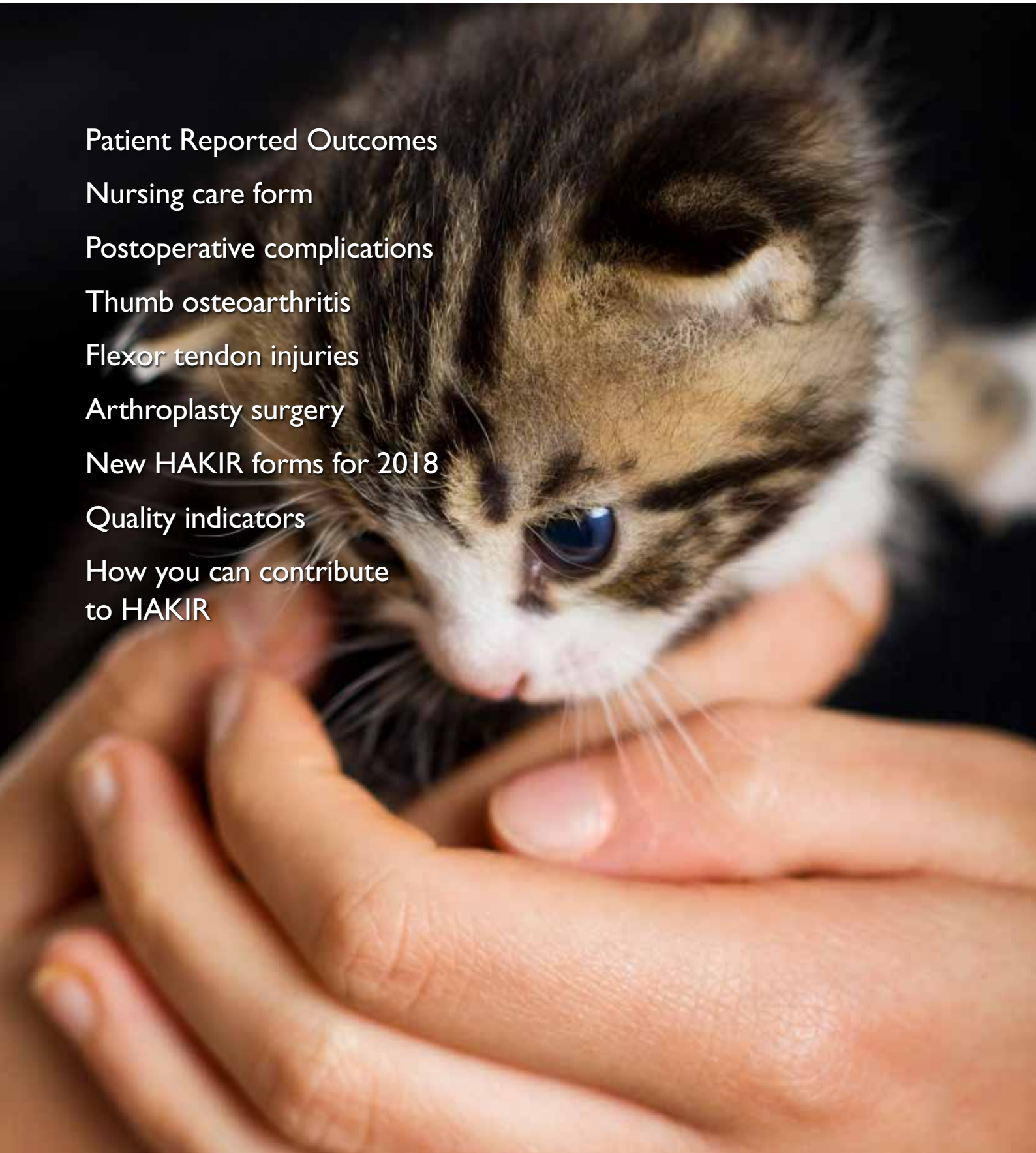
Annual Report 2018

HAKIR
HANDKIRURGISKT
KVALITETSREGISTER



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National Quality Registry for Hand Surgery

WHAT IS HAKIR AND WHAT DO WE WANT TO ACHIEVE?

HAKIR is a national quality registry for hand surgery that was started in 2010 on the initiative of the Swedish Society for Surgery of the Hand. Our main objectives are to enable improvement work and research that gradually improves healthcare, for example by reducing avoidable complications and reoperations, through individual-based monitoring of healthcare interventions and treatment results. An important aim is also to increase patients' participation in the care they receive. Through increased national and interprofessional cooperation, we also want to promote a uniform standard of quality hand surgery for everyone in our country.

HOW CAN WE ACHIEVE THIS?

Through a broad national cooperation, we shall endeavour to create registry routines that are as work saving as possible. Our long-term goal is to integrate the registry work into clinical practice. We shall continuously monitor and improve validity and reliability and ensure that data is complete. We shall create user-friendly models for the continuous feedback of register data to both patients and to healthcare providers so that this data can be used, for example, in improvement work and as a basis for national guidelines.

Introduction

The annual report for 2018 includes data that has been registered in HAKIR from its inception on 1 February 2010 up to and including 31 December 2018, unless indicated otherwise. The annual report is not a scientific analysis, and reported differences in results between methods and clinics must be interpreted with caution. In many cases, we have not yet collected enough data to rule out with any certainty the possibility that differences may be random in nature. There may also be incorrect registry entries that can affect the results. The purpose of the annual report is to arouse interest in our treatment results within the field of hand surgery in Sweden, and to stimulate a gradual improvement of care. By continuing with the long-term monitoring of quality in HAKIR and ensuring that the data entered in the register is accurate and complete, we will, over time, be able to learn a lot about which treatments work best for our patients.

REGISTERED OPERATIONS

At year-end 2018, 103,493 operations on 65,535 patients had been registered in HAKIR. In this year's report, we have excluded patients recorded in the registry but who have not yet undergone surgery. The participating units were the same nine as last year; the seven specialist clinics and two private units. The distribution of operations between the clinics in the period 2010 - 2018 is shown in Figure 1 and Table 1. It seems that a stable number of operations per year at most units are now being registered. One exception is the specialist clinic at Sahlgrenska Hospital in Gothenburg, and this is because the head of the hand department in September 2018 announced that they wish to "take a break" from HAKIR. Data is therefore missing for between October and December of 2018. We have hopes that the Gothenburg clinic will re-join in the autumn of 2019; more information about this below. The number of operations per year also varies in Örebro, where the coverage rate is still not complete, see below. In Stockholm, the number of operations performed has declined since 2015, probably due to carpal tunnel release, trigger fingers, etc. – being instead performed by private care providers. In Uppsala, we have seen some decline in the number of operations since 2017.

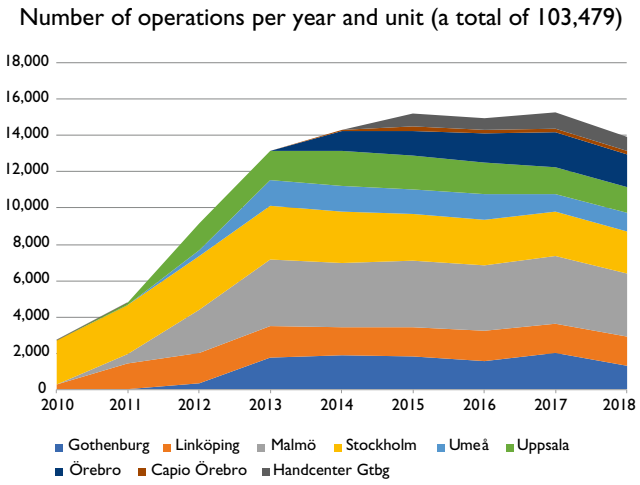


Figure 1. *Number of operations registered per year at the units. 13,917 operations were added during 2018.*

COVERAGE RATE

Coverage rate is a term that can be defined in different ways. Here it refers to the number of registered operations divided by the number of operations performed per unit (%). The latter data is retrieved from the respective unit's production statistics and is registered monthly by the local coordinators. We have a target of at least 80%. Some patients who have undergone surgery do not have a Swedish civic registration number, have a protected identity or have declined participation, which is why the target cannot be 100%. The coverage rate according to this definition is provided in Table 2. We post open data on the coverage rate for all units on the website, and since September 2018 also as a quality indicator on www.vardenisiffror.se (Healthcare in Numbers). Four units did not reach the target of 80% in 2018; the hospital clinics in Gothenburg, Umeå and Örebro as well as HandCenter Gothenburg. The average value for all units in 2018 was 81.5%, a slight drop compared to 2017.

Hospital clinics	2010	2011	2012	2013	2014	2015	2016	2017	2018	Total
Gothenburg	0	2	323	1779	1885	1816	1606	1997	1299	**10,707**
Linköping	283	1,459	1,674	1,715	1,567	1,622	1,645	1,616	1,607	**13,188**
Malmö	1	509	2,432	3,681	3,507	3,656	3,604	3,718	3,505	**24,613**
Stockholm	2,443	2,700	2,913	2,971	2,839	2,590	2,494	2,453	2,280	**23,683**
Umeå	1	0	331	1,372	1,394	1,333	1,429	1,011	1,038	**7,909**
Uppsala	13	141	1,495	1,635	1,956	1,878	1,721	1,439	1,453	**11,731**
Örebro	1	2	3	1	1,078	1,377	1,602	1,950	1,747	**7,761**
Private units										
Örebro Capio			**1**	**2**	81	246	239	167	203	**939**
Gothenburg Hand Center			**1**	**8**	7	662	594	891	785	**2,948**
Totalt	**2,742**	**4,813**	**9,173**	**13,164**	**14,314**	**15,180**	**14,934**	**15,242**	**13,917**	**103,479**

Table 1. Number of registered operations per year and unit.

Hospital clinics	Registered op in 2018	Performed op in 2018	Coverage rate 2018(%)
Gothenburg	1,299	1,700	76.4
Linköping	1,609	1,765	91.2
Malmö	3,505	3,806	92.1
Stockholm	2,280	2,581	88.3
Umeå	1,038	1,670	62.2
Uppsala	1,453	1,529	95.0
Örebro	1,747	2,592	67.4
Privata enheter			
Capio Örebro	159	183	86.9
Gothenburg Hand Center	785	1,190	66.0
Totalt	**13,875**	**17,016**	**81.5**

Table 2. Coverage rate in HAKIR, i.e. the number of registered operations / number of operations performed(%). For Capio Örebro, there was no information on operations performed for 4 months in 2018, which is why these months (42 registered operations) were excluded from the coverage rate calculation.

IMPROVEMENT ASPECTS - COVERAGE RATE

The coverage rate declined slightly in 2018. The same clinics as before seem to have trouble registering all their operations. To be able to use data for evaluation and for the credibility of the registry itself, it is important that all operations are included. By coming together and discussing registration routines, we may be able to learn from each other. Difficulties mentioned are that operating personnel belong to another organisational unit, for example, a central operating unit, and that there is no time allocated for working with quality monitoring. In the spring of 2019, HAKIR therefore announced the opportunity to receive funding for improvement projects pertaining to registry logistics. Three clinics conducted projects of this nature, but unfortunately not any of the four units with a low coverage rate. For the registry's part, we will not be dropping the issue but will instead contact the respective heads of departments to try to provide support for improvement. We now have coverage rate as an open quality indicator on www.vardenisiffror.se (Healthcare in Numbers) and we hope that this can yield a positive effect. The coverage rate in HAKIR is based on those patients who have a Swedish civic registration number, but quite a few of those who have undergone surgery only have a so-called reserve number, which is why we have not set a target of 100%. Going forward, we should find a way to exclude these patients from the statistics. One way is for the coordinators to produce monthly figures for people who do not have a Swedish civic registration number and who have undergone surgery. We could then have a target of 100% that is more accurate and easier to explain. This will be discussed at upcoming HAKIR meetings.

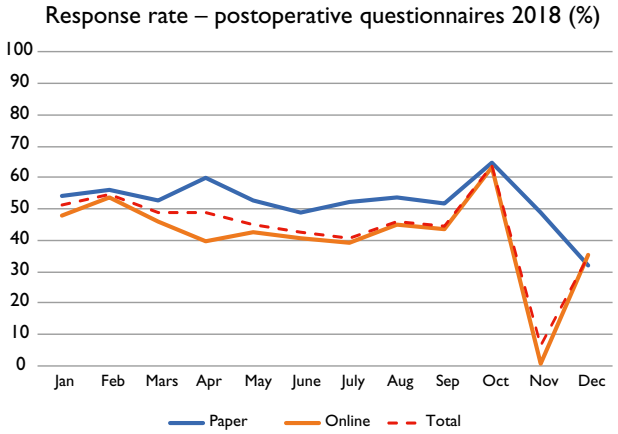


Figure 2. Response rate for postoperative questionnaires in 2018. A technical error resulted in very few online questionnaires being sent out in November, see the text. This also affected the response rate in December. Paper questionnaires make up about 30%.

RESPONSE RATE

Response rate for questionnaires is another measure of coverage rate. We also have open data reporting for this measure on the website.

Unfortunately there was an error in sending out the online questionnaires in November 2018 due to the switching of web hotels from Surftown to UnoEuro, this was not something which we requested ourselves and could therefore not anticipate the problem in time. Therefore, in November, only 20 questionnaires were sent out, compared to the normal distribution of at least ten times as many. The response rate per month is shown in figure 2. For this reason we are not including November in the response rate statistics. This means that the response rate for questionnaires distributed 3 and 12 months after surgery in 2018 will be 47.3%, which is slightly lower than for 2017.

AGE AND GENDER DISTRIBUTION

The mean age of patients registered in HAKIR was 52.0 (age range 0-107), 54.1 for women and 50.1 for men. Within specialised hand surgery, patients range from new- borns to 100-year-olds. The proportion of men was slightly higher than women (51.7%). It can be noted that male patients are predominant in the categories of children and young adults, while female patients are more common between the ages of 50 and 70 (see Figure 3). The gender distribution also varied between the clinics; male patients were more common in Stockholm (54.5%) and at HandCenter Gothenburg (55.1%), but they accounted for less than half in Örebro (42.7%), Capio Örebro (48.1%) and Umeå (48.3%). These differences are probably related to both case-mix and coverage rate.

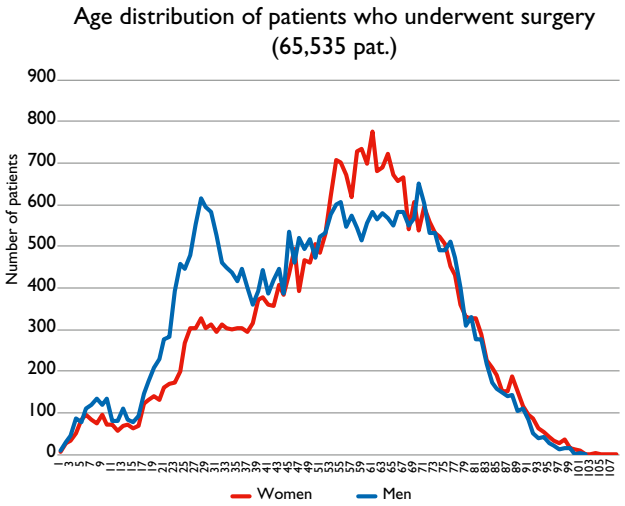


Figure 3. Age and gender distribution in HAKIR for patients who underwent surgery.

IMPROVEMENT ASPECTS - RESPONSE RATE

In order to be able to make individual comparisons of results before and after surgery, we need complete preoperative questionnaire responses. All staff at the clinics can help inform patients about the purpose of HAKIR and the importance of communicating their viewpoints. We can likely also improve the text and appearance of e-mail and text messages, but the requirements of GDPR(General Data Protection Regulation), for example, have prevented us from clearly printing the registry as a sender. Through our future mailings being sent via 1177, we will get around these problems, but we may risk that many patients will instead find it too complicated to log in using BankID. In comparison with other quality registries, and with many online surveys in private enterprises, we nevertheless have a good response rate – 50% is usually considered totally acceptable. We need to conduct a more detailed analysis of the group of patients who did not respond to the questionnaire to find out if the non-completion is systematic or random. Have they not responded because they are dissatisfied or because they are satisfied, or simply because they have not had the time or have not felt like it?

TYPES OF OPERATION

From the inception of HAKIR and up until 31 December 2018, 13,487 reoperations had been registered involving 10,284 patients. This means that 13% of operations performed in HAKIR were reoperations. The number of reoperations per patient varied between 1 and 23. 30% of patients had undergone surgery only once. The proportion of men was slightly higher among patients having reoperations (57.9% compared to 51.7% across the material). In addition, men who had underdone reoperation were on average younger than the women (45.3 compared to 50.2), a slightly greater age difference than for all patients operated on. This is most likely due to various case-mixes, where the younger men have a higher proportion of hand injuries, which may require reoperations, e.g. for removal of osteosynthesis material.

As in several previous annual reports, we can still see major differences in how reoperations are registered at the various clinics. Very few reoperations are registered in Umeå (71 reoperations; 0.9%) and Örebro (67 reoperations; 0.9%), which cannot be explained solely by differences in case-mix. From HAKIR's side, we have pointed out the problem for several years without any improvement being made. We will address it again at the Swedish Society for Surgery of the Hand's annual meeting and through re-initiated contact with the respective heads of department. They should personally be interested in being able to monitor reoperations and postoperative complications. At other clinics, the reoperation rate varied between approximately 9% (Malmö and Hand-Center Gothenburg) and 21.8% (Stockholm).

However, it must be pointed out that a high proportion of surgeries does not necessarily indicate poor quality of care. Patients with severe hand injuries and infections may need multiple surgical procedures to regain the best possible hand function. Of course, in clinics with extensive operations involving prosthetic implant surgery, more complications of this kind occur compared with units that do not use joint prostheses, and if many fracture surgeries are performed, many reoperations may be required for the removal of osteosynthesis material. The incidence of reoperations must be weighed against treatment outcomes, both in terms of function and how the patient perceives the results. In the future, we will be able to perform such analyses on HAKIR data, provided that accurate registration takes place.

The causes of reoperation also varied greatly between the units; see the further analysis in the section "Postoperative complications", page 20.

IMPROVEMENT ASPECTS - REOPERATIONS

If HAKIR is to be of real benefit as an indicator of the quality of care, we must be able to trust that data is being registered correctly, and reoperations are particularly important to monitor. Prior to the establishment of HAKIR, there was, for example, no national monitoring of joint arthroplasties, as orthopedics have had since the 1970s. Although results have been followed up at various clinics and in research projects, open reports of national data have been lacking. Many different joint implants have been used without evidence being compiled on how they work in the long term. Patients in different parts of the country have had varying degrees of treatment for osteoarthritis/arthritis, depending on the local treatment tradition.

If HAKIR is used as intended, we can identify joint implants that do not work optimally at an early stage and avoid these from being used. We can learn from each other's experience and offer uniform care across the country. Even in other types of operation, such as tendon surgery, nerve decompression and fracture surgery, we also need to monitor complications and reoperations. Furthermore, we need to monitor the incidence of severe postoperative infections, something which is currently rare but may cause major problems for patients.

In 2019, we will include pop-ups in the registry that appear if the same patient is registered for a new operation, to remind them to register reoperations correctly. HAKIR also hopes to get help to more effectively reach out to healthcare professionals and managers through the new knowledge management organisation being introduced in Sweden 2019.

Definition of a reoperation according to HAKIR
A new operation in the **same hand** for the **same diagnosis** or a reoperation due to a **postoperative problem** (complication) after a primary procedure, regardless of at which unit the primary procedure has been performed. If the patient undergoes reoperation on the other hand or for another diagnosis in the same hand, this is not counted as a reoperation. An example may be a patient who first undergoes surgery for carpal tunnel syndrome and then for trigger finger, or first in one hand and then in the other. However, the top priority is to always register postoperative complications, e.g. postoperative infections, tendon ruptures or secondary dislocation in fractures. Choose from the list of available options and avoid free text, as it is difficult to analyse. Sometimes a reoperation may be planned, for example, a multiple-stage operation or the removal of osteosynthesis material, and there are separate response options for this. Recurrence is expected in the case of Dupuytren's contracture, and for this diagnosis there is therefore a separate answer option for reoperation.

CASE-MIX

An analysis of main diagnoses for performed operations gives a rough picture of the case-mix at the various units. Figure 4 shows that the proportion of trauma diagnoses is about 50% in Stockholm and Uppsala but only 30% in Malmö, Umeå and Örebro, where you have a higher number of nerve entrapments and tendon sheath affections. In Örebro, trauma diagnoses accounted for only 17% of registered surgeries, but this may also be due to an insufficient coverage rate, see above. Note that acute infections are not included in Figure 4.

