

# Annual report 2014

HAKIR  
HANDKIRURGISKT  
KVALITETSREGISTER



Registered data

What do our patients think

Postoperative complications

Functional assessments

Specific goals for 2015



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# HAKIR – National Quality Register for Hand Surgery



## WHAT IS HAKIR AND WHAT DO WE WANT TO ACHIEVE?

HAKIR is a national quality register for hand surgery founded in 2010 on the initiative of the Swedish Society for the Surgery of the Hand.

Our main objective is to enable improvement work and research that gradually improves medical care by, for example, reducing avoidable complications and reoperations through individually based follow-up of treatments and outcomes. Another important objective is to increase patient participation in healthcare. Through greater national and interprofessional cooperation, we also want to work for good and equivalent hand surgery for everyone in Sweden.



## HOW DO WE GET THERE?

Through broad national support, we will work to establish register procedures that are as simple as possible. We strive to integrate the register work into daily clinical practice over the long term. We will continuously follow up and improve validity and reliability and ensure that data is complete. We will create user-friendly models for the continuous feedback of register data to both patients and care providers so that this data can be used, for example, in improvement work and as a basis for national guidelines.



# Introduction

*This annual report covers information that was registered in HAKIR at the participating units since the beginning on 1 February 2010 until 31 December 2014. The units joined the register at different times.*

The annual report's most important objective is to evoke questions and interest in the hand surgery care provided in Sweden. By showing what treatment methods are used, presenting how our patients perceive the outcomes and how their hands function after surgery, we can identify areas for improvement and areas for clinical research. This year's report provides many such ideas that we hope can lead to various improvements.

Prior to reading the report, it is important to point a few things out. An annual report for a quality register should not be seen and judged as a scientific publication. Such a publication would require further validation of register data and a more advanced statistical analysis.

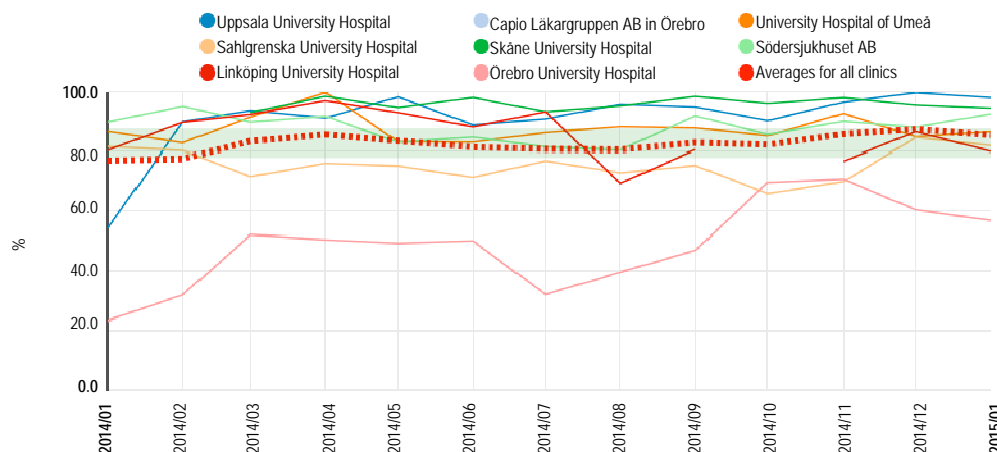
In the mass collection of data that a quality register entails, some errors always arise. These errors can sometimes be of a technical nature, but they are most often due to the human factor, that the patient or staff unintentionally registered information incorrectly. In most cases, the errors are not systematic. In 2014, we discovered that some patients misunderstood the last two questions in the postoperative questionnaire concerning satisfaction. Unfortunately, we cannot know for certain how extensive this incorrect registration was and we have to view the issue as a "teething problem" of a new register.

We have now added "smileys" to each end of the scale and preliminary follow-up shows that this has probably solved the problem, which only concerned the questions in the questionnaire regarding satisfaction. A broader validation of the questionnaire will be done as soon as we have an opportunity to do so. We will get expert help from the Registercentrum Syd in Karlskrona for this validation.

The response rate for our online survey has been too low since the beginning, at around only 30%. Early on, the problems with the online survey were mostly of a technical nature, but an investigation conducted in 2014-2015 showed that the way that people use their smartphones and computers and the general attitude to online survey notices probably also played a role. Through a pilot study in Stockholm in 2014, we were able to show that if we send out the questionnaire by e-mail instead of as a text message, followed by a text message reminder one day later, the response rate increased to 60%. This system is now generally used in HAKIR and we regularly monitor the response rate. For the paper survey, the response rate has been stable at between 50 to 60%, which can be seen as an acceptable level in a quality register. Paper surveys are, however, not a long-term sustainable solution because they are very labour-intensive and negative both financially and environmentally.

|              | NUMBER OF OPERATIONS | NUMBER OF PATIENTS | PERCENTAGE WOMEN (%) | AVERAGE AGE (YEARS) | AVERAGE AGE 95% CI (YEARS) |
|--------------|----------------------|--------------------|----------------------|---------------------|----------------------------|
| Gothenburg   | 4,005                | 4,099              | 50.8                 | 47.9                | 47.3-48.5                  |
| Linköping    | 6,715                | 5,863              | 48.9                 | 50.1                | 49.6-50.6                  |
| Malmö        | 10,097               | 10,239             | 49.9                 | 48.1                | 47.7-48.5                  |
| Stockholm    | 13,863               | 12,119             | 44.6                 | 46.5                | 46.1-46.9                  |
| Umeå         | 3,096                | 3,255              | 49.6                 | 48.4                | 47.7-49.1                  |
| Uppsala      | 5,252                | 4,713              | 47.0                 | 50.0                | 49.4-50.6                  |
| Örebro       | 1,076                | 1,414              | 55.1                 | 53.0                | 52.0-54.0                  |
| Capio Örebro | 81                   | 98                 | 56.1                 | 49.4                | 46.3-52.4                  |
| <b>Total</b> | <b>44,185</b>        | <b>41,800</b>      | <b>48.2</b>          | <b>48.3</b>         | <b>48.1-48.5</b>           |

*The number of registered operations and patients per unit from the beginning in HAKIR until 31 December 2014. 95 % CI = confidence interval. Different units participated for differing lengths of time. Capio Läkargruppen in Örebro is a private unit; the rest are hospital-based specialist clinics.*



Coverage ratio for the basic registration of operations for the participating units in 2014. For definition, see text. The dashed line shows the average for all units. The target (marked with a green zone) is that at least 80% of all operated patients should have been registered in HAKIR. The graph above is a segment of the dynamic graph that is available on [www.hakir.se](http://www.hakir.se).

The objective is that HAKIR will be completely paper-free within one to two years. The survey response dropout in this annual report is not optimal of course, but in our assessment, it is not a matter of a systematic, but rather a random dropout.

More troubling is the dropout in the extended follow-ups, i.e. the postoperative functional evaluations for selected surgical procedures such as flexor tendon suture, basal thumb arthritis surgery and joint replacement surgery. It may be difficult to motivate patients to come in to the unit for follow-up one year after surgery. In some places, clinic finances have been mentioned as a reason for not carrying out these follow-ups. At some units, however, there was a significant improvement in the follow-up rate in 2014-2015. At the Stockholm clinic, an improvement group was formed that regularly measures dropout, discusses causes and develops solutions to increase the percentage of patients followed up without at the same time increasing the staff's work load. This work has been very successful; see below.

## REGISTERED DATA

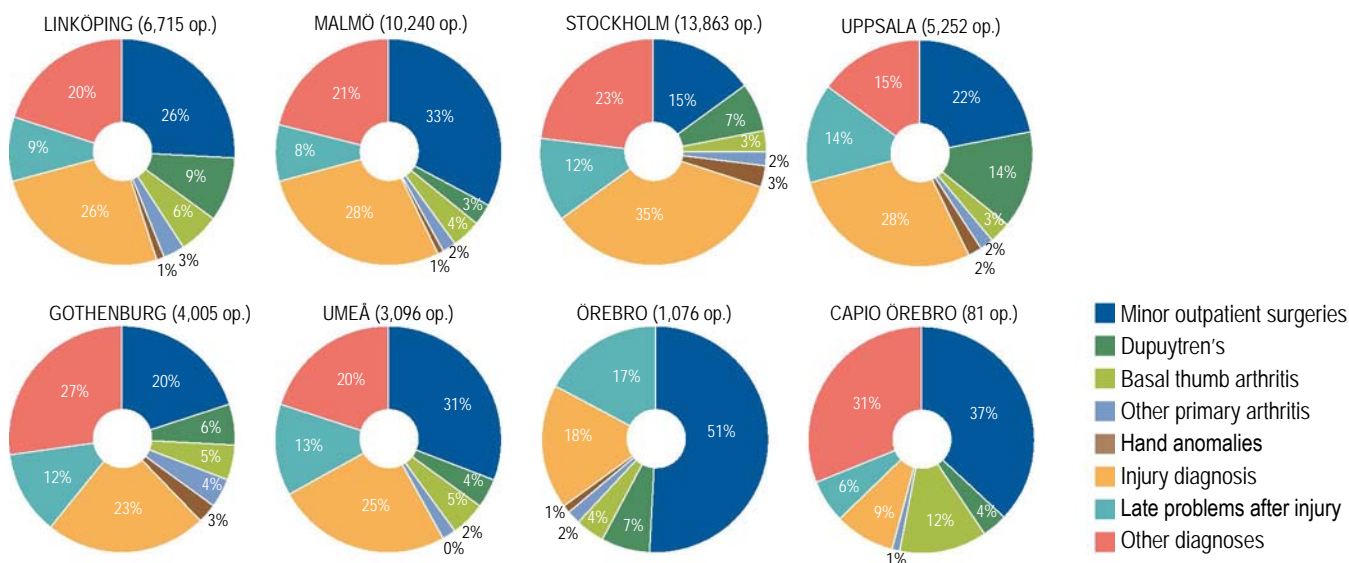
This annual report covers data from 44,185 operations on 41,800 patients (48.2% women) from seven specialist clinics and one private unit; see table below. 11,220 preoperative, 9,412 three-month postoperative and 8,565 one-year postoperative survey responses were registered and data from 1,746 preoperative, 938 three-month postoperative and 922 one-year postoperative functional evaluations within the extended registration.

The patients' average age was 48.3 years at the time of registration.

The operated patients at the specialist clinic i Örebro appear to be slightly older than those at the other clinics, but since the clinic does not yet have full coverage (see below), the comparison is uncertain. The Stockholm patients are younger, which may be due to a larger number of trauma patients and a large percentage of paediatric hand surgery; see section below on case mix.

## COVERAGE RATIO

The coverage ratio in the basic registration of operations in HAKIR is calculated as the ratio between registered and performed operations x 100 (%). The latter information is collected monthly from hospital statistics. Patients who do not have a Swedish personal ID number, have a protected identity or have declined registration in HAKIR are not included, which is why 100% cannot be the target. The percentage of such excluded patients may certainly vary, but we have set the coverage ratio target to a minimum of 80%. The coverage ratio for the participating units is presented openly on our website in a dynamic graph where the user can choose a desired unit and time interval. The information is automatically updated every month. The figure above shows a segment for the year of 2014. The two latest hospital departments to join, those in Gothenburg and Örebro, did not achieve the target in 2014. Gothenburg touched on the target at the end of the year, but on average Örebro had only registered half of its operations in HAKIR. Unfortunately, the figures remained unchanged for Örebro in 2015, but we hope for an improvement in the future. A complete coverage ratio is a prerequisite to be able to use register data scientifically.

