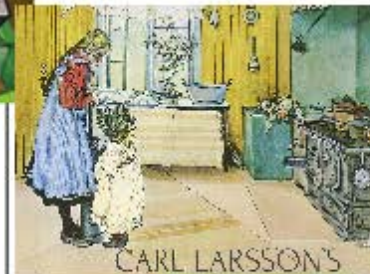


MAKING A SWEDISH PROMIS: A NEEDS ASSESSMENT

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Steering group: Staffan Lindblad, Jack Lysholm, Anders Tennlind, Thomas Troëng, Ulrika Frithiofsson and Monica Sterner; representing each of the six regional competence centers.



Sweden

- Population: 9.5 million
- Democratic monarchy
- Historical emphasis on egalitarianism



National quality registries.
Kunskap för bättre bidrag vård och omsorg



National Quality Registries

National Quality Registries are initiated and led by healthcare professionals

Contain individualised data on symptoms, interventions and outcomes.

Vision

Build an over-all knowledge system that is actively used on all levels for continuous learning, quality improvement and management of all healthcare services.



- Bipolar Affective Disorder
- ADHD Treatment Follow-up
- Amputation and Prostheses
- Ankle Arthroplasty
- Assisted Reproductive Technology
- Atrial Fibrillation and Anticoagulation
- Behavioural and Psychological Symptoms of Dementia
- Better Management of Patients with Osteoarthritis
- Bladder Cancer
- Brain Tumours
- Breast Cancer
- Breast Implants
- Cardiopulmonary Resuscitation
- Caries and Periodontitis
- Cataracts
- Catheter Ablation
- Cervical Cancer Prevention
- Child and Adolescent Habilitation
- Child & Adolescent Psychiatry
- Child Preventative Health
- Childhood Cancer
- Childhood Epilepsy
- Childhood Obesity
- Cleft Lip and Palate
- Colorectal Cancer Treatment
- Congenital Heart Disease
- Congenital Metabolic Diseases
- Corneal Transplant
- Cruciate Ligament Injuries
- Cystic Fibrosis
- Dementia
- Dependency
- Diabetes
- Ear, Nose and Throat Care
- Eating Disorders
- Electroconvulsive Therapy
- Endovascular Treatment of Ischemic Stroke
- Enhancement and Development of Evidence-Based Care in Heart Disease

- Follow-up of Persons with Cerebral Palsy
- Forensic Psychiatry
- Fractures
- Gallstone Surgery & Endoscopic Retrograde Cholangiopan-creatography
- Gender Dysphoria
- Gynaecological Oncology
- Gynaecological Surgery
- Haemophilia
- Hand Surgery
- Head and Neck Cancer
- Heart Failure