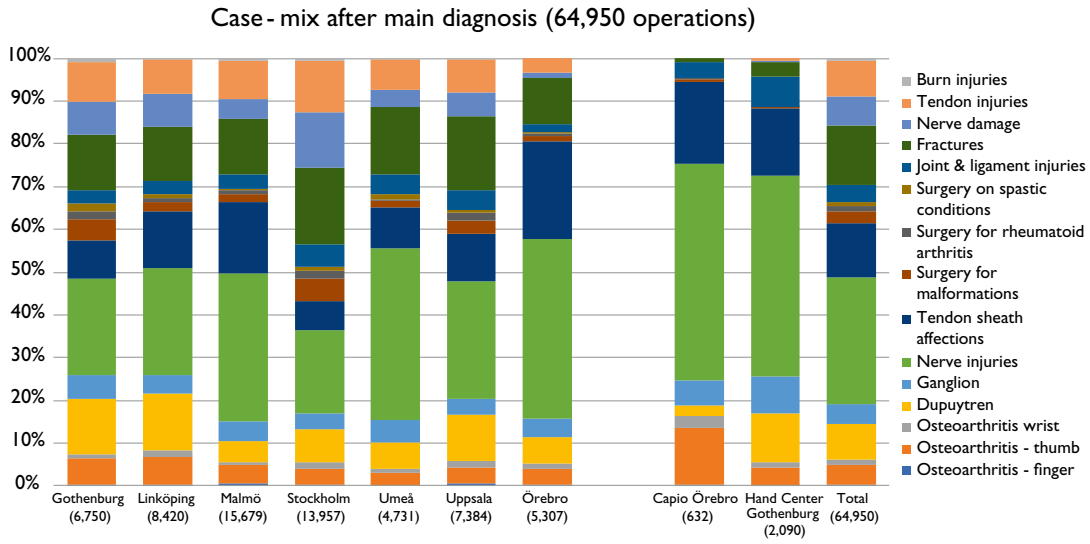


Figure 4. Distribution of main diagnoses for hand operations at the various units. 38,448 surgeries were not classified, including infections. This proportion was approximately 35-40% for all units, slightly lower for the private sector.

Patient Reported Outcomes

In this section of the annual report, we have in previous years described patient-reported outcomes for some of the most common diagnoses within hand surgery. This year, we are focusing a little more on things we know less about, but where we are starting to gather considerable data. The purpose is to spark questions regarding our treatment results and how we can improve them. In total, 70,266 questionnaire responses had been collected since the start of HAKIR, 28,238 before surgery, 22,626 questionnaires 3 months after surgery and 19,402 responses 12 months after surgery. Patients who completed the preoperative questionnaire but have not undergone surgery are not included in these figures.

ABOUT PROM AND PREM IN HAKIR

Since its inception in 2010, HAKIR has included patient-reported outcomes from surgery, so-called PROM (Patient Reported Outcome Measure) and PREM (Patient Reported Experience Measure) for all adult patients. PROM can be described as "What was the result?" and PREM with " How was the experience?" Our PROM questions consist of two parts. HQ-8 is our self-developed questionnaire consisting of eight questions about different hand-related symptoms and perceived disabilities in everyday activities graded on a scale of 0 - 100. A study of psychometric aspects for HQ-8 is under publication, see below. The eight questions in HQ-8 are thus not added together to get a total score, but rather assessed individually to be able to reflect different symptom patterns in different diagnoses. The other questionnaire is Quick DASH (Disabilities of the Arm, Shoulder and Hand), which is a validated survey with 11 questions that are added together to get a total score of 0-100, where 100 indicates maximum perceived disability. The questions concern both symptoms and activity restrictions and do not take into account which hand is dominant or choice of hand for performing activities. HAKIR currently also includes two PREM questions, one that relates to perceived results of the operation and one that relates to experience of the general care during the treatment period. Read more about the PREM questions further on in this section.

CARPAL TUNNEL SYNDROME

The main diagnosis in 15,764 operations was carpal tunnel syndrome, 65.4% were women and the average age was 55.9 (4-97) years old. Carpal tunnel release was the most common procedure in HAKIR, accounting for 15% of all operations. Data in HAKIR indicates that the vast majority of patients perceive the results of the operation to be positive, with about 80% satisfaction with the outcome. 65% indicate they are free from problems with numbness and 78% are free from problems with rest pain one year after surgery. We refer here to the output data report on the website and descriptions in previous annual reports for those who wish to look further into this matter.

HIGH MEDIAN NERVE ENTRAPMENT

Neurolysis of the median nerve at the forearm level was far more uncommon than carpal tunnel release, with only 331 operations. It was interesting to note that 70% of these operations were performed in Linköping, see Figure 5. In some clinics, only single surgeries had been registered. The patients were younger on average (48.7) than the carpal tunnel patients, with a slightly higher proportion of men. Unfortunately, not many questionnaire responses were yet available and you can see from the answers that there is great variation between patients. The spindle diagram in Figure 6, which shows mean values, indicates that satisfaction with the results is only 56% after one year. The most pronounced symptoms were weakness and pain on load. We need more data to assess the results. This is particularly important as there does not seem to be a consensus in Sweden within hand surgery regarding the treatment.

NEUROLYSIS OF THE RADIAL NERVE

The Linköping clinic had also registered most of the 288 radial tunnel syndrome operations, but here the distribution was more even between the units (see Figure 7). Surprisingly, the procedure seems to be common at the two private units. For this diagnosis, men (53%) dominated and the average age was 46.2. Patient-reported outcomes for those who responded seem to be somewhat better here, see Figure 8.

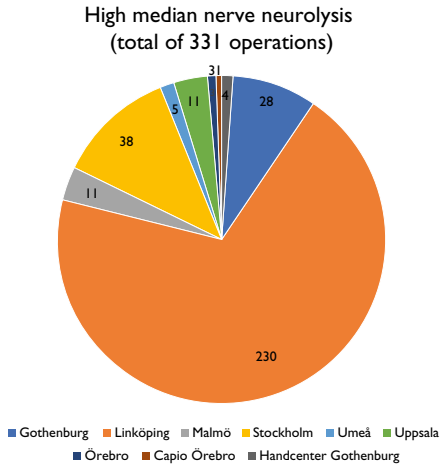
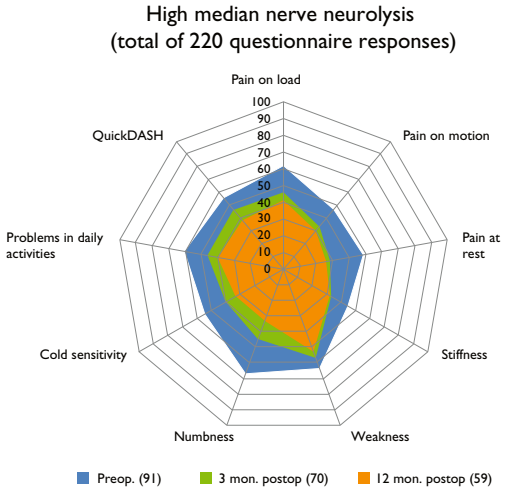


Figure 5. *Number of operations involving neurolysis of the median nerve at the forearm level. The figures indicate the number per unit.*



Figur 6. *Mean values for questionnaire responses in HQ-8 and total scores in QuickDASH before and after surgery for patients operated on using neurolysis of the median nerve at the forearm level. 0 indicates none, and 100 indicates maximum symptoms or perceived disability. Number of responses is given in brackets. Note that there are few responses, which is why the results are uncertain.*

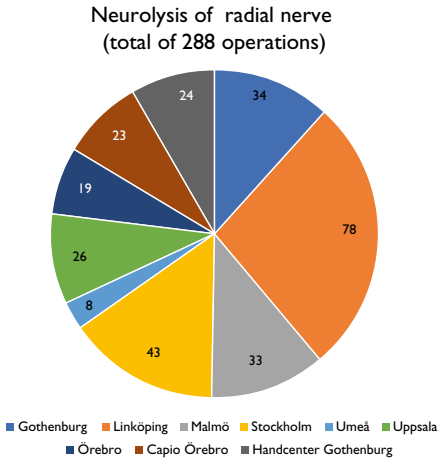
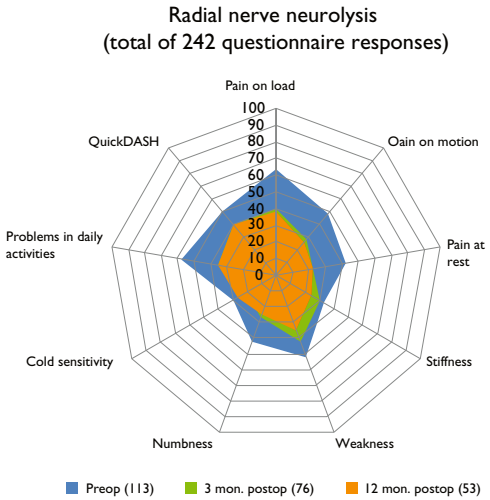


Figure 7. *Number of operations involving neurolysis of the radial nerve at the forearm level. The figures indicate the number per unit.*



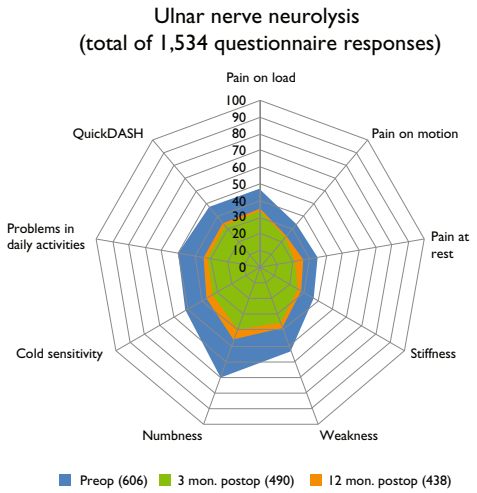
Figur 8. *Mean values for questionnaire responses in HQ-8 and total scores in QuickDASH before and after surgery for patients operated with neurolysis of the radial nerve. 0 indicates none, and 100 indicates maximum symptoms or perceived disability. Number of responses is given in brackets. Note that there are few responses.*

ULNAR NERVE ENTRAPMENT

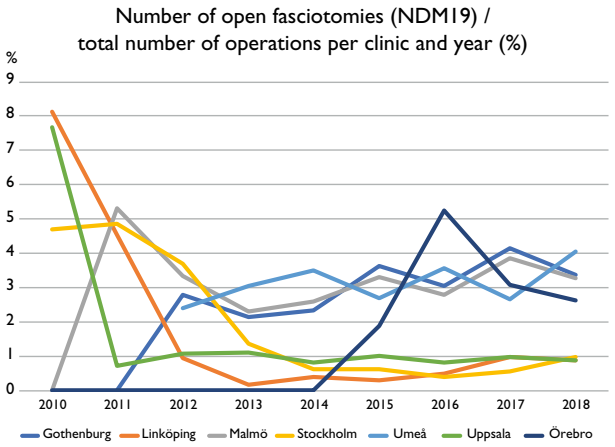
1,938 cases of ulnar neurolysis were registered, but preoperative questionnaire responses were only received from 606 patients (31%). The response rate three and twelve months after surgery was 25% and 23% respectively. Gender and age distribution were the same for those who responded/did not respond.

Unlike carpal tunnel release, ulnar nerve neurolysis was more common in men (51%) than in women, and patients were on average somewhat younger (51.5 years old). The diagnosis usually has causes other than for carpal tunnel syndrome. A scientific publication focusing on ulnar nerve entrapment in diabetics is under way, see below.

In previous annual reports, we have already reported clearly poorer results after neurolysis operations on the ulnar nerve compared with carpal tunnel release. The spindle diagram in figure 9 indicates mean values before and after surgery. Satisfaction with the results one year after surgery was on average only 60%. If we focus on the symptom that patients report to be most important, namely paresthesias, then 46% indicated that one year after the surgery, they had residual paresthesias corresponding to 50 or higher (out of 100) in the operated hand. The mean age of these patients was slightly higher (55.8 years old), as was the proportion of women (58%).



Figur 9. *Mean values for questionnaire responses in HQ-8 and total scores in QuickDASH before and after surgery for patients operated on using ulnar nerve neurolysis (regardless of level). 0 indicates none, and 100 indicates maximum symptoms or perceived disability. Number of responses is given in brackets.*



Figur 10. *Number of operations with fasciectomy for Dupuytren's contracture (NDM19) through total number of operations per clinic and year (%). Collagenase treatment was introduced in 2011 and is mainly used in Linköping, Stockholm and Uppsala. The various clinics have joined HAKIR gradually.*

51 of the only 185 patients who responded both before and one year after surgery (27%) felt that no change was achieved, or that there was even more numbness than before. We need to delve deeper into the diagnosis of ulnar nerve entrapment to try to improve our treatment outcomes. Interview studies and reviews of patient records can be methods used for this.

IMPROVEMENT ASPECTS - NERVE ENTRAPMENTS

Carpal tunnel release is a treatment that has good established evidence, and patient-reported data in HAKIR further confirms this. However, we still see a need to analyse and improve the treatment of ulnar nerve entrapment. In the case of high median nerve neurolysis, there appears to be significant regional differences in treatment traditions. One can only speculate on the causes for the variation. The results from a patient perspective do not seem convincing for those patients who answered the questionnaires, but we need more data to know this for sure. We would also need to compare with patients who received non-operative treatment. For radial tunnel syndrome, the patient-reported outcomes appear to be better, but more data is also needed here.

DUPUYTREN'S CONTRACTURE

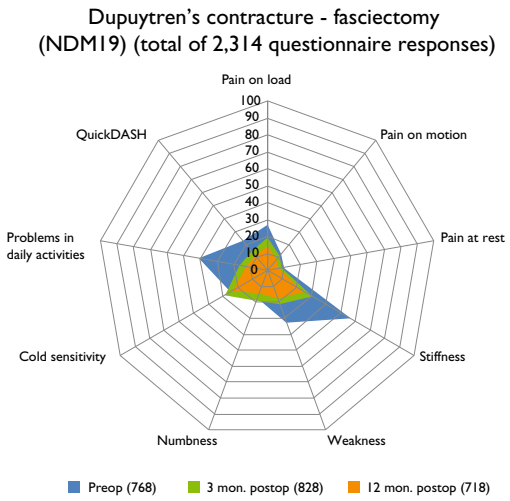
In total, there were 5,535 registrations of treatments for Dupuytren's contracture (M720) in 4,351 patients. The patients were on average 66.6 (22 - 95) years old and 82.2% were men. 42% had received more than one treatment; a maximum of 9 treatments per patient were entered in the registry.

2,598 of the registered treatments (46.9%) were open fasciotomies (NDM19). As previously reported, developments have been different at the hospital clinics since the introduction of collagenase treatment in Sweden in 2011. In figure10, the proportion of open surgery (fasciectomies) is shown in relation to the total number of surgeries at each clinic. Uppsala, Linköping and Stockholm, which use collagenase, have all significantly reduced their open surgery since 2011, while this development is not observed in the four other clinics that recommend needle fasciotomy. Unfortunately, it is difficult to compare the results between open surgery, needle fasciotomy and collagenase based on HAKIR data, partly because only a small proportion of the less invasive methods are monitored in the register and partly because we do not know how the selection was made for each method.

It can be assumed that non-operative methods are used to a greater extent on primary Dupuytren's contracture with a smaller proportion of difficult-to-treat PIP joint contractures, and that open surgery is done in more severe cases, recurrence, etc. An attempt at a comparative analysis is being made in an ongoing scientific study; see further on in this annual report.

Mean values for various hand symptoms and perceived disabilities for patients who underwent fasciectomy for Dupuytren's contracture are shown in Figure 11. The figure shows the value of our self-developed patient questionnaire HQ-8 as a complement to QuickDASH. Patients with Dupuytren's contracture are almost never in pain and therefore have a low score for QuickDASH. However, they experience a high degree of stiffness and problems performing daily activities, which we can better identify using HQ-8. We see no deterioration in these symptoms up to one year after surgery. Satisfaction with the results one year after surgery was on average 88.5%.

When it comes to patient-reported outcomes, it is best to always compare the patient with themselves, that is, to analyse individual changes. Unfortunately, we have not yet received enough preoperative questionnaire responses for such analyses. For the fasciectomy patients, there were responses both before and one year after surgery for only 247 patients.



Figur 11. *Mean values for questionnaire responses in HQ-8 and total scores in QuickDASH before and after surgery for patients operated on using fasciectomy for Dupuytren's contracture. 0 indicates none, and 100 indicates maximum symptoms or perceived disability. Number of responses is given in brackets.*

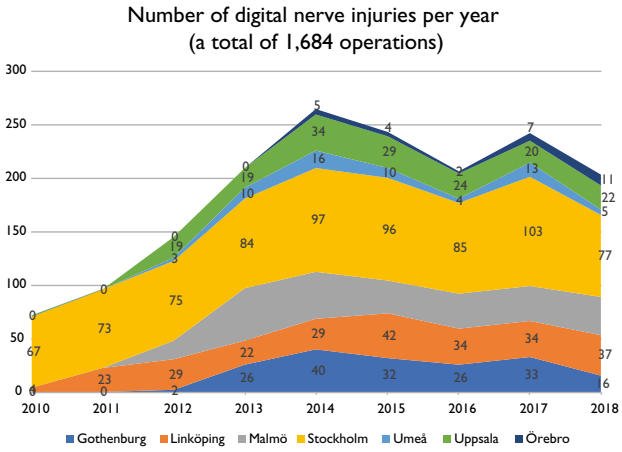
The improvement regarding stiffness averaged 29 steps on the scale (out of 100). 74 out of 247 (30%) reported being as stiff or stiffer as before their surgery.

IMPROVEMENT ASPECTS - DUPUYTREN'S CONTRACTURE

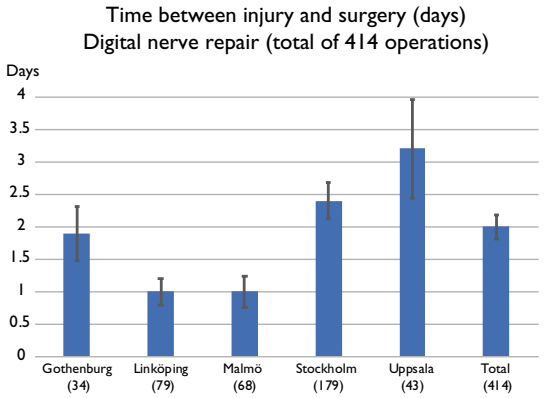
Dupuytren's contracture is one of the most common diagnoses within Swedish hand surgery, and open fasciectomy was until 7 years ago a very common procedure at all clinics. Collagenase injections and needle fasciotomies have completely changed the treatment panorama and have led to major regional differences. The less invasive methods have probably also led to increased indications for treatment. Our speciality area needs to jointly discuss the pros and cons of the different treatment methods with the aim of creating national guidelines. HAKIR can contribute through compiling patient-reported outcomes. Optimally, the results of all three methods would be monitored in the quality register so that we can compare across extensive patient materials. First, we would have to agree on when treatment of this inherently benign diagnosis is indicated.

DIGITAL NERVE INJURIES

Digital nerve injuries are very common in all hand surgery clinics, but are often combined with other injuries, such as tendon injuries and fractures. If you only include isolated digital nerve injuries to fingers and thumbs, there were 360 digital nerve injuries to thumbs and 1,327 to fingers, with a total of 1,687 operations. The patients were on average 37.5 (0 - 90) years old, and 39% were women. A total of between 200 and 250 isolated digital nerve injuries per year are registered, see Figure 12.



Figur 12. *Number of isolated digital nerve injuries, i.e. not combined with other injuries, per clinic and year. Please note that the clinics have gradually joined HAKIR. HandCenter Gothenburg had registered three injuries; these are not included in the figure.*



Figur 13. *Mean values for time between injury and surgery for isolated digital nerve injuries. Only eight injuries were registered from Umeå and two from Örebro, which is why these are only included in the total value. The number of injuries is stated in brackets. The error bars indicate a 95% confidence interval. Periods of 14 days or more are not included in the figure, since such a delay is probably not due to resources at the clinics. There were three such values in Gothenburg, two in Linköping, four in Malmö, one in Stockholm and two in Uppsala.*

It is likely that the actual number is considerably greater as some clinics have registered very few injuries. In sparsely populated regions, digital nerve injuries are probably operated on at orthopedic clinics, but this is less common in large cities. There was information on the date of injury for 429 operations. The time between injury and surgery was on average 2.0 days, with an average of 1 day. The differences between the clinics are shown in Figure 13. The same pattern is noted for flexor tendon injuries, and in Stockholm and Uppsala, patients have to wait longer for nerve suture than in Linköping and Malmö. This may also be a good quality indicator to monitor over time.

Patient-reported outcomes after isolated digital nerve injuries are shown in Figure 14. Cold sensitivity and numbness

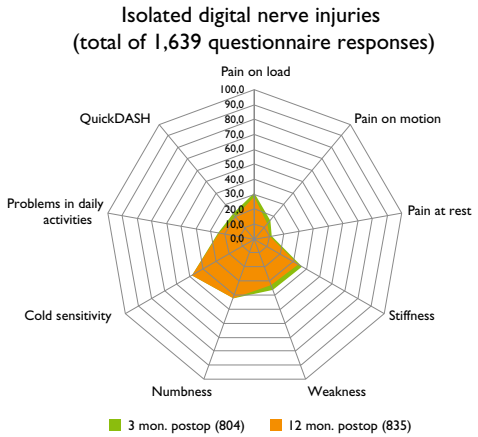


Figure 14. *Mean values for questionnaires responses in HQ-8 and total scores in QuickDASH after surgery on a digital nerve injury. 0 indicates none, and 100 indicates maximum symptoms or perceived disability. Number of responses is given in brackets.*

are the two symptoms that patients refer to most one year after their injury. We see once more that the HQ-8 questionnaire provides an important complement to QuickDASH, which indicates an almost normal value (19.3), while the two symptoms in HQ-8 score at between 42 and 48 (out of 100) without major improvement between three and twelve months.

IMPROVEMENT ASPECTS - DIGITAL NERVE INJURIES

Digital nerve injuries are common injuries that are often perceived as simple by the clinics. Postoperative rehabilitation programmes vary at the clinics and it is common for patients not to be monitored at all postoperatively through doctor's appointments. The close to 400 patients who responded to the HAKIR questionnaire after one year indicate significant persistent complaints of reduced sensitivity and cold sensitivity. Perhaps these results can be improved with more structured hand rehabilitation, such as early-stage sensitivity exercises and information on mitigating strategies in the case of cold sensitivity? Maybe we can perform better nerve sutures? The value of suturing digital nerves to less vital sensory areas is on the whole beginning to be questioned in scientific publications, and we need to investigate this more closely.