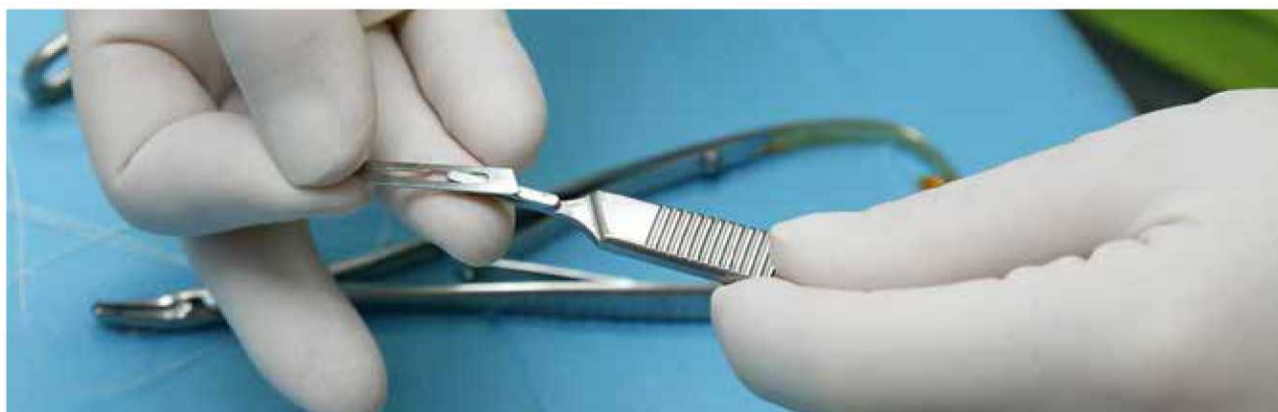


Percentage (%) of various diagnosis groups for the respective unit. Total 44,328 operation registrations. Note, however, that non-surgical treatment methods for Dupuytren's contracture are also registered; see text. Here, outpatient surgeries include carpal tunnel release, tendon sheath incision and ganglion surgery. Other diagnoses include rheumatoid arthritis, infections, other neurolyses, tumours and other conditions that could not be classified. Capió Örebro has to-date had very few registered operations.

## CASE MIX

By analysing the registered primary diagnosis in the basic registration, it is possible to obtain a perception of what kind of hand surgery is conducted at the various units. There is naturally an uncertainty due in part to directly incorrect registrations of the codes, but also due to the surgeon not putting the most important diagnosis first. For the units that had low coverage during the year, the analysis is extra uncertain and there may be reason to suspect that it is primarily acute operations that were missed. With these reservations, clear differences are nonetheless apparent in the units' case mixes; see the figure above. The percentage of minor operations in outpatient care varied where the Stockholm clinic was the lowest with 15% and the hospital ward in Örebro was the highest with 51% of registered operations in HAKIR.

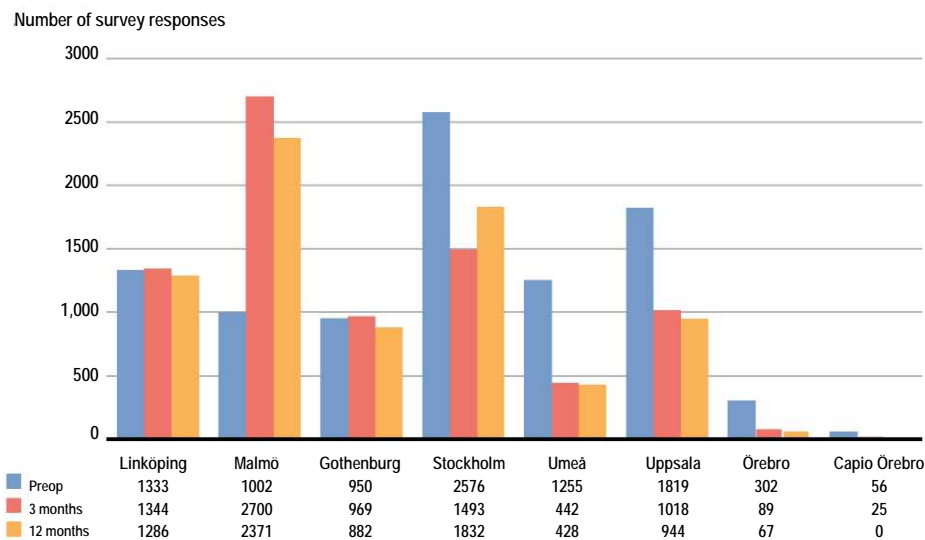
The percentage of injury diagnoses (S codes) and residual conditions after injury (T codes) were, however, the highest in Stockholm at 47%. In terms of treatment of Dupuytren's contracture, there was considerable variation; see further down in the annual report. The largest percentage of operations for hand anomalies was in Stockholm (3%; 372 operations) and Gothenburg (3%; 100 operations). Gothenburg had registered the most joint replacements and had the largest percentage of joint replacement surgery (4.7%; 190 operations) followed by Malmö (1.7%; 177 operations) and Örebro (1.7%; 18 operations). Up to the end of December 2014, 51 finger or thumb replantations (Gothenburg 1, Linköping 4, Malmö 12, Stockholm 15, Uppsala 14, Umeå 5) and 8 free flaps were registered in HAKIR. Another 161 arterial sutures were registered, most of which were radial and ulnar arteries. Note that the units have been in the register for varying lengths of time; for the total number of operations, see table p. 4.





# What do our patients think?

Up to 31 December 2014, 29,197 survey responses had been registered in HAKIR. 25,183 survey responses came from patients who had only been operated on once. To facilitate the interpretation of this data, only these responses are presented here. 9,293 surveys (37%) concerned preoperative perceptions, 8,080 three-month postoperative perceptions (32%) and 7,810 (31%) one-year postoperative perceptions, providing a fairly even distribution between the follow-up dates overall. However, the distribution of survey responses varied widely between the clinics; see the figures. The differences may be due to different procedures for the collection of survey responses, including differing percentages of paper surveys. As previously mentioned, paper surveys had an advantage with regard to response rate during the period.



Number of survey responses before and after surgery per participating unit. Patients who underwent more than one operation were excluded from this figure. Total 25,183 responses.

In total, the percentage of online surveys was 62.4%. The hand surgery units in Örebro and Capio Örebro only had online survey responses and the percentage was also high in Umeå (85.4%). The goal for HAKIR is an entirely paperless registration within one to two years. If we have now hopefully resolved the technical issues with the online survey and increased the response rate to an acceptable level, there are only advantages with this change.

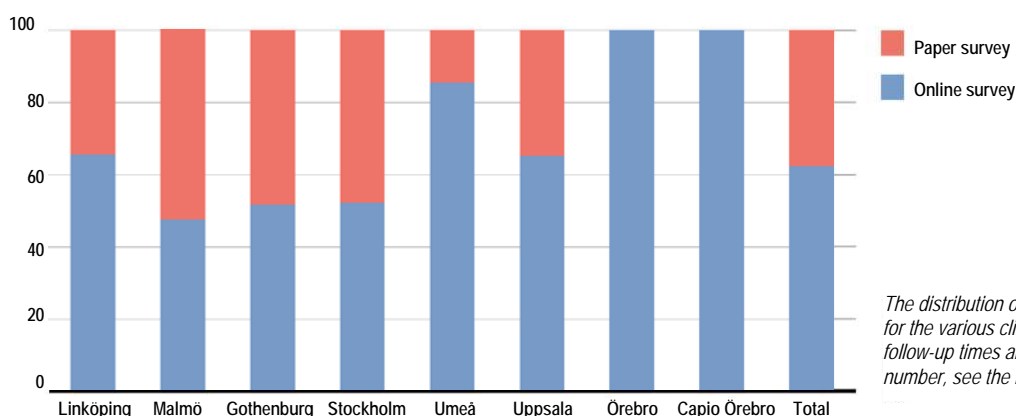
Our patient survey comprises two parts. The first part consists of questions about different symptoms from the hand and arm, such as pain, stiffness, loss of sensation, etc. We previously had a visual analogue scale (VAS) for these questions, but for the past few years, the responses are graded on a Likert scale 0, 10, 20, 30 etc. to 100, where 0 = no symptoms and 100 = maximal symptoms.

Postoperatively, we also have two questions regarding satisfaction, one about the surgical outcomes and one about the personal treatment at the clinic during the period of care. These responses are given in the same way as above, 0-100 with 10 points per step. Before HAKIR got started, a basic content validation was done of the first part of the questionnaire with acceptable results, but the validation needs to be redone.

The second part of the questionnaire is a validated questionnaire often used in scientific contexts for the evaluation of upper extremity surgery called DASH (Disabilities of the Arm, Shoulder and Hand). The short version (Quick-DASH) that we use contains 11 questions about perceived disabilities of the arm, shoulder and hand and the questions result in 1-5 points each. A total score is calculated where 0 = no disability and 100 = maximal perceived disability.



Questionnaires %



*The distribution of online surveys and paper surveys for the various clinics (%). Survey responses for all follow-up times are included in the figure. For the number, see the figure to the left.*

The questions in DASH vary widely, ranging from activities such as opening a jar and washing one's back to questions as to whether the symptoms disturb social activities with relatives, one's ability to work or one's sleep.

The Register Manager has asked Mikael Åström, statistician at Registercentrum Syd, to investigate how the DASH score correlates with age, gender and hand dominance. (The DASH questions do not distinguish between which hand the patient has problems in.) He analysed the 9,293 preoperative survey responses. The Pearson Correlation Coefficient is 0.0737, which indicates a weak positive correlation between increasing DASH score and increasing age. The average for DASH at ages 11-20 years was 37.5 and between ages 81-90 years 40.8. One cause may be that older people have different diagnoses with greater functional limitation, but age-related problems from the shoulder, elbow or other arm may also be of significance, i.e. such symptoms that we probably do not improve with our hand surgery. We also find a correlation between gender and DASH, where women indicate a higher value even after statistical compensation for the women being older in the material. Women indicated an average DASH of 44.0 and the men 31.1. This may also be due to differences in diagnoses between men and women, but there may also be other causes that would be of interest to investigate further. In terms of hand dominance, there is a statistical correlation between DASH score in surgery on the dominant hand (42.1 points) and the non-dominant hand (37.8 points). We will investigate the DASH results further in a scientific study because it is very important to know how the score works when we begin comparing different patient groups with one another.

HAKIR offers completely unique material comprising large amounts of data.

Many analyses can be done based on survey data and this is only a small selection. To make reliable comparisons, a more detailed review of data would be needed. The figure below shows that perceived disability has been reduced from a DASH score of approximately 40 before surgery to just over 20 one year after surgery for the entire group of patients in the annual report. The decrease appears to be the greatest at the Malmö and Örebro clinics. The difference between the units may be due to different case mixes. The expected improvement is different for different diagnoses and a large share of simpler cases, such as carpal tunnel releases or tendon sheath incisions, can yield a larger decrease in the DASH score.

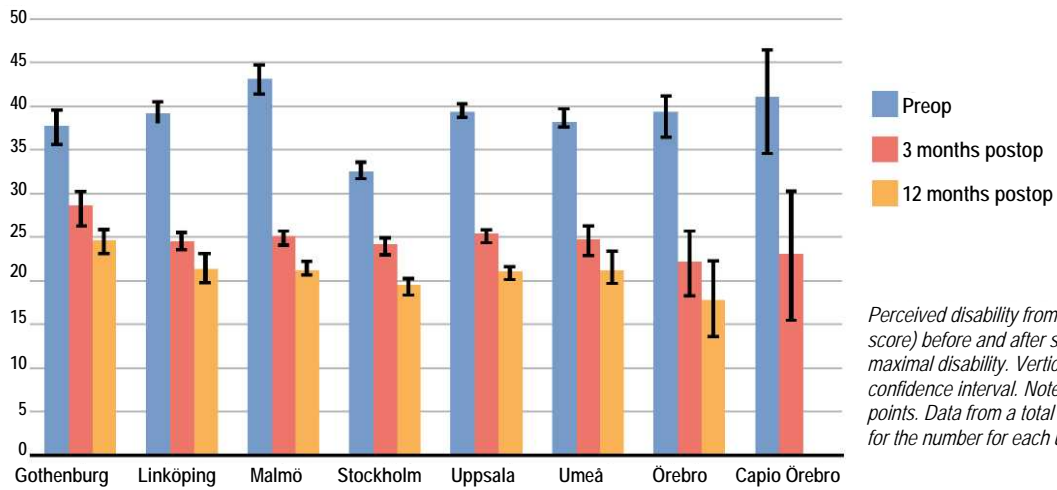
In the first part of the questionnaire, we also ask about the perceptions of achieved surgical outcomes and the perceptions of personal treatment at the clinic. Zero means that the patient is completely satisfied and 100 is completely dissatisfied; please refer to the figure below. We can note that we generally have very satisfied patients in Swedish hand surgery; see the figure below. After one year, satisfaction with the surgical outcomes averages 76% and satisfaction with personal treatment averages 91.5%. We do not see any major differences between the clinics despite a varying case mix (see above). However, it seems as if the patients' perceptions three months after surgery are somewhat similar to what they say when one year has passed, which may be of interest to discuss.