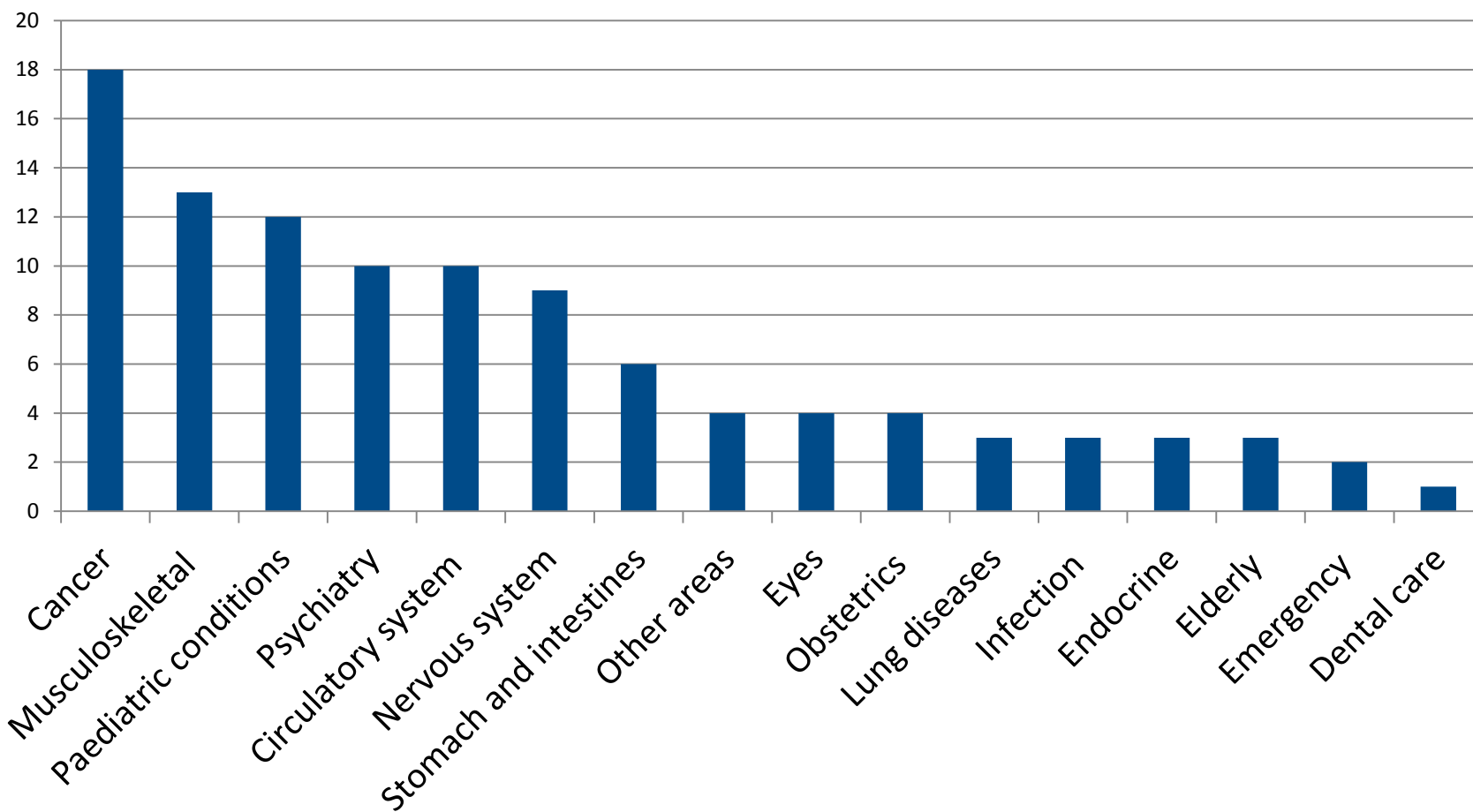
- Pancreatic Cancer
- Penile Cancer
- Perioperative Care (SPOR)
- Pituitary Disease
- Podiatric Surgery
- Pregnancy
- Preventative Care
- Primary Immunodeficiency
- Prostate Cancer
- Psychiatric Care Monitoring
- Psychosis Care
- Pulmonary Arterial Hypertension
- Rehabilitation for Visual Impairment
- Rehabilitation Medicine
- Renal Failure
- Respiratory Diseases
- Respiratory Failure
- Rheumatic Diseases
- School Health Services
- Shoulder and Elbow Arthroplasty
- Sleep Apnoea
- Spinal Dysraphism & Hydrocephalus
- Spine Surgery
- Stroke
- Systemic Psoriasis Treatment
- Testicular Cancer
- Thyroid Cancer
- Thyroid, Parathyroid and Adrenal Surgery
- Trauma
- Ulcer Treatment
- Vascular Surgery

Many areas of healthcare:
common & rare conditions;
nursing and primary to
tertiary care.

- Macular
- Malignant Melanoma
- Mammography Screening
- Neonatal Care
- Neurological Care (NEUROreg)
- Neuromuscular Diseases
- Obesity Surgery
- Oesophageal and Stomach Cancer
- Paediatric Kidney Disease
- Paediatric Orthopaedic Conditions
- Paediatric Rheumatology
- Pain Rehabilitation
- Palliative Care

108 NQRs

Number of NQRs in different healthcare categories



Organization

6 regional competence centres.

