

# SwedAnkle and a Swedish perspective on Patient Engagement in Quality Registers

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**LUNDS**  
UNIVERSITET



Skånes  
universitetssjukhus



**RELEVANCE**

# National Quality Registries in Sweden (NQR)

- About one hundred National Quality Registries provide the Swedish health care system with a unique opportunity to monitor quality and results.
- They contain individualized data about medical interventions, procedures and outcomes. They are integrated into clinical workflows and have the capacity to generate data in real time.
- Registries also contribute to innovative e-Health services, patient-centred approaches and decision support functionalities, as well as IT development and integration.

<https://skr.se/en/kvalitetsregister/omnationellakvalitetsregister.52218.html>

# Vision

National Quality Registries are used in an integrated and active way for continuous learning, improvement, research and management to create the best possible health and care together with the individual.

<https://skr.se/en/kvalitetsregister/omnationellakvalitetsregister.52218.html>

# National Program Areas

National Program Areas (NPO; Nationella Program Områden) are integrated in the National System for Knowledge Management in Health and Medical Care.

The NPO is responsible for developing treatment guidelines and finding indicators that reflect outcomes and demonstrate adherence to guidelines.

All quality registers are linked to at least one NPO and are the main source for compliance and outcome data.

<https://kunskapsstyrningvard.se/kunskapsstyrningvard/omkunskapsstyrning/nationalsystemforknowledge-drivenmanagementwithinswedishhealthcare.56857.html>

# National Program Areas

- Emergency care
- Child and adolescent health
- Cancers
- Endocrine diseases
- Cardiovascular diseases
- Skin and sexually transmitted diseases
- Infectious diseases
- Surgery and plastic surgery
- Women's diseases and childbirth
- Lung and allergy diseases
- Gastrointestinal diseases
- Diseases of the nervous system
- Kidney and urinary tract diseases
- Perioperative care, intensive care and transplantation
- Mental health
- Rheumatic diseases
- Musculoskeletal disorders
- Rare diseases
- Dentistry
- Health of the elderly
- Eye diseases
- Ear, nose and throat diseases

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# Musculoskeletal disorders

Area	Register
Amputations och prostheses	Amputations- och protesregistret (SwedeAmp)
Osteoarthritis	Svenska Artros-registret
Foot surgery	Nationella kvalitetsregistret för fotkirurgi (Riksfot)
Ankle surgery	Svenska Fotledsregistret (SwedAnkle)
Fractures	Svenska Frakturregistret (SFR)
Hand surgery	Handkirurgiskt kvalitetsregister (HAKIR)
Hip fractures	Nationellt kvalitetsregister för höftfrakturpatienter och deras behandling (RIKSHÖFT)
Cruciate ligament injuries	Svenska Korsbandsregistret
Hip and knee replacements	Svenska Ledprotesregistret (SLR)
Pediatric orthopedic surgery	Svenskt Pediatriskt Ortopediskt Kvalitetsregister (SPOQ)
Spine surgery	Svenska ryggregistret (SweSpine)
Shoulder and elbow surgery	Svenska Skulder- och Armbågsregistret (SSAR)



# Vården i Siffror (VIS; <https://vardenisiffror.se/>)

VÅRDEN I SIFFROR

Indikatorer ▾

Rapporter ▾

Mina enhetslistor

Dataexport

🔍 Sök efter indikatorer...

## Vården i siffror

Vården i siffror visar aktuell statistik som stöd för utvecklings- och förbättringsarbete i hälso- och sjukvården

Riket

Rimlig väntetid till vård- eller  
hälsocentral

63 % ▾

Riket

Rimlig väntetid till sjukhusvård

47.6 % ▾

Riket

Medicinsk bedömning inom tre dagar i  
primärvård, läkare

89.1 % ▾

Riket

Förtroende för sjukhus

69.6 % ▾

## Aktuellt



Nationellt programområde  
rörelseorganens sjukdomar -  
rapport på Vården i siffror



Swedehearts kvalitetsindex 2023  
klart - Motala och Västerås i topp



Ny utskriftsfunktion

2024-03-15



Hälso- och sjukvårdsbar  
2023

# Care in numbers (<https://vardenisiffror.se/>)

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Rapporter ▾

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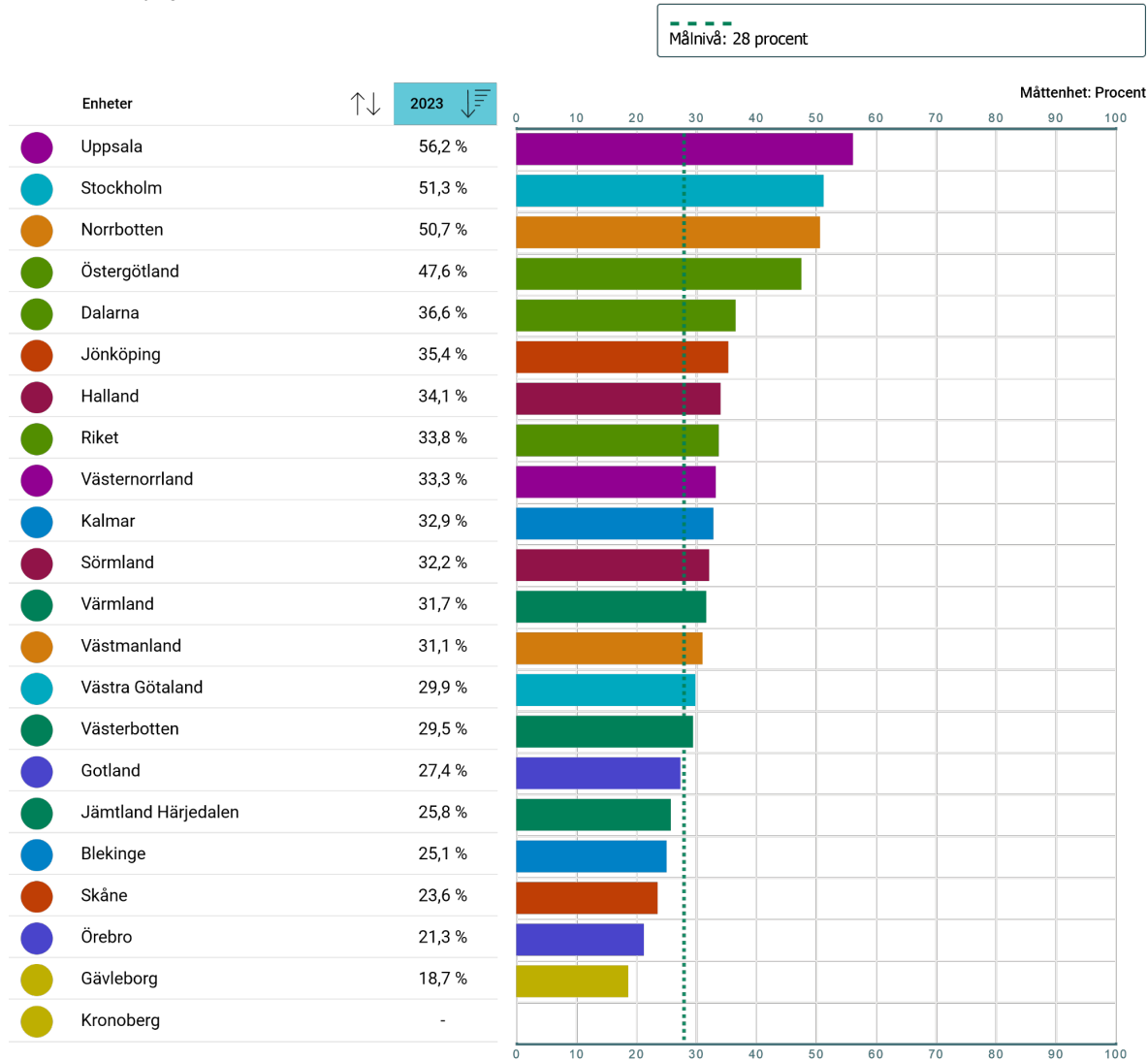


Hälso- och sjukvårdsbar  
2023

## Behandlingsval vid handledsfraktur

Andel handledsfrakturer som behandlas kirurgiskt

Önskat värde: Kan ej anges



Proportion of patients with wrist fractures that undergo surgery.