This may possibly be due to a high percentage of procedures that are already healed after three months.



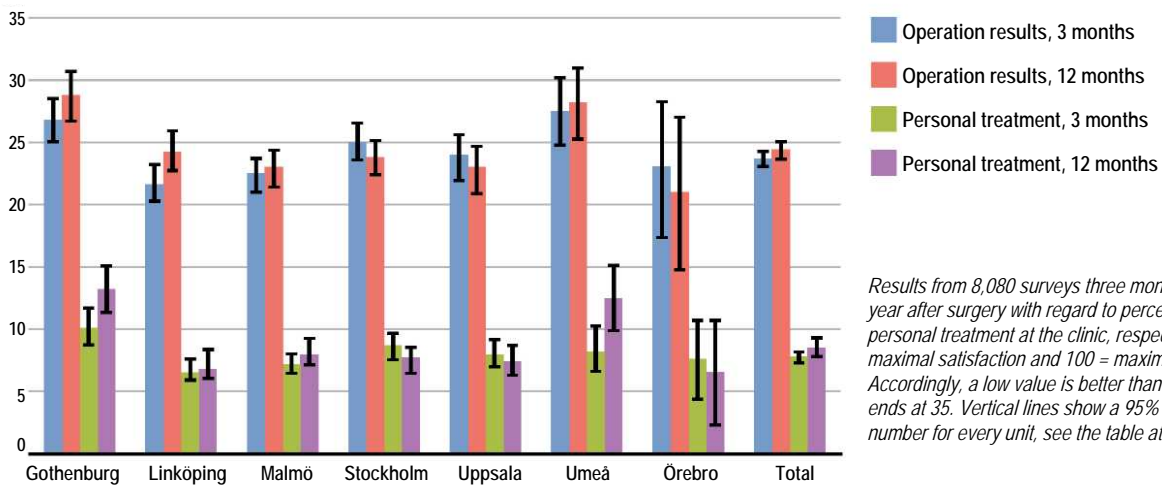


### DASH score (0-100)

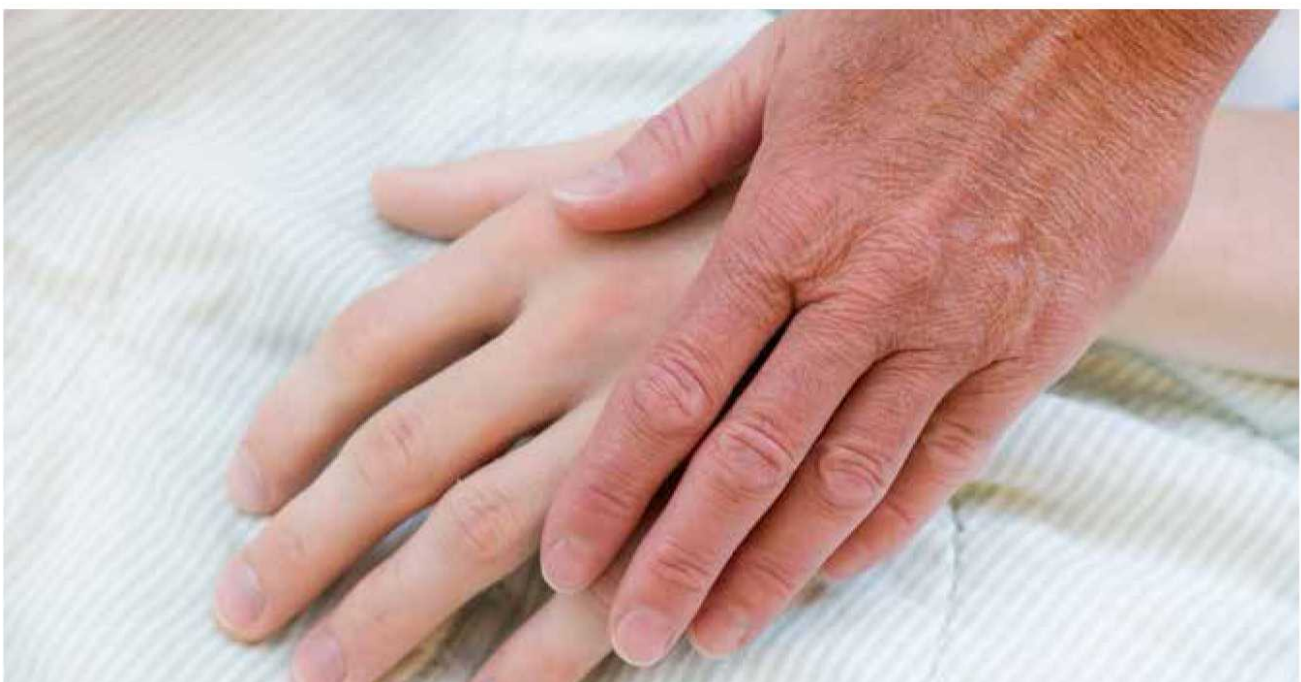


Perceived disability from arm/hand (DASH total score) before and after surgery. 0= none; 100= maximal disability. Vertical bars show a 95% confidence interval. Note that the y-axis ends at 50 points. Data from a total of 25,183 survey responses; for the number for each unit, refer to table at left.

### Perception of surgical outcomes and personal treatment (0-100)



Results from 8,080 surveys three months and 7,810 surveys one year after surgery with regard to perceived surgical outcomes and personal treatment at the clinic, respectively. Note that 0 = maximal satisfaction and 100 = maximal dissatisfaction. Accordingly, a low value is better than a high value. The y-axis ends at 35. Vertical lines show a 95% confidence interval. For the number for every unit, see the table at left.



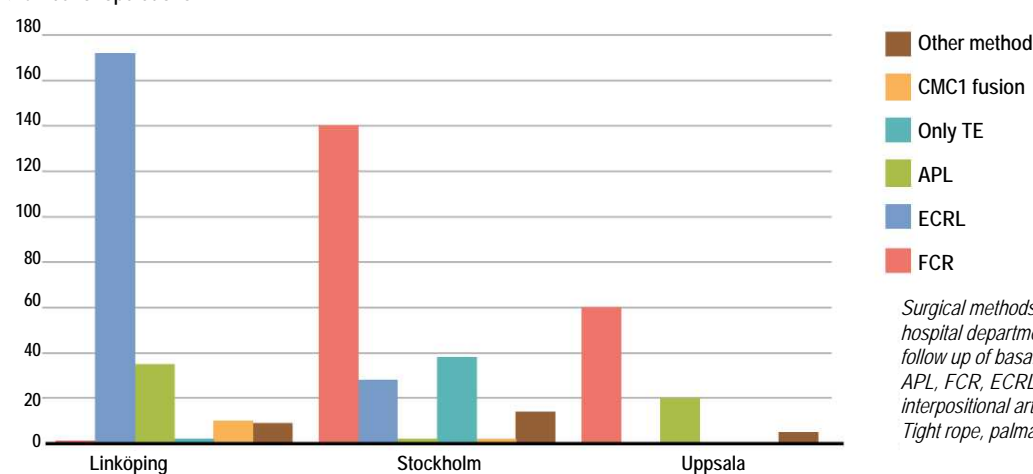


## EXTENDED REGISTRATION/FUNCTIONAL FOLLOW-UP

# Basal thumb arthritis surgery

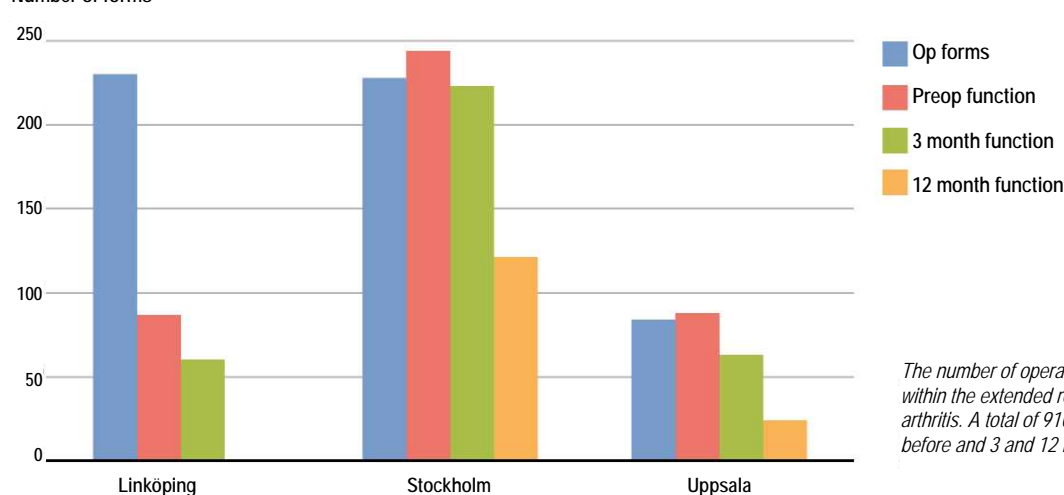
*Extended registration of surgery for basal thumb arthritis is done at the hospital clinics in Linköping, Stockholm and Uppsala and a total of 538 operations were registered. The treatment tradition appears to be trapeziectomy + interpositional arthroplasty with the FCR tendon in Stockholm and Uppsala and ECRL tendon arthroplasty in Linköping.*

Number of operations



*Surgical methods in 538 operations at the three hospital departments that participate in the extended follow up of basal thumb surgery; TE=Trapeziectomy; APL, FCR, ECRL=Trapeziectomy + different interpositional arthroplasties. Other method = e.g. Tight rope, palmaris longus, etc.*

Number of forms

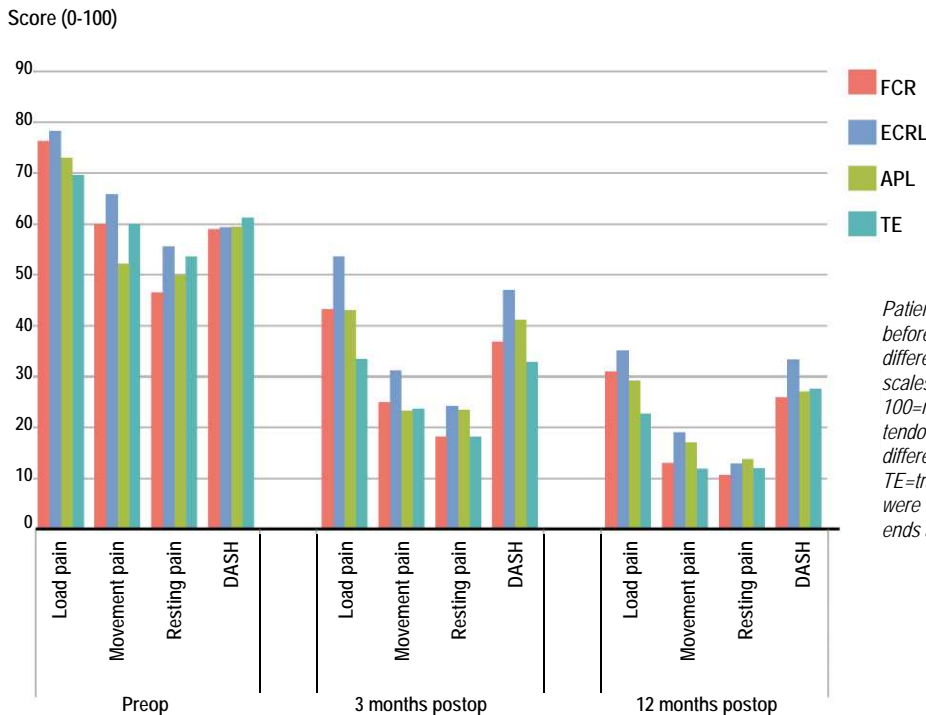


*The number of operation and function forms within the extended registration for basal thumb arthritis. A total of 910 functional follow-ups before and 3 and 12 months after surgery.*

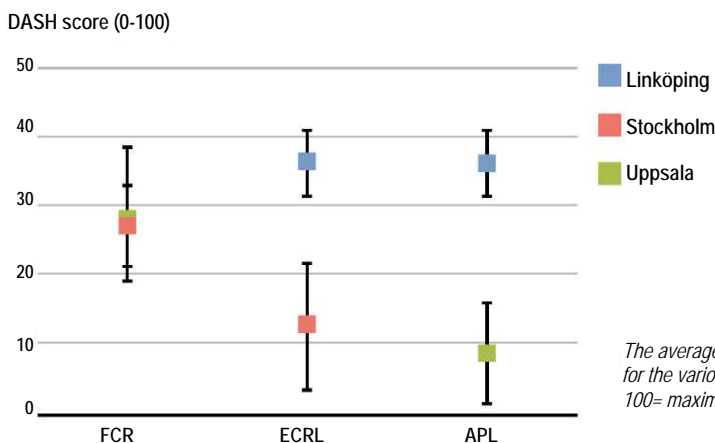
28 ECRL tendon arthroplasties had been performed in Stockholm and 55 APL arthroplasties in Uppsala and Linköping. 38 trapeziectomies without tendon arthroplasty were performed in Stockholm and 10 CMC 1 arthrodesis surgeries in Linköping during the period; see figure above. The average age for the operated patients was 60.0 years and 84.6% were women.