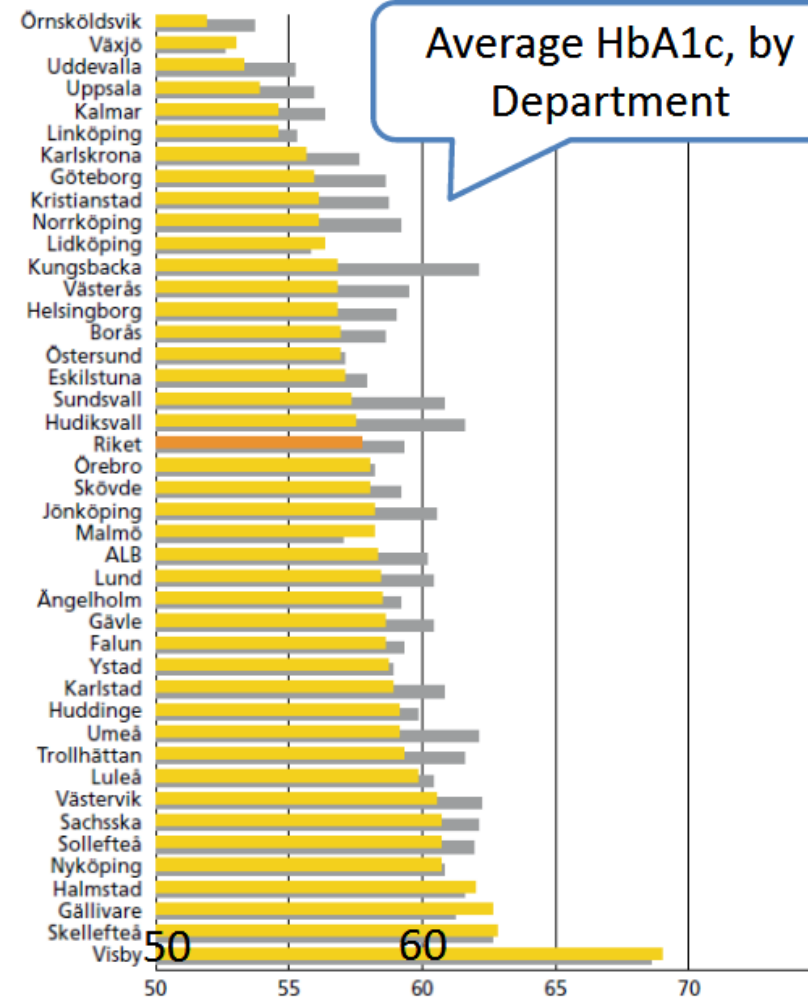
- promotes the development of new registries
- create synergistic effects by providing a service to and facilitating collaboration between registries.
- 60% of the NQRs have $\geq 80\%$ coverage of their target population



Pediatric Diabetes

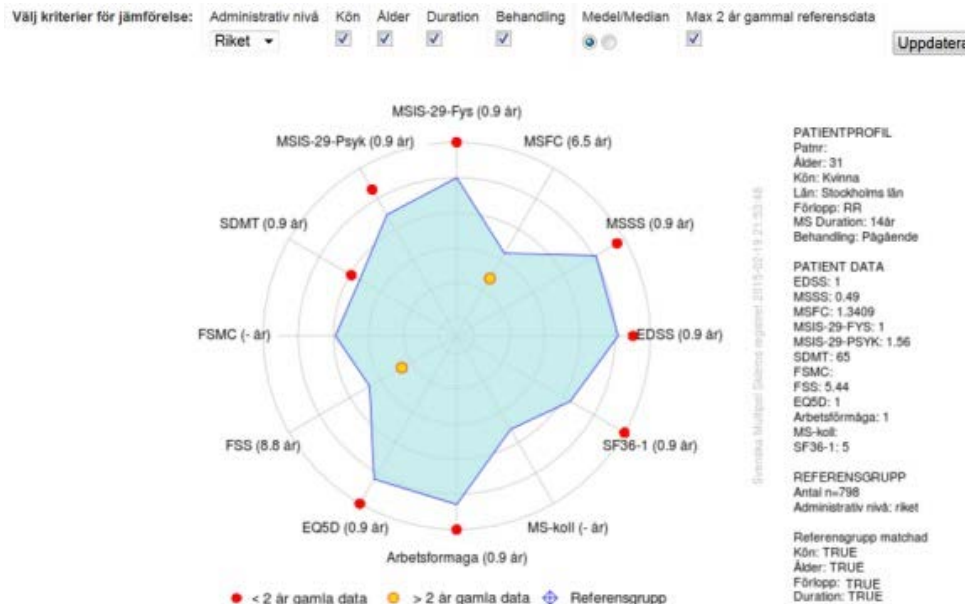
Two types of reporting

Figur 13. Klinikens medel-HbA1c (mmol/mol)



Annual open reporting of all data.