FINGER FRACTURES

3,841 operations with osteosynthesis of phalangeal fractures to fingers were registered. The number per clinic and year is shown in Figure 15. Between 500 and 550 operations are performed per year. The patients were on average 38.5 (0 - 104) years old, and 36.5% were men 15.2% were children under18 years old..

Time between injury and surgery is more difficult to interpret for phalangeal fractures than for tendon injuries

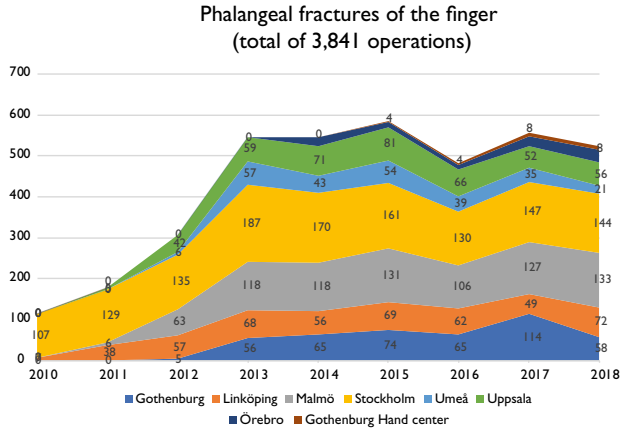


Figure 15. *Number of operated phalangeal fractures per clinic and year. Please note that the clinics have gradually joined HAKIR.*

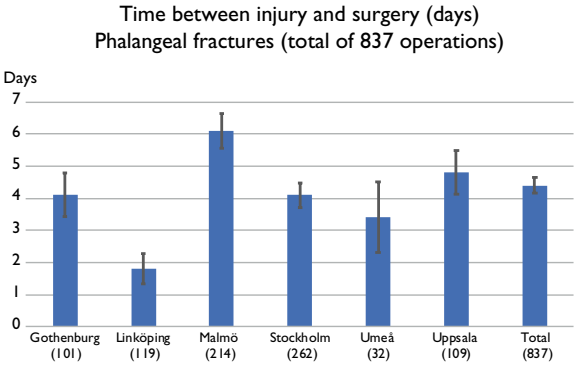


Fig 16. *Time between injury and surgery for phalangeal fractures. Number of injuries in brackets. The error bars indicate a 95% confidence interval. Periods of 14 days or more are not included in the figure. There were 13 such values in Gothenburg, 3 in Linköping, 34 in Malmö, 44 in Stockholm, 1 in Umeå and 17 in Uppsala. No information on date of injury was available from Örebro.*

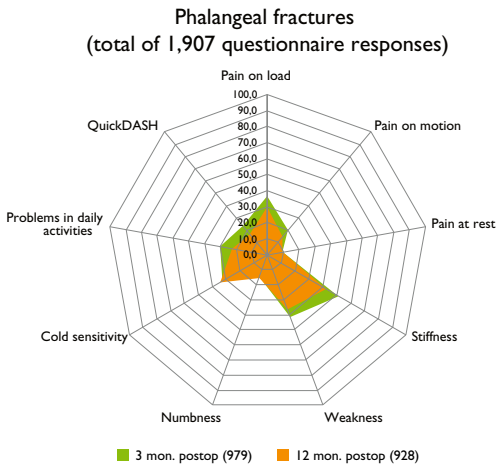


Fig 17. *Mean values for questionnaires responses in HQ-8 and total scores in QuickDASH after surgery for phalangeal fracture regardless of the surgical method. 0 indicates none, and 100 indicates maximum symptoms or perceived disability.*
Number of responses is given in brackets

and digital nerve injuries. A delay may be due to the patient seeking care at a late stage or being referred late, that the fracture was first treated with a cast but it was then dislocated and required surgery, or that the surgical resources were insufficient. Phalangeal fractures underwent surgery on average 4.4 days after the injury, see Figure 16. Linköping was once again the clinic where the injuries resulted in the quickest surgery after the injury.

Many injuries (14%) were operated on significantly later, and interim periods of over 14 days are not shown in the figure. It would be relevant to distinguish between open and closed fractures. The variable "intact skin?" was introduced for this purpose some years ago, but we do not have enough data for such an analysis yet.

Patient-reported outcomes after surgery for a phalangeal fracture are shown in Figure 17. Weakness and stiffness are common symptoms even one year after the injury, as well as cold sensitivity, while aches and disabilities do not seem to be dominant.

RARE DIAGNOSES

In addition to analysing and improving the results for common diagnoses within our speciality area, registry data can also be used to compile patient experiences regarding rare conditions. Those planning to study a specific disorder can easily identify all patients who have received surgery for this. Questionnaires can then be sent out or patients can be called in for examination. Of course, ethical research consent must be obtained in this case. The rules for research on registry data can be read on our website. However, everything is built around the coding in conjunction with surgery being correct and that non-specific codes are avoided. Some codes that are commonly used, such as M796 (Pain in limb) or M798 (Other specified soft tissue disorders) unfortunately do not allow any further analysis of the diagnosis. Table 3 lists the number of registered operations for some unusual disorders. Anyone wishing to know more is welcome to contact the registry holder.

QUESTIONS REGARDING EXPERIENCE (PREM)

As previously mentioned, we have two experience-related questions in the HAKIR questionnaire, their experience of the operation results and of the experience of general care received during the treatment period, both graded 0-100, where 100 is "completely satisfied".

Hand surgery patients were generally very satisfied with the interpersonal treatment they received, and there were no major differences between the participating units (Figure 18), see next page. Figure 19 shows satisfaction with the treatment results one year after the operation for a few different elective and acute diagnosis groups. Satisfaction was around 77% for the elective diagnoses and naturally a little lower for the injury diagnoses. Surprisingly, patients who underwent surgery for a digital nerve injury reported slightly worse results than patients with fractures and flexor tendon injuries.

The results should of course be interpreted with great caution as there may be several sources of error.

Congenital anomalies		Other unusual disorders	
Apert/Crouzon syndrome	49	Bone cyst	148
Arthrogryposis	38	Villonodular synovitis	196
Exostoses & enchondromatosis	96	Digital myxoid cyst	95
Vascular malformations	55	Pyogenic granuloma	416
Neurofibromatosis	25	Gout	90
Polydactyly, finger	198	Hypermobility syndrome	83
Polydactyly, thumb	180	Juvenile rheumatoid arthritis	41
Polydactyly, unspecified	35	Kienböck's disease	168
Reduction malformation, radial	85	Malignant tumour, melanoma	81
Reduction malformation, ulnar	11	Malignant tumour, squamous cell carcinoma	135
Reduction malformation, central	25	Malignant tumour, other	603
Reduction malformation, other	88	Necrotising fasciitis	104
Syndactyly	301	Late effects of stroke	70
Polysyndactyly	46	Spastic paresis, not CP	205
Trigger thumb	194	Cerebral Palsy	357
Other malformations	307	Tuberculosis	11

Table 3. *Number of registered surgeries for some more unusual diagnoses within hand surgery. Diagnostic codes have been taken from the registered main diagnosis, which is why the actual number is probably greater.*

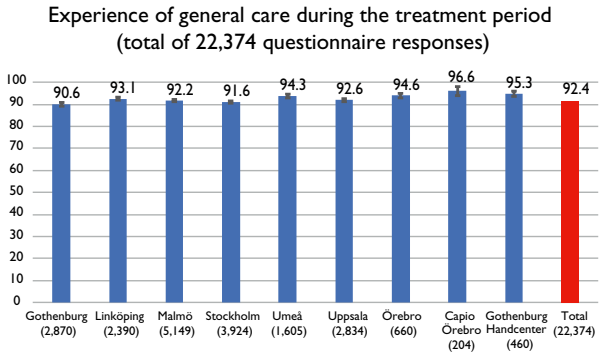


Fig 18. *Mean values for questionnaire responses to the question "How did you perceive general care you received during the treatment period?" 3 months after surgery. 100= completely satisfied; 0= completely dissatisfied. Number of answers is given in brackets. The error bars indicate a 95% confidence interval.*

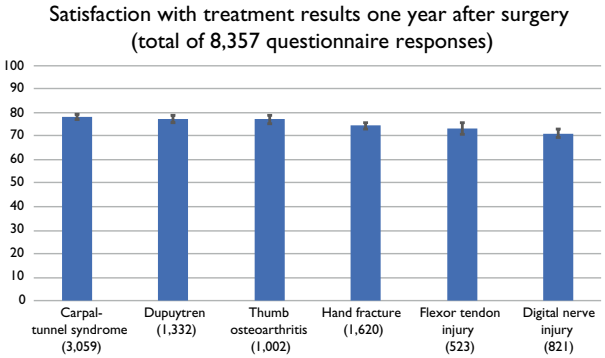


Fig 19. *Mean values for questionnaire responses to the question "How did you perceive the results of your operation?" 12 months after surgery. 100= completely satisfied; 0= completely dissatisfied. Number of responses is given in brackets. The error bars indicate a 95% confidence interval. The diagnostic breakdown includes all kinds of treatments.*

IMPROVEMENT ASPECTS - PREM QUESTIONS

We have for some time planned to change the PREM questions in HAKIR. The scale has previously been misunderstood by some patients, but we believe that this problem has been reduced by adding "smileys" at the ends of the scale. The main reason for a change is that the questions are too unspecific to be used for improvements at the clinics. We also believe that the standard time indications for monitoring in HAKIR – three and twelve months after surgery – are not optimal, as experience-related questions should be answered in conjunction with the experience. We believe that 3-4 weeks after surgery could be appropriate, which then requires a separate questionnaire. Despite the high level of ambition for HAKIR, we realise at the same time that many people in today's society have "questionnaire fatigue" and that we should limit ourselves to a few questions.

The central working group, in particular Nina Lindblad and Nour Al-Shaar, have during a 2018-19 project analysed the questions used in the National Patient Survey (NPE). The NPE is sent out to patients nationally, so far once a year. The questions are divided into 7 dimensions; Emotional Support, Information and Knowledge, Involvement and Participation, Continuity and Coordination, Accessibility, Respect and Interpersonal Treatment, and Overall Impression. The dimensions and the questions that reflect these are very well analysed and specially selected to capture patients' experiences in as complete a way as possible.

We reviewed the 125 questions in the NPE and selected two questions per dimension. These were presented to a selection of patients and to staff (nurses, assistant nurses, physiotherapists, occupational therapists, doctors and heads of department), who were instructed to grade how important each question was. We discussed the results on HAKIR Day in March 2019. The points of view were fairly consistent and we were able to select one question per dimension that was considered relevant.

As part of a pilot project, we plan to send out the new PREM questions to a selection of patients at the Stockholm clinic in the autumn of 2019. We have started a collaboration with Mina Vårdkontakter (My Healthcare Contacts, 1177) and are able to distribute the questionnaires through this platform. Patients will then receive an e-mail via 1177, log in with BankID, and complete the questionnaire. In addition to evaluating the new PREM questions, we also intend to investigate the response rate for questionnaires distributed via 1177. Our current questionnaire function is very cheap compared to 1177 and we will not switch over if we receive a lower response rate. However, it is likely that questionnaire distribution within healthcare will be done entirely through 1177 within a few years, and it is therefore interesting to try out this option at this early stage.

Nursing care form

Nursing is a natural part of the care provided within hand surgery. In most of the hand surgery specialist clinics, postoperative wound care, suture removal and plaster cast treatment are carried out by their own staff, nurses and assistant nurses. Patients are monitored throughout the care process until everything in their hand is healed after injury or surgery. There is much to learn from the nursing care provided and certainly some areas to improve as well. Therefore, a project was started in 2017 with the task of putting together a nursing care form for HAKIR.

The project group initially chose to focus on wound care, patients' experiences of suture removal and dressing changes, as well as patient information, but over time we hope to include additional care aspects, see below.

FORMS AND DIAGNOSES

The specialist clinics in Malmö, Stockholm and Uppsala register using the nursing care form. Since early 2017 and up to 31 December 2018, 845 forms relating to 489 patients had been registered, see Figure 20. Unfortunately, the rate of registered forms has dropped sharply over time, and in 2018 only about one third as many forms (31%) were registered compared with 2017.

Half of the forms were registered in Malmö, and slightly more in Stockholm than in Uppsala, see Figure 20. The most common diagnoses were, according to agreement in the project group, thumb osteoarthritis, tendon injury, Dupuytren's contracture and patients operated on for a hand infection, see Figure 21. The majority of treated wounds were surgical wounds (75%), some of which were primary infections, and open injuries and human bite wounds that did not require surgery. Information on the type of wound was missing for 23%.

AGE AND GENDER DISTRIBUTION

Half of the patients were men across the material as a whole, but female patients were somewhat more common in Uppsala (63%). The average age was 52 (8-84) years old overall, 48 for men and 55 for women. Among the men, tendon injuries (48%) and Dupuytren's contracture (24%) dominated. Arthritis/osteoarthritis was the largest diagnostic group among the women (48%) and tendon injuries accounted for 31%.

PATIENT INFORMATION

A large majority of patients surveyed (98-99%) indicated that they had received information both about the operation, the importance of keeping the hand elevated, and about postoperative pain management, as well as information upon being discharged, see Figure 22. There were no significant differences between the three clinics.

DRESSING AND WOUNDS

Among casts used, plaster of Paris strongly dominated (96%) over plastic casts at all the clinics. The type of dressing closest to the wound (wound bed protection) varied between the clinics, see Figure 23. This can of course be due to differences in the type of wounds, but also to different traditions and experiences.

Bandage problems were reported among 11% of patients, a slightly lower proportion at the Stockholm clinic, but this may be due to differences in patient selection. The most common problems were abrasions or pressure, and the dressing getting stuck.

Wound complications arose in 4.8%, of which 2.2% of the wounds showed signs of infection. Data is difficult to interpret because different types of wounds feature in the material. Similarly, it is currently impossible to analyse whether tobacco use or other healing-inhibiting factors were significant..

PAIN WHEN CHANGING DRESSING AND SUTURE REMOVAL

Very few patients experienced the removal of surgical dressing as painful, but 26% of 513 surveyed patients indicated pain of 5 or more on a 10-grade NRS scale during the suture removal, see Figure 24. Despite this, it was very uncommon to use resorbable sutures, with only 10 patients (1.9%) being indicated on the nursing care form as receiving such. However, actual use is probably greater as these patients are most likely not coming to have the wound redressed, but rather take off the dressing themselves at home. The proportion of women was higher (78%) and the age was slightly lower (48) among the 64 patients who indicated a high degree of pain (NRS>5) during suture removal.

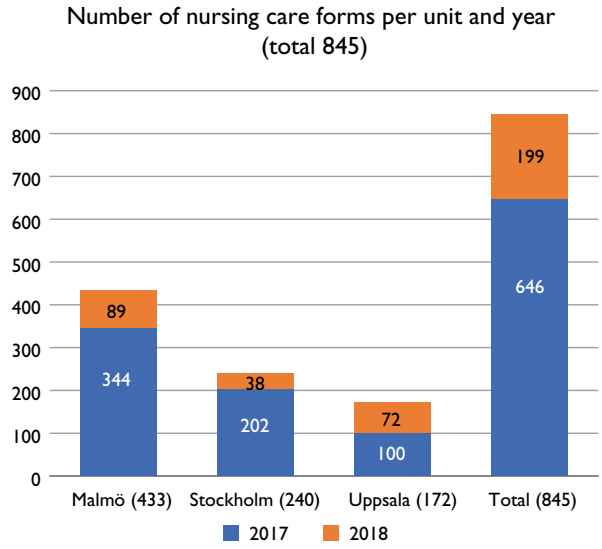


Figure 20. *Number of registered nursing care forms per clinic and year. Total number in brackets.*

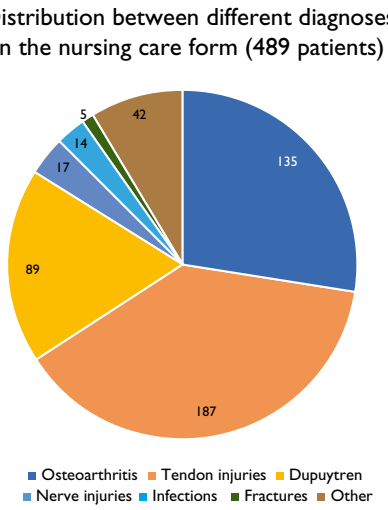


Figure 21. *The figures indicate the number of registrations per diagnosis.*

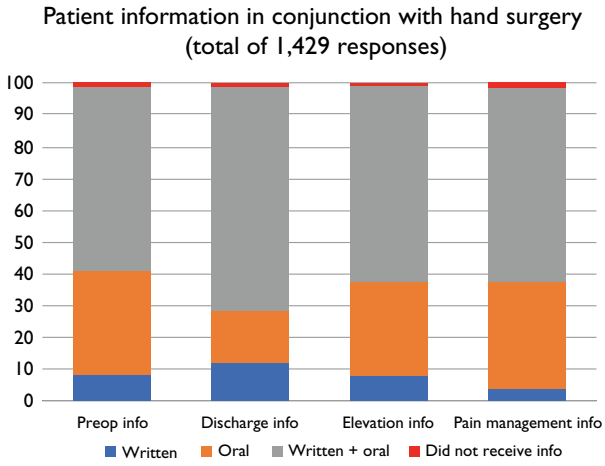


Figure 22. *Distribution of responses from patients regarding different types of information concerning the hand surgery (%).*

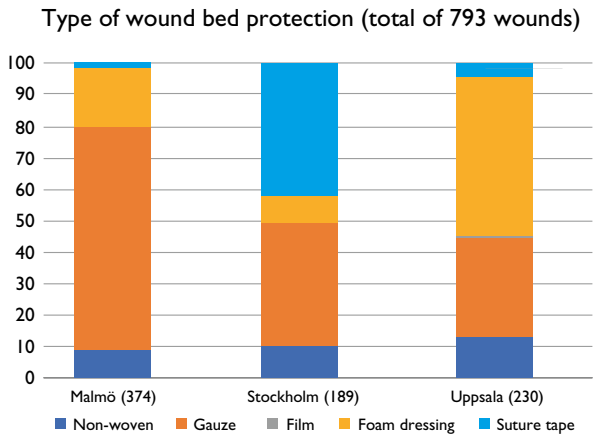


Figure 23. *Distribution between different types of wound bed protection per clinic (%). Total number of wounds in brackets*

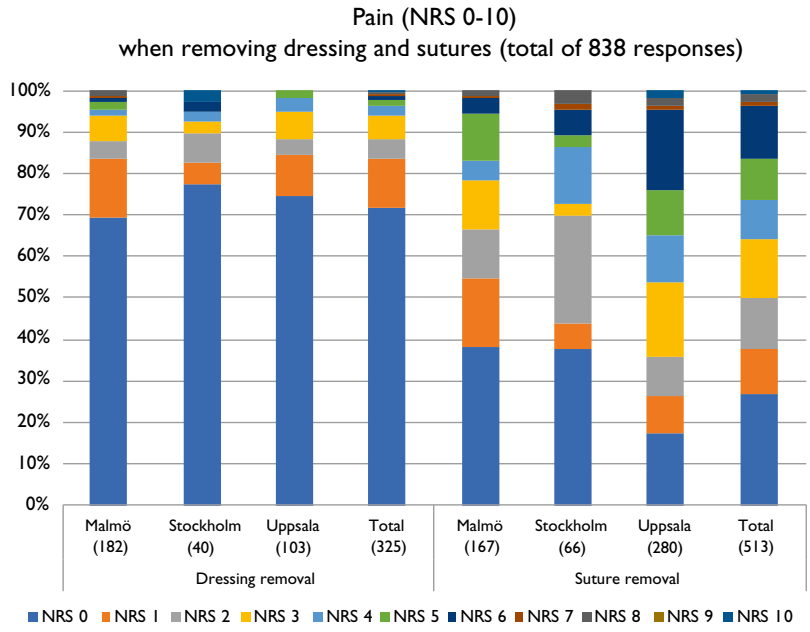


Figure 24. *Pain indicated by patients during dressing removal and suture removal respectively, using NRS (0-10). Proportion of responses per scale step (%). Number of answers per clinic and total in brackets.*

IMPROVEMENT ASPECTS - NURSING CARE FORM

HAKIR needs to redouble its efforts to get the registration procedures for the nursing care form up and running again and also distribute it to more clinics. Additional working hours for nurses and assistant nurses need to be allocated for improvement work and quality monitoring at the clinics. More evidence is needed to support various measures within, for example, wound care and treatment of postoperative pain. Aside from improved care for the patients, such an investment can also result in efficiency gains and save money. The nursing care form in HAKIR is a good tool for such improvement work, but we then need to get all clinics involved in this work.

Suture removal after hand surgery seems to be uncomfortable for quite a few patients. For children, all hand surgeons in Sweden use resorbable sutures, but these are very rarely used in adult patients. Aside from completely avoiding discomfort during suture removal, a lot of time can also be saved at the clinic by using resorbable skin sutures instead of the conventional nylon sutures. However, we must be sure that the wound healing is not disturbed, that there is no scarring and that no other problems arise. To ensure this, we need to be able to compare similar groups, preferably by randomisation. Such a study could very well be done via HAKIR as a so-called registry-based randomised controlled trial (RRCT). This could be led by nurses and assistant nurses at the hand clinics. We hope that there is interest in this and that in future HAKIR will have the opportunity to support such a study.

