ANNUAL REPORT 2023
SWESPINE 25 YEAR

FOLLOW-UP OF SPINE SURGERY IN SWEDEN 1998 - 2022

Contents

INTRODUCTION

This year's report from Swespine is a summary of the results of 25 years of work. We present what Swedish spine surgery has achieved over the years since the spine registry became national in 1998.

The registry covers five diagnostic groups:

1. Degenerative lumbar spine (LS)
2. Degenerative cervical spine (CS)
3. Deformity (DEF)
4. Primary infection (INF)
5. Metastases in the vertebral column (MET)

The largest group, LS, has been registered since the registry's inception, while CS, DEF, INF, and MET have been registered since 2006. In this report, we focus entirely on the registry's primary improvement mission – the outcome of surgery and its prerequisites – in the following sections:

- Geographical distribution of spine surgery in Sweden
- Review of the patient-reported outcome measures (PROMs) used.
- The latest year's 1-year and 5-year national follow-up
- Comparison of clinics regarding outcomes, coverage, and follow-up frequencies over time
- Longitudinal analysis of the five diagnostic groups over time
- Necessary measures for more reliable data and better outcomes

Responsible for the annual report

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Calculations and graphic presentation of funnel plots in section "Benchmarking" by statistician Henrik Hedevik, Linköping University

SUMMARY

The Registry

- The registry's starting point and data collection originate from surgeries conducted at public orthopaedic and neurosurgical clinics, as well as private spine units.
- The registry contains unique data absent in any available medical record system. These data are critical for assessing the patient value of spinal surgery. Within spinal surgery, there are essentially no "objective" outcome measures.
- In addition to purely factual data regarding diagnosis, surgery, and duration of care, all data concerning health status and surgical outcomes are patient-reported, utilizing subjective outcome measures known as PROMs (Patient Reported Outcome Measures). Data are collected both preoperatively and at follow-up intervals after 1, 2, 5, and 10 years.
- GA (Global Assessment), in combination with Satisfaction, is employed as the primary outcome measure for routine outcome monitoring.
- The number of spinal surgeries has consistently increased throughout all the years of the registry, until the onset of the COVID-19 pandemic in 2020.
- Private clinics account for a growing share of surgeries for degenerative conditions, both in the cervical and lumbar spine.
- Private financing (completely private or through health insurance) contributes to approximately 10% of this surgery.

In the registry, there are 169,812 surgeries up to 2021.

46 out of 47 clinics were connected to the registry in 2022.

The coverage rate is 86% (the proportion of registered operations out of the total performed)

Follow Up

1 yr. - 69%

5 yrs. - 55%

10 yrs. - 42%

173 publications based on registry data.

6 studies based on registry data started in 2022.

19 theses based on registry data during the registry's tenure.

Outcome

- In Figures 1-3, it is evident that the improvement in quality of life, as measured by EQ-5D, is sustained over time, at least up to the 5-year follow-up. Exceptions are central stenosis in both the lumbar and cervical spine (Myelopathy), which also involve older patients compared to other diagnoses. Details and changes over time are available in the "Longitudinal Outcome Analysis," page 49.
- Lumbar disc herniation continues to be the diagnosis with the best outcome after surgery, with no significant differences between various surgical methods.
- Spinal stenosis in the cervical and lumbar spine has worse outcomes than other diagnoses.
- For most patients with lumbar spinal stenosis, there is no need for fusion alongside decompression. There appears to be no advantage in preserving midline structures during decompression.
- Over time, there is no significant change in outcomes, except for Degenerative Disc Disease (DDD) in the lumbar spine, which improves over the years.
- For DDD, the outcome is at least as good with disc prostheses as with fusion. However, these are different patient groups.
- For cervical disc herniation with radiculopathy, the outcome with disc prostheses is not better than fusion and leads to more reinterventions than fusion.
- For central stenosis in the cervical spine with myelopathy, registry data suggest that anterior decompression with fusion may be better than posterior decompression.
- The number of surgeries for Rheumatoid Arthritis in the cervical spine has significantly decreased since 2006, because of new/improved pharmacological treatment.
- For idiopathic scoliosis, radiological correction is a primary treatment goal, although it is not documented in the registry. However, data show improved function and quality of life postoperatively.
- "Spontaneous" infection affects a patient group with high comorbidity. This leads to a high frequency of reinterventions and moderate effects on function and quality of life.
- Surgery for cancer metastases in the vertebral column has a single follow-up after 6 weeks. Data show improved walking ability and less pain.
- The outcomes after surgery for infection as well as metastasis must be interpreted with caution due to the very low follow-up frequency in these two groups.

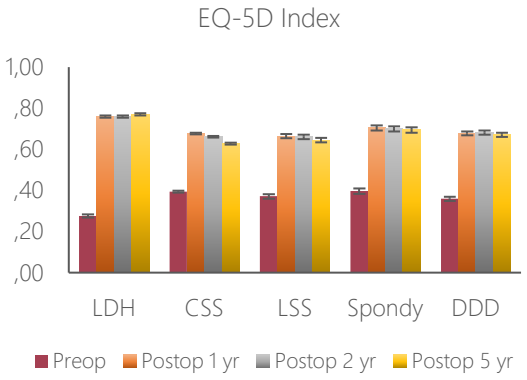


Fig. 1

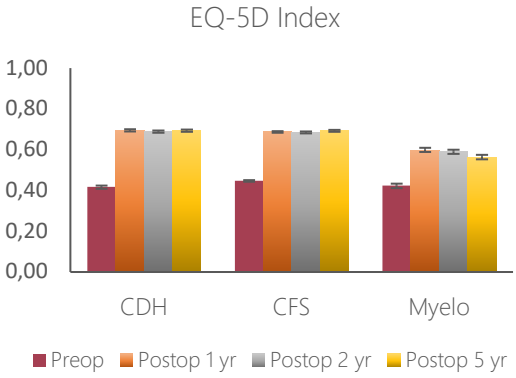


Fig. 2

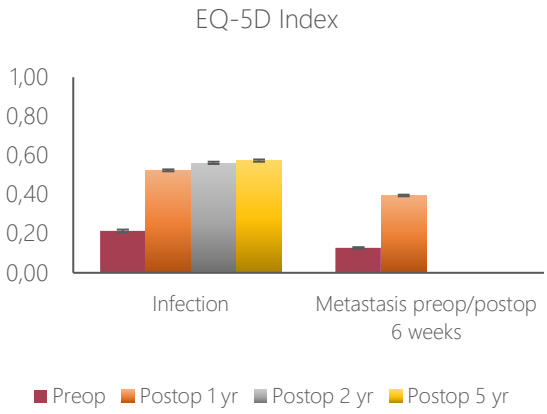


Fig. 3

Implant

- The registry contains approximately 450 different implant models, primarily various brands of pedicle screw systems and disc prostheses. Approximately 25 of these have been used in larger volumes.
- Over time, the use of different implant models varies significantly.
- Registry data do not provide an explanation for the large variation.

Benchmarking

- The primary mission of the registry is to create conditions for improving surgical outcomes. Comparing the outcomes of different clinics is a valuable and challenging method of seeking causes and improvement possibilities.
- The difficulties in making statistically reliable comparisons are evident from the funnel plots shown in the "Benchmarking" section, page 97. With small surgical volumes and significant data loss in the registry, confidence intervals and the uncertainty in interpreting the data become substantial. Hence, reducing data loss is crucial.
- Data loss occurs in three areas – at baseline, at the registration of surgical data (coverage rate), and at follow-up. Each clinic is responsible for the first two areas, where there is significant room for improvement. The third area is more challenging, and the steering committee has an important task in finding attractive ways for patients to respond to the follow-up questionnaires. University clinics consistently experience the highest data loss in baseline and surgical registration.

Erratum on page 99.

Improvement Projects

- The registry's three most important projects are to reduce loss in baseline data, increase coverage rates, and improve follow-up frequencies.
- The replacement of the 10-year follow-up (which has a response rate of <50%) with a 3-month follow-up to enhance the registration of postoperative complications should be considered.
- The evaluation and upgrade of the algorithms for case-mix adjustment is encouraged to increase the accuracy in annual clinic comparisons.
- The importance of radiology data (MRI, CT, x-ray) as predictors of outcome, should be evaluated.
- Computer aided radiological classification is a prerequisite of inclusion of such data in the registry and should be considered.

Abbreviations and explanations

Outcome measures

For elaborated explanations, see p. 45

GA (Global Assessment)	- Change of pain appreciation after surgery
Satisfaction	- Satisfaction with outcome after surgery
NRS (Numeric Rating Scale)	- Pain appreciation
ODI (Oswestry Disability Index)	- Functional outcome, thoracolumbar
NDI (Neck Disability Index)	- Functional outcome cervical
EQ-5D (Euroqol)	- Health related quality of life
EMS (European Meylopathy Scale)	- Spinal cord function
PmJOA (Patient modified myelopathy scale, Japanes Orthopedic Association)	- Spinal cord function
SRS-22r (Scoliosis Research Society questionnaire).	- Spine functional outcome, scoliosis
EOSQ24 (Early Onset Scoliosis Questionnaire)	- Spine functional outcome, early scoliosis

GA is the **primary outcome measure** in the analyses reported.

Rating of outcome is as follows:

Success means reply option **"Pain free"** or **"Much better"** pain.
Failure means reply option **"Worsened"** pain.
Indefinite means reply option **"Somewhat better"** or **"Unchanged".**

Diagnostic groups

LS	- Degenerative lumbar spine
CS	- Degenerative. cervical spine
DEF	- Deformity
INF	- Infektion
MET	- Spinal Metastases

Diagnoses

LDH	- Lumbar disc herniation
CSS	- Central spinal stenosis (lumbar)
LSS	- Lateral spinal stenos (lumbar)
DDD	- Degenerative disc disease
Spondy	- Isthmisk spondylolysis/-olisthesis
CDH	- Cevical disc hertniation
CFS	- Cervical foraminal stenosis
Myelo	- Myelopathy
RA	- Rheumatoid arthritis

Development of a National Spinal Surgery Quality Registry

- Swespine, Over the Past 25 Years; Reflections from a Registry Holder.

Peter Fritzell, Registry Holder 1998-2023

Over the course of 25 years as the registry holder for a national quality registry like Swespine, many changes and developments have occurred. Numerous stakeholders have provided input, and reaching consensus on all matters in a changing world is not always straightforward. Additionally, the operation is entirely dependent on external actors such as the Swedish Association of Local Authorities and Regions (SKR) and the National Board of Health and Welfare (Socialstyrelsen), as well as a multitude of working groups with various origins and mandates, all of which aim to influence the design, structure, and utility of the registry. In this text, I will provide both historical and contemporary perspectives, some of which may also be found in our annual reports. Regardless, these are my thoughts after a quarter-century as a registry holder.

Overall, it has been an extremely interesting period with many insights into how a registry machinery can and should be constructed and maintained to function in a complex environment and under constantly changing circumstances. Today, Swespine is considered the world's leading national quality registry in the field of spinal surgery, with numerous exciting collaborations, publications, both nationally and internationally, and many more initiatives in the pipeline.

I would like to express my gratitude to all members of the Steering Committee, both past and present, for their fantastic work. This especially applies to our "lynchpin," our registry coordinator Carina Blom, who has been with us throughout the journey. Alongside many other stakeholders, we have contributed to securing and enhancing the quality of care and, not least, research, both nationally and internationally.

I. Historical background – Data Collection for Healthcare Development [1,2]

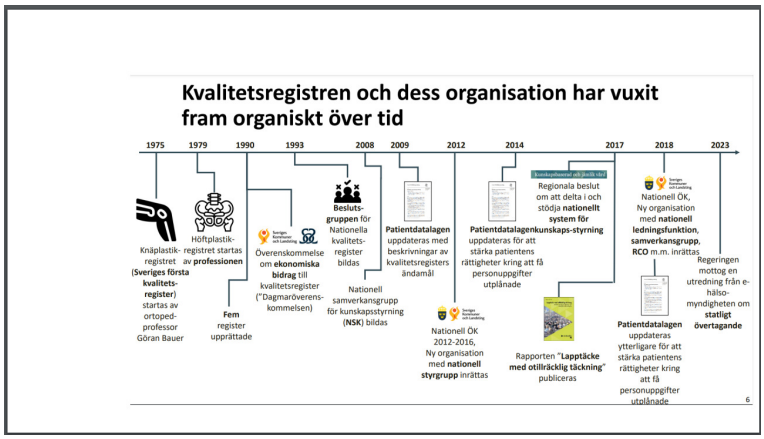
Nurse Florence Nightingale (1820–1910) and physician Ernest Codman (1869-1940) played crucial roles over a century ago in shaping the view of data collection and outcome reporting in healthcare. Codman coined the term "The End Result Idea" in the early 1900s. Both of their insights and contributions came during times of great turbulence, characterized by rapid events and a lack of ethical guidelines, which often defined healthcare. Florence drew many of her experiences and development proposals from her work with patients during the Crimean War (1853–56). Codman fell out of favour with colleagues due to his proposals to trace outcomes back to the care provided at the treating clinic, as many physicians saw it as a threat to their practice. This attitude gradually changed during the 20th century, especially after World War II.

II. Spinal Conditions

In an SBU report from 2000 (Alf Nachemson et al.), back pain was described as the second most common human ailment after the common cold, with 80% of people experiencing significant back problems at some point[3]. The spine is a central structure around which all other organs are placed. The head sits at the top, the arms originate from the shoulders attached to the scapulae, which are connected to the spine, and the same applies to the legs and pelvis. Our "posture" is, simplistically, dependent on the spinal joints and their interaction through various joints (including the ribs that form the ribcage), capsules, fasciae, ligaments, and muscles. In the spinal canal, the spinal cord sends nerves to all the body's organs, including those in the chest and abdominal cavity. This means that many conditions can be traced back to the spine in terms of their origin. Therefore, diagnosing various spinal conditions, selecting the optimal treatment, and identifying and recording relevant variables for treatment outcome evaluation are often complex tasks.

III. Swedish Quality Registries

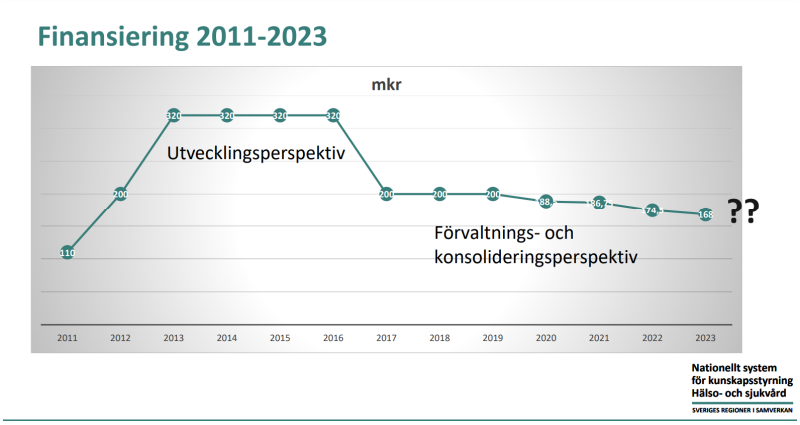
Swedish quality registries in the healthcare sector have existed since the 1970s when the first knee prosthesis registry was established in Lund in 1975, followed by the hip prosthesis registry in Gothenburg in 1979. Over the following decades, many diagnostic areas followed suit, and by the mid-2010s, there were over 100 such registries, with a significant expansion of central and regional National Working Groups (NAG), including National Program Areas (NPO), and most recently, the National Board of Health and Welfare's establishment of a working group for e-health[23]. *See figure below:*



230908/ The National Board of Health and Welfare´s working group for e-health/

When the former chairman of the Swedish Association of Local Authorities and Regions (SKL), now the Swedish Association of Regions (SKR), Jan-Erik Synnerman, around the turn of the century, was asked by me in a taxi on the way to a meeting how they wanted the national quality registries to be managed and developed, he replied that they had decided to follow the Chinese saying "Let a thousand flowers bloom." This meant allowing each registry for different diagnostic groups to develop on its own to access the greatest possible diagnosis-specific expertise and creativity. This approach resulted in considerable creative freedom, and in our case, it led to extensive structural work, including the relatively rapid dissemination of registry use to the country's operating spinal surgical clinics (which vary between 45-50 per year). This approach from SKL has gradually changed, and in 2006, Synnerman described how the registries had lived in a "no man's land" for too long, and that registry structures needed to be coordinated, including the measures/variables that were used.

This pursuit of centralization of both used variables and data storage/usage has continued and is now the overriding goal of central actors. In the early 2010s, SKL and the National Board of Health and Welfare (Socialstyrelsen) had a pronounced enthusiasm for national registries (which still exists, but they now want to be more involved in detailed control), describing registry data as a "gold mine" for securing and developing quality in healthcare, including research. Before 2011, the registry economy was relatively uncertain, with annual hopeful applications to SKL. However, this changed dramatically around 2012. During a four-year period, from 2013 to 2016, the annual registry allocation increased to 320 million SEK per year. After these years, the situation looks different again. Now, the reliance is on increased digitization in society to make data collection, storage, retrieval, and data usage more efficient and cost-effective. This has been questioned by many actors "on the ground." See the following image:



Jack Lysholm/230908

IV. A Spinal Surgical Registry

A spinal registry was created in Lund in 1993 by Björn Strömqvist and Bo Jönsson, among others. The registry was taken over by the Swedish Society of Spinal Surgery (4s) in 1998, including responsibility for administration and development. This decision was made because it was believed to have better prospects to make the registry, now called Swespine, national rather than regional. Colleagues from Lund have continued to be represented in the Steering Group throughout this journey.

In a dissertation from 1995, by Bo with Björn as a supervisor, the importance of using PROMs instead of relying primarily on retrospective studies and surgeon-assessed outcomes was emphasized[5].

Complexity. Due to the complexity of spine conditions, both in terms of diagnosis and treatment, it was decided, after in-depth discussions, to only register surgical treatments. This was primarily because the range of non-surgical treatments and their follow-up was considered too extensive and difficult to define, which would make relevant interpretation "impossible." One important reason was that we did not want to overextend ourselves. Different surgical treatments combined with extensive and often complex diagnostic areas were a sufficient challenge. The idea of including non-surgical diagnoses and treatments in Swespine in the future is not ruled out.

Steering Group. A national Steering Group with geographical representation from north to south was established, with the registry holder as the convener. In the first year/years, the focus was on determining relevant measurement variables that could capture what was considered important to support and help both the profession and patients make the most informed choices regarding diagnosis, surgery, rehabilitation, and follow-up, as well as to be able to track potentially unwanted events after surgery. The overall goal was to use registry data to secure and improve healthcare quality and support research.

The Steering Group consists of representatives from the surgical profession (orthopaedic/neurosurgeons), nursing (nurses), primary care (general practitioners), rehabilitation (physiotherapists/chiropractors), and patients[25]. The registry holder and a registry coordinator coordinate the activities. Patients are represented through focus group interviews (see Variables below) because there is no patient association for patients treated with spinal surgery. The Steering Group collaborates with its registry centre, Registercentrum Sydost (RCSO)[12] in Region Jönköping County (RJl)[11].

Registry Office. After in-depth discussions, the Swedish Society of Spinal Surgery (4s, www.4s.nu) decided early on to create a Registry Office, where salaried secretaries could assist with the follow-up of clinic's operated patients, while the clinics themselves are responsible for registration at the time of surgery. The clinics that wished to do so could sign up for membership in the Registry Office through our registry coordinator. Currently, 33 out of 46 clinics have their results followed up by this office, while non-affiliated clinics follow up their patients themselves. There is no room for more clinics to join today.

Variables. The issue of what to register, i.e., what, how, and when, can be managed through careful evaluation of relevant variables. PROM (Patient Reported Outcome Measure), which Swespine primarily relies on, describes how the patient perceives the result of the given treatment. Following demands from SKL at the time, PREM (Patient Reported Experience Measure) was also incorporated into the registry. These were developed with the help of focus group interviews with patients from the three different types of hospitals participating in Swespine: University Hospitals, County Hospitals, and Private Clinics. The report has been published on the 4s website since 2016[6].

Registration and Follow-up. We decided early on to prioritize registration in close connection to surgery. Follow-up was determined to occur after 1, 2, 5, and 10 years. The time intervals were chosen because several procedures were believed to create a situation where the surgical method could also affect the spine/life quality in the long term. For example, it could apply to a fusion surgery of one or more segments that could lead to increased stress on the joints around the operated area, with long-term increased morbidity. Another implant we wanted to follow for a long time was disc prostheses. It is also interesting, when the opportunity arises, to compare the outcomes after operated patients with those who underwent non-surgical treatment. Of course, other measures, such as complications, reoperations, implants, and various process measures like operation time, length of stay, sick leave, etc., are also included.

Another reason for our four follow-ups is to provide data for cost-effectiveness studies. To make relevant cost calculations for both direct (healthcare) and indirect (societal costs, e.g., sick leave, which accounts for about 80% of the total costs,) costs, a regular follow-up is important. This would advocate that the 2-year follow-up be retained even though we have been able to show that patient-reported outcomes do not vary between the first and second year after surgery.

In recent years, the Follow-Up (FU) has remained at approximately 70%[13]. The discussion to follow up after 3 months, possibly to gain a better understanding of potential adverse events and complications perceived by the patient, is ongoing within the Steering Group.

Follow-up Method: Alongside the increased digital patient reporting, we have chosen to retain the option of using paper forms. This decision is partly attributed to the fact that a significant proportion of our patients undergo surgeries for lumbar spinal stenosis (the narrowing of the spinal canal, accounting for over 50% of all operations), with an average age of

approximately 70 years. Many of these patients are not accustomed to digital reporting, though this may change in the foreseeable future. From a perspective of change, we have been able to reduce the number of secretaries in the office by half since our inception. In 2023, a total of 2.2 full-time positions are currently employed, compared to the peak of around 5. A concern in this era of the proliferation of digital communications is that patients may abstain from responding via digital means, making the availability of paper forms relevant. Presently, in 2023, approximately 70% of patients are being followed up digitally.

Patient Information: Patients are informed about the implications of participating in the registry through written instructions available on the website. Information is also displayed on notice boards in the waiting rooms of the clinics, and registering physicians provide information. For many years, we have employed the "opt-out" approach, which means that if a patient, after receiving the information, does not actively opt out of registration, it proceeds. This approach is internationally accepted and legally approved, also minimizing the risk of low registration rates. It is made explicit that participation is voluntary, and that one can have their data removed from the registry at any time without providing a reason[7].

Compensation - Professionalism - Quality: Right from the outset, our Steering Committee made it clear that the annual financial resources sought from the Swedish Association of Local Authorities and Regions (SKL) must adequately cover compensation for the registry holder, registry coordinator, registry office, and the Steering Committee itself to ensure professionalism, compliance with standards, and quality. Handling such an extensive and demanding task on a voluntary basis, such as creating data structures, storing data on relevant platforms, collaborating with statisticians, data analysts, and health economists, ensuring and enhancing the quality of care with the support of registry data, presenting comparative outcome data for both the profession and the public, supporting registry research, collaborating with other registries both nationally and internationally, and engaging with platform providers, is only feasible through compensated individuals within the relevant professions.

Newsletter: Swespine will commence quarterly newsletters starting in 2023, initiated by our member from PV, Olof Thoreson. The newsletter will provide updates on the developments in the registry world and can be accessed on our website[25].

Annual Report: Starting in 2023, the annual report will feature a new layout, which is an important effort to make the results more accessible and comprehensible for all stakeholders. A commendable job in this regard has been carried out by the working group, which was assigned this task in March 2023, consisting of Catharina Parai, Olof Thoreson, Olle Hägg, and Carina Blom.

V. Registry Platform

All data is stored on a central registry platform, where operating clinics have free access to their own data primarily for use in securing and improving quality. For research purposes, access to data from other clinics is also available, subject to application to the 4S and approval from the Ethical Review Authority (EPM, formerly EPN)[8].

Swespine has had to transfer data on two occasions from the registry platforms we were using, most recently in 2022-23 from Decerno to MedSciNet, now CSAM, and previously from the Cytise platform to Decerno in 2006. Our new platform was recommended by the Register Centre we are affiliated with, RCSO, and everything has finally been completed in 2023. Overall, it took two years, which is like the previous migration. It's important to note that these transfers have allowed significant improvements in the registry to be implemented, so the migration has also been used for positive purposes.

Spine conditions are often complicated, with many different sub-diagnoses and a variety of treatment options for patients who can be between "1-100 years old" Therefore, an extensive and carefully thought-out fine-grained structural work is required to register and provide useful information in a relevant way, that can assist the profession and ultimately the patients. This is one reason why it is important to have a very close collaboration with computer programmers connected to the platform who are familiar with the problems and possibilities.

VI. Legal Aspects

With the amount of data circulating about individuals, there is a risk that this data may be misused or fall into the "wrong hands." Therefore, the European Union introduced the GDPR (General Data Protection Regulation)[9] in 2018, which is legislation on the management of personal data. In Sweden, it is referred to as the Data Protection Regulation (Dataskyddsförordningen). This regulation governs how personal data can be handled, which has required a strict review of what data can be disclosed to the profession, clinics, patients, and other organizations like ViS (Vården i Siffror) and RUT/VR (Register Utilization Tool/Vetenskapsrådet)[10] with whom we have had collaborations for several years.

Regarding research, we have the practice that the board of the Swedish Spine Surgical Society assesses the appropriateness of data disclosure in each individual case, and almost always, as part of this assessment, approval from EPM is required. The authority that ultimately must approve the disclosure is CPUA (Centralt Person Uppgifts Ansvarig), in our case, Region Jönköpings län (Rjl). Each healthcare provider is a PUA (Personuppgiftsansvarig) under the Personal Data Act (Personuppgiftslagen). When data is in a registry, each respective CPUA is also PUA. Much of this is handled practically on behalf of Swespine by Håkan Löfgren in the Steering Group because he is employed in Rjl, which is the registry's principal. It's a pragmatic solution. Håkan is also the treasurer of Swespine. The fact that the registry holder is also employed by the region has been practical. In connection with the change to employment outside the region, a special agreement must be drawn up.

The legal field can be quite complex, and we have received assistance from an employed lawyer at SKR, in recent years, Manolis Nymark. Our Register Centre, with Christina Petersson as the current head, can also provide help in this area (see Section VIII).

VII. Registry Centre Organization (RCO)[11]

Each healthcare region has taken on the task of running an RCO. In all six healthcare regions, there is a Registry Centre (RC) and a Regional Cancer Centre (RCC). The RC and the quality register-related activities within the RCC together form an RCO. Registry Centres provide support to quality registries at the start, development, and operation of the registry. All National Quality Registries are connected to an RCO. Register Centres hold regular meetings in the RCO Collaboration forum to discuss strategic areas where cooperation and knowledge exchange are important for registry development. The purpose is to increase collaboration and reduce competition and clarify the distribution of responsibilities between registries and Register Centres. Each region responsible for an RCO should provide support for the start, development, and operation of the registries and contribute to increasing the use of registries in healthcare improvement work and research.

RCSO (Register Centre Sydost)[12] situated in Jönköping, where our CPUA is also located, is the centre that should support Swespine with advice and actions as described above. Over the years, we have particularly wished for help from statistical expertise as well as health economics. However, we have not received this due to budget constraints. Since the beginning of 2023, we have chosen to hire a statistician, Henrik Hedevik, who works at Linköping university, and has solid knowledge of registry work through his previous involvement with the cruciate-ligament registry. This hiring has been made possible through the grants we have received from SKR.

VIII. Spine Surgery Research in Sweden

Research in the field of spine surgery in Sweden is primarily conducted using registry data today. We have also published several articles in international journals in collaboration with Nordic and other European countries. Each year, between 10 to 20 studies using Swespine data are published (in 2022-23, there have been 24 so far), and about twenty theses since 2000 are based on this data. So far, there are around 180 published articles based on Swespine data[13].

IX. National Projects/Collaborations

SKR (Swedish Association of Local Authorities and Regions)[14]. Swespine has, over the years, maintained a collaboration with SKR, which is a membership and employer organization (not a governmental authority). All municipalities and regions are members of SKR. SKR's mission is to support and contribute to the development of the activities of municipalities and regions, serving as a network for knowledge exchange and coordination. This role includes providing services and professional guidance on all matters within which municipalities and regions are active. Courses and conferences are offered, including to national quality registries, and Swespine/register holder has, over the years, participated in many physical "roundtable discussions." These were suspended during the COVID-19 pandemic but have resumed in the autumn of 2023. Ongoing online meetings with SKR, RCSO, and NKRF are regularly conducted.

Swespine was upgraded by SKR to the highest certification level, C1, in 2017, based on the quality of its operations. This entails, among other things, a greater opportunity to receive central funding. We now report twice a year (previously four times), firstly through Q1 with a deadline in the spring (March) and then through Q4 with a deadline in the autumn (September), about everything that is happening within our diagnostic area. These reports include a description of the assurance and development of healthcare quality measured in various ways, as well as research production, the annual activity report, finances/budget, funding applications, and future plans, as well as the Annual Report. These are also openly available on the 4s website[13].

Clinic Projects. Over the years, several initiatives have been undertaken to increase interest in optimal participation in registry work at the country's clinics. In a project launched by SKL (Swedish Association of Local Authorities and Regions), Swespine/Steering Group received a grant of 400,000 SEK to visit all clinics interested in receiving registry information and on-site guidance. We visited a total of about 25 clinics on-site in the mid-2010s and had virtual meetings with most others. This resulted in a significant increase in registration frequency, i.e., completeness.

Value-Based Healthcare was initiated in 2013 in collaboration with the Swedish Spine Society (HSF), the Steering Committee, and three major private clinics: Stockholm Spine Centre (SSC), Nacka, and the Ryggkirurgiska Kliniken i Strängnäs (RKS). Health economists from Quantify Research (QR) participated in this group. The project resulted in a system linking reimbursement from the Stockholm County Council (SLL) to patient-reported outcomes one year after surgery. A report from Linköping University described the multi-year project as both negative and positive. Primarily, the reimbursement level linked to Patient-Reported Outcome Measures (PROMs) was criticized for being too low (10%), and SLL was criticized by participating clinics for lacking flexibility in making changes to the model based on practical knowledge gained during the project. Value-Based Healthcare is described here[15].

Dialog Support: As a result of the collaboration with SLL, we developed a tool that, based on registry data, can be used to discuss potential surgical outcomes with patients. We call this tool "Dialog Support"[16], and it is available to healthcare professionals and the public through our website[13].

Legally, the tool cannot be used as a "decision support," a term that is highly debated, meaning it cannot be used to make surgical decisions. However, it can be helpful in guiding both the healthcare professional and the patient to reasonable conclusions about surgical outcomes at the group level. The group level is legally significant here. Using registry data in clinical practice in this way should, in my opinion, be one of the primary objectives of running quality registries. The tool has gained international attention and has been available in an English version since 2020 on one of the world's largest spine surgery websites, Eurospine[17].

SVEUS: This was another project in which the Steering Committee participated. It had its roots in the popularity of Value-Based Healthcare in the mid-2010s. The SVEUS project was carried out over several years in collaboration between various regions and health economists at IVBAR. SVEUS was a research and development effort aimed at developing better methods for value-based monitoring and reimbursement of healthcare. Seven regions and counties participated with support from the Ministry of Health and Social Affairs, and the work was conducted in close cooperation between principal authorities, specialty associations, quality registries, and patient associations. In total, more than 50 organizations were involved. A report was presented in 2015[26].

ViS (Vården i Siffror): Here, everyone, including the public, can inspect patient-reported outcomes/clinics one year after surgery for lumbar spinal stenosis, lumbar disc herniation, and cervical disc herniation. The results are adjusted for case-mix to ensure the most reliable comparisons possible. Data is continuously updated and is based on group outcomes from Patient-Reported Outcome Measures (PROMs) over the past ten years[18].

RUT (Register Utilizer Tool) /VR (Vetenskapsrådet)[10]: Swespine has been participating in this since 2022. The metadata tool RUT provides a structured overview of the data available in Swedish registries and biobank sample collections. RUT describes the contents of the registries with standardized and detailed metadata, allowing advanced searches and comparisons of different variables from multiple perspectives. RUT includes information about the meaning and value range of registry variables, enabling researchers to evaluate whether the variables can be used to answer specific research questions.

NKRF (Nationella Kvalitetsregisterföreningen)[19]: To involve the medical profession in the activities related to national quality registries, NKRF was created in 2016. It is striking how, over the years, central authorities such as the National Board of Health and Welfare (Socialstyrelsen) and the Swedish Association of Local Authorities and Regions (SKR) have acted without considering the experiences and viewpoints of the profession. The establishment of NKRF has not significantly addressed this issue, as many of the so-called national working groups within various areas (NAG) choose not to involve the profession/registry holders in their respective activities. Perhaps this can change.

NPO (Nationellt programområde)[20]: All national quality registries must be connected to an NPO with a subtitle describing the area within Healthcare of Sweden (HoS) it pertains to. In our case, this is "musculoskeletal diseases," based in the Västra Götalandsregionen (VGR). In 2022, Allan Abbott in the Steering Committee, along with representatives from the field of spine surgery, including Peter Försth, chairman of 4s, led a working group that developed national recommendations for specific symptoms and diagnoses, Standardiserat vårdförlopp (SVF). This covers the path up to potential spine surgery but not the actual surgical treatment itself.

X. Collaboration with Industry

Collaboration with the industry has become an opportunity supported by the central authority to help economize the operations of national quality registries. The key condition for these agreements with companies is that they must be legally comprehensive, particularly regarding de-identified data to prevent tracing individuals. The compensation currently cannot result in a profit for the register but is intended to cover the costs associated with delivering data.

The international EU regulation MDR (Medical Device Regulation)[21] that came into effect in 2021 has been crucial in fostering collaboration with the industry. Medical device companies find it relatively straightforward to use national registers for monitoring their medical products and implants. The purpose of MDR, according to legislators, is to enhance patient safety through improved oversight and control. Swespine has collaborated with DePuy/J&J[22], providing the company with information on their used implants. This collaboration has resulted in the delivery of two sets of reports prepared primarily by Olle Hägg, an essential member of the Steering Group, and Carina for structural review.

DePuy/J&J has expressed interest in further annual reports, and negotiations regarding the pricing for these reports are ongoing. The company currently requests detailed time estimates for each contribution from Swespine, while Swespine is seeking a fixed price per report. Delivered reports are stored behind a firewall on Swespine's website, and access is provided via mobile Bank-ID. The reports can be found under the "Start" section: [Swespine Reports] (https://www.swespine.se/).

XI. Trends in National Quality Registries

In Sweden, there is currently an ongoing trend towards increased centralization, especially regarding the registry platforms. Private actors (where Swespine is currently hosted through CSAM Health Group AS, recently rebranded to Omda) appear to be devalued in favour of public ones. So far, signals from Swespine's RCSO indicate that there is no immediate concern. However, one of the National Working Groups (NAG) is working on the issue, and within the next year, decisions regarding the direction of this centralization may become clearer. Ongoing investigative work is taking place in national working groups, including the NASG DA (National Working Group for Data Analysis), with the aim of coordinating variables, analyses, and more in national registers.

E-Health is another significant trend. Socialstyrelsen (The National Board of Health and Welfare) has been tasked with exploring e-health, where a central aspect seems to be the consolidation of all data on a central registry platform. The purpose is to facilitate what is termed "knowledge-based care"[23].

Regarding future projects, each national register must annually report to SKR on what they consider important. For 2024, Swespine has described and requested funding for the following points:

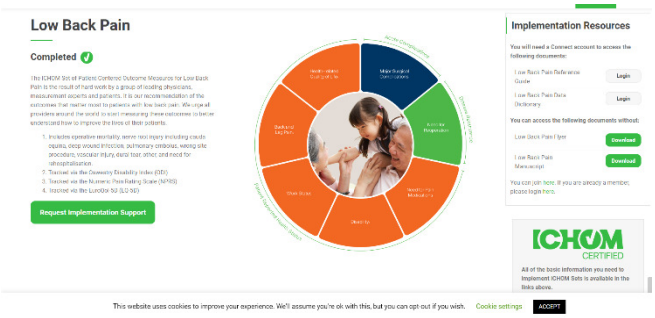
- Validation of surgical and diagnosis data, as well as reoperations and other complications, through cross-referencing with other registers (PAR, individual hospital registers, possibly SPOR) and by reviewing patient records.
- Registration of complication data is complex, likely underreported, and extensive work is needed to establish better routines for capturing such data.
- Evaluation of introducing patient self-registration of follow-up data via the internet. This method reduces the workload for the registry and healthcare in terms of data entry. However, initial analysis shows a decrease in follow-up frequency since the registry implemented this routine. More detailed analysis is required to evaluate the changes and explore opportunities for improving follow-up frequency while maintaining the labour-saving method.
- Developing digital alternatives to sending letters to patients for follow-up after 1- and 2-years post-operation. Alternatives like text messages, KIVRA, and 1177 are being discussed.

Accessibility for people with disabilities, such as the deaf and blind. Since 2022, SKR has required that registries provide equal access to information on their websites for these individuals. This means that all registries must offer audio information for the visually impaired. Swespine is working on this, but it involves financial considerations, which are not straightforward to resolve.

XII. International Registry Collaborations.

During the 2010s, several countries expressed interest in benefiting from the experiences achieved in Swespine, and the registry structure was made available at a "purchase price" to Denmark, Iceland, the Netherlands, and Finland. Other countries like Italy, New Zealand, Canada, the UK, and Switzerland have contacted Swespine over the years for registry-related advice and assistance. Members of the Steering Group have presented the registry at numerous registry conferences around the world.

ICHOM. Between 2012 and 2014, representatives from Swespine (Peter Fritzell, who served as a working group leader, Olle Hägg, and Björn Strömqvist) were invited to join the International Consortium for Health Outcomes Measurement (ICHOM). After nearly two years and many online meetings, a recommendation was made to endorse a set of variables relevant to covering spinal disorders and the follow-up of treatment outcomes[24].



Stanmore Initiative 2023. In 2023, an initiative was launched by Stanmore University for international European collaboration on data to be included in national quality registers. The task of leading the work on the selection of Patient-Reported Outcome Measures (PROM) was assigned to two members of the Steering Committee, Olle Hägg (OH) and Peter Fritzell (PF). A physical meeting took place in the UK earlier this year, with OH attending in person and PF virtually. Several virtual meetings have been conducted during the spring, summer, and autumn, and a physical meeting in Frankfurt is scheduled in conjunction with Eurospine's annual meeting on 4-6 October. PF will attend in person, while OH will participate virtually. Industry partners are actively involved, including the company we collaborate with, DePuy/J&J, due to the requirements imposed by the Medical Device Regulation (MDR)[21].

XIII. Reflections from Me as the Outgoing Registry Holder.

Many Swedish national quality registries are currently unique assets that position Sweden prominently on the global stage concerning healthcare planning and evaluation. These registries can help us ensure and enhance quality while contributing to cost-effectiveness, considering the perspectives of healthcare professionals, patients, the public, as well as research and economics. The financial aspect is crucial and must be an integral part of the profession's thinking.

Therefore, we possess a robust national and international standing in the domain of registries, with ample opportunities for global collaboration. Presently, it appears that there is some redundancy in efforts at the central level. This means there is uncertainty regarding the future placement of registry data and how it will be collected and delivered. Over the past years, numerous national working groups with often similar objectives have been established, albeit from different perspectives. The discussion surrounding registry platforms exemplify this "double work."

There is a prevailing trend to centralize national registry management through large public registry platforms and data analysis units. This future might be unavoidable, but based on my experience, it may diminish the ability of individual diagnostic groups to comprehend their specific and pertinent questions. Having programmers and administrators familiar with the unique aspects of various diagnostic groups is, in my experience, crucial for the smooth operation of a registry.

Economically and from an efficiency perspective, there might be an overestimation of the potential for large units with employed technicians, programmers, and administrators to save money and enhance efficiency. Regardless of my beliefs, we are presently heading towards this reality, and we must do our utmost to contribute to ensuring that the outcome is as good as possible. Pragmatism is ultimately essential in this endeavour.

Soon, we have an exciting annual meeting with Swespine in focus, to be held in Stockholm on 9-10 November. The board of the Swedish Society for Spine Surgery has decided that the 2023 annual meeting should focus on "Swespine 25 years." Register holders from different countries have been invited, and four themes have been selected:

- *THEME 1: Prediction of outcomes using register data - Practical examples*
- *THEME 2: Devices to be registered and how (MDR) - Practical examples*
- *THEME 3: Variables included in a spine register*
- *THEME 4: The future - How can we cooperate? National, international, and cultural perspectives*

The preparations for the annual meeting have been ongoing for the past six months, and invitations have been sent to register holders from Denmark, Norway, Finland, the UK, the Netherlands, and the European Union (Spine Tango). We have received a very positive response from all invitees, and multiple participants are expected from each country. We are genuinely looking forward to an exciting meeting at the Hasselbacken conference centre, where we regularly convene.

In conclusion, members of the Steering Committee have been invited to numerous conferences over the years, both at the national and international levels, to present Swespine and the results derived from our data. Personally, I am making my presentations available to the profession through 4s via our website, behind a firewall. Carina is working on this, and we will inform everyone when it is ready. Each colleague is free to use this material based on their own professional needs.

Once again, I would like to express my gratitude for an immensely rewarding and intellectually stimulating period as the registry holder for Swespine. I wish my successor at the turn of the year, Björn Knutsson at Sundsvall/Umeå University, and a member of the Steering Committee, a warm welcome to take the helm.

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NATIONAL OVERVIEW 2022

In total, 11,122 index operations* were registered in Swespine during 2022. This includes the diagnostic groups of degenerative lumbar spine, degenerative cervical spine, deformity, infection, and metastasis.

Distribution of Spine Surgeries by Region

The total spine surgery performed in 2022 is distributed regionally, per 100,000 inhabitants, as shown in Fig.4.

The largest proportion was conducted in the following regions:

- Region Jönköping: 165
- Region Stockholm: 164
- Region Uppsala: 163
- Region Västra Götaland: 130
- Region Blekinge: 122

The high frequency of spine surgeries is concentrated in regions where private clinics are situated (except for Blekinge). This implies both that these regions have significant access to spine surgery and that patients from other regions may also seek treatment at these clinics.

*Index Operation = the surgery that generates follow-up assessments at 1, 2, 5, and 10 years. A reintervention does not trigger separate follow-up but is included in the assessment of the index operation. If a new index operation (i.e., a new diagnosis and/or new location) is performed, the follow-up of the previous index operation is discontinued.

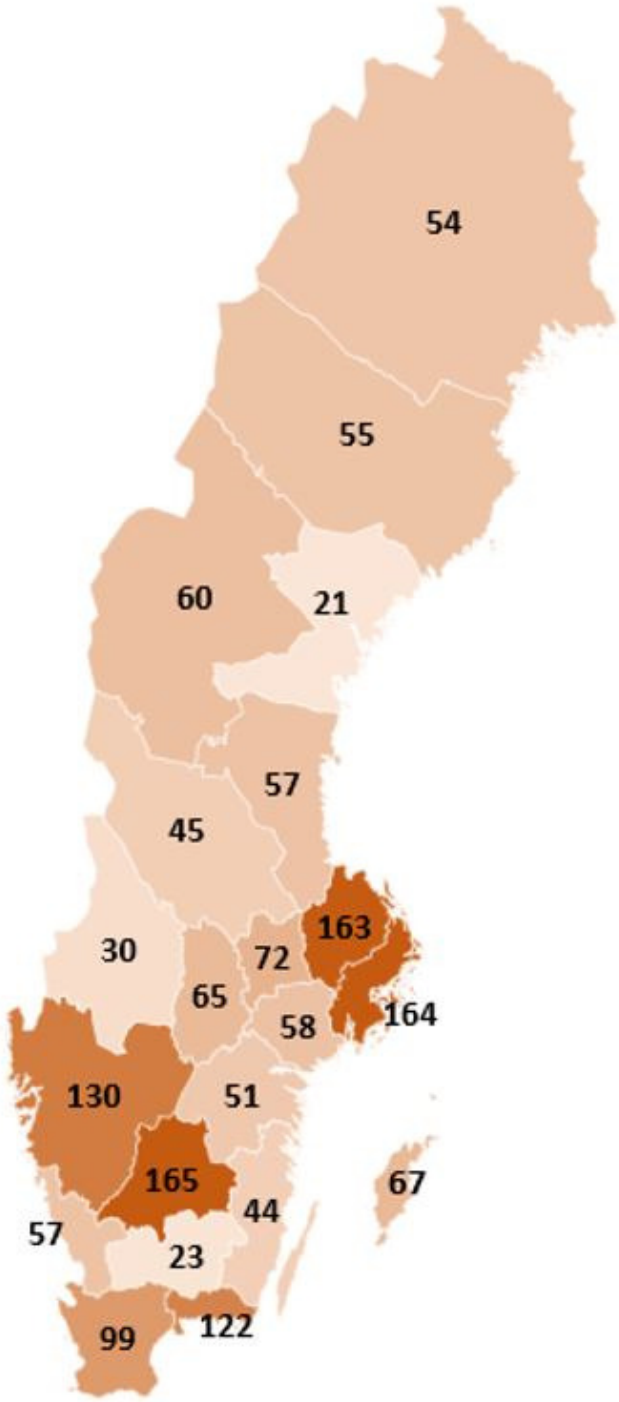

Fig.4

Distribution of Diagnostic Groups in 2022

The total spine surgeries performed in 2022, amounting to 11,122 operations, are primarily composed of degenerative lumbar and cervical spine conditions. The distribution is illustrated in Figure 5.

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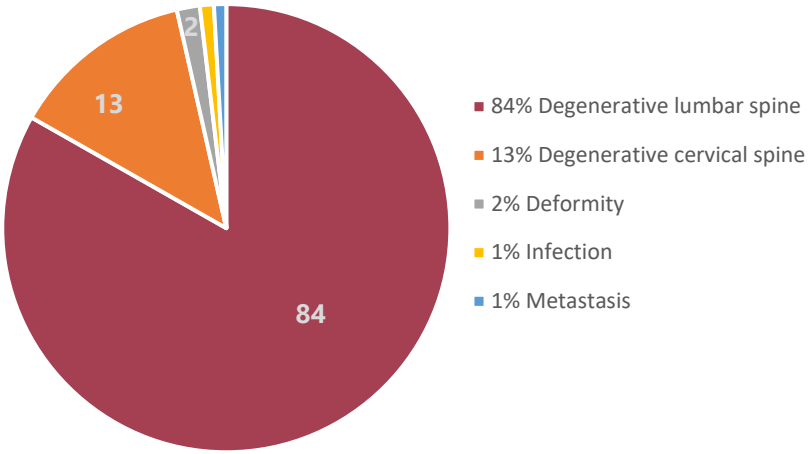

Fig. 5

Total Number of Spine Surgeries Per Year

The registration of spine surgeries in Swespine commenced in 1998 with only a few clinics participating. Since then, several clinics have joined, leading to an increase in the number of surgeries over time. The registry currently encompasses over 86% of the country's surgical procedures. However, following 2020, we observe a slight decrease in the volume of surgeries performed, which is likely attributable to the COVID-19 pandemic that began at the end of 2019 (see Fig. 6).

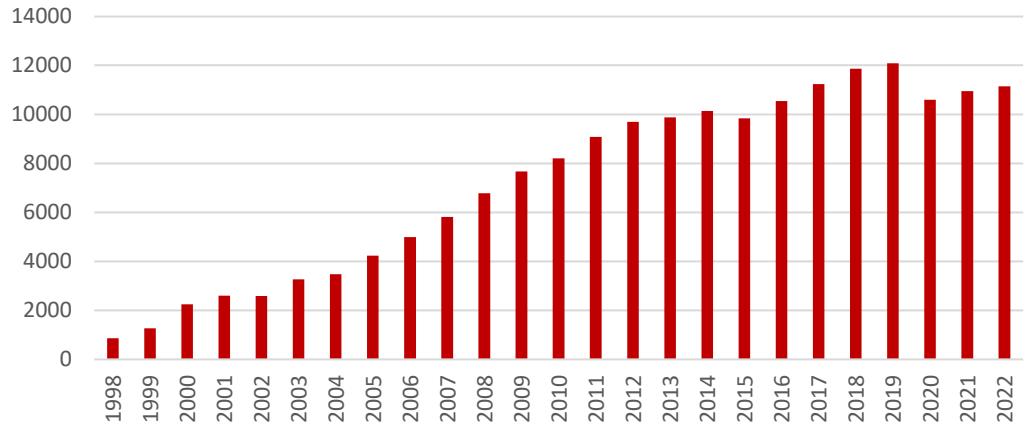

Fig. 6

Follow-Up Frequency at 1 Year

All surgeries are subject to follow-up assessments at 1, 2, 5, and 10 years, during which the patient's perspective on their disease and health after the surgery is collected. The questionnaires/tools used include EQ5D index, EQ5D VAS, Oswestry Disability Index (ODI), Neck Disability Index (NDI), European Myelopathy Scale, P-mJOA, SRS22r, EOSQ24, and a registry-specific form that captures data such as BMI, smoking status, workability, satisfaction, leg/back pain, rehabilitation, and complications. The data quality of the registry for research and quality improvement in healthcare heavily relies on a high response rate, which is reported for the two largest diagnostic groups, degenerative lumbar spine, and degenerative cervical spine, in Figure 7.

Registration of cervical spine surgery was introduced to the registry in 2006.

For a detailed presentation of PROM (Patient Reported Outcome Measure), please refer to page 44.

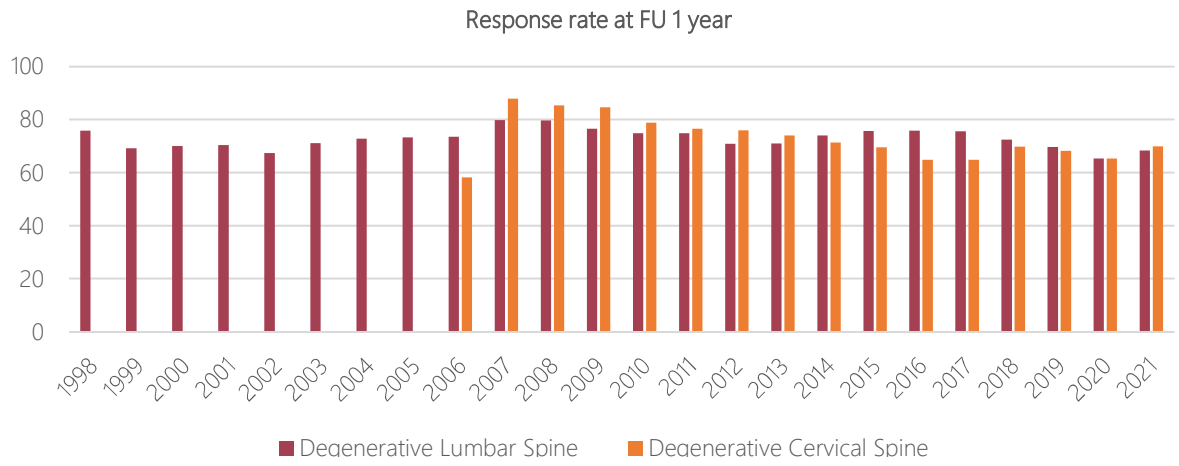

Fig. 7

Completeness

The Swedish Spine Registry, Swespine, was initiated in 1993. The registry's purpose is to document all spine surgeries performed in Sweden at orthopaedic, neurosurgical or private spine clinics, excluding fractures and primary tumours, which are to be recorded in other quality registries. Completeness (%)= Primary spine surgeries in Swespine compared to primary spine surgeries in the Patient Registry (PAR), divided by year for the years 2015-2021, are depicted in Figure 8.

The coverage rate is calculated as a percentage with the following formula: Numerator - The number of primary spine surgeries registered in Swespine, performed during the current year. Denominator - The total number of primary spine surgeries registered in either Swespine or the Patient Registry, conducted during the current year.

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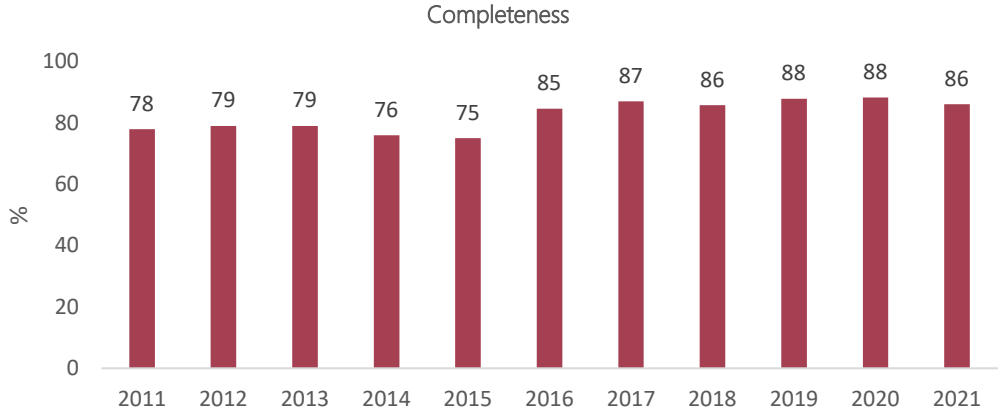

Fig. 8

Lumbar Spine Surgery Performed in 2022

In 2022, a total of 9,339 patients who underwent lumbar spine surgery have been registered, with contributions from a total of 46 clinics (see Figure 9).

Lumbar Spine Surgery Follow-Up in 2022

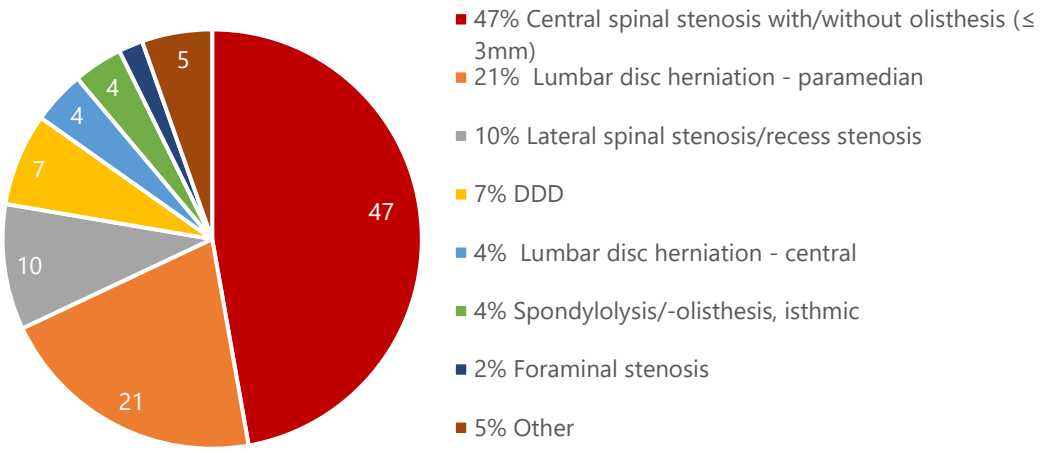

Fig. 9

Follow-up at 1 year has been conducted on surgeries performed the previous year, which is 2021. Follow-up at 5 years has been carried out on surgeries performed in 2017.

Lumbar Spine Diagnosis Description

The lumbar spine surgeries performed are registered under various diagnoses (ICD10), as described in this annual report. In the following statistical presentations, the results for each diagnosis are grouped and reported according to the table below.

Diagnostic group	Diagnosis, ICD10
Lumbar disc herniation - LDH	Paramedian M51.1K, Central M51.1K
Central Spinal stenosis - CSS	Without olisthesis M48.0K with olisthesis M48.0K + M47.8
Lateral Spinal stenosis - LSS	Lateral M48.8K och foraminal M99.6K
Spondylolistes - Spond	Spondylolysis/-olisthesis M43.0/M43.1
Degenerative Disc Disease - DDD	Low back pain M99.0/M99.1
Other	Degenerative Scolios M41.8, Coccygeal pain M53.3, SI-joint pain M46.1, Synovial facet cyst M67.2, Redmaining back pain after decompression M47.9, Other

Number of Surgeries and Follow-Up at 1 and 5 years for Lumbar Spine Surgery Performed in 2021/2017 by Diagnosis Group.

	LDH		CSS		LSS		Spond		DDD	
Number and Follow-UP	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
Operations 2021	2 194	100	4 061	100	1 066	100	374	100	627	100
Follow-UP 1 year (op 2021)	1 273	58	3 069	76	777	73	246	66	414	66
Follow-Up 5 years (op 2017)	1 088	51	2 648	59	593	57	222	61	335	53

Results for Herniated Discs – Paramedian and Central Disc Herniation

Demographics	Operation 2021	Operation 2017
Follow-Up %	58	51
Age (mean)	44	44
Male gender (%)	55	56
Smoker yes (%)	7	10
Duration leg pain >1 year (%)	25	26
Pain killers regularly (%)	64	66
Narcotic pain killers (%)	47	57
Previous spine surgery (%)	14	13

ODI

ODI (Oswestry Disability Index) results before and at 1 vs. 5 years for patients operated for disc herniation in 2021 and 2017, Figure 10.

