SwedAnkle and a Swedish perspective on Patient Engagement in Quality Registers

Björn Rosengren
MD, PhD, Professor (full), Senior Consultant
Departments of Orthopaedic Surgery and Clinical Sciences
Skåne University Hospital and Lund University
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/nationalsystemforknowledgedrivenmanagementwithinswedishhealthcare.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**
- Rare diseases
- Dentistry
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Musculoskeletal disorders

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

Vården i siffror

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

Riket
Rimlig väntetid till vård- eller hälsovården
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 sjukvårdsbarometr 2023
Care in numbers (https://vardenisiffror.se/)

Vården i siffror

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

- **Riket**
  - Rimlig väntetid till vård- eller hälsocentral
    - 63 %
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- **Riket**
  - Medicinsk bedömning inom tre dagar i primärvård, läkare
    - 89.1 %
  - Förortöende för sjukhus
    - 69.6 %
Proportion of patients with wrist fractures that undergo surgery.

Target level 28%
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.
Adverse event within 90 days after hip replacement surgery for osteoarthritis.

Target level <5%
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.nationelltclinisktunskapsstod.se/globalassets/nkk/nationell/media/dokument/kunskapsstod/vardprogram/nationellt-vardprogram-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

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

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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.

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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.

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SwedAnkle
Nationella fotledsregistret

https://swedankle.se/
ÅRSRAPPORT FÖR 2022 PUBLICERAD

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

MER INFORMATION
Arthroplasty and artrodesis
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

Rörlighet

Oro/Nedstämdhet

Smärtor/Besvär

Aktiviteter

Hygien

Preoperativt

Postoperativt 1 år

Postoperativt 2 år
Prosthesis survival per modern design model
Arthrodesis survival (non-revision) per fixation method

Kumulativ revisionsfrihet

Year

0 2 4 6 8

Platta
Märgspik
Öppen skruv
Artroskopisk skruv
Steering group

Registry director
Björn Rosengren (Orthopedic surgeon)
Skånes Universitetssjukhus i Malmö

Patient representatives
Ingrid Altin
Däla-Järna

Kerstin Nilsson
Göteborg

Other members
Anders Henricson (Orthopedic surgeon)
Falu 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
1 AV 2

FOTLEDSSREGISTRET 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 fotledsproteser
Information om registrering
Nationell patientinformation och patientens rättigheter
Patient information

• Why to participate
• Information on surgery and results
• Patient rights
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 miniatyrer av respektive årsrapports förstasida.

- Årsrapport 2022 (PDF-format, 4 MB)
- Årsrapport 2021 (PDF-format, 4 MB)
- Årsrapport 2020 (PDF-format, 4 MB)
- Årsrapport 2019 (PDF-format, 4 MB)
- Årsrapport 2018 (PDF-format, 4 MB)
- Årsrapport 2017 (PDF-format, 4 MB)
- Årsrapport 2016 (PDF-format, 4 MB)
- Årsrapport 2015 (PDF-format, 2.4 MB)
- Årsrapport 2014 (PDF-format, 2.4 MB)
- Årsrapport 2013 (PDF-format, 2.4 MB)
- Årsrapport 2012 (PDF-format, 2.4 MB)
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].
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