Postoperative wound infections that result in a reoperation are registered in HAKIR, but the majority of wound infections are of a lighter degree and treated with antibiotics and redressing the area. We would need to have a more complete infection registration procedure in place for HAKIR and we are happy to receive suggestions on how this could be done. In the future, we hope to be able to obtain information on antibiotic prophylaxis during surgery via SPOR, the Swedish PeriOperative Registry, see other parts of this report.

Postoperative pain relief has been one of the causes of widespread opioid abuse in the United States and several other countries, especially after orthopedic surgeries. Excessively high quantities of pain medication have been regularly prescribed and the patients are often poorly informed of the risks and about the gradual reduction method. Monitoring postoperative pain in relation to prescriptions and the intake of painkillers after hand surgery would be a very relevant and important future extension of the nursing care form.

Complicated postoperative procedures

Of the 13,487 reoperations in the annual report material, the stated cause was "postoperative problem" in 5,940 (44%) cases, the remainder being multiple-stage operations, extraction of osteosynthesis material or reoperations for Dupuytren's contracture, see Figure 25. Among the reoperations for postoperative problems, primary surgery had been performed at another clinic in 32% (external cases). The causes behind reoperations after surgery at the same clinic (internal cases) are shown in Figure 25 and Table 4. Information on where primary surgery was performed was missing for 698 operations since this variable was first introduced in 2012.

In the figure, the reoperations that lack information on the primary surgery are counted as "internal".

Causes behind reoperation vary widely between clinics (see Figure 25 A-I). Multiple-stage operations are common in Malmö, Stockholm and Uppsala, but rare in Gothenburg, Linköping, Umeå and Örebro. The removal of osteosynthesis material to prevent complications is very common in Linköping, Stockholm and Uppsala. In Stockholm, this was the cause of internal reoperation in 39% of cases.

	Total number of reoperations	% reoperations of all op	% reop due to postop problems of alla op
Gothennburg (10,707)	1,743	16.3	7.3
Linköping (13,188)	1,780	13.5	4.7
Malmö (24,613)	2,200	8.9	3.2
Stockholm (23,683)	5,166	21.8	6.4
Umeå (7,909)	71	0.9	0.7
Uppsala (11,731)	2,042	17.4	7.2
Örebro (7,761)	67	0.9	0.3
Capio Örebro (939)	144	15.3	7.4
Handcenter Gothenburg (2,948)	274	9.3	3.3
Totalt (103,479)	13,487	13.0	4.7

Tabell 4. *Number of reoperations, proportion of reoperations of all operations, and proportion of reoperations due to postoperative problems. Total number of operations in brackets.*

The type of postoperative problem after primary surgery at one's own clinic also varied, see Figure 26. Overall, adhesion formation/stiffness was the most common cause (14%), followed by infection (11%) and wound healing problems (9%). The 502 reoperations due to postoperative infection correspond to an infection rate of 0.48%, which can be considered very low for a surgical specialty dealing with a high proportion of trauma. Tendon ruptures accounted for 6% and prosthetic complications for 5% of all complications. The most unusual were postoperative bleeding and donor site complications, each of which accounted for less than 1%. As before, many complications have been registered as another cause (as much as 37%), in some cases with free-text specification.

IMPROVEMENT ASPECTS - POSTOPERATIVE PROBLEMS

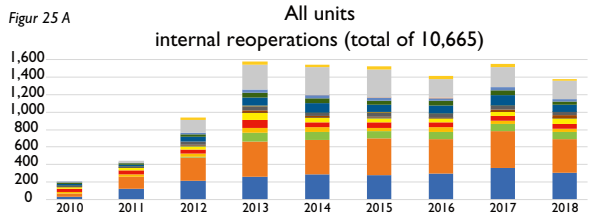
The dynamic report on our website contains open data on reoperations due to postoperative problems. It is therefore easy for heads of department and quality managers to access and report their own data in comparison with other units. During 2019, we improved the layout of the report by, for example, adding an overview, "dashboard" when the page opens where you can easily choose your own clinic and time frame and access your results straight. We now hope that HAKIR data is used more diligently at the clinics in order to monitor postoperative complications.

Postoperative infections are uncommon after hand surgery despite the fact that many hand injuries are contaminated and have necrotic tissue. We observe no difference in infection rates over the years. However, it should be noted that HAKIR currently only registers infections that have led to reoperation. Our hope is to be able to expand the nursing care form in the future so that we also identify wound infections that have only been treated with antibiotics and dressing changes.

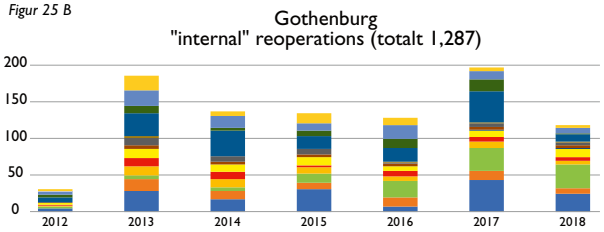
Our planned collaboration with the Swedish Perioperative Registry (SPOR) was put on hold during 2018-19 due to time constraints and a change of staff at RC Syd, but it will now be resumed. We very much hope that in the future, we will also be able to gather information about, for example, preoperative antibiotic prophylaxis and surgery time in order to be able to correlate with infection rates for different types of procedure.

We would like to reiterate that the person registering information should use the answer options already available and avoid free text. We need to add "recurrence after tumour surgery" and "secondary osteoarthritis development", as they are often found in the free-text responses.

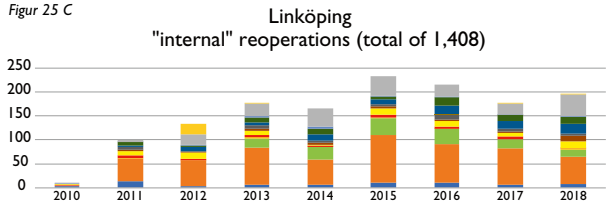
Figur 25 A



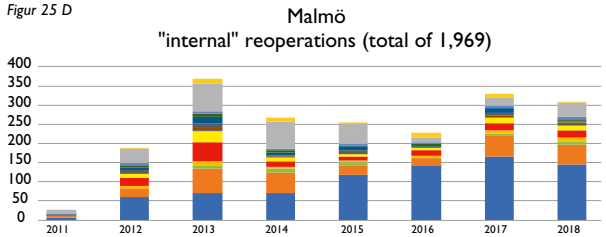
Figur 25 B



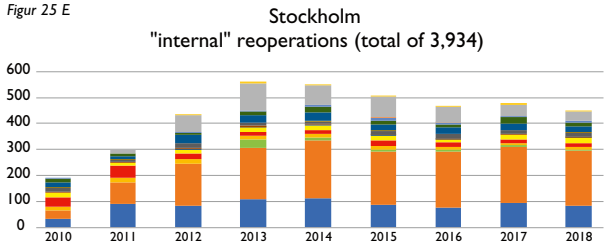
Figur 25 C



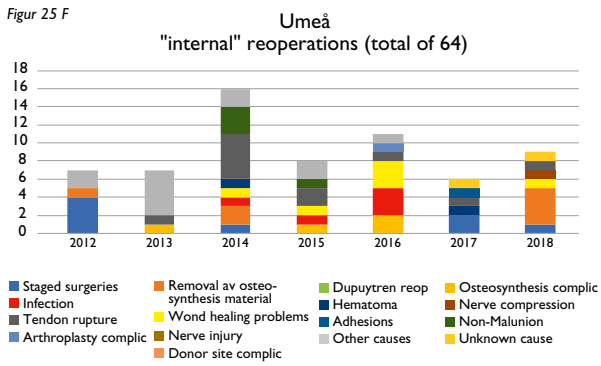
Figur 25 D



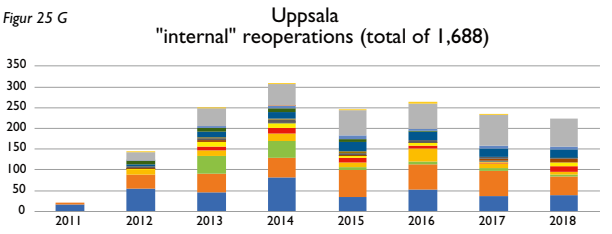
Figur 25 E



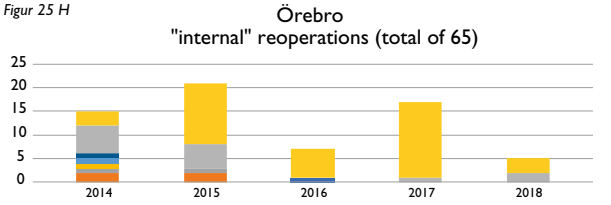
Figur 25 F



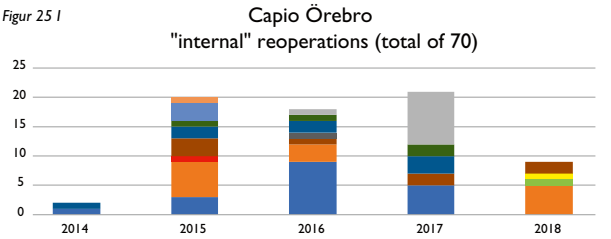
Figur 25 G



Figur 25 H



Figur 25 I



Figur 25 J

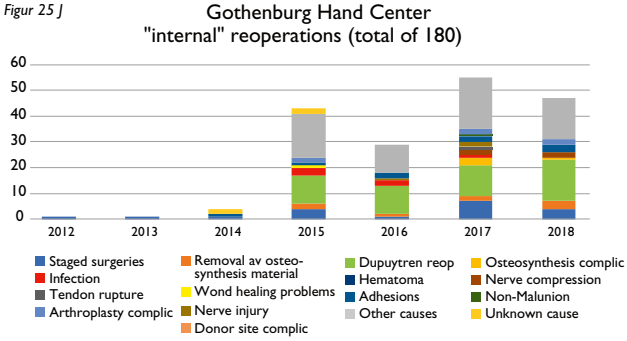
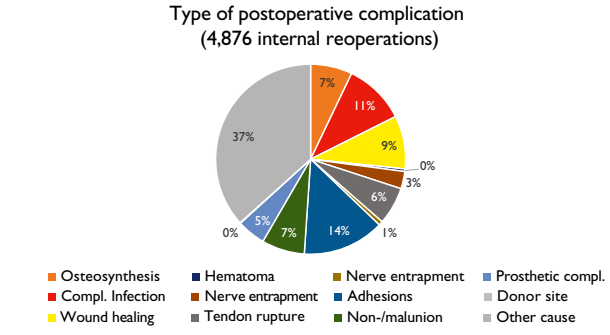


Fig 25 A-I. *Number of reoperations after primary procedure at own unit = internal reoperations. Note that this variable, as well as reoperation for Dupuytren, was only introduced in 2013, and the figures for previous years are uncertain. Also note the different scale on the Y-axes*



Figur 26. *Distribution between different types of postoperative problems (%) after primary surgery within own unit = internal reoperation. Only 21 reoperations due to hematoma, 34 for nerve injury and 4 for donor site complications.*

Extended registration in HAKIR

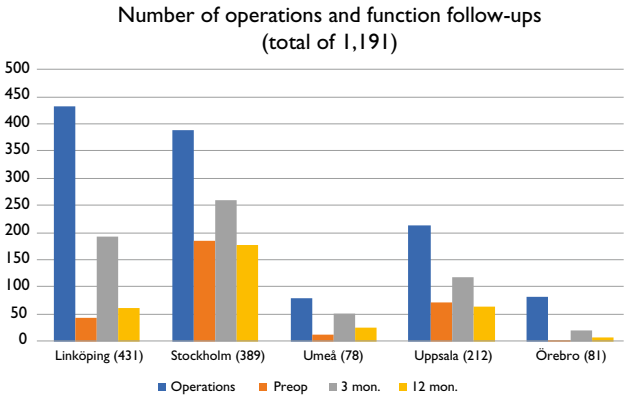
Extended registration means that the patient, in addition to the basic registration, where PROM, PREM and postoperative problems are registered, is also offered monitoring of hand function, for example strength, mobility and sensitivity before and after their surgery or injury.

Six of seven specialist clinics are currently participating in one of the extended registrations; currently thumb arthritis surgery, flexor tendon injuries and arthroplasty surgery. Several new forms have also been introduced in 2018, see separate section. In order for compiled results to be useful, complete and accurate registrations are required. Patients need to be motivated and informed about the benefits of monitoring treatment results and quality of care so that they take the time to come for a follow-up examination one year after their surgery. Our experience is that the vast majority of patients appreciate that we are focusing on their care in order to become even better.

THUMB OSTEOARTHRITIS

Thumb osteoarthritis affects 15 - 25% of middle-aged women and is half as common among men. Primary care services are usually responsible for the investigation and diagnosis as well as for initial treatment with information, osteoarthritis school, orthoses and medical treatment. Surgical procedures vary internationally and in Sweden.

In this year's report, the patients who have been monitored in basic and extended registration respectively are reported here in separate sections. In the extended registration, the clinics in Linköping, Stockholm, Umeå, Uppsala and Örebro participate, and here we get information about exactly which surgical method was used, for example, the type of tendon interposition as well as the measured strength and mobility.



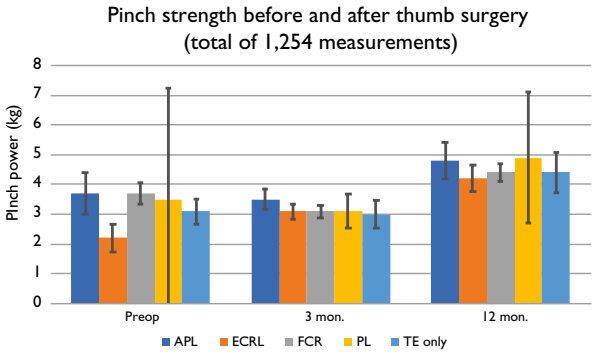
Figur 27. *Number of operations and function follow-ups within extended registration for thumb osteoarthritis. Note that one year has not passed since the surgery on the 163 patients who were operated on in 2018, see the text. Total number of operations per clinic in brackets.*

Extended registration

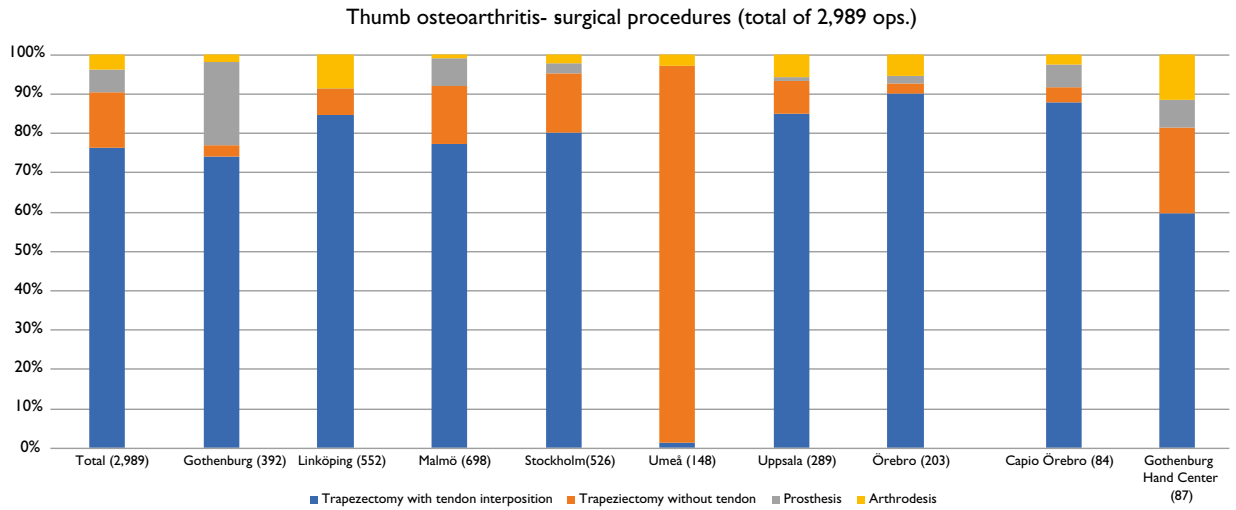
A total of 1,191 surgeries on 1,086 patients were registered within the extended registration of thumb osteoarthritis surgery (HAKIR 05A). Distribution among the clinics by number of forms is shown in Figure 27. The follow-ups appear to work well in Stockholm, Umeå and Uppsala, while few preoperative and one-year surveys have been done in Linköping and Örebro.

The patients were on average 62.7 (35 - 93) years old and 82% were women.

A large majority of the patients (82%) underwent a trapeziectomy and interposition arthroplasty. Only 28 CMC 1 arthrodeses and 61 trapeziectomies without tendon interposition were registered, the latter mainly from Stockholm (53). As before, we see major regional differences in the choice of tendon interposition. ECRL tendon interposition (379) and FCR tendon interposition (369) were about as common, with ECRL being used mostly in Linköping and to some extent in Stockholm, while FCR is used in Stockholm and Uppsala. APL interposition (230) is done at all clinics. Tendon interposition with the palmaris longus tendon (according to Hulin) is done in Örebro and Umeå. The choice of surgical method seems to therefore be strongly dependent on local tradition and experience. Note that this applies to the patients who have been registered in the extended follow-up. The basic registration shows the distribution between the methods in figure 29 above, where implant surgery is also included in the figures. See also



Figur 28. *Strength in the thumb grip (three-point pinch) in kg before and after thumb base surgery with trapeziectomy and different types of tendon interposition. APL, ECRL, FCR and PL = different types of tendon interposition and TE = Trapeziectomy without tendon interposition.. The error bars indicate a 95% confidence interval. The reason for the large spread for the PL group is very few measurements. The reason for the low value for ECRL before surgery is unclear..*



Figur 29. *Distribution between different surgical procedures for thumb osteoarthritis (%) per unit. The number of operations in brackets*

interesting registry findings in the section on arthroplasty surgery.

The extended follow-up includes the measurement of strength and mobility. Strength in the thumb grip (three-point pinch) for patients operated on with different types of tendon interposition and trapeziectomy without tendon interposition are shown in Figure 27. Number of measurements before, and 3 and 12 months postop. was for APL (37, 115, 56), for ECRL (82, 189, 76), for FCR (142, 225, 155) for PL (5, 31, 13) and for TE (54, 47, 27). No clear differences are seen between the methods, but the number of measurements is still small for some surgical methods and the data shown is not paired but rather indicates mean values for the different points in time.

Thumb osteoarthritis in the basic registration

3,986 operations were registered on main diagnosis code M18 (thumb osteoarthritis). If you remove 327 reoperations and 34 multi-stage operations as well as 438 surgeries performed during 2018, 3,187 surgeries remain for analysis.

Surgical methods

Figure 29 shows the distribution between different surgical methods thumb osteoarthritis. Trapeziectomy without tendon interposition seems to be common in Umeå, although these operations were not included in the extended follow-up, see above. Implant surgery is rare, except in Gothenburg, where almost one-fourth of the thumb patients (22%) had undergone arthroplasty surgery. In Malmö, this proportion was 7%. Also refer to the section on arthroplasty surgery further on.

Patient-reported outcomes

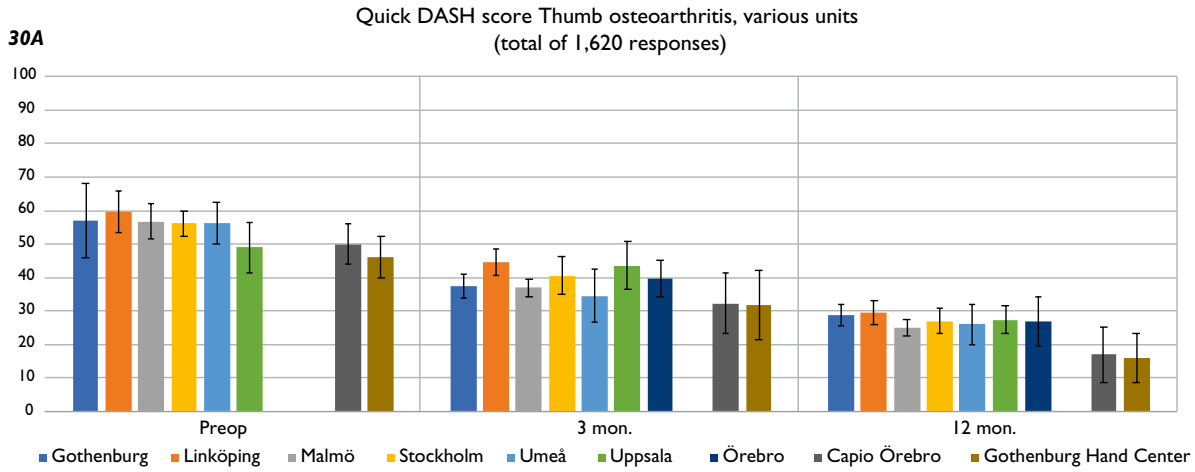
For unclear reasons, the registry holder received a data file where a large amount of preoperative questionnaire responses were missing, and because this was discovered late, there was no time to redo all the analyses.