Presentation to physician

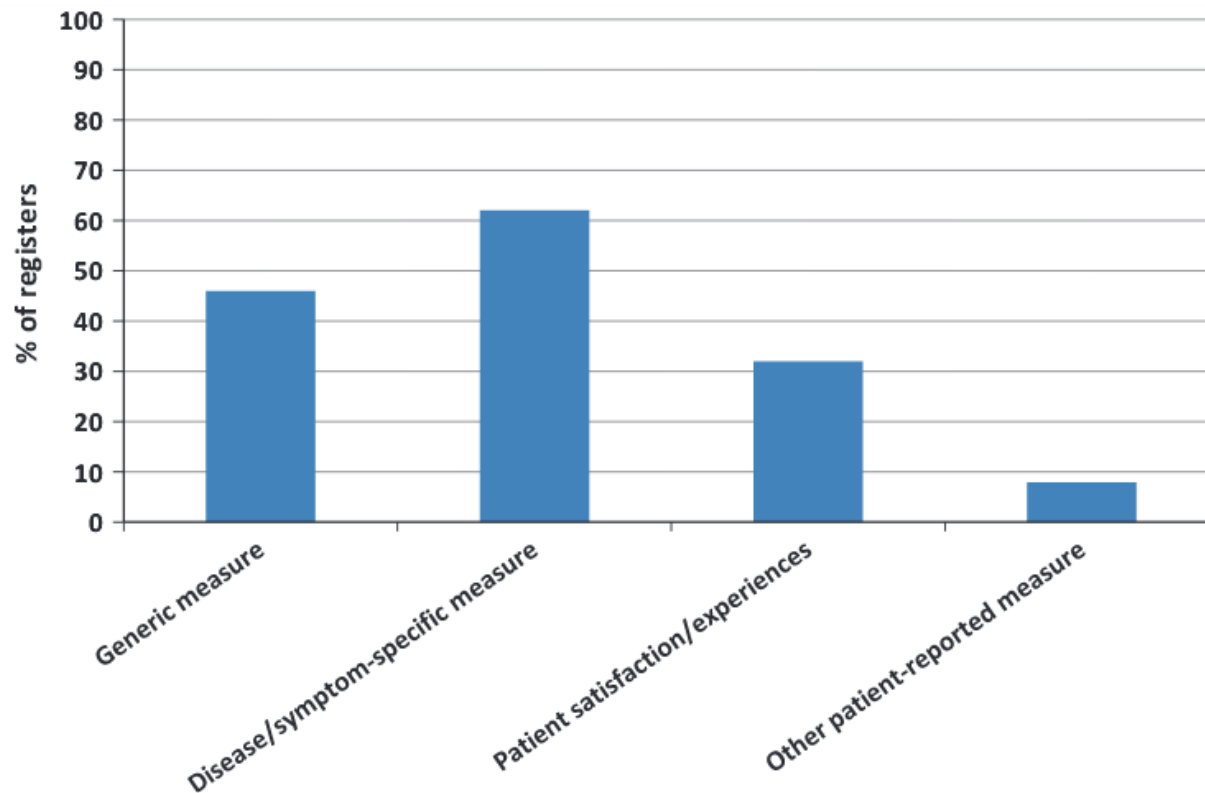


Patient-reported outcomes in the Swedish National Quality Registers

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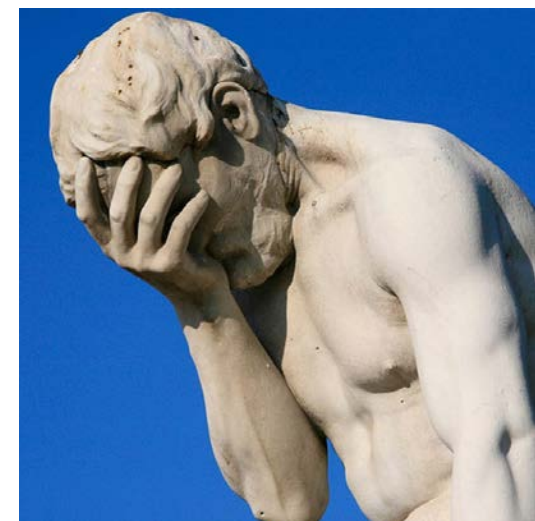


Library of Questionnaires

- EQ-5D
- HAQ
- Kidscreen
- Diabkids
- ESS
- MSIS-29
- PDQ8
- BASDAI
- TSQ
- FSMS
- NMS
- MPOC

Problems

- Not all Registries are using PROMs
- PROs are not documented as thoroughly as traditional medical outcomes.



Why is there limited take up of PROMs in NQRs?

- Educational issues
 - Limited understanding of PROMs
 - Unfamiliar with how this data is used
 - PROMs are not valued by clinicians
- Supply issues
 - Lack of instruments (or lack of translated instruments)
 - Alternatively: too many instruments to choose from.
- Administrative issues
 - Unwillingness to burden patient with many questions.
 - Requires additional resources / costs

The action taken by the Swedish Health Service

1) Certification – funding is based on quality in these 5 areas!

(i) Completeness - target population.

(ii) Coverage - healthcare units.

(iii) Validity - reflects the real world of patients and healthcare (includes PROM).