Target level 28%

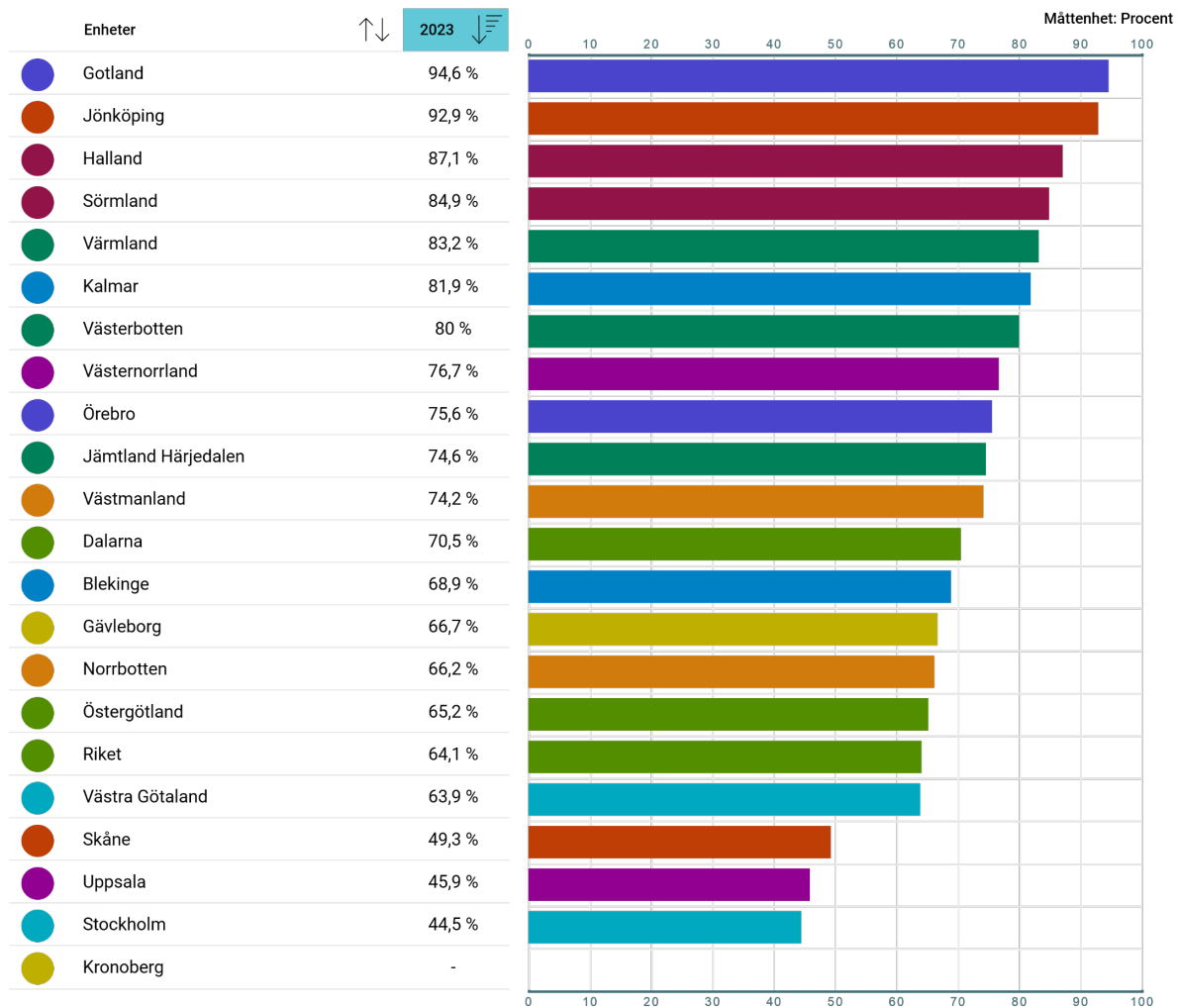
Urval

Kön: Totalt, Ålder: Totalt, Period: År

## Operation inom en vecka vid handledsfraktur

Andel patienter med handledsfraktur som opereras inom en vecka. Avser frakturer där operation var förstahandsval.

Önskat värde: Högt



Proportion of patients with wrist fractures that undergo surgery within a week. Only cases where surgery was the first choice are included.

Target level high.