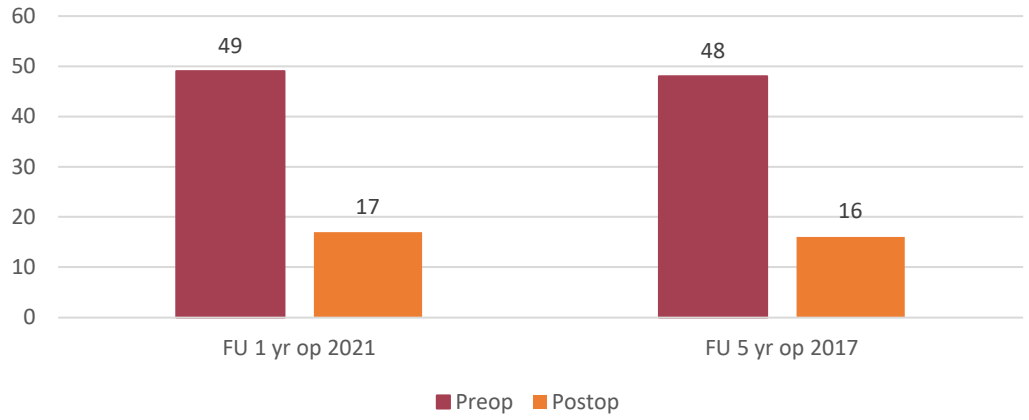

Fig. 10

SATISFACTION

The percentage of patients satisfied with the surgical outcome at 1 year and 5 years, Figure 11.

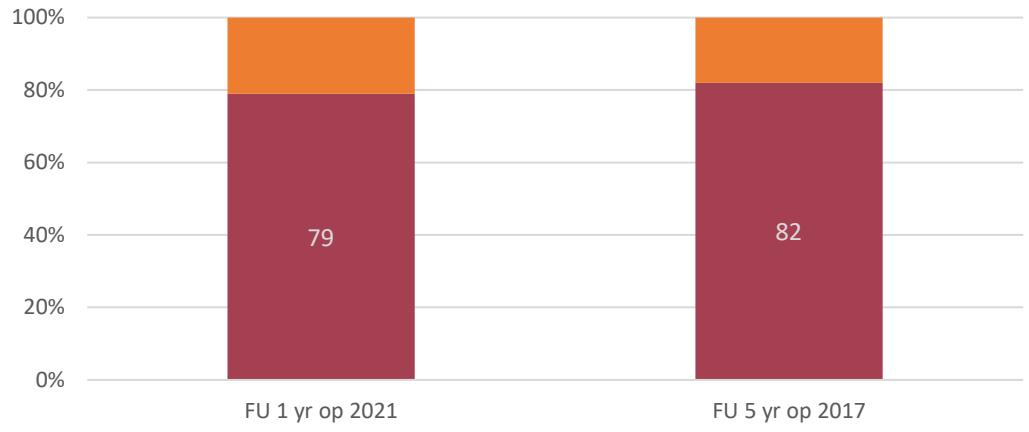

Fig. 11

Leg pain (GA)

Patient perceived leg pain at FU 1 and 5 years. The two diagrams illustrate Success rate (Fig 12) and Failure rate (Fig 13). The difference between Success and Failure is the Indefinite proportion.

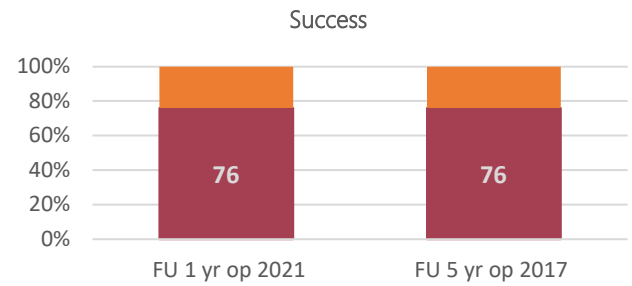

Fig. 12

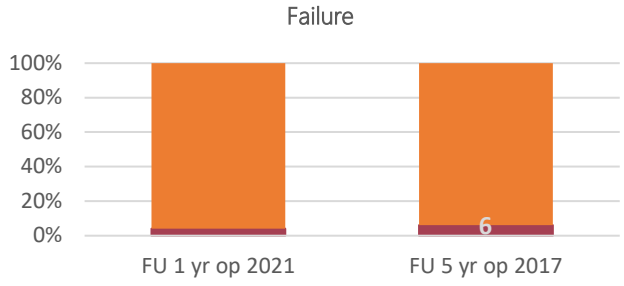

Fig. 13

EQ-5D dimensions

Patient's perceived quality of life before and 1 year after the surgery is presented in two charts. Figure 14 illustrates the preoperative quality of life, where individuals reported having severe issues with pain and activities. Figure 15 demonstrates the perceived quality of life 1 year after the surgery, where significant problems with pain and activities have improved.

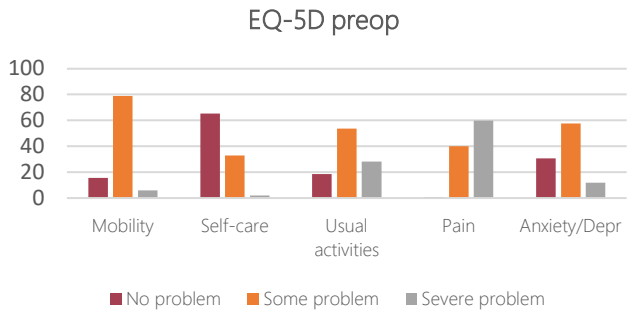

Fig. 14

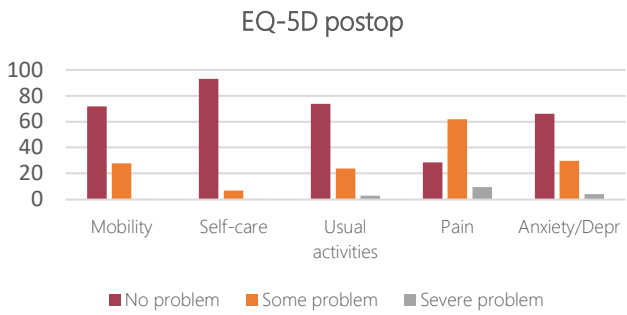

Fig. 15

Reintervention within 1 year	No	% tot op
Removal recurrent LDH (AWW99+ABC16/26)	56	2,6
Evacuation hematoma (NAW89)	6	0,3
Redecompression (same/new level) remaining stenosis (ZSZ00+ABC50/53/56)	6	0,3
Redecompression (same) recurrent stenosis (AWW99+ABC50/53/56)	3	0,1
Drain deep infection (NAW69)	2	0,1
Repair dural injury (AWW99) ?????	2	0,2
Other procedure	5	0,2
Totalt	80	3,7
New index operation in the lumbar spine within 5 years	**No**	**%**
New index operation, primary op 2017	162	7,5
New index operation all years	2948	6,9

Out of the 7.5% who underwent a new index operation within 5 years, 42% were operated on for a new herniated disc, 32% for DDD, 12% for central spinal stenosis, 8% for lateral stenosis, and the remaining cases were distributed among other lumbar spine diagnoses.

Results for Central Spinal Stenosis - Central Spinal Stenosis with and without olisthesis

Demographics	Operation 2021	Operation 2017
Follow-Up %	76	82
Age (mean)	68	68
Male gender (%)	48	47
Smoker yes (%)	5	5
Duration leg pain >1 year (%)	65	65
Pain killers regularly (%)	55	53
Narcotic pain killers (%)	35	37
Previous spine surgery (%)	21	19

ODI

ODI (Oswestry Disability Index) outcome before and at 1 and. 5 years after surgery in 2021 or 2017 for patients diagnosed with Central Spinal Stenosis or, Figure 16.

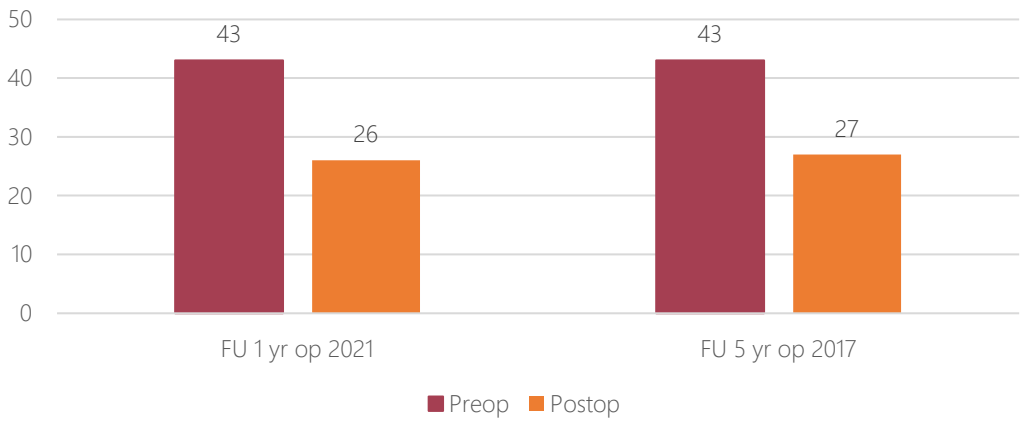

Fig. 16

SATISFACTION

The percentage of patients satisfied with the surgical outcome at 1 year and 5 years, Figure 17

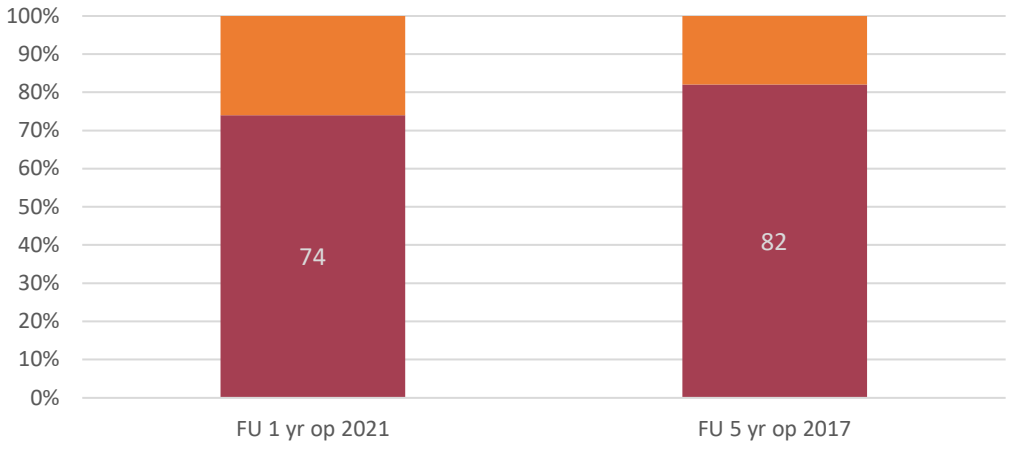

Fig.17

Leg Pain (GA)

Patient perceived leg pain at FU 1 and 5 years. The two diagrams illustrate Success rate (Fig 18a) and Failure rate (Fig 18b). The difference between Success and Failure is the Indefinite proportion.

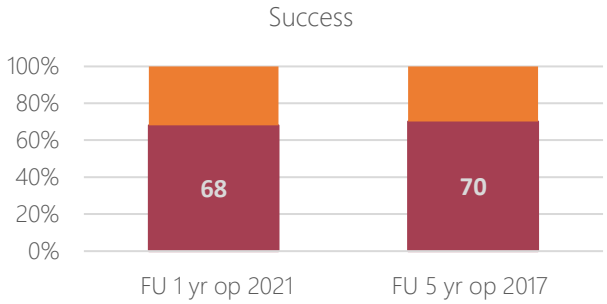

Fig. 18a

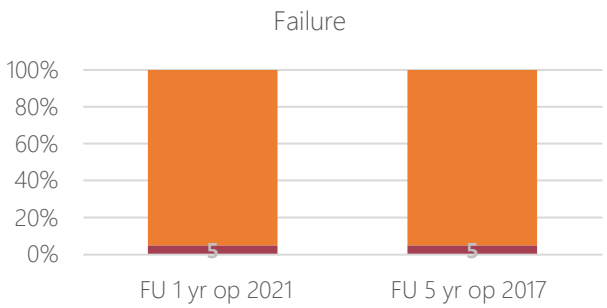

Fig. 18b

EQ-5D dimensions

Patient perceived quality of life before the operation and 1 year after the surgery is presented in two charts. Figure 19a illustrates the preoperative quality of life, where individuals reported having severe issues with pain and activities. Figure 19b demonstrates the perceived quality of life 1 year after the surgery, where significant problems with pain and activities have improved.

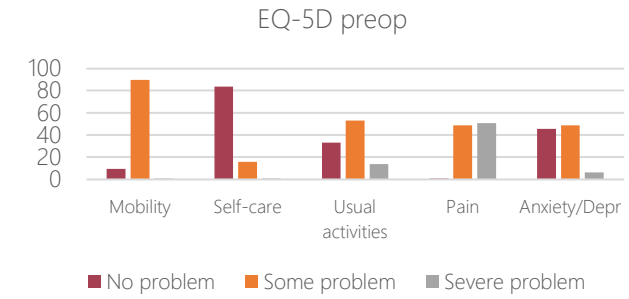

Fig. 19a

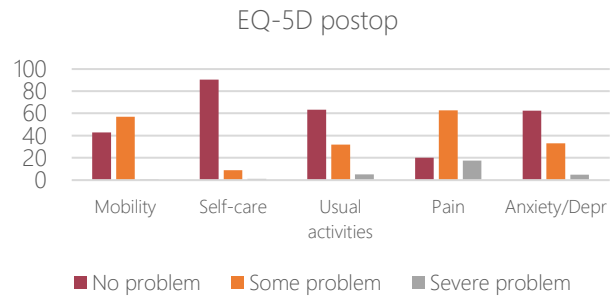

Fig. 19b

Reintervention within 1 year	No	% of op
Evacuation hematoma (NAW89)	23	0,6
Redecompression (same level) remaining stenos (ZSZ00+ABC56)	10	0,3
Drain deep infection (NAW69)	9	0,2
Removal recurrent LDH (AWW99+ABC16/26)	6	0,2
Redecompression (same level) recurrent stenosis (AWW99+ABC56)	5	0,1
Removal implant (NAU49)	4	0,1
Refusion (NAW99+NAG*)	4	0,1
Other	21	0,5
Total	82	2

New indexoperation in the lumbar spine within 5 years	Antal	%
New indexoperation, primary operation 2017	260	6,6
New indexoperation al years	4314	6,9

Out of the 6.6% who underwent a new index operation within 5 years, 58% were operated on for central spinal stenosis, 19% for lateral/foraminal spinal stenosis, 8% for herniated discs, 6% for DDD, and the remaining cases were distributed among other lumbar spine diagnoses.

Results for Lateral Spinal Stenosis - Lateral and foraminal spinal stenosis

Demographics	Operation 2021	Operation 2017
Follow-Up %	73	77
Age (mean)	59	59
Male gender (%)	48	43
Smoker yes (%)	6	6
Duration leg pain >1 year (%)	63	67
Pain killers regularly (%)	57	57
Narcotic pain killers (%)	39	48
Previous spine surgery (%)	27	22

ODI

ODI (Oswestry Disability Index) Outcome before and at 1 and. 5 years after surgery in 2021 or 2017, for patients diagnosed with Lateral or Foraminal stenosis, Figure 20.

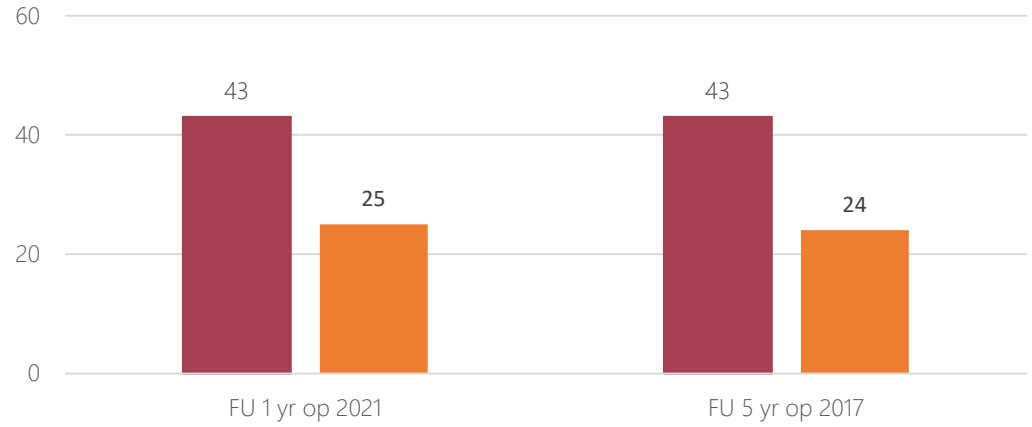

Fig. 20

SATISFACTION

Percentage of patients satisfied with the surgical outcome at 1 year and 5 years, Figure 21.

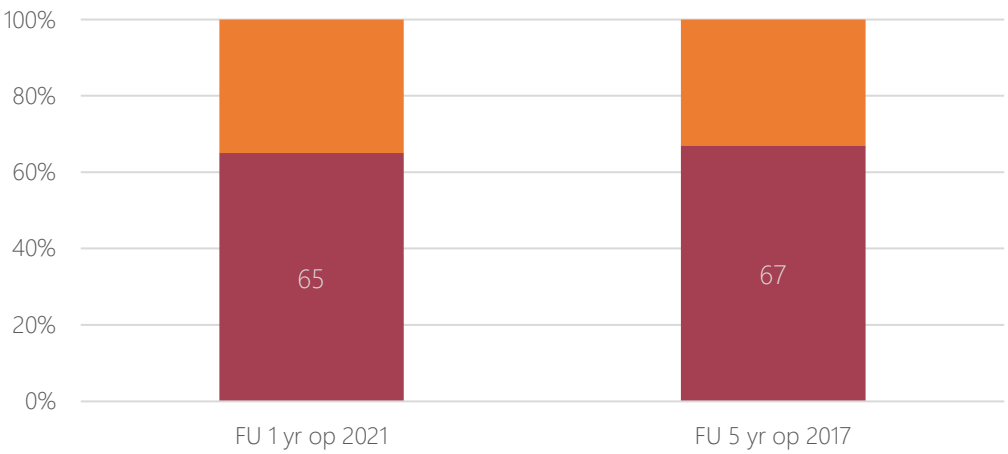

Fig. 21

Leg Pain (GA)

Patient perceived leg pain at FU 1 and 5 years. The two diagrams illustrate Success rate (Fig 22) and Failure rate (Fig 23). The difference between Success and Failure is the Indefinite proportion.

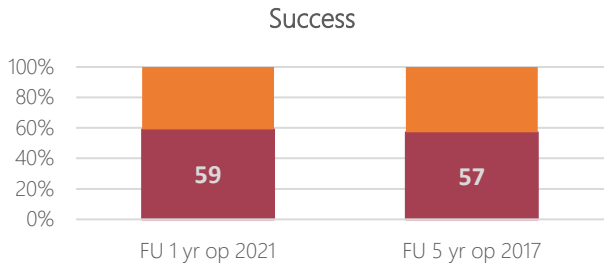

Fig. 22

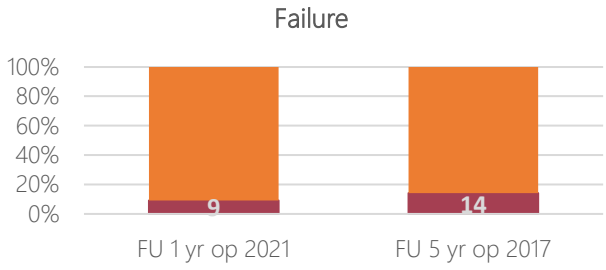

Fig. 23

EQ-5D dimensions

Patient perceived quality of life before the operation and 1 year after the surgery is presented in two charts. Figure 24a illustrates the preoperative quality of life, where individuals reported having severe issues with pain and activities. Figure 24b demonstrates the perceived quality of life 1 year after the surgery, where significant problems with pain and activities have improved.

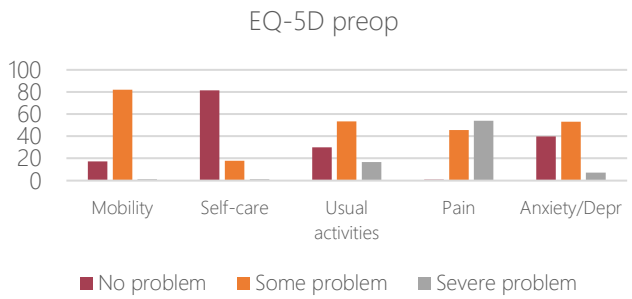

Fig. 24a

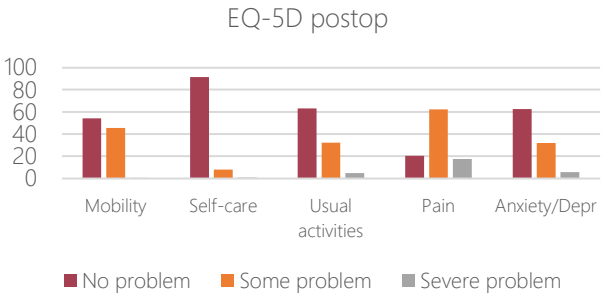

Fig. 24b

Reintervention within 1 year	No	% of op
Drain deep infection (NAW69))	8	0,8
Evacuation hematoma (NAW89)	5	0,5
Redecompression (same/new level) (ZSZ00+ABC50/53/56)	5	0,5
Adjustment implant (NAW99+NAG49/79/99)	3	0,3
Refusion (NAW99+NAG*)	2	0,2
Revision pseudarthrosis (NAW99)	1	0,1
Redecompression (same level) recurrent stenosis (AWW99+ABC56)	1	0,1
Removal implant (NAU49)	1	0,1
Removal recurrent LDH (AWW99+ABC16/26)	1	0,1
Other	2	0,2
Total	29	2,7

New indexoperation in the lumbar spine within 5 years	No	%
New indexoperation, primary surgery 2017	82	10
New indexoperation all operation years	960	8,1

Out of the 10% who underwent a new index operation within 5 years, 39% were operated on for lateral/foraminal spinal stenosis, 31% for central spinal stenosis, 9% for herniated discs, 8% for DDD, and the remaining cases were distributed among other lumbar spine diagnoses.

. Results Isthmic Spondylolysis/Spondylolisthesis

Demographics	Operation 2021	Operation 2017
Follow-Up %	66	76
Age (mean)	51	51
Male gender (%)	52	49
Smoker yes (%)	4	7
Duration back pain >1 year (%)	81	82
Duration leg pain >1 year (%)	68	65
Pain killers regularly (%)	45	44
Narcotic pain killers (%)	34	44
Previous spine surgery (%)	8	6

ODI

ODI (Oswestry Disability Index) outcome before and at 1 and 5 years surgery in 2021 or 2017 for patients diagnosed with spondylolysis/-olisthesis, Figure 25.

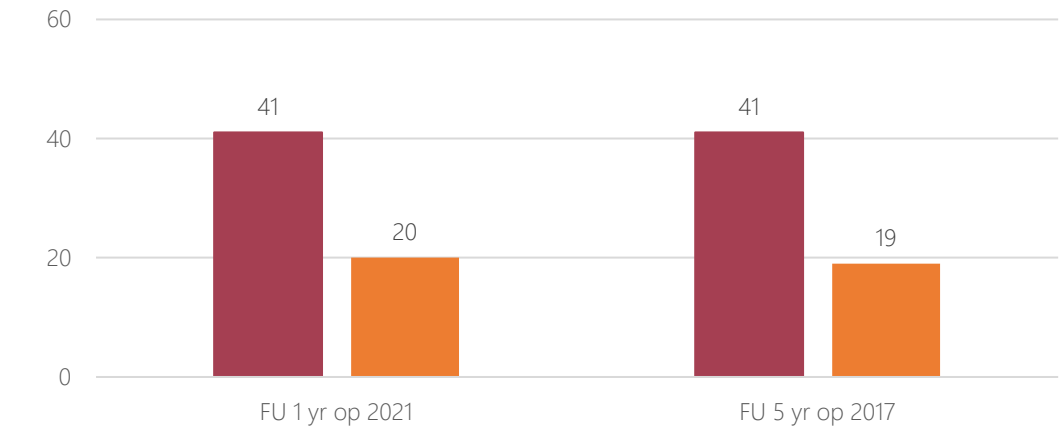

Fig. 25

SATISFACTION

Percentage of patients satisfied with the surgical outcome at 1 year and 5 years, Figure 26.

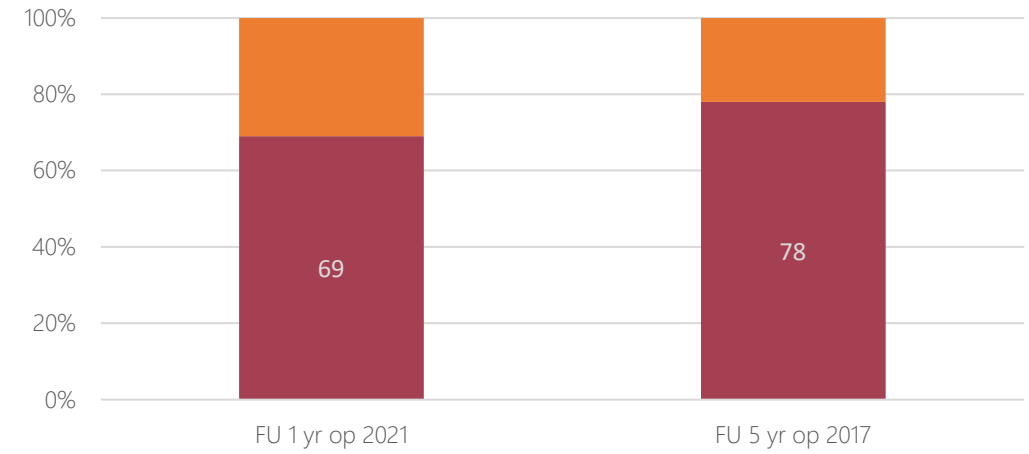

Fig. 26

Back and Leg pain (GA)

Patient perceived leg and back pain at FU 1 and 5 years. The two diagrams illustrate Success rate (Fig 27) and Failure rate (Fig 28). The difference between Success and Failure is the Indefinite proportion.

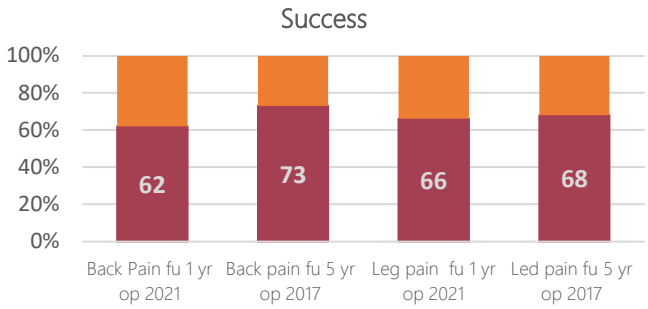

Fig. 27

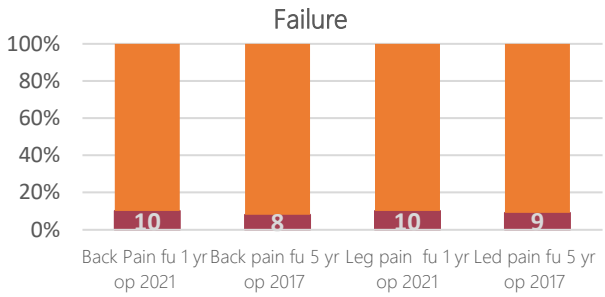

Fig. 28

EQ-5D dimensions

Patient perceived quality of life before the operation and 1 year after the surgery is presented in two charts. Figure 29 illustrates the preoperative quality of life, where individuals reported having severe issues with pain and activities. Figure 30 demonstrates the perceived quality of life 1 year after the surgery, where significant problems with pain and activities have improved.

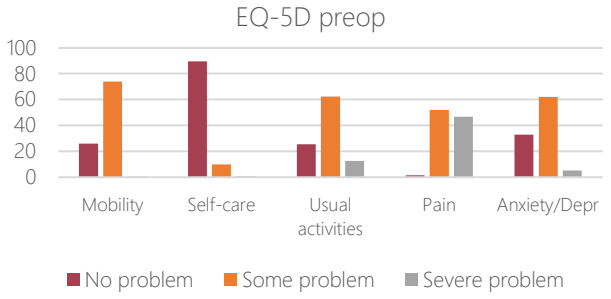

Fig. 29

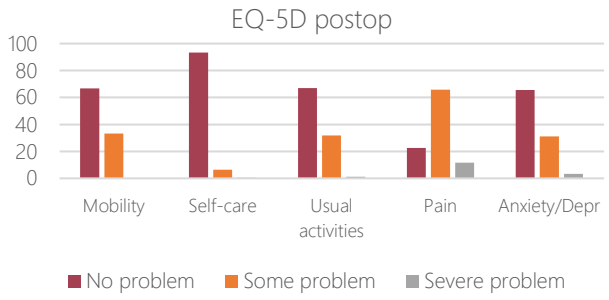

Fig. 30

Reintervention within 1 year	No	% of op
Refusion (NAW99+NAG*)	8	2,1
Drain deep infection (NAW69)	6	1,6
Removal implant (NAU49)	4	1,1
Evacuation hematoma (NAW89)	2	0,5
Repair dural injury (NAW99)	1	0,3
Adjustment implant (NAW99+NAG49/79/99)	1	0,3
Other	1	0,3
Total	22	6,2

New indexoperation within 5 years	No	%
New indexoperation, primary surgery 2017	21	6,1
New indexoperation all operation years	282	4,3

For those who underwent surgery for spondylolisthesis in 2017, 6.1% received a new index operation within 5 years. Out of these, 21% were operated on for new spondylolysis/spondylolisthesis, 25% for lateral/foraminal spinal stenosis, 17% for central spinal stenosis, 12% for DDD-related pain, 4% for herniated discs, and the remaining cases were distributed among other lumbar spine diagnoses.

Results for Degenerative Disc Disease

Demographics	Operation 2021	Operation 2017
Follow-Up %	66	71
Age (mean)	46	45
Male gender (%)	46	45
Smoker yes (%)	2	3
Duration back pain >1 year (%)	89	90
Pain killers regularly (%)	52	58
Narcotic pain killers (%)	46	55
Previous spine surgery (%)	36	30

ODI

ODI (Oswestry Disability Index) outcome before and at 1 and. 5 years after surgery in 2021 or 2017 for patients diagnosed with degenerative disc disease, Figure 31.

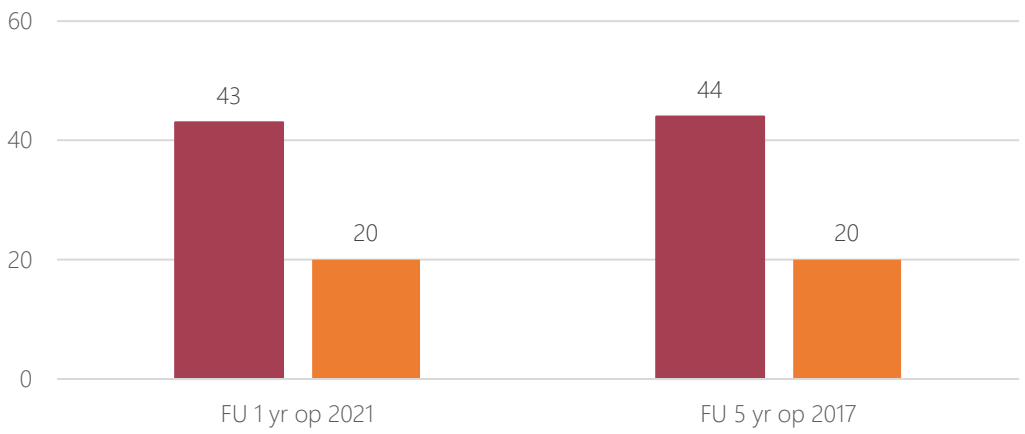

Fig. 31

SATISFACTION

Percentage of patients satisfied with the surgical outcome at 1 year and 5 years, Figure 32.

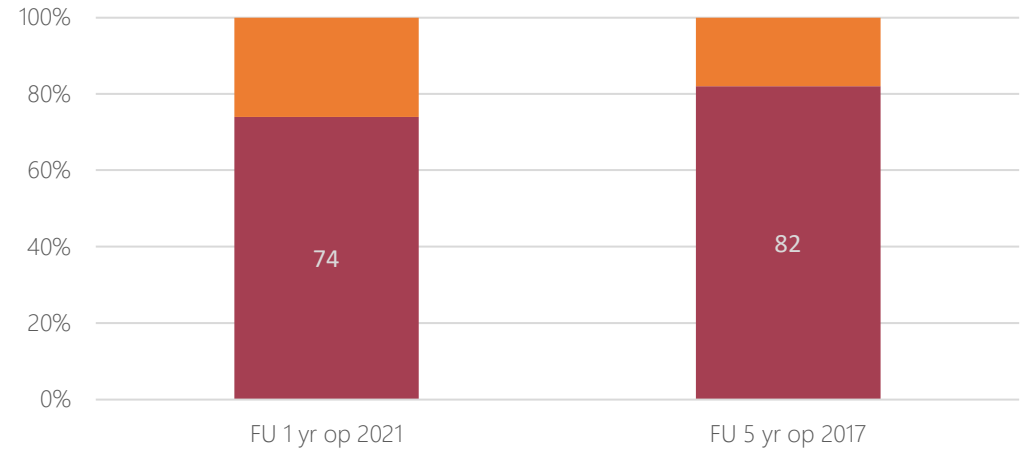

Fig.32

Back Pain (GA)

Patient perceived leg and back pain at FU 1 and 5 years. The two diagrams illustrate Success rate (Fig 33) and Failure rate (Fig 34). The difference between Success and Failure is the Indefinite proportion.

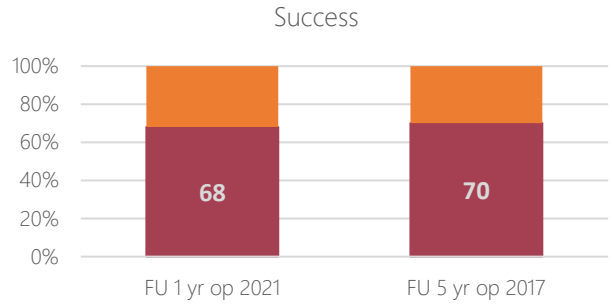

Fig. 33

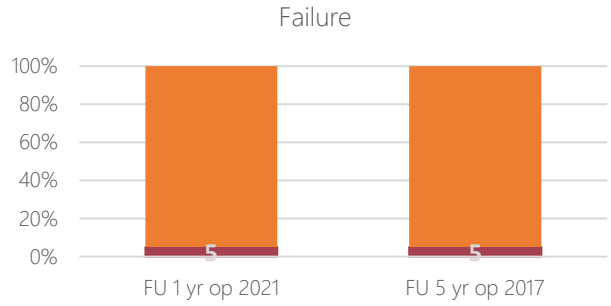

Fig. 34

EQ-5D dimensions

Patient perceived quality of life before the operation and 1 year after the surgery is presented in two charts. Figure 35 illustrates the preoperative quality of life, where individuals reported having severe issues with pain and activities. Figure 36 demonstrates the perceived quality of life 1 year after the surgery, where significant problems with pain and activities have improved.

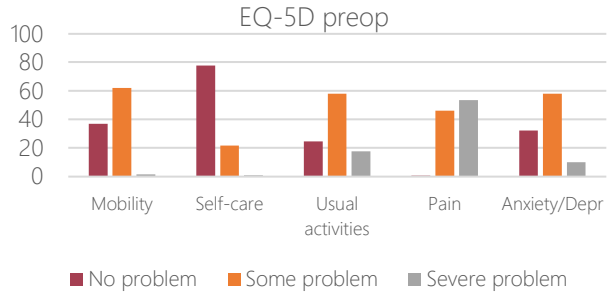

Fig. 35

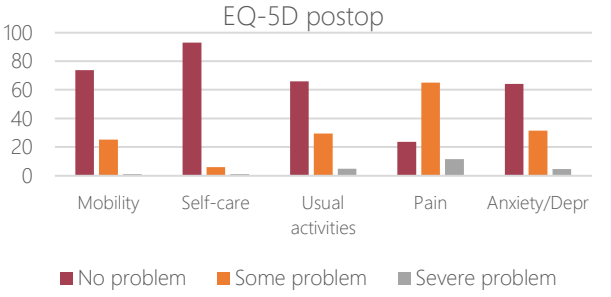

Fig. 36

Reintervention within 1 year	No	% of op
Drain deep infection (NAW69)	5	0,8
Adjustment implant (NAW99+NAG49/79/99)	3	0,5
Removal implant (NAU49)	3	0,5
Drain superficial infection (NAW59)	2	0,33
Repair dural injury (AWW99)	1	0,2
Refusion (NAW99)	1	0,2
Revison pseudarthrosis (NAW99+NAG*)	1	0,2
Other	4	0,6
Total	20	3,2

New indexoperation in the lumbar spine within 5 years	No	%
New indexoperation, primary surgery 2017	24	5,4
New indexoperation all ioperation years	584	5,7

For those who underwent surgery for degenerative disc disease in 2017, 5.4% received a new index operation within 5 years. Out of these, 39% were operated on for lateral/foraminal spinal stenosis, 15% for central spinal stenosis, 12% for SI joint issues, 8% for lateral spinal stenosis, 4% for back pain after stenosis decompression, and the remaining cases were distributed among other lumbar spine diagnoses.

Cervical Spine Surgery Performed in 2022

In 2022, a total of 1,486 patients who underwent cervical spine surgery have been registered, with contributions from a total of 27 clinics, as shown in Figure 37.

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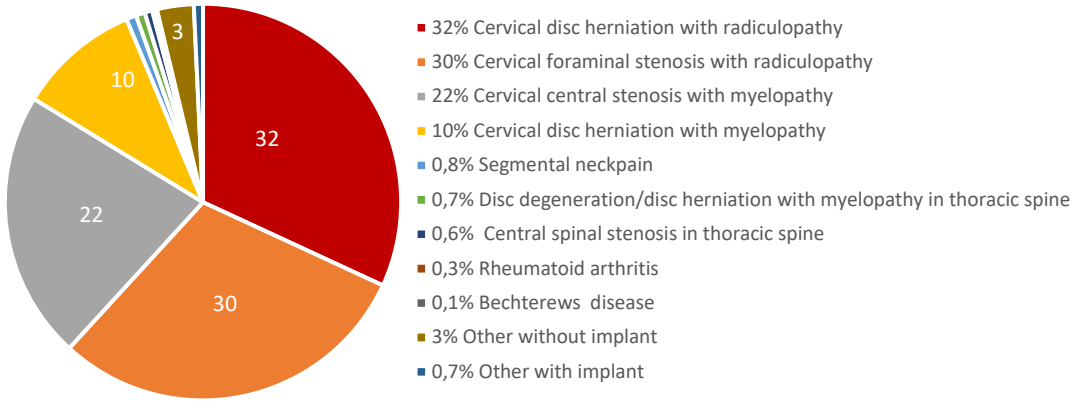


Fig. 37

Cervical Spine Surgery Follow-Up in 2022

Follow-up at 1 year has been conducted on surgeries performed the previous year, which is 2021. Follow-up at 5 years has been carried out on surgeries performed in 2017.

Cervical Spine Diagnosis Description

Cervical spine surgeries are categorized under various diagnoses (ICD10), and the results are presented according to the table below in this annual report.

Diagnosgrupp	Diagnoser
CDH	Cervical disc herniation with radiculopathy M50.1+G55.1 (1)
CFS	Cervical foraminal stenosis with radiculopathy (M48.8A+G55.3 / 47.2+G55.2)
Myelo – CSM/CDM	Cervical central stenosis with myelopathy (M48.0A+G99.2 / M47.1+G99.2), Cervical disc herniation with myelopathy (M50.0+G99.2)

Number of surgeries and follow-Up at 1 and 5 years for ervical Spine Surgery performed in 2021/2017 by diagnosis.

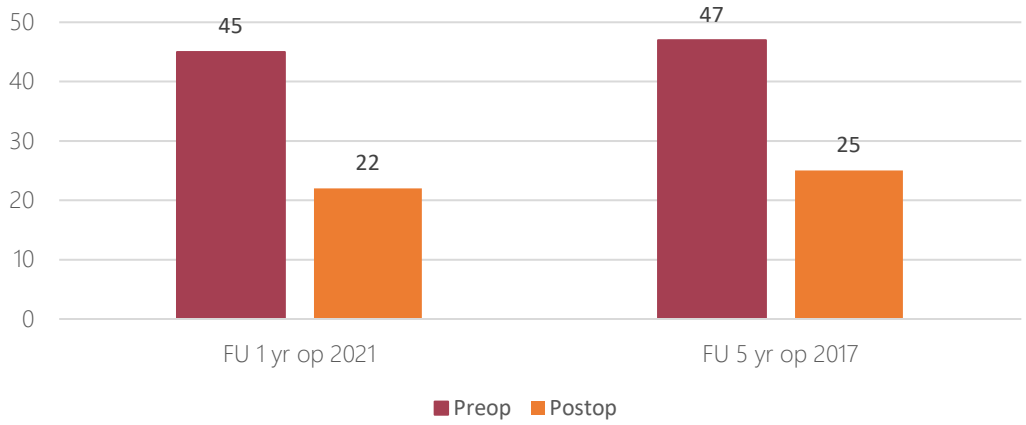
	CDH		*CFS*		*CSM*		*CDM*	
No and Follow-Up	*No*	*%*	*No*	*%*	*No*	*%*	*No*	*%*
Operation 2021	493		399		157		223	
Follow-Up 1 year (op 2021)	299	62	253	63	100	64	140	63
Follow-Up 5 year (op 2017)	212	46	229	58	101	58	77	48

Results for Radiculopathy CDH - Cervical disc herniation with radiculopathy

Demographics	Operation 2021	Operation 2017
Follow-Up %	61	68
Age (mean)	49	49
Male gender (%)	46	46
Smoker yes (%)	9	14
Duration arm pain >1 year (%)	52	42
Pain killers regularly (%)	62	62
Narcotic pain killers (%)	45	51
Anti-neuropathic drugs (%)	61	Not registered 2017
Previous spine surgery (%)	11	10

NDI -Neck disability index

NDI (Neck Disability Index) outcome before, and at 1 and 5 years after surgery for patients diagnosed with Cervical Disc Herniation with radiculopathy, Figure 38.



Fia. 38

SATISFACTION

Percentage of patients satisfied with the results of the surgery at 1 year and 5 years, Figure 39.

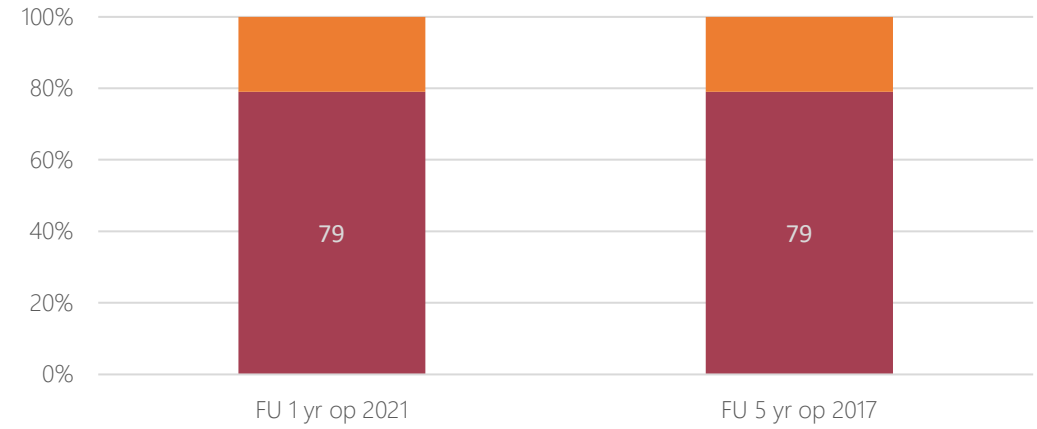


Fig. 39

Arm Pain (GA)

Patient perceived arm pain at FU 1 and 5 years. The two diagrams illustrate Success rate (Fig 40) and Failure rate (Fig 41). The difference between Success and Failure is the Indefinite proportion.

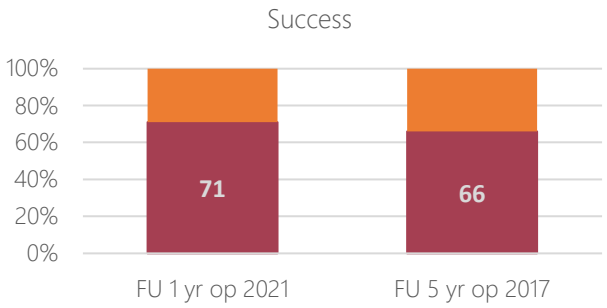


Fig.40

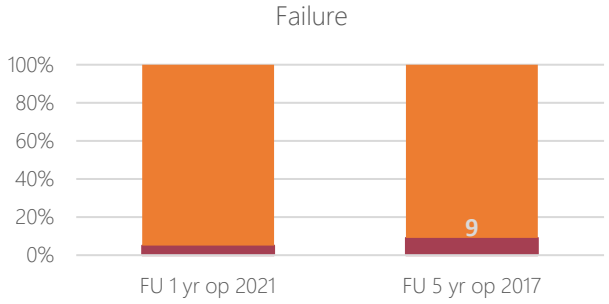


Fig. 41

EQ-5D VAS

Patient's estimated health state on the VAS scale, where 0 represents the worst imaginable health and 100 represents the best imaginable health. Here, the preoperative and postoperative health states are presented, as shown in Figure 42

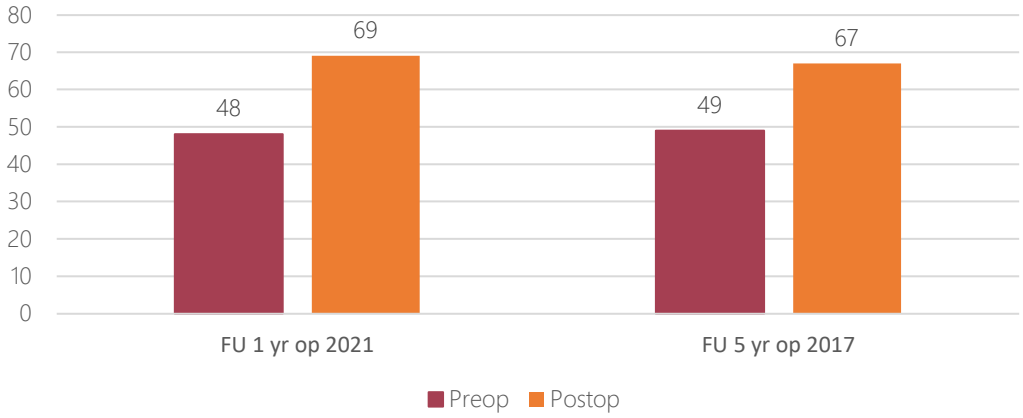


Fig. 42

Reintervention within 1 year	No	% of op
Redecompression (same level) remaining stenosis (ZSZ00+ABC56)	3	0,6
Removal implant (NAU49)	1	0,2
Total	4	0,8

New cervical index operation within 5 years	No	%
New index operation, primary operation 2017	36	8,9
New index operation all years	285	4,8

For those who underwent surgery for Cervical Disc Herniation with Radiculopathy (CDH) in 2017, 8.9% received a new index operation within 5 years. Out of these, 67% were operated on for Cervical Foraminal Stenosis with Radiculopathy, 19% for Cervical Disc Herniation with Radiculopathy, 6% for Cervical Central Spinal Stenosis with Myelopathy, and the remaining cases were distributed among other cervical spine diagnoses.

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Results for CFS - Cervical foraminal stenosis with radiculopathy

Demographics	Operation 2021	Operation 2017
Follow-Up %	63	72
Age (mean)	54	54
Male gender (%)	53	54
Smoker yes (%)	10	9
Duration arm pain >1 year (%)	33	29
Pain killers regularly (%)	53	49
Narcotic pain killers (%)	39	42
Anti-neuroptahic drugs (%)	48	Not registered 2017
Previous spine surgery (%)	24	21

NDI -Neck disability index

NDI (Neck Disability Index) outcome before, and at 1 and 5 years after surgery for patients diagnosed with Cervical Foraminal Stenosis with radiculopathy, Figure 43.

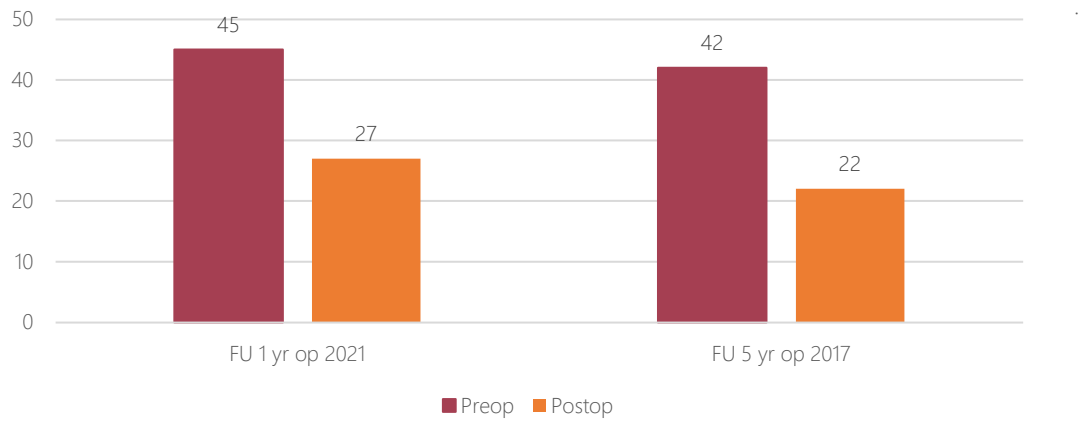

Fig. 43

SATISFACTION

Percentage of patients satisfied with the results of the surgery at 1 year and 5 years, Figure 44.

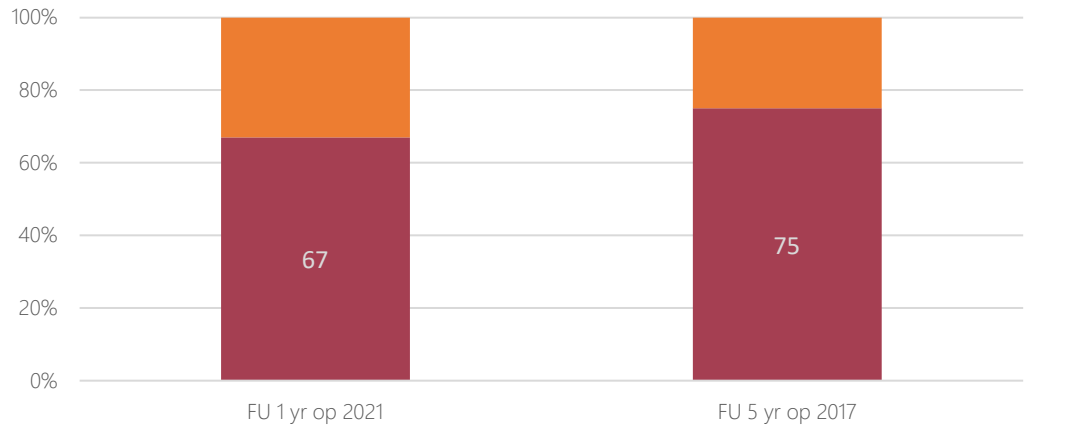

Fig. 44

Arm Pain (GA)

Patient perceived arm pain at FU 1 and 5 years. The two diagrams illustrate Success rate (Fig 40) and Failure rate (Fig 41). The difference between Success and Failure is the Indefinite proportion.

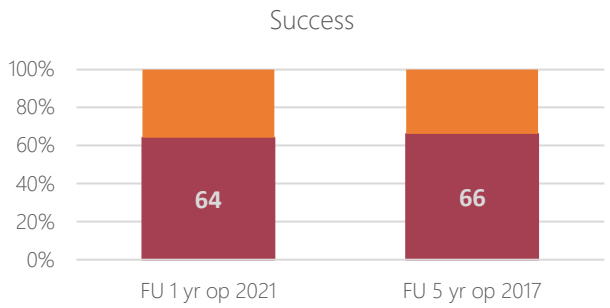

Fig. 45

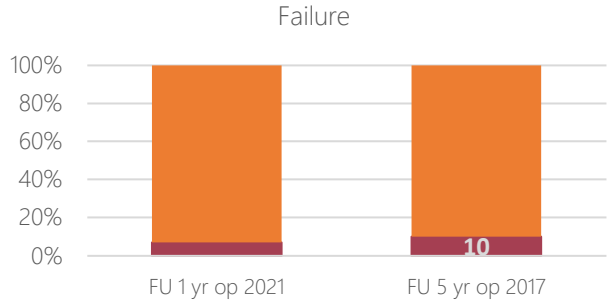

Fig. 46

EQ-5D VAS

Patient's estimated health state on the VAS scale, where 0 represents the worst imaginable health and 100 represents the best imaginable health. Here, the preoperative and postoperative health states are presented, as shown in Figure 47.

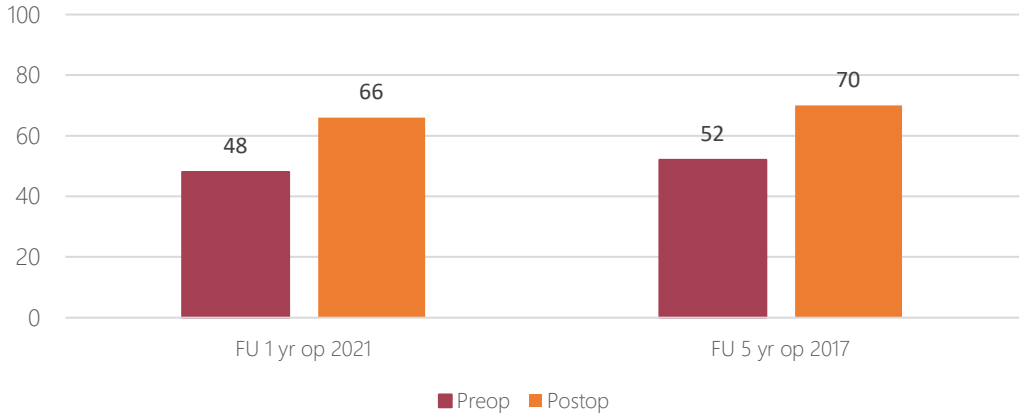

Fig. 47

Reintervention within 1 year	No	% of op
Evacuation hematoma (NAW89)	2	0,5
Refusion (NAW99+NAG*)	1	0,3
Redecompression (same level) remaining stenosis (ZSZ00+ABC56)	1	0,3
Total	4	1

New cervical index operation within 5 years	No	%
New index operation, primary op 2017	20	6,6
New index operation all years	201	5,6

For those who underwent surgery for Cervical Foraminal Stenosis with Radiculopathy (CFS) in 2017, 6.6% received a new index operation within 5 years. Out of these, 60% were operated on for Cervical Foraminal Stenosis with Radiculopathy, 35% for Cervical Disc Herniation with Radiculopathy, and 5% for Cervical Central Spinal Stenosis with Myelopathy.

Results for Cervical Myelopathy – Anterior decompression

Demografi	Operation 2021	Operation 2017
Follow-Up %	64	33
Age (mean)	54	57
Make gender (%)	54	54
Smoking yes (%)	14	14
Duration arm pain >1 year (%)	43	54
Pain killers regularly (%)	45	48
Narcotic pain killers (%)	31	46
Anti-neuropathic drugs (%)	39	Not registered 2017
Previous spine surgery (%)	10	11

P-mJOA (modified Japanese Orthopedic Association)

Degree of disability related to myelopathy, 1 year and 5 years after cervical spine surgery, for patients operated on in 2017 and 2021, as shown in Figure 48. P-mJOA was introduced in 2021.

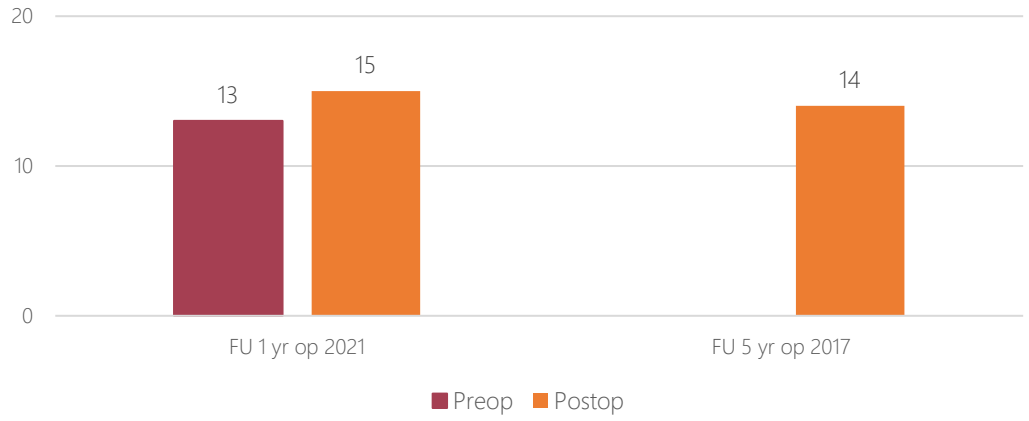

Fig.48

SATISFACTION

Percentage of patients satisfied with the results of the surgery at 1 year and 5 years, Figure 49.