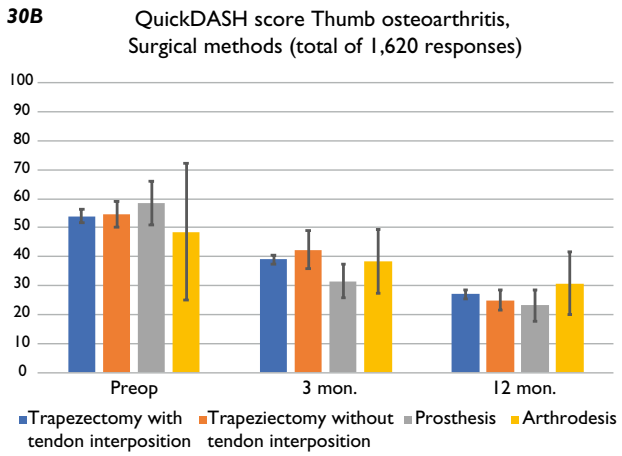
The true figure for preoperative questionnaire responses for thumb osteoarthritis was 1,104, which gives a response rate of 37%. A more complete analysis will be possible for the next annual report. The analysis below has therefore only been done using 338 questionnaires responses before surgery and 1,050 responses one year after surgery. This gives a response rate of 33% one year after surgery, but only 11% preoperatively. No definite differences in patient-reported outcomes are observed, neither between the clinics nor between the different surgical methods, see Figure 30 A and B.

The distribution of responses on the scale 0-100 regarding rest pain (question 3 in the questionnaire) and pain on load (question 1) is shown in Figures 31 A and B. The majority of patients feel that they do not have pain at rest in their operated hand one year after surgery (31A), but the dispersal between the responses is much greater for pain on load (31B). 29% (307 patients) indicate 50 or higher for pain on load one year after surgery, which leaves reasonable room for improvement in our treatments.

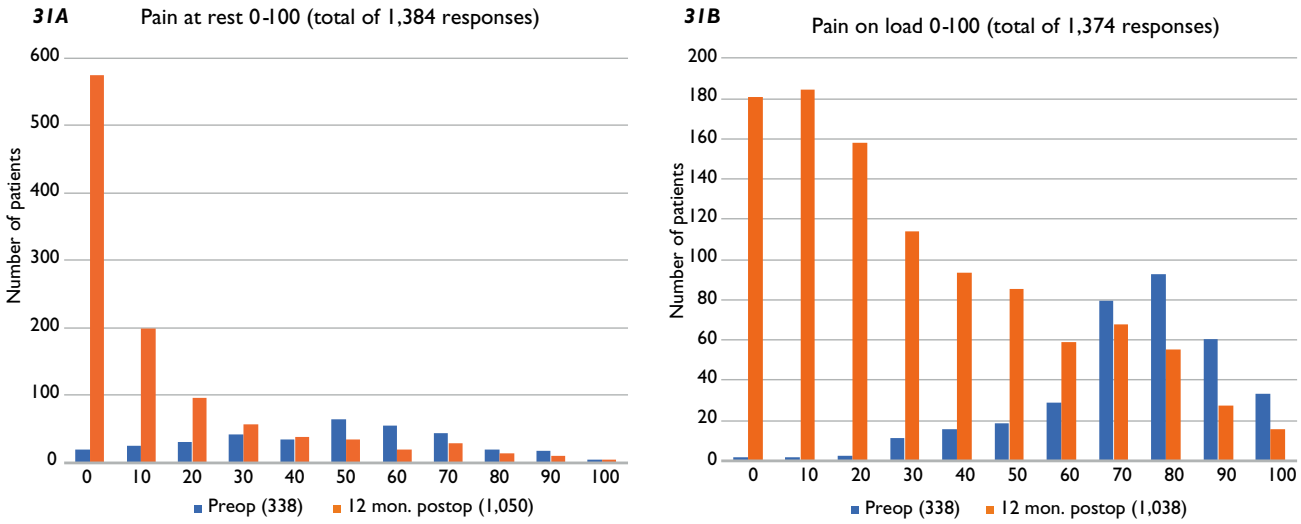
Patients with persistent pain on load

A closer analysis of the 307 patients who indicated a high degree of pain on load (>50) one year after their surgery shows the same proportion of women as among all who responded, and that the patients were only marginally younger (mean of 61.1 years old). However, these patients had reported a higher degree of complaints even before surgery, with an average of 77.1 for pain on load (compared with 71.5) and a higher degree of perceived disability prior to the operation (QuickDASH) 60.0 (compared with 54.3). Unfortunately, it is not the case that these patients experienced an equal improvement from a higher level of complaint; on average they had improved only 10 points compared to 36 points for the whole group, see Figure 31. Both the distribution between different surgical methods and between different units were the same for patients with poorer perceived results as for the whole group. Therefore, it is not easy to identify, based on the HAKIR data, why these patients did not become pain-free after their surgery.

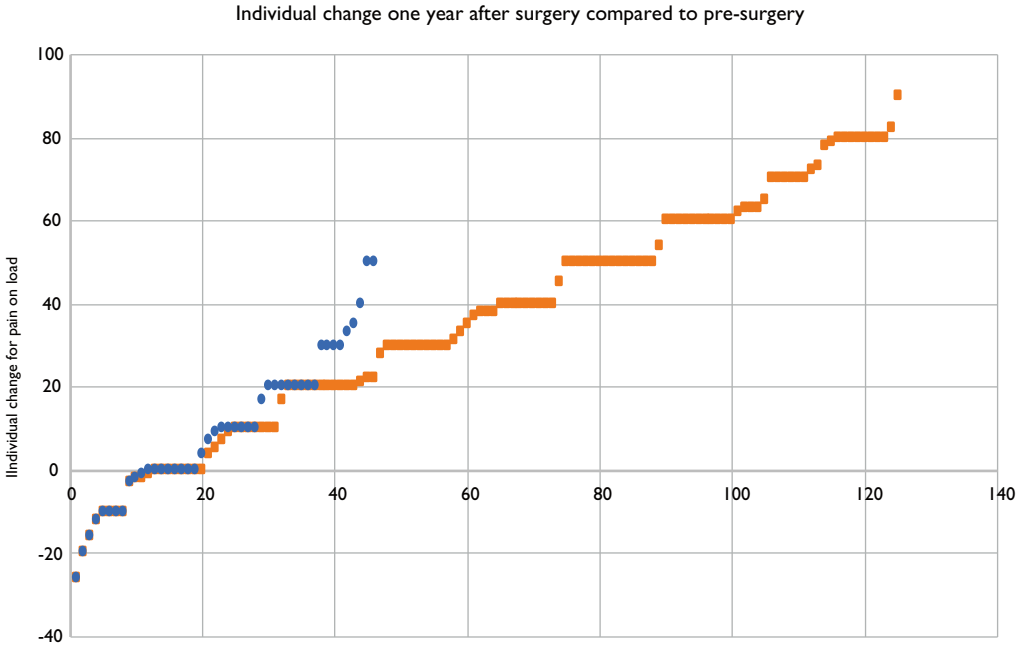




Figur 30. *Perceived disability in the hand and arm (Quick-DASH score 0-100) before and after surgery at the different units (A) and for the different surgical methods (B). The error bars indicate a 95% confidence interval.*



Figur 31. *Perceived degree (0-100) of pain at rest (A) and pain on load (B) in the operated hand before and one year after thumb surgery, regardless of the surgical method. Number of answers in brackets. All preoperative responses are included in the figure, not just those who also responded after one year. Only 124 responded on both occasions. However, the distribution across the response options was very similar. Note the different scale on the Y-axes.*



Figur 32. *Individual change in perceived pain on load before, compared to one year after surgery for those patients who indicated 50 or more at the one-year point (Blue dots; 46 responses) compared to all responses (Red dots; 125 responses). Each point indicates a patient. Minus values indicate perceived deterioration.*

IMPROVEMENT ASPECTS - THUMB OSTEOARTHRITIS

The large variations we see nationally in the treatment of thumb osteoarthritis are probably due to local traditions. We need to monitor treated patients long-term to be able to identify methods that produce worse results based on both symptoms experienced by patients and examination findings. We need to define and agree on indications for surgery.

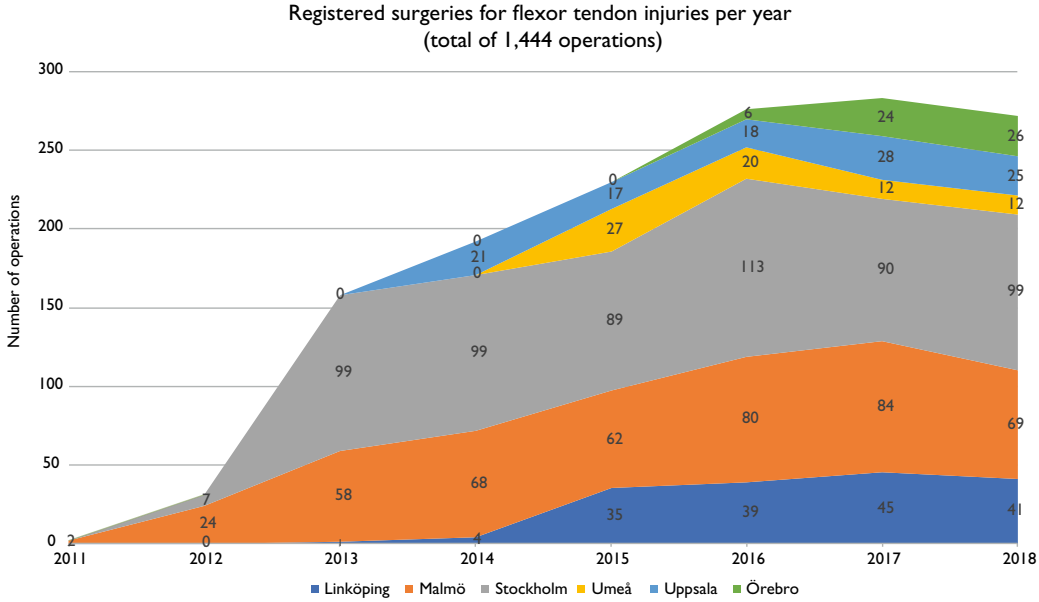
We need to become better at obtaining information on patients' experiences before surgery because patient-reported outcomes (PROM) are best described as individual changes for each patient. Also preoperative functional examinations need to be more complete in Linköping, Umeå, Uppsala and Örebro. With a well-established routine, this does not entail much more work. We welcome Malmö and Gothenburg, which do extensive arthroplasty surgery, to also participate in the extended follow-up of thumb osteoarthritis.

As previously reported, we have not been able to identify any definite differences between different types of tendon arthroplasty or between trapeziectomy with or without tendon interposition, neither in patient-reported outcomes or in thumb grip strength. This is well in line with scientific studies that have been done internationally. Nevertheless, most Swedish hand surgeons choose to perform tendon interposition. HAKIR gives us a unique opportunity to evaluate our treatments in a Swedish context and with many more patients than in the scientific studies that have been done previously.

Not showing differences between treatment methods does not mean that all patients are satisfied with the outcome. Almost 30% indicate significant pain on load in their operated hand one year after surgery. We cannot find any definite causes for this and the problem needs to be elucidated in another way, such as through qualitative interview studies with patients in order to identify causes of persistent complaints. It would also be of value to interview patients treated non-operatively as a comparison.

Flexor tendon injuries

Up until 31 December 2018, 1,444 surgeries (1,638 tendon injuries) had been registered using the extended surgery form for flexor tendon injury (HAKIR 02A). The mean age of these patients was 36.7 (median 34, range 0-87), 35 patients (2.4%) were children under 18 years of age and 72% were men. The right hand was injured in 46.8% of cases, the left in 52.9%, and both hands in 0.3%.



Figur 33. *Number of registered surgeries for flexor tendon injuries zone I and II per year and clinic.*

PARTICIPATING UNITS

The number of surgeries for flexor tendon injuries zone I and II at each clinic per year is shown in Figure 33. Stockholm registers the most injuries per year, around 100, in Malmö about 80 injuries, in Linköping about 40 per year and in Örebro and Uppsala around 25. In Umeå, the number of injuries per year has not been constant, which is why it is uncertain whether all injuries have been registered in HAKIR. We will attempt to validate the information during the upcoming audits at the clinics.

TIME FROM INJURY TO OPERATION

Registration of the injury date was included for 1,298 surgeries for flexor tendon injuries. Prior to the annual report, we have validated the date data for the 106 operations that were suspected of being inaccurate through local individuals comparing it against data in patient records at each clinic. We found that dates were incorrectly registered for 18 operations and that 9 operations did not meet the inclusion criteria, e.g. secondary suture after rupture or tendon transplant. For 79 operations, the time between injury and surgery was more than 14 days. The review of patient records showed that the delay was owing to the patients themselves in about half of the cases and that the injury had primarily been missed at a health centre or emergency room in half of the cases, see Table 5. Causes related to the healthcare services were most common in Stockholm and Umeå, while patient-related causes were most common in Uppsala.

	Patient´s delay	Health care related delay	Unclear	Number of pat. with a time >14 days
Linköping 165)		2	1	3
Malmö (447)	1	6		7
Stockholm (596)	19	24		43
Umeå (71)	4	4		8
Uppsala (109)	9		1	10
Örebro (56)	0	2		2
Total (1,444)	33	38	2	73

Table 5. *Cause of a delay of more than 14 days between injury and operation for flexor tendon injuries. Number of flexor tendon patients per clinic in brackets.*

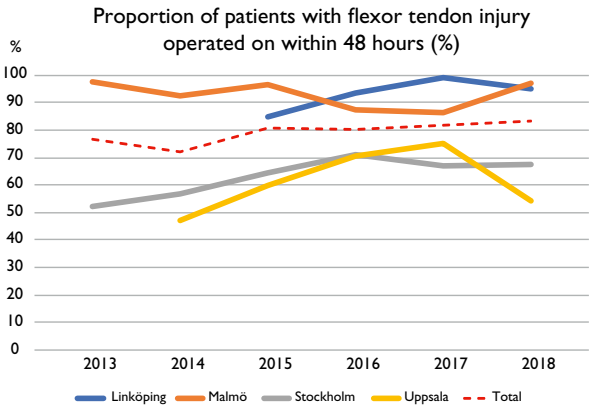


Figure 34. *Proportion of patients with a flexor tendon injury who were operated on within 48 hours (%) per clinic and year. Red dashed line shows average value for all clinics. Total of 1,298 operations.*

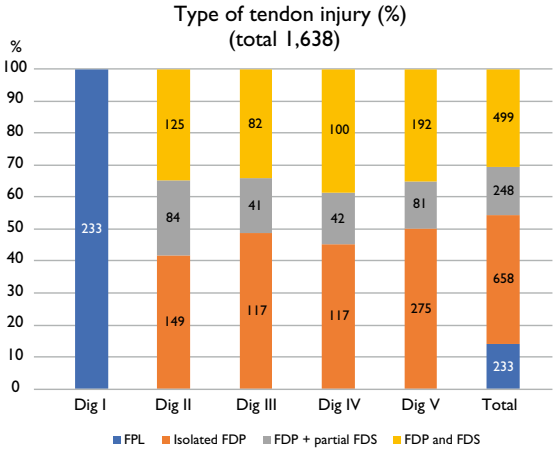
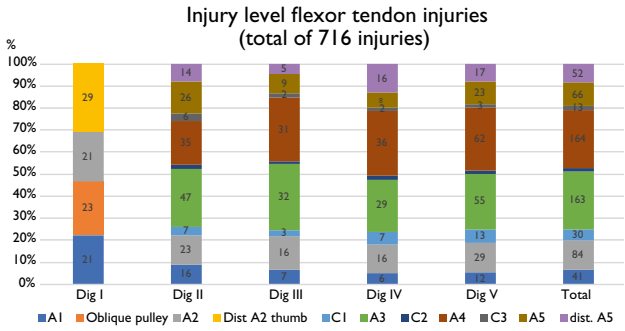


Figure 35. *Distribution of flexor tendon injuries in thumb and fingers (%). The figures indicate the number of injuries.*



Figur 36. *Distribution of different injury levels (%). The figures indicate the number of injuries.*

To improve the data quality and reduce the risk of errors, we are now putting in blocks for injury dates after surgery dates and pop-ups that give alerts for reoperations and periods of this length delay is probably not due to the factors we want to highlight, but perhaps more likely caused by a patient-related or healthcare services-related delay outside the clinic. The indicator shows differences between the clinics where Malmö and Linköping operate on almost all flexor tendon injuries within 48 hours, while the proportion is only around 60-70% in Stockholm and Uppsala. The trend over time is shown in Figure 34. Örebro and Umeå had registered too few injuries per year, so these clinics are not shown in the figure.

TYPE OF TENDON INJURY

Of 1,638 tendon injuries, 233 (14%) were incisions to the FPL tendon in the thumb and the rest were finger injuries. Distribution between various tendon injuries is shown in Figure 35. Little finger injuries were most common, accounting for 33.5%. Around one third of the injuries (35.3%) included both flexor tendons (FDP + FDS), and this was about as common in all fingers. Digital nerve injuries occurred in 42% of cases and was more common in radial phalanges; 51% in the thumb and forefinger, 42% in middle fingers, 40% in ring fingers and 33% in little fingers. This is probably due to both anatomy and different injury mechanisms.

The injury level in the finger was registered for 716 injuries. In fingers, the tendon injury was at the PIP joint level in 59% of cases (C1, A3, C2, A4), see Fig. 36. Reinsertions (distal injuries) accounted for only 8.4% in the fingers, but 30% in the thumbs.

SURGICAL TECHNIQUE

The number of strands in the core suture is shown for the thumb tendons in Figure 37A and finger tendons in Figure 37B. Four strands were used in 73% of cases for thumb tendons and in 79% for finger tendons. There is a slight variation between the clinics, where two-strand sutures appear somewhat more common in Linköping and six-strand sutures seem slightly more common in Umeå.

REHABILITATION PROGRAMME

Information on a postoperative rehabilitation programme was included for 92 thumb tendon injuries and 538 finger tendon injuries. Early active mobilisation had been used for 75% of the thumb injuries and 74% of the finger injuries. Malmö has consistently used early active mobilisation during the entire period, while Linköping has up until 2018 used the four-finger Kleinert method (passive flexion with rubber band flexion pull in four fingers). Stockholm has up until 2015 used the one-finger Kleinert method in multiple cases, see Figure 38. In recent years, early active mobilisation has increased gradually and was applied to 92% of finger tendons in 2018 (see Fig. 39).

JOINT MOTION

In the dynamic output data report published on www.HAKIR.se, joint motion for different types of flexor tendon injuries and suture and rehabilitation techniques for the different clinics can be easily discerned. Note that you always have to look for how many measurements the graph is based on and interpret the results with caution.

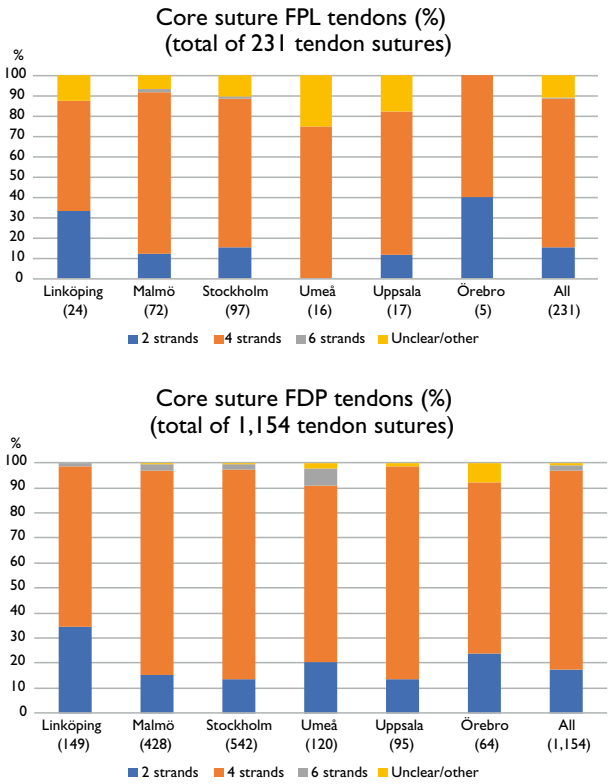


Figure 37 A och B. *Proportion of different strands in the core suture for thumb tendons (A) and finger tendons (B) for the different clinics. Number of sutured tendons per unit in brackets.*

A common way to report results after a flexor tendon repair is Total Active Motion (TAM), which indicates active flexion minus any extension defect totalled for the three joints of the finger (MCP + PIP + DIP joint; for the thumb, MCP + IP joint). The normal TAM for a finger is 260 degrees, and for the thumb, 130 degrees. Figure 40 shows the result of 1,172 goniometer measurements of TAM per finger with spread measurements. We do not see any clear differences in results between the different fingers.

TAM three months after surgery was on average 199 + 3.1° (76% of normal value) in the fingers and 94 + 7.2° (72%) in the thumbs. At twelve months, TAM was 219 + 3.8° (84%) in the fingers and 115 + 8.5° (88%) in the thumbs. The joint mobility was thus improved by about 20 degrees during the period 3 and 12 months after surgery. Therefore, rehabilitation cannot be considered completed at 3 months.

Joint mobility is often presented according to Strickland as a percentage of normal TAM and categorised under "excellent", "good", "fair" and "poor". Figures 41 A-E show proportions of the different groups of results for all patients for the four clinics that had a sufficient number of measurements. Uppsala only had 16 measurements at 3 and 12 months after surgery, and Örebro had 4 measurements after 3 months and no 12 months measurements. These two clinics do not appear to have the follow-up procedures in place yet.

GRIP STRENGTH

According to the form, grip strength is measured with a Jamar dynamometer at 3 and 12 months, but in several cases the strength has not been measured at 3 months in order to avoid the risk of tendon rupture. Figure 42 shows that the strength in the operated hand has almost been restored one year after surgery.