Surgical methods cannot be described for the other units in HAKIR since they do not yet participate in the extended follow-up where this is registered.

98% of patients operated in Stockholm and 95% of the Uppsala patients were subject to functional follow-up three months after surgery, and 26% in Linköping. One-year follow-up had been done on 49.5% of patients in Stockholm and 28% in Uppsala, but no one-year follow-ups had been registered in Linköping; see figure. It is unfortunate that Linköping is not included because it would have been important to be able to compare the treatment outcomes.



Patient-reported symptoms and a total score for DASH before, and three and 12 months after surgery for four different surgical methods; see explanation above. All scales go from 0-100 where 0=no symptoms and 100=maximal symptoms. For the FCR and ECRL tendon arthroplasties, the number was 37-54 for the different points in time. For APL arthroplasties and TE=trapeziectomy without tendon arthroplasty, there were too few responses registered (n=7-19). The y-axis ends at 90 points.



The average for DASH one year after surgery with a 95% confidence interval for the various tendon arthroplasties performed at the three clinics. 0= none; 100= maximal disability. The y-axis ends at 50.

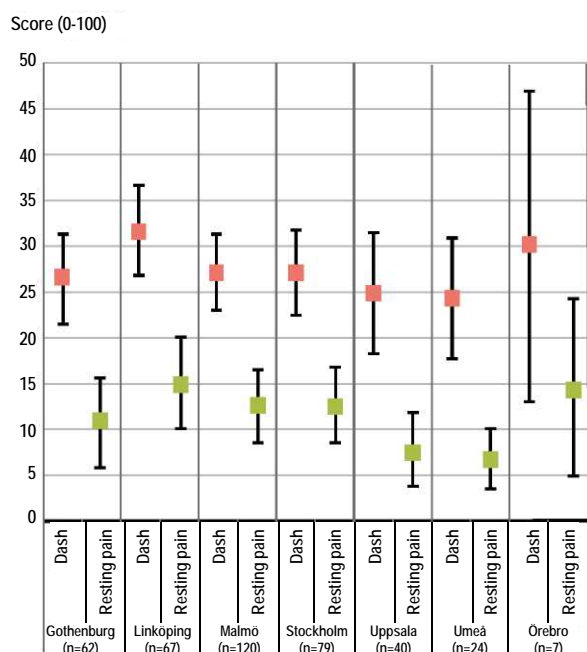
## PATIENT-REPORTED OUTCOMES

We have chosen to present DASH scores that reflect the general perception of hand and arm function and the three survey questions that concern pain (load pain, movement pain, resting pain) because the latter often constitute the most important indication for surgery. Both DASH and symptom scores go from 0-100, where 0 is no symptoms and 100 is maximal symptoms/disability.

For all trapeziectomies, with or without tendon arthroplasties, we see a decrease in the DASH score from approximately 60 before surgery to approximately 30 one year after surgery, which in a clinical sense can be seen as a substantial decrease; see figure. Hence, perceived disability is reduced through surgery. However, we found no differences (95% confidence interval) between the different tendon arthroplasties. Resting pain decreased from approximately 50 to just over 10 in the group as a whole. Most of the patients (61%) said that they had little, or no resting pain (value < 10) one year after surgery.

However, the value for load pain in the operated thumb after one year was indicated as substantially higher at 32 on average. There was, however, a smaller number of patients who indicated significantly better results both in terms of load pain and DASH score (<10).

Hence, we found no major differences in the outcomes between the different tendon arthroplasties. However, there may be differences in how the different tendon arthroplasties are carried out at the different units; see figure above. FCR arthroplasties at the Uppsala and Stockholm clinics had almost identical averages for DASH after 12 months while the averages differ for APL and ECRL tendon arthroplasties performed at different clinics. Is it possible that local traditions as to how a certain operation is done and/or the selection of postoperative rehabilitation plays a role? APL tendon arthroplasties carried out at the Uppsala clinic and ECRL tendon arthroplasties at the Stockholm clinic were the groups that had the best outcomes both in terms of DASH score and load pain, but the number of responses in each group was small which is why the results are uncertain.



Patient-reported outcome (DASH score and resting pain 0-100) one year after basal thumb surgery at seven hospital departments based on survey responses in the basic registration (n=399). Vertical bars show a 95% confidence interval. Note that the y-axis scale ends at 50 points and there are very few survey responses from the hospital department in Örebro.

To investigate if there were differences between different clinics' one-year outcomes after basal thumb surgery regardless of method for tendon arthroplasty, survey data was obtained from the basic registration for all patients operated for basal thumb arthritis (diagnosis code M18; n=399 survey responses). Here, we cannot distinguish different kinds of tendon arthroplasty because this is not stated in the basic registration. Basal thumb prosthesis and arthrodesis surgeries were excluded. We did not find any certain differences in patient-reported outcomes between the clinics as a whole; see figure.

To attempt to further identify possible causes of differences in outcomes for individual patients, survey responses for individual surgeons were also obtained. The surgeon's initials were missing from many registrations and sometimes, different variants of initials were difficult to interpret, which is why these responses were excluded. Only surgeons with > 6 survey responses were included in the figure below. We see a wide variation in patient-reported outcomes one year after surgery. All patients had given a DASH score <10 for only three surgeons from two clinics in the complete material, but there was a small number of responses from these surgeons (2-4) and they are therefore not included in the figure.

The objective of this analysis is not to point anyone out, but to try to identify areas for improvement and learn from each other. Is it the interposition in itself, the stability of the base of the thumb, the surgeon's experience or something in the postoperative treatment that is the most important? How significant are individual patient factors, such as expectations and requirements of hand function?

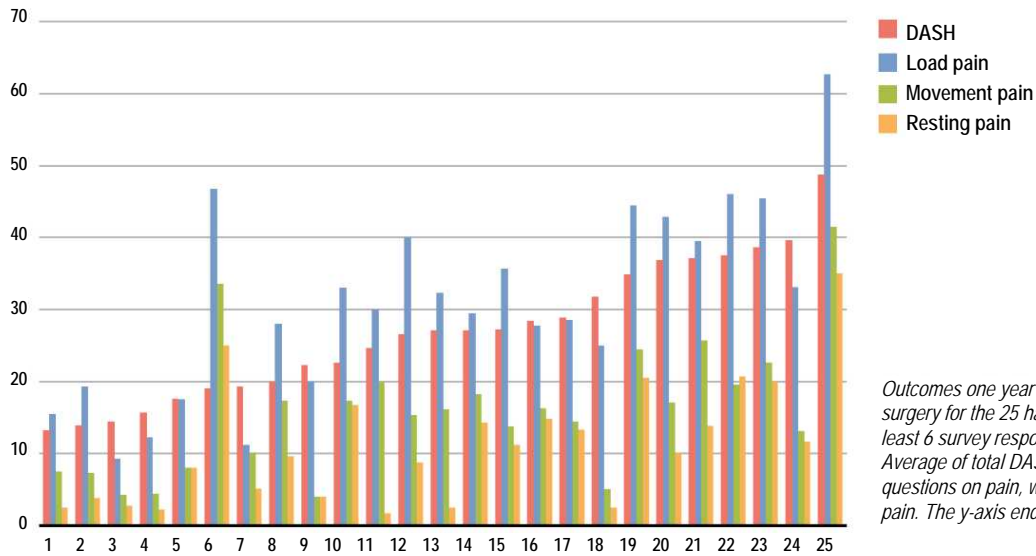
## FUNCTION MEASUREMENTS

Measurement of pinch strength (609 measurements in total) preoperative and postoperative for all basal thumb surgery patients showed as expected reduced strength in the thumb grip three months after surgery, 3.0 kg compared with 4.2 kg before operation; see figure. In a one-year follow-up, pinch strength was more than the preoperative value (4.5 kg), but not on par with the contralateral hand (5.5 kg). The strength of the overall grip was also diminished three months after surgery, but almost on par with the contralateral hand one year after surgery. This information may be important to convey to our patients.

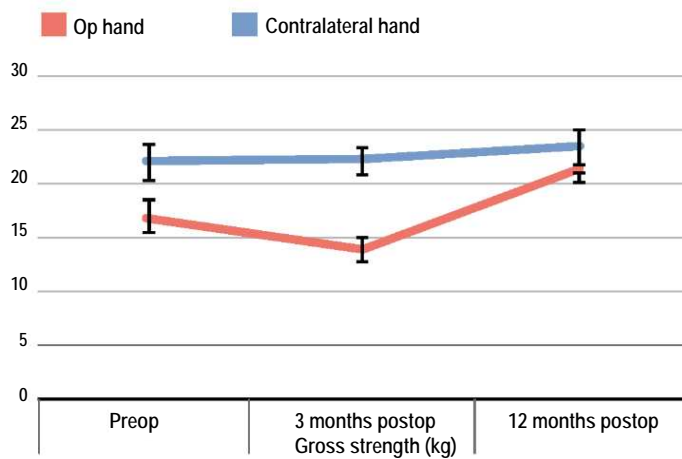
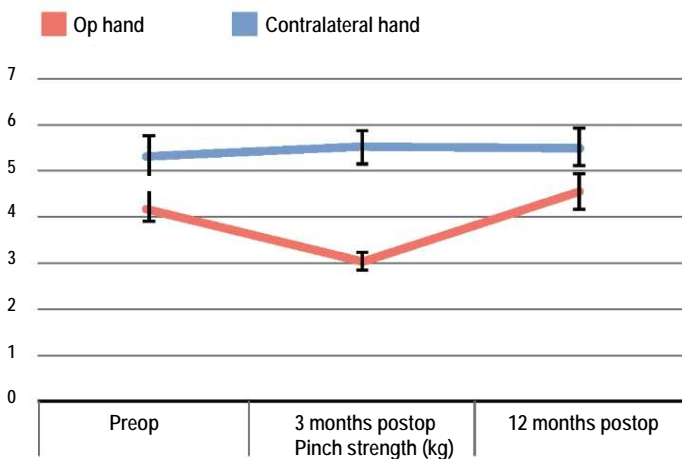
The results from the follow-ups of basal thumb surgery over a few years at three clinics have accordingly already indicated interesting results. For example, how is it that DASH scores one year after surgery with the same interpositional method can vary between 38 and 4 and the degree of resting pain can vary between 20 and 4? There appears to be significant differences in how the same kind of tendon arthroplasties are done. We need to learn more about what is important in terms of surgical techniques and postoperative aspects for these patients. Many patients still have load pain and perceive significant disability one year after surgery. How can we define and better guarantee a good outcome? Through continued follow-up in HAKIR, with more participating clinics and shared discussions in the speciality and with our patients, we should be able to improve the treatment outcomes for one of our most common diagnoses. It would also be of interest to gather a broader base of patients operated with trapeziectomy without tendon arthroplasty and patients operated with basal thumb prosthesis as a comparison.



Score (0-100)



Outcomes one year after basal thumb surgery for the 25 hand surgeons that had at least 6 survey responses registered (n=6-24). Average of total DASH score and value for questions on pain, where 100 = maximal pain. The y-axis ends at 70.