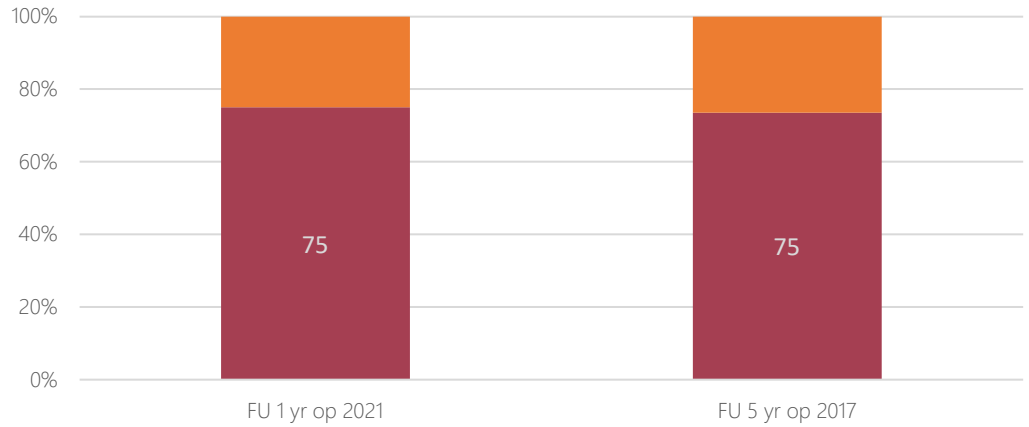

Fig. 49

EQ-5D dimensions

Patient perceived quality of life preoperatively and 1 year after surgery. Two diagrams are presented, with Figure 50 showing the preoperative quality of life, where patients report having severe problems with pain and activities. Figure 51 displays the perceived quality of life 1 year after the surgery, where severe problems with mobility and activities have improved.

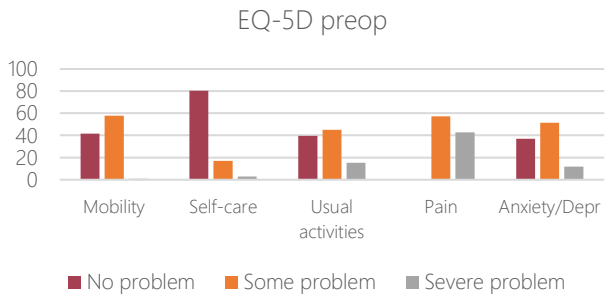

Fig. 50

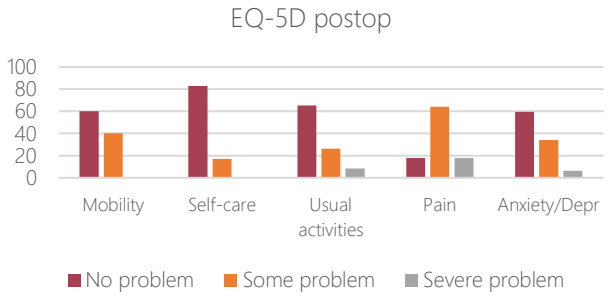

Fig. 51

EQ-5D VAS

Patient's estimated health state on the VAS scale, where 0 represents the worst imaginable health and 100 represents the best imaginable health. Here, the preoperative and postoperative health states are presented, as shown in Figure 52.

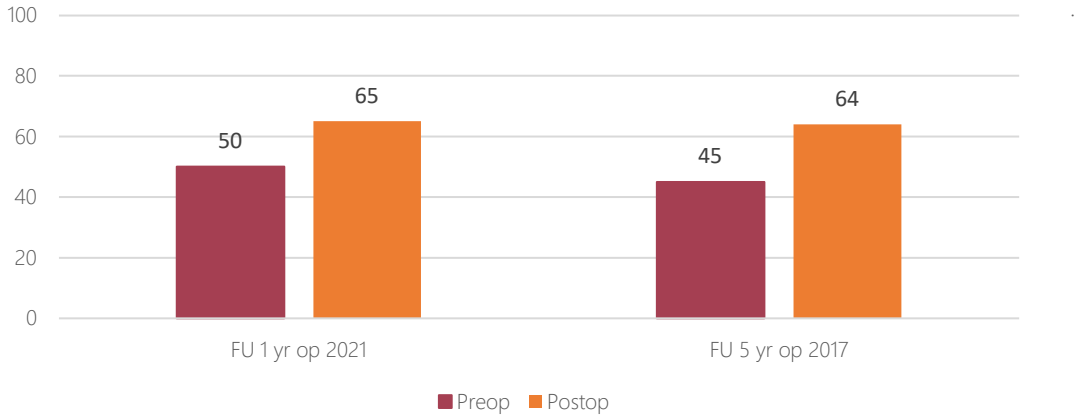

Fig. 52

Reintervention within 1 year	No	%
No reintervention within 1 year	-	
Total		

New cervical index operation within 5 years	No	%
New index operation, primary op 2017	7	5
New index operation all years	74	3,6

For those who underwent surgery for Myelopathy with an anterior approach in 2017, 5% received a new index operation within 5 years. Out of these, 43% were operated on for Cervical Central Spinal Stenosis with Myelopathy, 29% for Cervical Foraminal Stenosis with Radiculopathy, and 29% for Cervical Disc Herniation with Myelopathy.

Results for Cervical Myelopathy – Posterior decompression

Demographics	Operation 2021	Operation 2017
Follow-UpU %	63	60
Age (mean)	66	65
Make gender (%)	59	57
Smoking yes (%)	11	17
Duration arm pain >1 year (%)	47	50
Pain killers regularly (%)	41	39
Narcotic pain killers (%)	35	33
Anti-neuropathic drugs (%)	33	-
Previous spine surgery (%)	11	20

P-mJOA (modified Japanese Orthopedic Association)

Degree of disability related to myelopathy, 1 year and 5 years after cervical spine surgery, for patients operated on in 2017 and 2021, as shown in Figure 53. P-mJOA was introduced in 2021.

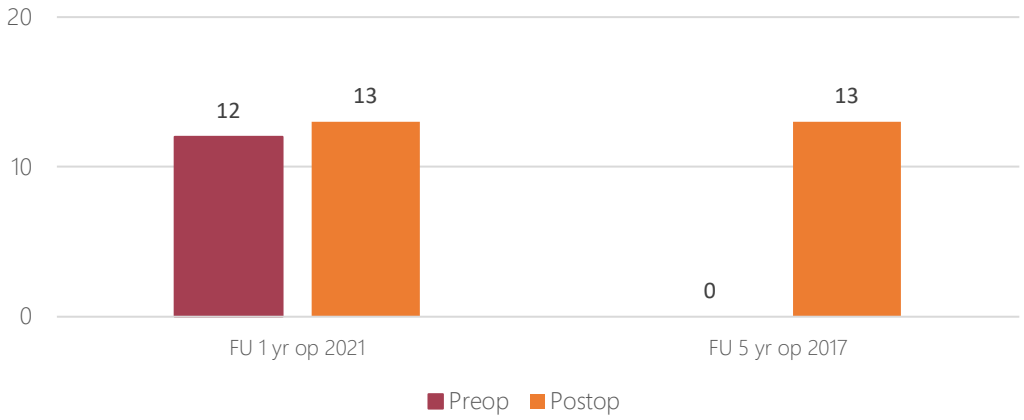

Fig. 53

SATISFACTION

Percentage of patients satisfied with the results of the surgery at 1 year and 5 years, Figure 54.

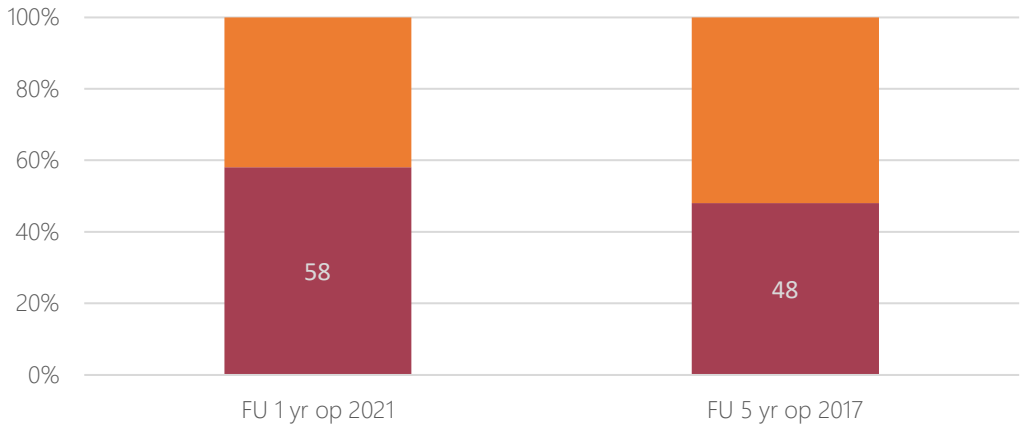

Fig. 54

EQ-5D dimensions

Patient perceived quality of life preoperatively and 1 year after surgery. Two diagrams are presented, with Figure 55 showing the preoperative quality of life, where patients report having severe problems with pain and activities. Figure 56 displays the perceived quality of life 1 year after the surgery, where severe problems with mobility and activities have improved.

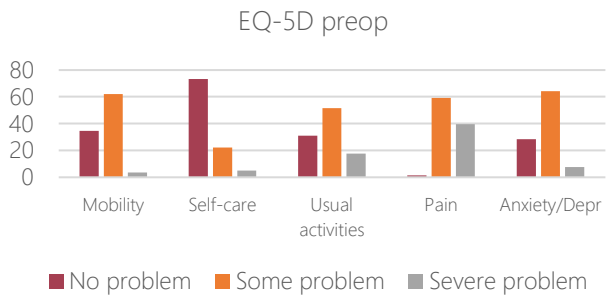

Fig. 55

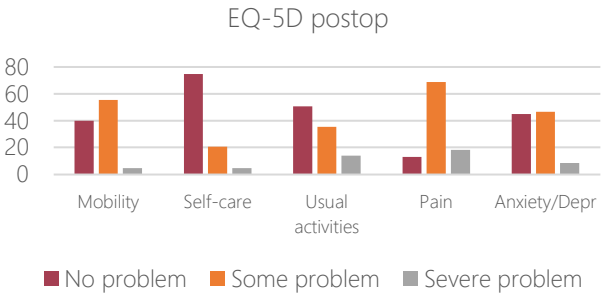

Fig. 56

EQ-5D VAS

Patient's estimated health state on the VAS scale, where 0 represents the worst imaginable health and 100 represents the best imaginable health. Here, the preoperative and postoperative health states are presented, as shown in Figure 57.

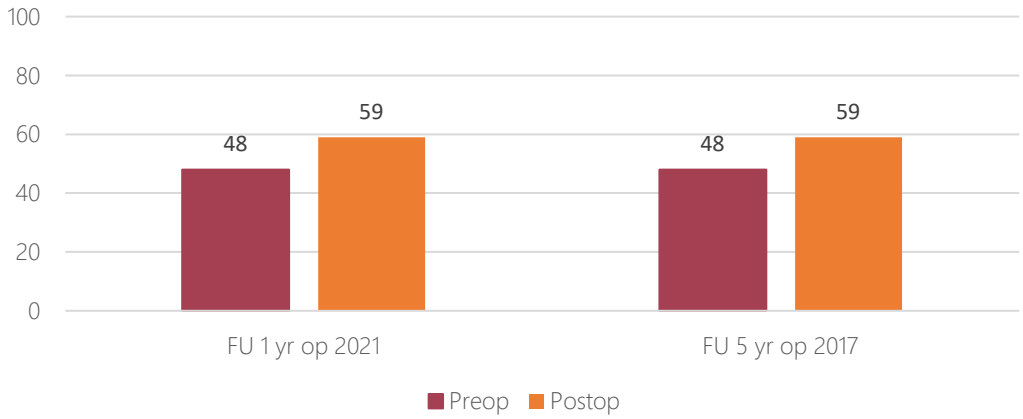

Fig. 57

Reintervention within 1 year	No	% of op
Drain deep infection (NAW69)	5	2,2
Evacuation hematoma (NAW89)	2	0,9
Redecompression (same/new level) (ZSZ00+ABC50/53/56)	1	0,5
Total	8	3,6

New cervical index operation within 5 years	No	%
New index operation, primary op 2017	2	1,6
New index operation all years	36	2

For those who underwent surgery for Myelopathy with a posterior approach in 2017, 1.6% received a new index operation within 5 years. Out of these, 50% were operated on for Cervical Central Spinal Stenosis with Myelopathy, and 50% for Cervical Foraminal Stenosis with Radiculopathy.

Deformity Surgery Performed in 2022

In total, there were 188 deformity patients registered from a total of 8 clinics in 2022, as shown in Figure 58.

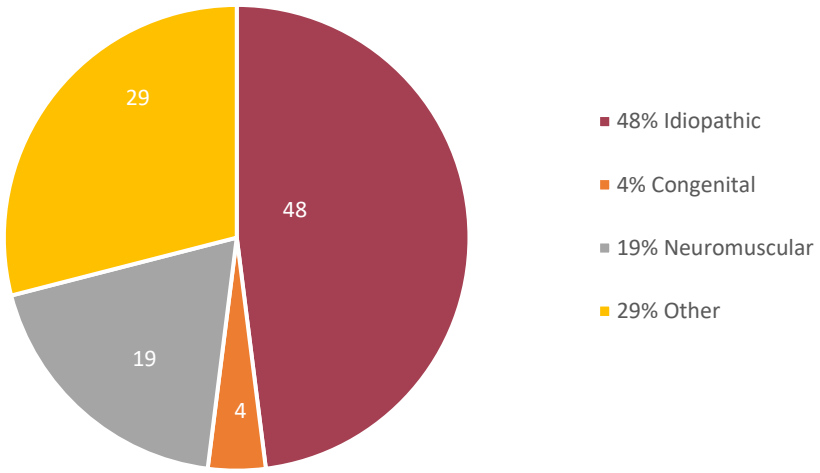

Fig. 58

Follow-Up on Deformity surgeries in 2022

Idiopathic scoliosis is the diagnosis within the deformity category with functional and activity aspects of the same nature as the other diagnostic groups in the registry. The other diagnoses are heterogeneous groups often characterized by severe disabilities, both mentally and somatically. The improvements achieved in this group are poorly captured in Swespine. Therefore, we only present follow-up data for idiopathic scoliosis. It should be noted, however, that the most important outcome measure for idiopathic scoliosis, radiological correction, is not available in the registry.

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	Idiopathic scoliosis	
No and follow-up	No	%
Operations 2021	119	
Follow-Up 1 year (op 2021)	60	50
Follow-Up 5 years (op 2017)	30	44

Diagnostic description

Performed deformity surgeries are recorded under several diagnoses (ICD10) in Swespine. In the following descriptive statistics, the results for each diagnosis are grouped and presented according to the table below.

Diagnostic group	Diagnosis (ICD10)
Idiopathic scoliosis	Infantile (0-3 år; M41.0), Juvenile (4-9 år; M41.1), Adolescent (>10 år; M41.2)

Results for Deformity -Idiopathic scoliosis

Demographics	Operation 2021	Operation 2017
Follow-Up (%)	51	67
Age (mean)	17	17
Female gender (%)	76	71
Age at diagnosis	12	11
Normal mobility (%)	100	96

SRS-22r

SRS-22r (Scoliosis Research Society-22r) is a tool used to measure the quality of life in patients with idiopathic scoliosis. It includes five questions for each of the following domains: pain, self-image, function, mental health, as well as two questions about satisfaction with treatment. Figure 59.

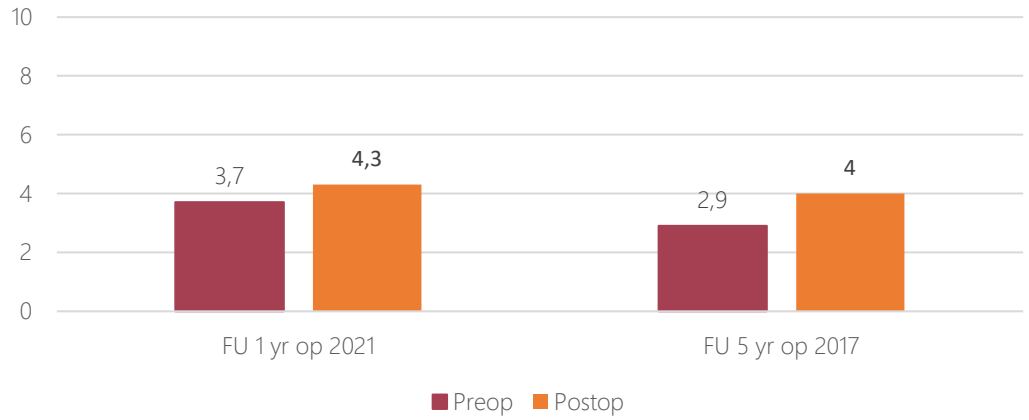


Fig. 59

EQ-5D VAS

Patient's estimated health state on the VAS scale, where 0 represents the worst imaginable health and 100 represents the best imaginable health. Here, the preoperative and postoperative health states are presented, as shown in Figure 60.

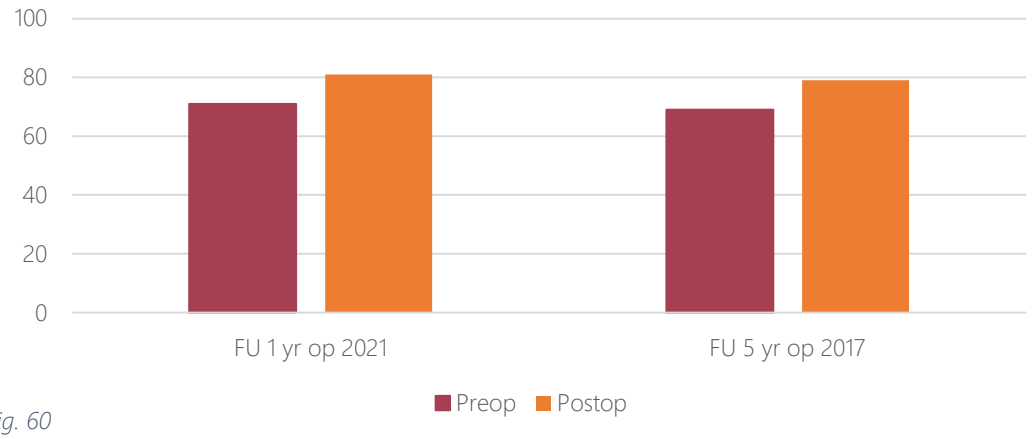


Fig. 60

Reintervention within 1 year	Antal	%
No reintervention registered	-	-
Total		

Deformity analysis and outcomes can be found in the section "Longitudinal Outcome Analysis".

Metastatic Spinal Surgeries Performed in 2022

In total, 100 surgeries were performed for metastases in the year 2022 at 10 clinics. For results, please refer to the section 'Longitudinal Outcome Analysis' and 'Diagnosis-Related Development - Metastases'. Indications for metastatic surgery are presented in Figure 61. The primary tumour was reported to be known in 63% of cases and are further displayed in the following table.

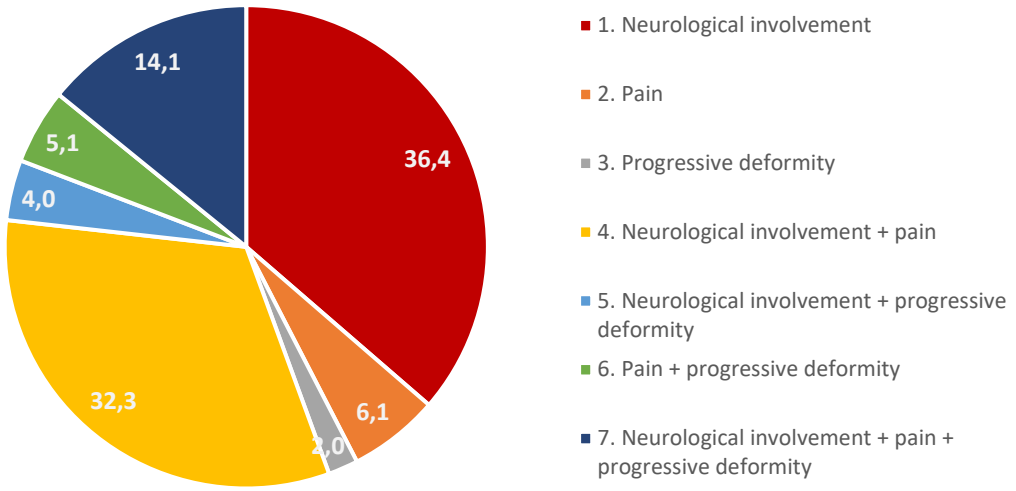


Fig. 61

Primary tumor (established morphology in 63%)	Antal	%
Prostate (C61.9)	16	31
Breast (C50.9)	7	14
Pulmonary (C34.9)	5	10
Renal (C64.9)	4	8
Intestine (C26.0)	4	8
Hematopoietic (C90.0)	2	4
Other	13	25

The patients' neurological impact was distributed as follows on the Frankel scale:

A: 1%, B: 3%, C: 44%, D: 39%, E: 12%.

The surgical procedures performed were divided between posterior and anterior decompression and potential fusion. 94% of the patients underwent posterior decompression.

Tumour resection was performed in 74% of cases, with 6% as excision, 24% as marginal excision, 71% as intralesional excision, and 0% as RF ablation.

Spinal Surgeries for Primary Infection conducted in 2022

A total of 34 surgeries have been registered for infection in 2022 at 6 clinics. The number of surgical cases is so small that we do not consider it meaningful to evaluate individual years. An overview of outcomes over time can be found in the section Longitudinal Outcome Analysis. The distribution of infection diagnoses is presented in Figure 62.

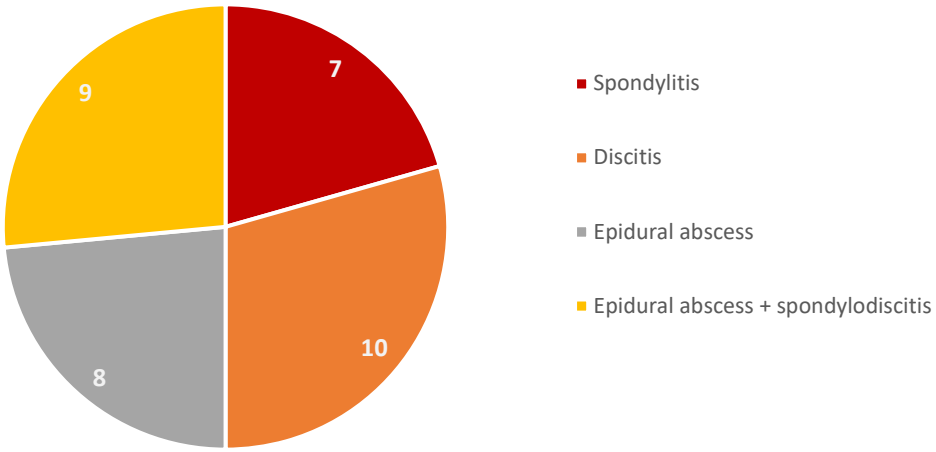


Fig. 62

PATIENT-REPORTED OUTCOME MEASURES

Patient-reported outcome measures (PROMs) are extensively used as outcome measures in spine surgery. This chapter provides a brief overview of the measurement properties of PROMs, along with a description of each PROM. In Swespine, seven multiple-item questionnaires and two single-item measures are recorded (see Table 1). The generic measure of quality of life, EQ-5D, is the only one answered by all diagnostic groups. The two single-item measures consist of the pain scale NRS (Numeric Rating Scale), which is recorded for all diagnostic groups except metastasis, and the retrospective GA (Global Assessment), which is recorded for all diagnostic groups except the infection group.

In spine science literature, there are around a hundred different PROMs, indicating that optimal measures are lacking. Working groups around the world aim to standardize the use of PROMs by recommending a few "key measures." Since the registry was initiated 25 years ago, PROMs have been both added and removed.

PROM	Lumbar Spine	Cervical Spine	Deformity	Infection	Metastasis
Multiple-item questionnaires					
EQ-5D + EQ-VAS	X	X	X	X	X
ODI	X		X		
NDI		X			
PmJOA		X			
EMS		X			
SRS-22r			X		
EOSQ-24			X (<15 years)		
Single-item questions					
$NRS_{RYGG/NACKE}$	X	X	X	X	
$NRS_{BEN/ARM}$	X	X	X	X	
Retrospective single-item questions					
$GA_{RYGG/NACKE/MET}$	X	X	X		X
$GA_{ARM/BEN/MET}$	X	X	X		X

EQ-5D =Euroqol 5 dimensions; ODI = Oswestry Disability Index; NDI = Neck Disability Index; PmJOA = patient-derived modified Japanese Orthopaedic Association score; EMS = European Myelopathy Scale; SRS-22r = revised Scoliosis Research Society questionnaire; EOSQ-24 = Early Onset Scoliosis 24-item questionnaire; NRS =Numeric Rating Scale for back/neck/leg/arm pain; GA = Global Assessment of back/neck/leg/arm pain; GAmet = Global Assessment of pain and function after metastasis surgery

Measurement Properties

To utilize and interpret the results of a PROM, it's essential to understand its measurement properties. Assessing the significance of changes over time for this type of outcome measure is challenging, which is why this area is given more attention below.

Reliability refers to the extent to which a PROM is free from measurement errors in different situations, for populations, and over time.

Validity regards the extent to which a PROM measures what it's intended to measure. The term includes various types of analyses that are especially important during the development of a PROM.

Floor and ceiling effects fall under the concept of validity and pertain to situations where a significant proportion of respondents either score the lowest or highest possible points. If floor or ceiling effects are substantial (typically 15-20%), the outcome measure is not sensitive enough to provide a complete reflection of the variation within the target population.

Responsiveness, or the ability to detect change over time, concerns a PROM's capability to identify a change. A PROM can be good at showing changes at a group level when results are presented, for example, as mean or median values. However, it is not sufficient to merely demonstrate a statistically significant difference; you also need to prove that the difference is meaningful for patients and could lead to a change in clinical practice. Determining the lowest change in score of clinical importance, is a complex area marked by conceptual confusion. There are many abbreviations that all aim to define a

meaningful change and may sound very similar – the most well-known being MCID, the Minimal Clinically Important Difference. In reality, these abbreviations can have widely varying meanings.

To disentangle these concepts, one can imagine that the responsiveness of a PROM is characterized based on three fundamentally distinct perspectives:

a) the smallest statistically detectable change

b) the smallest detectable patient-reported change

c) the smallest clinically meaningful change

The smallest statistically detectable change is the smallest change in a PROM's score that can be distinguished from the instrument's measurement error. The lowest statistically detectable change helps us differentiate real changes from random measurement errors.

The smallest patient-reported change is often measured using so-called anchor-based methods. Typically, patients themselves serve as anchors by simply responding to a question that quantifies the degree of perceived change after surgery, which is then related to the score in the specified PROM. In Swespine, there is the anchor question Global Assessment: "How is your leg/arm pain today compared to before the operation?" with response options: had no leg/arm pain before the operation / 1 completely gone / 2 much improved / 3 somewhat improved / 4 unchanged / 5 worse. By determining that the cut-off point for a PROM's result should be between "somewhat improved" and "unchanged," you can obtain a value for the smallest patient-reported change.

It is essential to reflect on the extent to which the smallest patient-reported change is meaningful from both a patient's and a healthcare perspective.

This is why, as clinical experts or researchers, we can sometimes determine how large a patient-reported improvement should be to be considered meaningful, which we can call the smallest clinically meaningful change. It is not uncommon for the smallest statistically detectable change to exceed the value of the smallest patient-reported improvement, making it impossible to be certain that there is a real improvement due to the surgery and not just random variation. This uncertainty leads to placing the cut-off for the smallest clinically significant change in a PROM's result between "somewhat improved" and "much improved" rather than between "unchanged" and "somewhat improved."

The numerical values for the above-mentioned concepts a), b), and c) vary depending on the population, diagnosis, surgical intervention, and context. This must be considered when using PROMs as outcome measures in studies comparing groups or measuring changes over time. It is tempting to choose the lowest value found in the literature to detect differences, but there is a risk that a potential difference lacks clinical significance or cannot be distinguished from chance. Swespine recommends considering all three perspectives—patient, physician, and statistically detectable change—when using PROMs as outcome measures in studies.

In the following report on PROMs in Swespine, an approximate value or range is provided for the smallest statistically detectable change and the smallest patient-reported change. Note, however, that the latter also includes values defined as the smallest clinically meaningful change!

Practical usability (feasibility) means investigating how user-friendly a PROM is in terms of factors such as the number of questions and administration. Shorter questionnaires are generally preferred.

Instruments

EQ-5D

Scope: EQ-5D is a standardized self-assessment scale used to describe and measure health and health-related quality of life. The instrument is used in health economic evaluations by estimating the quality-adjusted life year (QALY), as well as in clinical studies, quality registries, and population surveys.

EQ-5D consists of two parts:

a) A questionnaire with five questions in which the individual assesses their health in the areas of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each question has three response options with varying severity: no problems, moderate problems, severe problems.

b) A thermometer-like scale graded from 0 to 100, where the individual rates a value for his or her current health status.

Reporting: The EQ-5D index is a weighted health index that can vary from 1 to -0.594. The EQ profile reports each dimension individually. The EQ-VAS isa self-assessed health status between 0 and 100.

Calculation of EQ-5D Index: The answers provided by an individual in the questionnaire can be represented in the form of 5 digits, signifying a health state (e.g., 11212). The health state can be converted into an index value using a valuation system. The so-called time-trade-off method (TTO) provides a preference-based valuation of the health state. This means that a group of individuals from the general population has assessed what it would be like to live in a certain health state for 10 years and then specify how many years they would be willing to give up to instead live in full health.

In Swespine, the EQ-5D index is calculated based on the British TTO-based valuation system, despite the existence of valuation systems for the Swedish population, because the former is used in several countries and may thus facilitate international comparisons.

Note that there is now an EQ-5D with five response options, as used, for example, in the Swedish joint prosthesis registry.

Interpretation: A value of 1 corresponds to full health, and 0 represents a health state that the population values as being as bad as being dead. The minimum statistically detectable change ranges from 0.28 to 0.43. The minimum patient-reported change in the EQ index varies from about 0.09 to 0.43 depending on the context. It has been shown that the statistically detectable change is often larger than the patient-reported change, making changes in EQ-5D index at the individual level very uncertain.

ODI

Scope: ODI is a disease-specific instrument designed to measure function in relation to low back pain. It is one of the most used disease-specific outcome measures in spinal surgery research. It consists of a questionnaire with 10 questions, each with 6 response options. The questions pertain to how individuals can manage everyday situations such as walking, standing, social situations, and work, as well as how they experience pain.

Reporting: The result is expressed as an index value ranging from 0 to 100.

Calculation: ODI is calculated using the formula: (total score) x 100 / (5 x the number of questions answered) = disability percentage.

Interpretation: A higher value indicates a lower level of function. The developers of ODI recommended the following interpretation: 0–19: minimal disability, 20–39: moderate disability; 40–59: severe disability; 60–79: crippled;80–100: bed-bound. The minimum statistically detectable change has been reported to be between approximately 8 and 13. The minimum patient-reported change varies from approximately 9 to 20.

NDI

Scope: The NDI aims to measure the impact of neck pain on everyday activities. Questions and response options resemble those in the ODI.

Reporting: In Swespine, the result is expressed as an index value ranging from 0 to 100%. However, it is not uncommon in studies to report NDI scores on a scale between 0 and 50 points.

Calculation: In Swespine, NDI is calculated using the formula: (total score) x 100 / (5 x the number of questions answered) = disability percentage.

Interpretation: A higher value indicates a lower level of function.

The minimum statistically detectable change has been reported as approximately 10. The minimum patient-reported change varies from approximately 10 to 27.

P-mJOA

Scope: P-mJOA is a patient-customized version of the physician-administered modified JOA scale, which measures degree of disability caused by myelopathy. A study from 2018 demonstrated that the two scales have very high concordance in psychometric properties, and therefore, the interpretation of P-mJOA is currently the same as for mJOA.

Components: The instrument comprises four questions about upper and lower extremity function, sensory function in the hands, and bladder function.

Reporting: Results are expressed in points, with a minimum score of 0 and a maximum of 18.

Interpretation: Lower scores indicate more severe myelopathy. A recommended interpretation is as follows: 17–15 = mild myelopathy, 14–12 = moderate myelopathy, 11–0 = severe myelopathy. The minimum patient-reported change for mJOA, regardless of myelopathy severity, has been measured at 2 points. For mild myelopathy, a change of 1 point is reported, for moderate myelopathy, a 2-point change, and for severe myelopathy, a change of 3.6 points.

European Myelopathy Scale

Scope: As the name suggests, this instrument aims to measure the degree of myelopathy through questions about gait, hand function, proprioception, bladder and bowel function, and paraesthesia.

Reporting: Response options are scored from 1 to 3, 4, or 5 and summed to a minimum of 5 points and a maximum of 18 points. Higher scores indicate more severe myelopathy.

Interpretation: A recommended interpretation is as follows: 18–17 points = normal status, 16–13 = mild myelopathy, 12–9 = distinct functional impairment, 8–5 = severe disability.

There is no reported minimum statistically or patient-reported changes for this scale.

EOSQ-24

Scope: The Early Onset Scoliosis 24-item questionnaire (EOSQ-24) reports the function of a child with early onset scoliosis from the perspective of their caregiver. It was introduced in Swespine in 2021. The purpose of this tool is to measure the caregiver's subjective perception of the child's health. EOSQ-24 can be used in clinical studies and for comparing the impact of the disease on the child's quality of life, its effect on parents, and the family's economic burden. Comparisons can be made with age-matched healthy children and their families.

Components: The questionnaire consists of 24 questions concerning the patient's health-related quality of life, the impact of the disease on the family, the family's finances, and satisfaction. Quality of life is measured across eight domains, in total 16 questions: general health, pain/discomfort, lung function, mobility, physical function, daily activities, fatigue/energy levels, and emotional impact. The impact on the family is measured with six questions within the domains of the disease's impact on parents and financial effect. Satisfaction is reflected in two questions, one for the child and one for the parents.

Reporting: Each question has five response options, from 1 to 5, ranging from "poor" to "excellent." The scale score ranges from 0 to 100.

Calculation: To transform raw data into interpretable scores, the algebraic mean within each domain is calculated and inserted into the following equation: ((algebraic mean - 1) / 4) x 100. It's also possible to calculate the mean of all domains, providing a value for overall quality of life.

Interpretation: Children with idiopathic scoliosis generally appear to report higher values compared to children with congenital or neuromuscular scoliosis. However, there are still no studies defining the minimum statistically detectable or patient-reported change for this questionnaire.

SRS-22r

Scope: The SRS-22 was developed in the 1990s and revised in subsequent years. It has been used in Swespine since 2008. The current version, SRS-22r, was translated into Swedish and validated in 2013. The instrument aims to measure the quality of life in patients with idiopathic scoliosis, with five questions in each of the domains: pain, self-image, function, mental health, and two questions about satisfaction with treatment.

Reporting: Each question has 5 response options, scored from 1 (worst) to 5 (best). The total score ranges from a minimum of 22 to a maximum of 110. Domains can be reported separately as index values or combined into a total index.

Calculation: Scores are summed within each domain and divided by the number of questions. A total index is not calculated if data from more than two domains are missing.

Interpretation: Values for a Swedish normal population were established in 2017. In that study, total indices in different age groups varied between 4.4 and 4.7.

NRS (Numeric Rating Scale):

Scope: The Numeric Rating Scale asks the patient to mark a number from 0 (no pain) to 10 (worst pain imaginable) that best represents their pain level over the past week. Due to its simplicity, NRS is widely used in disciplines where pain is measured.

Reporting: NRS is often reported as the mean or median value.

Interpretation: The minimum statistically detectable change varies between approximately 1 and 5, while the minimum patient-reported change ranges from 1 to 6 depending on the context.

GA (Global Assessment):

Scope: In Swespine, the Global Assessment asks how the patient perceives their pain in the back/neck and leg/arm compared to preoperative pain. GA has no measurement point before the operation, distinguishing it from other PROMs. It is retrospective and can be influenced by memory, unlike other PROMs (which are prospective). It is also independent of missing baseline data, providing a larger calculation base and less uncertainty. There are six response options: 0 had no back/neck/leg/arm pain before the operation/1 completely pain-free/2 much improved/3 slightly improved/4 unchanged/5 worse. In the Metastasis diagnosis group, GA questions have a different format with fewer response options.

Reporting: Reported in the percentage of respondents per response option. Often, the categories "completely pain-free" and "much improved" are reported as a single entity, as a measure of a successful surgical outcome.

Interpretation: Since GA specifically asks about the effect of spine surgery, it cannot be evaluated in a normal population. And as GA only has postoperative measurement points, it is not possible to obtain minimum values (of the MCID type) for changes over time. If groups are to be compared, the proportion of each population that has reported a specific response option is presented, followed by a statistical analysis and clinical evaluation of any differences between the groups.

Satisfaction:

Scope: There are three response options: 1 satisfied, 2 uncertain, 3 dissatisfied. Response option 1 is considered a successful outcome. Satisfaction is reported and interpreted in the same manner as GA.

Comments:

The simple retrospective question, Global Assessment, has been shown to have a good correlation with PROMs measuring pain and function and can, therefore, be used as a single outcome measure when clinics evaluate their results for common degenerative spine conditions such as herniated discs and spinal stenosis. However, for procedures like deformity surgery, it is appropriate to report the PROM that is specific to the condition. Both retrospective and prospective PROMs have limitations in their measurement properties, reducing their reliability. Therefore, in clinical studies, it is recommended to report multiple PROMs, whose results should be consistent, and it is important to ensure that the chosen PROMs are relevant to the target population and context.

LONGITUDINAL OUTCOME ANALYSIS

Overview

After 25 years of work on the registration of spinal surgeries in the country, we have reached a point where it is time to aggregate and evaluate the results of our efforts. The dataset is the entire Swespine database, including all surgeries from 1998 to 2021, providing us with complete 1-year follow-up data until 2022. It's essential to remember that we do not have complete registration of all spinal surgeries in the country. The extent to which we capture data is often described using three key concepts:

1. ***Coverage*** – Reporting rate at the clinic level, indicating how many of the country's clinics actively participate in Swespine. The number of clinics has varied over the years, depending on the opening/closure of several private clinics, and currently amounts to 47, with all except one neurosurgical clinic participating to varying degrees (98%).
2. ***Completeness*** - Reporting rate at the individual level, reflecting how many of the actual performed spinal surgeries are registered in Swespine. The actual surgeries performed are the sum of spinal surgeries registered in either Swespine or the PAR registry (the National Board of Health and Welfare's patient registry). Neither of the registries captures all surgeries. It is somewhat surprising that not all surgeries are reported to PAR, given that it is a legal obligation. The registration frequency has increased in recent years and is currently at 86%.
3. ***Follow-up frequency*** – the number of follow-ups of the registered index surgeries at various intervals, FU1 (follow up 1 year), FU2, FU5, FU10.

Coverage and follow-up frequency over time are described and commented on in the "Benchmarking" section, p.99.

All the outcomes presented are unadjusted values.

At the same time, we emphasize that the data presented does not come from more or less distorted studies but represents the clinical reality as it is for both patients and healthcare providers. The total number of registered Index surgeries (the first-time surgery for a diagnosis, generating a follow-up questionnaire) is 169,812 until the year 2021.

In the early years, only surgeries for Degenerative Lumbar Diagnoses were registered. Surgeries for Degenerative Cervical Diagnoses, Metastasis, Infection, and Deformity began to be recorded in 2006 (Fig.63). The major volume is still Degenerative Lumbar Diagnoses. The five diagnostic groups comprising Swespine will be evaluated in separate sections.

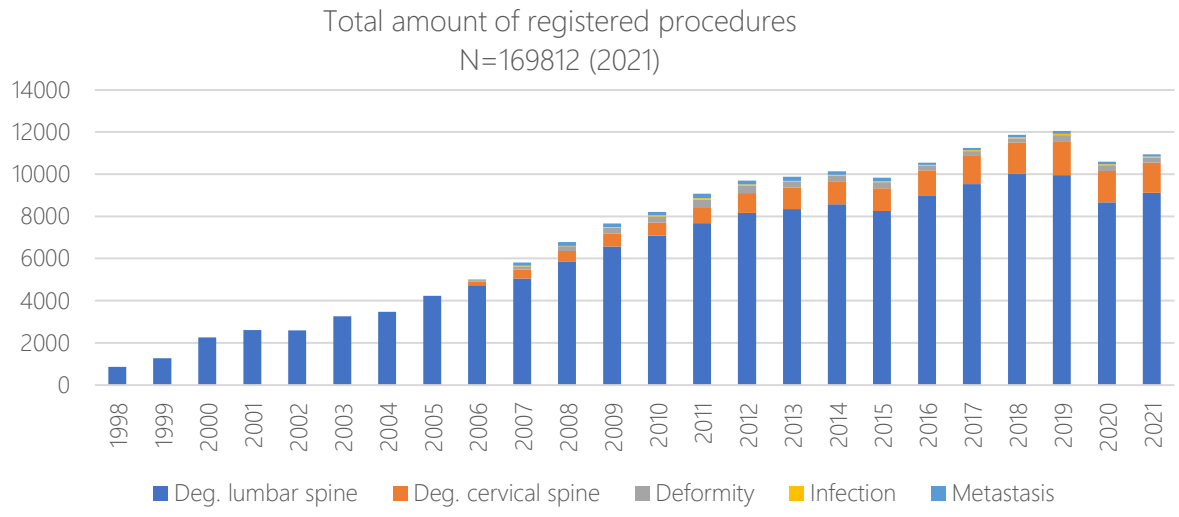


Fig. 63

Follow-up frequency is reported separately for each diagnostic group. As an example, Fig.64 shows the follow-up frequency over time for the different FU occasions for Degenerative Lumbar cases. Across the entire dataset, FU1 is 73%, FU2 is 65%, FU5 is 59%, and FU10 is 58%. In recent years, the follow-up frequency has gradually decreased somewhat. It was 78% at FU1 in 2001, 71% in 2012, and 67% in 2021. A similar trend is observed for Degenerative Cervical cases.

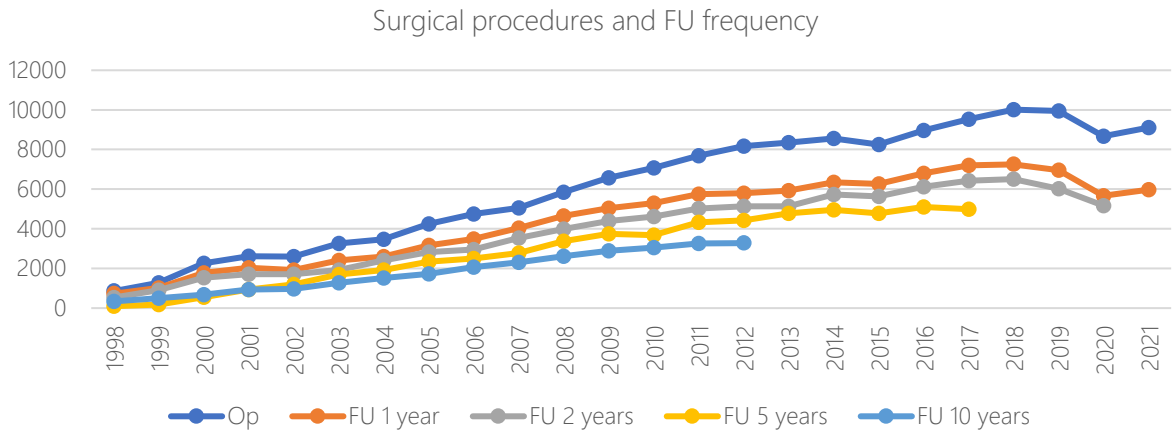


Fig. 64

The three types of clinics in Swespine (University Hospitals, County Hospitals, and Private Clinics) have different spectrums of diagnoses and surgeries. While the relationship between University and County Hospitals remains relatively constant over the years, Private Clinics have progressively performed more surgeries for both Degenerative Cervical and Lumbar conditions (Fig.65+66).

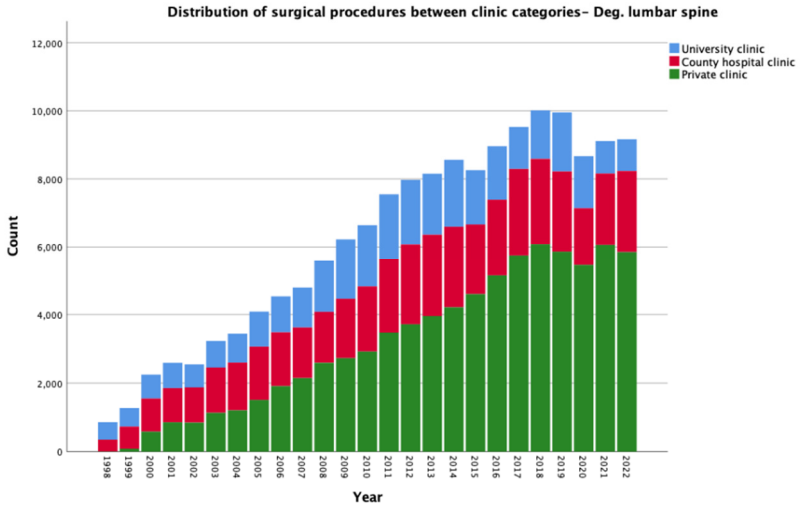


Fig. 65

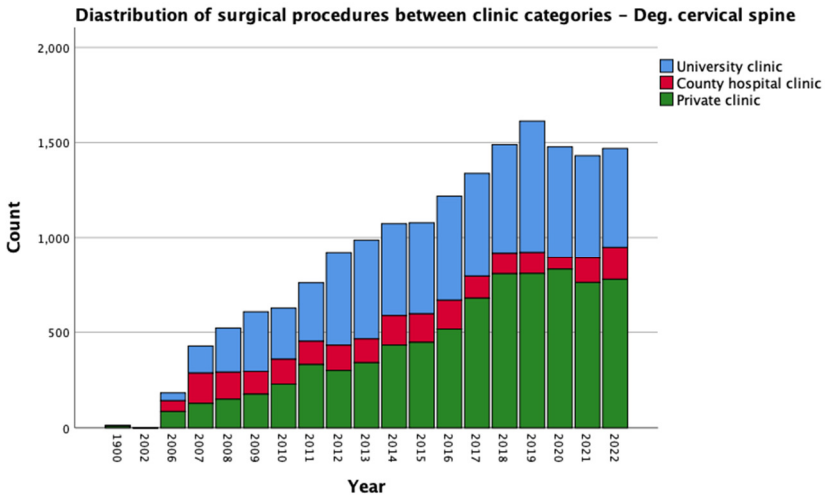


Fig. 66

Financing of Degenerative Cervical and Lumbar surgeries has been recorded since 2011. Over the years, the relative proportion of private financing (insurance companies or entirely private) has slowly increased and now amounts to approximately 10% (Fig.67+68).

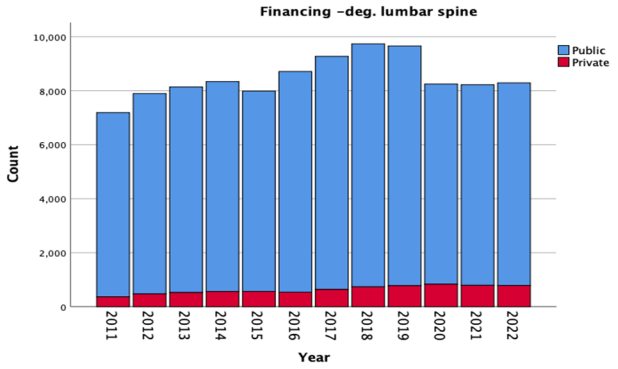


Fig. 67

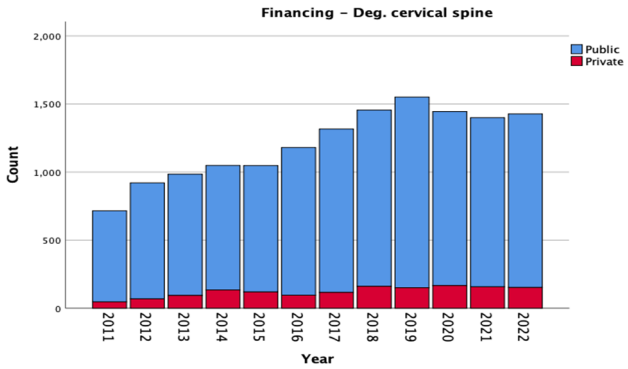


Fig. 68

Smoking, which has been documented as a negative factor for surgery outcomes in several studies, both in general surgery and spinal surgery, has decreased significantly over the years. As an example, smoking is presented for the group of degenerative lumbar diagnoses (Fig.69). The reduction in smoking is similar in all diagnostic groups.

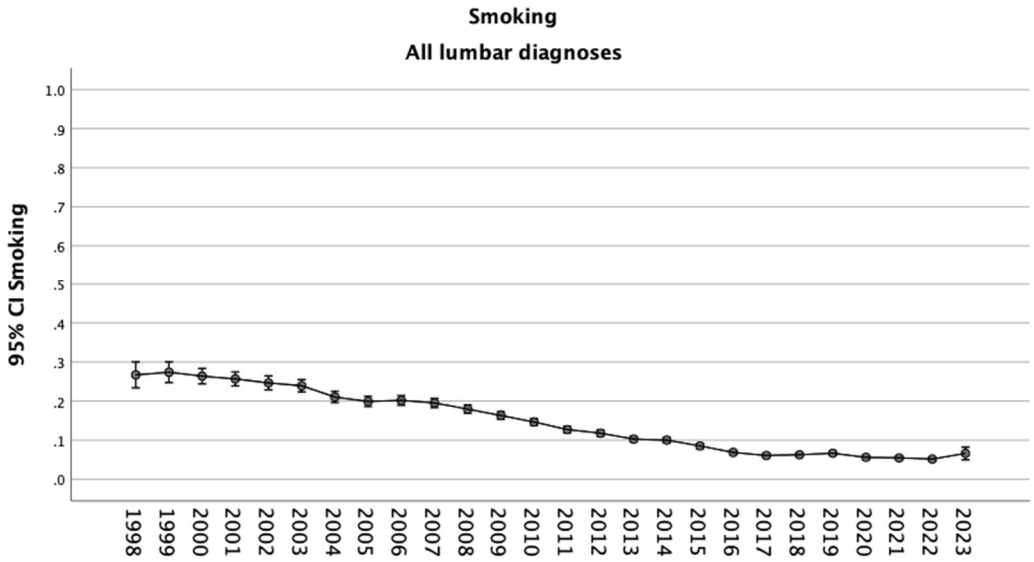


Fig. 69

OUTCOME DEVELOPMENT RELATED TO SPECIFIC DIAGNOSES

Degenerative Lumbar Spine -Disc Herniation

A total of 42,979-disc herniation surgeries have been registered until the year 2021. Of these, 2,957 have undergone only decompression, while a smaller group has undergone other procedures.

Excision of disc herniation (conventional, microscopic, or endoscopic) has been performed on 37,158 patients. This group forms the basis for the analysis below. The number of surgeries has increased gradually but seems to have levelled off in recent years, possibly due to pandemic effects (Fig.70).

Baseline data:

The average age is 44 years, and the age distribution is shown in Fig.71. Women make up 44% of the cases. The average age has increased slightly over time (Fig.72). The follow-up frequency is 65% at 1 year and 37% at 5 years.

Preoperative duration of leg pain is summarized in Fig.73, indicating the number of cases with different pain durations. Fig.74 and Fig.75, illustrating the proportion of cases with pain duration of 3-12 months and <3 months, demonstrate a relative increase in cases with pain duration 3-12 months, but no clear change in the proportion with a duration <3 months. This can be interpreted as Swedish spine surgeons maintaining a conservative approach to early surgery while becoming less inclined to operate on patients with pain durations exceeding 1 year.

Surgical Technique:

Conventional and microscopic discectomy are rather evenly distributed over the years. Since 2015, very small volumes (in total 191) of endoscopic discectomy have been performed at Sahlgrenska University Hospital (Fig.76).

Outcomes:

Outcomes are most easily and clearly summarized using the Global Assessment, where a "Successful outcome" is defined as "Pain-free or Much better" regarding leg pain. Successful outcomes over time are presented in Fig.77 (1 year) and Fig.78 (5 years): approximately 75% have successful outcomes.

The proportion of patients satisfied with the outcome (about 75%) is shown in Fig.79 (1 year) and Fig.80 (5 years).

Failure, defined as patients who experience more pain after the operation, affects a small group, around 2-3% (Fig.81 at 1 year). The aggravation seems to persist and is essentially unchanged after 5 years (Fig.82).

Quality of life, at 1 and 5 years, measured by the EQ-5D Index, improves from about 0.25 to about 0.7 (Fig.83-85).

Successful outcome regarding leg pain is similar in the two major groups - conventional (75.1%) and microscopic (74.9%) discectomy. Of the 89 endoscopic cases (47%) with 1-year follow-up, 77.5% were successful.

Reintervention within 1 year:

A total of 1,545 reinterventions have been registered, with the majority being excision of recurrent disc herniation (n=926, equivalent to 4.8% of index operations). The distribution over time and by different procedures is shown in Fig.86. There are 4 registered reinterventions (2 recurrent disc herniations and 2 Other) after endoscopic surgery.

In Swespine's first year, relatively few reinterventions for recurrent disc herniation were registered, whereas more of the "Other" type were performed. The incidence of excision of recurrent disc herniation seems to have decreased in recent years (Fig.87). This trend is also observed for dural repair, while deep infections have only been registered in the last five years. The overall relative incidence of reoperation has decreased over the past 10 years (Fig.88).

Comment:

At the national level, there have been no dramatic changes in either baseline data or outcomes. There is no noticeable difference in short or long term when comparing surgical methods. Endoscopic surgery is still exceptional, not permitting further comparisons. A reduced incidence of surgery for recurrent disc herniation may reflect more accurate diagnostics and surgical techniques. Deep infections recorded in recent years may be a concern. A disturbing factor that makes conclusions less certain is the low follow-up frequency, the lowest of all degenerative diagnostic groups.