RESULT OF FLEXOR TENDON SUTURE ON CHILDREN

In the extended form, there were 114 operations registered for patients under the age of 18, including 13 children under the age of 6. Unfortunately, there were no joint mobility measurements for these young children, but for the whole group in category 0-18 years old, there were good values for TAM, both at 3 months (226 + 12.4°; 27 measurements) and one year after surgery (261+ 18,6°; 17 measurements). Each of the 17 of the children studied reached the level of "Excellent" or "Good" at 12 months. 16 children underwent reoperation, but only 1 tendon rupture, involving a 1-year-old child, was registered. Unfortunately, a certain amount of insufficient reporting is probable.

DIFFERENCES BETWEEN WOMEN AND MEN

Among 1,229 finger tendon injuries (FDP), 72% were men. The average age for the 887 men was 36.2, and for the 342 women it was 35.9. TAM at 3 months averaged 199 degrees for men (437 measurements) and 196 degrees for women (144 measurements), that is to say, both were "good" according to Strickland. At 12 months, the average for men was 216 degrees (285 measurements), i.e. "good", and 228 degrees for the women (98 measurements), i.e. "excellent". However, there is a major drop-off at 12 months, which is why it is difficult to say whether women really achieved better mobility than men.

REOPERATIONS AND TENDON RUPTURES

Patients who experience a tendon rupture are not included in the report on joint mobility. A tendon rupture may be seen as a failure of treatment and something that we should try to prevent as far as possible. Therefore, from a quality point of view, it is very important that complete registration in HAKIR is achieved.

Of the 1,444 patients who underwent flexor tendon repair, 172 (12%) had undergone reoperation (before 1 January 2019). Fifty patients had been reoperated more than once. Tendon rupture was the most common cause of reoperation (4.1%), followed by tenolysis due to adhesion formation (3.2%). Only 0.07% of patients underwent reoperation due to postoperative infection.

Following closer analysis of the 57 patients who experienced a rupture of the sutured tendon, it turns out that 14 of these were thumb tendons (FPL), see Table 6. Stockholm had a particularly high rupture frequency for thumb tendons, 11.8%, i.e., more than one in ten tendon sutures did not hold

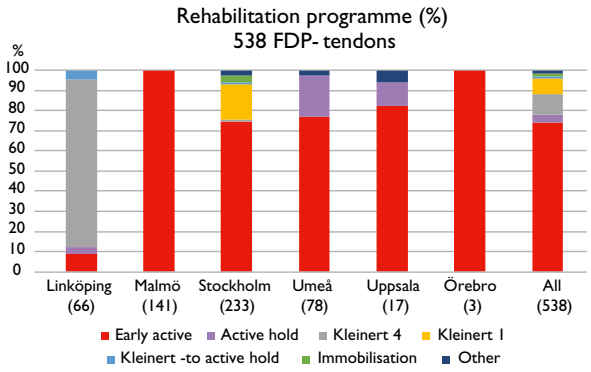


Figure 38. *Proportion of different postoperative rehabilitation programmes per clinic (%). Number of patients in brackets.*

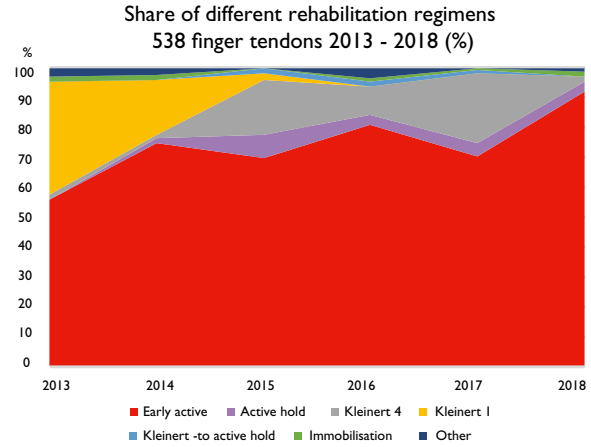


Figure 39. *Share of different rehabilitation programmes over time (%).*

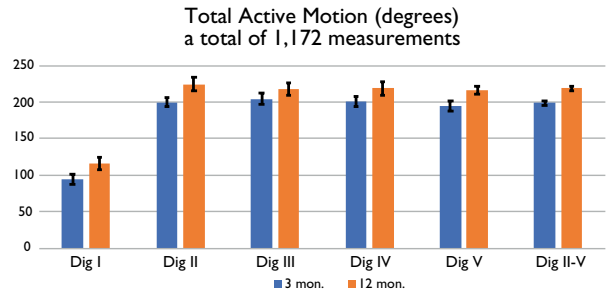
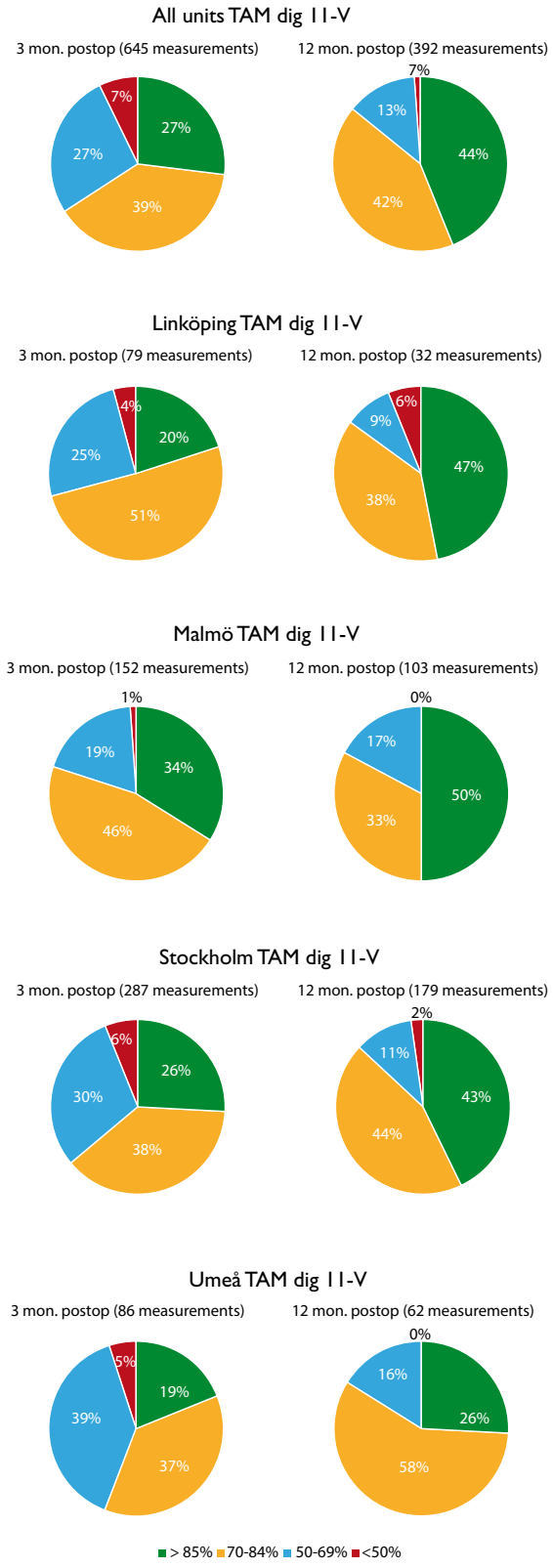


Figure 40. *Total Active Motion (TAM) in thumb and fingers three and twelve months respectively after surgery. The spread measurements show a 95% confidence interval.*

postoperatively. It is also interesting that 12 of the 14 patients who experienced a rupture of the thumb tendon were men, and that the average age was higher; 48.8 compared with 36.8 for all tendon injury patients. We noted this already in the annual report for 2017 and the rehabilitation regimen for thumb tendons was subsequently changed in Stockholm to a more cautious programme. Fortunately, there was only one thumb tendon rupture (Stockholm) in 2018. It is a little premature to say for sure whether the improvement is due to the problem having been highlighted in HAKIR, but that may well be the case. Another difference between the clinics which

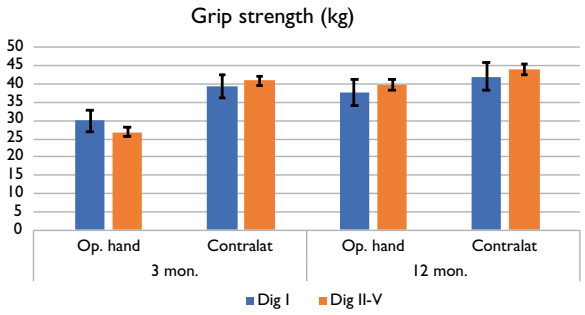


Figur 41 A-E. *Proportion (%) of patients who regained active motion rated Excellent (green= TAM>85% of normal value); Good (yellow= 70-84%), Fair (orange= 50-69%) and Poor (red= <50%) respectively, three months and twelve months after surgery. Note that there are few measurements in some groups.*

had the highest number of thumb tendon ruptures and others is the time between injury and surgery (see Figure 34). Could it be that thumb tendons are more sensitive to delay than finger tendons? Could a more distal injury level in the thumbs be a cause of more ruptures? More detailed analyses will be performed in future scientific studies.

Finger tendon ruptures (FDP II-V) were less common than for thumb tendons, see Table 6, and also varied less between clinics. As in previous years, neither Örebro nor Umeå registered any tendon ruptures at all, despite both clinics having registered a total of 205 tendon injuries during the period, and they should reasonably have had at least 4-5 ruptures. HAKIR has pointed out the low reoperation rate at both clinics on several occasions. We will follow this up through validation work going forward.

Unfortunately, there are still some quality deficiencies in the data, and a thorough analysis of rupture frequency and causes of complications would require specific validation work involving a review of patient records. A doctoral dissertation project focusing on this has been started in 2018, see below.



Figur 42. *Strength in grip (kg) three and twelve months after surgery in operated hand and healthy hand respectively. The error bars indicate a 95% confidence interval. For FPL, there were 94 measurements at three months and 59 at 12 months. For FDP, there were 399 and 338 measurements respectively..*

	Linköping	Malmö	Stockholm	Umeå	Uppsala	Örebro	Total
FPL (14)	0	1,4	11,3	0	11,8	0	6,1
FDP II-V (33)	5,6	2,2	3,1	0	2,3	0	2,7

Tabell 6. *Rupture rate (%) of total number of sutured thumb tendons (FPL) and finger tendons (FDP II-V) respectively per clinic. Number of ruptures in brackets. Note that the total number is low, which is why the percentages are uncertain.*

IMPROVEMENT ASPECTS - FLEXOR TENDON INJURIES

Correct registrations are crucial for a quality registry. We have set up blocks where possible and pop-up messages to warn of suspected incorrect values in order to try to minimise erroneous registrations. Data is also validated regularly and incorrect values are corrected where possible. For example, reoperations following primary flexor tendon suture, prompted by a rupture or a tenolysis, should not be re-registered using the Extended Form (02A).

Instead, ruptures and tenolyses are registered as reoperations in the Basic Form (002) and the correct cause is to be entered (tendon rupture after primary suture, or reoperation due to adhesion problems).

Flexor tendon injuries are included in all specialist clinics' work and the majority of patients are followed up on at least three months after surgery via hand rehabilitation activities. It should therefore be possible to enter complete follow-up data in HAKIR across the board. Several clinics have created good routines, but not all. We hope to see an improvement.

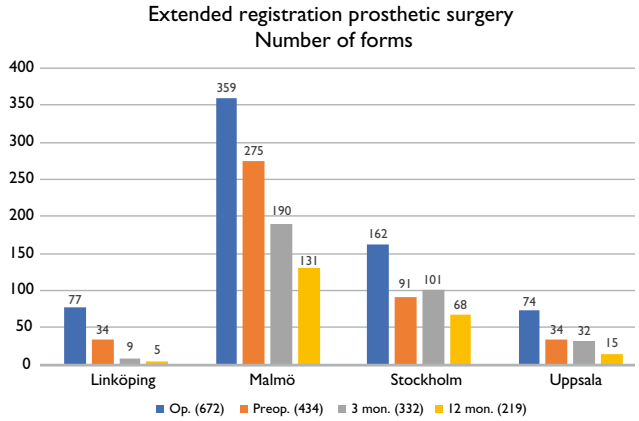
We continue to note differences between the specialist clinics in terms of time between injury and surgery for flexor tendon injuries. In two regions, almost all flexor tendon injuries are operated on within 2 days, while patients in other regions may have to wait 4-5 days for surgery for this acute injury. So far, we do not have enough data to show whether the delay is of significance to complications such as tendon rupture, infections or stiffness in the fingers. For thumb tendons, the rupture frequency was very high at the two clinics that had the longest waiting time; one out of ten sutured tendons had burst. We did not observe the same difference for flexor tendons in the fingers, and perhaps thumb tendons are more sensitive due to different anatomy. We will follow the results closely in the future. The time from injury to surgery has been added as a hospital-wide quality indicator at Södersjukhuset in Stockholm and we hope that this can lead to shorter lead times. The difference in lead times is probably due to the fact that these injuries cannot be operated on at certain clinics during the weekend.

Prior to the annual report, we have also performed a review of the causes for delays of more than 14 days when suturing flexor tendon injuries. In a good number of cases, these were incorrectly included patients, for example tendon ruptured that had been re-sutured. We also found in several cases that the diagnosis had been delayed at the primary visit to a health centre or emergency room. This was especially common in Stockholm, perhaps because there are many different healthcare providers that assess acute hand injuries. In other regions, it was common for the patient to underestimate their injury and to seek medical care at a late stage. The field of hand surgery may need to improve its training and information on flexor tendon injuries to reduce these problems. A missed flexor tendon injury can lead to complications, cause prolonged convalescence and lead to high societal costs.

In general, the outcomes are quite good for flexor tendon injuries in our country. The rupture frequency is in line with international data and most patients have regained acceptable range of motion after one year. At the same time, this is a large diagnostic group within hand surgery and every tendon rupture or tenolysis operation entails significant discomfort to the patient and high costs for society. Continued resources for specialised hand rehabilitation are crucial to achieving good results. It will be interesting to see if we can improve mobility and reduce the proportion of ruptures by introducing the new surgical techniques that are now being launched, for example a more generous venting of flexor tendon pulleys and "wide awake" surgery, where the quality of the tendon suture can be tested directly during the operation. We will include these new variables in the surgery form.

Arthroplasties

Four units are participating in extended registration of joint prosthesis surgery. Up until 31 December 2018, 672 surgeries had been registered in the extended form in HAKIR (see Figure 43). The Malmö clinic accounted for just over half of the operations (53%) and Stockholm for a quarter (24%). Of all registered surgeries, 64.6% had preoperative examinations, 49.4% had three-month examinations and 32.6% had twelve-month examinations. If all surgeries in 2018 are excluded, 36% had been followed up one year after surgery.



Figur 43. *Number of registered forms per participating unit within extended registration for prosthesis surgery. The figures indicate the number of forms. 66 operations performed in 2018, where one year has not yet passed from the surgery, are included in the figure. The rates of follow-up are therefore probably somewhat higher than presented..*

THUMB JOINT IMPLANTS

A total of 77 thumb implants were registered for 71 patients. The patients were on average 62.3 (44 - 85) years old and 80.3% were women. Swanson prostheses (silicone trapezium prosthesis; 38 prostheses) accounted for half, the second most common being Nugrip (pyrocarbon) (22) followed by Elektra (6) and Moovis (two-component prostheses; 5) and pyrocarbon prostheses for the STT joint, STPI (5). As so few new prosthetic surgeries were registered in 2018, no further analysis will be done here.

However, in the basic registration of the main diagnosis of thumb osteoarthritis (M18) and the surgery code for joint prosthesis, there were 192 surgeries. In addition, there were 28 surgeries registered involving the removal of thumb base prostheses. It is interesting to compare the number of operations with thumb prostheses between the units and over time, see Figure 44. Very few or no thumb prostheses were implanted in Linköping, Stockholm, Uppsala and Umeå or in the private units. In Malmö, many prostheses were implanted in 2013, but after that the number has decreased. Gothenburg is the unit where by far the most prostheses have been implanted, averaging at 16 per year during the years when the clinic has been involved for a full year. Unfortunately, we cannot see which type of implant that was used from the basic registration.

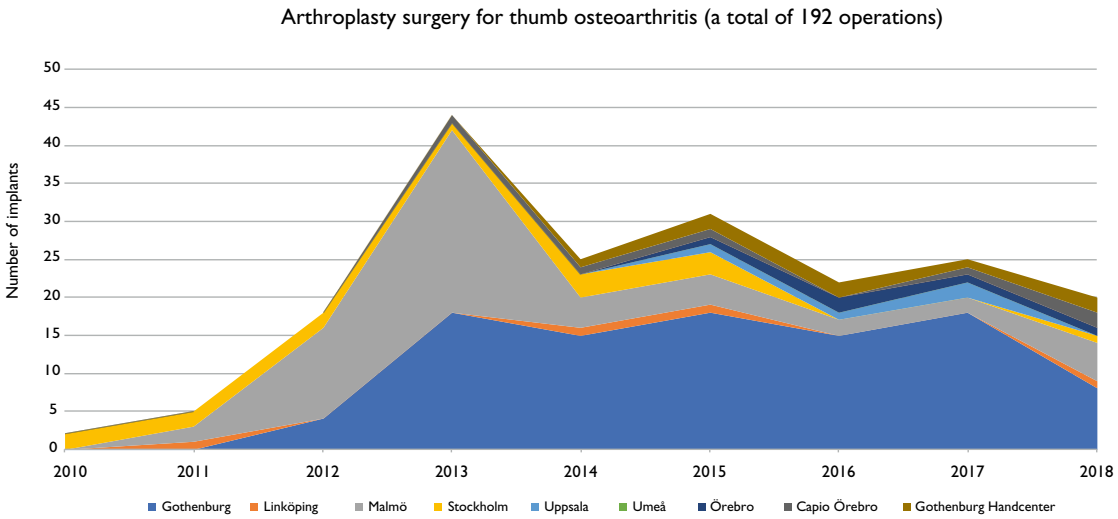


Figure 44. *Number of operations with the main diagnosis thumb osteoarthritis (M18) and the surgery code for joint prosthesis (NDB59) per participating unit and year within basic registration. Umeå had not registered any surgery involving a thumb prosthesis. Note that the clinics have joined HAKIR gradually. Gothenburg has no data for after September 2018.*

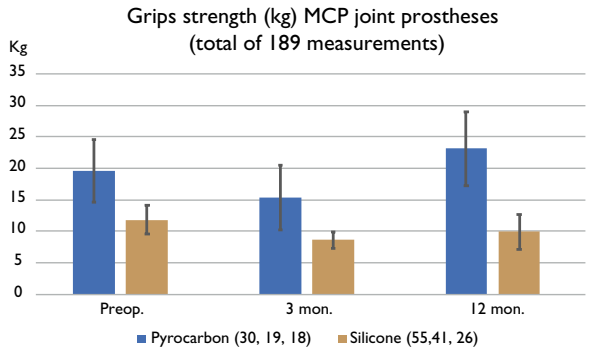


Figure 45. Grip strength using a Jamar Dynamometer (kg) for patients operated on with MCP joint prosthesis before and after surgery. The error bars indicate a 95% confidence interval. Number of measurements before and 3 and 12 months after surgery in brackets.

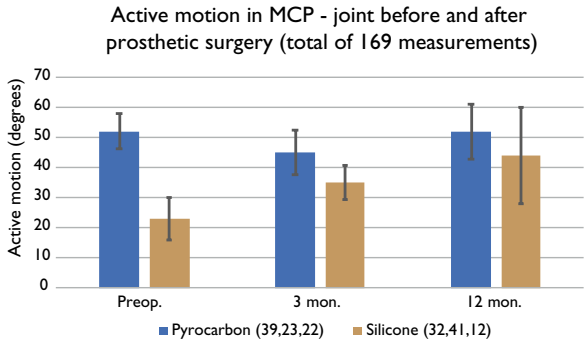


Figure 46. Active motion (degrees) in the MCP joint before and after prosthetic surgery. The error bars indicate a 95% confidence interval. Number of measurements before and 3 and 12 months after surgery in brackets.

MCP JOINT PROSTHESES

A total of 222 surgeries and 520 MCP joint prostheses were registered. Silicone prostheses (e.g. Swanson) were most common (414), followed by pyrocarbon (46) and then SR Avanta (9). For 51 prostheses, the prosthetic model was not registered. Pyrocarbon prostheses were most common for the index and middle finger, while silicone prostheses were almost as common in all MCP joints. The patients' average age was 63.1 (32-88) years old, and 79.7% were women.

Figure 45 shows grip strength before and after surgery involving pyrocarbon and silicone prostheses respectively, and Figure 46 shows active motion in MCP joints after surgery. Patients with pyrocarbon prostheses had both better strength and mobility before surgery. The groups are not comparable; the proportion of men in the pyrocarbon group was 36% with an average age of 60, while the proportion of men in the silicone prosthesis group was only 13% with an average age of 64. Many patients in the pyrocarbon group were probably men with post-traumatic osteoarthritis, while rheumatics dominated the silicone prosthesis group. Mobility in the MCP joint did not improve in the pyrocarbon group, but improved quite a lot in the silicone prosthesis group, which was mainly due to a reduced extension deficit from 49 degrees preoperatively to 17 degrees one year after surgery.

The two patient groups started with about the same level of perceived disability (QDASH=51.6 for pyrocarbon and 48.1 for silicone), but the pyrocarbon group showed a more pronounced decrease after one year (to 23.1, compared to 42.9). In cases of rheumatism, many other problems that affect perceived disability in the arm and hand are conceivable.