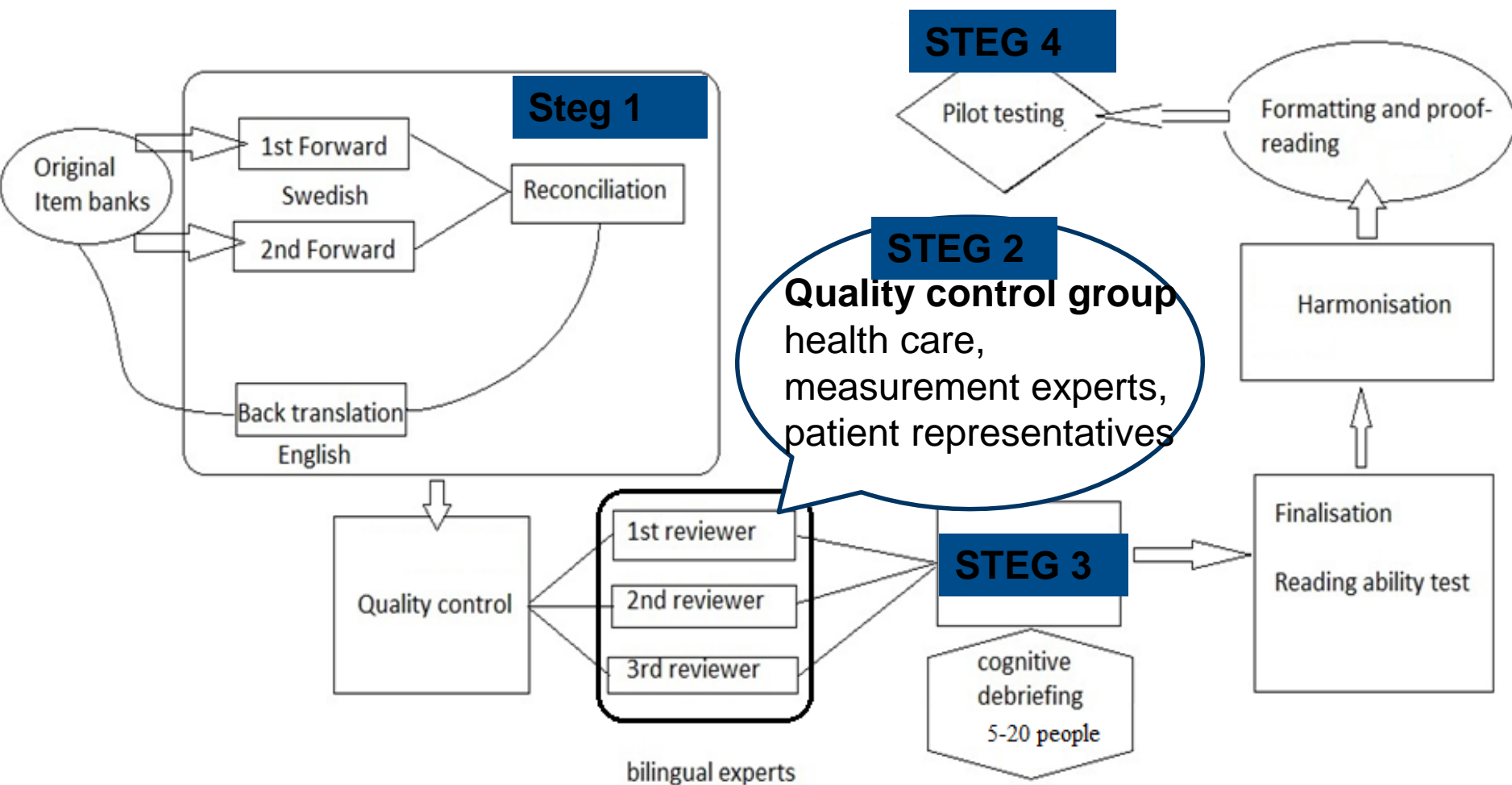
(iv) Promptness /speed of data collection.

(v) Comparability – across clinics /other NQRs

2) Swedish item-banking project

- ❖ Translation and linguistic validation.
- ❖ Establishment of a network of active users and researchers working with item banks in general.
- ❖ Workshops and seminars to inform and identify potential future users and stakeholders.
- ❖ Creation of a secure national data collection methodology.