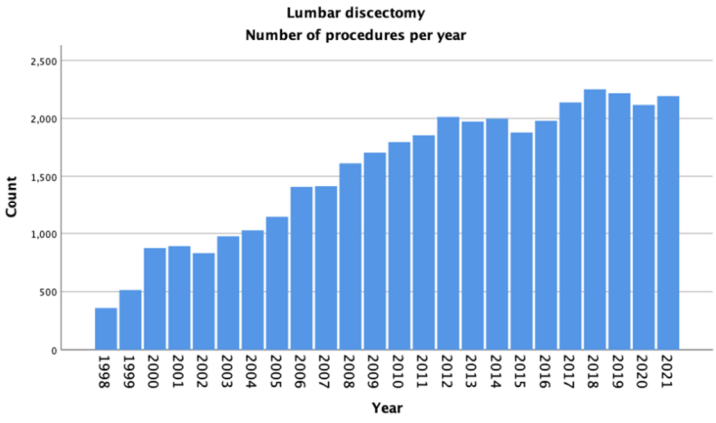


Fig. 70

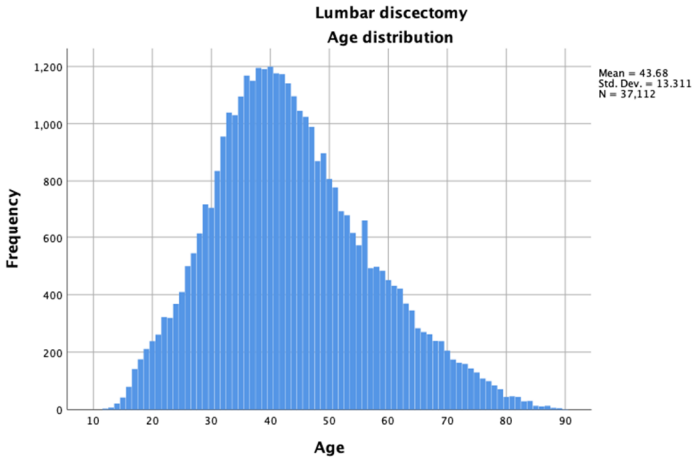


Fig. 71

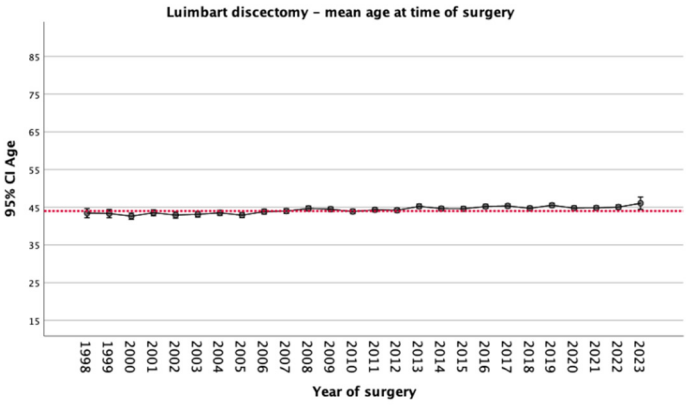


Fig. 72

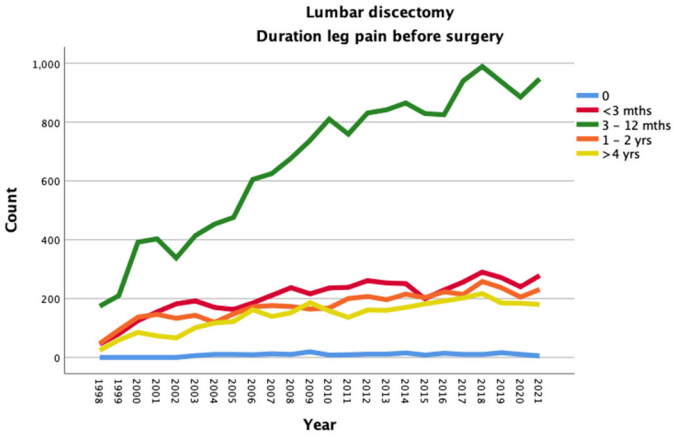


Fig. 73

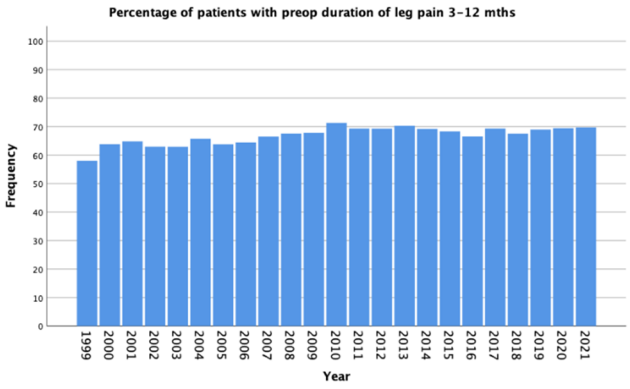


Fig. 74

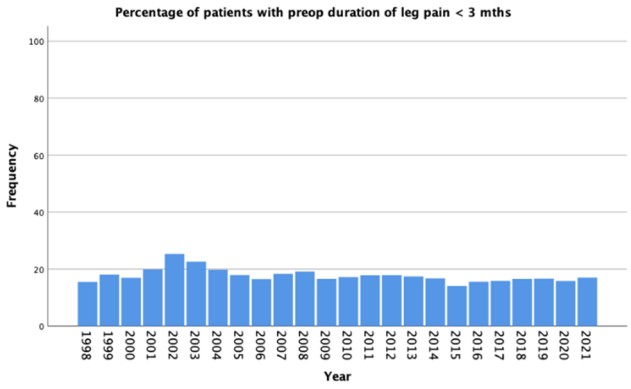


Fig. 75

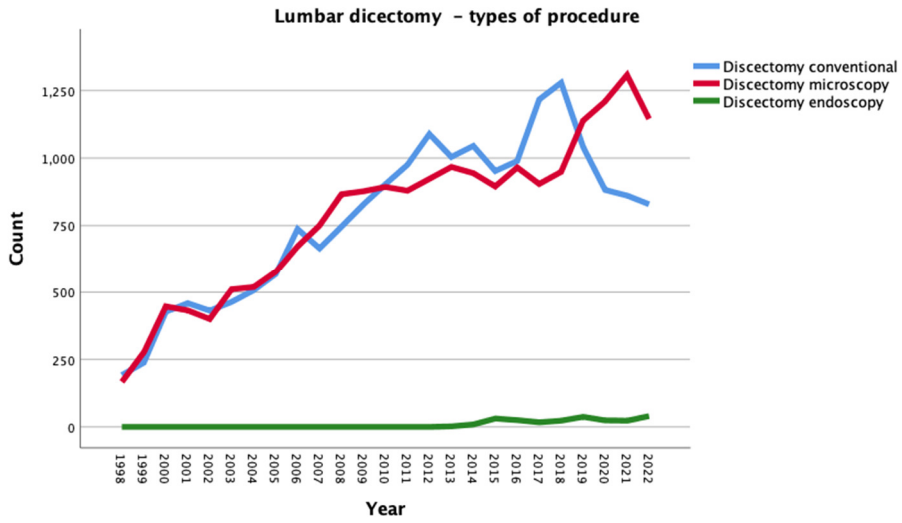


Fig. 76

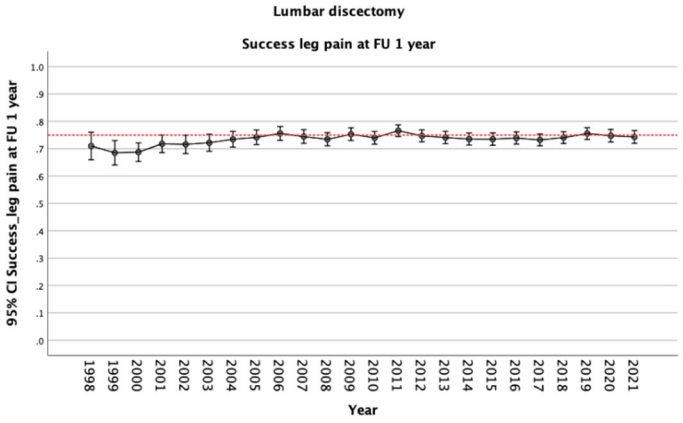


Fig. 77

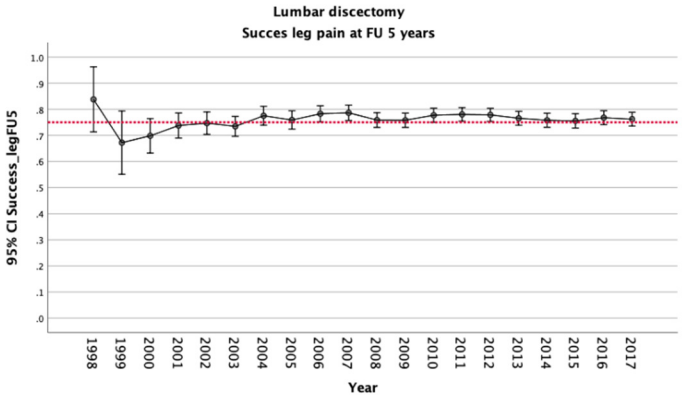


Fig. 78

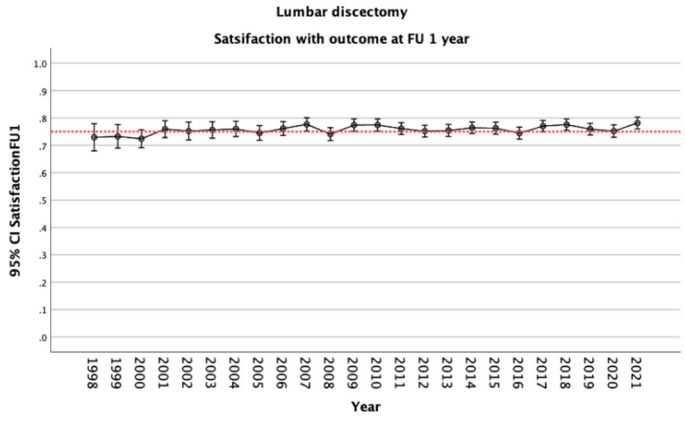


Fig. 79

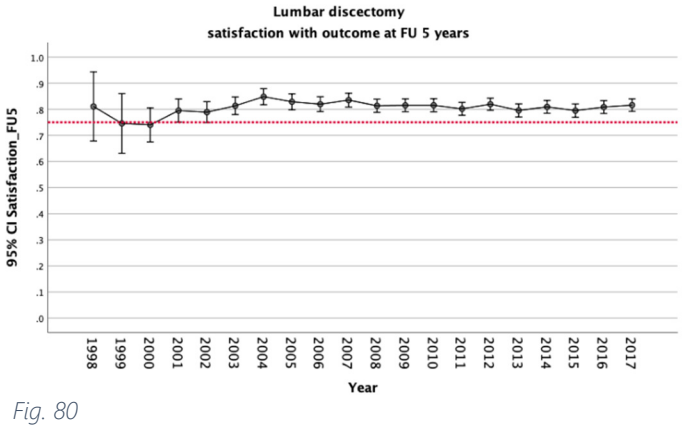


Fig. 80

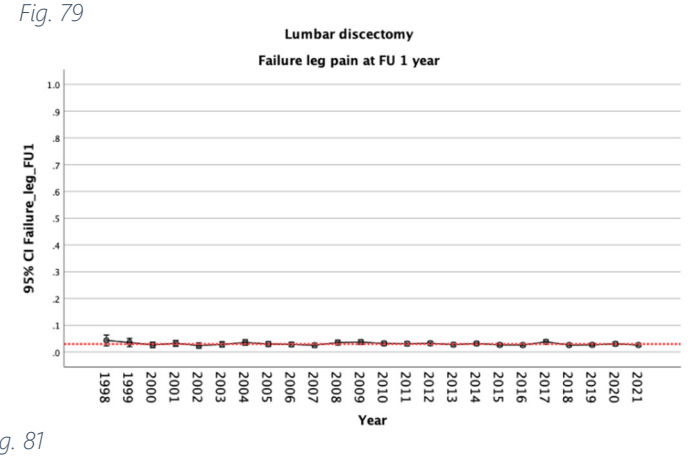


Fig. 81

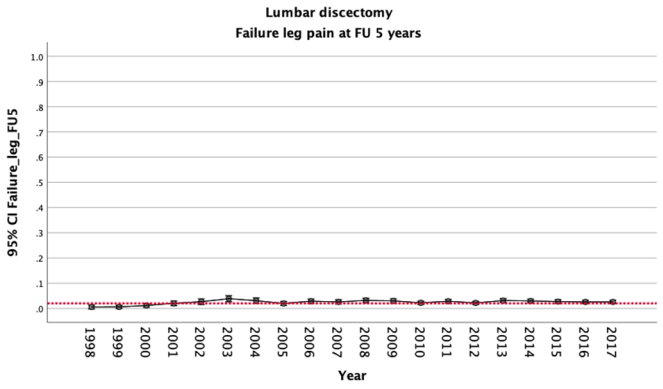


Fig. 82

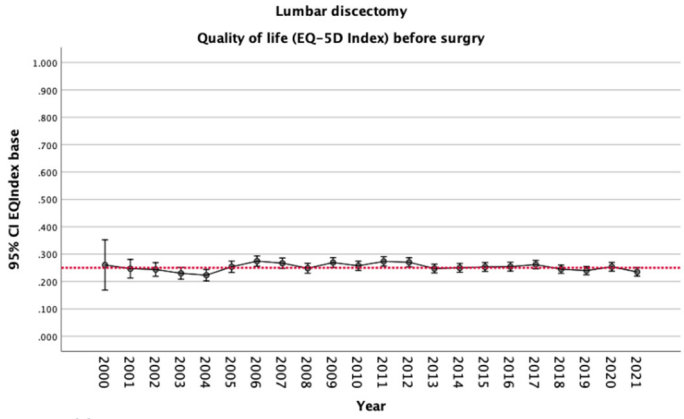


Fig. 83

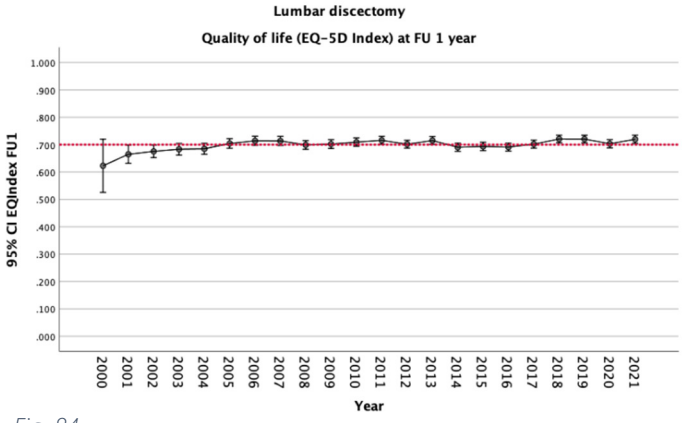


Fig. 84

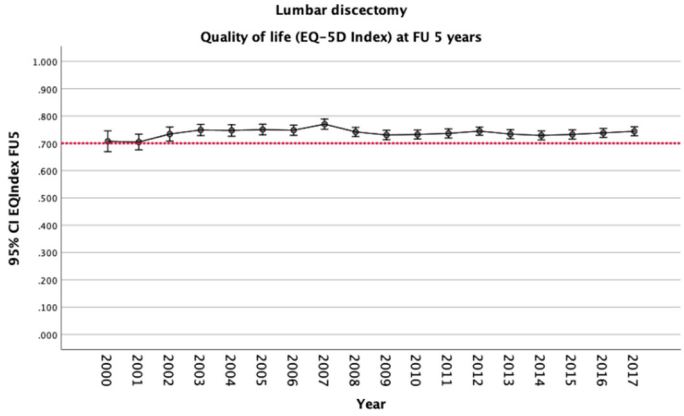


Fig. 85

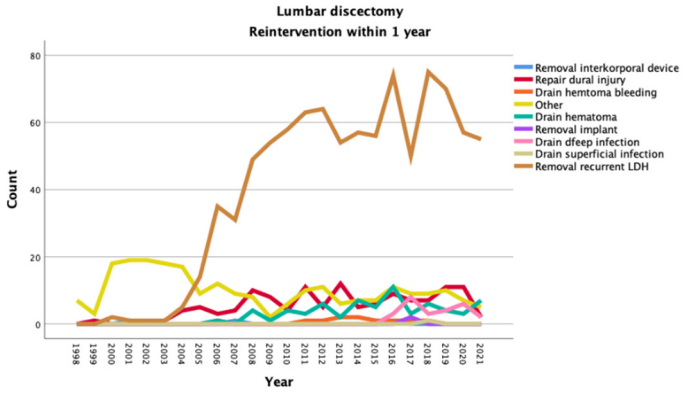


Fig. 86

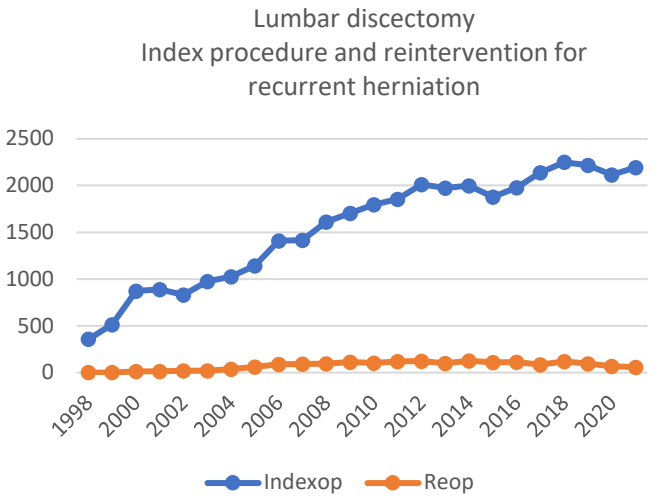


Fig. 87

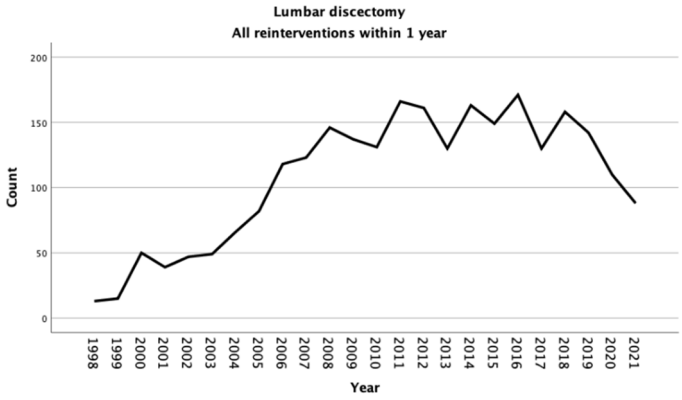


Fig. 88

Degenerative Lumbar Spine - Central spinal stenosis

a. All

There are 65,027 registered surgeries for Central Lumbar Spinal Stenosis until 2021. The number of surgeries has significantly increased over the years (Fig.89). The distribution between spinal stenosis with and without concurrent spondylolisthesis is shown in Fig.90. The follow-up frequency is 78% at 1 year and 59% at 5 years.

Baseline data:

Women account for 48% of cases. The average age is 68 years, as depicted in Fig.91, and remains relatively constant over time (Fig.92). About 70% have had leg discomfort for at least 1 year before the operation (Fig.93). The two main surgical procedures, decompression, and decompression with fusion, are distributed over time as shown in Fig.94.

Outcomes:

Just under 60% have a successful outcome after 1 year (Fig.95), but there is some deterioration after 5 years (Fig.96). No significant change occurs over time.

The effect of the operation on back pain is similar (Fig.97+98).

Before surgery, about 70% had a walking distance of <500m (Fig.99), at 1 year follow-up, 65% could walk >500m (Fig.100), and this was maintained at 5 years (Fig.101). Remarkably, a relatively large group, about 29%, reported persistent significant walking difficulties (<100m).

Over time, there has been no significant change in preoperative quality of life (approximately 0.35) or in the improvement achieved at both 1-year and 5-year follow-ups (about 0.6), as measured by the EQ-5D Index (Fig.102-104).

Satisfaction with the surgical outcome is approximately 65%, with no significant difference between 1-year (Fig.105) and 5-year follow-up (Fig.106) or over time.

a. Stenosis without spondylolisthesis

The number of operated cases is 49,537. Of these, 49% are women. The average age is 68 years, with no change over time (Fig.107). The predominant surgical procedure is decompression without fusion (Fig.108).

Outcome:

Just under 60% have successful outcome in both leg and back pain after 1 and 5 years (Fig.109-112).

There is no difference in outcomes between decompression with or without fusion, regarding either back or leg pain (Fig.113+114).

Reintervention within 1 year:

The number of registered reinterventions is 2,441 (5%). Of these, 950 are redecompressions, 215 are dural repairs, 301 are hematoma drainage, 155 are implant extractions, and 59 are deep infection drainage.

b. Stenosis with spondylolisthesis

The number of registered operations is 15,490, of which 72% are women. The average age is 68 years, 70 years in the group that underwent only decompression and 65 years in the group with decompression + fusion. The frequency of decompression with/without concurrent fusion has undergone a significant change over the years (Fig.115), based on register-based research that provided evidence that fusion is not necessary in the majority of cases of stenosis + spondylolisthesis. A total of 41% have been operated on with the combination of decompression + fusion.

Outcome:

The outcome at both 1 year and 5 years have remained unchanged (approximately 60% successful) in recent years despite a significant reduction in the frequency of fusion (Fig.116-119). Measured with EQ-5D Index, the outcome is similar (from

preoperative approximately 0.35 to 1 year and 5 years follow-up, approximately 0.65) (Fig.120+121). When comparing the outcomes in the two groups (with/without fusion), there is a slight difference in favour of fusion, for both leg and back pain (Fig.122+123), as well as a difference in the change in EQ-5D Index (Fig.124). The difference is statistically significant due to the large cohorts but numerically small – EQ-5D Index 0.07 at 1 year and 0.04 at 5 years when comparing the entire groups. The magnitude of the difference is of questionable clinical significance and is also calculated based on unadjusted outcomes.

Reintervention within 1 year after decompression:

The number of registered reoperations is 216 (2.6%). Of these, 58 are redecompression, 53 are hematoma drainage, 34 are dural repairs, and 12 are deep infection drainage.

Reintervention within 1 year after decompression+ fusion:

The number of registered reoperations is 266 (4.1%). Of these, 79 are implant extractions/adjustments, 33 are hematoma drainage, 31 are refusions, 29 are dural repairs, 19 are redecompression, and 5 are deep infection drainage.

Comment:

Two observations emerge as the most important in the evaluation of stenosis surgery.

1. 1. For most patients with central spinal stenosis, there is no need for fusion in conjunction with the decompression procedure. It is possible that there is a subgroup of patients with stenosis + spondylolisthesis who may have better outcomes with fusion. This group is yet to be defined. Our data also suggest that the reintervention rate for complications is higher after the combination of decompression + fusion compared to decompression alone.
2. 2. Despite several dissertations and nearly 15 registry-based publications analysing predictors of surgical effectiveness in spinal stenosis, the outcome is still the least unfavourable among the degenerative diagnostic groups we have evaluated. While the age is relatively high, one can also suspect that the indication for surgery is too broad and needs better specification.

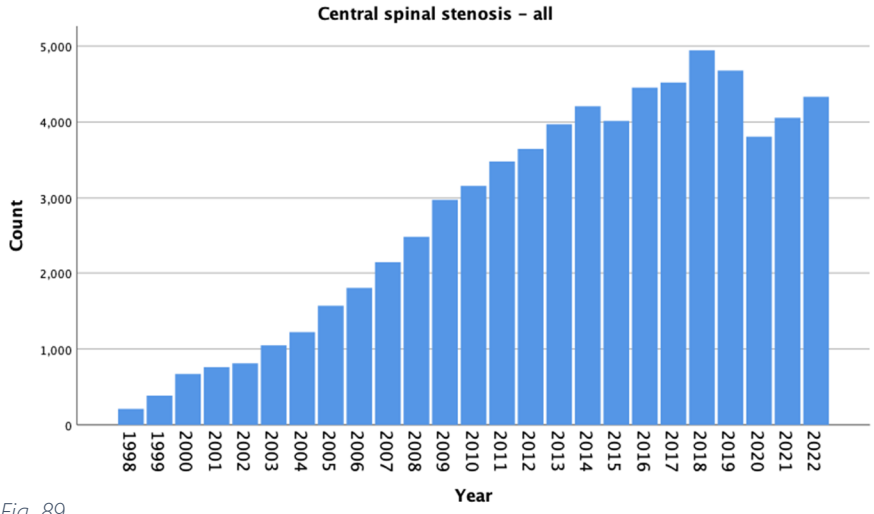


Fig. 89

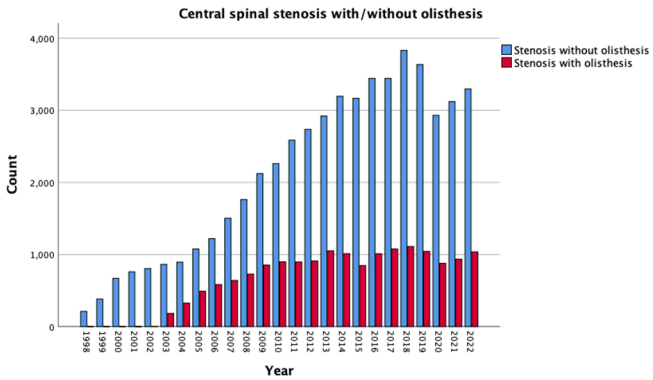


Fig. 90

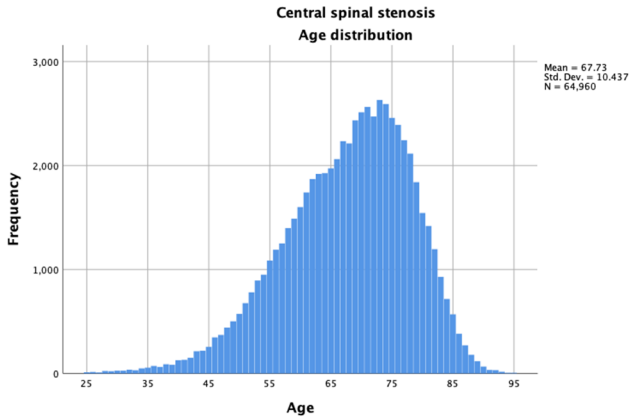


Fig. 91

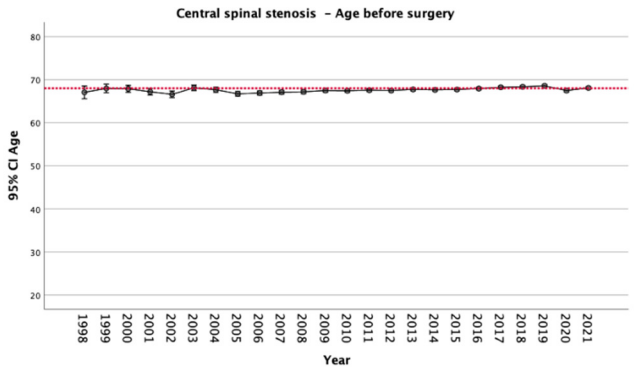


Fig. 92

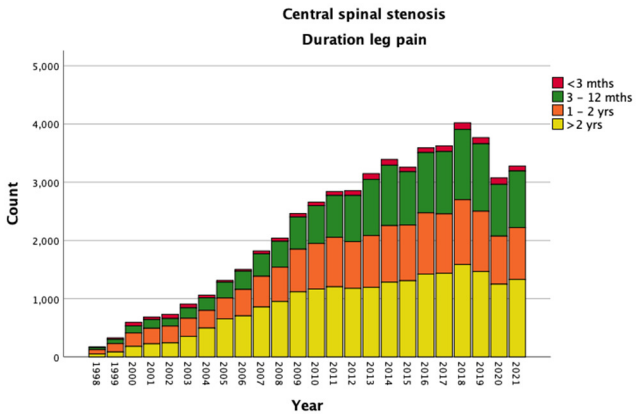


Fig. 93

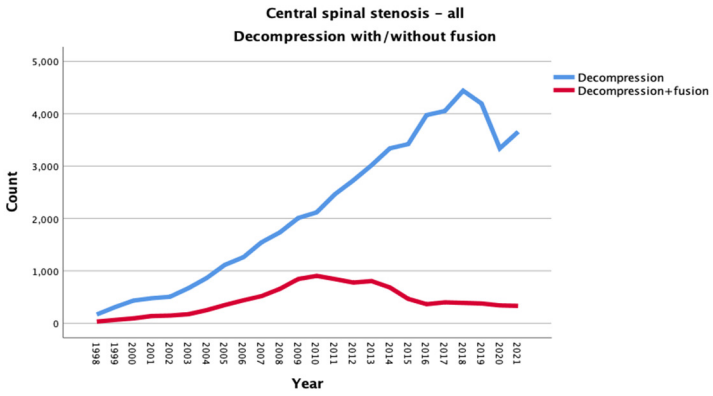


Fig. 94

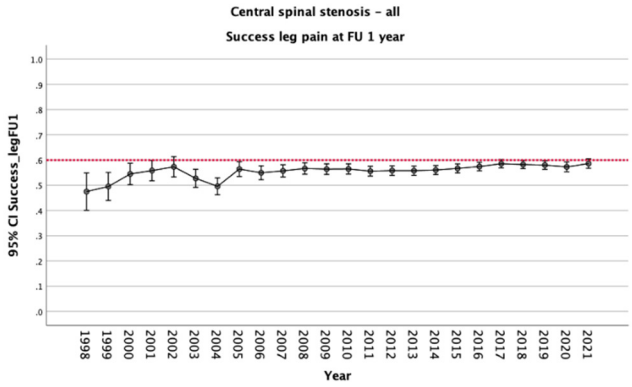


Fig. 95

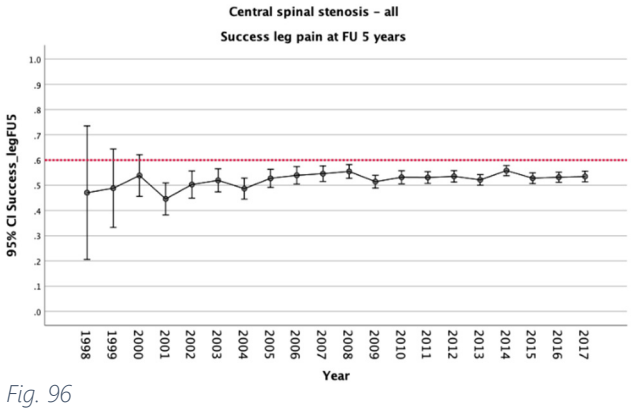


Fig. 96

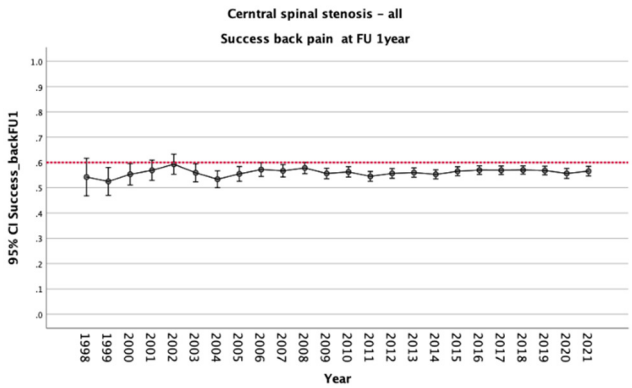


Fig. 97

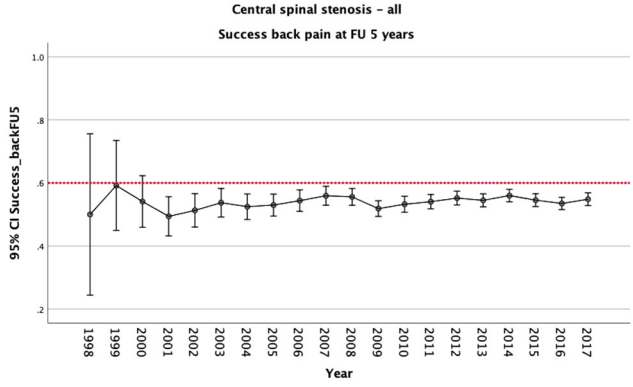


Fig. 98

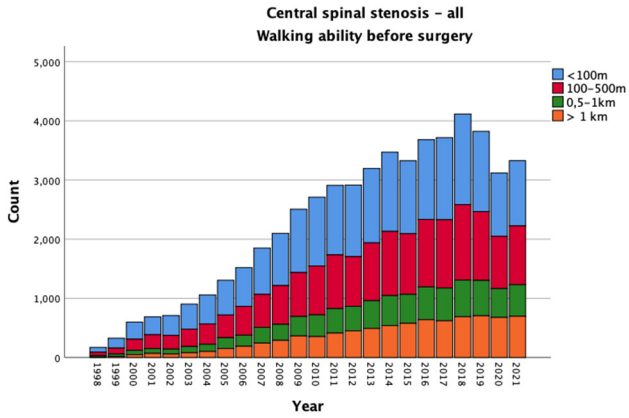


Fig. 99

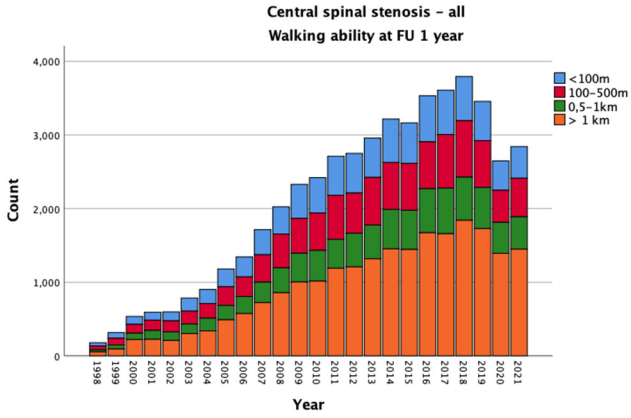
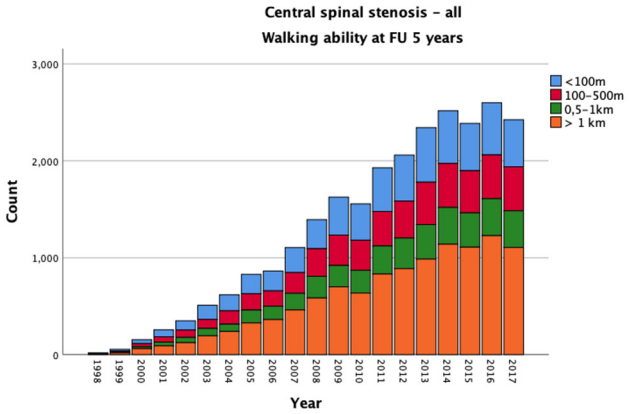


Fig. 100



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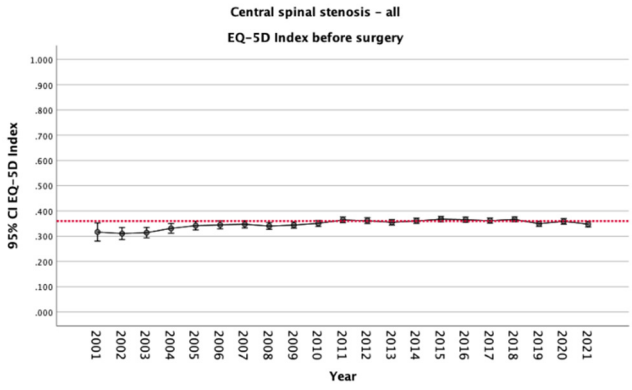

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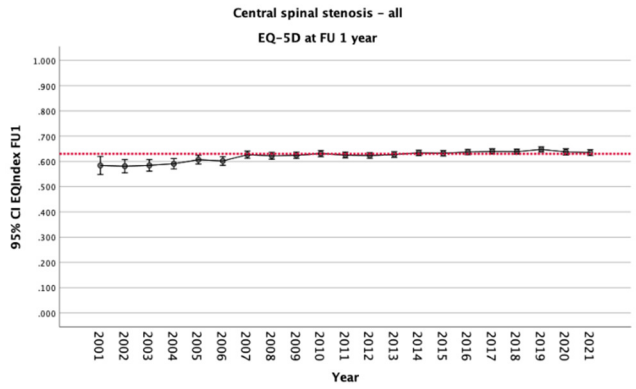

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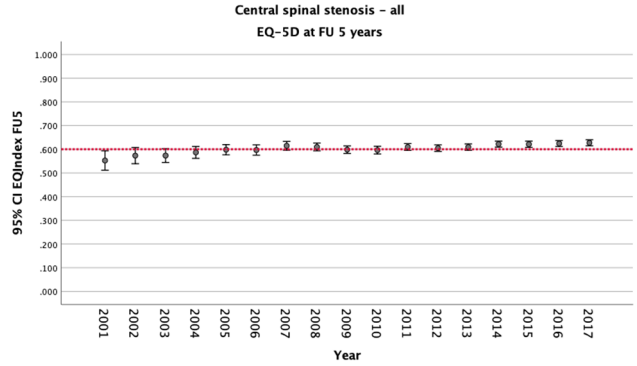

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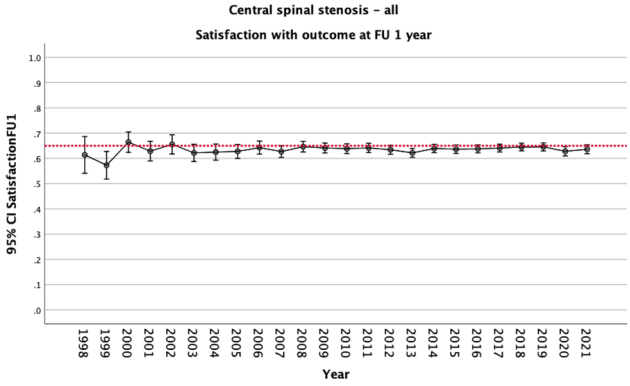

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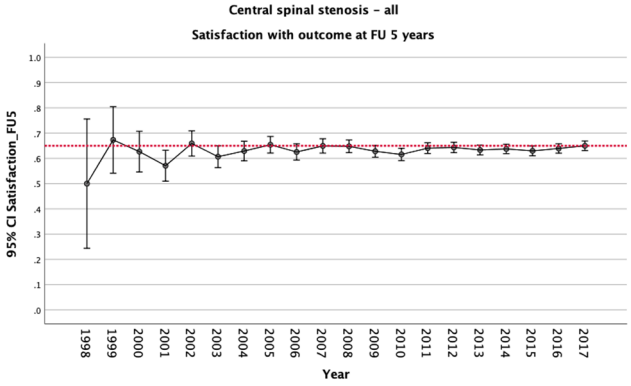

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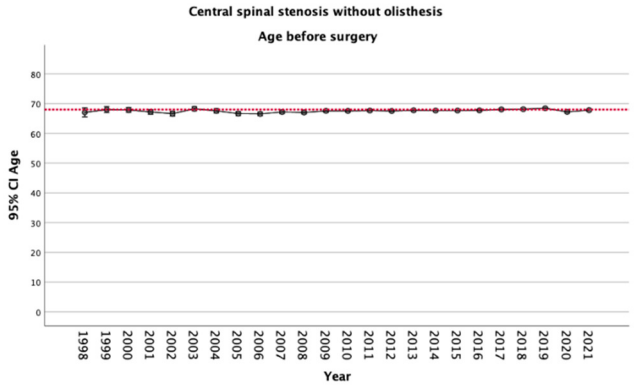

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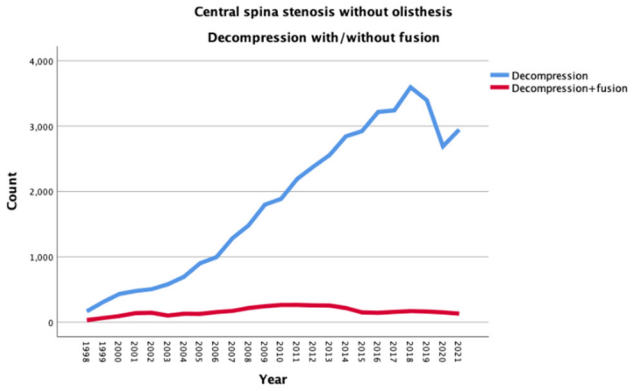

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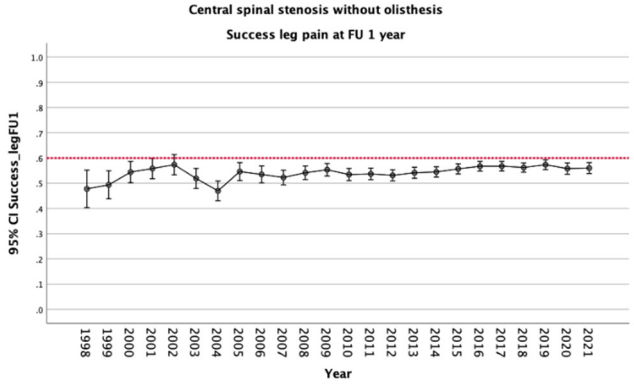

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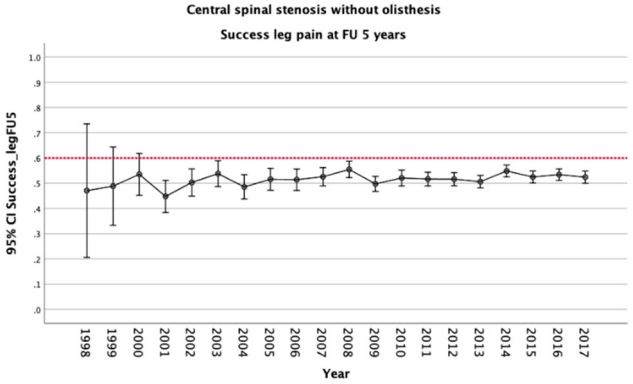

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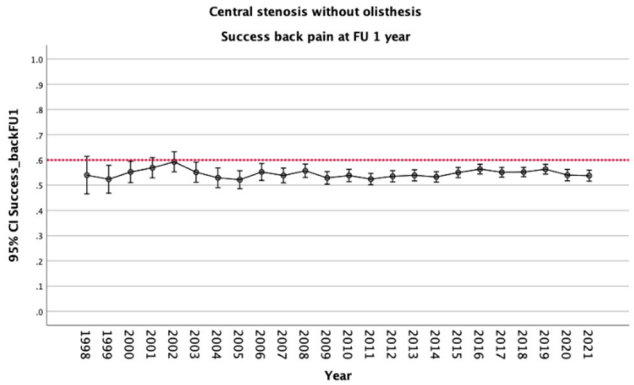

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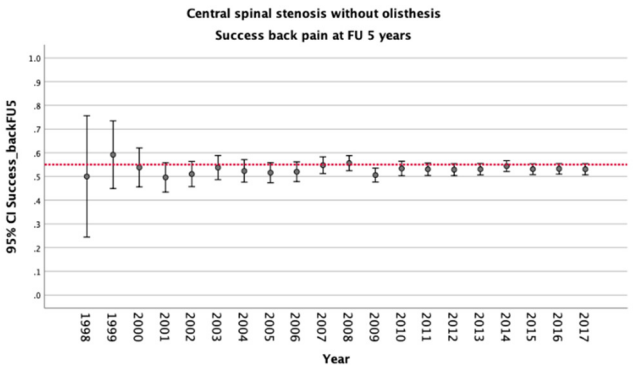

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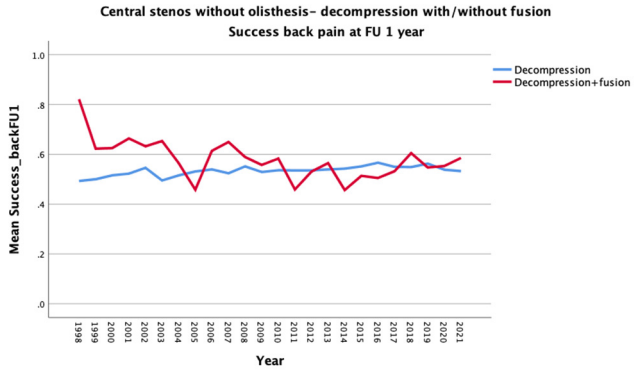

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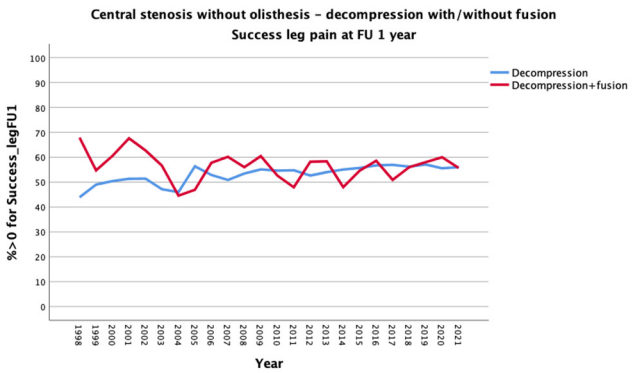

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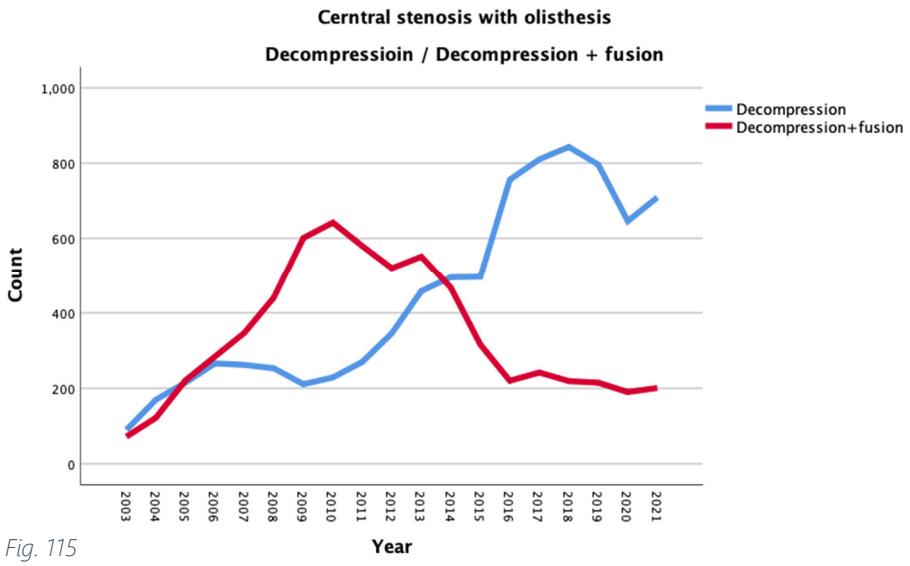

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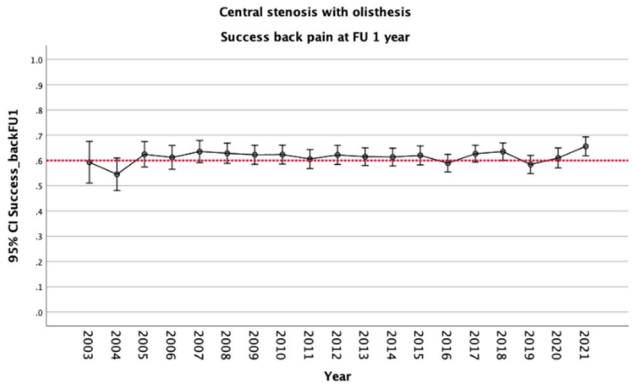

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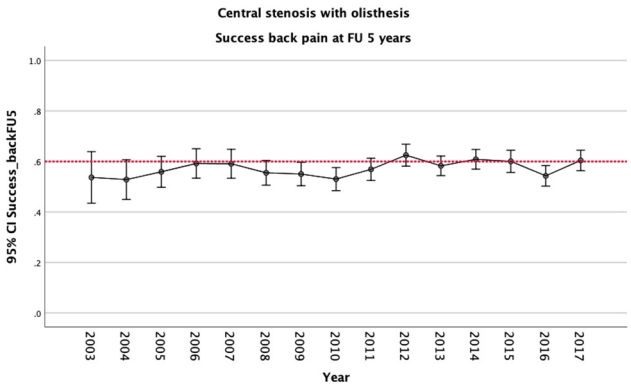

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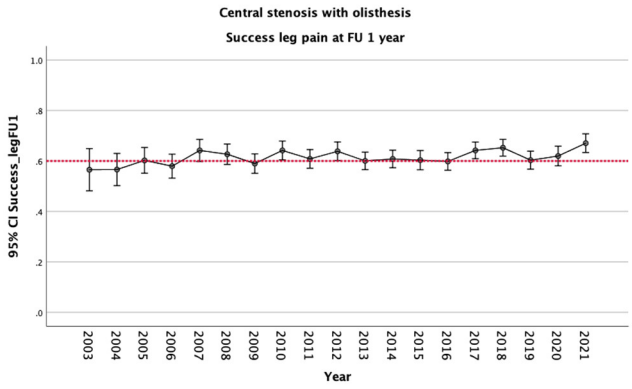

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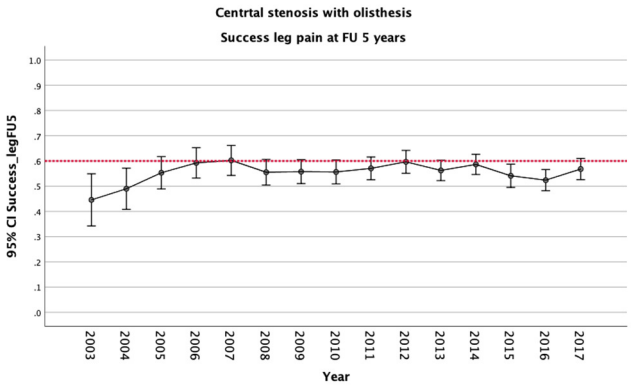

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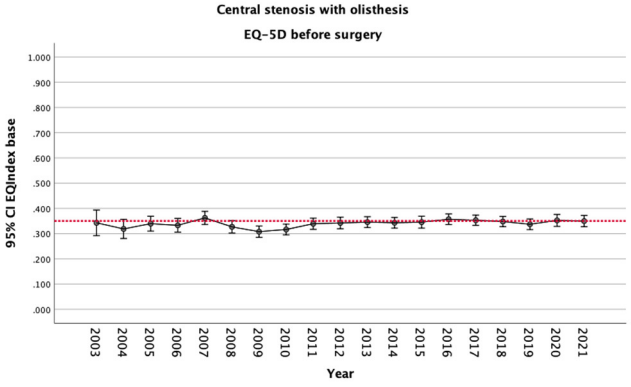

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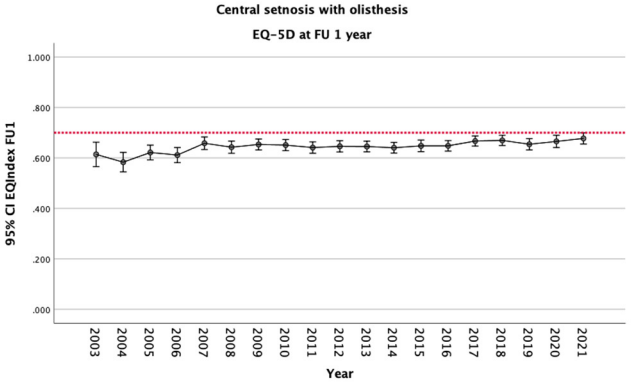

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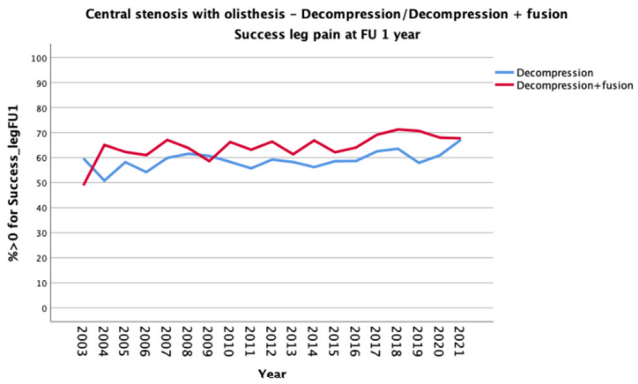

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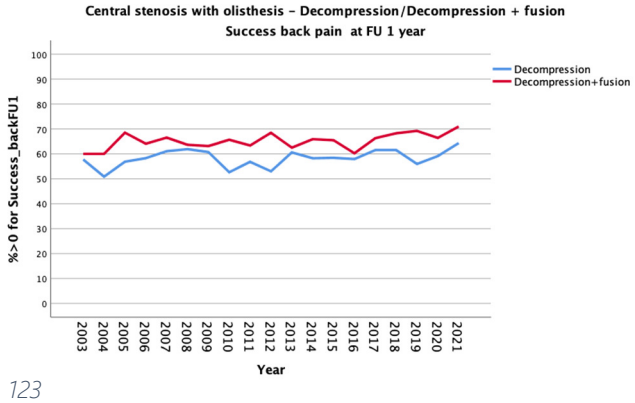

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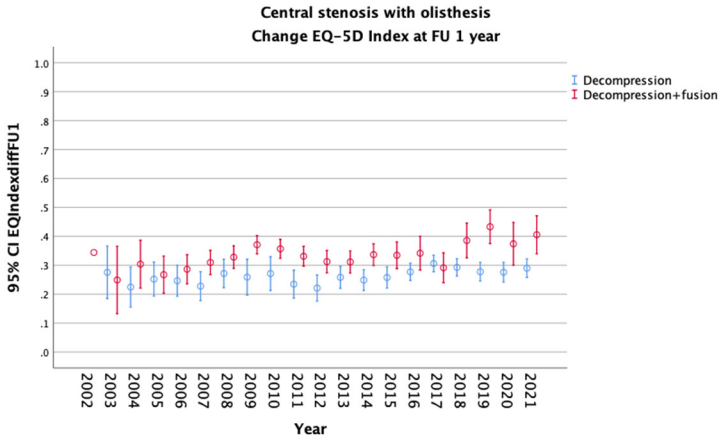


Fig. 124

Degenerative Lumbar Spine - Lateral Spinal Stenosis

The diagnosis of lateral stenosis is not clearly defined, primarily because the distinction between subarticular recess stenosis and foraminal stenosis is unclear. Characteristically, there is usually unilateral leg pain, more of a radiculopathy type than the typically bilateral claudication type seen in central stenosis.

Moreover, the diagnostic group is quite heterogeneous, ranging from a unilateral recess stenosis at one level (which can be addressed with partial facetectomy) to foraminal stenosis at multiple levels due to asymmetric disc collapse with lateral slip and scoliosis (which may require multi-level TLIF correction). This means that comparisons of surgical methods are not meaningful and would require additional radiological evaluation.

In this evaluation, we consider the clinical presentation and analyse the entire group undivided as Lateral Stenosis.

Baseline data:

The number of registered surgeries is 12,824, of which 56% are unilateral (Fig.125).

The distribution between the main surgical procedures is shown in Fig.126. The majority undergo decompression alone.

The average age is lower than central stenosis, 60 years, with a spread as shown in Fig.127 and essentially unchanged over time (Fig.128). Women account for 51%. Some form of comorbidity is present in 20%.

Approximately 40% have experienced leg pain for over 2 years (Fig.129).

The follow-up frequency is at FU 1 year = 75%,and at FU 5 years = 56%.

Outcome:

Just under 60% report a successful outcome at FU 1 year (Fig.130), which persists at 5 years (Fig.131). A slight trend towards better outcomes is seen over time. Likewise, there is a trend towards fewer failed cases (Fig.132).

The outcome measured by EQ-5D Index shows an increase from approximately 0.35 preoperatively to around 0.6 at 1-year follow-up (Fig.133+134). Satisfaction with the outcome is approximately 60% (Fig.135).

Reinterventions:

Within 1 year, 451 out of 12,864 (3.6%) have undergone reinterventions, including 108 cases of redecompression, 45 cases of dural repair, and 52 cases of implant adjustment/ (Fig.136).

Comment:

Lateral stenosis is a heterogeneous group with a wide range of cases, from minor procedures addressing unilateral one-level subarticular stenosis to multi-level TLIF due to degenerative scoliosis or lateral olisthesis with foraminal stenosis. As a group, the outcome is like central stenosis and not quite on par with the outcomes for disc herniation and SRS. There is a need to closely examine the subgroups with additional radiological evaluations.