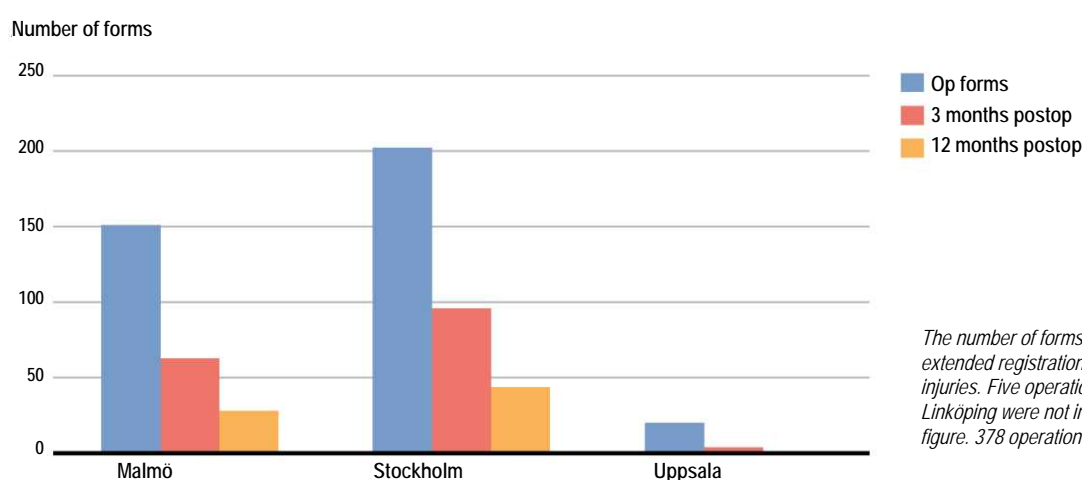


Strength in a three-point pinch and overall grip (Jamar) in kg before and after surgery for patients operated for basal thumb arthritis with trapeziectomy with or without tendon arthroplasty (n=107-235 at the different points in time). Vertical lines show a 95% confidence interval.



# Zone II flexor tendon repair

In 2014, the Malmö and Stockholm clinics participated in extended registration of flexor tendon injuries within the tendon sheath area. A small number of flexor tendon injuries had been registered in Uppsala (n=20) and Linköping (n=5). As of 31 December 2014, 378 flexor tendon operations and 235 function follow-ups had been registered; see figure. The average age for the operated patients was 36.4 years and 70.4% were men.

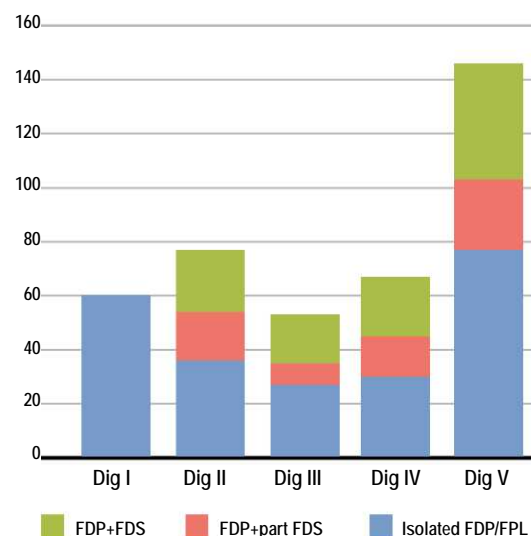


In order to analyse possible differences in outcomes between different surgical or rehabilitation techniques, we need complete postoperative follow-ups. The percentage of patients followed up has gradually improved for the two clinics that participated in 2014; see figure. In July 2015, three-month follow-ups had been registered for 65% of the patients. The percentage was probably even higher since data from paper forms not yet entered are not included. The improvements are due to consistent work to review the follow-up procedures at the two clinics.

Patients with flexor tendon injuries are usually still undergoing treatment at the clinics three months after surgery, which is why it should be realistic to gather this data. The rehab departments have considerable responsibility here, but if the doctors also point out the importance of following up the outcomes, we will probably be able to achieve our goals more quickly and obtain useful data. We believe that the majority of our patients appreciate the fact that we follow up our treatment outcomes.



Number of tendon injuries



Type of tendon injury (n=403). FDP=Flexor digitorum profundus; FDS = Flexor digitorum superficialis; FPL = Flexor pollicis longus.

## TYPE OF TENDON INJURY

The most common flexor tendon injury was an isolated division of the deep flexor tendon of the little finger (FDP V), followed by a tendon injury in the thumb (FPL). For dig II-V flexor tendon injuries, half were isolated FDP injuries and 30% total FDP+FDS injuries, with the same pattern in all fingers; see figure. 48 patients (13%) had flexor tendon injuries in more than one finger.

Digital nerve injuries occurred in 44% of the injured fingers and were most common in the thumb and index finger; see figure.

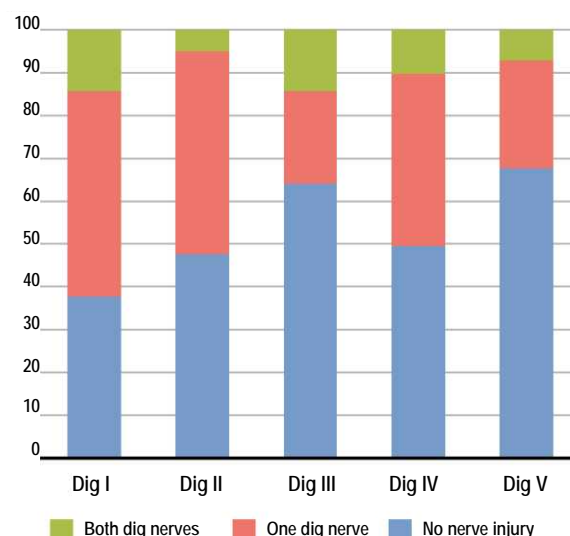
## TIME BETWEEN INJURY AND SURGERY

There appears to be different treatment traditions at the clinics regarding time prioritisation of the repair of flexor tendon injuries. Patients in Stockholm and Uppsala waited an average of 3.8 days longer for surgery after their injury than patients in Malmö. We currently have too little data to be able to indicate for certain whether or not this leads to differences in treatment outcomes (joint mobility, number of ruptures, surgical site infection, satisfaction, etc.).

| CLINIC    | NO. OF PAT. | AVERAGE (DAYS) | 95% CI (DAYS) | MEDIAN (DAYS) |
|-----------|-------------|----------------|---------------|---------------|
| Malmö     | 116         | 1.8            | 1.1 - 2.4     | 1.0           |
| Stockholm | 176         | 6.6            | 4.8 - 8.4     | 2.5           |
| Uppsala   | 18          | 6.6            | 1.5 - 11.6    | 3.5           |

Time between flexor tendon injury and surgery. Note that delays may also be due to primary delay in the handling of the injury.

Percentage nerve injuries (%)



Percentage of flexor tendon injuries in the respective finger with or without simultaneous digital nerve injury.

## SURGICAL TECHNIQUES

There also appears to be differences between the clinics with regard to suturing techniques; see table. Loop sutures, so-called Tsuge sutures, were the most common technique at all three clinics, comprising 83% of all sutures in Malmö and 73% in Stockholm. In Stockholm, a modified Kessler suture was used in nearly 20% of the operations, however. Under "other technique", we find some sutures that can be distal reinsertions (zone I) and these are not actually included in the registration in HAKIR. We have, however, decided to also include zone I injuries beginning in 2016; see below. They will then be analysed separately.

| CLINIC    | MODIF KESSLER | LOOP SUTURE TSUGE | OTHER TECHNIQUE |
|-----------|---------------|-------------------|-----------------|
| Malmö     | 8             | 122               | 18              |
| Stockholm | 39            | 145               | 14              |
| Uppsala   | 8             | 10                | 2               |

Number of patients operated with different techniques for core suture of the flexor tendon. At present, only one type of suture can be registered per patient, but in most cases, the same technique is used for all injured fingers.

Differences also existed in the choice of suture material for the core suture. In Malmö, so-called Fibre wire, a new and very strong suture material, is used in 73%, while braided polyester was most common in Stockholm (80%), where nylon sutures were also used in approximately 10% of the cases. Fibre wire and polyester loop sutures are very similar to work with and the selection may conceivably be due to the surgeon's personal preference, local procurements at the clinics or financial reasons. We do not yet know if the choice of suture material is a factor that affects the outcome.

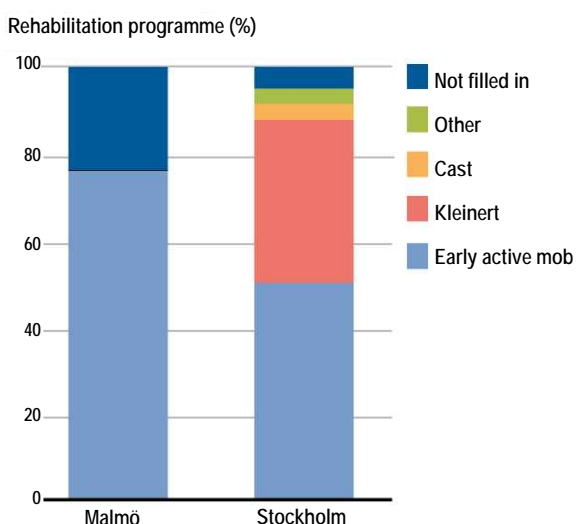


| CLINIC    | BRAIDED POLYESTER | NYLON | PDS | STEEL WIRE | FIBRE WIRE | OTHER MATERIAL |
|-----------|-------------------|-------|-----|------------|------------|----------------|
| Malmö     | 18                | 1     | 8   | 5          | 104        | 6              |
| Stockholm | 154               | 19    | 2   | 3          | 6          | 9              |
| Uppsala   | 12                | 4     | 2   | 1          | 0          | 0              |

Suture material for the core suture. Number of patients. Only one material per operation can be registered.

## MOBILISATION REGIMEN

There were also differences between the clinics with regard to the choice of postoperative rehabilitation; see figure. Early active mobilisation was the only regimen used in Malmö, while only half of the patients followed this regimen in Stockholm. In total, 74% of the patients were mobilised with an early active regimen, 22% with Kleinert and 4% with a cast or other regimen.



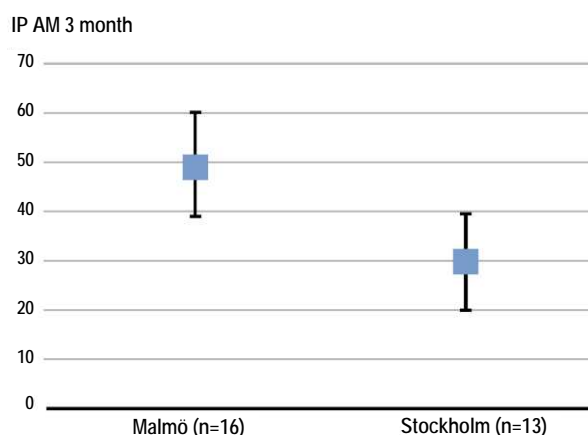
Percentage of patients (%) distributed over the various postoperative rehabilitation programmes. Information from 3-month follow-up (137 patients). The Kleinert group includes two patients who received 4-finger Kleinert, the rest were one-finger Kleinert. Information was unavailable for 14 Malmö patients, but they probably also followed the programme for early active mobilisation.

## ACTIVE MOBILITY

The three-month outcome for mobility of the IP joint for 29 sutured thumb flexor tendons (FPL) is shown in the table. The active mobility (IP AM) was 19 degrees larger among the Malmö patients. There was too little data for 12-month follow-up for reliable analysis.



|              | 3 months     |                  |
|--------------|--------------|------------------|
|              | MALMÖ (N=16) | STOCKHOLM (N=13) |
| IP flex      | 48           | 36               |
| IP ext       | -0.4         | 6.9              |
| IP AM        | 49           | 30               |
| IP AM 95% CI | 36-61        | 19-40            |
| IP AM median | 45           | 35               |



Active mobility (degrees) of the thumb's distal joint (IP joint) after flexor tendon suture of the thumb at 3-month follow-up. IP AM = Active flexion minus active extension. The minus sign means hyperextension over the zero plane. The vertical lines in the diagram show 95% CI = confidence interval.