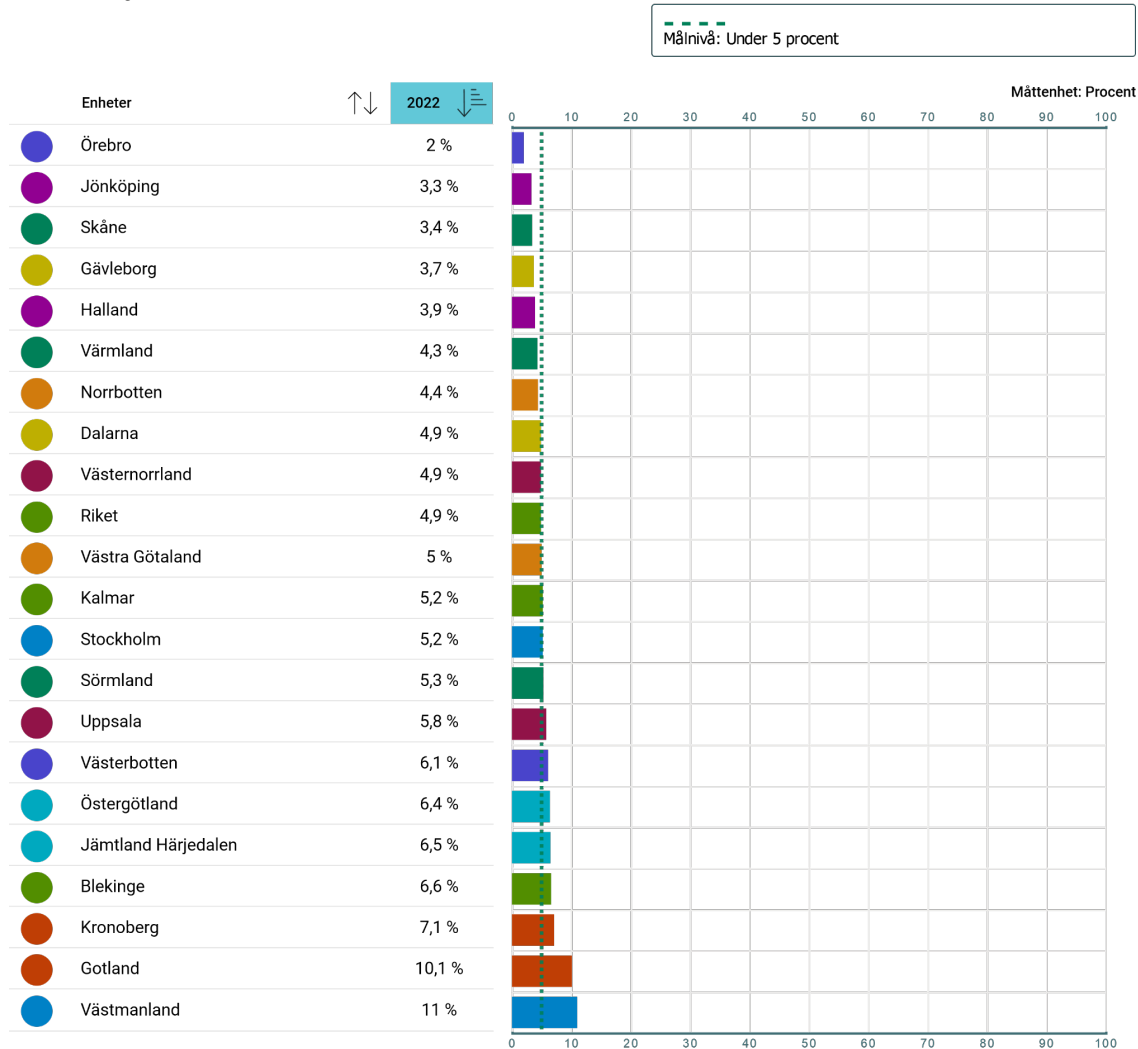
Urval

Kön: Totalt, Ålder: Totalt, Period: År

### Oönskad händelse 90 dagar efter höftprotresoperation vid höftledsartros

Andel patienter med höftledsartros i gruppen "vanliga patienten" som drabbas av en oönskad händelse inom 90 dagar efter höftprotresoperation. Mätperioden är tre år, där det redovisade året är det sista.

Önskat värde: Lågt



Adverse event within 90 days after hip replacement surgery for osteoarthritis.

Target level <5%

Urval

Kön: Totalt, Ålder: Totalt, Period: År

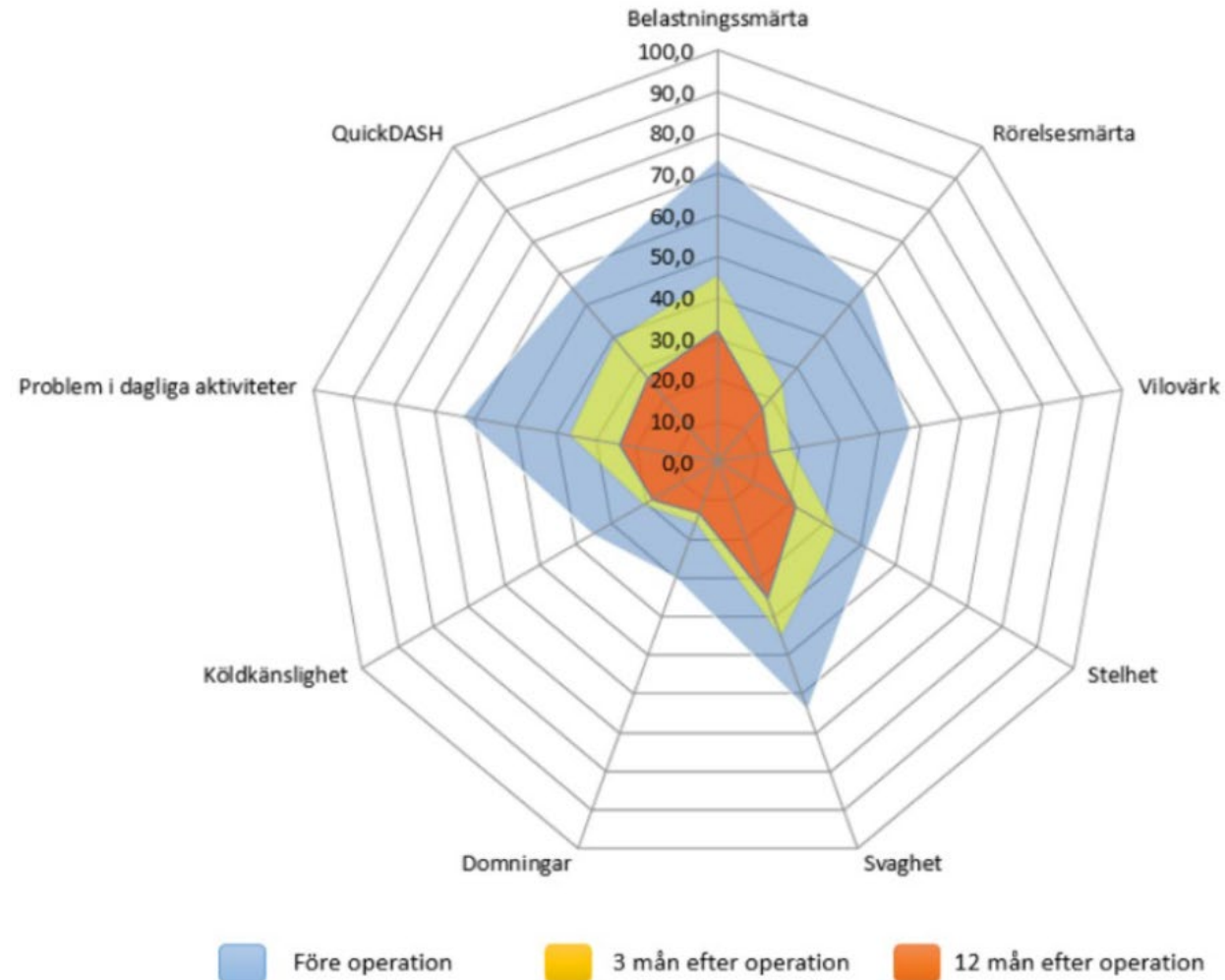
# National care program for thumb osteoarthritis

Support document for the treatment of thumb base osteoarthritis  
– in primary and specialized care