Swedish translation process



10,000 metres for adult measures

Global-10
Orthopaedics
- St Göran's,

Global-10
Breast
cancer
- Huddinge,

Outstanding adult
item banks
- Karolinska

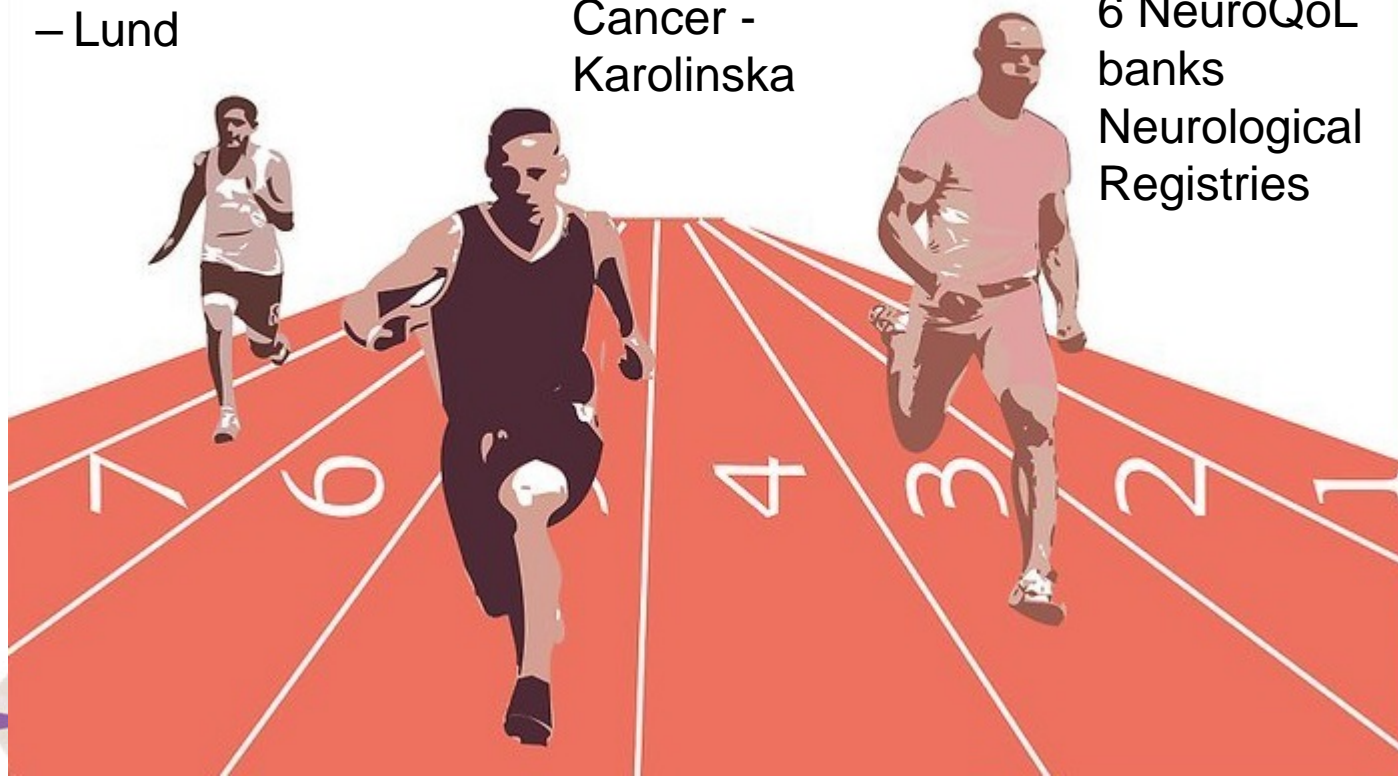
Fatigue short form-7
Polio,
- Skåne,

Profile-29
Systemic sclerosis
– Lund

Sexual function
Cancer -
Karolinska

6 NeuroQoL
banks
Neurological
Registries

Profile-57
Norway



3000m Steeplechase for child measures