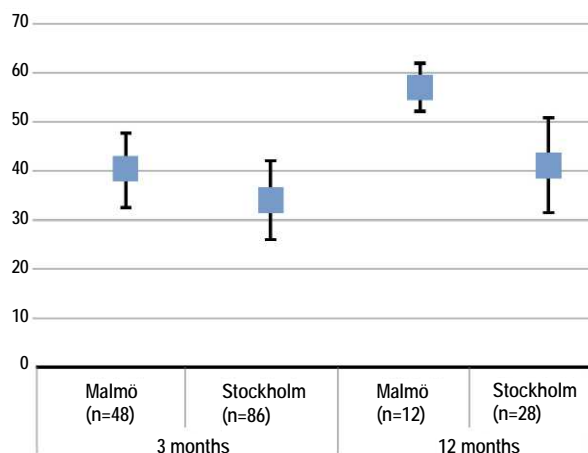
For patients with profundus tendon injury in the fingers (FDP), active mobility in the distal joint (DIPAM) after one year was 16 degrees greater among the Malmö patients; see table and diagram below and on following page.

|               | 3 month      |                  | 12 month     |                  |
|---------------|--------------|------------------|--------------|------------------|
|               | MALMÖ (N=48) | STOCKHOLM (N=86) | MALMÖ (N=12) | STOCKHOLM (N=28) |
| DIP flex      | 46           | 38               | 65           | 48               |
| DIP ext       | 7            | 4                | 8            | 7                |
| DIP AM        | 40           | 34               | 57           | 41               |
| DIP AM 95% CI | 33-47        | 29-38            | 47-66        | 32-51            |
| DIP AM median | 40           | 30               | 55           | 35               |





DIP AM 3 and 12 months



Active motion (degrees) in DIP joint at 3- and 12-month follow-up after suture of profundus tendon. Number of tendons within parentheses. DIP AM= DIP flexion minus DIP extension defect. Averages and 95% CI = 95% confidence interval.

The difference in averages may be due to random variation and we need more observations to investigate this. There may also be more factors that affect the outcome, e.g. different kinds of tendon injuries (FDP/FDS), incorrectly included zone I injuries and percentage of patients with associated nerve injury. It may also be that different suture techniques and rehabilitation regimens actually led to different outcomes in the form of mobility.

## TENDON RUPTURES

The number of reoperations due to ruptures of sutured FDP tendons within the extended registration was 2/126 (1.6%) in the Malmö material and 5/168 (3.0%) in the Stockholm material. There were no comments on further tendon ruptures or complications in the function form. A description of the patients that had a tendon rupture can be found in the table. All ruptured tendons were sutured with loop sutures and five of seven were mobilised according to an early active regimen. Men were overrepresented.

These results should be interpreted with great caution as all tendon ruptures do not lead to reoperation and incorrect registrations may also occur. We will improve the registration of tendon ruptures in the next register revision.

Analysis of 378 flexor tendon operations in HAKIR shows that there are differences in treatment regimen between Malmö and Stockholm both with regard to surgery and rehabilitation. We found both a somewhat better active distal joint mobility and lower rupture rate in the Malmö material. The causes need to be further analysed and a larger patient material will be able to show if the results hold or not. We need to conduct national discussions on the optimal treatment regimen for these very common injuries within hand surgery.

The steering committee for HAKIR decided jointly in autumn 2014 that 2015 would be the "Year of the Flexor Tendon" in that all participating specialist clinics would carry out functional follow-up of flexor tendon injuries in the tendon sheath area (zone II). Unfortunately, not all clinics have done this yet, but we hope to achieve the goal in 2016.

The first quality register in hand surgery was a flexor tendon register that never obtained national coverage, however. We hope for better success with HAKIR and are already well on the way.

In discussions in 2015, the national working group decided to carry out some minor changes in the registration of flexor tendon injuries within HAKIR. Injury level (A1-A5 pulley) will be registered and reinsertion (zone I) will be included. Registration of tendon ruptures will be clarified. We hope that future analysis of the results will be even more reliable through these changes.

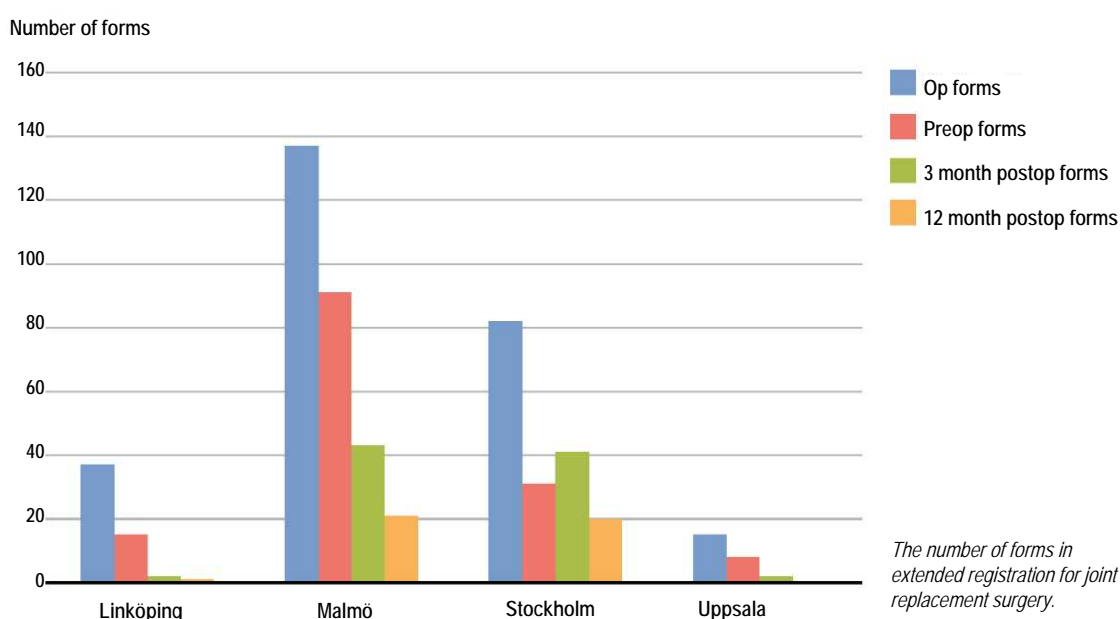
| CLINIC    | AGE (years) | SEX   | TENDON  | SUTURE TECHNIQUE | MOB REGIMEN      | TIME INJURY TO OP   | TIME OP TO REOP |
|-----------|-------------|-------|---------|------------------|------------------|---------------------|-----------------|
| Malmö     | 48          | Man   | FDP V   | Loop, Fibre Wire | Active           | Information missing | 60 days         |
| Malmö     | 29          | Man   | FDP V   | Loop, Fibre Wire | Active           | 1 day               | 29 days         |
| Stockholm | 73          | Man   | FDP V   | Loop, polyester  | Active           | 15 days             | 17 days         |
| Stockholm | 52          | Man   | FDP II  | Loop, polyester  | Kleinert         | 5 days              | 43 days         |
| Stockholm | 48          | Man   | FDP II  | Loop, polyester  | Active           | 1 day               | 11 days         |
| Stockholm | 25          | Man   | FDP III | Loop, polyester  | Cast compliance? | 5 days              | 13 days         |
| Stockholm | 23          | Woman | FDP III | Loop, polyester  | Active           | 1 day               | 43 days         |

Description of the 7 patients who had a rupture after primary suture of the profundus tendon within zone II. For one Stockholm patient, deficient compliance by the patient was stated as the cause of the rupture.



# Joint replacement surgery

Four hospital departments, Linköping, Malmö, Stockholm and Uppsala, participated in 2014 in the extended registration of joint replacement surgery. In total, 271 joint replacement operations had been registered and 275 functional evaluations before and after surgery. The percentage of patients followed up three months after surgery varies between 50% in Stockholm to 5.4% in Linköping. For the one-year follow-up, the percentage is even lower and there are also deficiencies in the number of preoperative function forms; see figure.



There are as yet too few operations to be able to present results per clinic. 271 joint prostheses were operated into 215 patients. 80.2% were women and the average age was 61.5 years (95% CI 60.0-63.0).

## OPERATED JOINTS AND PROSTHESIS TYPES

|               | PRIMARY | REVISION | CEMENT FIXATION |
|---------------|---------|----------|-----------------|
| Base of thumb | 41      | 5        | 0               |
| MCP           | 98      | 62       | 1               |
| PIP           | 66      | 5        | 16              |
| Radiocarpal   | 12      | 3        | 8               |
| DRU           | 14      | 0        | 0               |

Number of prostheses in the respective joint at primary or revision operation and the number of prosthetics where cement was used. DRU= distal radioulnar joint

The most common joint replacement surgery was in the MCP joint and a Swanson prosthesis was the most common prosthesis type.

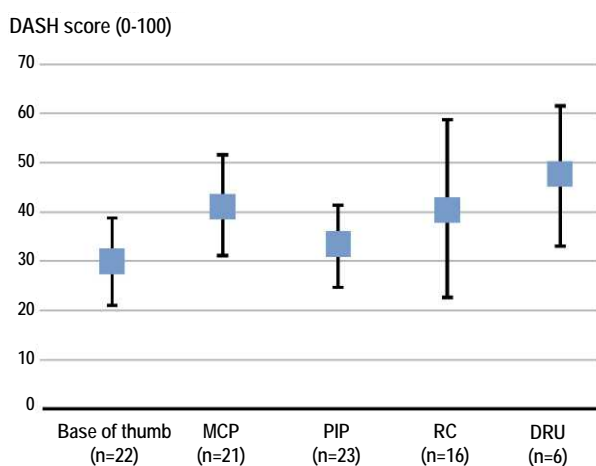
Unfortunately, we can confirm that we have not succeeded in getting the information out to the surgical staff on how prosthesis type should be registered. The prosthesis tag number has often been entered, but equally often another irrelevant number from the prosthesis label has been entered. This means that, at present, it is not possible to present with certainty what type of prosthesis has been used and we therefore refrain from such a presentation here. Fortunately, this problem can be corrected afterwards through a record review at the respective clinic, which is work that will begin in the autumn. We will need to revise the operation form to guarantee that correct information is registered. Register management regrets that we did not discover and resolve this serious problem earlier.

## OUTCOMES

No complications had been registered for joint replacement surgery in the function form. In the basic registration, there were 41 reoperations due to prosthesis complications registered for the four clinics in the extended registration.



It is not currently possible to state a reliable revision rate, which would require a much more detailed analysis and longer follow up. It is also difficult to report outcomes for certain because the follow-ups are not complete. The figure below shows three-month outcomes with regard to averages for DASH score for various joint prostheses. The only relevant interpretation right now is that most patients perceive significant functional limitation three months after surgery. It may be of most interest to note that the group of patients undergoing joint replacement surgery of the base of the thumb indicate approximately the same average for DASH at three months as the patients who underwent interpositional arthroplasty. It would be of interest to investigate this more closely when we have received more data for one-year follow-up.



Average total DASH score (0-100) three months after surgery for patients who underwent joint replacement surgery. Number of patients within parentheses. Vertical lines show a 95% confidence interval. RC = radiocarpal joint, DRU=distal radioulnar joint. The y-axis ends at 70 points.

It is too early to present functional outcomes, but for 23 PIP joint prostheses the average for active mobility at three months was 44 degrees (95% CI 36-53) with 23 degree extension (=extension defect at 23 degrees) and 67 degree flexion.

For joint replacement surgery, both longer follow up and information on radiology findings are needed. We also need to include all units in Sweden where joint replacement surgery is done. In total, there were 672 joint replacement operations in the basic registration, of which 252 were from units that do not yet participate in the extended registration. In HAKIR, there is every possibility of creating an adequate quality follow-up of joint replacement surgery, but we have to try to nationally find logistics and a registration model that make these follow-ups reasonable to handle at the clinics.

These patients often still come to the clinics for postoperative examinations, but it is important that we standardise so that we also get data into the register. Only then can we find out which prostheses work and which ones give rise to various complications. We can then also begin to compare the outcomes of joint replacement surgery with other surgical methods, such as for arthritis of the base of the thumb and wrist. We can confirm that the prosthesis registration in HAKIR is not yet optimal and this will have to be a task for a national working group to improve as soon as possible. We have begun to discuss making 2017 the year of joint replacement surgery in HAKIR.