National Program Area for Musculoskeletal Diseases

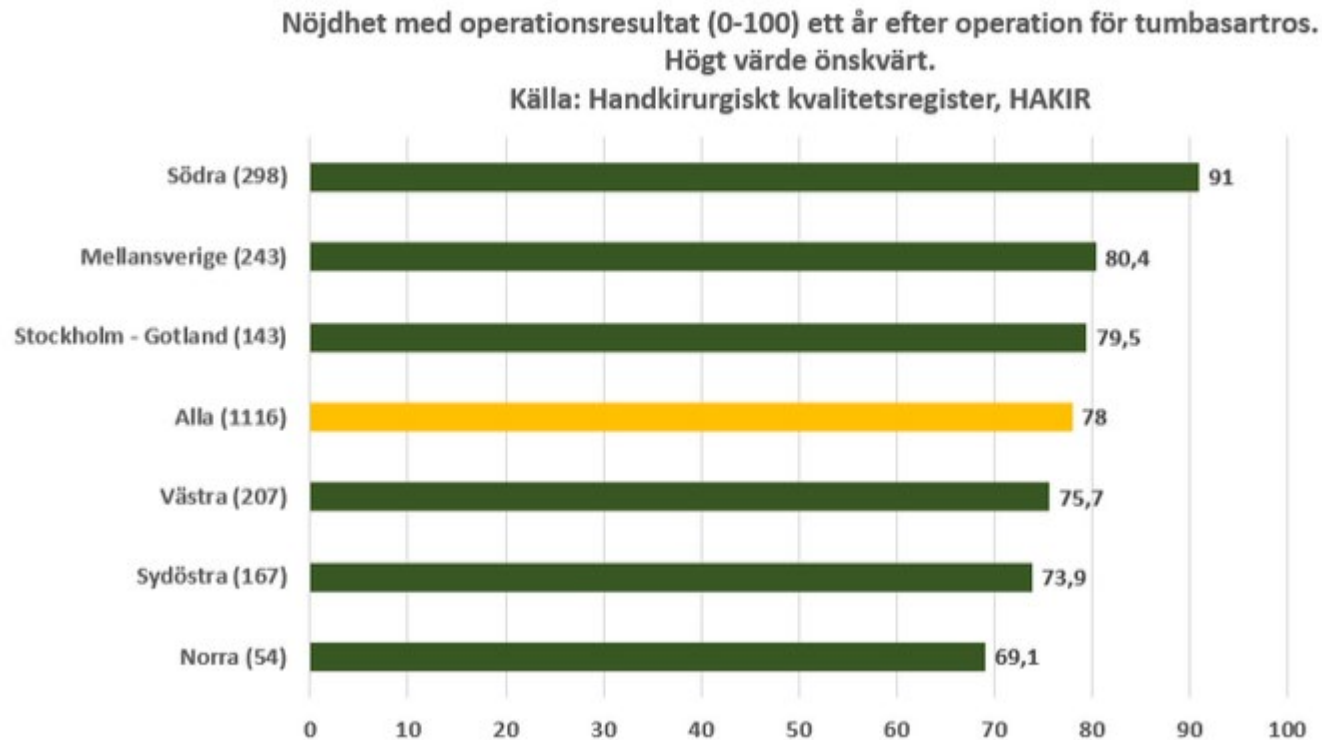
[https://www.nationelltklinisktkunskapsstod.se/globalassets/nkk/nationell/media/dokument/kunskapsstod/wardprogram/nationellt-wardprogram-for-tumbasartros.pdf](https://www.nationelltklinisktkunskapsstod.se/globalassets/nkk/nationell/media/dokument/kunskapsstod/vardprogram/nationellt-wardprogram-for-tumbasartros.pdf)

# Disability before and after surgery for thumb osteoarthritis





# Satisfaction 1 year after surgery for thumb osteoarthritis





# The steering group

- The steering group should take account of the professions' and patients' interest in quality follow-up of healthcare and collaborates with the CPUA authority on issues relating to the disclosure of data for research purposes, for example.
- The steering group should include at least one patient representative

# Official guide to patient engagement in National Quality Registries



<https://skr.se/en/kvalitetsregister/omnationellakvalitetsregister.52218.html>

# The perspectives of patients

One of the challenges for a steering group in a NQR is to take advantage of the knowledge that patients have about living with an illness and/or disability, about undergoing different treatments and what is important in the encounter with healthcare to be able to live a good life.

<https://skr.se/en/kvalitetsregister/omnationellakvalitetsregister.52218.html>

# The perspectives of patients

- The use of patient-reported measures is important to gain access to patients' perspectives on care and health but cannot replace active patient participation in the registry work.
- Patients (and relatives) live around the clock with a disease and can formulate their important goals, aspects of treatment, effects/side effects, treatment, participation, information, care chain, etc., how the registry could support self-care and disease control, and how results from the registry can be presented and communicated to patients and the public.

# The perspectives of patients

Patient engagement can facilitate the production of target group adapted patient versions of the registry results, annual reports, etc., so that the results data are accessible and understandable to everyone.

The presentation of outcome data needs to be designed so that it is relevant and understandable for patients and the general public. It should be available as reports on the register's website and can also be reports aimed at patients.

<https://skr.se/en/kvalitetsregister/omnationellakvalitetsregister.52218.html>

# The patient perspective in practice

Patient organizations exist in most areas of long-term illness and should be the primary source of patient representation.

Acute or short-term disease and condition registries, intervention/surgery registries, or general population registries, may need to use other methods. Examples of such methods can be reference groups and focus groups or other systematic interview methods.

<https://skr.se/en/kvalitetsregister/omnationellakvalitetsregister.52218.html>

**SwedAnkle**  
Nationella fotledsregistret



<https://swedankle.se/>



# SwedAnkle



OM SVENSKA NATIONELLA FOTLEDSREGISTRET LÄNKAR KONTAKT

Sök



START NYHETER PATIENTINFORMATION PUBLIKATIONER REGISTRERING STATISTIK LOGGA IN

2 AV 2

## ÅRSRAPPORT FÖR 2022 PUBLICERAD

2023-11-10 | Fotledsregistrets (SwedAnkles) årsrapport för verksamhetsåret 2022 är nu publicerad och tillgänglig för nedladdning.

MER INFORMATION >



Om Svenska Nationella  
Fotledsregistret



About Swedankle (in  
English)