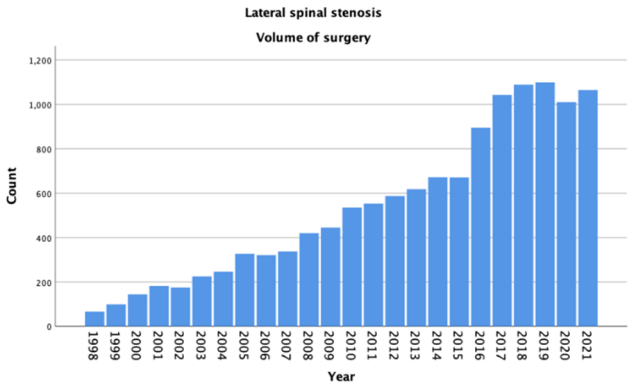
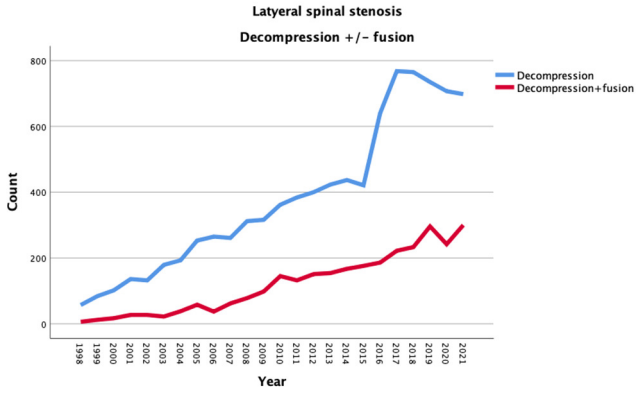


Fig. 125



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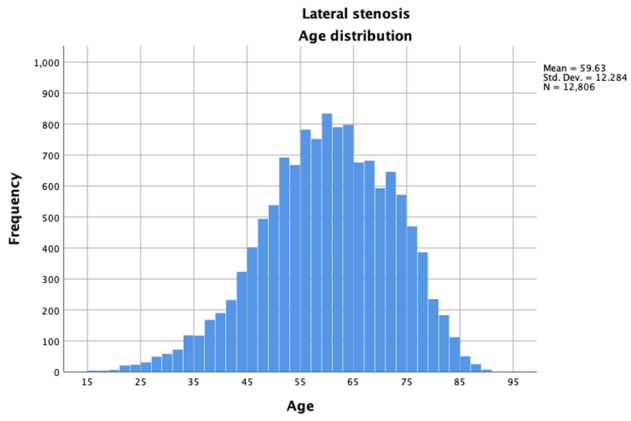

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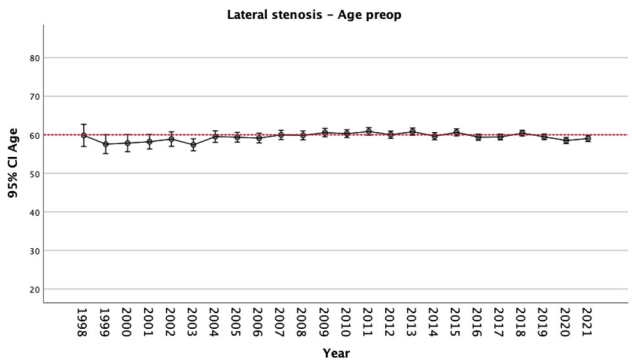

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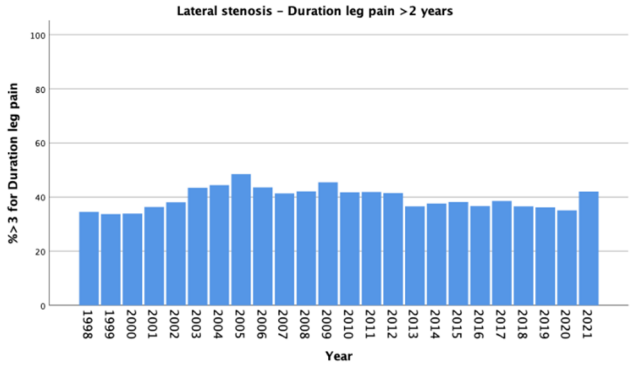

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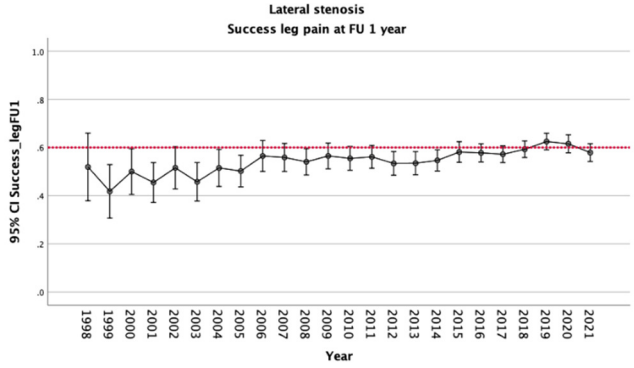

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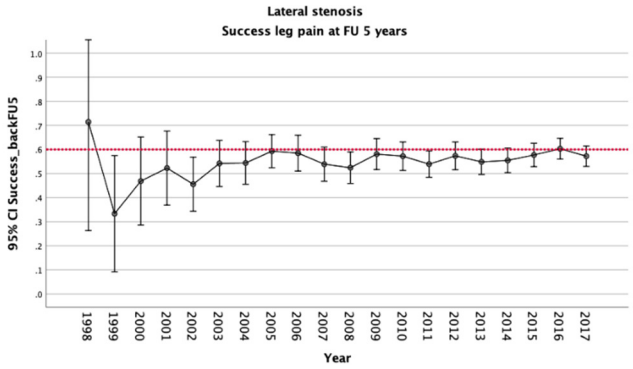

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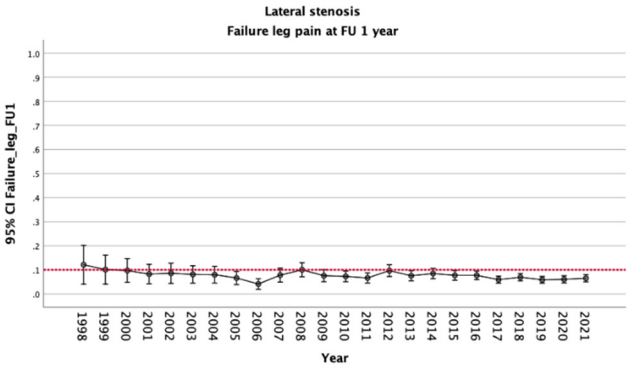

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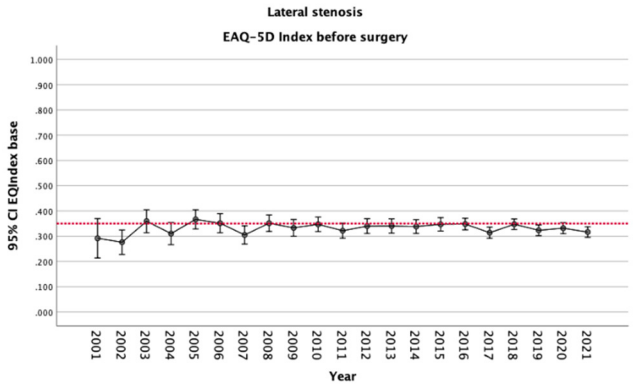

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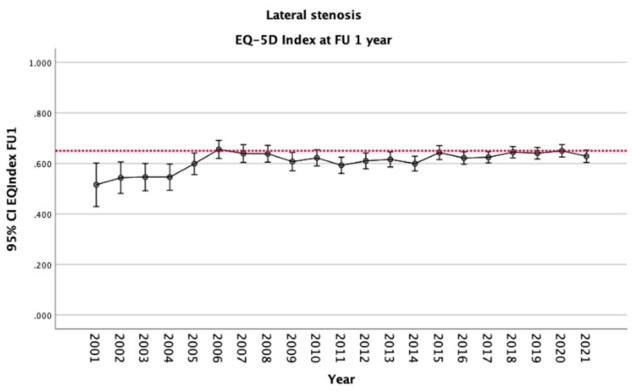

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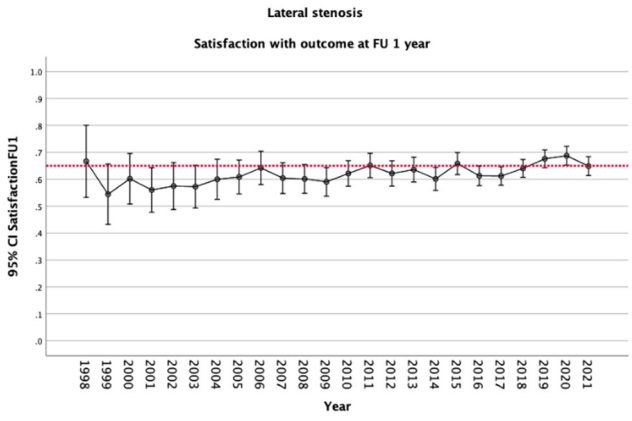

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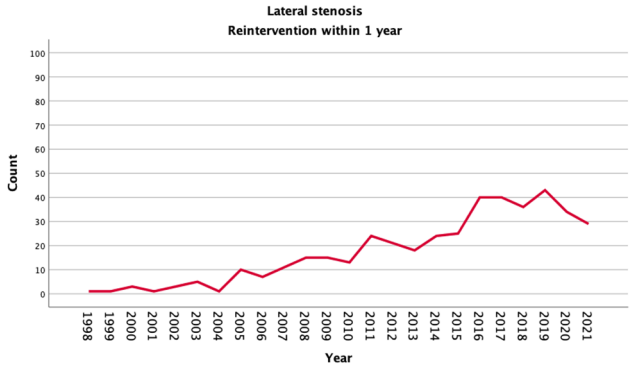


Fig. 136

Degenerative Lumbar Spine - Spondylolysis/-olisthes

Baseline Data:

Spondylolysis and spondylolisthesis are recorded as one diagnostic group. There is no grading of the slip. The number of registered surgeries is 6,561 as of 2021. Women make up 52% of the cases. The average age is 49 years, which has slowly increased over the years (Fig.137), with a distribution as shown in Fig.138.

Most surgeries are performed at the L5-S1 level (Fig.139+140).

The main surgical methods are shown in Fig. 141, indicating that the majority undergo the combination of decompression + posterior fusion. Of the fused cases, 76% are posterior fusion, with no significant changes over time (Fig.142).

Typical for spondylolysis-olisthesis patients is approximately equal amounts of leg and back pain – NRS leg 5.4 and NRS back 6.1. There are no significant changes over time (Fig.143+144).

Outcome:

The outcomes are also analysed in the group, without differentiation of the degree of slip. Unlike the other diagnostic groups, both leg and back pain should be evaluated to get a picture of the surgery's success. Improvement in back and leg pain seems to be of the same magnitude at 1 year follow-up (Fig.145+146) and appears to persist at least up to the 5-year follow-up (Fig.147+148).

Slightly over 5% report worse leg and back pain at 1 year follow-up (Fig.149+150).

The outcome measured by the EQ-5D Index is shown in Fig.151-152. The degree of improvement is of similar magnitude as the SRS group. When comparing the outcome between patients who undergo posterior fusion (PLF) in addition to decompression and those who undergo PLIF/TLIF, no significant differences are observed (Fig.153+154).

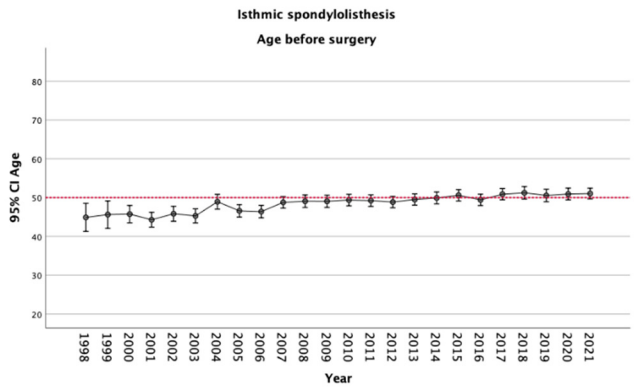
However, this should be viewed with caution as specific radiological differences and indications may exist between the two groups. It is not meaningful to further examine and analyse the group that underwent decompression only, as it is small, and there may be specific circumstances within this group.

Reinterventions within 1 year:

In the Fusion group, the frequency is 3.7% (n=54), in the Decompression+Fusion group, it is 5% (n=197), with a distribution over time as shown in Fig.155. Type of procedures: Refusion 53, Implant adjustment 65, Implant extraction 41, Hematoma drainage 2, Dural repair 7, Redecompression 6, Deep infection drainage 123.

Comment:

The diagnostic group Spondylolysis/Olisthesis is quite heterogeneous, ranging from spondylolysis that can be addressed with limited repair of the pars defect to spondyloptosis that may be subject to reduction attempts through a combined anterior-posterior approach. Registry data show that the group has an outcome similar to DDD. The relatively small subgroups at the extremes of the spectrum are interesting and potentially contain valuable knowledge, which could be captured in separate evaluation studies of the "Other" diagnosis and surgical method group.



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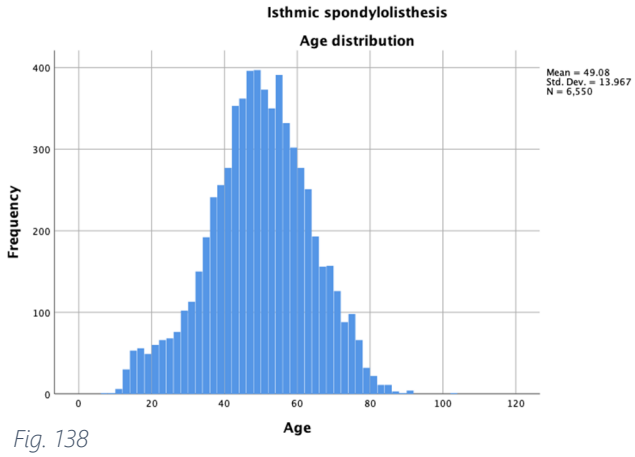

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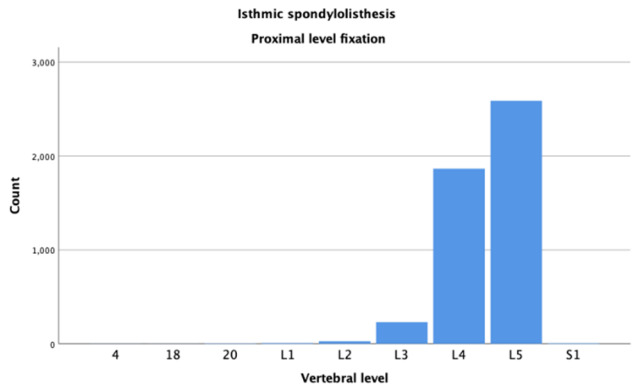

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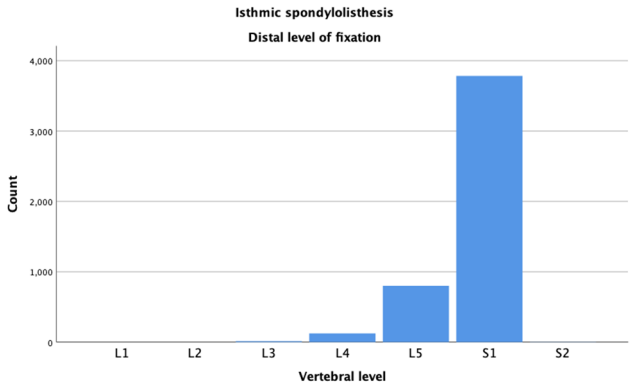

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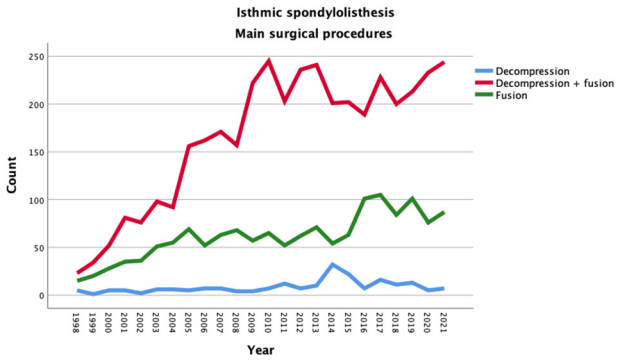

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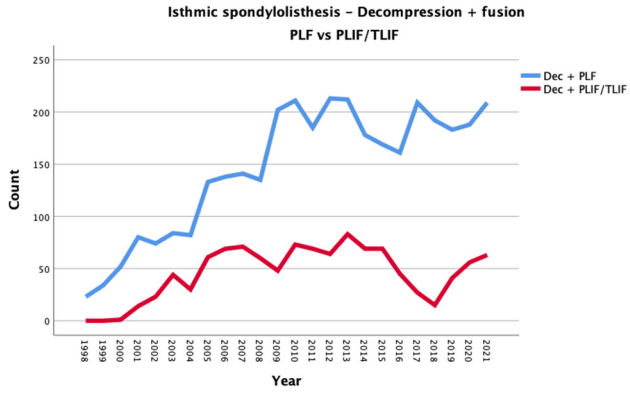

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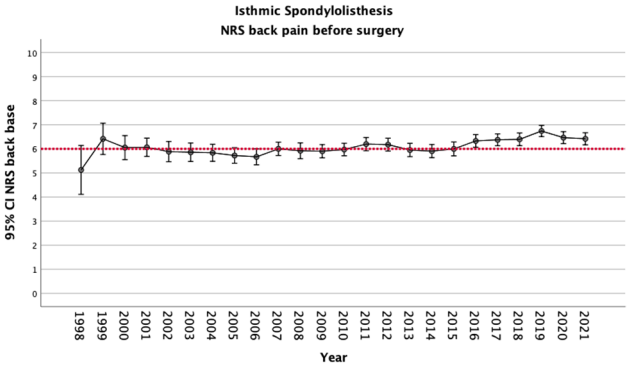

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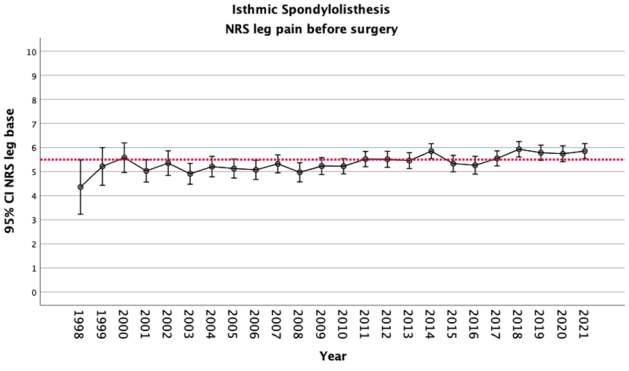

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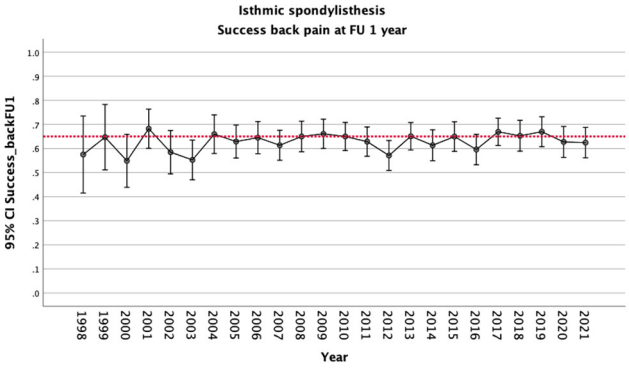

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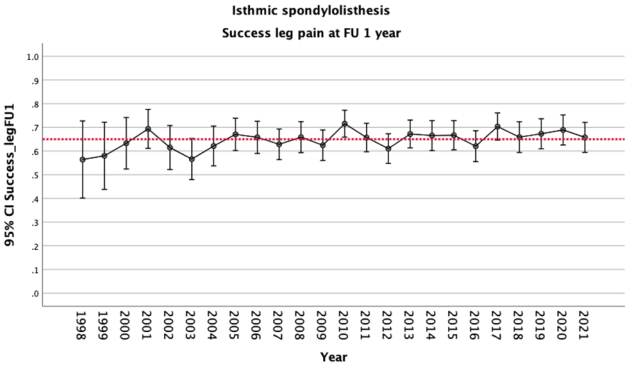

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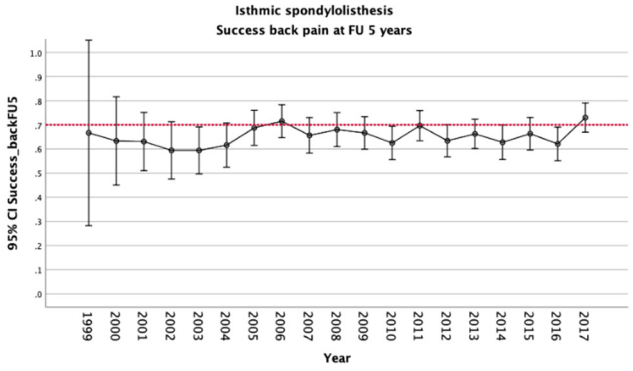

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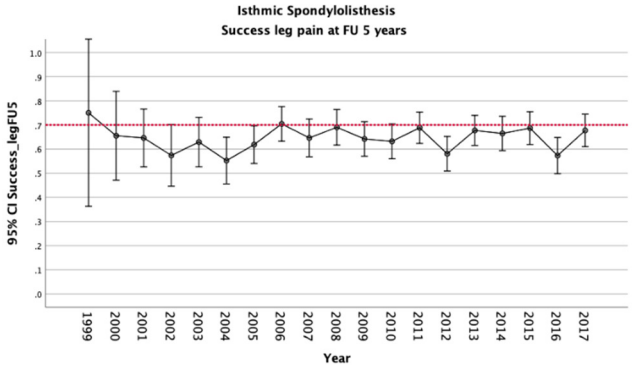

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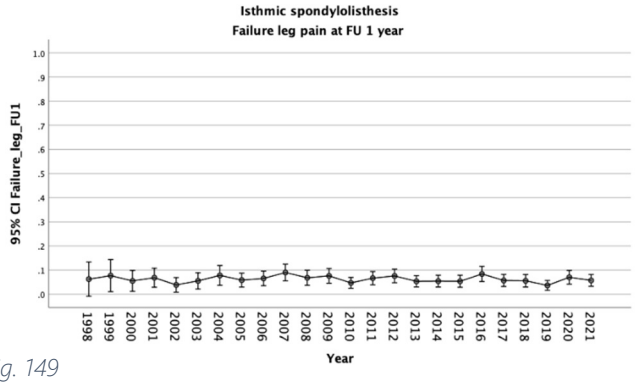

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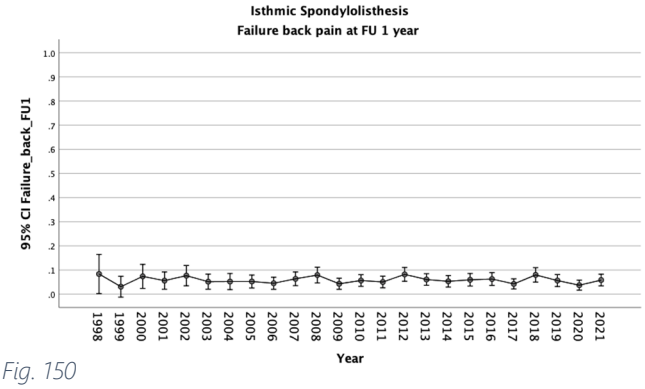


Fig. 150

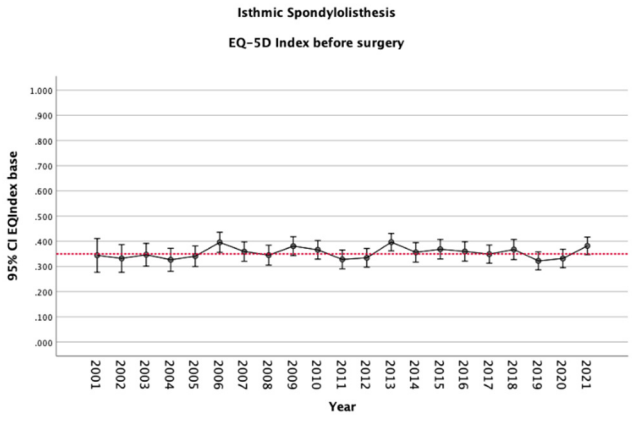
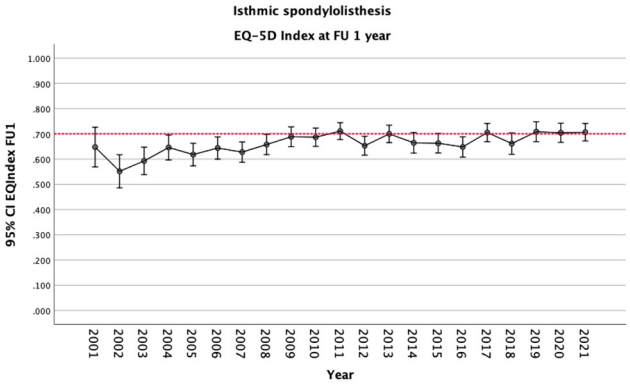


Fig. 151



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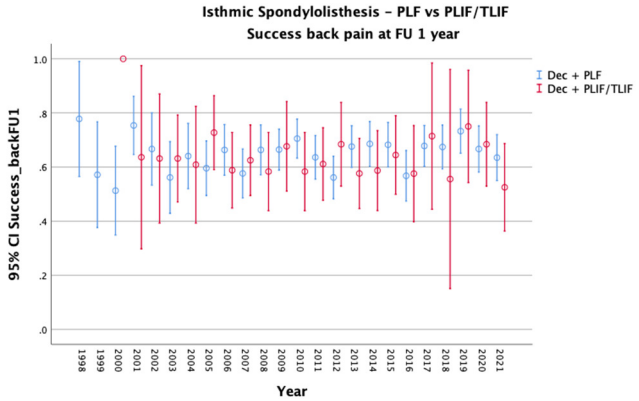

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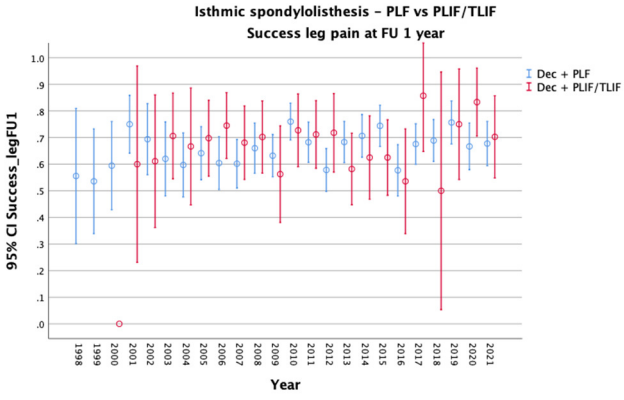

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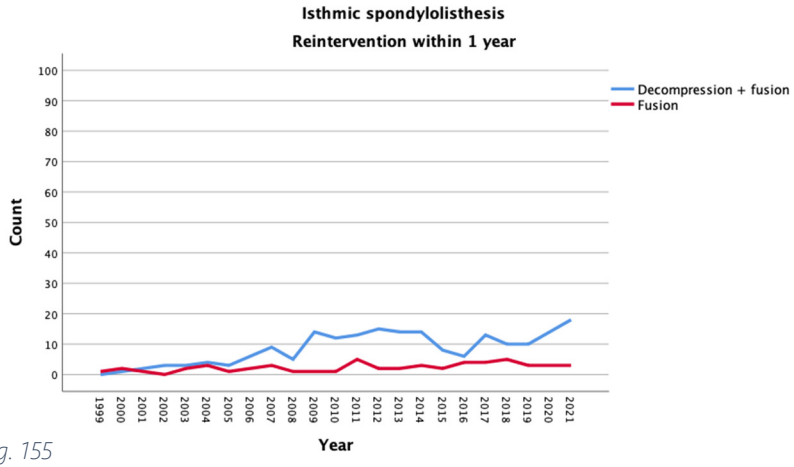


Fig. 155

Degenerative Lumbar Spine – Degenerative disc disease (DDD)

a. All

Baseline data:

The number of registered surgeries for DDD is 12,339 as of 2021. They increased significantly until 2008 but have since accounted for a gradually decreasing proportion of lumbar spine surgeries (Fig.156).

The preoperative mean age is 45 years with a distribution as shown in Fig.157, and it has remained essentially unchanged over time (Fig.158). Women make up 53% of the cases.

About 70% have had back pain for more than two years (Fig.159), a decreasing proportion has had previous lumbar surgeries (Fig.160), and nearly 90% are on sick leave before surgery (Fig.161).

The main surgical methods used are illustrated in Fig.162.

The most common method is fusion + instrumentation with pedicle screw systems, in about 30% of cases complemented with interbody implants. Fusion without instrumentation has been rare and is hardly performed anymore.

Total disc replacement (TDR) has been used in 1,591 cases (13%).

Outcome:

The follow-up rates are FU 1 year = 75% and FU 5 years = 44%.

Measured by Global Assessment, the proportion with successful outcome at 1 year follow-up has gradually improved over the years (Fig.163) and is now about 75%. The same trend exists at 5-year follow-up (Fig.164).

Measured by the EQ-5D Index, the trend towards improvement over time is also apparent. It increases from about 0.3 to about 0.7 (Fig.165-167).

Back function measured by ODI shows similar conditions. The index decreases from about 45 preoperatively to about 20 at 1 year and 5 years of follow-up (Fig.168-170).

Regarding social function after surgery, substantial changes have occurred. Postoperatively, the duration of sick leave is decreasing (Fig.171), and more patients are returning to work (Fig.172).

About 5% report worse back pain at both 1-year and 5-year follow-ups, with no significant changes over time (Fig.173+174).

b. Fusion vs TDR

TDRs were performed between 2003 and 2020. They ceased after being strongly questioned due to what was described as a complicated surgical method and hazardous reinterventions with serious consequences. It is important to study the data in the register on TDR and compare outcomes and reported complications/reoperations with fusion.

To begin with, it should be noted that both for fusion and TDR, implant brands have varied significantly over the years without any known underlying quality evaluation. Implants started to be registered in 2006. The range of disc prostheses used is shown in Fig.175.

The variation is equally significant for implants in conjunction with fusion, both regarding posterior pedicle screw systems and interbody devices (Fig. 176+177).

Outcome:

When comparing the entire groups, 62% of fusion patients and 73% of TDR patients report a successful outcome in their back pain. A comparison over time is shown in Fig.178-179. The proportion reporting worse back pain at 1 year follow-up is shown in Fig.180.

The outcome measured by EQ-5D Index suggests that the quality of life was higher in TDR patients preoperatively and remains so at 1 year follow-up (Fig.181+182).
Similar conditions are seen for ODI, meaning less functional impairment preoperatively and at 1 and 5 years of follow-up (suggesting better outcome), as shown in Fig.183-185.

The TDR group also differs in several other respects from the Fusion group (Fig.186-195).

The frequency of surgeon-reported reinterventions is higher after fusion (14.8%) than after TDR (5.2%).

The major volume of reinterventions after fusion is the removal of implants where the cause was assessed to be pain related to the pedicle screw system and refusion due to pseudarthrosis (Fig.196). After TDR, the most common specified reinterventions are drainage of bleeding, followed by adjustment/extraction of the disc prosthesis (Fig.197). A common reason for reintervention appears to be dislocation of the disc prosthesis (Fig.198). The largest groups of causes ("Other") and reinterventions ("Other") are unspecified. Additionally, 117 new index operations were performed after TDR, with the majority being related to DDD. The data do not specify whether this was in the segment with the disc prosthesis or in another segment (Fig.199+200).

Comment:

The outcome of DDD surgery, according to the outcome measures in Swespine, is on par with the outcome of disc herniation surgery. It has gradually improved over the years, both after fusion and TDR. The reasons for this cannot be directly inferred from the registry data. The relative reduction in the incidence of DDD surgery over time might be interpreted as a stricter indication for surgery for this condition (contrary to many concerns about widening indications resulting in more surgeries following emergence of private spine clinics). The outcome of disc prosthesis surgery is at least as good as fusion. Preoperative data suggest that the TDR group is younger, with lower symptom severity and comorbidity – factors that can positively affect the outcome. The registry data do not indicate any serious complications, but these may exist in unregistered reoperations for bleeding or under "Other."

The large and rapid changes in implant use, both for pedicle screw systems and disc prostheses, are striking. The explanation cannot be inferred from registry data.

Recommended additional analyses:

1. TDR
   A few years ago, leading Swedish orthopaedic surgeons strongly criticized the risk of (and possibly actual) serious complications and hazardous reinterventions after TDR. This led to the immediate cessation of these surgeries. The registry does not contain any data suggesting serious complications, but not all surgeries and reinterventions may have been registered. A thorough study through medical record review should be conducted to obtain a final answer to this question.
2. Implant
   What drives the relatively frequent implant changes? Is there a link to complications, reinterventions, or outcomes? Are there known/described problems with different implants? What is the impact of the marketing of the various implant brands? Is the implant range on the market of such good quality that other factors have a greater impact? The topic should be discussed, and a proper study design contemplated..

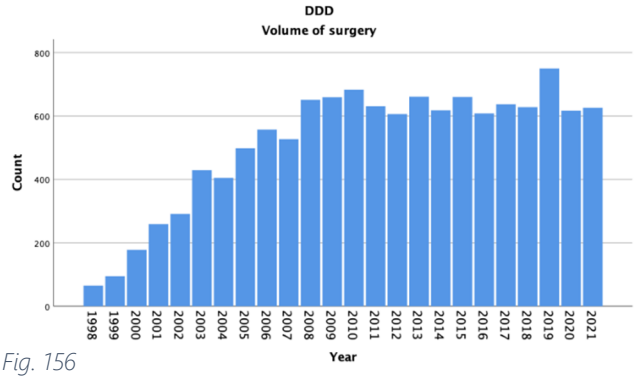
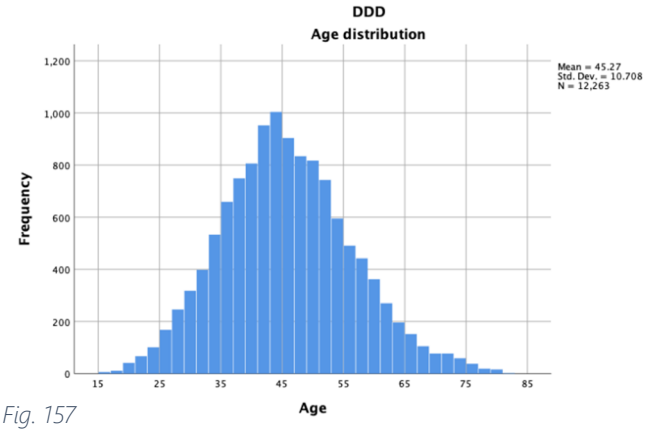


Fig. 156



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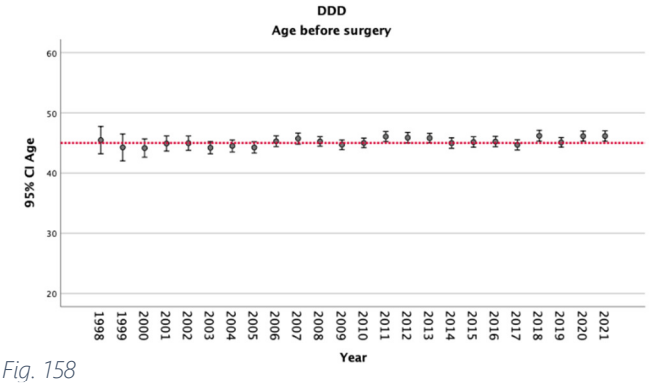

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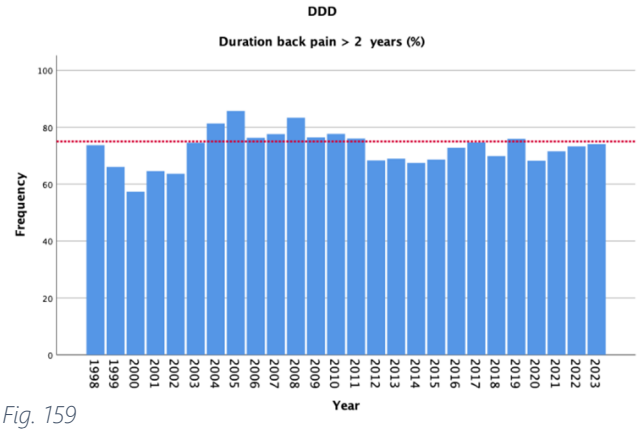

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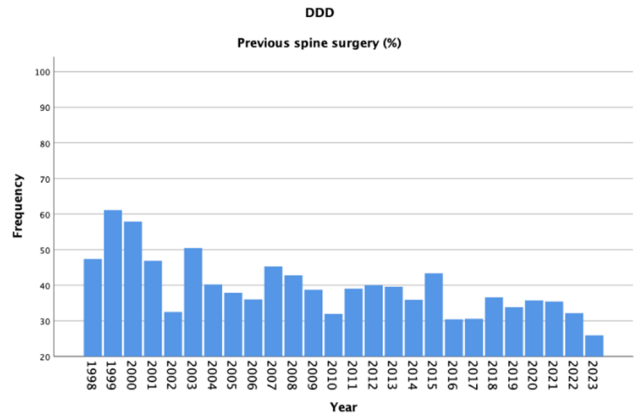

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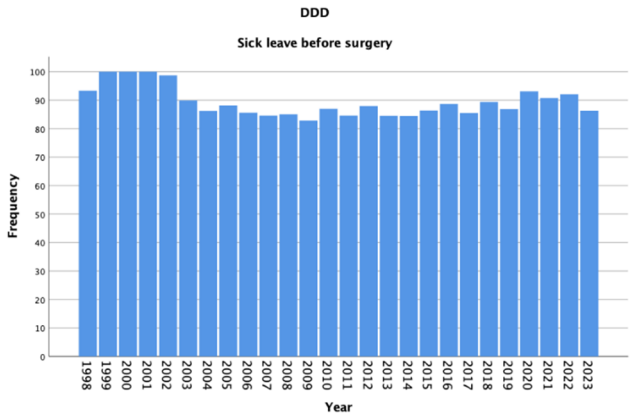

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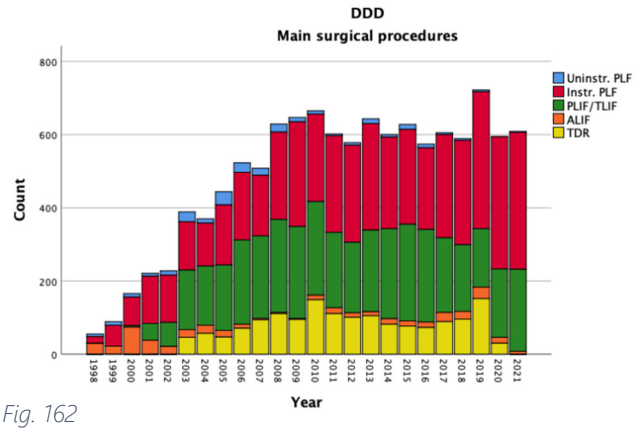

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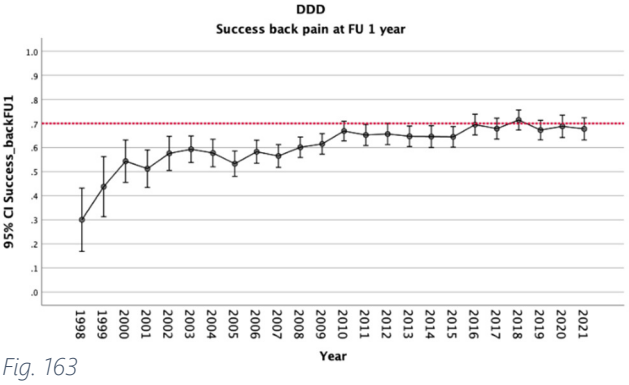

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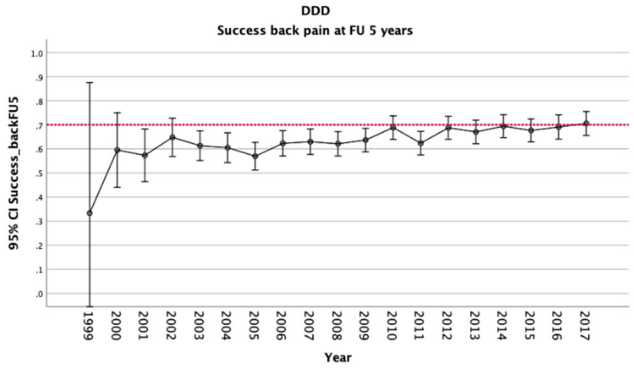

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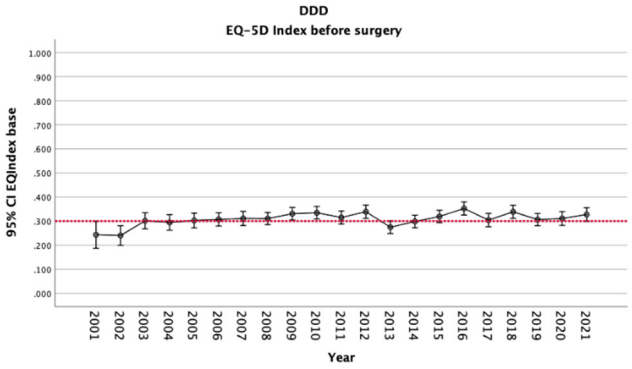

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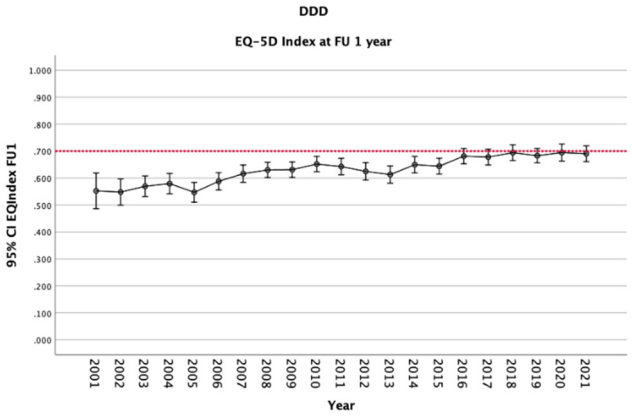

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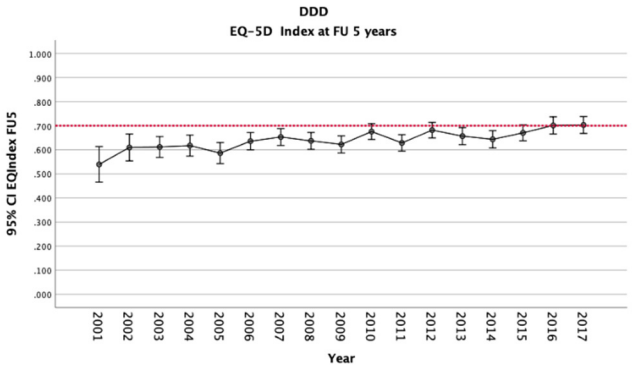

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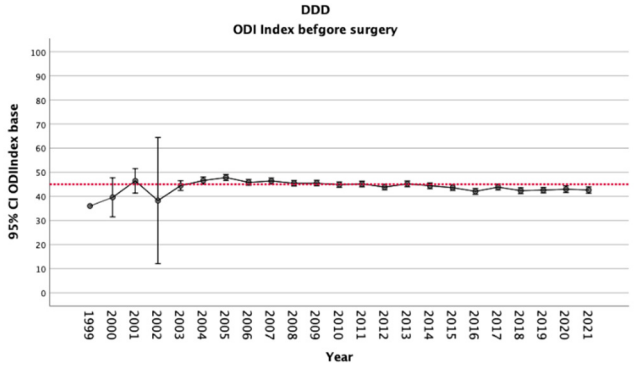

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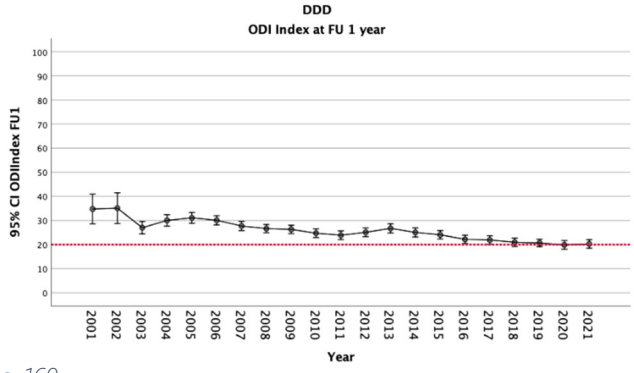

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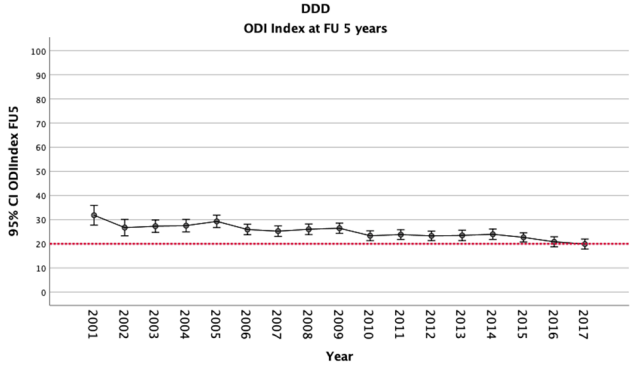

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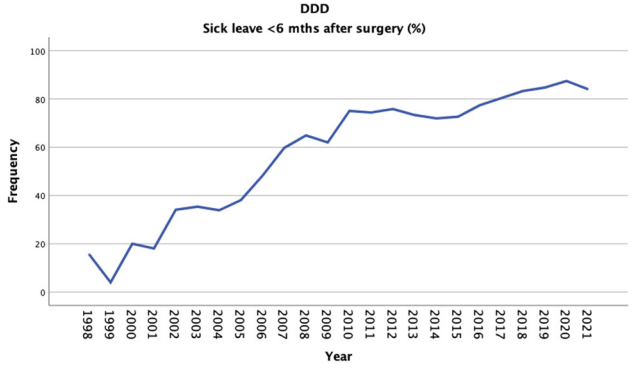

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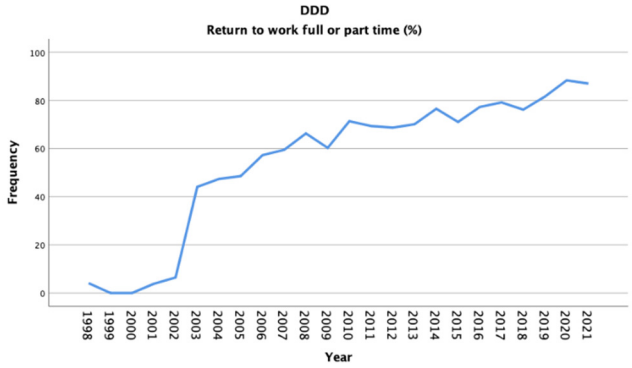

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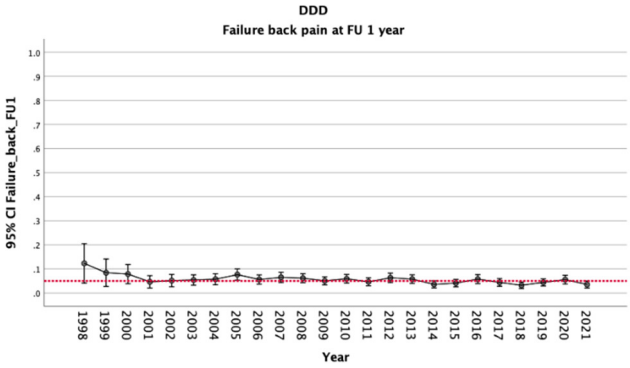

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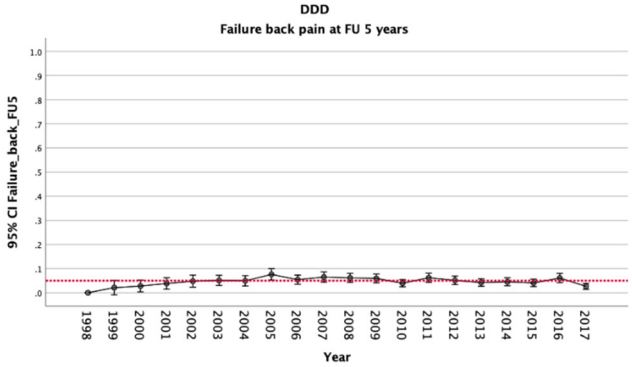

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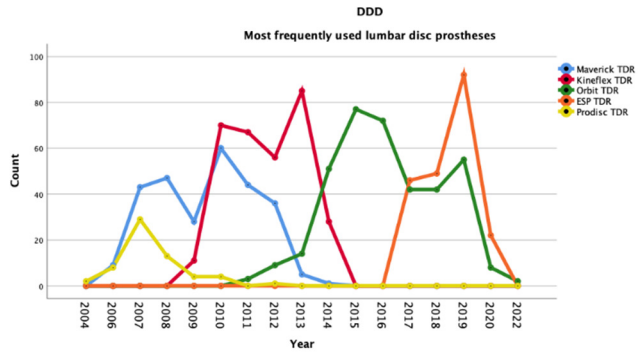

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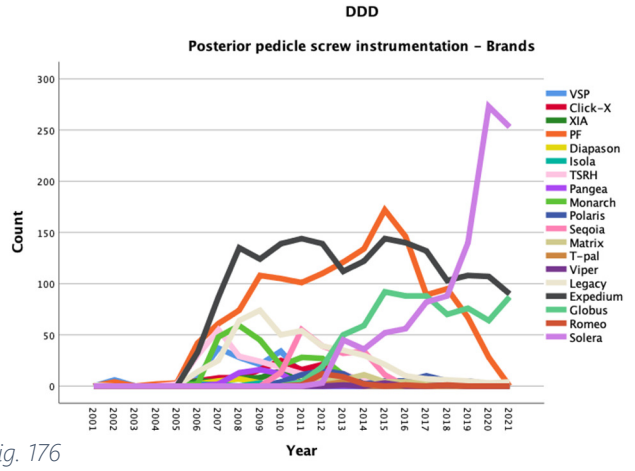

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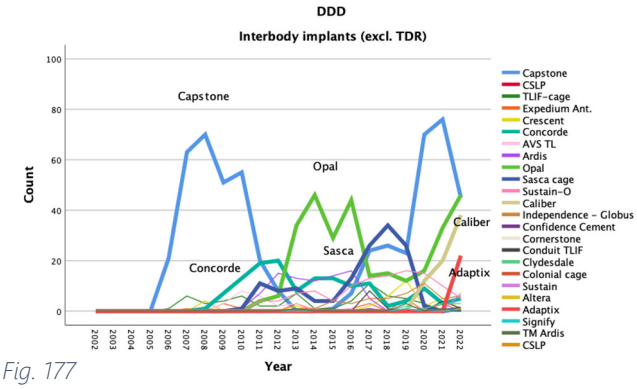

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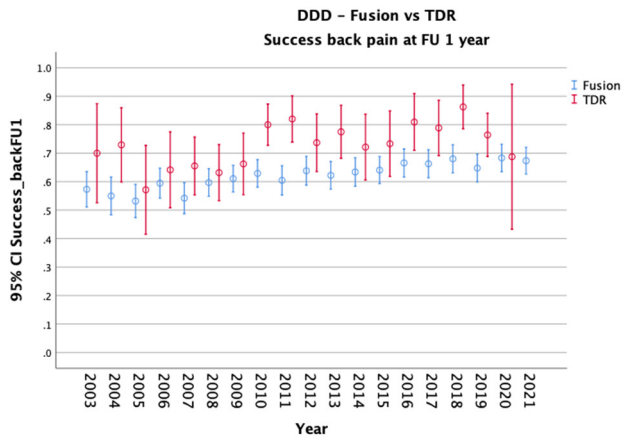

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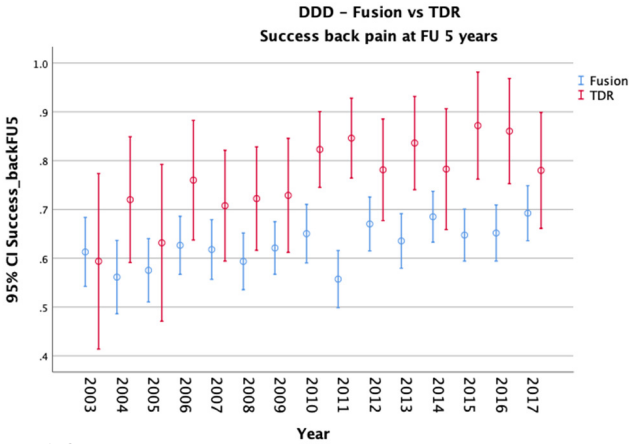

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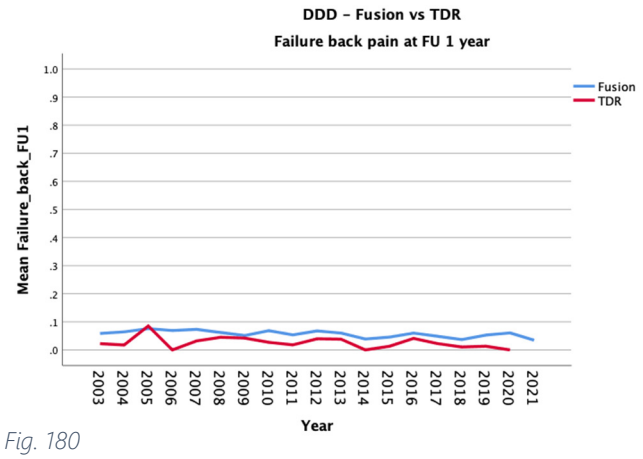

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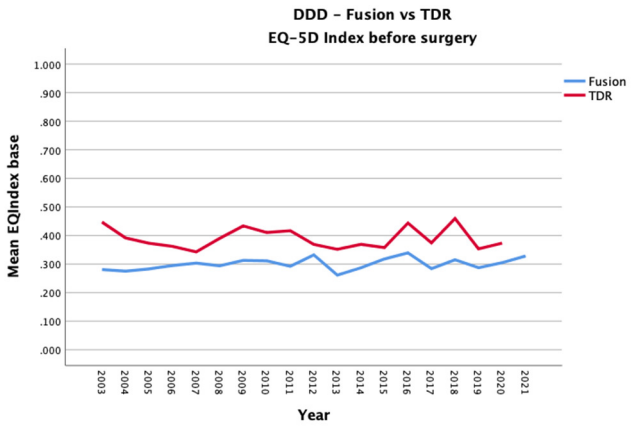

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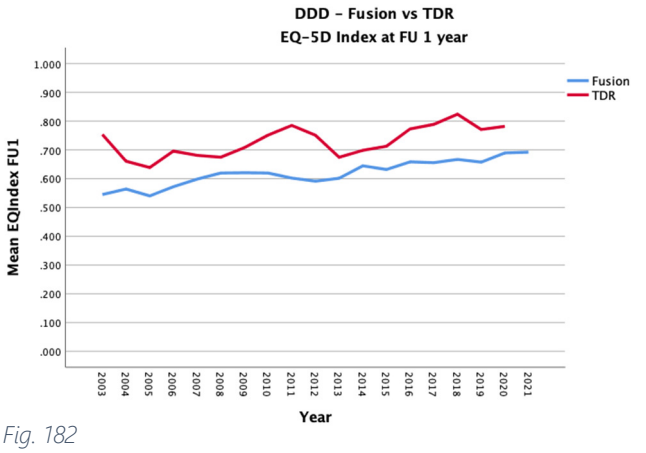

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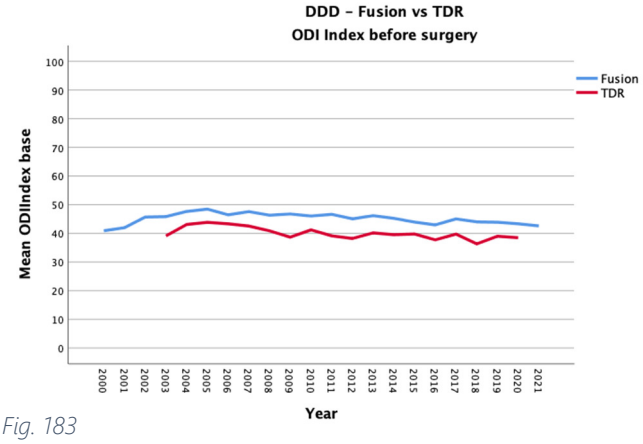

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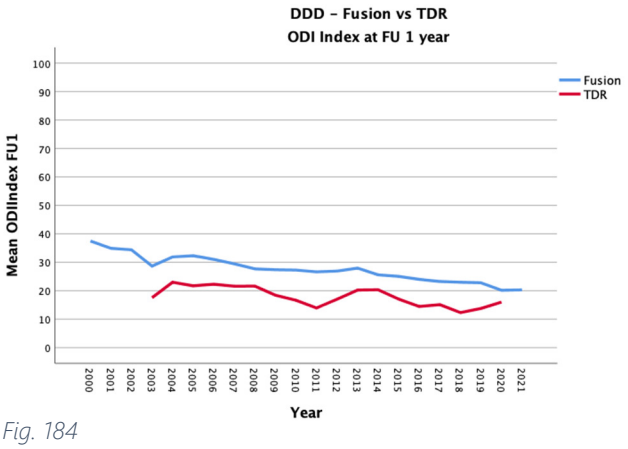

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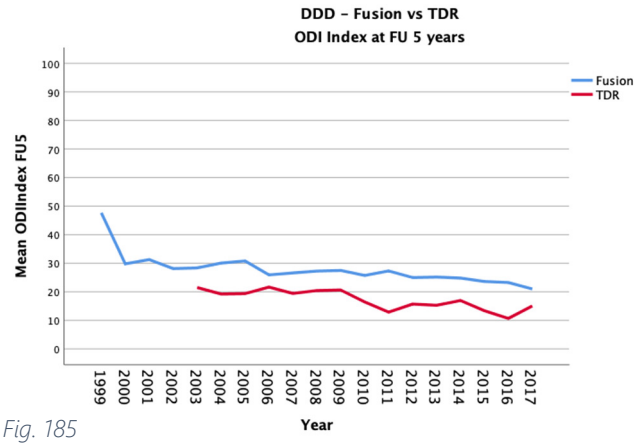

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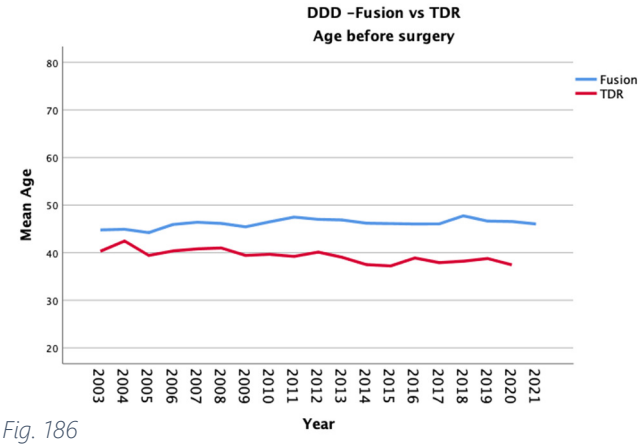

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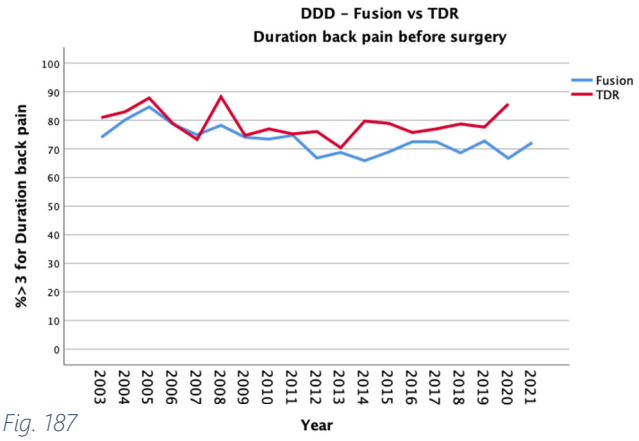

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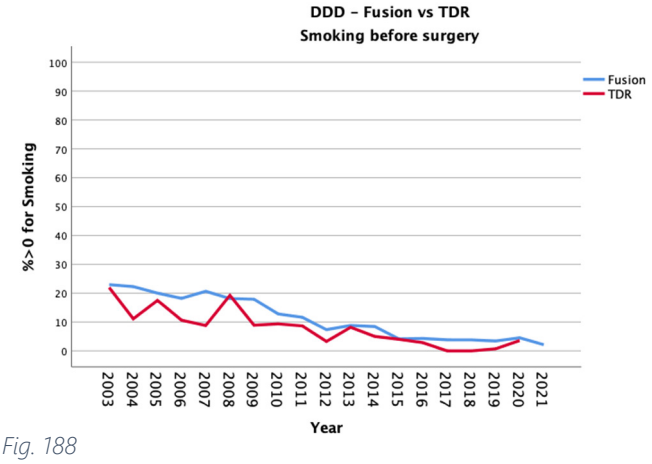

