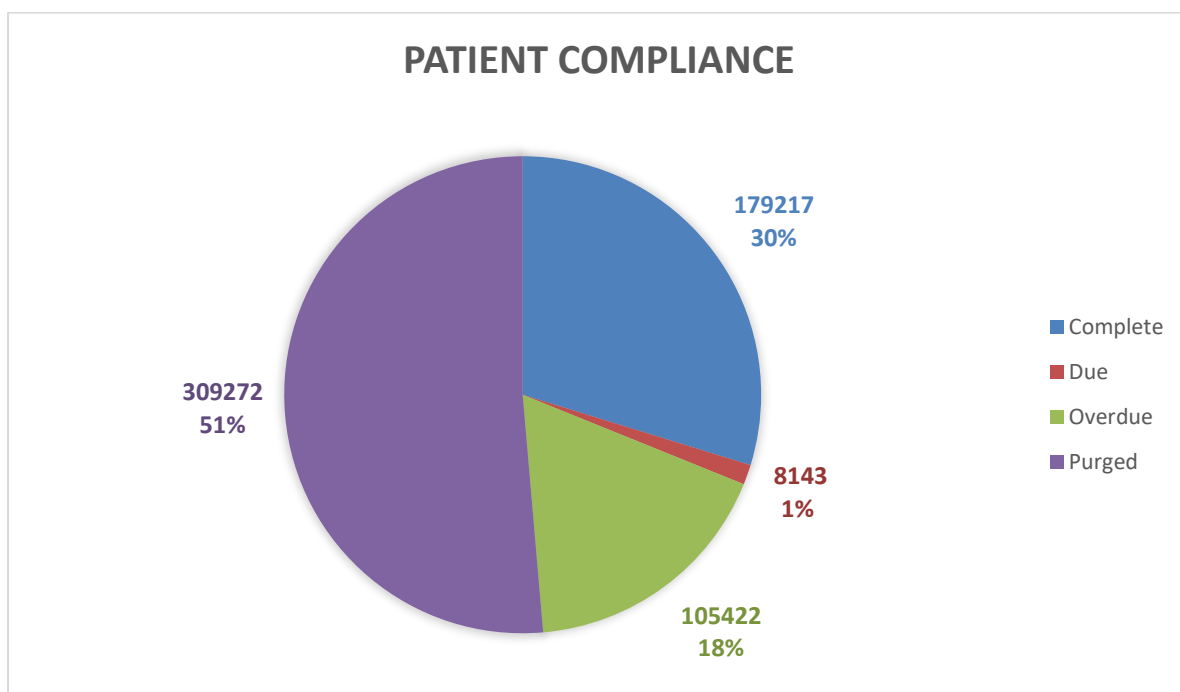






Patient compliance data is measured as follows:

- Complete scores – All scores completed by patients
- Due scores – Scores due for completion within the timeframe of 14 days' post intervention
- Overdue scores – Scores that are incomplete after 14 days' post intervention
- Purged – Scores are purged 90 days after the date they're due if they remain incomplete



Conclusion

The year 2016/17 has been an extremely successful year for the British Spine Registry. Overall statistics demonstrate that the number of users and patients on the system has increased significantly year on year.

Looking back over the year, there are still some significant areas of improvement for the Registry.

The collection of patient email addresses is essential and this must become a mandatory item when adding patient demographics at the point of being added to the Amplitude system.

The number of patients currently in the BSR, who have a contactable email address, is just 36%. A 1% increase on the previous year 2015/16. Without the collection of patient email addresses, the Registry's compliance will be hindered, therefore affecting the overall validity of the data being gathered.

Recording consent on patients is essential and we are entering an era that we will soon have to remove patient identifiable data from the system if it is not. We urge all users to review the consent status of their patients and correct it on the system retrospectively.

We can only make the registry better if we have user feedback. Please drop an email to the support team or registry lead and we will look into and prioritise registry requests in future upgrades.

If a training session would be of interest to your team, please contact the Amplitude Customer Support Team, or the spine registry lead, who will assist in organising a visit for you.

The BSR Steering Group would like to take this opportunity to thank all active users of the Registry, as without you all data collection wouldn't be possible.

Organisation

The BSR is powered by Amplitude and works collaboratively to ensure the registry's continuing success. Amplitude provides the BSR with the support desk and annual system support and maintenance.

The steering group is proactive and kept up to date regarding different issues, advice and feedback and it acts on this where appropriate.

If you are a member who would like to offer your feedback, raise issues or require support or advice in using the system, please contact the customer support desk on **customer.support@amplitude-clinical.com** where we can assist with your enquiry or escalate to the appropriate person.

The Steering Group

Mike Hutton
mike.hutton@nhs.net
BSR Chairman [BASS]

Lee Breakwell
Leebreakwell@nhs.net
Registry Lead [BSS]

BSR Amplitude Account Manager

Louise Claridge
louise.claridge@amplitude-clinical.com
0333 014 6363

Customer Support

customer.support@amplitude-clinical.com
0333 014 6363