Mer om register hos  
Registercentrum Syd



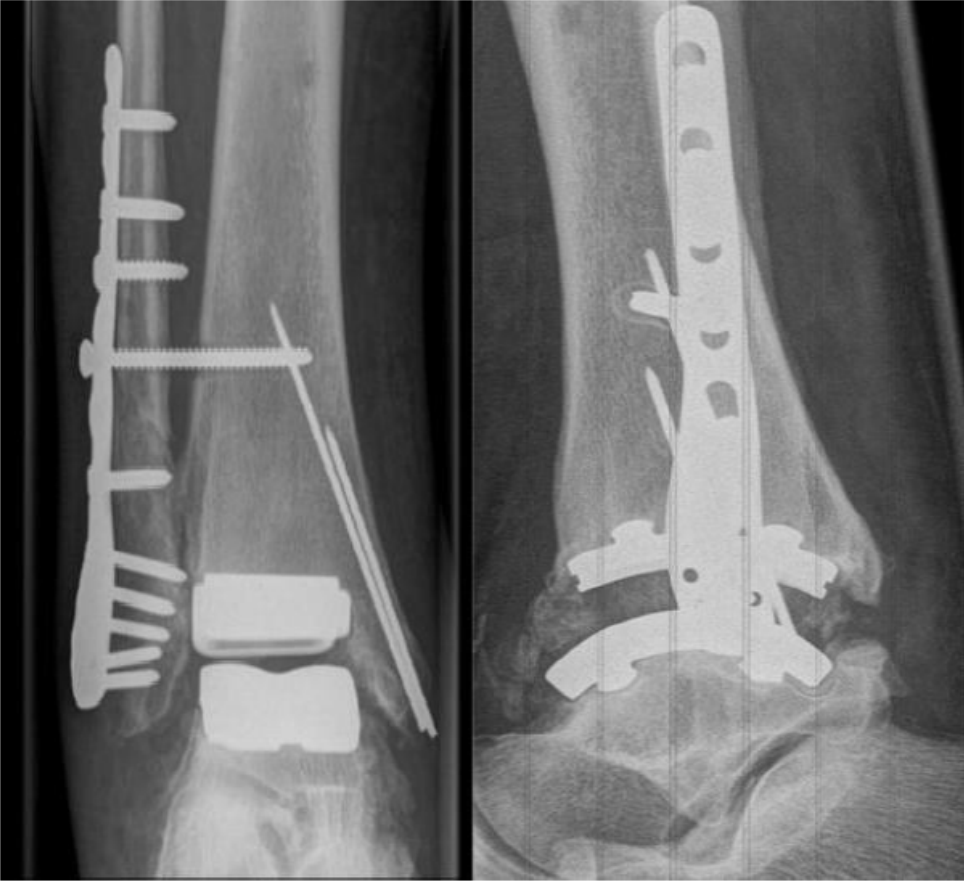
Patientinformation

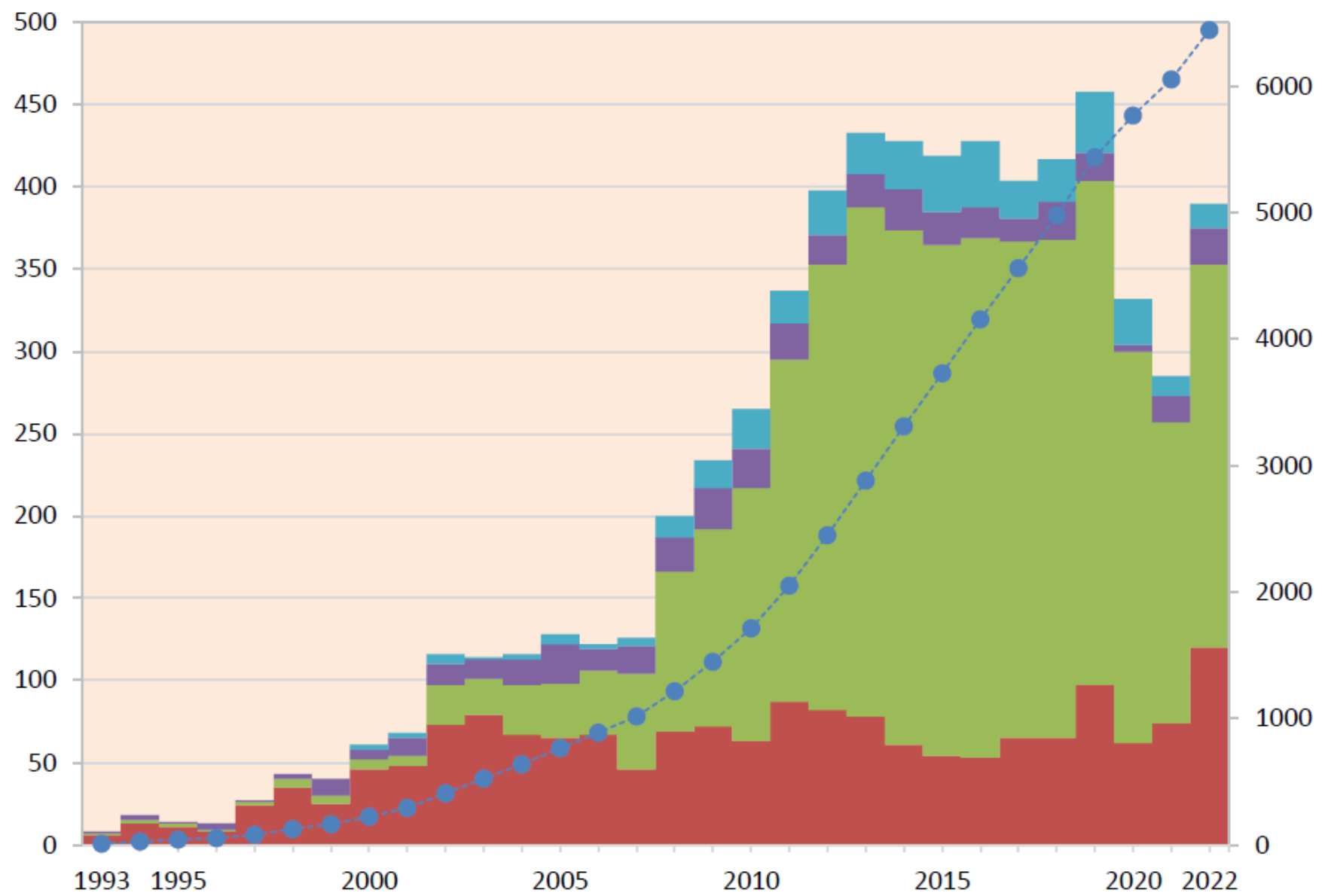


Kvalitetsindikatorer hos  
Vården i siffror



# Arthroplasty and arthrodesis





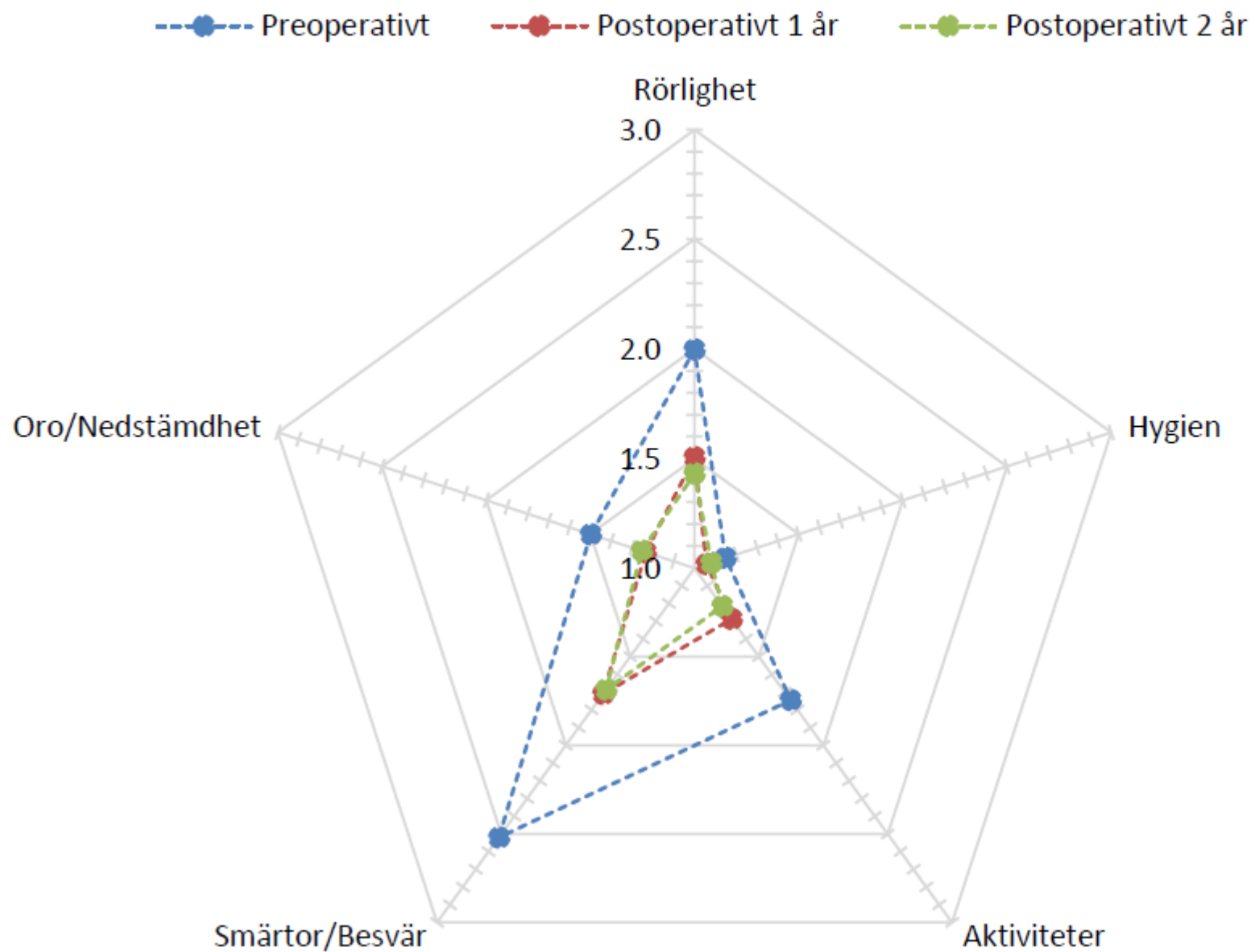
■ Primärprotes      ■ Primärartrodes  
■ Protesrevision #1      ■ Reartrodes #1