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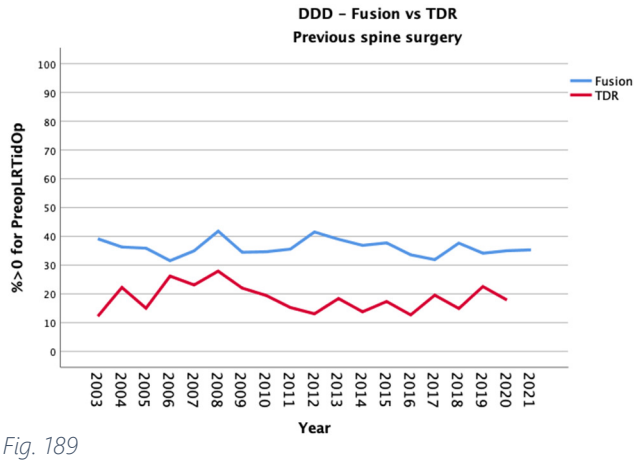

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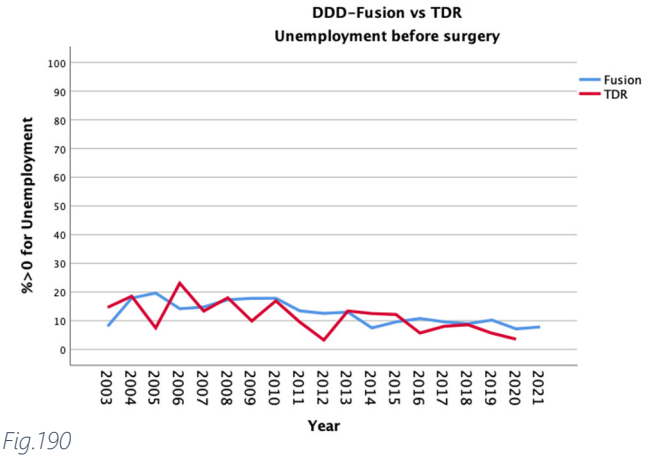

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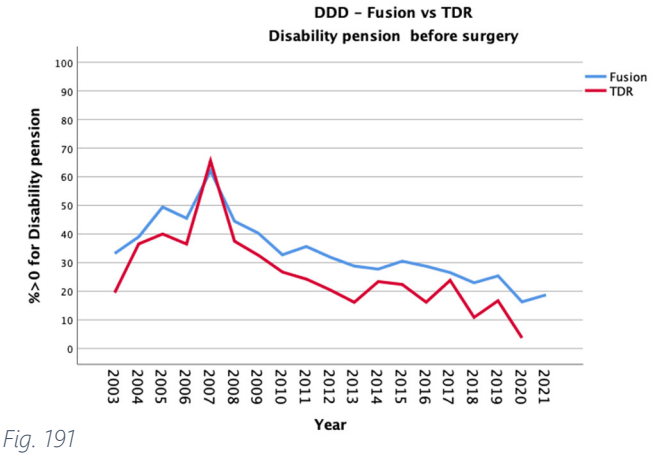

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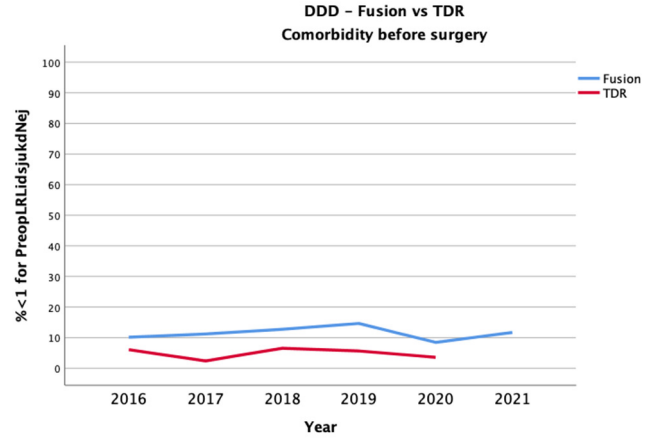

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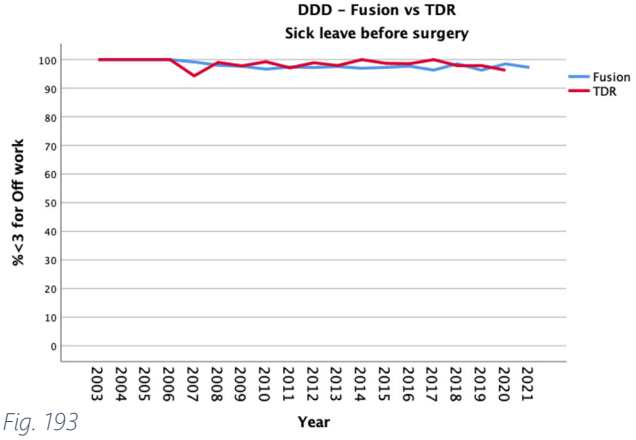

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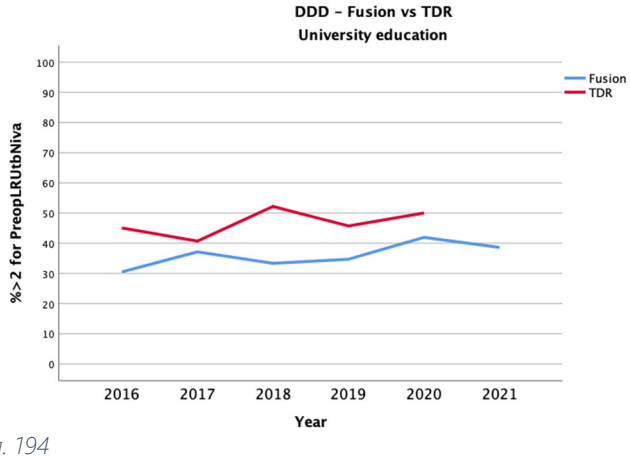

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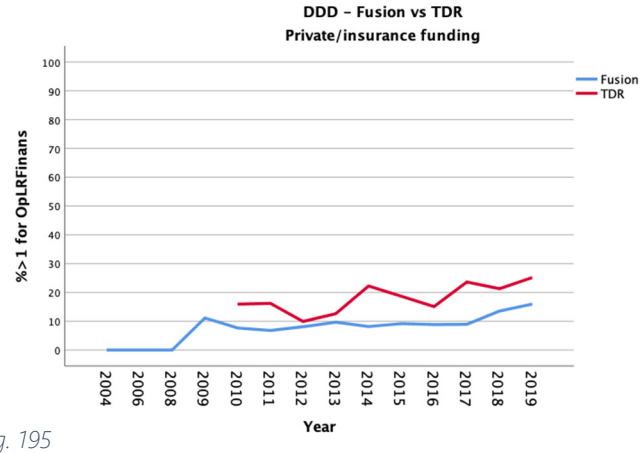

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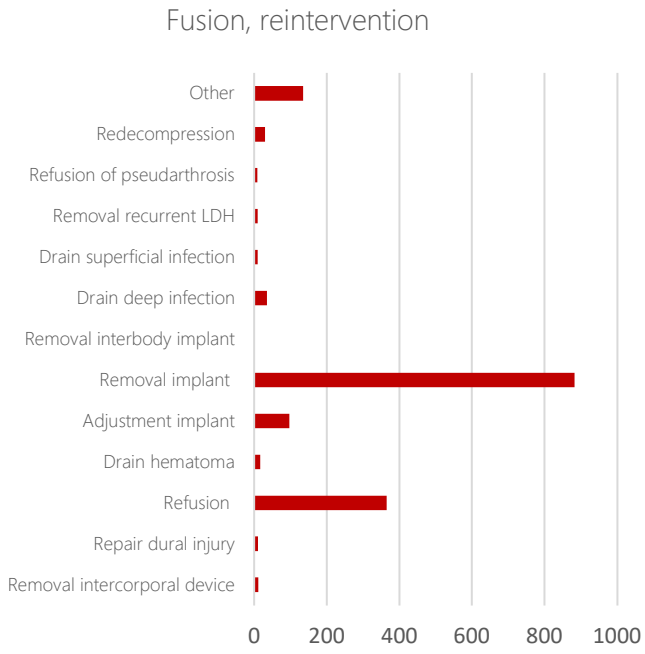

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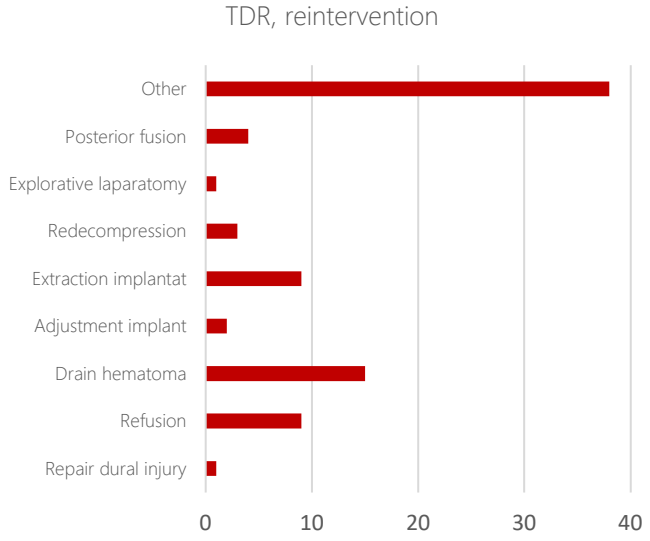

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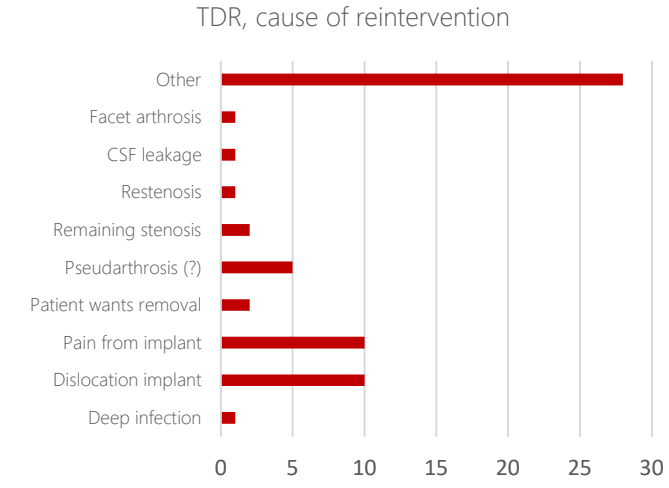

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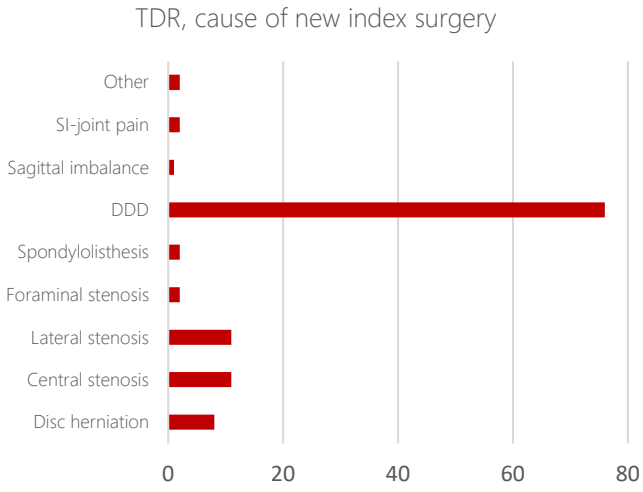


Fig. 199

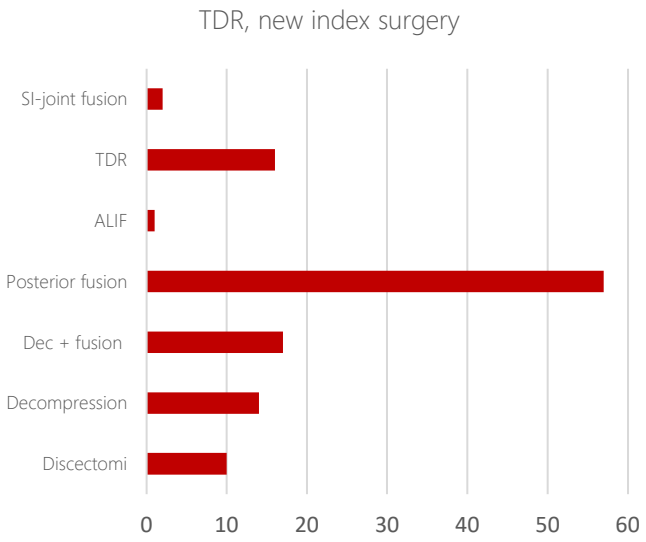


Fig. 200

Degenerative Cervical Spine

Overview

Cervical spine procedures began to be registered in 2006. A total of 15,815 surgeries have been registered through 2021. The average age is 54 years, with 52% being women.

Of the registered surgeries, 10,348 were performed for cervical radiculopathy (6,251-disc herniations and 4,097 foraminal stenoses), 4,321 for myelopathy, and 207 for rheumatoid arthritis (Fig.201).

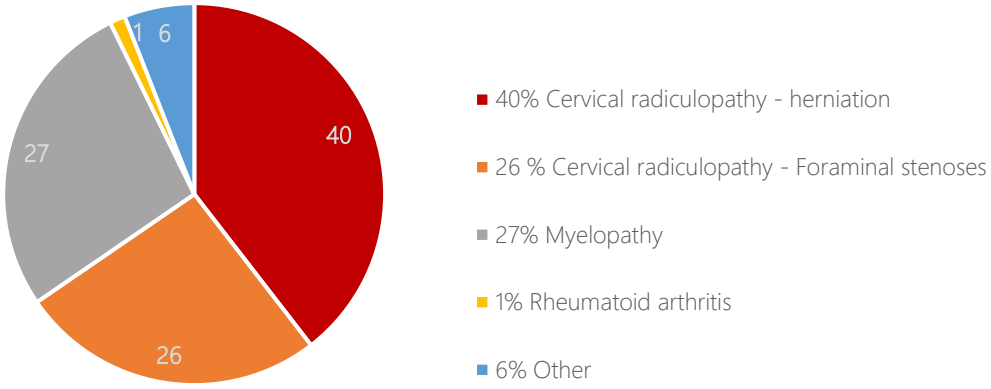


Fig. 201

Cervical Radiculopathy

Disc Herniation

There were 5,811 operations for disc herniations. The follow-up rates are FU 1 year = 69%, FU 5 years = 61%. The average age is 49 years, with no significant variation over time (Fig.202). Women make up 51% of the cases.

The dominant surgical method is anterior discectomy with fusion (Fig.203), with varying use of plates or interbody cages over the years (Fig.204). TDR, performed in 271 cases, are evaluated separately at the end of this section.

Fusion Outcome:

Successful outcome for arm pain is achieved in nearly 70% (Fig.205) and appears to persist over time (Fig.206). There is no discernible difference in outcomes when comparing different implant combinations (Fig.207).

Neck pain, experienced by 96% of patients, also improves after the operation (Fig.208+209), and satisfaction with the outcome appears to be good and lasting (Fig.210+211).

The outcome measured by the EQ-5D Index increases from 0.3 preoperatively to 0.7 at 1-year follow-up (Fig.212+213).

Reinterventions Within 1 Year:

A total of 67 (1.2%), including 11 for bleeding, 10 for refusion, and 39 for "Other procedures".

Total disc replacement (TDR) outcome and comparison with fusion:

TDR was mainly performed before 2012 (Fig.214). There are so few cases per year that it's not meaningful to evaluate them yearly.

Successful outcome for arm pain was better for TDR at FU 1-year at a group level (Fig.215). However, this difference has disappeared at FU 2 years and 5 years (Fig.216+217). The calculation is made using unadjusted data, and it should be noted that the TDR group is younger (average age 44 years) and has lower comorbidity (9% vs. 23% in the fusion group).

Reinterventions Within 1 Year:

A total of 13 (4.8%), including 2 implant extractions and 9 "Other actions."

Comment:

TDR, performed in relatively few cases, decreased significantly after a thesis demonstrating that the outcome was not better after TDR compared to fusion.

Registry data confirm that the long-term outcome is not superior with TDR compared to fusion and that the reintervention rate appears to be higher with TDR.

Foraminal stenosis

There have been 4,097 registered surgeries for foraminal stenosis. The average age is 45 years, and 52% are women. There is a slightly lower frequency of foraminotomy (posterior procedure) than discectomy + fusion (anterior procedure), as shown in Fig.218.

Outcome:

Successful outcome regarding arm pain is achieved in just over 60% and remain stable over time (Fig.219+220). Satisfaction with the outcome is at approximately the same level (Fig.221+222).

The outcome regarding arm pain and neck pain does not show a clear difference when comparing foraminotomy and discectomy + fusion (Fig.223+224).

Measured with the EQ-5D Index, the quality of life increases from about 0.4 preoperatively to just under 0.7 at 1-year follow-up (Fig.225+226).

Reinterventions Within 1 Year:

A total of 105 (2.6%), including 15 for redecompression, 11 for bleeding, and 53 for "Other procedures."

Comparison between Disc Herniation and Foraminal Stenosis:

For the entire groups, successful outcome for arm pain is 68% for disc herniation and 64% for foraminal stenosis. When comparing over time, there are no significant changes in successful outcomes or exacerbated pain (Fig.227-229).

The groups differ to some extent – patients with foraminal stenosis are slightly older, more frequently experience long-standing arm pain, and have more often undergone previous cervical spine surgery (Fig.230-232). There is no apparent difference in comorbidity (Fig.233).

Comment:

The small difference in outcomes after surgery for radiculopathy caused by disc herniation versus foraminal stenosis is of questionable clinical significance, considering that the compared values are unadjusted.

Cervical Myelopathy

In the registry, there are 4,231 registered surgeries for cervical myelopathy. Diagnoses provided in conjunction with myelopathy include Disc Herniation and Spinal Stenosis. The radiological difference between these two is often not clear-cut, as disc protrusion is usually part of the picture of spinal stenosis, even though significant facet arthrosis is probably more common in the diagnosis of spinal stenosis. The common denominator is compression of the spinal cord with myelopathic symptoms. Therefore, we have chosen to analyse the two diagnoses as one group.

The average age is 61 years, 53% are women. These patients differ from patients with radiculopathy in several aspects, including higher age and more comorbidity (Fig.234+235).

The primarily used surgical methods are shown in Fig.236. It shows that anterior decompression and posterior decompression without fusion have increased, while posterior decompression + fusion constitutes a decreasing proportion.

The implants used in cervical spine surgery show as much and as unexplained variation as in lumbar spine surgery. As illustration, three different anterior implants and implant combinations are shown (Fig.237-239).

Outcome:

The outcome measure Global Assessment (Success = Pain-free/Very much better) cannot be used for myelopathy because the main symptom is not pain but gait and fine motor dysfunction. The EMS (European Myelopathy Scale) has been used since registration started but has been criticized due to its limited responsiveness (sensitivity to change). It is not originally a PROM (Patient-Reported Outcome Measure) but is reported by the treating surgeon. It has been used in Swespine as a PROM but has never been validated as such. Therefore, it was supplemented with the patient-reported outcome measure P-mJOA in 2020.

Measured with EMS, the outcome is as shown in Fig.240-242. The change (improvement) is undoubtedly small – an increase of just under 1 unit. But one should not expect a significant change. The clinical experience – and the information that patients receive before surgery – is that its primary purpose is to prevent deterioration and possibly achieve some improvement. This is what EMS shows. It is also important that the small improvement recorded seems to persist over time, at least up to 5 years of follow-up.

P-mJOA has complete follow-up data for only one year (2021), so it is not possible to evaluate it with great reliability yet. Calculated on the data available, the value preoperatively is 12.7 (SD 3.8), and at FU 1-year 13.9 (SD 3.6), a difference of about 1 unit.

Measured with the EQ-5D Index, the quality of life increases from 0.31 (SD 0.33) preoperatively to 0.65 (SD 0.31) at 1-year follow-up and 0.65 (SD 0.32) at 5-year follow-up. The satisfaction rate at FU 1 year was 71%, and at 5 years 70%.

Comparison of Anterior and Posterior Decompression:

Outcome measured with EQ-5D Index (Fig.243-245) and Satisfaction (Fig.246+247) can be used to compare the effect of anterior and posterior decompression. Since neck pain is a significant feature preoperatively (81%), the successful outcome of neck pain can be compared (Fig.248-249). All three measures (EQ-5D Index, Satisfaction, and success neck pain) suggest a better result for anterior decompression than for posterior decompression.

Reinterventions Within 1 Year:

A total of 132 reinterventions (3.2%), including 17 for bleeding, 15 for deep infection, 12 for refusion, 10 for redecompression, and 38 for "Other procedures."

Comment:

The primary intended effect of surgery for cervical myelopathy, i.e., preventing the progression of symptoms, has been achieved, and the effect appears to persist for at least 5 years. The impression is that the outcomes regarding both quality of life and satisfaction are better after anterior decompression than posterior decompression. However, considering that radiological conditions are probably different, as are other patient characteristics, comparisons should be subject to great caution.

Rheumatoid arthritis

Rheumatoid Arthritis has been a common indication for cervical spine surgery for many years, especially instability in the CO-C1-C2 area with pain and impending myelopathy, but also in other segments. With new medications and early treatment, the need for cervical spine surgery has drastically diminished.

In the registry, there are 207 surgeries with a clear decrease over time (Fig.250). The age is shown in Fig.251. Women make up 79% of this group. The most common procedure is posterior fusion without decompression (Fig.252), and the majority have been performed in the proximal two segments (Fig.253+254).

Outcome:

The predominant complaints are neck pain (in 93% with NRS=6), while arm pain (in which local RA symptoms may also be included) is present in 53% (with NRS=3) of patients. Successful outcome for neck pain is 61% at FU 1-year and 55% at 5-years. It is not meaningful to make annual comparisons because the cases are so few.

Satisfaction with the outcome is 78% at FU 1-year and 80% at 5-years.

Measured with EQ-5D Index, the preoperative quality of life is 0.25 (SD 0.33), at FU 1-year 0.54 (SD 0.32), and at 5-years 0.52 (SD 0.33).

Reinterventions within 1 year:

A total of 11 reinterventions are registered, including 4 adjustments of implants, 1 refusion, and 1 due to bleeding.

Summary:

The cervical spine surgery performed for RA during the existence of Swespine is considered to have been relatively successful in terms of both pain and quality of life.

Comment:

The outcomes over time do not show a clear change in any of the diagnostic groups. Radiculopathy generally shows better outcomes and prognosis than myelopathy. Registry data confirm this clinical experience.

Registry data confirm previous studies and show that disc replacement, compared to decompression + fusion, does not offer any advantage for patients with radiculopathy caused by disc herniation.

The main surgical methods for foraminal stenosis appear to provide similar outcomes. However, we do not know if the patients are entirely comparable – there may be, among other things, radiological differences. This topic should be studied further.

For myelopathy patients, registry data give the impression that anterior decompression provides slightly better outcomes than posterior, regardless of whether posterior decompression is performed with or without fusion. Here too, radiological differences could govern the choice of procedure and affect the outcome, and patient characteristics may be different. Further studies of the issue are recommended. The significant variation in implants over time has no explanation in registry data.

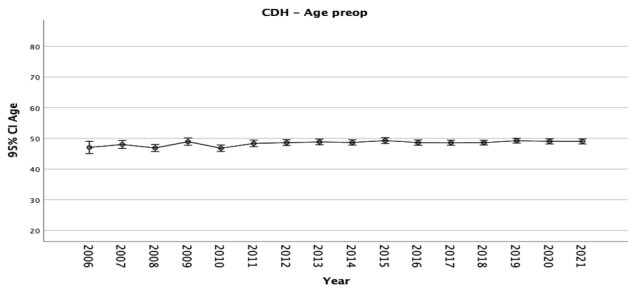


Fig. 202

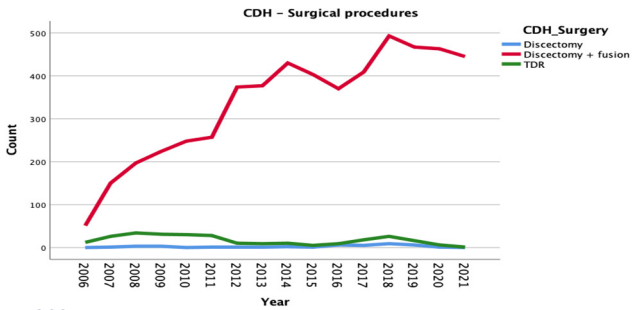


Fig. 203

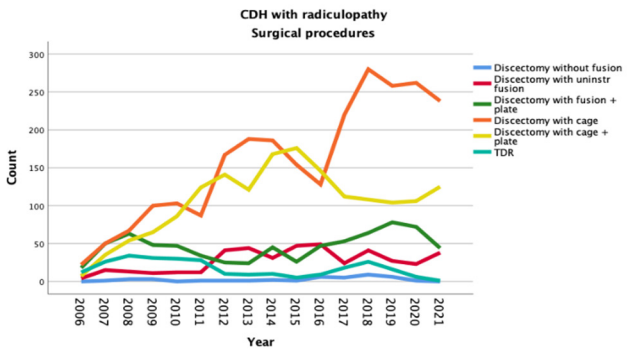
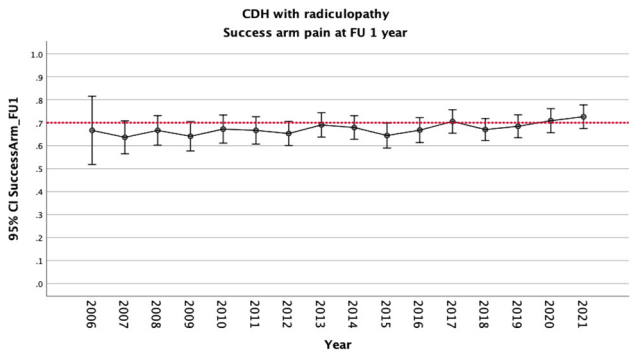


Fig. 204



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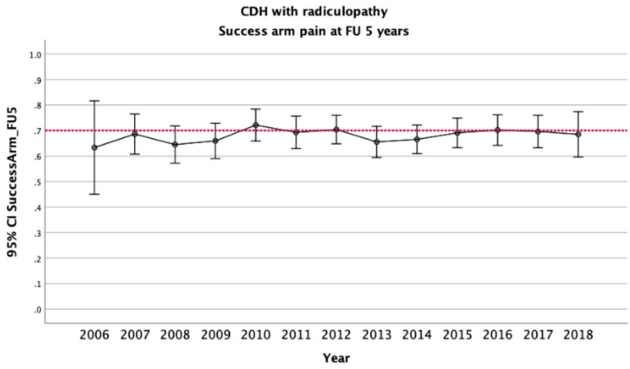

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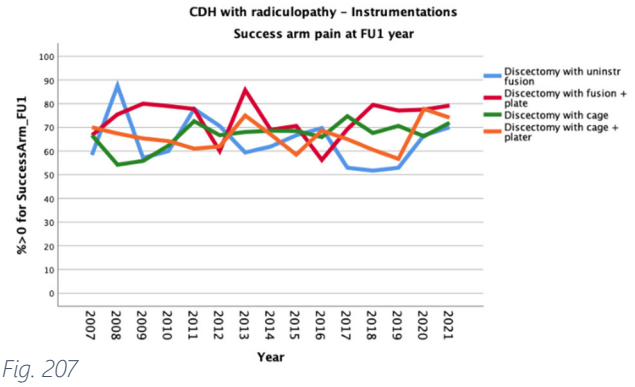

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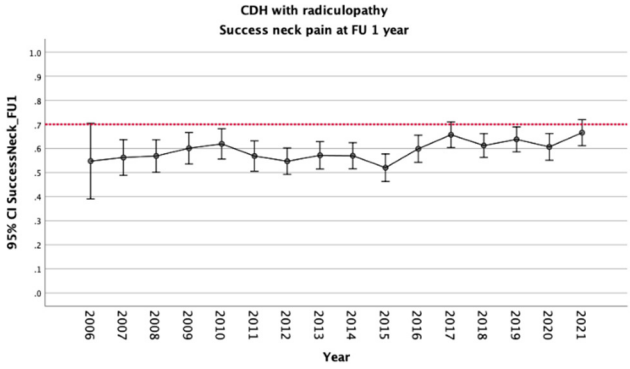

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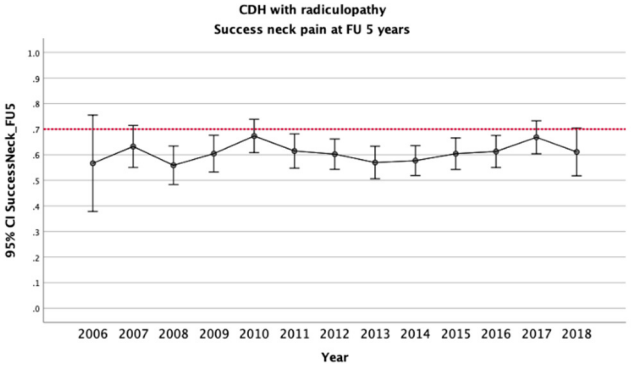

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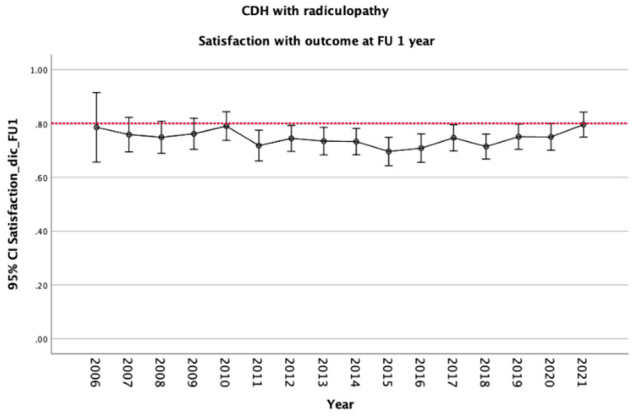

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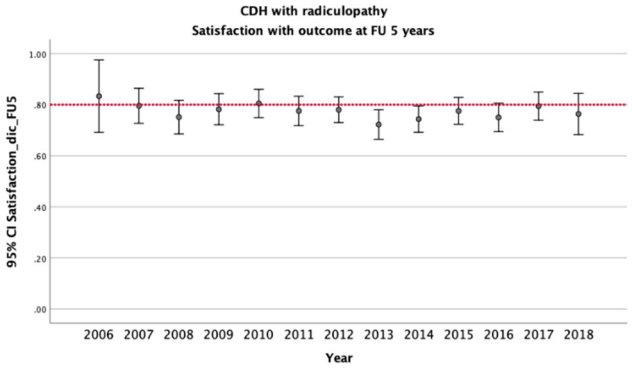

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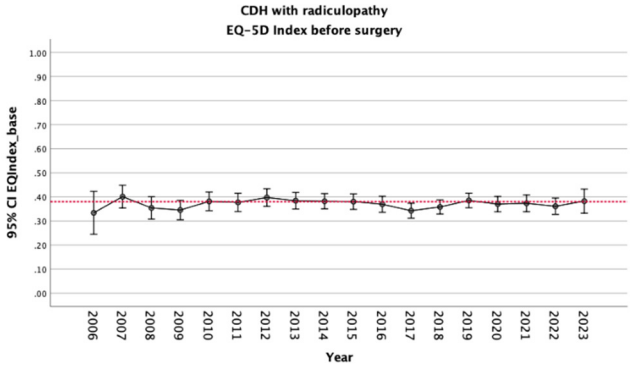

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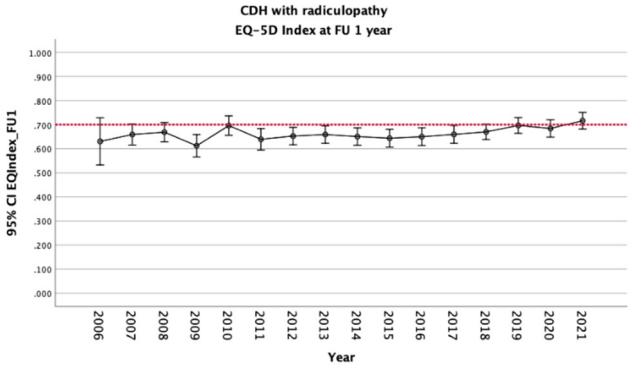

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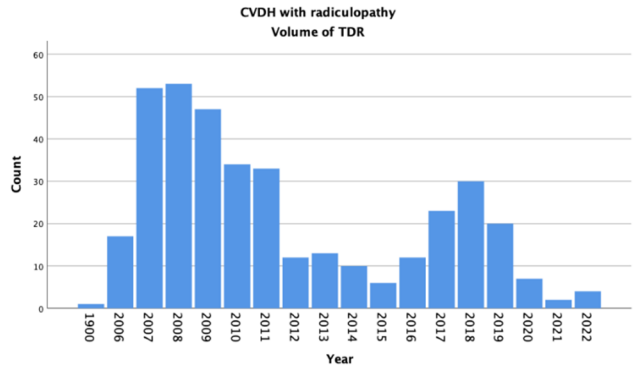

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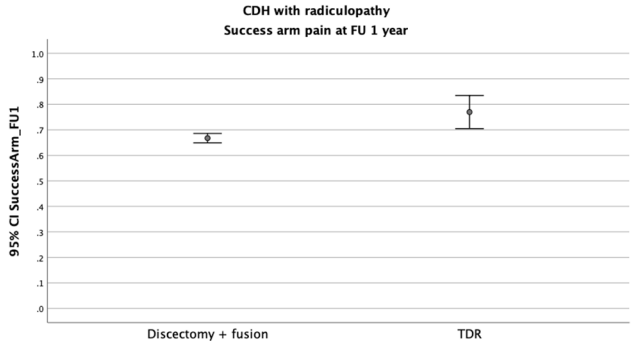

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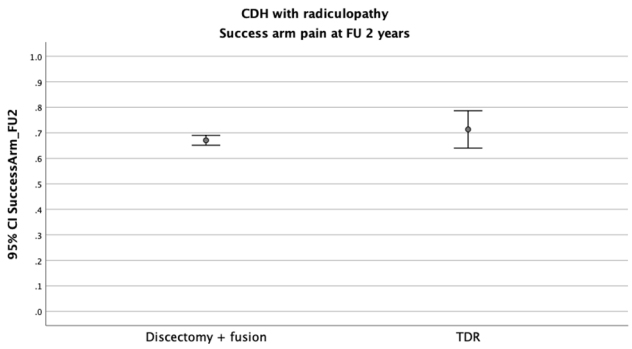

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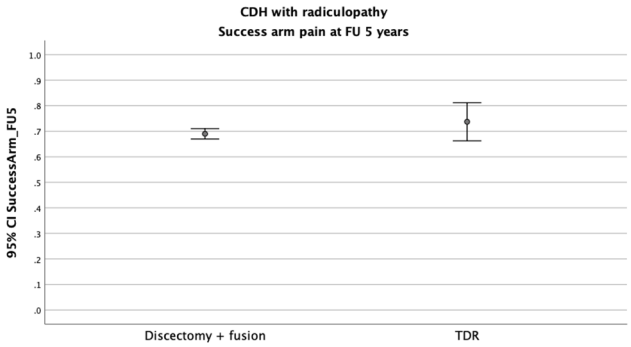

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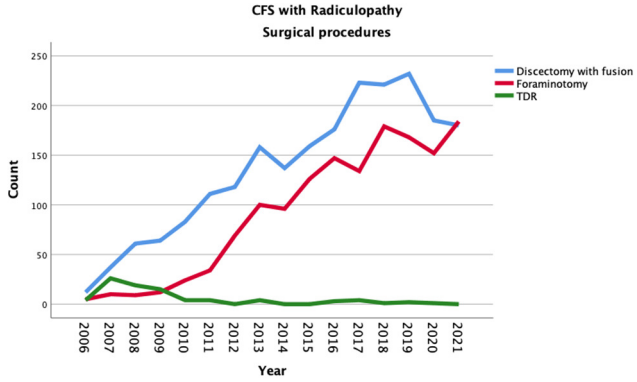

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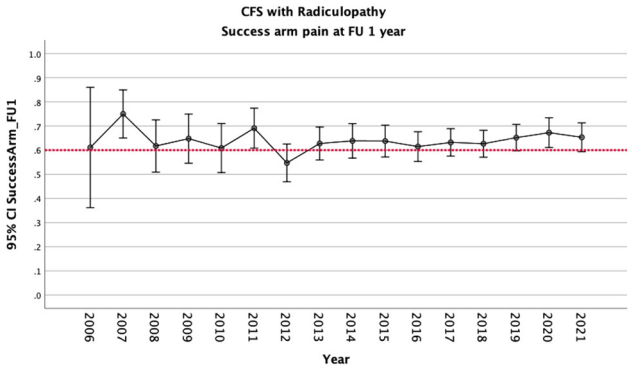

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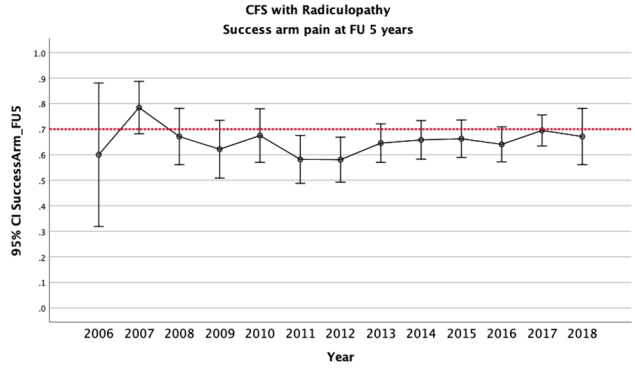

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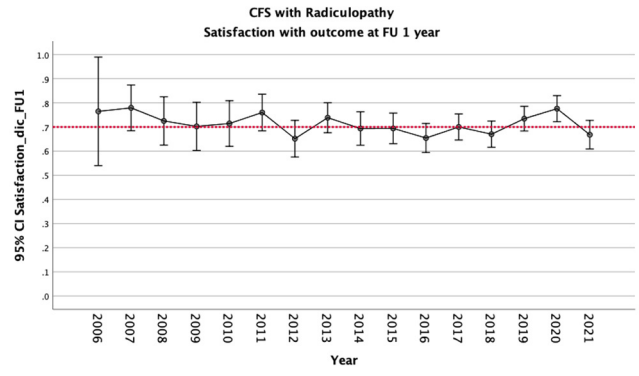

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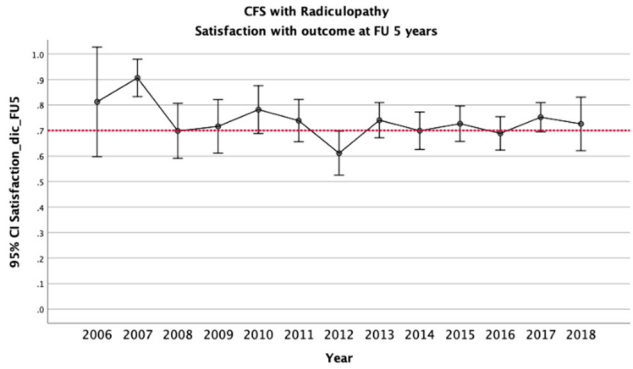

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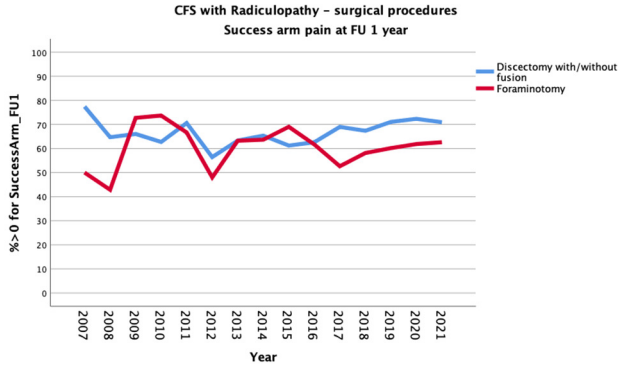

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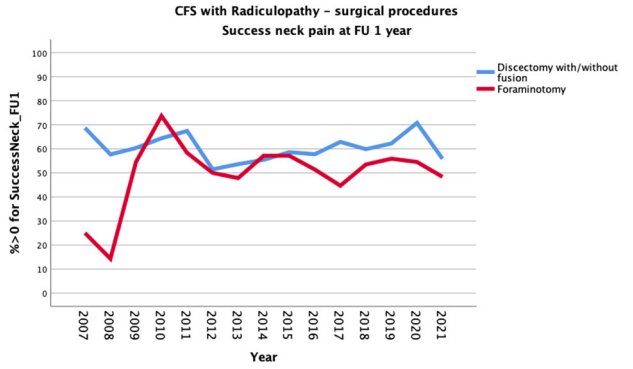

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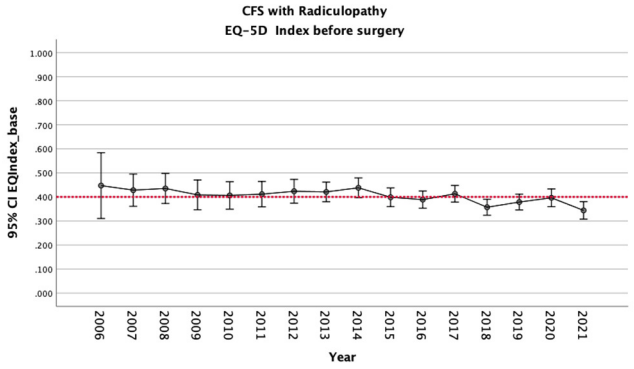

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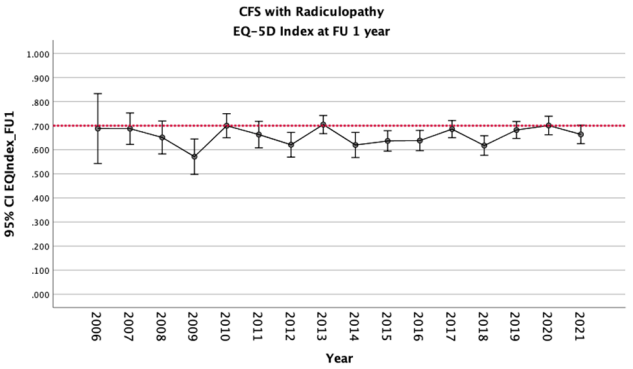

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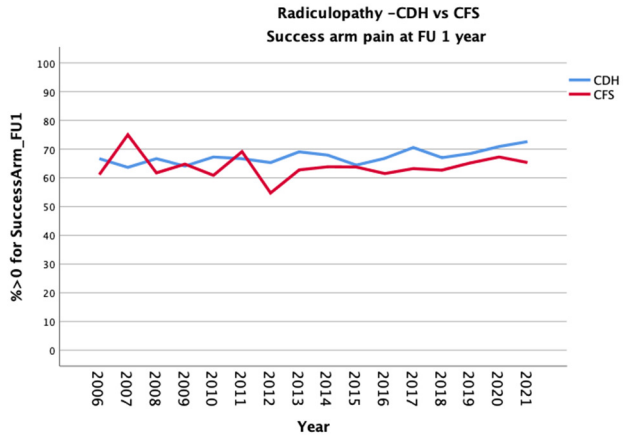

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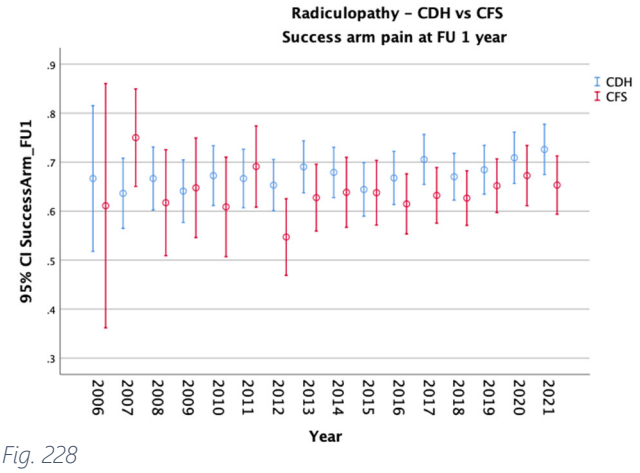

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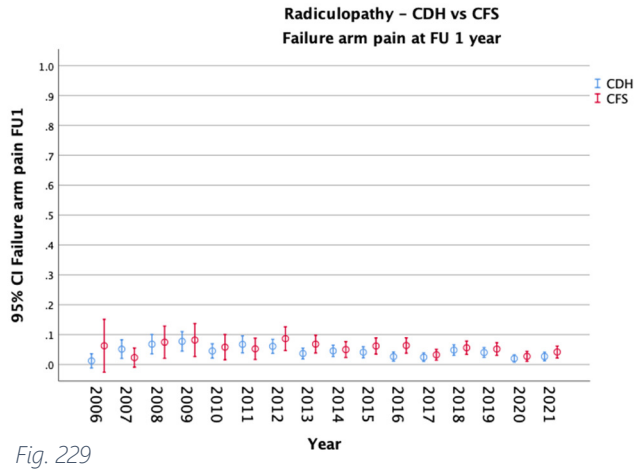

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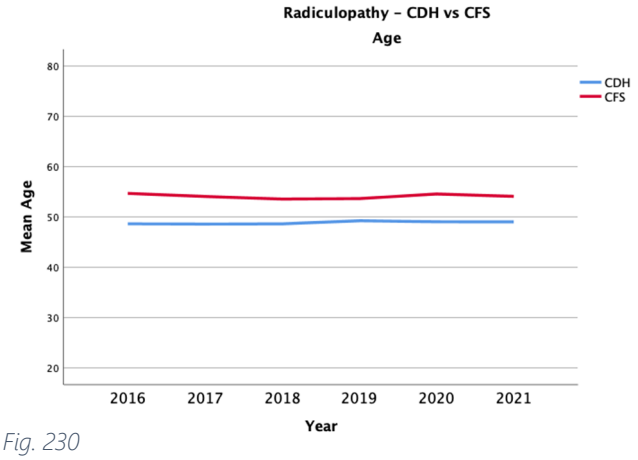

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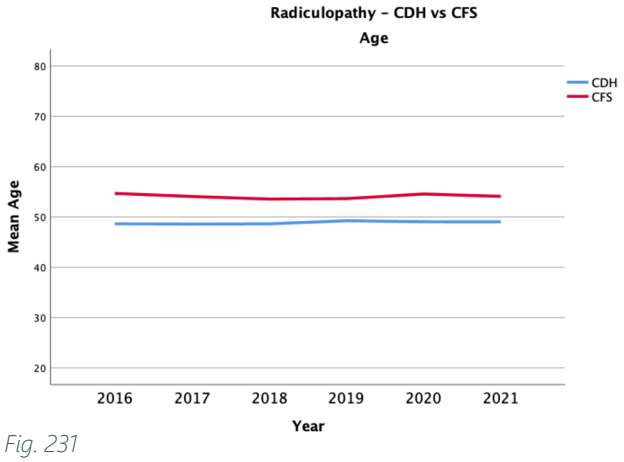

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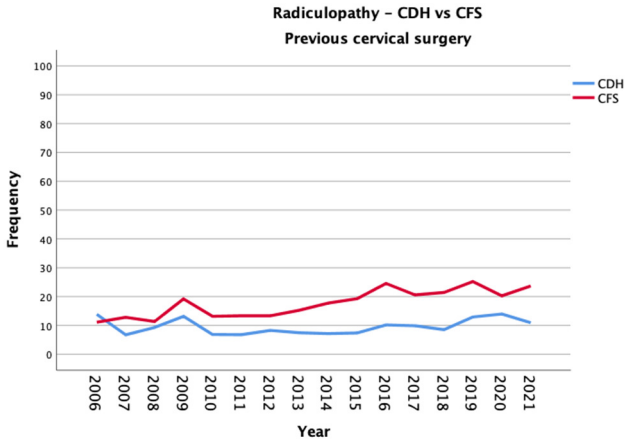

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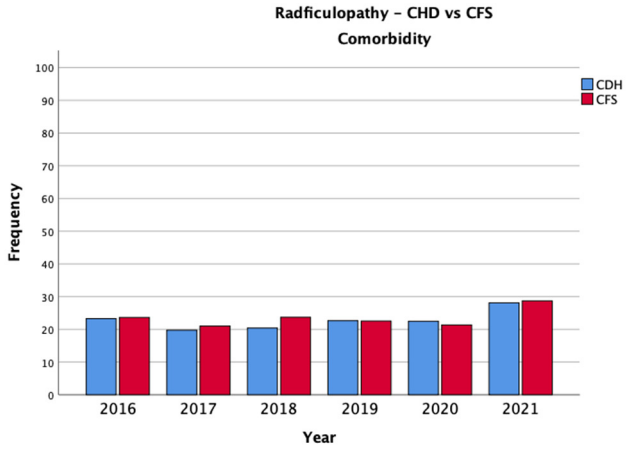

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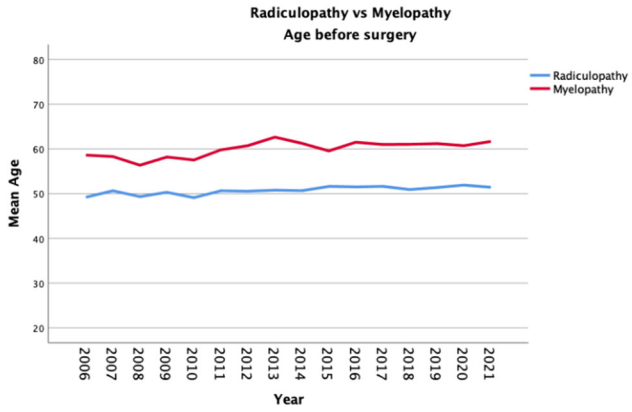

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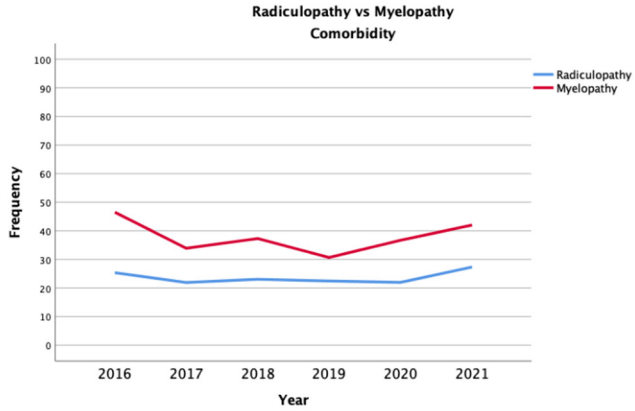

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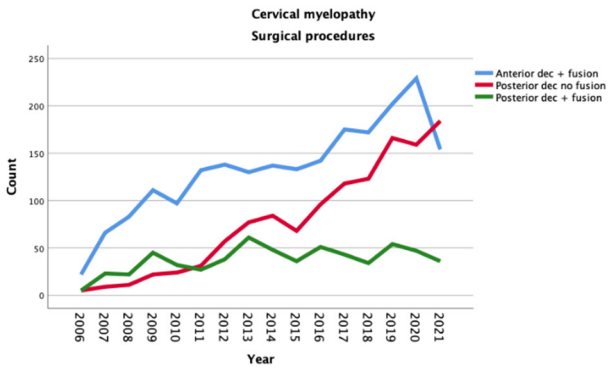

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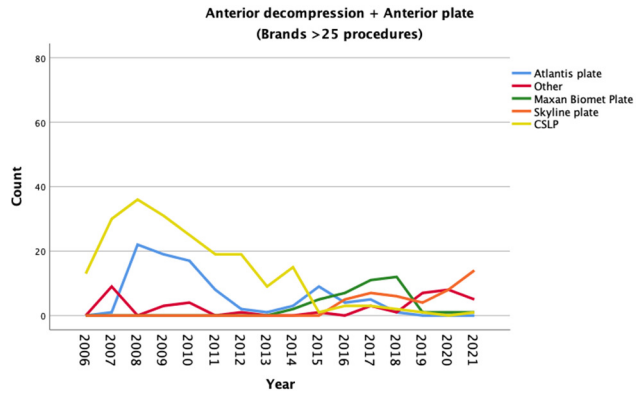

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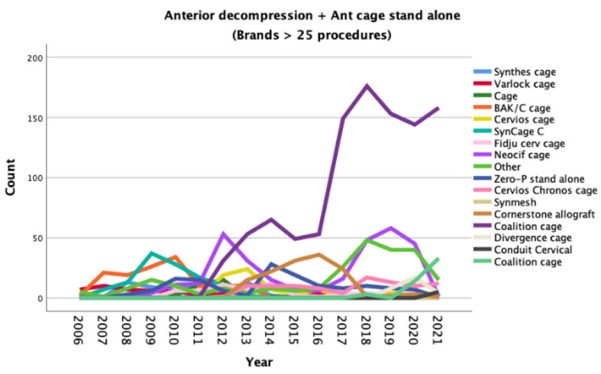

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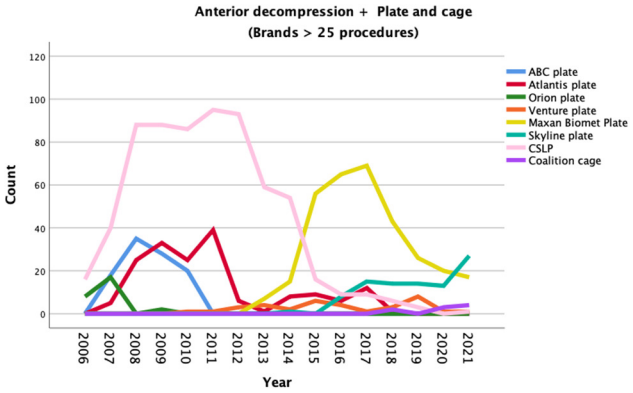

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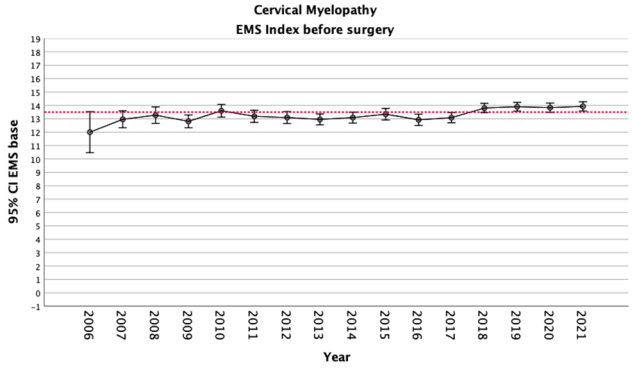
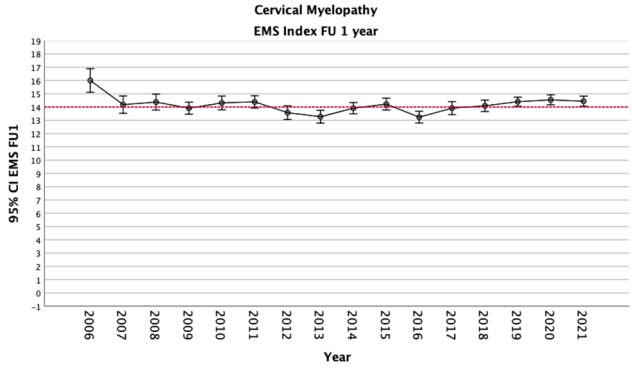


Fig. 240



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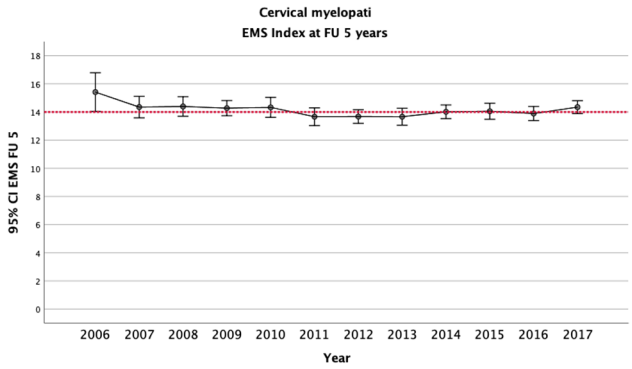

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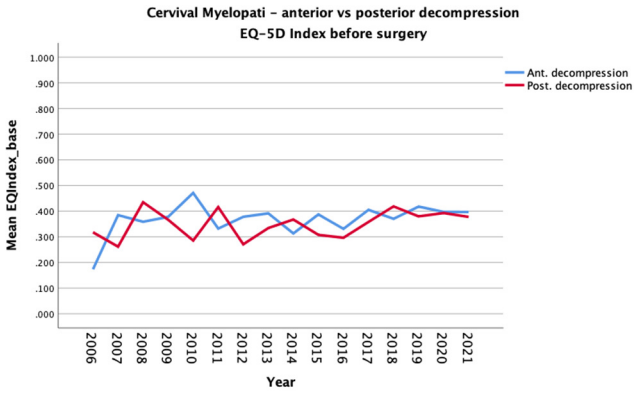

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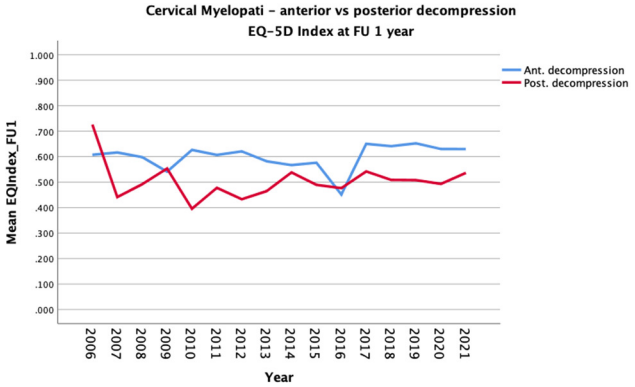

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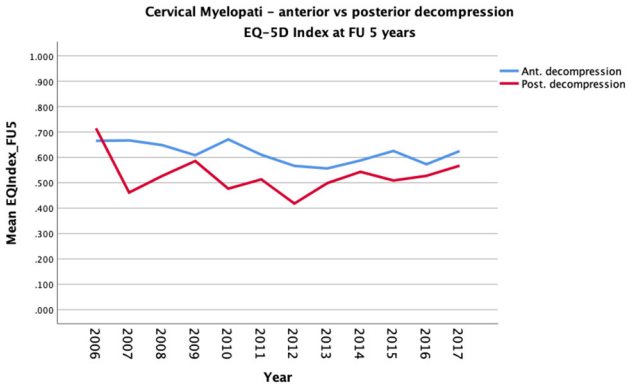

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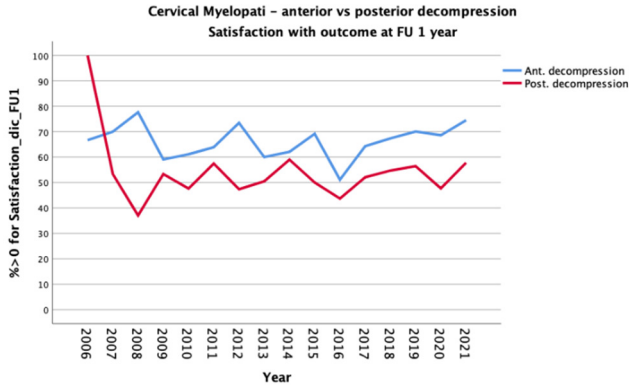

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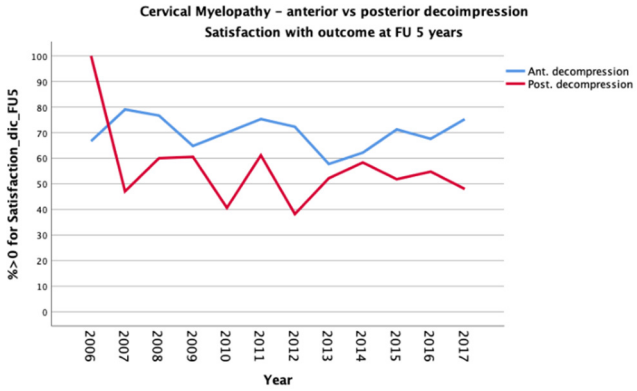

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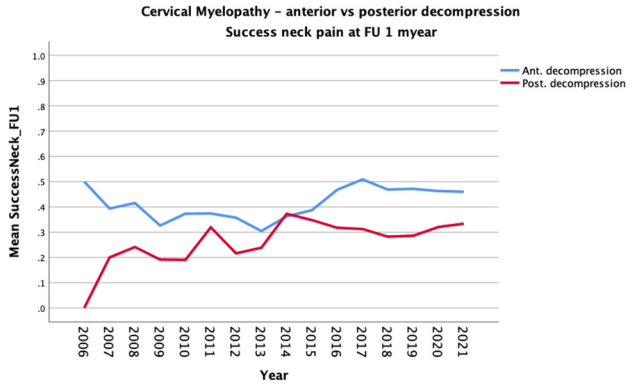

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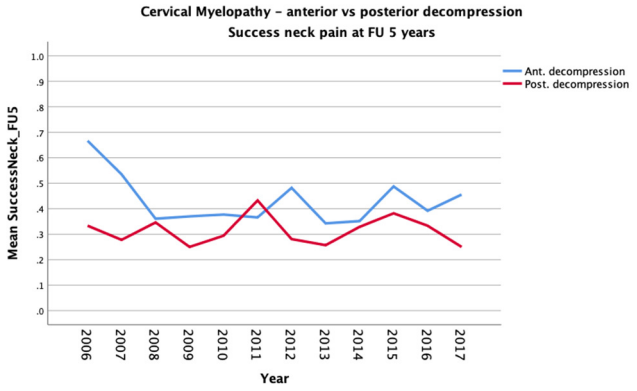

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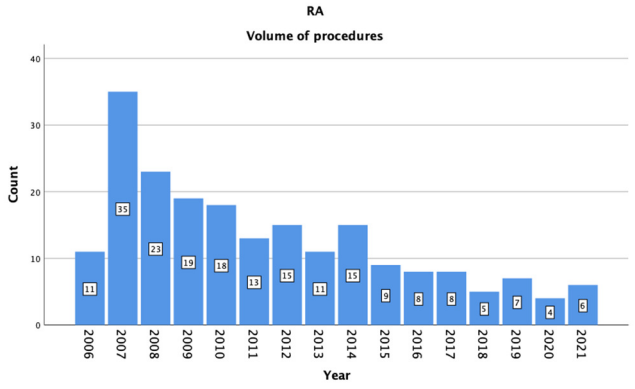

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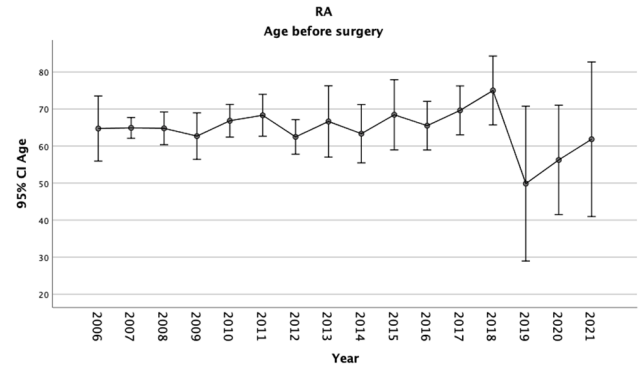

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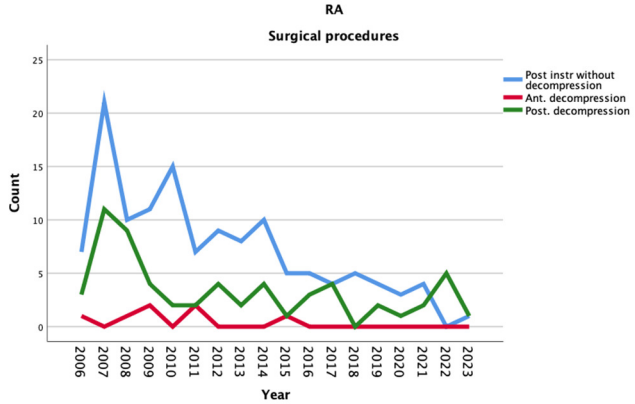

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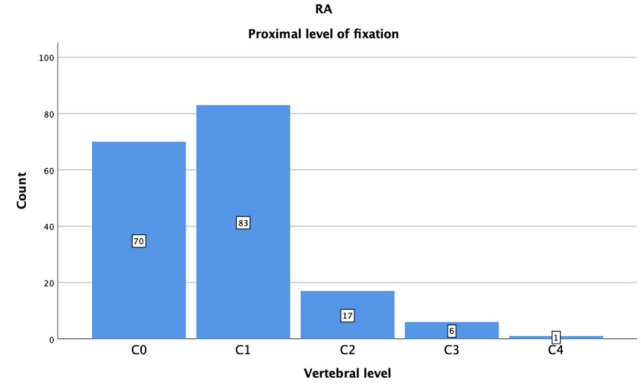

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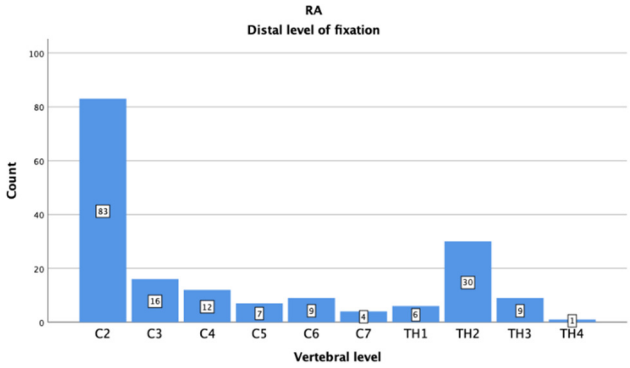


Fig. 254

Deformity

Overview

In total, 3,975 deformity procedures have been registered during the current period. The distribution across diagnostic groups and over time is shown in Figure 255 and 256.