# Collagenase treatment of Dupuytren's contracture

*Dupuytren's contracture is a very common diagnosis at Swedish hand surgery clinics. In HAKIR, more than 3,000 treatments are registered; see table below. Review of data from the basic registration shows that there are large differences in treatment principles between the clinics. However, the table shall be interpreted with caution since not all clinics register their non-surgical treatments, mainly needle fasciotomies, in HAKIR and they are accordingly probably underrepresented in the table.*

Injection with collagenase for the treatment of Dupuytren's contracture was introduced in Sweden in 2011 and three out of seven specialist clinics, Uppsala, Stockholm and Linköping, have used the method regularly and to a large extent. All three clinics have also participated in the follow up of these patients in HAKIR during different time periods. At the other four clinics, collagenase is currently used to a lesser extent and randomised studies are under way there for comparison between needle fasciotomy and collagenase. Unfortunately, as mentioned above, not all of these patients are currently registered in HAKIR. The percentage of operated patients (code NDM19) was high at the hospital departments in Malmö, Umeå and Örebro. At the Gothenburg clinic, closed fasciotomy (code NDM09) was common. Approximately 40% of the patients with Dupuytren's were operated, the rest were treated in another manner. A significant change in treatment principles has accordingly occurred since the introduction of collagenase and it is important to evaluate the outcomes.

|              | Operation   |                   | Injection             |                         |
|--------------|-------------|-------------------|-----------------------|-------------------------|
|              | FASCIECTOMY | CLOSED FASCIOTOMY | COLLAGENASE TREATMENT | PERCENTAGE OPERATED (%) |
| Gothenburg   | 98          | 160               | 0                     | 38.0                    |
| Linköping    | 111         | 0                 | 522                   | 17.5                    |
| Malmö        | 276         | 3                 | 0                     | 98.9                    |
| Stockholm    | 487         | 0                 | 510                   | 48.8                    |
| Uppsala      | 82          | 0                 | 654                   | 11.1                    |
| Umeå         | 104         | 6                 | 0                     | 94.5                    |
| Örebro       | 57          | 6                 | 0                     | 90.5                    |
| Capio Örebro | 3           | 0                 | 0                     | 100.0                   |
| <b>Total</b> | <b>1218</b> | <b>175</b>        | <b>1686</b>           | <b>39.6</b>             |

*Various treatment methods for Dupuytren's contracture and percentage of open fasciotomies per unit. A total of 3,079 registered treatments. Data from basic registration in HAKIR.*

The follow-up of collagenase treatments in HAKIR covers 1,107 treatments and 2,186 functional evaluations; see figure. Follow-up is extensive in Stockholm, while Uppsala has opted not to conduct examinations at three months and many one-year follow-ups are missing. There were 134 collagenase treatments registered from Linköping, but less than 10 follow-ups.

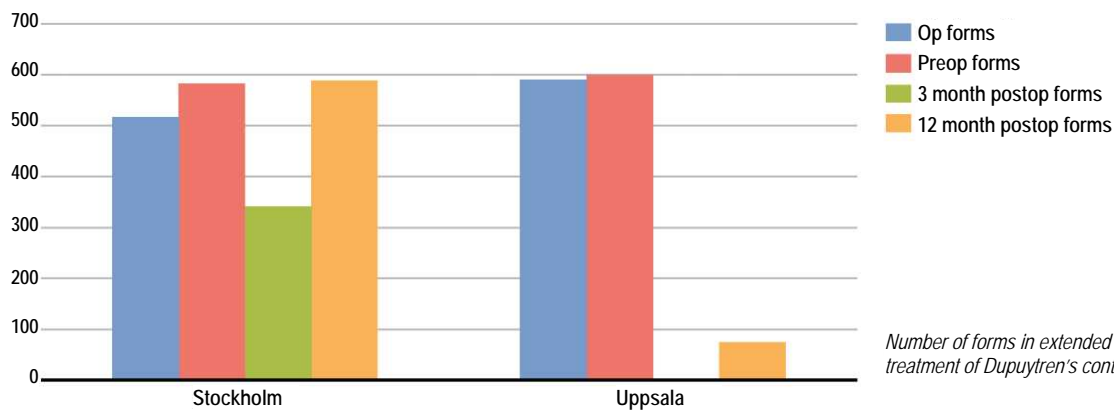
Unfortunately, it is difficult to present the results regarding remaining extension defects and recurrence because several patients were treated on several occasions, in several fingers and in both hands, which makes the analysis difficult and very time consuming. The register structure in HAKIR is not optimal for this kind of follow-up either. The vast majority of patients treated with collagenase were men (83.3%) and the average age was 68.4 years. In 89% of cases, the little finger or ring finger had been treated.

Skin ruptures in connection with the extension procedure arose in just over one fourth of the treatments (26%), while the majority had minor ulceration; see figure. The rupture rate was possibly somewhat higher in Linköping, but the selection of cases and different reporting procedures may have played a role. Otherwise, very few complications were reported and none of a more serious nature. For six patients, transient swelling of the lymph nodes was reported (approximately 0.06%) and volar plate injury had arisen in one PIP joint. Underreporting of symptoms is, of course, conceivable. No flexor tendon rupture after collagenase treatment was reported during the period.

The follow-ups show that perceived disability evaluated according to DASH decreased from 22.6 to 11.2 one year after collagenase treatment. From the basic registration, in which all clinics participate, we can obtain survey data for patients treated with other methods. DASH score one year after collagenase treatment proved to be the same as after open fasciotomy; see figure.

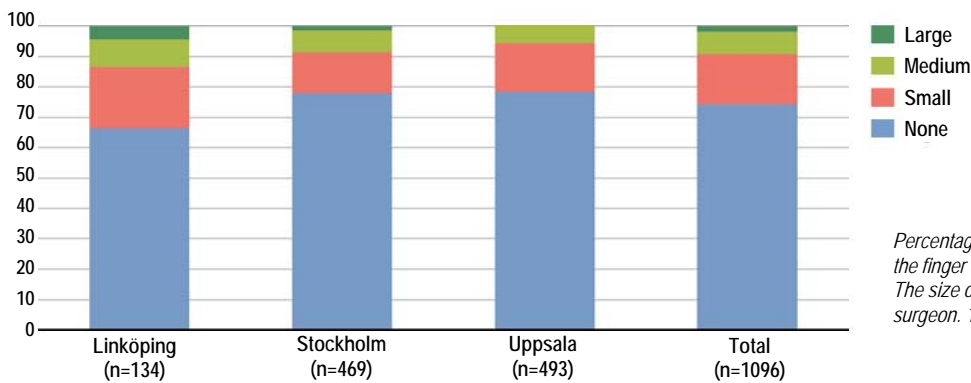


Number of forms



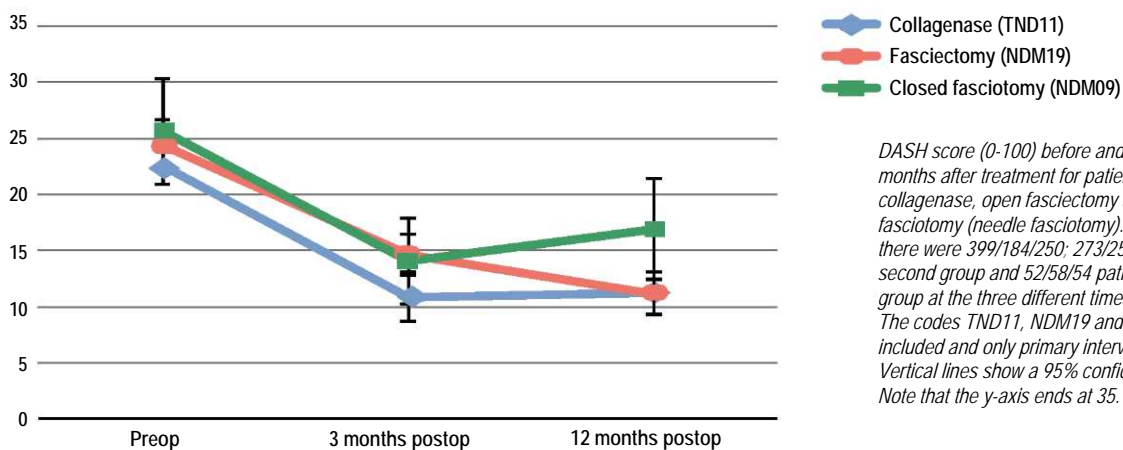
Number of forms in extended follow-up of collagenase treatment of Dupuytren's contracture.

Skin ruptures (%)



Percentage and size of skin ruptures upon extension of the finger after collagenase treatment (%). The size of the skin lesion was estimated by the surgeon. 1,096 treatments in total.

DASH score (0-100)



DASH score (0-100) before and three and 12 months after treatment for patients treated with collagenase, open fasciectomy and closed fasciotomy (needle fasciotomy). In the first group, there were 399/184/250; 273/250/252 in the second group and 52/58/54 patients in the third group at the three different times. The codes TND11, NDM19 and NDM09 are included and only primary interventions. Vertical lines show a 95% confidence interval. Note that the y-axis ends at 35.

Survey responses for closed fasciotomies (NDM09), so-called needle fasciotomies, were mainly from the Gothenburg clinic and the average for DASH of these patients was somewhat higher at one year; see figure. The material is smaller, however, and the spread wider. Patient satisfaction with the collagenase treatment was indicated at an average of 78% (n=260) after one year. Patients treated with fasciectomy (n=262) indicated an average of 79%, while those treated with closed fasciotomy indicated an average of 69% (n=73) satisfaction after one year.

We currently do not know if these are significant differences or not. Continued follow-ups will hopefully give us indications of what methods work on different kinds of patients. It would be very valuable if all needle fasciotomies and collagenase treatments could be consistently included in the basic registration. It would quickly provide us with large groups to compare between.



# Complicated courses of treatment

An important objective of HAKIR is to follow up, analyse and try to reduce the number of postoperative complications. We do not capture complications that have not led to a new operation, but hope to be able to supplement the registration in the future through our new care form and through functional follow-ups in the extended registration. In 2014-2015, we worked on the validation of the complication registrations through discussion groups at the clinics and an online survey to members of the Swedish Society for the Surgery of the Hand. We found that the definition of "complication" was unclear and that the actual word caused concern for negative comparisons and the laying of blame. The term "complicated course of treatment" will therefore be used in continuation and by this, we mean a course of treatment that was not expected, and that in this case led to an unplanned, "avoidable", reoperation. Continued discussions and adjustments of the register parameters will probably be needed to further clarify the terms. We hope to achieve an open and objective registration of various problems that may arise after surgical treatments of the hand. Analysis of postoperative complications must also be done at the detailed level in the future, related to what primary operation is involved, e.g. analysis of ruptures after a flexor tendon repair, detachment of joint prostheses or pseudarthrosis after skeletal surgery. HAKIR can provide statistics to facilitate such improvement work, but we need to form national working groups to make progress in this effort.

36,629 primary operations in one stage and 2,604 multi-stage operations had been registered. 1,396 operations were "removal of osteosynthesis material to prevent complication" and "other cause of reoperation" was indicated for 1,851. 1,705 reoperations due to postoperative complicated course of treatment had been registered; see table. This corresponds to 4.2% of all operations during the period. In 32.2%, the primary operation had been performed at a different clinic, an external "complication". Hence, the percentage of reoperations due to postoperative complication for patients operated at the own clinic (internal cases) was 2.6%. For 274 reoperations, there was no information on the primary operation and they are therefore not presented here. From Umeå, only 13 reoperations (0.4%) due to postoperative complication had been reported and from the hospital department in Örebro, four (0.4%) had been reported. This must reasonably be an underreporting, which is why we do not present these clinics in the table. The private unit Capio Örebro is included with only 81 operations and one reoperation and is therefore also not in the table.

The most common registered reason for reoperation due to complication was adherence formation/contracture (67% of internal cases) followed by postoperative infection (75.2% internal). For reoperation due to nerve injury, external cases were dominant (77.8% external). Third

|            | OSTEOSYNTHESIS-REL. |          | INFECTION |          | SKIN NECROSIS |          | HEMATOMA |          | NERVE COMPR/COMPARTMENT |          | TENDON RUPTURE |          | NERVE INJURY |          |
|------------|---------------------|----------|-----------|----------|---------------|----------|----------|----------|-------------------------|----------|----------------|----------|--------------|----------|
|            | Internal            | External | Internal  | External | Internal      | External | Internal | External | Internal                | External | Internal       | External | Internal     | External |
| Gothenburg | 14                  | 10       | 19        | 6        | 20            | 4        | 0        | 1        | 2                       | 3        | 13             | 10       | 1            | 9        |
| Linköping  | 5                   | 3        | 13        | 6        | 24            | 3        | 0        | 0        | 8                       | 7        | 19             | 7        | 0            | 3        |
| Malmö      | 20                  | 9        | 52        | 10       | 38            | 5        | 4        | 0        | 5                       | 4        | 17             | 2        | 0            | 3        |
| Stockholm  | 56                  | 49       | 88        | 33       | 46            | 13       | 6        | 10       | 12                      | 16       | 41             | 31       | 7            | 16       |
| Uppsala    | 33                  | 9        | 19        | 8        | 20            | 2        | 1        | 0        | 3                       | 3        | 17             | 6        | 2            | 4        |
| Total      | 128                 | 80       | 191       | 63       | 148           | 27       | 11       | 11       | 30                      | 33       | 107            | 56       | 10           | 35       |



The third most common reason was osteosynthesis-related complications. These are especially important to observe in connection with the sharply increased percentage of operations in recent years with volar plates for distal radius fractures, where the osteosynthesis material in some cases can cause tendon ruptures. A research project from Linköping based on HAKIR data is planned. Reported prosthesis complications were most common in Gothenburg, probably related to a high percentage of such operations.