# PROMs/PREMs

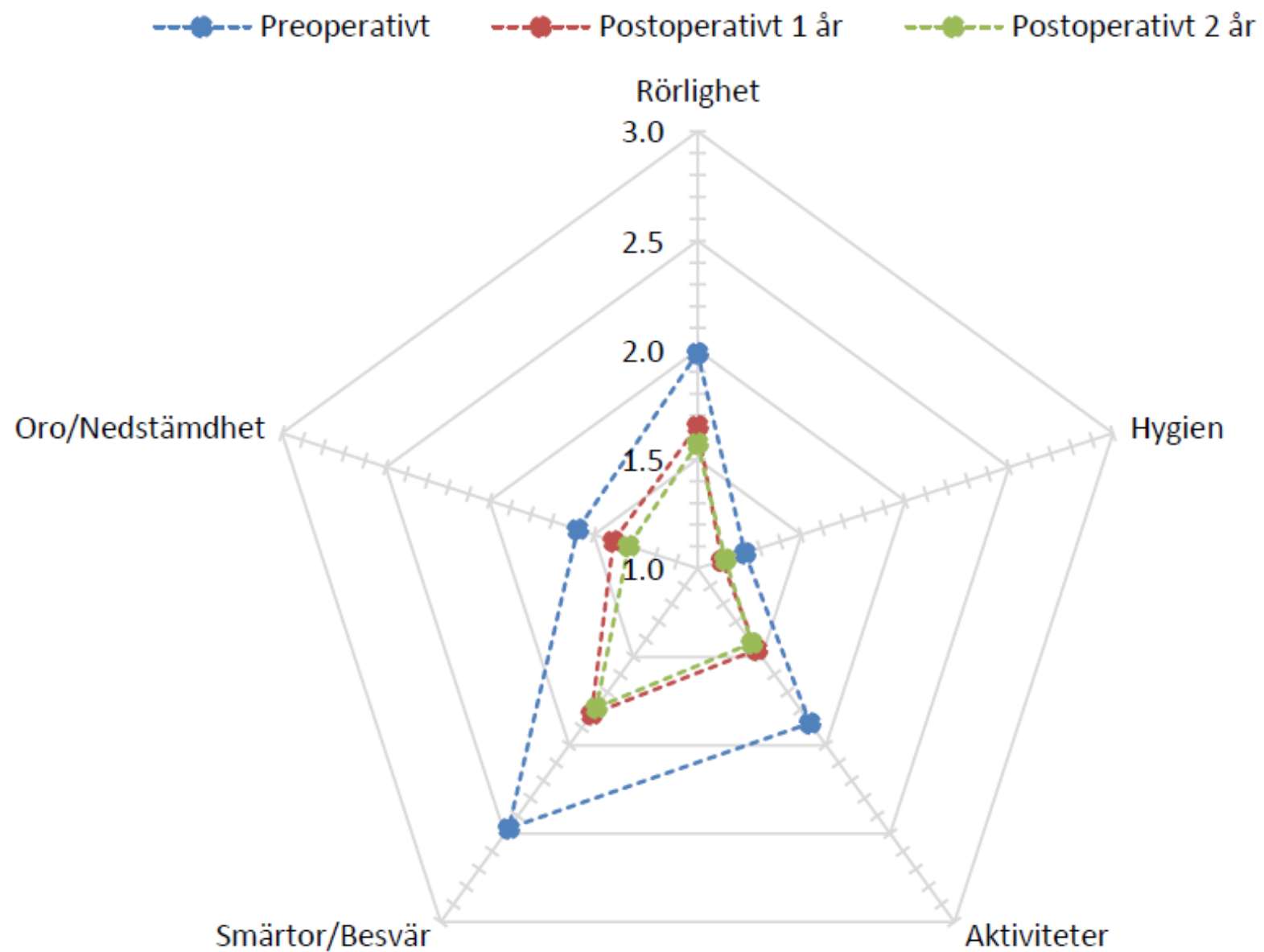
Collected through the Swedish official digital health care platform (1177)

- EQ5D
- SEFAS (SElf reported Foot Ankle Score)
- Satisfaction with surgery (onle postop)
  