The distribution of registered surgeries among the country's university clinics is presented in Figure 257. Given the low registration rate at all university clinics, the illustrated distribution may not accurately reflect the actual situation.

Idiopathic scoliosis

This largest diagnostic group comprises 1,843 registered surgeries. Females constitute 79% of the cases. The average age is 18 years (Figure 258), showing little variation over time (Figure 259).

Mobility is normal in 97%, and walking aids are used by 2%. Mental function is normal in 97%, while mild developmental disorders are reported in 2%. Approximately half of the cases are of Lenke type 1 (Figure 260). About 75% experienced some degree of back pain, with an average NRS value of 3.4 (SD 2.7).

The main surgical procedures are shown in Figure 261, where it is evident that the vast majority undergo posterior correction with fixation/fusion. Anterior correction was more common ten years ago.

The follow-up frequency for the entire group is 60% at FU 1 year and 42% at 5-years.

Outcome:

The primary outcome measure, radiological correction, is not recorded in Swespine. However, dysfunction and back pain are also parts of the preoperative scoliosis syndrome.

Measured by SRS-22r, the outcome is presented in Figure 262-264 (improving from 3.6 preoperatively to 4.1 at FU1 and 4 at FU5).

Both function (ODI Index) and quality of life (EQ-5D Index) are at relatively little affected preoperatively and show slight improvements at both FU1 and FU5.

Measured by the ODI (Figure 265-267), back function improves from around 20 to about 10, and with the EQ-5D Index (Figure 268-270), quality of life improves from about 0.7 to around 0.8.

Back pain is reported in 80% of patients. Measured by NRS, the intensity in those with back pain is about 4 preoperatively, about 2.5 at FU1, and about 3 at FU5 (Figure 271-273).

Reinterventions:

Reinterventions due to complications and subsequent operations (planned new procedures) occur. The distinctions between these are not entirely clear and require a more thorough analysis and control than what is feasible within the scope of the annual report.

Complications:

Complications during the perioperative and current care period have been registered in a total of 98 cases. These include 1 fatality, 60 dural injuries, 2 partial and 1 complete spinal cord injury, and 32 "other" complications.

Neuromuscular scoliosis

A total of 661 surgeries have been registered for this group. The average age is 15 years, with the distribution as shown in Figure 274. Females make up 45% of the cases.

This is a group with a very severe disease-complex, 71% being wheelchair-bound, 8% requiring walking aids, and 5% bedridden. About 15% have mild developmental disorders, and 57% have severe developmental disorders. The seriousness of the disease is also reflected in the ASA classification (Figure 275).

The vast majority undergo posterior correction and fusion. In recent years, a smaller number of lengthening implants have been used (Figure 276).

The follow-up frequency for the entire group is 42% at FU1 and 26% at FU5. In this severely ill group, several children may have died before the follow-up appointments, so the reported figures may be misleading.

Outcome:

PROMs are not useful metrics in this group. Registered mobility at FU1 and FU5 is not significantly affected. The primary goal for these surgeries—improved sitting ability and better care conditions—is not registered as an outcome measure.

Complications:

A total of 92 complications have been registered during the perioperative and current care period, including 3 fatalities, 37 dural injuries, 1 partial spinal cord injury, and 55 "other" complications.

In summary, this is a severely afflicted and heterogeneous group with several subdiagnoses and a high risk of complications. Scoliosis correction can significantly improve their quality of life and care conditions.

Congenital scoliosis

This group consists of 279 cases with an average age of 14 years (Figure 277), and 59% are females. There are individual cases of higher ages.

Functionally, this group differs from neuromuscular scoliosis. Ninety-five percent have normal mobility, and 4% require walking aids. Mental function is normal in 89% of cases, while 9% have mild developmental disorders. The ASA classification indicates significantly lower comorbidity compared to neuromuscular cases (Figure 278).

In this scoliosis group as well, posterior correction and fusion are the most common surgical procedures (Figure 279).
The follow-up rate was 52% at 1-year follow-up (FU1) and 33% at 5-year follow-up (FU5).

Outcome:

Quality of life, as measured by the EQ-5D Index, is relatively high preoperatively, at 0.73 (SD 0.27). It increases to 0.81 (SD 0.25) at FU1 and is 0.74 (SD 0.29) at FU5. The EOSQ24 questionnaire has recently been introduced into the registry to assess scoliosis in children under 15 years, but there are currently no follow-up data available for evaluation.

Comment:

For the idiopathic scoliosis group, radiological correction is a primary treatment aim that is not captured in the registry. However, PROMs indicate improved function and quality of life after surgery. In the case of neuromuscular scoliosis, the kind of preserved/improved function, which is the aim of surgery, is also not directly apparent in registry data. Hopefully, the introduction of EOSQ24 will provide a clearer picture of outcomes for younger children.

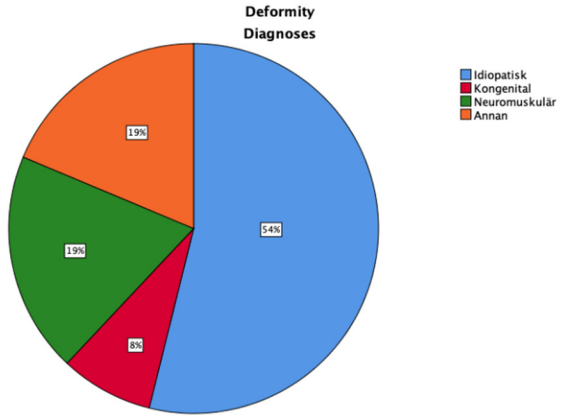
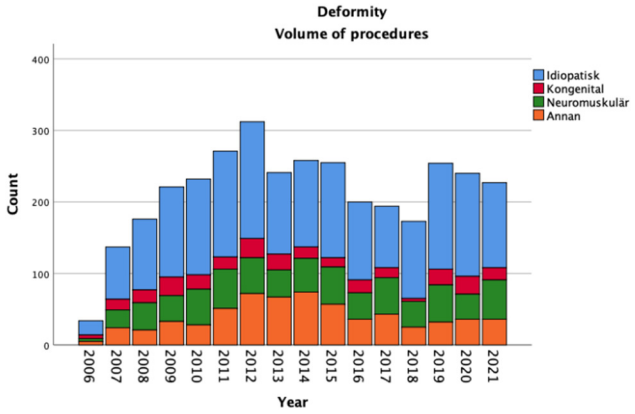


Fig. 255



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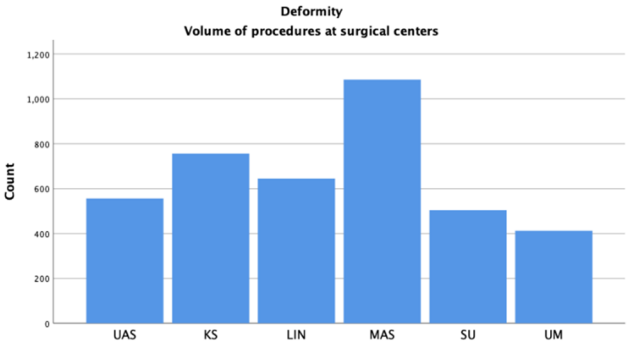
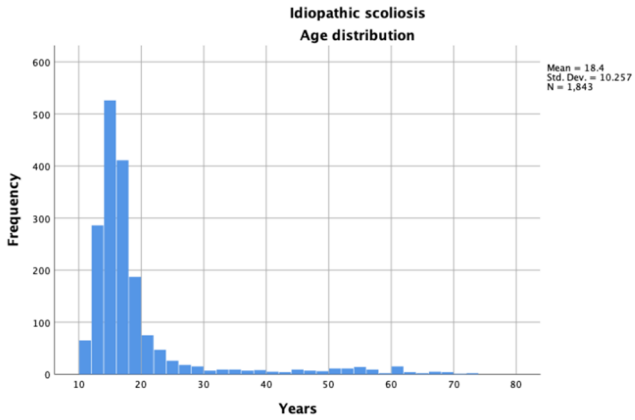


Fig. 257



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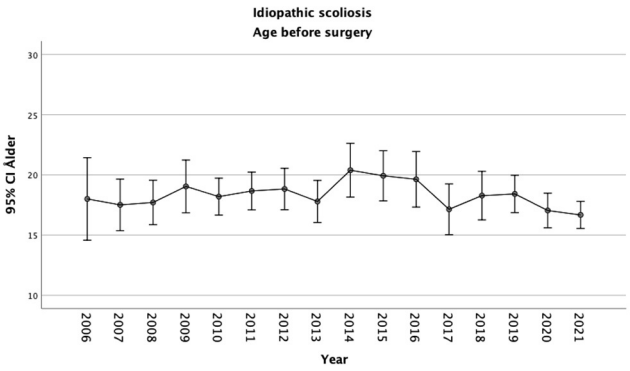

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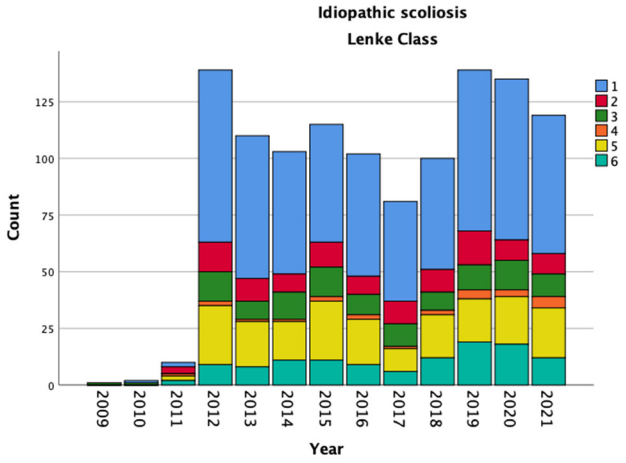

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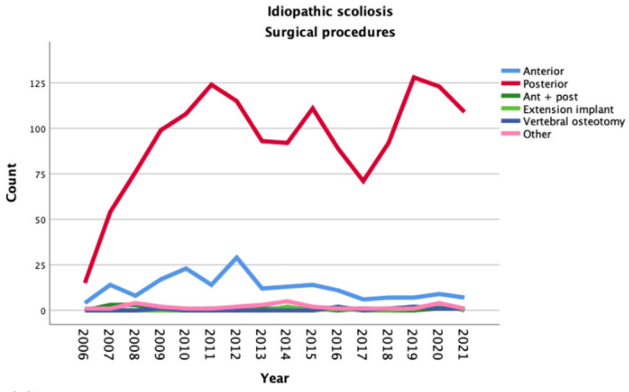

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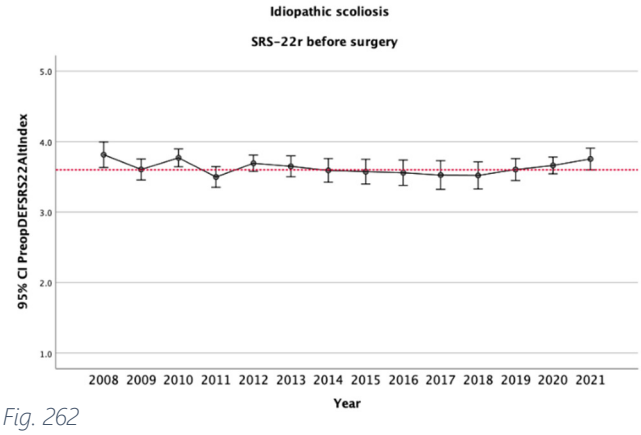

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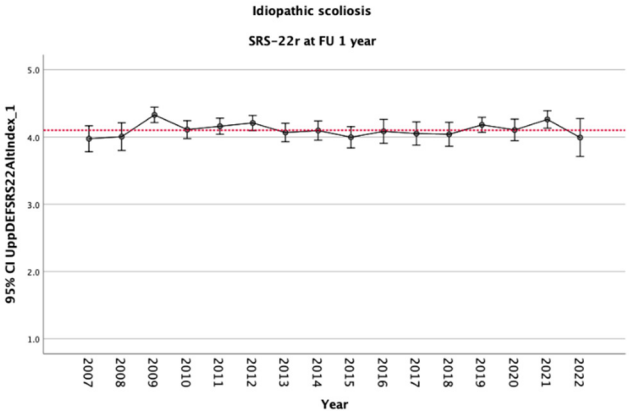
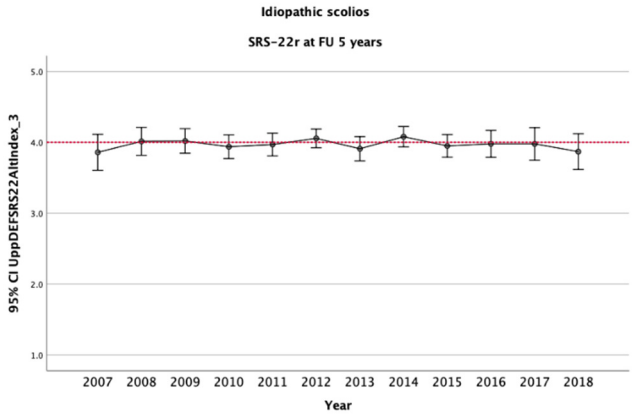


Fig. 263



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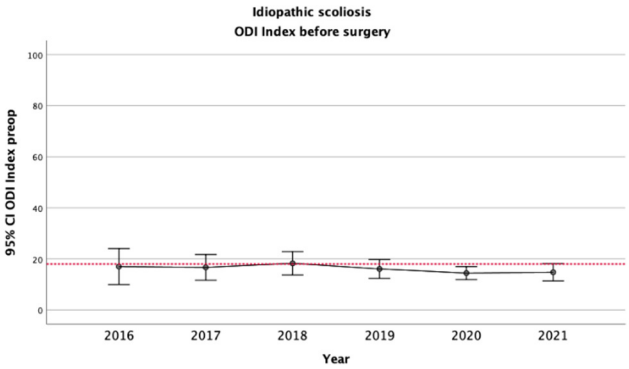

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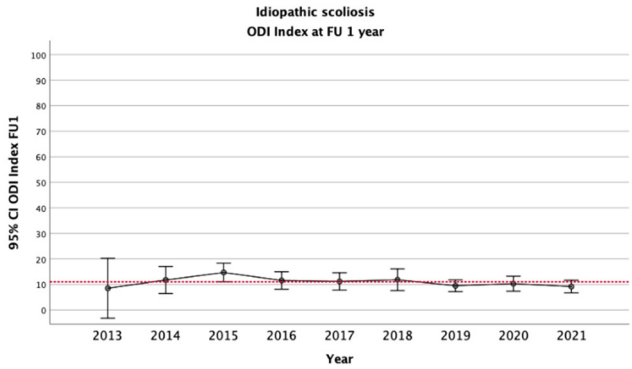

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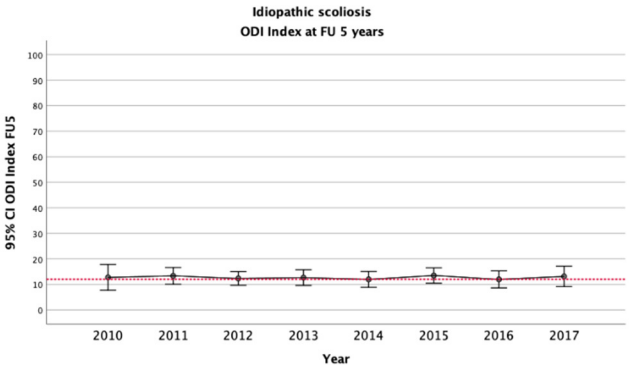

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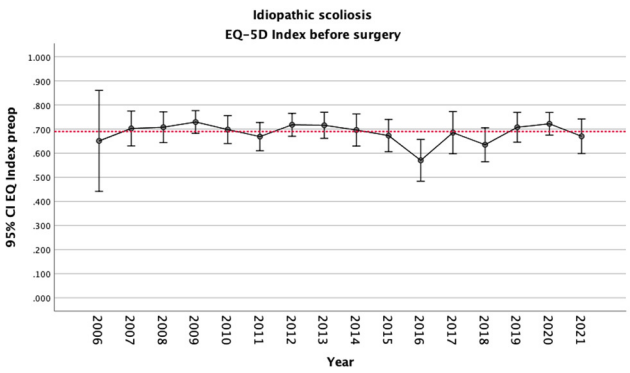

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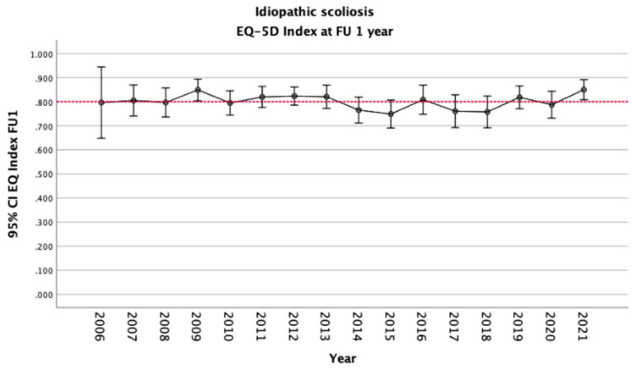

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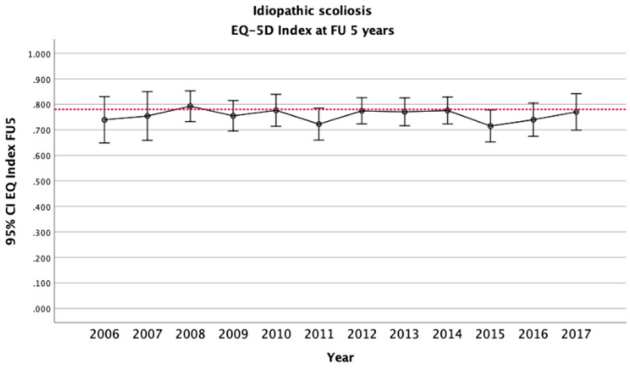

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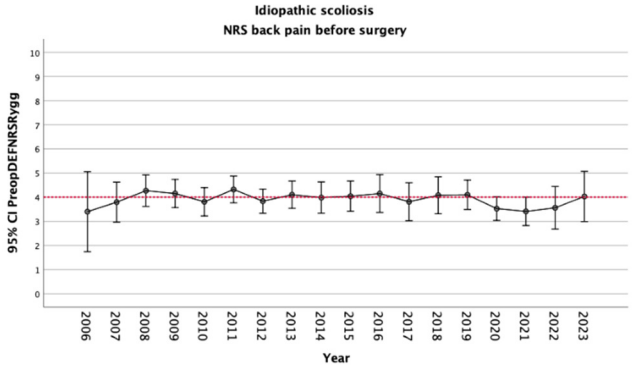

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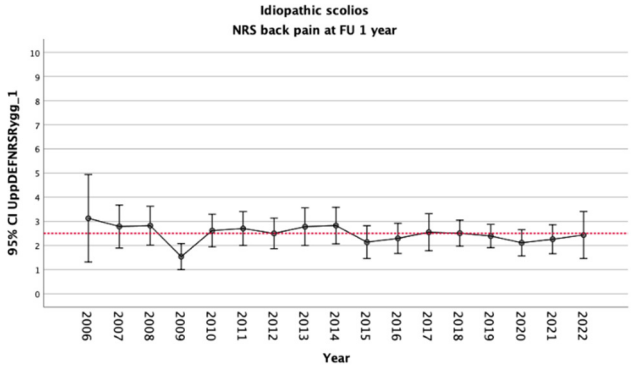

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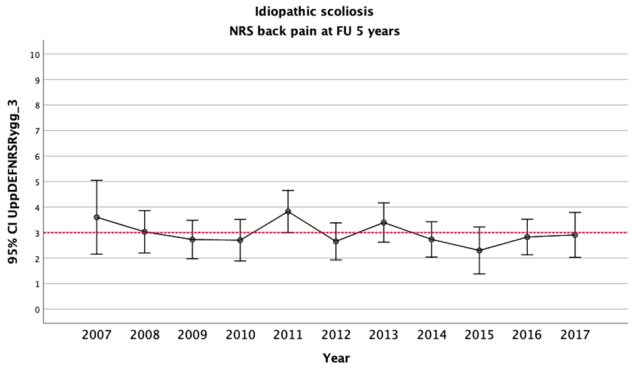

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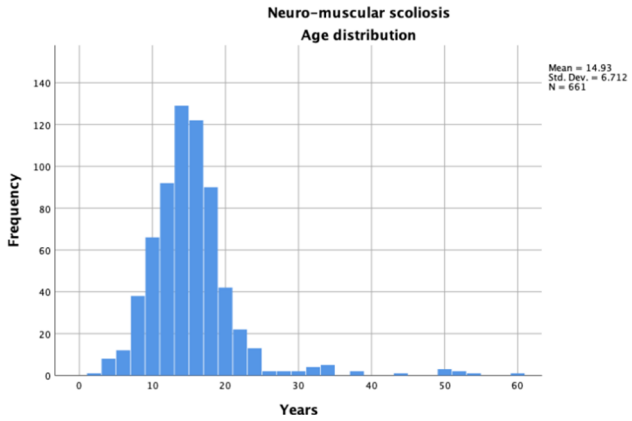
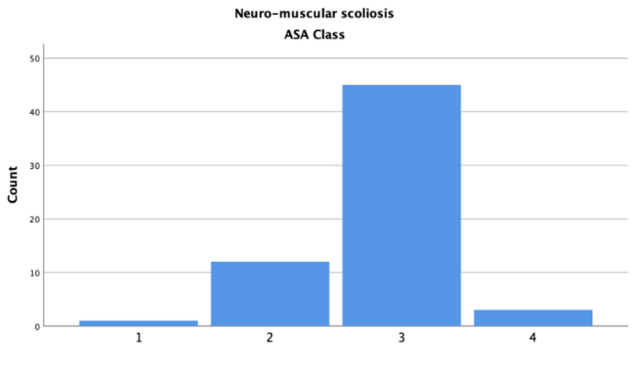


Fig. 274



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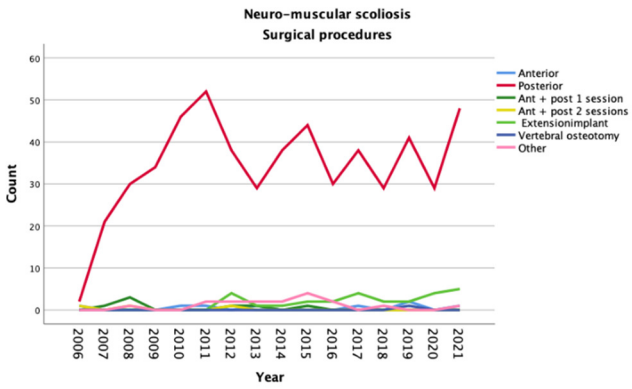

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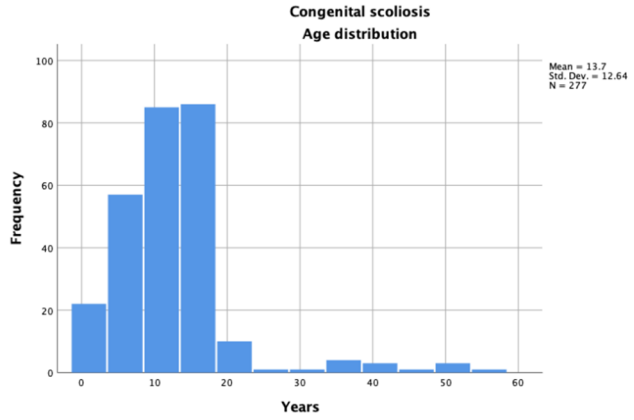
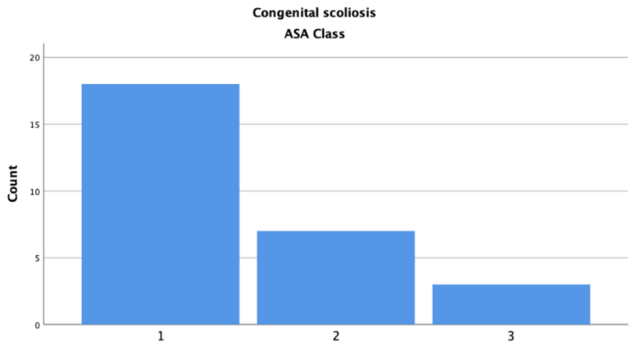


Fig. 277



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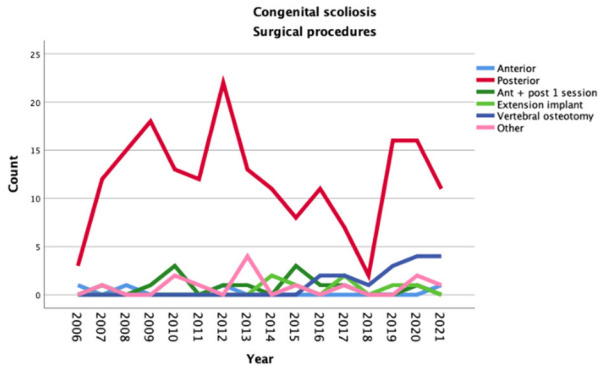


Fig. 279

Infection

Between 2007 and 2021, a total of 845 surgeries for non-operational infections have been performed, distributed as shown in Figure 280. The follow-up rate is low, with 48% at FU 1-year and 27% at 5-years. Men make up 60% of the patients with an average age of 61 years, with variations as depicted in Figure 281 and no significant changes over time (Figure 282). Patients with infections often have a high frequency of comorbidities (Figure 283).

Most cases involve spondylitis/spondylodiscitis with or without an epidural abscess (Figure 284). The primary indication for surgery is usually neurological deficits (Figure 285).

Infections can affect the entire spinal column, but they are most common in the lumbar spine (Figures 286 and 287). The primary aetiology is Staphylococcus aureus (Figure 288).

Most commonly, posterior decompression is performed (Figures 289 and 290), with less than 50% complemented by posterior fixation and a smaller group receiving anterior implants with or without posterior fixation (Figures 291 and 292). Like other diagnostic groups, the use of implants shows significant variations over time (Figure 293).

Outcome:

At the FU 1-year, slightly over 60% of patients are satisfied with the outcome, which may decrease over time, but statistically not significant due to large confidence intervals (Figures 294 and 295). When the entire group is evaluated, 64% are satisfied at FU1, and 68% at FU5.

Successful outcome is reported by 60-70% at FU1, with a wider range at FU5 (Figures 296 and 297). For the entire group, 61% consider outcome successful at FU1 and 54% at FU5.

There is a significant amount of missing preoperative EQ-5D Index data, making it difficult to evaluate changes over time. At the 1-year follow-up, the EQ-5D Index is slightly over 0.5 (Figure 298). Calculated for the entire group, the preoperative value is 0.23 (SD 0.46), 0.53 (SD 0.36) at FU1, and 0.57 (SD 0.36) at FU5.

The reintervention rate is relatively high at approximately 10%, with a spectrum as shown in Figure 299.

Comment:

"Spontaneous" spinal infections requiring surgery occur in individuals (usually men) with relatively high morbidity. Treatment appears to be quite demanding, with a high rate of reintervention and moderate long-term outcome. Considering the high drop-out rate at 1-year follow-up and even more at 5-years (likely reflecting the relatively infirmity of the group), outcome figures are very uncertain and may be considerably more unfavourable than what can be inferred from registry data.

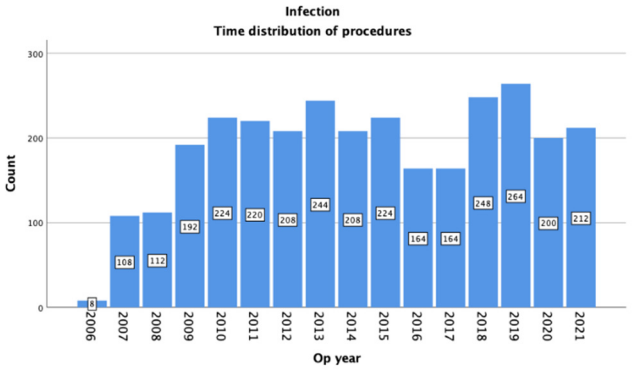
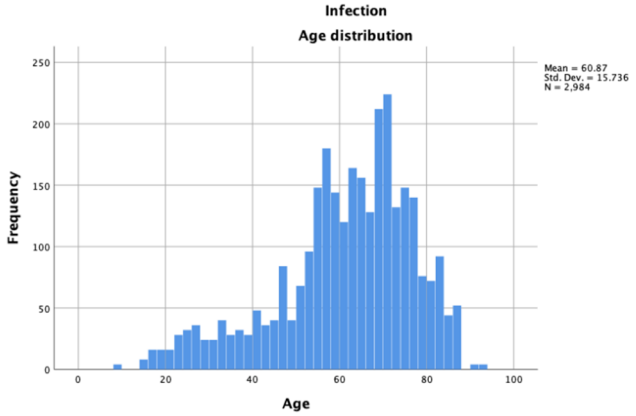


Fig. 280



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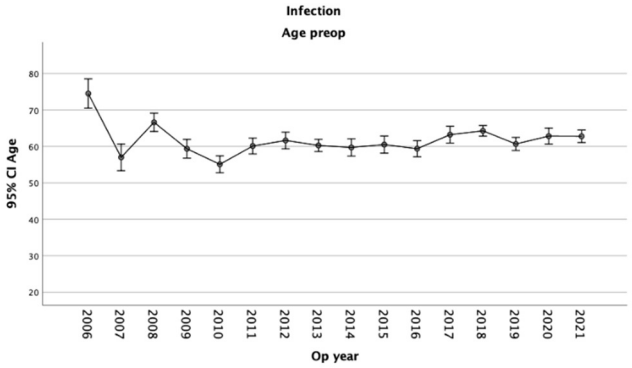

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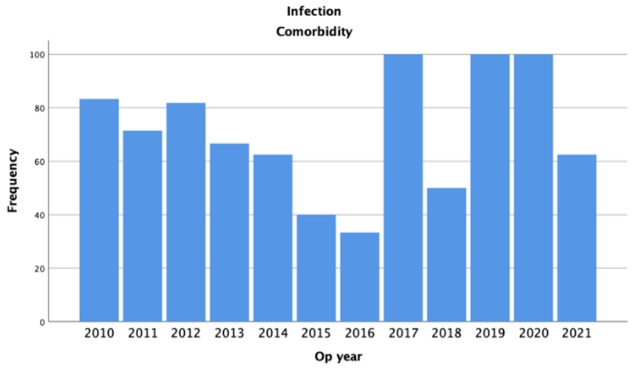

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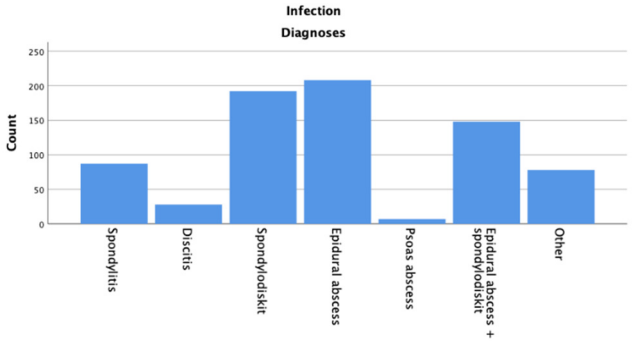

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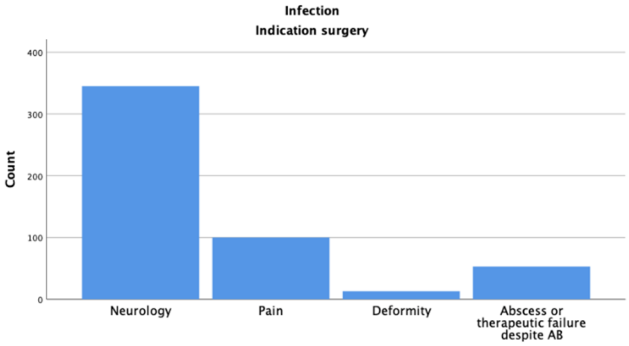


Fig.285

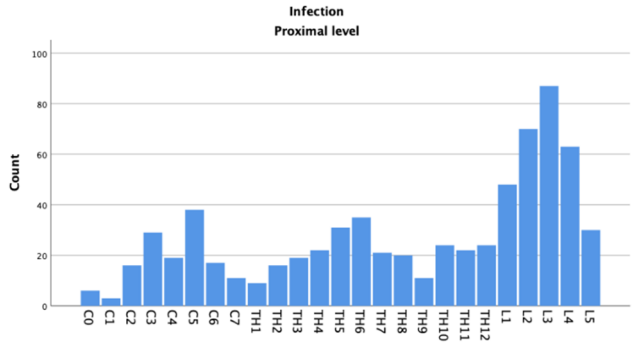
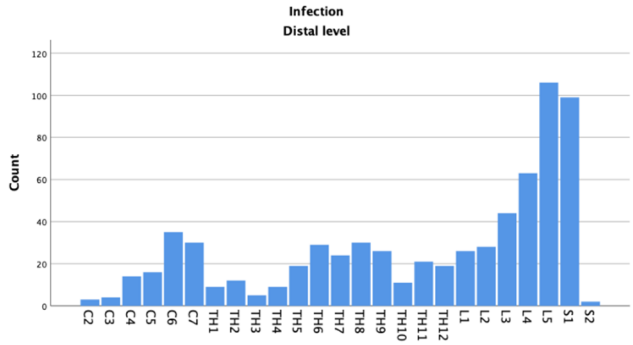


Fig. 286



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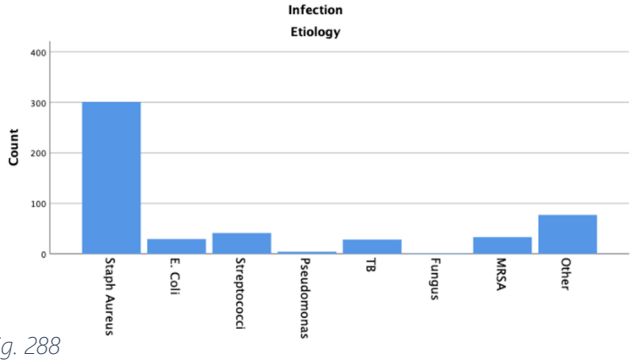

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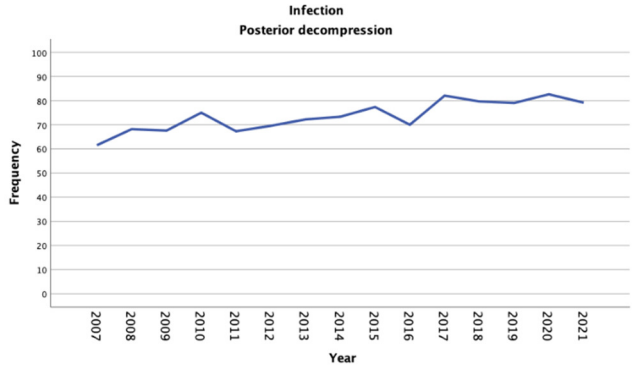


Fig. 289

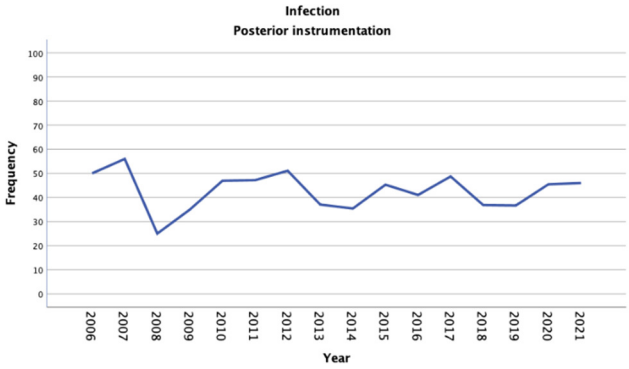
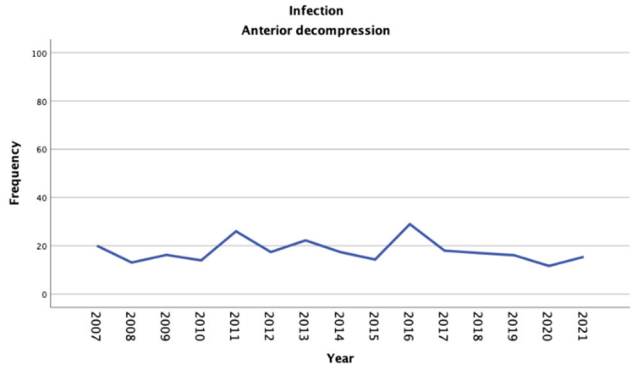


Fig. 290



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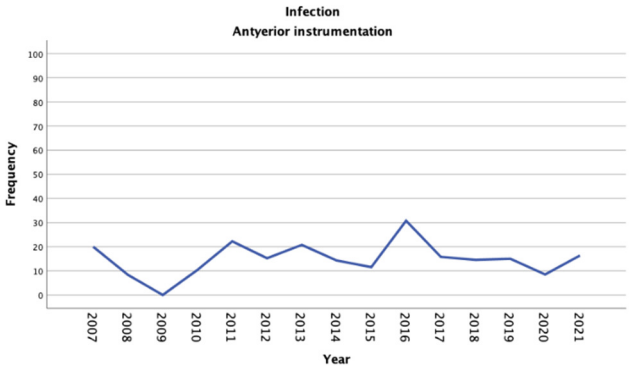


Fig. 292

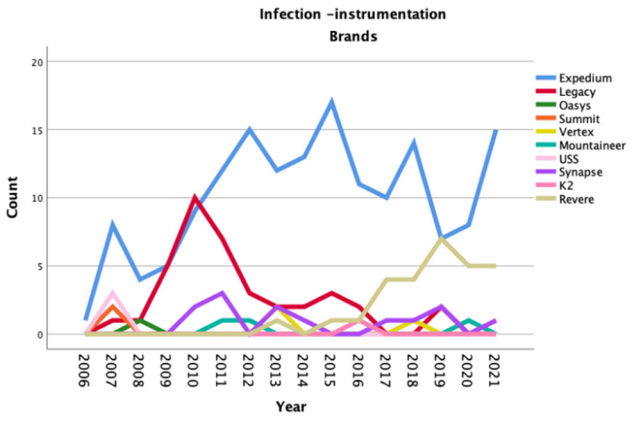


Fig. 293

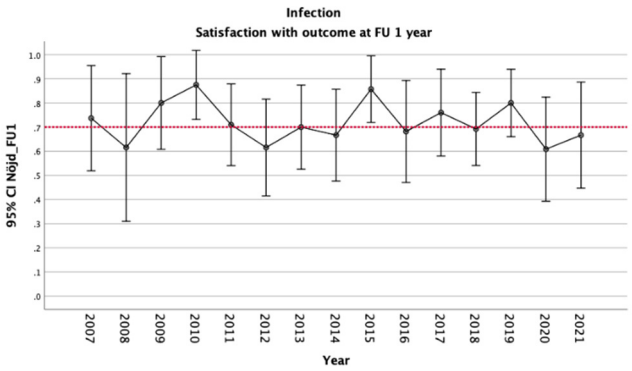


Fig. 294

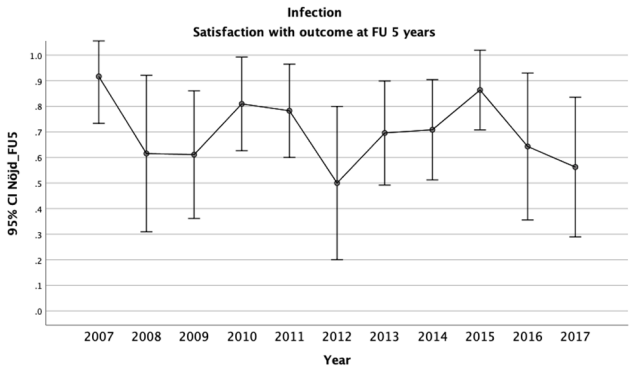


Fig. 295

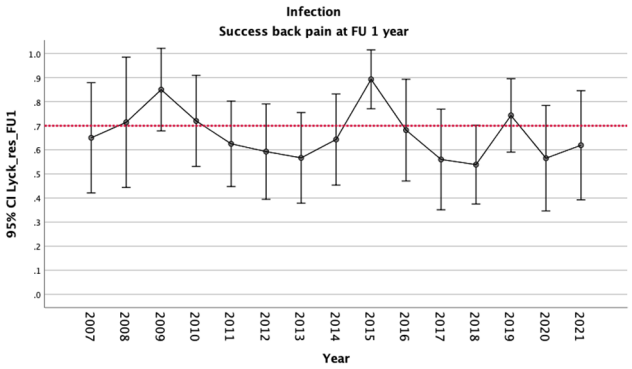
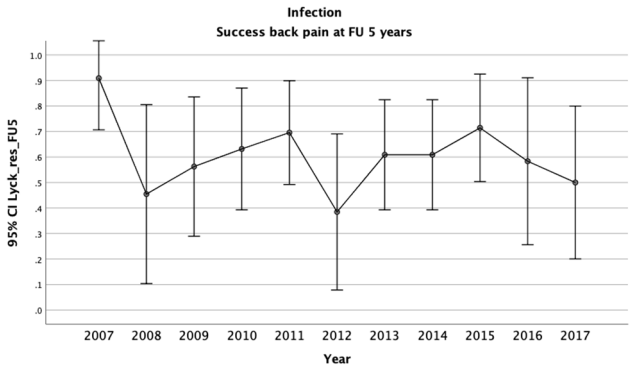


Fig. 296



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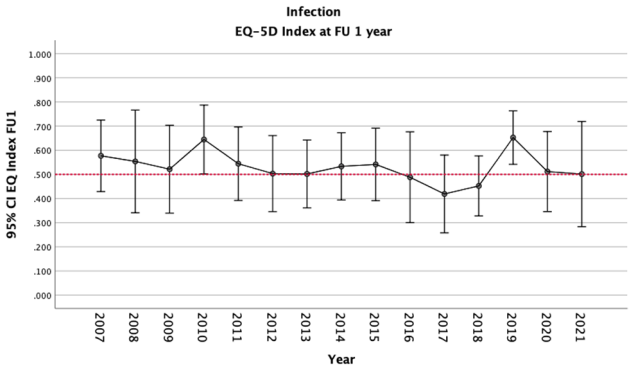


Fig. 298

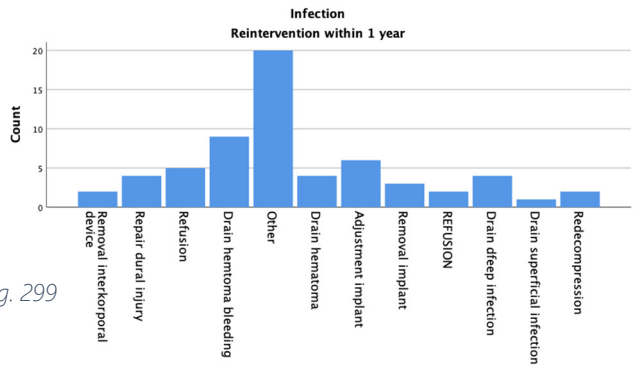


Fig. 299

Metastasis

Since surgery for metastases of the spinal column was initiated in 2006, a total of 2,481 cases have been registered, with some decline in recent years (Figure 300).

The majority are men (66%) with an average age of 66 years (Figure 301). The follow-up rate at the single point (6 weeks) is relatively low, 49%.

There is a predominance of prostate cancer as the primary tumor (Figure 302), and the main indication for surgery is the onset of neurological deficits (Figure 303). Most cases have moderate or mild neurological deficits (Figure 304). The mid-thoracic spine appears to be the most common site of metastasis (Figures 305 and 306).

The vast majority undergo posterior decompression of the spinal cord, with simultaneous fixation in 73%, without significant change over time (Figure 307). In most cases, intralesional or marginal resection of tumour tissue is performed, which means only enough to relieve the spinal cord/nerve roots, without the ambition to remove the entire metastasis (Figure 308).

Outcome:

At the 6-week follow-up, the majority reside in their own homes (Figure 309), and have walking ability with assistive devices (Figure 310). One half has improved strength in legs/arms (Figure 311), and the majority has less pain than preoperatively (Figure 312).

The quality of life measured by the EQ-5D Index is very low preoperatively and has improved significantly (but not to more than the preoperative level for several degenerative conditions) 6 weeks FU (Figures 313 and 314).

Comment:

The goal of improving quality of life, preserving walking ability, and relieving pain seems to have been achieved to some extent at the 6-week follow-up. However, all follow-up data must be interpreted with great caution because the dropout rate is more than 50%. The registry does not contain data on reinterventions or survival time.