In summary, the reporting of complicated postoperative courses of treatment is very important information and it is important that all clinics report and analyse their data. We already have a monthly report by e-mail to the unit managers, but our planned dynamic output data reports will substantially facilitate the improvement work at the clinics. Direct comparisons between the clinics shall as yet be made with great caution due in part to different case mixes, but also because the reporting rate appears to vary quite a bit.

| ADHERENCE/<br>CONTRACTURE |          | NON-/MALUNION |          | PROSTHESIS COMPL. |          | DONOR SITE COMPL. |          | OTHER COMPL. |          | PERCENTAGE COMPL./TOTAL NO. OP (%) |          |          |                         |
|---------------------------|----------|---------------|----------|-------------------|----------|-------------------|----------|--------------|----------|------------------------------------|----------|----------|-------------------------|
| Internal                  | External | Internal      | External | Internal          | External | Internal          | External | Internal     | External | Total                              | Internal | External | Percentage external (%) |
| 32                        | 31       | 11            | 14       | 25                | 6        | 0                 | 0        | 29           | 17       | 277                                | 4.1      | 2.8      | 40.1                    |
| 23                        | 6        | 23            | 8        | 10                | 0        | 0                 | 0        | 16           | 5        | 189                                | 2.1      | 0.7      | 25.4                    |
| 20                        | 5        | 12            | 5        | 13                | 3        | 0                 | 0        | 34           | 5        | 266                                | 2.1      | 0.5      | 19.2                    |
| 84                        | 42       | 43            | 38       | 9                 | 1        | 0                 | 0        | 51           | 24       | 716                                | 3.2      | 2.0      | 38.1                    |
| 24                        | 6        | 21            | 13       | 10                | 3        | 0                 | 0        | 28           | 8        | 240                                | 3.4      | 1.2      | 25.8                    |
| 183                       | 90       | 110           | 78       | 67                | 13       | 0                 | 0        | 158          | 59       | 1688                               | 2.9      | 1.4      | 32.3                    |



# Summary

*HAKIR celebrated its fifth anniversary as a quality register in February 2015. Our first years were characterised by start-up and development efforts. We have gradually added all seven specialist clinics for hand surgery in Sweden. Private hand surgery units are welcome and two joined in 2014-2015.*

A few more units registered their interest in joining. Some hand units at orthopaedic clinics have also been in touch and on the long term, we are of course interested in also offering their patients quality follow-up in HAKIR. The difficulty is, however, the mixed surgical activities at an orthopaedic clinic with problems controlling dropout of hand operations. An important principle in HAKIR is that all operations at a unit shall be included so that we can monitor dropout using hospital statistics. Through cooperation and discussion with the orthopaedic clinics, we should definitely be able to resolve this on the long term.

We believe that the strategy of first starting up on a small scale has been wise. When starting a new register, problems and "teething issues" always arise, which may be of a technical, organisational, human or mixed nature. This has also been true for HAKIR, but we are now pleased that the register in general functions well, with a relatively small personnel input and good coverage ratio at most affiliated clinics. We are a bit worried about the lack of improvement in the coverage ratio at individual units, but hope that our attention to the problem can lead to a positive development.

In the first five years, we have made significant technical improvements in the register platform and online survey in cooperation with Registercentrum South (RCO Syd). We are particularly pleased that we now seem to have identified the model for the collection of online survey responses that provides the best response rate. The interprofessional collaboration in the national working group has been key throughout the process to resolving various other problems that have arisen. Extensive commitment and a positive spirit of collaboration characterise these meetings and the group forms the actual foundation of the register.

In 2014, we were also able to strengthen our central register working group by one person, which meant that we obtained much better order in the documentation, logistics, legal matters, data handling and other necessary register work. We believe and hope that we have also been able to further improve our support for the local coordinators.

Something we wish we had made more progress with is our output data reports. Our register platform 3C was modern and functional when it was introduced, but is now in major need of being updated. The platform is stable and secure, but has the disadvantage that it is difficult to easily extract data. We have therefore applied for and received funding in 2015 to develop flexible output data reports. We have ordered reports intended for coordinators and unit managers and reports for improvement work. Unfortunately, everything has been slowed by the procurement rules for IT services in Region Skåne, but we hope this can work itself out in the autumn. RCO Syd is working on the issue.

The extended registrations are important to be able to compare surgical and rehabilitation methods in a scientific manner and on behalf of the register management, we believe that follow-ups of treatment outcomes shall be seen as a given part of healthcare. They provide an opportunity to capture and address potential problems early on and to allow the patient to express his or her opinion and get feedback. There is a great deal to learn from such follow-up. It is important that the management of the clinics prioritise their participation in these follow-ups and in the collection of complete data. With well-conceived logistics and standardisation, the registration does not demand as many resources as it may initially seem. Standardised follow-up of care also creates security for the patients in that they feel listened to and know that complications cannot be concealed and "swept under the rug".





If in the future we are to be able to scientifically compare different outcomes in hand surgery, we need to have complete follow-ups of large patient groups.

The registration of complications in HAKIR has been discussed in various professional contexts over the year and some changes in the registration will be introduced in 2016; see box below. We hope that this leads to an even more honest and objective registration of postoperative problems as a basis for improvement efforts. Follow up will be done. Some changes will also be made with regard to the registration of flexor tendon injuries; see below. The outcomes presented above indicate regional differences and we need to supplement with data to analyse this further.

The annual report work identified a serious problem in the extended follow-up of joint prostheses where the type of prosthesis was not correctly registered. We will make changes so that this works in the future and supplement the information that is missing. Joint replacement surgery is costly and it is important to evaluate the outcomes of new prostheses that are introduced. Prosthesis registers have been very successful in orthopaedics.

For several years, the participating clinics have sought to expand HAKIR so that the register also reflects the care conducted in hand surgery and in turn enables improvement work and research in the area.

In spring 2015, the central working group has also, in cooperation with the national working group and the steering committee for HAKIR, allocated funding for and initiated a one-year project that aims to develop a care form. A project group with participation of representatives from Skåne University Hospital in Malmö, Capio Läkargruppen in Örebro, Uppsala University Hospital and Södersjukhuset in Stockholm has been appointed and the final report is planned for October 2016.

Another effort that will begin in 2016 is a collaboration with the Hand Unit in Malmö on their electronic form for hand status, called DIGMA. The road there is surely long, but the vision for the future is that hand therapists use a common national status form in the patient medical record and that relevant output data can automatically be transferred to HAKIR without double documentation.

A great deal remains to improve and develop in HAKIR of course. A quality register is never "finished". Technical functions can be improved and logistics simplified. Collected data gives rise to new questions, which lead to new needs for register parameters and output data reports. It is important that the basic requirements of complete and valid data are constantly monitored.

We who work centrally with HAKIR would like to thank all of the patients and employees who contributed to the register during the year. A special thank you goes to statistician Tomasz Czuba at RCO Syd for his invaluable help, quick service and pleasant cooperation.

## PLANNED CHANGES 2016

### Basic form

The term of "postoperative complication" will be changed to "postoperative complicated course of treatment"

Tendon ruptures after primary tendon repair will be specified among causes of reoperation

A field will be added to more clearly distinguish a primary infection from a postoperative surgical site infection

A field will be added to distinguish an open hand injury from one where the skin is intact

### Extended follow-up of flexor tendon injuries

Injury level (pulley A1-A5) will be added to the operation form

Injuries in zone I will also be included (reinsertions); they can then be analysed separately

Possibility to register different suture techniques/materials for different fingers

Dominant hand will be added to the function form (possibly for more diagnoses)

### Extended registration of joint replacement surgery

Specification of prosthesis type will be added to the operation form and completed by the surgeon





# How did it go in 2014-2015?



The registration of complications shall be analysed locally at the clinics and improvements shall be proposed to ensure complete and correct registration. A national complication group shall be formed and work, among other things, on definitions of various terms to increase validity.

*Goal achieved. Funding was sought for a complication project in which the hospital departments in Stockholm, Malmö, Uppsala, Umeå and Gothenburg participated. Everyone contributed improvement suggestions. The registration of complications was also discussed at national meetings and improvements were agreed on. The majority of these proposals will be carried out in 2015. Work will continue on improving registration.*



Extended registration for zone II flexor tendon injuries shall have been introduced at all participating clinics.

*Goal partially achieved. In 2014, Malmö and Stockholm participated in the flexor tendon registration and a small number of flexor tendon injuries were registered in Uppsala and Linköping. More clinics introduced this registration during the so-called "Year of the Flexor Tendon" in 2015, and we hope to be able to achieve the goal of all clinics participating in 2016.*



Clinics that participate in extended registration shall have worked out procedures to discover and reduce dropout in registrations.

*Goal partially achieved. Documentation exists in a "check list" for all clinics where they describe their respective procedures for how they work on discovering and reducing dropout in all registration. Extended registration is done at four clinics (Stockholm, Uppsala, Malmö and Linköping) and of these, all are assessed to have procedures for discovering dropout.*



Technical improvements in the data platform shall have been carried out, a pop-up function for information upon registration, continuous identification and deregistration of deceased patients, improved procedures for authorisation allocation and better procedures for the update of the patient information brochure. *Goal partially achieved.*

*A pop-up function is developed and implemented in the register platform. Improved procedures for authorisation allocation and update of the patient information brochure have been implemented. The work of continuously identifying and deregistering deceased patients has begun and is estimated to be complete in 2015.*



Organisation change of the central working group and the steering committee shall have been carried out. Clearer work descriptions for the working group. Quorum formation in the steering committee shall be improved and expertise from more professional categories shall be added. If possible, a patient representative shall be tied to the steering committee.

*Goal achieved. New work descriptions for the central working group have been created and the expertise in the steering committee has been extended to be represented interprofessionally by expertise from the professions of physician, nurse, public health officer and occupational therapist. Focus groups with patient representatives are planned for spring 2016.*



A new follow-up of the response rate for the online survey shall have been done and in the event of continued low response rates, additional improvement measures shall have been implemented. E-mail messaging function shall have been introduced if this entailed an acceptable response rate (> 60%).

*Goal achieved. The postoperative online surveys are now sent out throughout Sweden by e-mail and text messaging, in contrast to only text messaging. This initially increased the response rate to 60%. We are monitoring the development and if the good results are not maintained, further steps are being planned.*



At least two scientific projects based on register data shall have been started.

*A master's project concerning patient-reported outcomes after basal thumb surgery in Uppsala is finished. Student projects on operated finger phalanx fractures in Stockholm have been conducted and will be submitted for publication in 2015.*



# Specific goals for 2015-2016

- All units that operate flexor tendon injuries shall have started extended registration for these injuries in HAKIR
- A national project on developing a care form in HAKIR shall have been carried out.
- Translations of patient information and forms for staff shall be complete for at least five languages.
- Quality indicators that cover the entire registration in HAKIR shall exist and be nationally based.
- Interactive output data reports shall be available and adapted for staff, management and patients, respectively.
- Archive procedures for documentation in the form of paper forms shall be in place and be nationally based.
- National procedures and technical conditions shall exist for the registration of the same patient over regional borders.
- Work shall have begun on investigating potential consequences and developing procedures for the registration of data for those not capable of making decisions.
- An annual wheel with important dates for annually recurring work that concerns coordinators, register managers and central working groups shall exist.

Stockholm, September 2015

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HAKIR is a national quality register for hand surgery founded in 2010 on the initiative of the Swedish Society for the Surgery of the Hand.