Profile-25
Diabetes
- Halland

Profile-25
Healthy population
- Gothenburg

Profile-25
Pediatric
Orthopedic
register

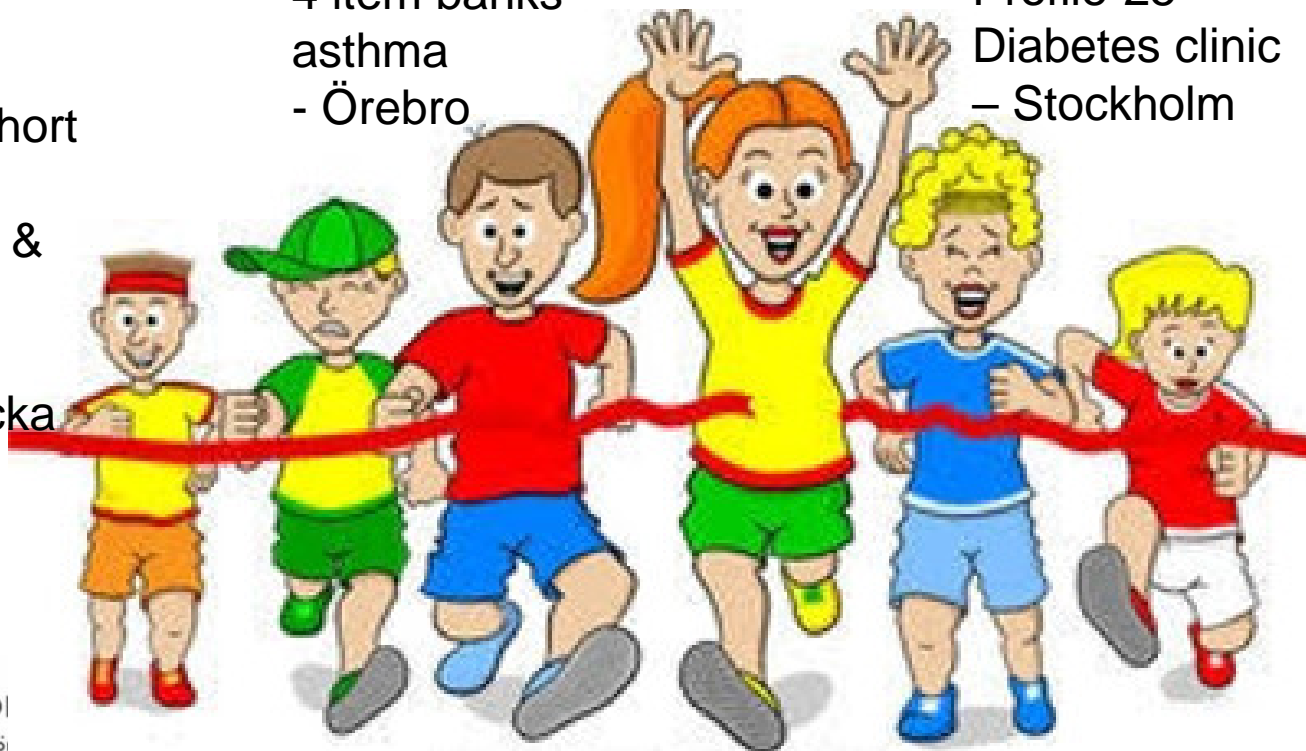
Profile-25
Norway

4 item banks
asthma
- Örebro

Profile-25
Diabetes clinic
– Stockholm

Set of 6 short
forms
(PROMIS &
ToolBox).
Obesity-
Kungsbacka
council –

All remaining
pediatric item
banks
Karolinska
Institute & Child
cancer registry

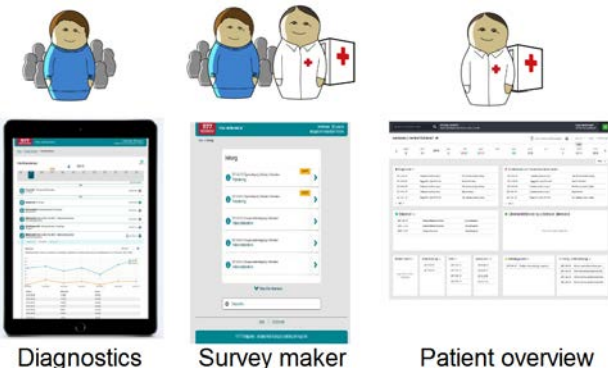