- Preop
- Postop 1, 2, 5, 10 years

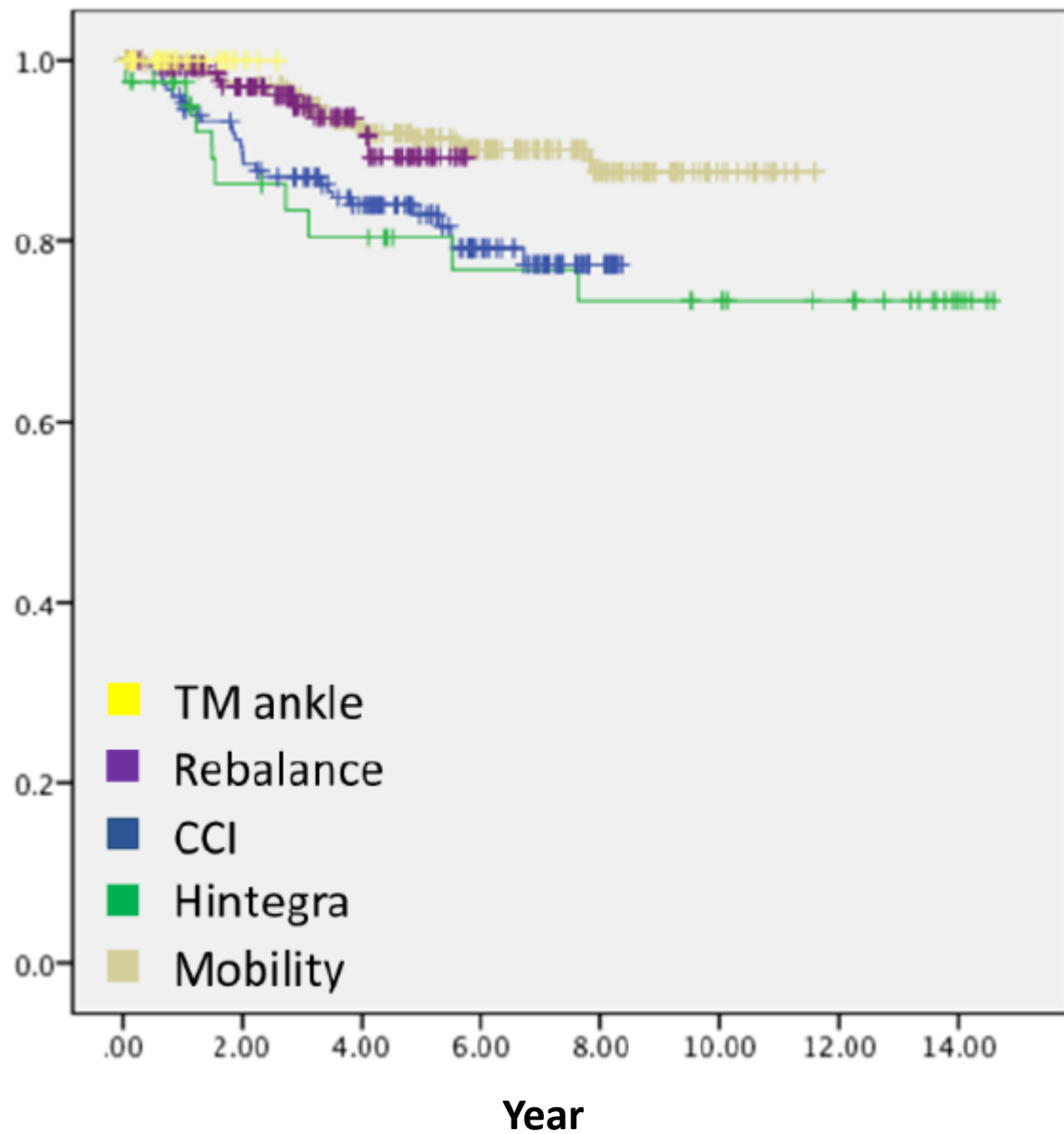
# EQ5D-3L Ankle replacement



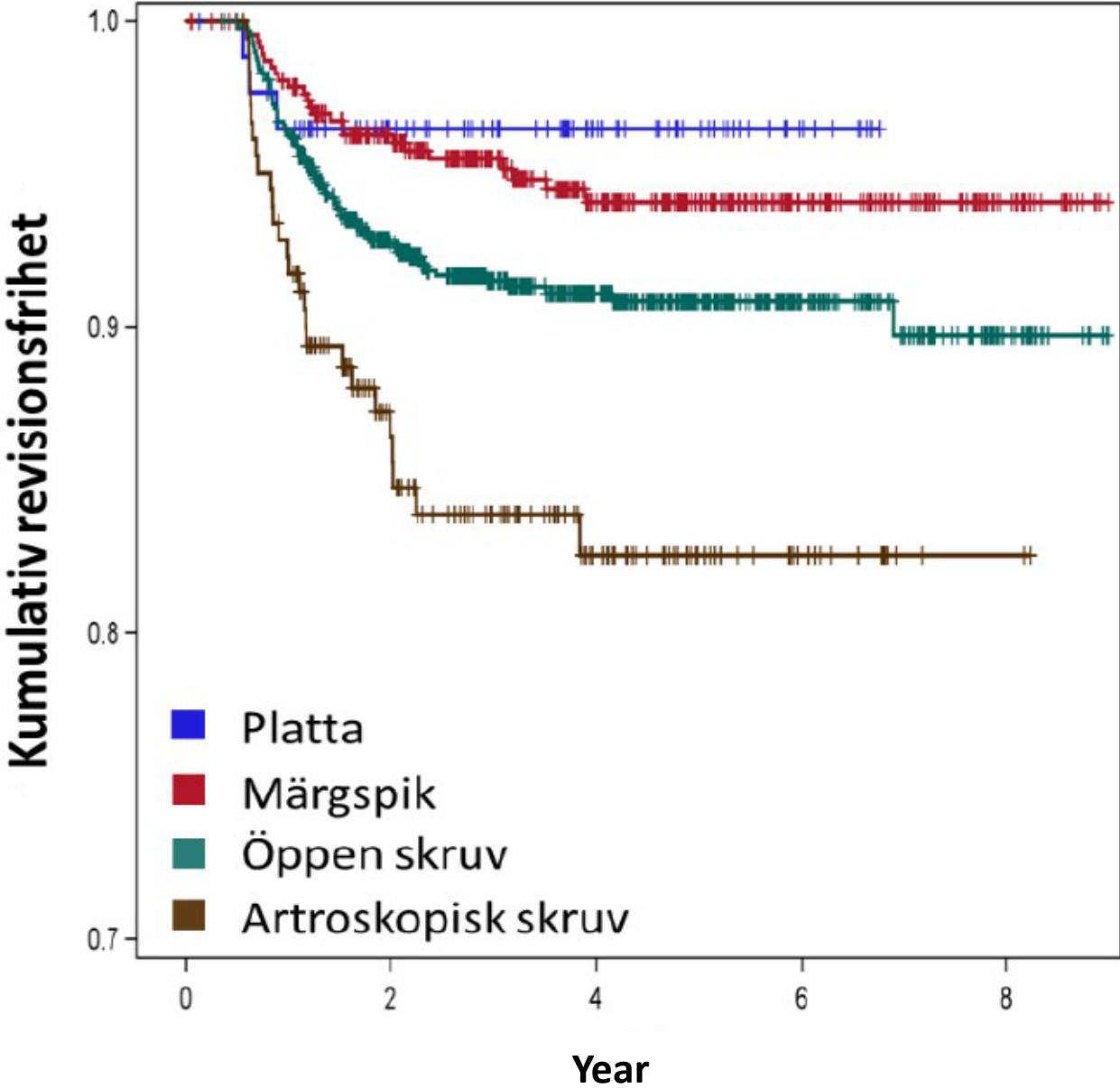
# EQ5D-3L Ankle arthrodesis



Prosthesis survival per modern design model



Arthrodesis survival (non-revision) per fixation method



# Steering group

## **Registry director**

Björn Rosengren (Orthopedic surgeon)  
Skånes Universitetssjukhus i Malmö

## **Patient representatives**

Ingrid Altin  
Dala-Järna

Kerstin Nilsson  
Göteborg

## **Other members**

Anders Henricson (Orthopedic surgeon)  
Falun Lasarett

Johan Fintland (Orthopedic surgeon)  
Sahlgrenska Universitetssjukhuset i Mölndal

Kristian Xintaris (Orthopedic surgeon)  
Capio Ortopediska Huset i Stockholm

Åse Hautau (Physiotherapist)  
Atleva FotCenter i Göteborg



# Steering group

6-12 meetings per annum

Organizes 1-2 annual meetings for users

Always a session on the patient perspective

# SwedAnkle



OM SVENSKA NATIONELLA FOTLEDSREGISTRET LÄNKAR KONTAKT

Sök

START NYHETER **PATIENTINFORMATION** PUBLIKATIONER REGISTRERING STATISTIK LOGGA IN

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## FOTLEDSREGISTRET FINNS NU HOS VÅRDEN I SIFFROR

**2024-02-23** | Svenska Nationella Fotledsregistret finns nu  
med hos Vården i siffror med sex indikatorer.

MER INFORMATION



Allmänt om  
fotledsprotoser  
Information om  
registrering  
Nationell  
patientinformation och  
patientens rättigheter



Om Svenska Nationella  
Fotledsregistret



About Swedankle (in  
English)