PIP JOINT PROSTHESES

A total of 194 surgeries and 233 PIP joint prostheses dig. II-V were registered. The majority (48%) were operated on in Malmö, 24% in Stockholm, 17% in Uppsala and 10% in Linköping. The patients' average age was 64.0, and 86.1% were women. 70% had primary osteoarthritis (Bouchard), 9% had inflammatory joint disease and 21% had post-traumatic or another cause of osteoarthritis. Of the 233 PIP joint prostheses, pyrocarbon prostheses were most common (52%), followed by SR-Avanta-SBI (19.7%) and silicone prostheses (15%). Unfortunately, information on the prosthetic model was not included in 13.3% of cases..

An indication for PIP joint prosthesis surgery is usually pain during joint mobility. A good effect on these problems was already seen three months after surgery for all prosthetic models, with the reservation that the number of respon-

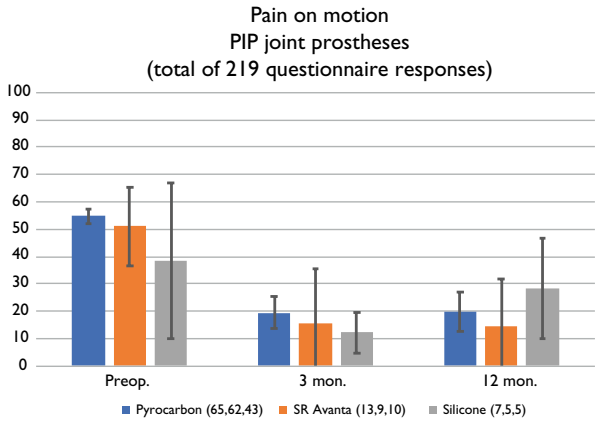
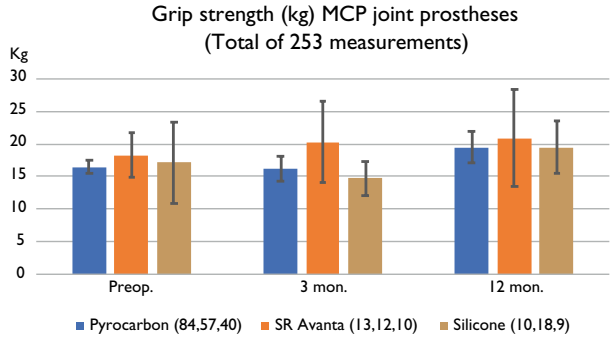


Figure 47. Mean pain (0-100) on motion without load (question 2 in HQ-8) before and after PIP joint prosthetic surgery. The error bars indicate a 95% confidence interval. Number of measurements before and 3 and 12 months after surgery in brackets. The significant spread for the silicone prostheses is due to the small number of responses.



Figur 48. Grip strength using a Jamar Dynamometer (kg) for patients operated on with PIP joint prosthesis before and after surgery. The error bars indicate a 95% confidence interval. Number of measurements before and 3 and 12 months after surgery in brackets.

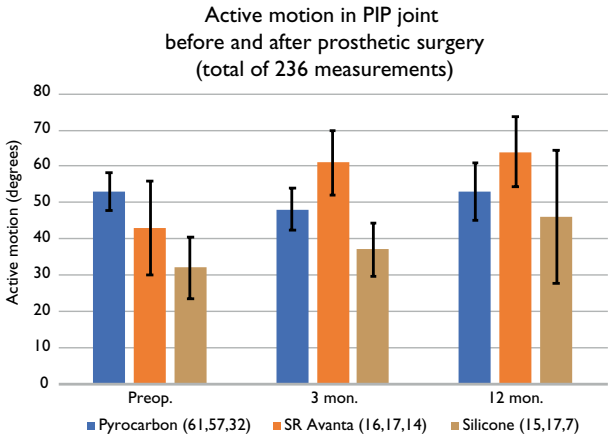


Figure 49. Active motion (degrees) in the PIP joint before and after prosthetic surgery. The error bars indicate a 95% confidence interval. Number of measurements before and 3 and 12 months after surgery in brackets.

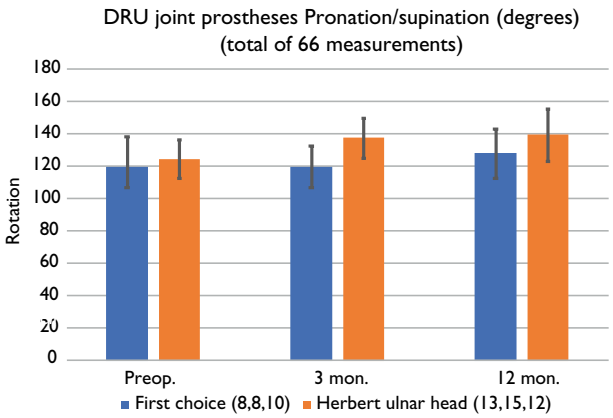


Figure 50. Active total pronation/supination (degrees) after prosthetic surgery in the DRU joint. The error bars indicate a 95% confidence interval. Number of measurements before and 3 and 12 months after surgery in brackets.

ses for silicone prostheses was very low, see Figure 47.

Grip strength for patients who underwent surgery with different types of PIP joint prostheses is shown in Figure 48, and active joint mobility is shown in Figure 48. It is possible to discern differences in postoperative joint mobility between the prosthesis models, but so far the variation is too great to say whether or not this difference is random in nature. One year after surgery, 4 out of 32 pyrocarbon prostheses (12%) and four out of 14 SR-Avanta prostheses (28%) had hyperextension in the PIP joint. None of the silicone prostheses had this problem.

WRIST JOINT IMPLANTS

107 operations involving a wrist prosthesis were registered; 92 and 68% were women. 54 were radiocarpal joint prostheses, 51 were distal radioulnar (DRU) joint prostheses and 2 were intercarpal prostheses (pyrocarbon prostheses for the STT joint).

DISTAL RADIOULNAR JOINT PROSTHESES

41 out of 51 DRU joint prostheses (80%) were implanted in Malmö, four each in Linköping and Stockholm, and two in Uppsala. 28 prostheses were Herbert Ulnar Head and 14 were First Choice (all from Malmö). For six operations (3 each in Linköping and Malmö), there was no information on the prosthesis model. The First Choice prostheses were well monitored (8 of 14 patients underwent complete preoperative examinations, as well as three and twelve months after surgery). Active rotation (pronation + supination) for the two DRU prosthesis models is shown in figure 50. Supination was most restricted. There is no definite difference in mobility before and after surgery, nor between the two prosthesis models, but the number of examinations is low. There were also too few questionnaire responses to identify differences between different DRU joint prostheses, but for the entire group, QuickDASH was 56.2 before surgery, 44.0 at three months and 27.9 one year after surgery. Pain on load averaged at 64, 50, and 36 at the three time points and satisfaction was 79%. Therefore, the prosthetic surgery seems to have decreased, but not completely done away with, perceived disabilities and pain issues.

RADIOCARPAL JOINT PROSTHESES

The distribution between the clinics was Malmö (23), Linköping (19), Stockholm (10) and Uppsala (2). Several different prosthesis models featured; Remotion, Universal II, Motec and Maestro. Unfortunately, preoperative examinations were only registered for 15 out of 51 patients – 13 Malmö patients and two from Stockholm, none from Linköping or Uppsala. Results regarding grip strength, wrist mobility (flexion + extension) and QuickDASH score before and after surgery are shown in Table 7.

	Grip strength (kg)	Active motion (degree)	Number of measurements	Quick-DASH score	Number of questionnaire responses
Before surgery	14	58	15	57,1	17
3 months after surgery	14,5	54	19	39,3	20
12 months after surgery	20	60	14	30,4	16

Table 7. Mean values for grip strength with a Jamar Dynamometer (kg), active joint mobility (flexion + extension) and total score for QuickDASH before and after surgery with radiocarpal wrist prosthesis. Note that there are few measurements and questionnaire responses.

REOPERATIONS

315 reoperations were registered for the 673 prosthetic surgeries, 100 of which involved various complications. Many were implant ruptures of silicone prostheses, persistent pain problems and joint stiffness. Only seven infections (1%) were registered.

IMPROVEMENT ASPECTS - ARTHROPLASTY REGISTRATION

The results of the arthroplasty registration in HAKIR raise many questions. For example, based on the registered arthroplasty surgeries now found in HAKIR, there is a significant national variation in the frequency of procedures, choice of implant and to some extent outcomes. However, it is difficult to draw definite conclusions because we do not have complete registrations.

What primarily complicates the evaluation of the results is the suspected scale of unreported procedures performed at the country's specialist clinics and the limited frequency of follow-up examinations for patients undergoing surgery. Therefore, it would be good to implement a fresh initiative with regard to arthroplasty registration in HAKIR.

First and foremost, it is deemed important to include all hand surgery specialist clinics in this work. A functioning national arthroplasty register within the area of hand surgery could for several reasons be made mandatory and something that all heads of departments should endorse. Arthroplasty surgery is expensive for society and if there are no resources to examine patients postoperatively, we must at least register which prosthesis models are used as well as all revisions and other complications. It is likely that follow-ups of arthroplasty surgery are being done as scientific studies at several clinics, but open and complete data access and national discussions would provide answers more effectively regarding the value of different prostheses. HAKIR is an excellent forum for establishing such evidence.

New forms in HAKIR

BRACHIAL PLEXUS INJURIES

Surgery on the brachial plexus became the focus area of national healthcare in 2016 with responsibility assumed by Umeå and Stockholm. The monitoring of the quality of care is obvious in this context and a working group from the two clinics has so far put together a total of six different forms in HAKIR intended for brachial plexus injuries, three for birth-related injuries and three for traumatic plexus injuries. These forms began to be used gradually in October 2018. Figure 51 shows the number of forms registered so far, a total of 144. The work with developing common follow-up forms is under way. All operations on adult plexus patients that have been registered in the basic registration have been followed up with questionnaires as per the usual routine.

BIRTH-RELATED INJURIES

The county of birth for 52 children with birth-related injuries is shown in Figure 52. A noticeable number of foreign-born children (21%) had been registered. Right-side injuries were slightly more common (54%) than left-side (44%) and only 1 child had a bilateral injury. 4 out of 41 mothers had diabetes and the birth weight for the children averaged at 4,270g (900-5,800g; median 4,300g). 8 children weighed over 5kg at birth and 35 (69%) weighed over 4kg. All but one child were full term births. 44 children (81%) were born with vertex presentation, two with breech presentation and 8 with another presentation. In 18 deliveries, a vacuum extractor had been used, and in another 4, a manual solution or pressure was used. 5 clavicle fractures and 4 humerus fractures had been registered, and 2 children had asphyxia during childbirth. As many as 9 out of 41 mothers had had complications during previous deliveries, three of which were previous plexus injuries.

The severity of the plexus injury at 4 weeks of age according to Narakas had been assessed for 13 children, three of whom were assessed as level 1 (C5-C6 injury), nine were assessed as level 2 (C5-C7), and one as level 3 (total plexus injury).

Only four surgeries with primary reconstruction had been registered, one of which was a double registration. Of the three infants that underwent surgery, 2 had ruptures C5-C6, one had a rupture C6-C7 and one had ruptures C5-C6 and an avulsion C7. All were reconstructed with nerve grafts and transfers of the accessory to the suprascapular nerve.

Secondary reconstructions had been performed on 34 patients 1-44 years old (mean 12.6, median 12 years old). 27 operations were shoulder surgeries, 22 of which were subscapular muscle lengthenings, 4 were shoulder relocations and 1 was an internal rotational osteotomy of the humerus. Two operations were pronation osteotomies of the forearm.

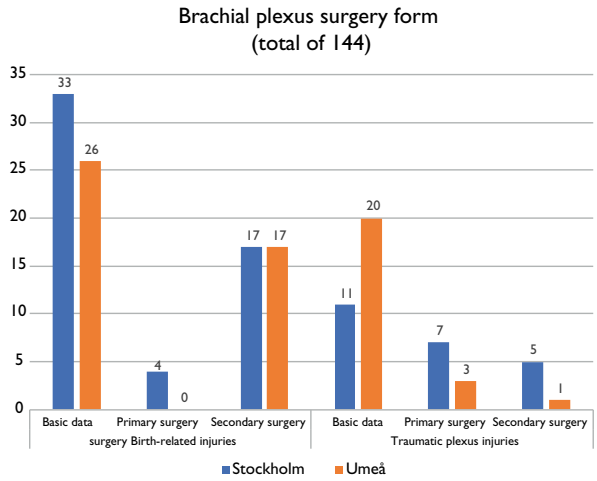


Figure 51. Number of registered forms for brachial plexus injuries. A total of 77 forms had been registered in Stockholm and 67 in Umeå.

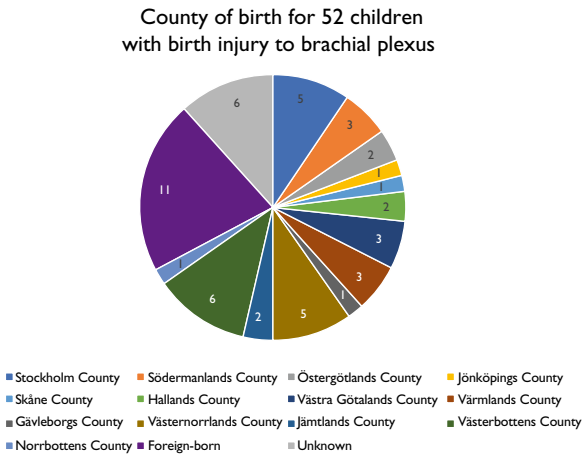


Figure 52. County of birth. Number of children per county is indicated by figures.

TRAUMATIC BRACHIAL PLEXUS INJURIES

30 patients, of which 27 were men, were registered regarding basic data. Time from injury to assessment was 2 - 367 days. High-energy trauma was indicated for 13 of them, low-energy for 12, and 3 were iatrogenic injuries. 10 primary surgical procedures were registered. The patients who underwent surgery were between 10 and 57 years old (mean 31.1, median 35) and were all male.

A preoperative MRI and neurophysiology had been performed in half of the cases. No nerve reconstruction was performed on three of the ten patients. Of the four supraclavicular injuries, three had avulsion of at least 2 cervical roots. With the infraclavicular injuries, axillary nerve reconstruction was performed on three patients and an Oberlin nerve transfer on one. Only six secondary reconstructions were registered, where the average age was 34.8 and where these too were all male patients. One patient had previously undergone nerve reconstruction. There was one muscle transfer for external rotation and two for elbow flexion, as well as three wrist arthrodeses.

SCAPHOID SURGERY

A scaphoid form has been in HAKIR since its inception in 2010, but has not been used until now. During 2018, hand surgeons in Stockholm and Malmö developed the form, which during the Autumn began to be used in Stockholm. Hopefully, more clinics will join in the future. Ten fractures and 20 cases of pseudarthrosis were registered up until 31 July 2019.

Scaphoid fractures

All 10 patients who underwent surgery were men, and the average age was 35.4 (19 - 52) years old.

Information on the injury date was only included for six of the ten patients. The time from injury to surgery for these was on average 8.8 days (1 - 19 days). Incorrect registration of the injury date must be suspected for three patients, with a waiting period of several hundred days. We will verify and correct this error.

All fractures except one were waist fractures, two fractures were part of wrist dislocations. Five fractures were fixed with compression screws and three were pinned. Bone transplantation was done in two cases.

Scaphoid non-unions

The twenty patients averaged 30.9 (17-56) years old, and 30% (6 patients) were women. The injury date was known in five patient cases and the time from injury to surgery was on average 4.2 years. Localisation was proximal in five patients, waist in ten and distal in two. 16 out of 20 pseudarthrosis cases were operated on using pins, and four with compression screws. In all cases, a bone transplant was used, in one case from the radius, the rest from the iliac crest.

Seven patients had their functionality examined before surgery, and eight patients one year after surgery. Unfortunately, surgery data was missing for many patients and none had been examined both before and after surgery.

INTERCARPAL ARTHRODESES AND PROXIMAL ROW CARPECTOMY

This form was also available in a previously unused version but was revised and launched in 2018. 26 operations were registered (up until 31 July 2019), eight four corner fusions, five LCs, five STTs, one SC, and 7 proximal row carpectomies. All intercarpal arthrodeses except for one four corner fusion were fixed with pins. All but two were bone grafted and the donor site was the iliac crest for all but one, where bone was instead taken from the radius. For 22 patients, the indication for surgery was either previous scapholunate ligament injury (SLAC) or scaphoid non-union advanced collapse (SNAC). Four patients had Kienböck's disease. Twenty-five patients had their functionality examined, but as for the scaphoid form, too little data is available to present results.

SURGERIES IN CEREBRAL PALSY

Cerebral Palsy (CP) is the most common cause of physical disability in children, but nevertheless does not receive as much attention within our speciality area. Children with CP who undergo hand surgery need to be monitored all the way up to adulthood since, for example, the results of tendon transfers change as the child grows. The form for CP surgeries in HAKIR has been developed by a national working group of hand surgeons with experience in CP hand surgery. It was completed and ready to use in the spring of 2019 but we have no registered forms thus far.

Children with CP in Sweden are monitored long-term through the national monitoring programme CPUP, with which HAKIR cooperates closely. Arm and hand operations are incompletely described in CPUP, which is why the registration in HAKIR provides a good complement. We intend to merge and analyse aggregated data in both registries in the future.

CONGENITAL ANOMALIES OF THE ARM AND HAND

Malformation registries have been kept in Sweden for many years, but they do not have enough detail to describe the anomalies from a hand surgery perspective. These are rare diagnoses and it is difficult in a small country like Sweden to gather enough experience on the best treatment regimens.

A collaboration project with colleagues from Norway, Denmark and Finland was initiated in 2018 and we have agreed on the common variables to register, even though we will have separate registries. We also collaborate with the newly started American hand anomaly registry CoULD and have been given access to all their forms. By having the same variables as the United States, we can also eventually merge our data even with this large population. We hope to be able to complete our HAKIR form in the autumn of 2019.

IMPROVEMENT ASPECTS - NEW FORMS

The reader may wonder why the data was presented here when so few registrations have been made. The purpose of this is to show that the forms are now available in HAKIR and that we are gradually collecting information that we can use together to improve care. This applies to both rare diagnoses such as brachial plexus injuries and malformations and larger diagnostic groups such as scaphoid surgery and intercarpal arthrodeses. It can be assumed that most patients with all these diagnoses are treated for a long time at the clinics because the healing time is at least 3 months, and often much longer.

By standardising the monitoring and logistics for data collection, registering in HAKIR should not require so much effort. We can learn something from each individual patient treatment if we follow up in the same way. The clinics that want to start using the new forms should first contact us at HAKIR so that we can help with the start up. Sufficient resources must be allocated within the hand rehabilitation units, and the hand surgeons must be committed to having all patients included in the registrations.

Quality indicators

Indicators that reflect the quality of care are needed both for the principals to be able to follow up on the care being provided, but also as a basis for improvement work and as information for patients.

Evaluating hand surgery care is complex. We treat many different types of injuries and illnesses and we have patients of all ages. Hand surgery care is not intended to save or extend lives, but to improve the quality of life and reduce disability. Quality indicators must therefore include patient-reported measures to a large extent. Since the beginning, HAKIR has gathered feedback in the form of PROM and PREM and we are now starting to get enough good data for creating quality measures. In the autumn of 2018, we included hand surgery's first two indicators on www.vardenisiffror.se (Healthcare in Numbers), the coverage rate in HAKIR and the time between injury and surgery for flex- or tendon injuries. Outcomes for these are shown in Figures 53 and 54, where we have also presented a statistical comparison between the measured values.