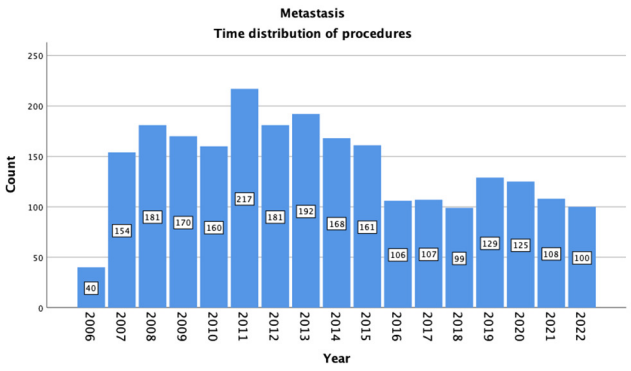


Fig. 300

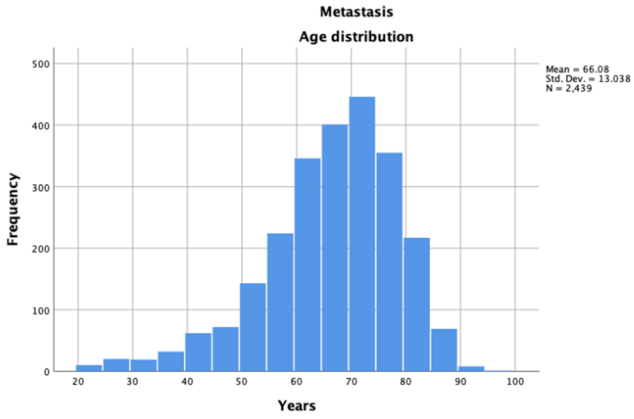
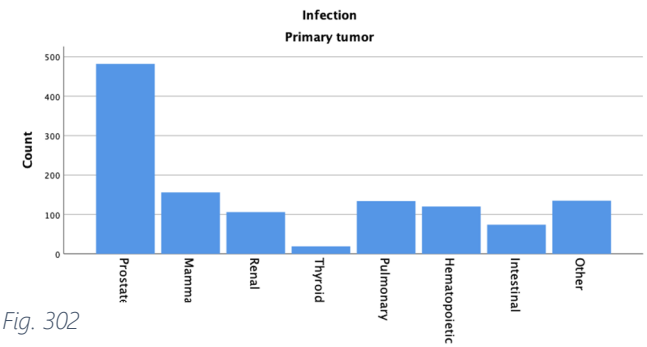


Fig. 301



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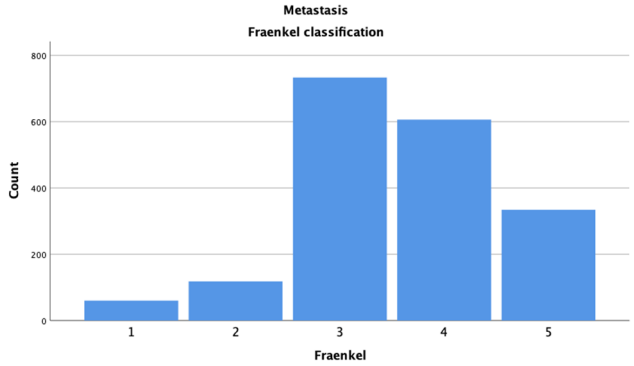


Fig. 303

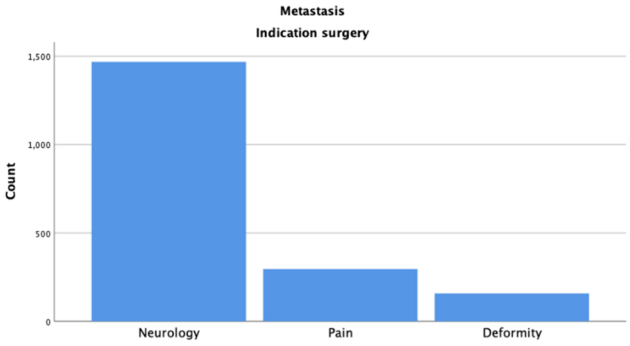
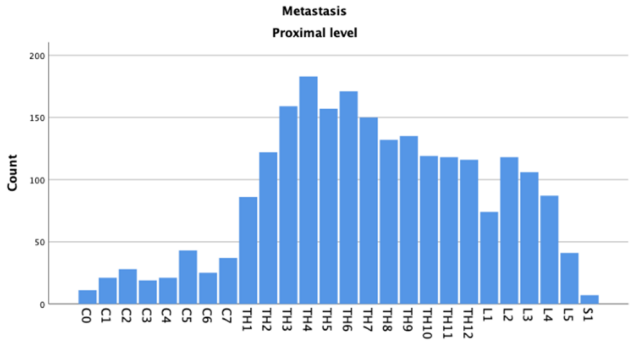


Fig. 304



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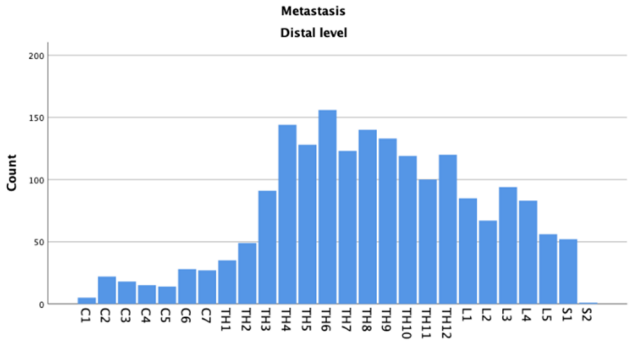


Fig. 306

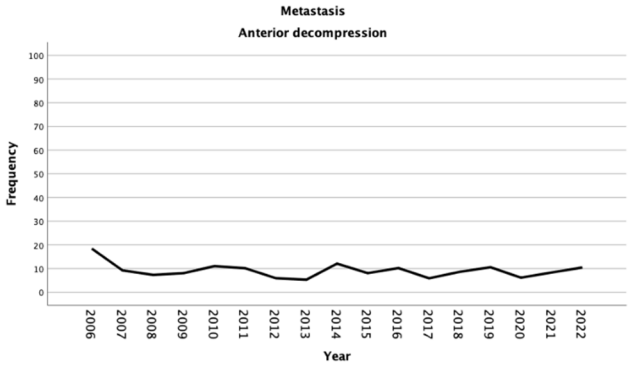


Fig. 307

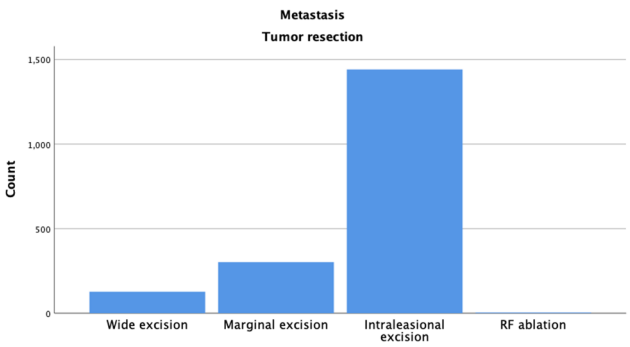


Fig. 308

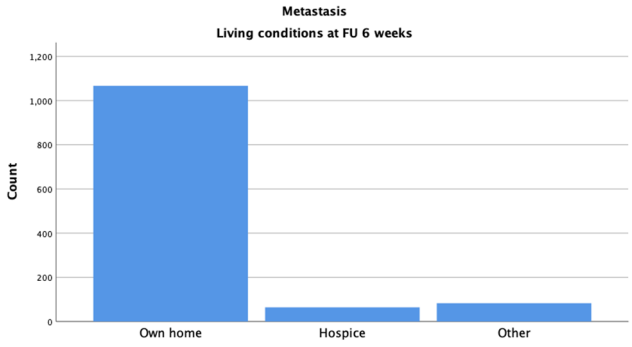


Fig. 309

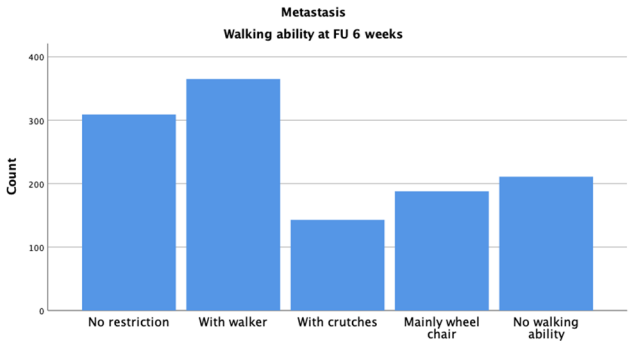


Fig. 310

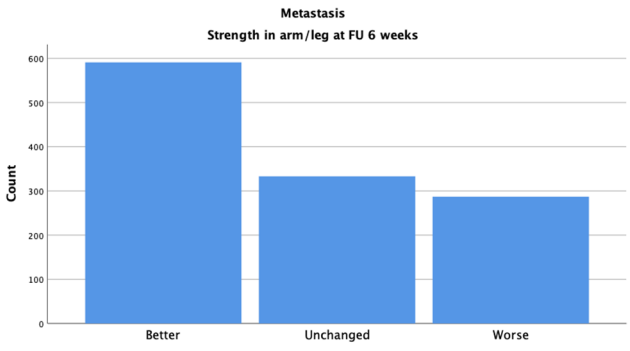


Fig. 311

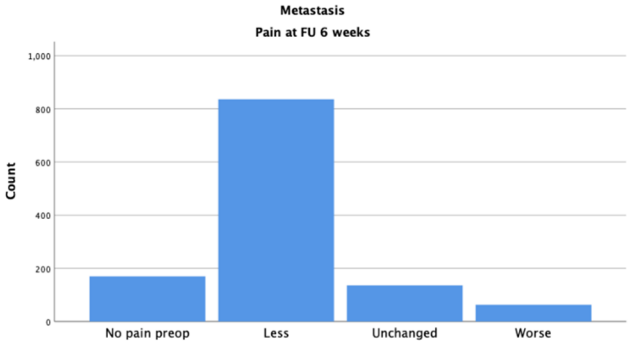


Fig. 312

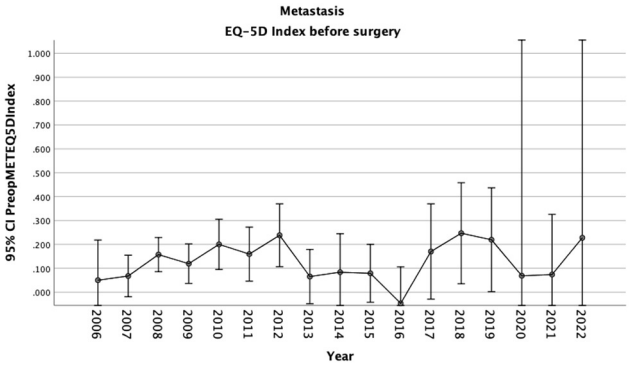


Fig. 313

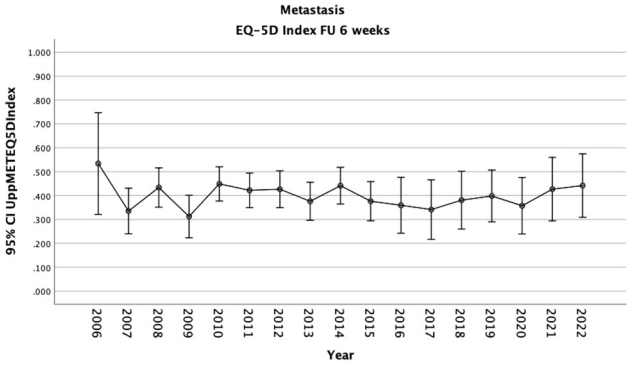


Fig. 314

BENCHMARKING

Swespine's primary purpose is to collect information as a basis for improving the outcomes of the nation's spine surgery. The best method is to compare the outcomes of individual clinics – benchmarking. Differences raise questions about causes, which each clinic and spine surgeon should try to answer. This generates knowledge that can lead to improvement. Therefore, we have chosen to have a separate section on benchmarking and its results.

Outcomes for CSS

As an example of benchmarking, which will be an important part of future annual reports, we present the results for Central Spinal Stenosis. The funnel plots shown after the text have observed (unadjusted) values for Successful Outcome in leg pain (Pain-Free/Much Better) in Figures 320-325 and observed (unadjusted values) for Satisfaction in Figures 326-331. All values are at FU 1 year. The plots show the outcomes in 2-year periods from 2011 to 2021.

The interpretation of funnel plots:

Funnel plots are a graphical method that can be used to visualize the variation in the results of patient-reported data at different clinics. We have chosen to present the plot in a horizontal format. The horizontal axis (x-axis) shows patient volume, i.e., the number of operations carried out during a 2-year period. The vertical axis (y-axis) shows the proportion (%) of patients who have rated a successful outcome (pain-free or much improved) or satisfaction. The horizontal grey line illustrates the total proportion of patients who have rated a successful outcome or satisfaction, based on all the clinics represented in the diagram, which could be interpreted as the result at an average clinic. The red lines, which together form a "funnel," consist of a confidence interval (95%) around the total proportion, illustrating the precision of the total proportion in relation to patient volume. This means reduced precision for low patient volumes and increased precision for high patient volumes. The interpretation is that clinics below the lower red line have worse outcomes than the average clinic on the patient-reported outcome measure, and clinics above the upper red line have better outcomes than the average clinic.

In this year's report, no case mix adjustment of individual clinic outcomes is made. The algorithm for adjustment was developed 10 years ago. It needs validation on current data structures, a task that will be carried out during the coming year.

Even unadjusted values contain important information. One should just keep in mind that there are significant differences between university, county, and private clinics regarding operated patients, such as age, comorbidity, and possibly also the complexity of stenosis. According to our overall analysis, differences within clinic types are small. This means that comparisons within each clinic type group are valuable, and likely, there are only minor changes when data are case mix adjusted.

So, find your clinic, follow it over time, and compare it with other clinics of the same type!

However, there are problems that affect the registered outcome and make comparisons uncertain, whether the outcome is adjusted or not. It is a triple problem – 1. dropouts in the registration of baseline data, 2. dropouts in the primary registration of surgery (completeness), and 3. dropouts in follow-up (follow-up rate).

Clinics with large surgical volumes generally have high completeness, which makes their outcomes and comparisons more reliable. Conversely, clinics that report few cases are problematic. If volume also decreases due to low completeness and potentially low follow-up rate, the uncertainty in the evaluation of outcomes becomes significant, even if the values are case mix adjusted. For example: A clinic with 70% completeness, 70% registration of baseline data and 70% follow up of spinal stenosis, has, in effect, in a best case 34% of all performed operations available for evaluation, in a worst case only 19%, when measuring outcome with a prospective PROM. This does not provide much confidence in conclusions.

This also means that individual clinics cannot accurately assess their own quality, nor do they have the means to carry out the most critical quality work in spine surgery – improving outcomes for patients.

The problem with case mix adjustment is that all variables included in the model must have valid values. Each drop in each variable reduces the calculation base, so that adjusted values can be worse than unadjusted if the drop is large.

Completeness

The coverage rate is calculated annually by the National Board of Health and Welfare's Register Service. Below, data from 2015 is presented. The benchmark is set at 85%, the level of completeness that SKR (Swedish Association of Local Authorities and Regions) requires as a minimum for the registry to achieve Certification Level 1, which provides the highest level of financial funding. In 2021, Swespine was just above this benchmark, at 86%. All clinics that fall below this level lower the average and jeopardize the registry's funding.

Fig. 316 shows 10 clinics that had a completeness rate below 80% in 2015. Several clinics have improved, but 6 of them still have an unacceptably low completeness rate.

Fig. 317 displays the clinics that had a completeness rate above 80% in 2015. Six clinics have notably declined in their completeness rate in the most recent calculation in 2021.

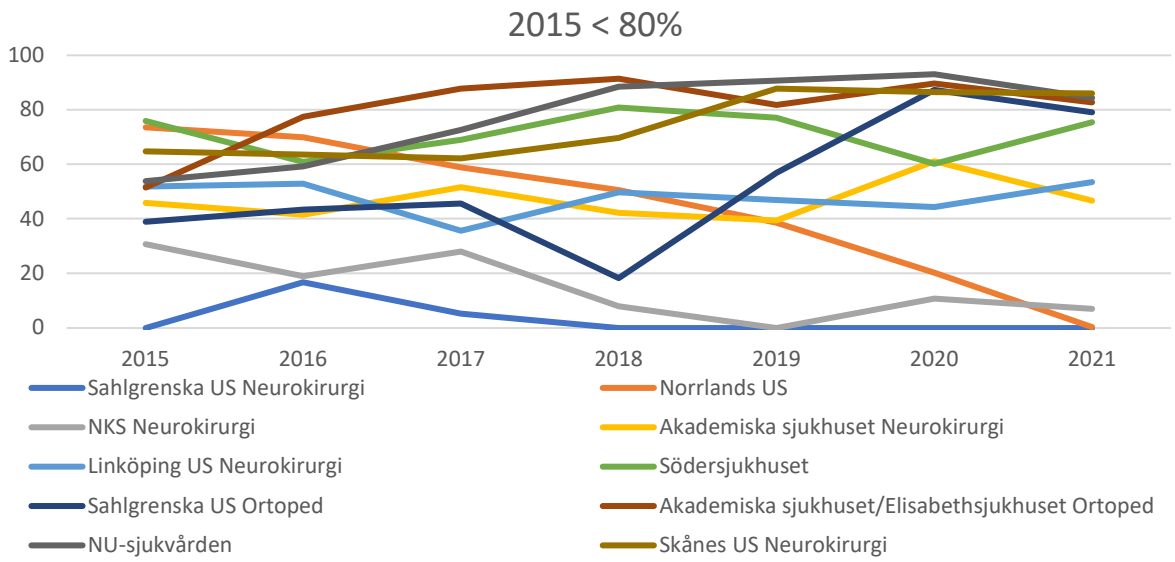


Fig. 315

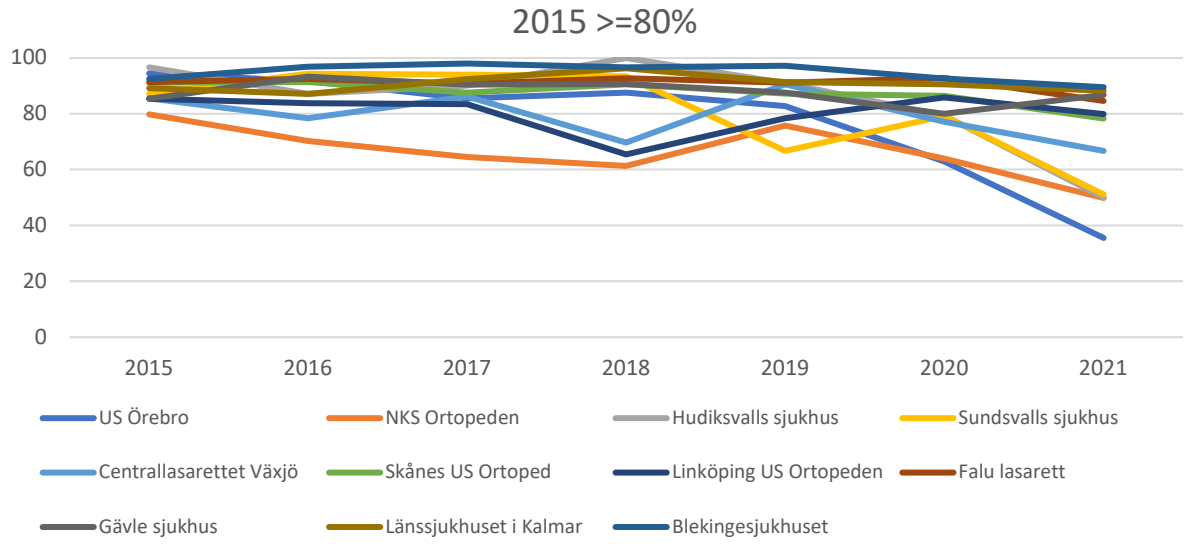


Fig. 316

Registration of Basic Forms

Loss of basic forms reduces the base for calculating outcomes using measures that assess the difference between preoperative and follow-up, i.e., ODI, NDI, EQ5D, NRS, P-mJOA, and SRS-22. Figure 317 shows that university clinics are performing the worst. County hospitals and private clinics are quite similar. In general, there are opportunities for almost every clinic to increase their registration of basic data.

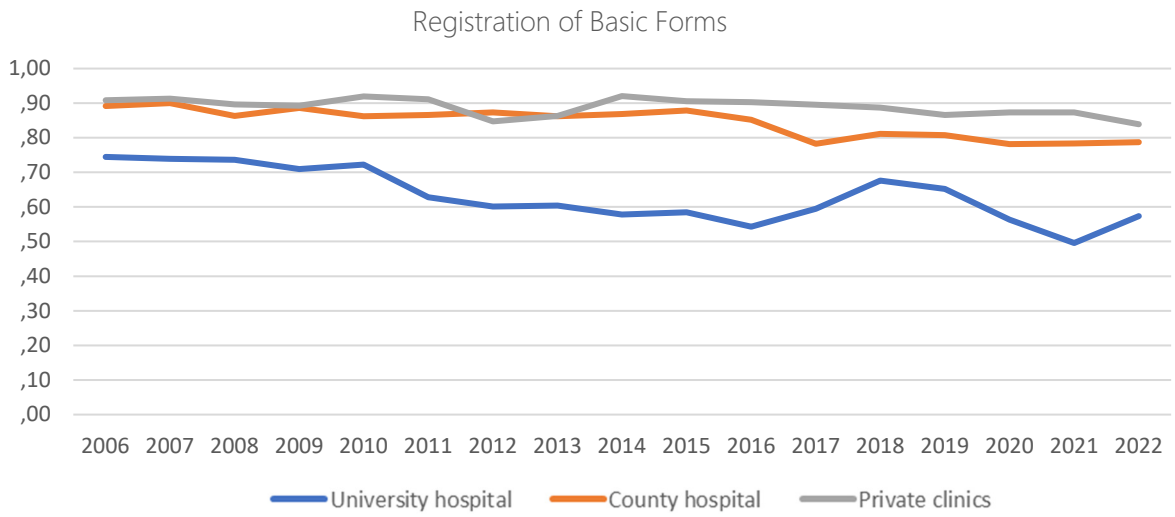


Fig. 317

Follow-Up Frequency

Similar trends are observed among county hospitals and private clinics over time. University hospitals followed this pattern until 2017. After that an unexplaned drop (Figure 318). It seems that the decline affected all university hospitals, but there are also indications of a general improvement.

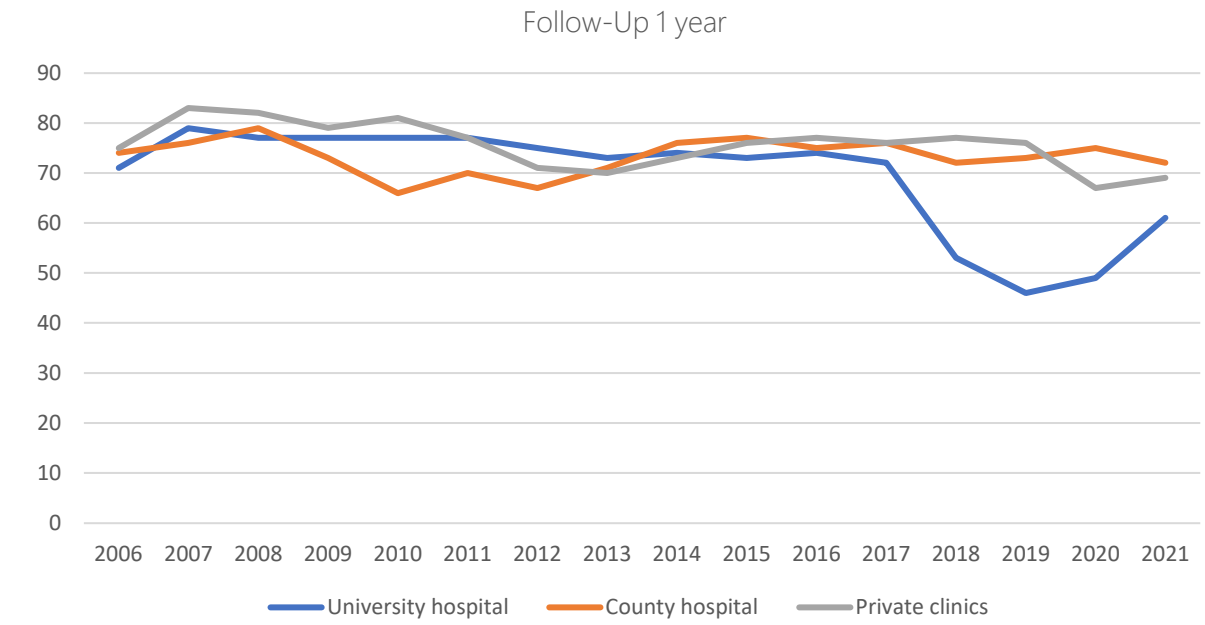


Fig. 318

When comparing the follow-up frequencies of clinics using the registry office with clinics managing follow-ups themselves (others), there are no significant differences noted (Figure 319). There is a worrying trend of decreasing frequencies in follow-ups via the registry office. This coincides temporally with the introduction of digital invitations for patients to self-report follow-up data online. Only after a reminder by mail do patients receive paper forms with response envelopes. This issue requires evaluation and corrective action.

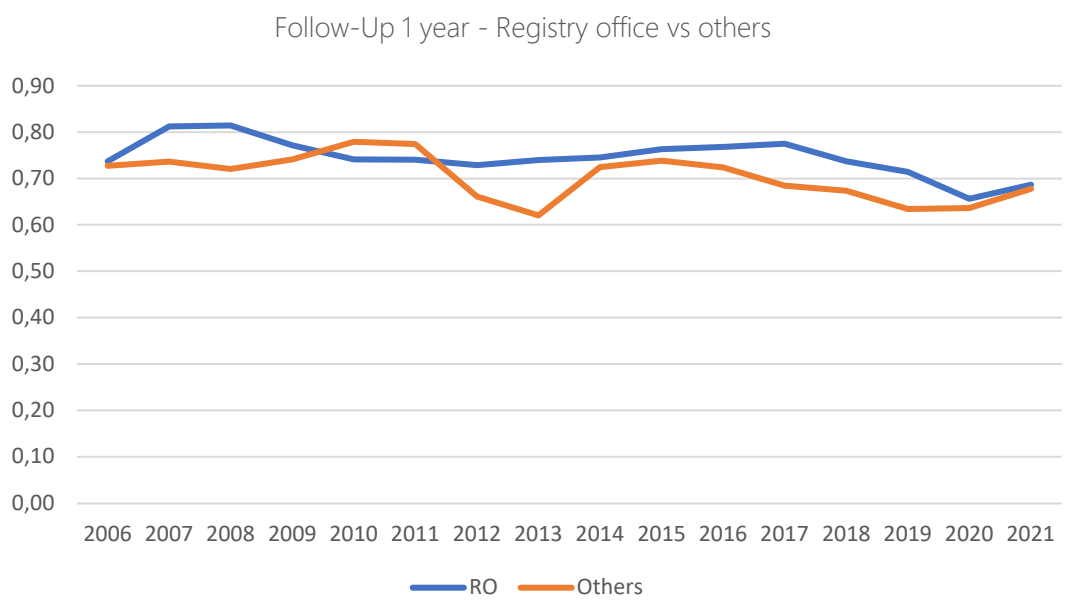


Fig. 319

Comment:

Improvement of outcome of surgery is the most important effort of Swespine. The quality of data deteriorates when there is substantial data loss, resulting in uncertain data interpretation. The financial stability is jeopardized if the completeness falls below the current level. It is within the purview of individual clinics to address this issue. Practical methods and workflows within individual clinics can facilitate data registration without overburdening surgeons or secretaries. An important project for the steering committee in the coming years is to aggregate and disseminate this knowledge. An initial step involves each surgeon digitally entering operation data directly into the registry during the surgical procedure.

Funnel plots Central spinal stenosis

Translation of the clinic abbreviations in the diagrams can be found on page 109.

1. Success Follow-Up 1 year

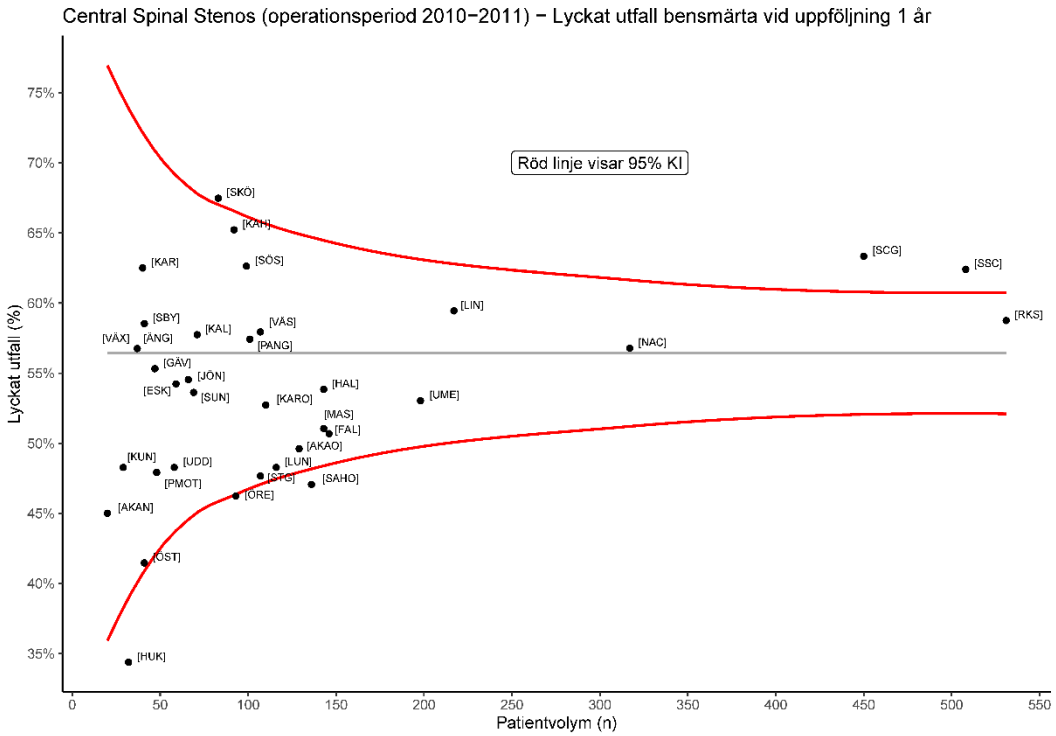


Fig.320

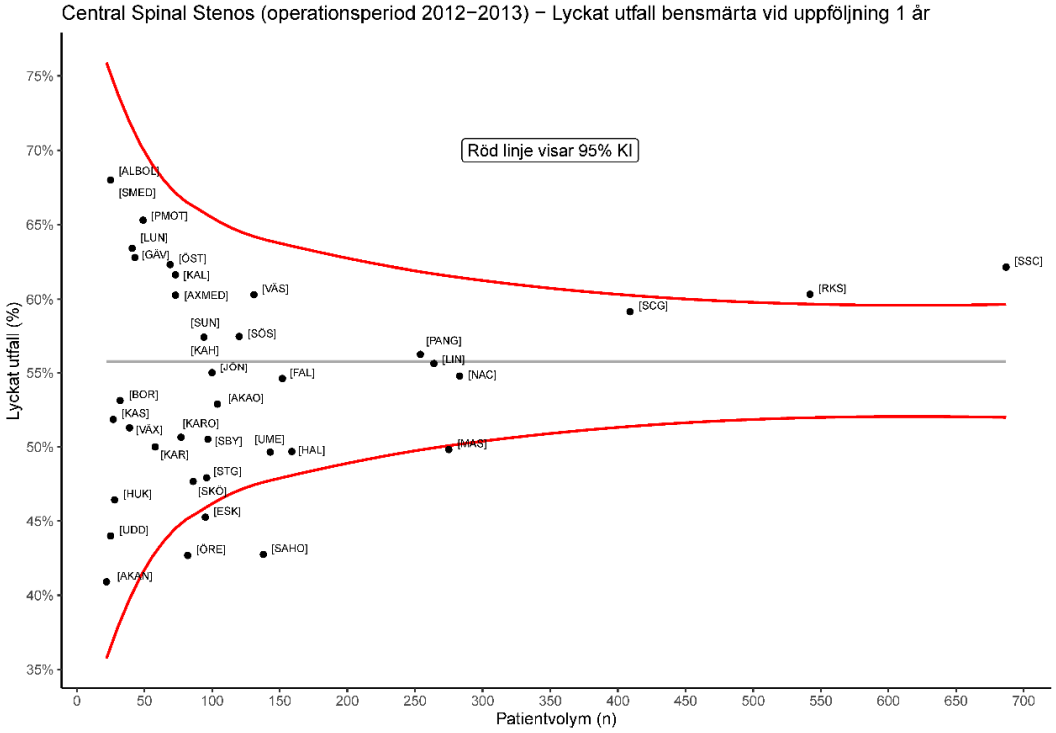


Fig. 321

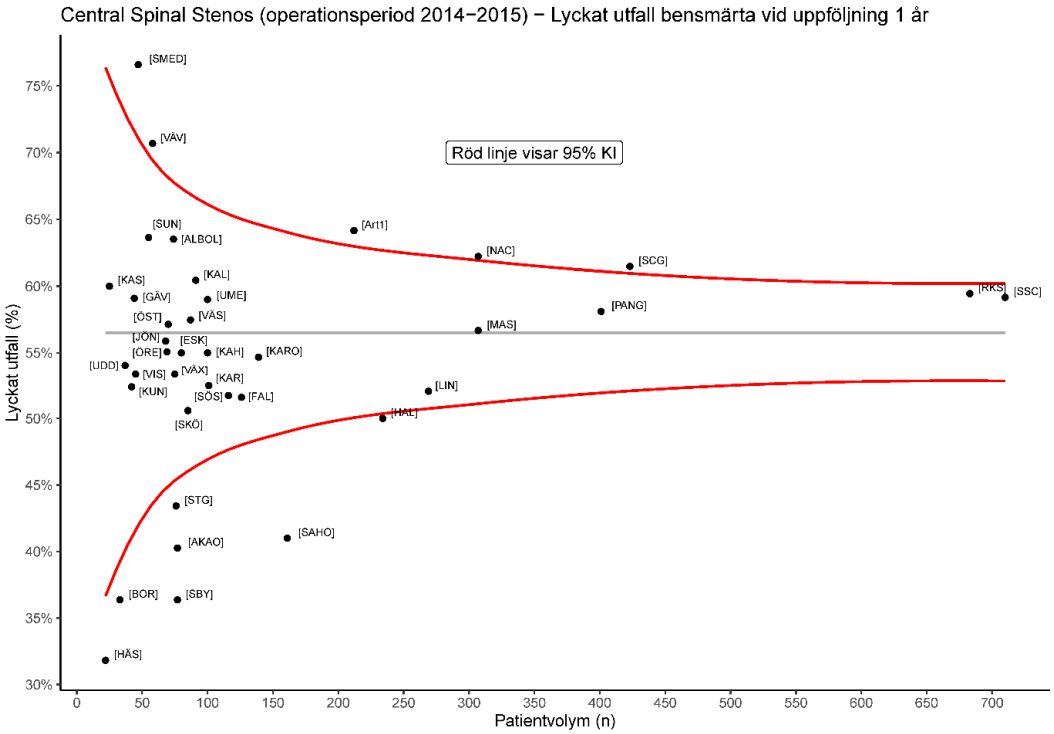


Fig. 322

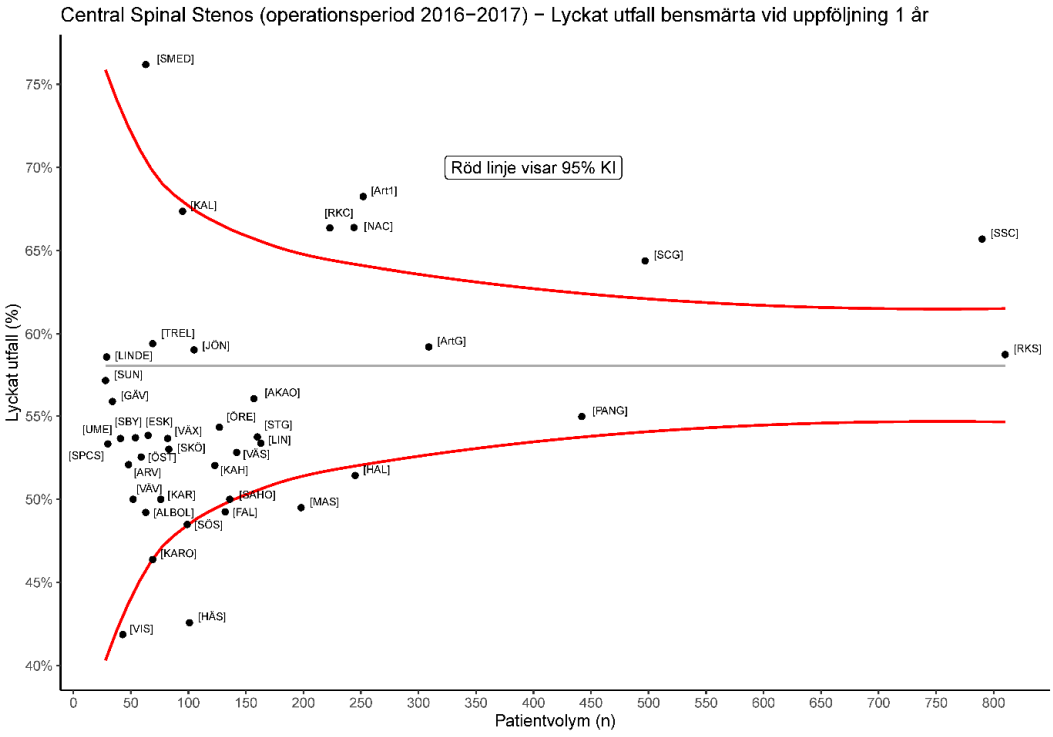


Fig. 323

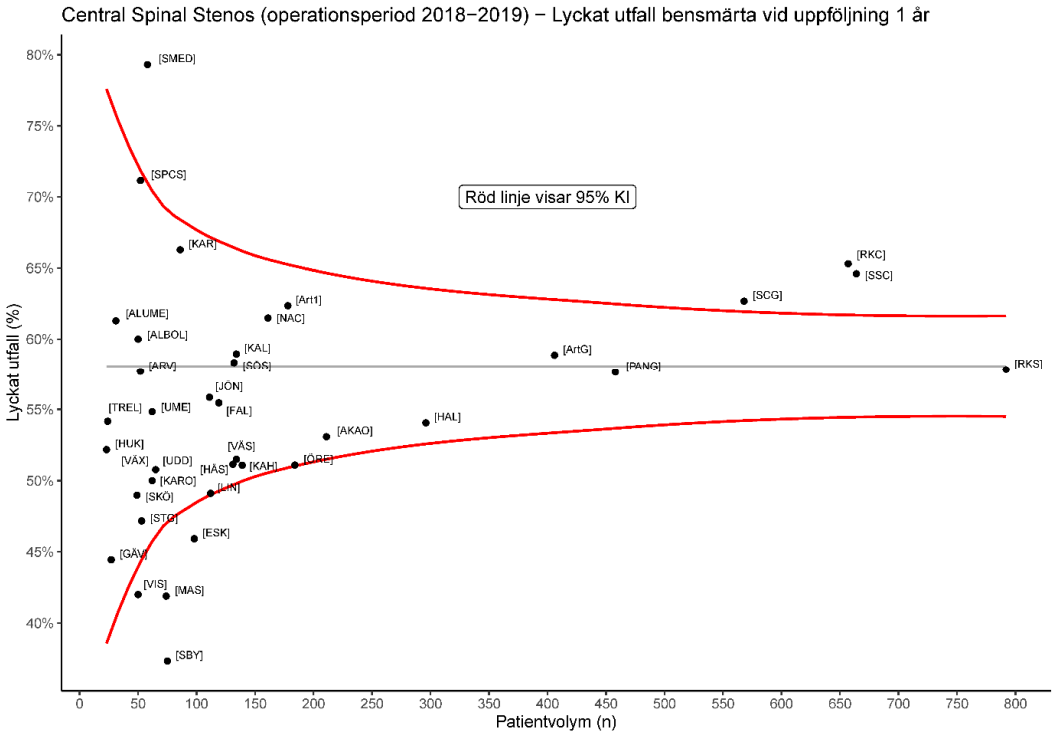


Fig. 324

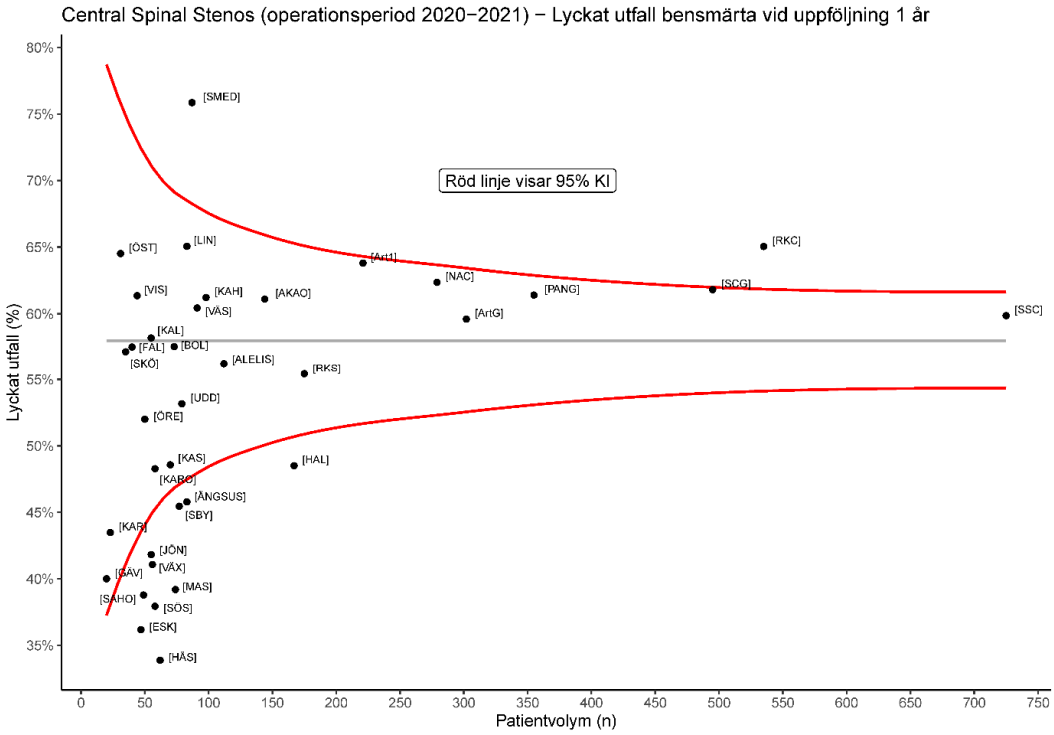


Fig. 325

2. Satisfaction Follow-Up 1 year

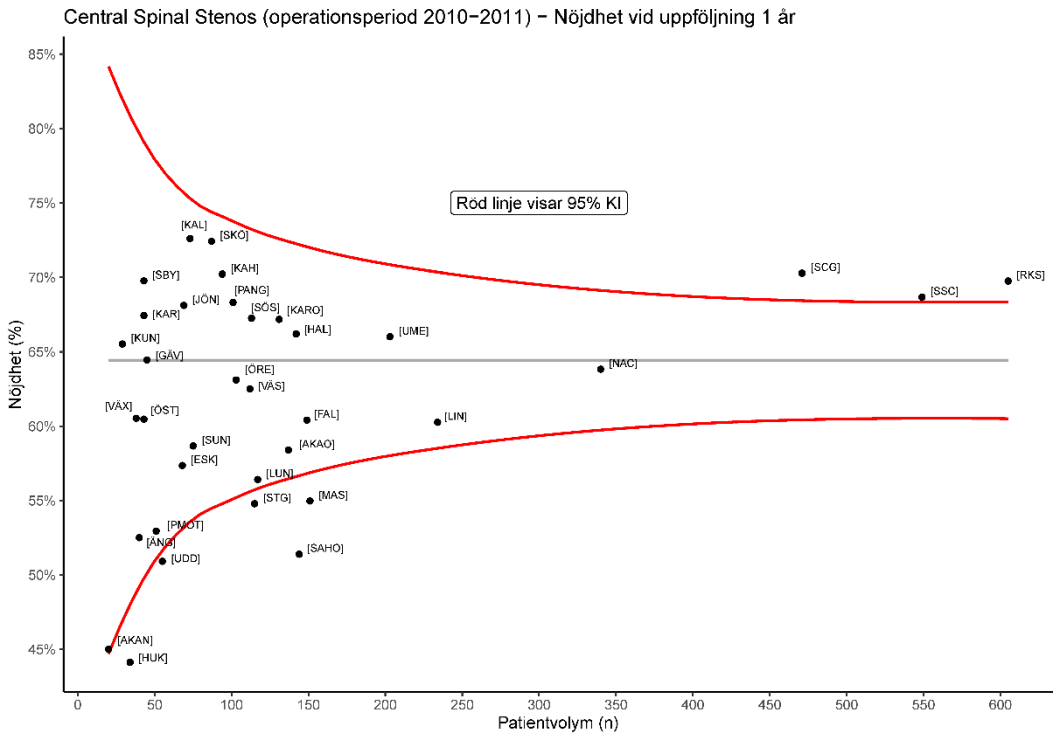


Fig. 326

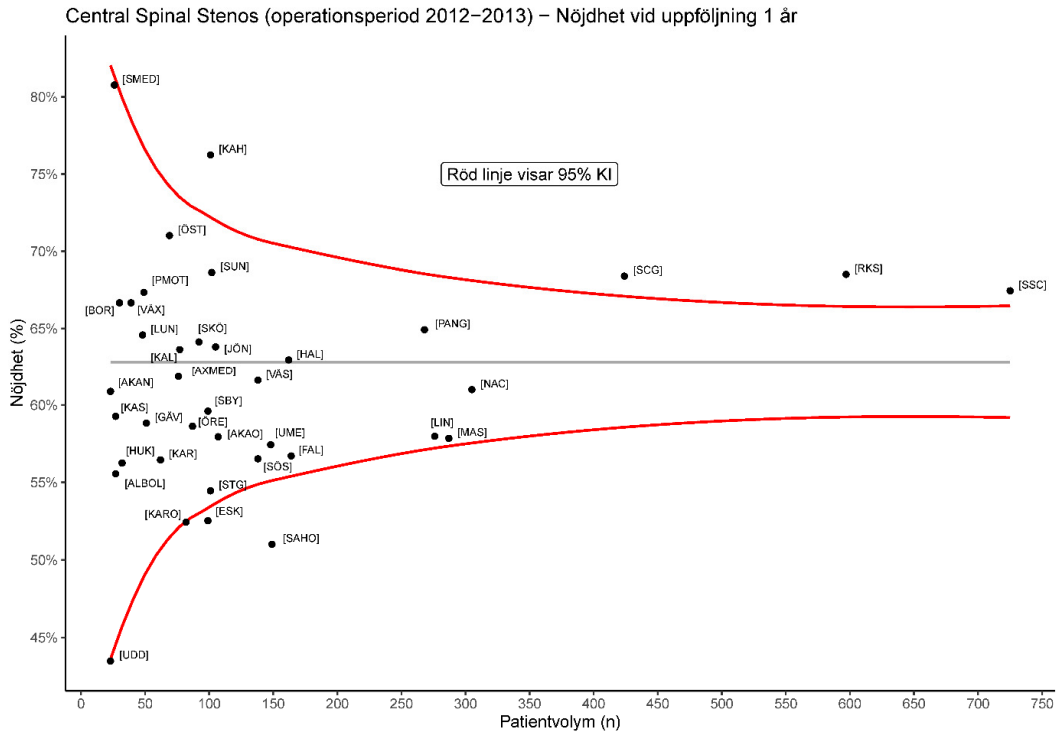


Fig. 327

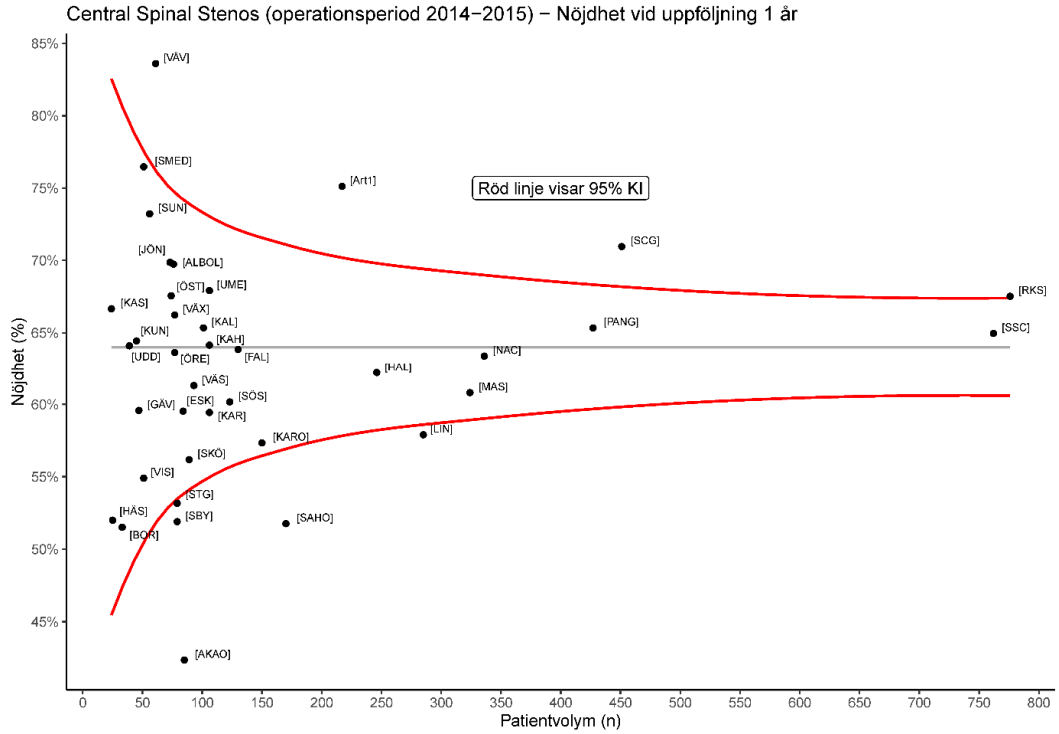
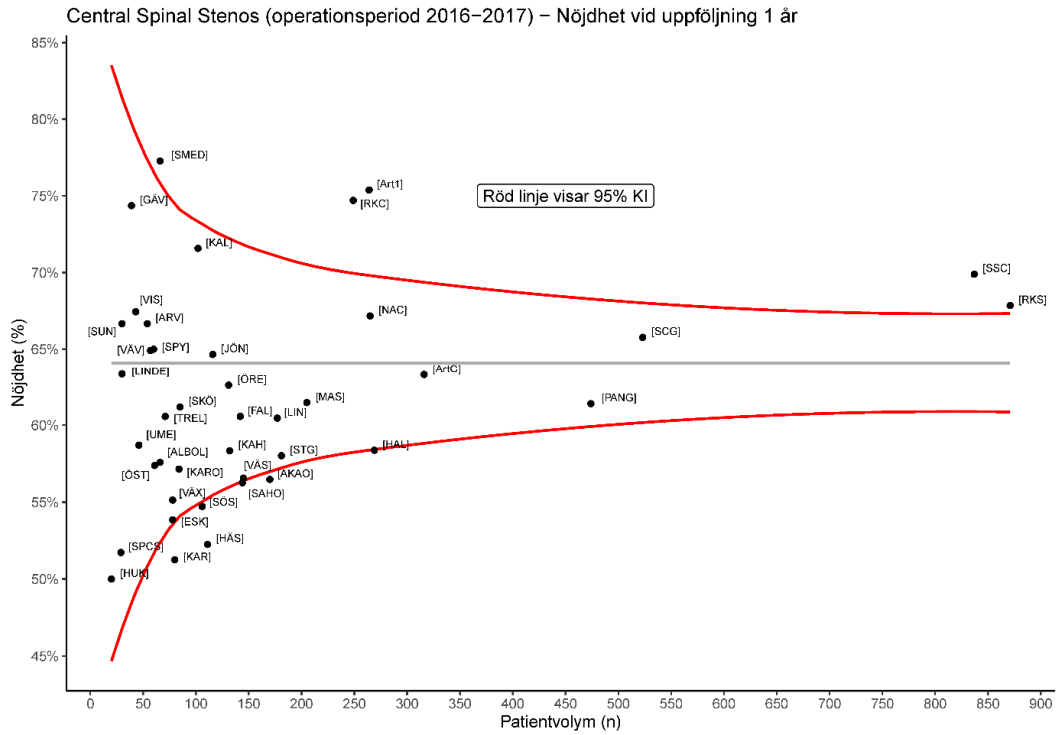


Fig. 328



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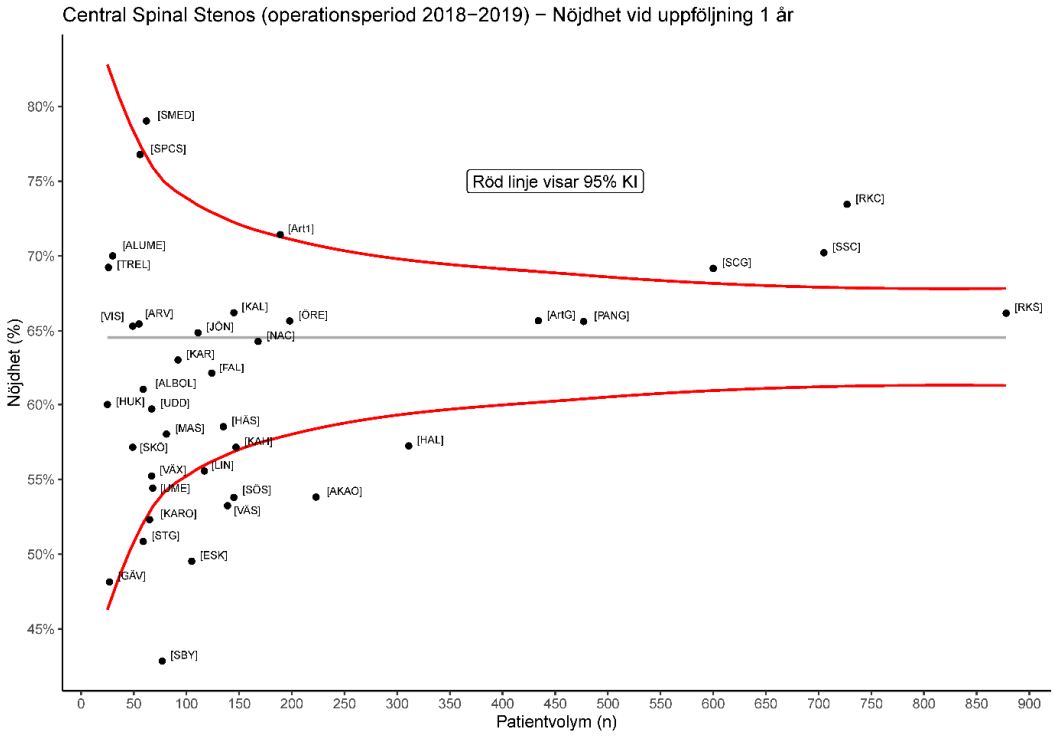

Fig. 330

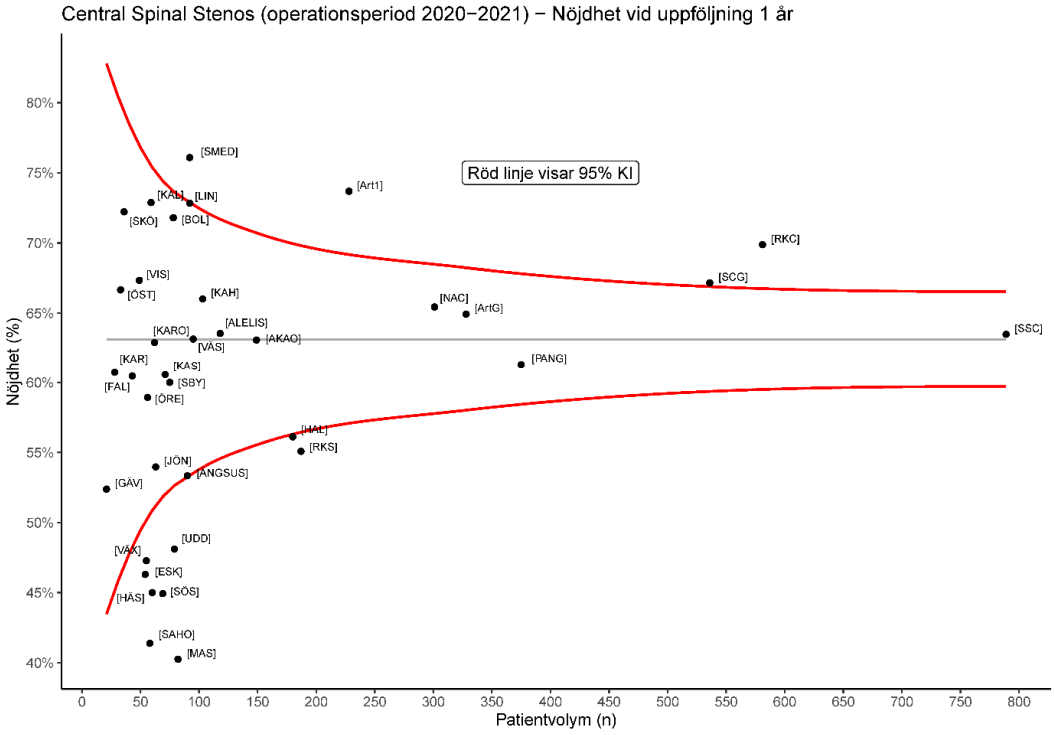

Fig. 331

Abbreviation of hospital name

Abbr.	Hospital name
AKAN	Akademiska Sjukhuset Uppsala (Neuro)
AKAO	Akademiska Sjukhuset Uppsala (Orto)
ALBOL	Bollnäs Sjukhus Aleris AB Sjukvård
ALELIS	Aleris Elisabethsjukhuset
ALMALM	Aleris Malmö Arena
ALUME	Aleris Specialistvård Umeå
Art1	Art Clinic Jönköping
ArtG	Art Clinic Göteborg
ARV	Arvika Sjukhus
AXMED	Axess Medica
BOL	Bollnäs Sjukhus
BOR	Borås sjukhus
CAR	Carlanderska Sjukhemmet
DAN	Danderyd sjukhus
EKS	Höglandssjukhuset Eksjö
ELI	Axess Elisabethsjukhuset AB
ESK	Mälarsjukhuset Eskilstuna
FAL	Falu lasarett
GÄV	Gävle sjukhus
HAL	Hallands sjukhus Halmstad
HEL	Helsingborg lasarett
HUD	KS Huddinge
HUK	Hudiksvall sjukhus
HÄS	Hässleholm sjukhus
JÖN	Länssjukhuset Ryhov Jönköping
KAH	Blekingesjukhuset Karlshamn
KAL	Länssjukhuset Kalmar
KAR	Centralsjukhuset Karlstad
KARN	Karolinska Universitetssjukhuset (Neuro)
KARO	Karolinska Universitetssjukhuset (Orto)
KAS	Karlskoga lasarett
KUN	Kungälvs sjukhus
LIN	Universitetssjukhuset i Linköping (Orto)
LINDE	Lindesberg lasarett
LINN	Universitetssjukhuset i Linköping (Neuro)
LUN	Skånes Universitetssjukhus Lunds
LUNN	Skånes Universitetssjukhus Neurokirurgen
MAS	Skånes Universitetssjukhus Malmö

Abbr.	Hospital name
MOT	Motala lasarett
NAC	Aleris Specialistvård Nacka Närsjukhus
NOR	Vrinnevisjukhuset Norrköping
NÄL	Norra Älvsborgs sjukhus
OSCS	Ortho & Spine Center Skåne
OSK	Oskarshamn sjukhus
PANG	Aleris specialistvård Ängelholm
PMOT	Aleris Specialistvård i Motala AB
RKC	Ryggkirurgiskt Centrum Stockholm AB
RKS	Ryggkirurgiska Kliniken Strängnäs
SAB	Sabbatsberg Närsjukhuset
SAHO	SU/Sahlgrenska (Orto)
SBY	Sunderby Sjukhus
SCG	Capio Spine Center Göteborg
SIM	Simrishamn sjukhus
SKE	SÄS Skene
SKÖ	Skövde KSS Ortopedi
SMED	SportsMed
SOP	Sophiahemmet
SPCS	Specialistcenter Scandinavia
SSC	Capio Spine Center Stockholm
STG	Capio S:t Göran
SUN	Sundsvall sjukhus
SÖS	Södersjukhuset SÖS
TREL	Trelleborg lasarett
UDD	Uddevalla sjukhus
UME	Norrlands Universitetssjukhus Umeå
VAR	Hallands sjukhus Varberg
VIS	Visby lasarett
VÄS	Västmanlands sjukhus Västerås
VÄV	Västerviks sjukhus
VÄX	Centrallasarettet Växjö
YST	Ystad lasarett
ÄNG	Ängelholm sjukhus
ÄNGSUS	Skånes Universitetssjukhus Ängelholm
ÖRE	Örebro Universitetssjukhus
ÖST	Östersunds sjukhus

Published articles based on Swespine-data

Total number of articles based in whole or in part on Swespine published in 2022 n=19, in bold at the end of the table. There are additional studies accepted for publication.

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