Mer om register hos  
Registercentrum Syd



Patientinformation



Kvalitetsindikatorer hos  
Vården i siffror

# Patient information

- Why to participate
- Information on surgery and results
- Patient rights

# SwedAnkle



OM SVENSKA NATIONELLA FOTLEDSREGISTRET LÄNKAR KONTAKT

Sök



START NYHETER PATIENTINFORMATION PUBLIKATIONER REGISTRERING STATISTIK LOGGA IN



PUBLIKATIONER

ÅRSRAPPORTER

## LADDA NER



Årsrapport 2022 (PDF-format, 4 MB)



Årsrapport 2021 (PDF-format, 4 MB)



Årsrapport 2020 (PDF-format, 4 MB)



Årsrapport 2019 (PDF-format, 6 MB)



Årsrapport 2018 (PDF-format, 4 MB)



Årsrapport 2017 (PDF-format, 6 MB)



Årsrapport 2016 (PDF-format, 2 MB)



Årsrapport 2015 (PDF-format, 2 MB)



Årsrapport 2014 (PDF-format, 2 MB)



Årsrapport 2013 (PDF-format, 2 MB)



Årsrapport 2012 (PDF-format, 2 MB)

## ÅRSRAPPORTER

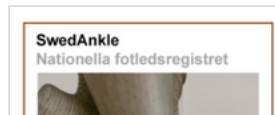
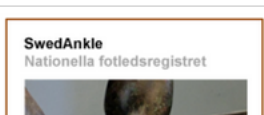
På denna sida kan du ladda ner årsrapporter från Svenska Nationella Fotledsregistret, antingen via nedladdningsboxen eller genom att klicka på bilderna nedan. Bilderna är miniatyurer av respektive årsrapports förstasida.



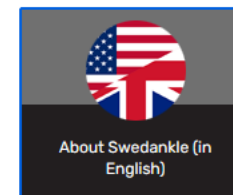
Årsrapport 2022 (klickbar miniatyr till PDF-format, 4 MB)



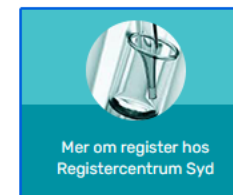
Årsrapport 2021 (klickbar miniatyr till PDF-format, 4 MB)



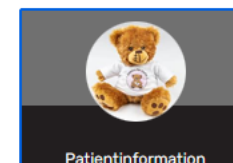
Om Svenska Nationella Fotledsregistret



About Swedankle (in English)



Mer om register hos Registercentrum Syd



Patientinformation



# Narrative about contribution to care

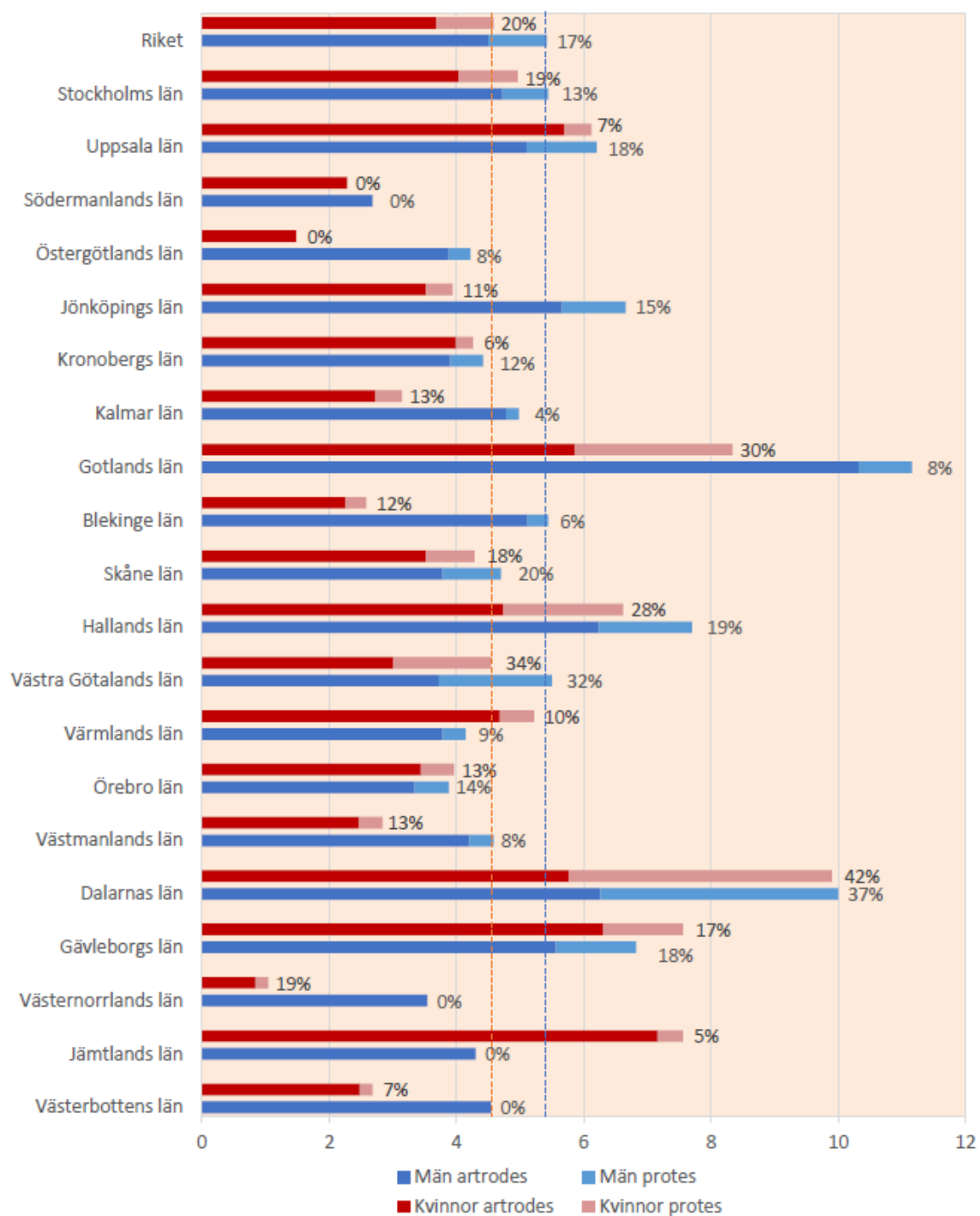
## **Is it possible to undergo bilateral ankle arthrodesis?**

Arthrodeses of both ankles are unusual. It was previously thought that the mobilization limitations would make ambulation tangible. However, when no other option is possible or appropriate, bilateral ankle arthrodesis may be necessary. A study from the register showed that these patients are mostly satisfied with adequate function [1].

# Narrative about contribution to care

## **Which surgical method (prosthesis or arthrodesis) is preferred by patients?**

A study from the registry of patients with prostheses in one ankle and arthrodesis in the other found no patient-perceived difference (PROM/satisfaction) between prosthesis and arthrodesis. Most patients were satisfied with both ankles [1].



*Incidence (per 100,000 and sex) of surgery with primary arthrodesis or prosthesis in the ankle per region 2017–2021 according to the National Board of Health and Welfare's statistical database.*

*The percentage number next to each bar indicates the proportion of surgical procedures for each sex that was ankle replacements. The dashed vertical lines depict the national incidence for men and women respectively.*

# SwedAnkle

## Nationella fotledsregistret