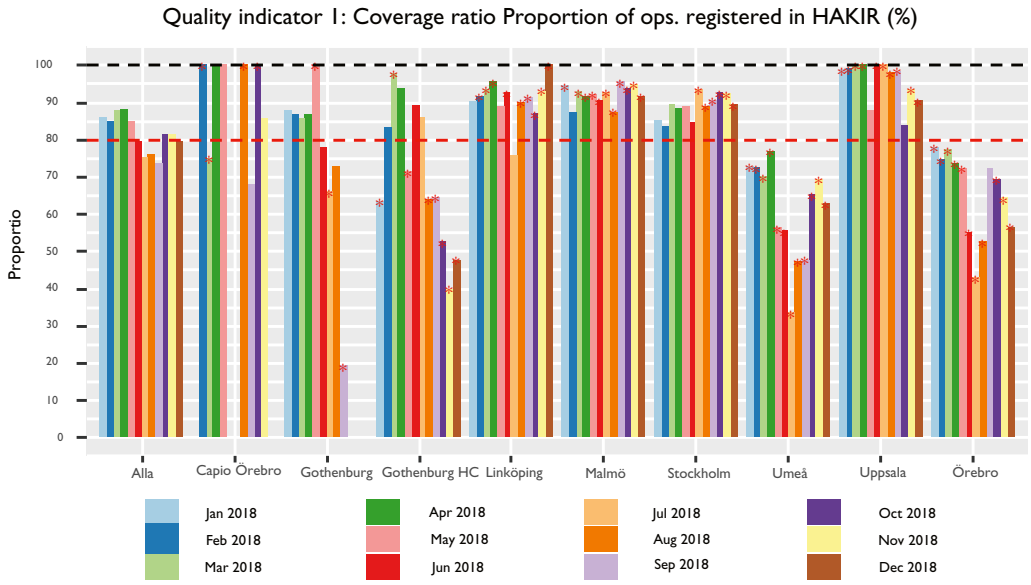


Figure 53. *Coverage in HAKIR during 2018; i.e., number of registered operations/number of performed operations (%). Asterisk denotes a statistically significant difference between values. Red dashed line our current taget value of 80%.*

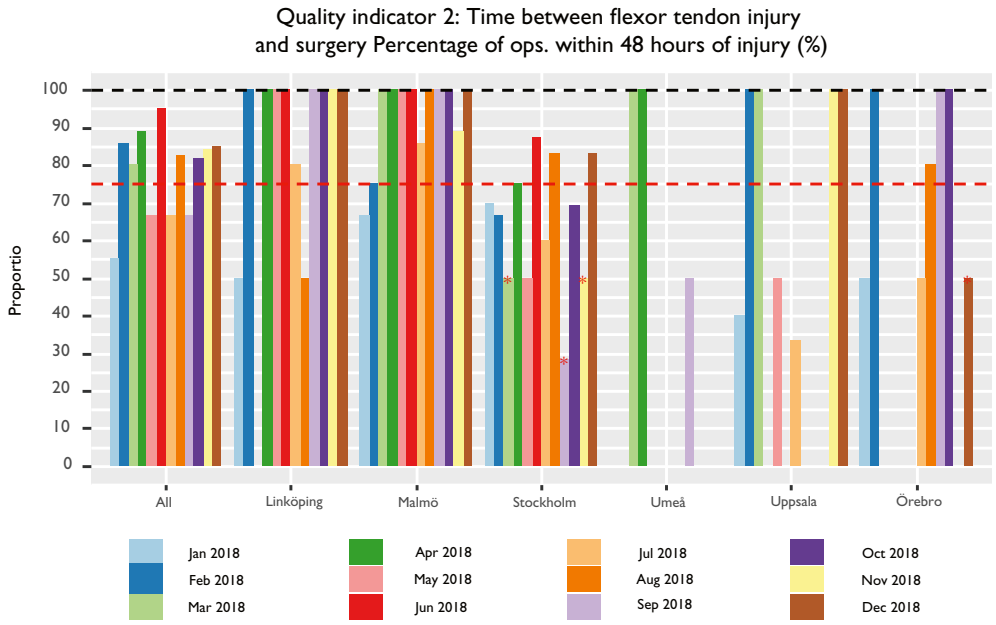


Figure 54. *Proportion of patients operated on within 48 hours of a flexor tendon injury (%). Asterisk indicates that the value is statistically different from the rest of the month. Red dashed line indicates our current target value of 75%.*

IMPROVEMENT ASPECTS QUALITY INDICATORS

Coverage rate in the quality register is a process measure. Registering complete data is a basic requirement if we are to monitor the quality of care within hand surgery.

The second indicator, which shows the proportion of patients with a flexor tendon injury who have to wait more than 48 hours to have their tendon repaired, is also a process measure. This measure is intended to monitor the field so as to reduce national differences in emergency surgery resources in the long term. In HAKIR, we have noted that such differences are significant between different regions. In many flexor tendon injuries, the wound injury is small and it can be difficult to claim priority over other injuries in an emergency hospital.

At the same time, complications, such as tendon rupture, infection and adhesion, can cause great suffering and high costs for healthcare. The results from HAKIR indicate that the risk that sutured thumb tendons will rupture may be higher if suturing is not done directly. We need to collect more data over a longer period to assess this risk factor with more certainty.

Either way, all patients in Sweden should reasonably receive equivalent care for flexor tendon injuries. At least 300 patients with this diagnosis are operated on every year in Sweden and the healing time is at least three months. Great resources are being spent on rehabilitation and these are injuries that are treated at all hand surgery specialist clinics.

We need to continue working to establish more quality indicators as this is one of the main purposes of national quality registries. By comparing ourselves to each other, we can be encouraged to improve and get support in tackling problem areas. Additional process measures, which shows lead times, waiting times and the like, may be called for. We also need a number of outcome measures, but in this respect there is difficulty finding comparable groups. When we improve our experience measures (PREM), some of these, such as participation and information, can be good measures to compare between the units.

We at HAKIR look forward to further discussions on this.

How to use HAKIR

The most important aim with a quality registry is to improve care. We believe that HAKIR already fulfils this purpose in several ways. However, some of what is described below will only come to fruition within healthcare after a longer period of time.

NATIONAL AND INTERPROFESSIONAL COOPERATION

Since the inception of HAKIR in 2010, all professions within hand surgery have been involved, which has led to an increased exchange of knowledge between the clinics. The rehabilitation units, which in hand surgery are integrated into the clinics, have done a great job of compiling measurement manuals for the evaluation of hand status, most recently a nerve injury manual. Nurses and assistant nurses have discussed nursing aspects and have compared routines, for example, in wound care. A scientific steering group has been formed and several national research projects have been started. An annual report group met on two occasions in the spring of 2019. National collaborations have previously been less common within our speciality area.

INTERNATIONAL COOPERATION

During 2018, the registry holder has given lectures for the hand surgery associations in Switzerland and the Netherlands, and has also presented HAKIR at the international hand surgery congress in Berlin (IFSSH) in June 2019. A Swiss colleague has investigated the prevalence of hand surgery quality registries internationally. The few registries that exist are mainly specific joint prosthesis registries. HAKIR is the only registry that currently includes PROM/PREM and the only one that monitors all types of hand surgery.

LOCAL IMPROVEMENT WORK

HAKIR is working hard to increase the use of registry data for improvements in healthcare. Improved output data reports on the website facilitate this and we have had several workshops for users. Good conditions for local quality work have been established and projects have been carried out during the year, for instance in Uppsala, Malmö and Stockholm. Improved wound care, better logistics for registry work and follow-up of tendon ruptures are some examples.

PATIENT INVOLVEMENT

By compiling patient-reported outcomes (PROM and PREM) for all patients in HAKIR, we get a broader and more accurate picture of the treatment results for different diagnoses. We, along with the patients, can have a more solid foundation for decisions about treatments. Our output data reports on the website can be used both for information before and after surgery and to detect deviating care processes. Patient focus groups have been used to ensure the validity of the HQ-8 questionnaire, and a scientific paper on the psychometric aspects of the survey will be published shortly. We have also involved patients in the project with new PREM questions, see above.

NURSING PROJECT

The nursing care form at three clinics has opened up national discussions regarding wound care, postoperative pain relief, etc. Local improvement projects have been implemented in Uppsala, among other locations, and have resulted in better routines.

QUALITY INDICATORS

Two indicators have been published on www.vardenisiffror.se (Healthcare in Numbers) and we plan to expand the range of indicators as soon as we can. It would be preferable to have more process measures similar to lead times, waiting times. One of the current indicators is being introduced as a hospital-wide quality measure in Stockholm in 2020. The national programme areas within knowledge management have now started up and HAKIR hopes to play an active role in working with national guidelines for the most common diagnoses.

RESEARCH PROJECTS

Tendon ruptures after plate fixation of radius fractures

Carin Rubenson is a hand surgeon in Linköping. Plate fixation of the body's most common fracture; the radius fracture can over time cause damage to extensor tendons and flexor tendons. These injuries are almost always treated at the hand surgery clinics and the procedures are registered in HAKIR. The study analyses, among other things, the occurrence of tendon injuries in relation to choice and placement of the osteosynthetic material. Doctoral project.

Factors affecting rehabilitation and outcomes after flexor tendon surgery.
Jonas Svingen is a physiotherapist at the hand surgery clinic in Stockholm and a doctoral student at Karolinska Institutet. Several studies using HAKIR data are included in he doctoral project. A randomised multi-centre study of a mobile application, with extended patient information for rehabilitation following flexor tendon repair, has been carried out and will now be published. An ongoing registry study is planned to ascertain factors impacting the risk of reoperation following flexor tendon suturing and a study of patient-reported outcomes.

Nerve entrapments in the arm/hand of diabetics. ***Malin Zimmerman*** is a resident physician in orthopedics in Helsingborg and ***Ilka Anker*** is an orthopedic specialist. Malin defended her doctoral thesis at Lund University in 2018 which contained patient-reported outcomes from HAKIR relating to carpal tunnel release in diabetes patients. Ilka is a doctoral student and studies ulnar nerve neurolysis through also utilising corresponding data relating to people with diabetes. The data has been merged with data in the National Diabetes Register, NDR. This data compilation also incorporates data from Statistics Sweden (SCB), with the aim of looking at predictive factors for postoperative results and how socioeconomic factors affect the outcome in both conditions. The manuscripts have been submitted for publication and have both been presented at the annual congress of the American Society for Surgery of the Hand (ASSH) in 2018 and at the IFSSH meeting in Berlin in 2019. Two student thesis projects have also been generated at Lund University based on these studies.

Patient-reported outcomes after digital nerve injuries and median and ulnar nerve injuries.
Drifa Frostadottir is a resident physician at the hand surgery clinic in Malmö and a doctoral student at Lund University. The purpose of the project is to gain deeper knowledge of the functional level and daily activities in different groups of patients. The questionnaire responses in HAKIR are merged with the National Diabetes Register (NDR) and Statistics Sweden (SCB) to relate results to diabetes and various socioeconomic factors. The analyses have been initiated. A student thesis project by Deniz Demirag regarding digital nerve injuries in HAKIR was presented in the autumn of 2018 at Karolinska Institutet.

Patient-reported outcomes after surgery for thumb osteoarthritiss
Martin Roginski is a resident physician and ***Maria Wilcke*** is specialist physician in hand surgery in Stockholm. They have analysed patient survey data from HAKIR for 1,850 patients before and after trapeziectomy for thumb osteoarthritis. The patient-reported outcomes after 1 year were good with the same improvement seen regardless of gender and age. However, pain on load and weakness persist to some extent. The results are no different following trapeziectomy with or without tendon interposition, but only a small proportion were operated on using the latter method. The manuscript has been submitted for publication.

Patient-reported outcomes after collagenase treatment, needle fasciotomy and surgery for Dupuytren's contracture
Madeleine Harryson is a resident physician in hand surgery in Örebro and is conducting analysis within the framework of a resident project that centres on patient-reported symptoms after various treatments for Dupuytren's contracture. Statistical analysis of data is ongoing.

Validation and psychometric analysis of the patient survey (HQ-8).
Ingela Carlsson holds a PhD and is an occupational therapist at the hand surgery rehabilitation department in Malmö. She is in charge of a research project that aims to evaluate the validity of the 8 survey questions in HAKIR that relate to different symptoms from hand and arm (HQ-8 questionnaire). Among other things, the project analyses content validity, terminology validity, floor and ceiling effects, and possible non-responses. The manuscript has been submitted and is currently being supplemented with analyses of the ability of the questions to measure change over time (responsiveness). These analyses are basic in nature and important as a basis for scientifically evaluating the effect of various measures among patients with a hand surgery diagnosis.

Summary

The quality registry HAKIR has been up and running since 2010, but not as long at all clinics. Within a few years, we will most likely have added more units within the area of private hand surgery. There is much that works well in the registry, but there are still features to improve and develop. Automatic data transfer is something that is high on the wish list, as is the case for many other registries. We hope to continue with this through the collaboration with the anesthesia register (SPOR). We need to improve our PREM (experience-related questions) to create a better basis for improvement work, and we need to develop additional quality indicators.

At several of the large specialist clinics, the registry logistics work well, while others continue to have problems with coverage rate and data validity. We will therefore devote extra resources to this in the coming year. These efforts require working hours, which we hope to receive funding for as this is crucial for the registry's future. We need to entice the Gothenburg clinic to rejoin the registry and we need to visit the clinics to help establish effective routines at all locations.

In HAKIR, we have gathered a lot of information about how hand surgery patients perceive their care. Some results are expected, while others raise questions that require further analysis. It is unique within hand surgery and generally uncommon in healthcare to place such strong focus on patient-reported outcomes, as we have in HAKIR. At the same time, this is absolutely necessary within a speciality area such as hand surgery, where we are not expected to save lives but rather in the best case scenario increase the quality of life for our patients. We are convinced that the results from the registry will lead to significant improvements in care in many different ways in the future. However, improvements are made gradually and are not always measurable in numbers. Increased national and interprofessional cooperation is something we have already achieved and will continue to develop. Several national research projects are under way and publications should be forthcoming shortly.

A standardised registration of complications has not previously existed within hand surgery. By systematically using the collected registry data at the clinics, we should be able to gradually reduce various postoperative problems for our patients. Registry studies that analyse the causes of ruptures following flexor tendon suturing are ongoing and will lead to more patient-centred and improved care. By analysing the impact of the time it takes between injury and surgery for flexor tendons, nerves and fractures, we will be able to ascertain whether or not a few day's delay will produce a worse result. Should it prove to be negative, this will have major consequences for the emergency surgery resources at the hospitals.

Registry data indicates that we have different treatment traditions around Sweden. We do not yet know how important this is for the results, but there is a need for national discussions concerning indications and choice of treatment methods within several diagnoses. We hope that the new knowledge management organisation entailed by the National Programme Areas will focus the work in this direction and that HAKIR is able to participate in the work.

This annual report has been preceded by two planning meetings in a national interprofessional group consisting of Ingela Carlsson, occupational therapist in Malmö and hand surgeons Anders Nilsson, Gothenburg, Lars Dahlin and Tony Abramo, Malmö, Sara Edsfeldt, Uppsala, Maria Wilcke, Stockholm, Simon Farnebo, Linköping and registry specialist Erik Ackzell, Registercentrum Syd and the registry holder. The group has been given the opportunity to comment on the content, but

the data has been compiled by the registry holder, who also assumes full responsibility for any possible miscalculations and inappropriate formulations. Data has been analysed as carefully as possible with the limitations that have been in place. As previously written, the report has no scientific purpose but seeks to arouse interest in the use of registry data for research and improvement work. The forms for the annual report work will need to be developed further as we gather more and more data.

Unfortunately, in the summer of 2019, our dear national registry coordinator Nina Lindblad resigned to take on another role. Nina has worked with HAKIR almost since its inception and has been a great advocate for the registry. Through her perpetually friendly, helpful and happy demeanour, she has been a first-class problem solver. People outside the registry office are probably not aware of how many IT problems and hacker attacks have been averted at an early stage through Nina's attention and commitment. HAKIR wishes her all the best for her new job. In September, we welcome our new coordinator, Maria Mering, who currently works for the Swedish National Quality Register of Gynecological Surgery. Erik Ackzell started as our new registry specialist in September 2018.

We enjoy a fruitful collaboration down in Lund and we have a long list of priorities that we are trying to get through despite new projects coming up all the time.

We would like to thank all the competent staff from different professions around the country who have contributed in various ways to our joint quality registry. We are proud of what we have achieved with our registry and hope that HAKIR will be of great benefit to our patients both locally and nationally in the future.

Lastly, we want you all to note the date for HAKIR's 10-year anniversary which will take place on 7 February 2020 in Stockholm. Everyone who works within the area of hand surgery is welcome. The link to sign up will be available in the autumn. See you there!

Stockholm, August 2019

Marianne Arner
Registry holder

Annual Report Group: Ingela Carlsson, Anders Nilsson, Lars Dahlin, Tony Abramo, Sara Edsfeldt, Maria Wilcke, Simon Farnebo, Erik Ackzell.

How did it go in 2018-19?

At least one quality indicator shall be reported to www.vardenisiffror.se (Healthcare in Numbers).

Two quality indicators have been entered – coverage rate in HAKIR and time from injury to surgery for flexor tendon injuries. Updates are done monthly. Additional quality indicators shall be developed.

Extended registration of flexor tendon injuries in zones I and II shall be implemented at all hospital clinics.

Unfortunately, the Gothenburg clinic did not start registering flexor tendon injuries in 2018, and in September the clinic discontinued all registration. We hope that they will return in autumn 2019. The other six specialist clinics register and follow up on flexor tendon injuries. The proportion of patients undergoing follow-up varies between the units. We are also working on securing complete registrations across the board.

Diagnosis and surgery forms for brachial plexus injuries were to have been entered in the registry.

Six different forms for birth-related and traumatic brachial plexus injuries have been added to the platform and registrations have commenced, see above.

A national interprofessional working group for arthroplasty hand surgery was to have been formed with the aim of making prosthesis registration more complete and long-term.

This work has been difficult to get started. Four clinics have been registering joint prostheses for several years. Two clinics that also have extensive prosthesis operations, Örebro and Gothenburg, have not yet started and it has been difficult to engage their interest. HAKIR needs increased support from heads of operations and from specialist associations to gain some traction in this matter. Hopefully we also get help from the work within the National Programme Areas (NPO).

Audits were to have been conducted in at least two clinics and the registration of reoperations specifically discussed.

An audit was conducted at the Hand Surgery Clinic in Uppsala in September 2018. Most of the registrations worked acceptably, but we identified some areas of improvement, including the follow-up of flexor tendon injuries. An audit was planned in Umeå in connection with the national HAKIR day in November 2018, but this did not transpire as the national day was cancelled at short notice.

At least two scientific publications on HAKIR data.

During 2018 and up until spring 2019, four papers based on HAKIR data have been submitted for publication and are in various stages of revision. We hope that they will be published later in 2019.

Collaboration with the Swedish Perioperative Registry (SPOR) regarding automatic data transfer from surgical programmes was to have been started as a pilot project..

We planned to start the pilot project as early as autumn 2018, but had to postpone due to a change of registry managers at RC Syd. A new attempt is planned in the autumn of 2019, possibly in collaboration with the CPUP register, see above.

A collaboration with the Swedish Fracture Register (SFR) was to have started with an analysis of cooperation opportunities.

The design and variables of the two registries were examined as part of a resident physician's project (Sindre Gunleiksrud, Stockholm) in the spring of 2019. The report, entitled "Between Two Registers? A description of the current situation for registering hand fractures in quality registers" Mellan två register? can be read on the website. The Fracture Register has a more detailed classification of fractures and treatment, while HAKIR has a greater focus on patient-reported outcomes and complications. We plan to continue discussions with SFR in order to try to establish a more uniform quality monitoring of hand fracture treatment

Goals for 2019-20

GENERAL GOALS

Goals that require a great deal of involvement outside the registry

- **Full participation of all seven specialist clinics.**
  We hope that Gothenburg will resume registrations in HAKIR in the autumn of 2019
- **Full coverage rate at all participating units.**
  Some clinics have fundamental problems. Heads of operations and coordinators need to go through routines and stimulate improvement.
- **Correct registration of reoperations at all clinics.**
  Some clinics have fundamental problems. Heads of operations and coordinators need to go through routines and stimulate improvement.
- **Publish at least three scientific papers based on HAKIR data.**
  Many projects are under way. We hope for additional publications in the near future.

SPECIFIC GOALS

- **Conduct a validation study.**
  The purpose is to identify the proportion of incorrect registrations of diagnosis and surgery codes. The study shall be submitted for publication. Routines shall be created for continuous correction of incorrect codes.
- **Start the pilot project with SPOR.**
  Applies to automatic transfer of surgery data from patient records. Collaboration with registry centres in Uppsala and Lund, AddPro and SPOR. Probably a joint project with the CPUP register.
- **Start the pilot project with new PREM questions and mailings via 1177.**
  Patient experience questions (PREM) were selected from the National Patient Survey (NPE) in 2018, and we will test out distributing these questions a few weeks after surgery via 1177. Collaboration with 1177, Registercentrum Syd and AddPro.
- **Conduct audits at participating clinics.**
  The purpose is to review registration routines, propose improvements and discuss the use of registry data in healthcare.
- **Re-initiate a nursing group in HAKIR.**
  Budget permitting, HAKIR shall offer the clinics project grants to introduce and improve the registration of nursing data.

How you can help improve HAKIR

Heads of department

- Highlight and present HAKIR data regularly to all staff. It is easy to generate your own unit's data in the dynamic reports on the website. Contact us at the HAKIR office if you need help.
- Follow up on any differences between your own unit and other clinics, for example in terms of reoperation rate, coverage rate, etc.
- Encourage employees to become involved in HAKIR. Start an interprofessional improvement group that, for example, follows up on coverage rate and extended follow-ups. Set aside time for this work. Meet with the registry coordinator regularly for consultation purposes.
- Create routines and logistics so that registrations are as automatic as possible. Include HAKIR follow-ups in existing care programmes for different diagnoses.
- Encourage the start of scientific projects focused on HAKIR data, such as Master's projects and resident physician projects.
- Encourage transparency and honesty surrounding registry data. Comparisons between units are not done to compete, but rather to learn from each other.

Registry coordinators

- Give feedback to the head of department regarding how HAKIR works at the unit and what needs improvement. Assist in the generation of data when needed.
- Ensure that surgery forms are complete and correctly filled out, otherwise ask the doctors to supplement their entries. If something looks wrong - check it again.
- Monitor how registry work is performed out at the clinic, and provide support and encouragement where needed.
- Feel free to contact us at the HAKIR office if you need help with something, if something is not working well, or if you have ideas for improvement.

Staff at the clinic

- Tell the patients about the purpose of HAKIR and that it is important that they participate; we want to know how they perceive the care provided because we want to improve on the care. A little extra verbal information can motivate the patient to fill in post-operative questionnaires and show up for follow-up examinations of their function.
- It is good if the doctors can support surgical staff and secretaries when registering data. It is especially important that diagnosis codes, surgery codes and cause of reoperation are correctly filled in.
- In particular, ensure that joint prosthesis operations are correctly registered. Increased engagement on the party of doctors is a great help.
- Be as careful as possible when registering. Incorrect registration means that data cannot be used. Please contact the HAKIR office if anything is unclear or if you need assistance.
- When following up on rehab within the extended follow-ups, ask the patients if they have completed their postoperative questionnaires and remind them that it is important that they do so. In the case of a rupture or suspected rupture of a sutured flexor tendon in zone I or II, note this in the function form. questionnaires and remind them that it is important that they do so.

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HAKIR
HANDKIRURGISKT
KVALITETSREGISTER

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