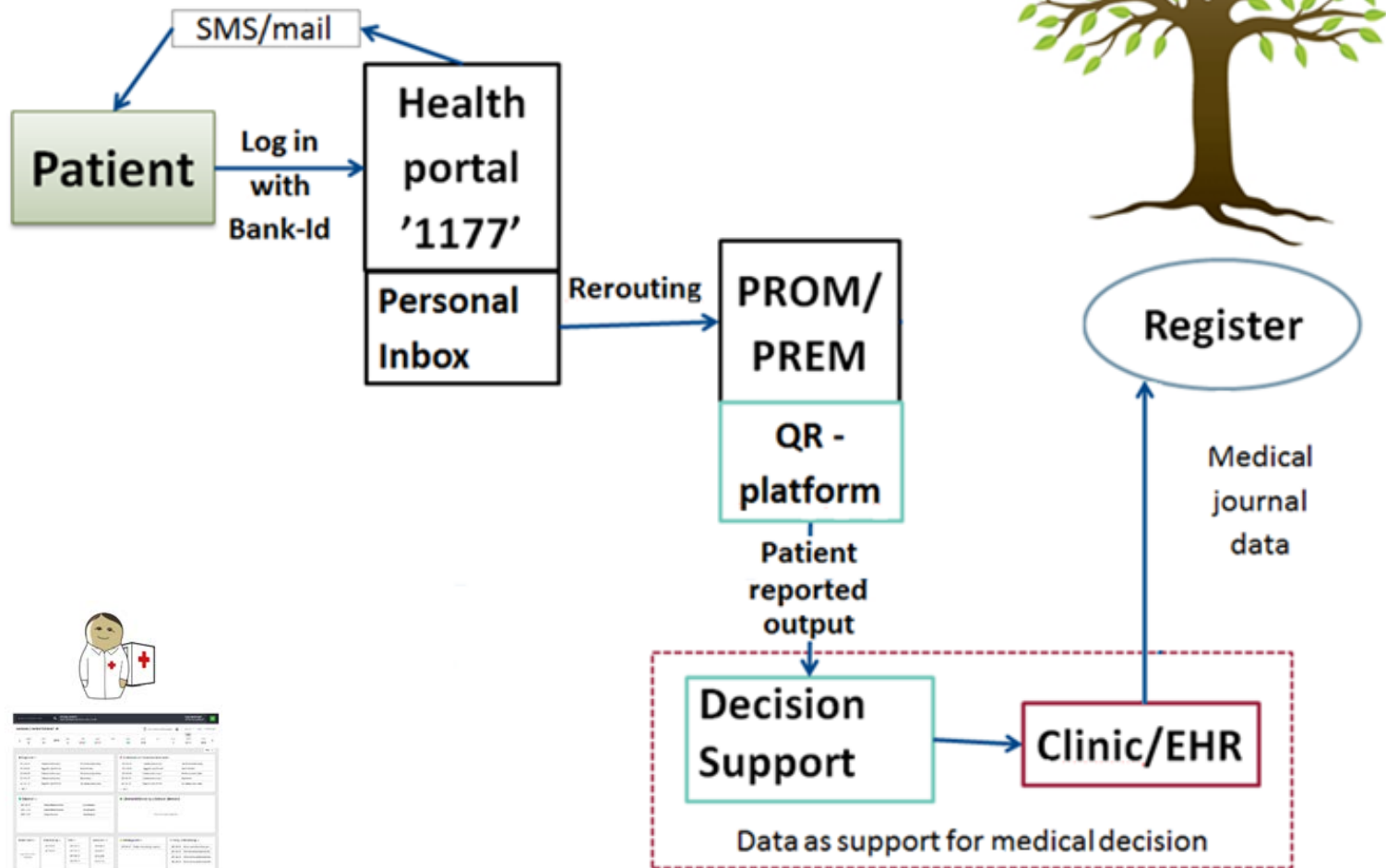


We work with:

- Range of different conditions
- Registries, hospital, schools
- PROMIS, NeuroQoL, ToolBox
- Language specific reference scores in the general population

The technical solution

Infrastructure for patient reported outcomes

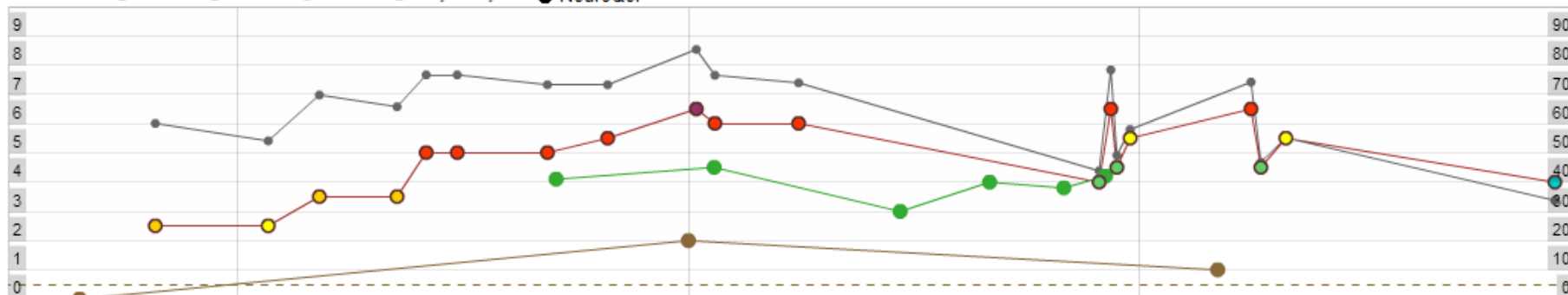


Nytt besök Rehab Besöksblankett Rapportera fel/ändring Sök patient Lägg till diagnos PER-registreringar Min sida

compos

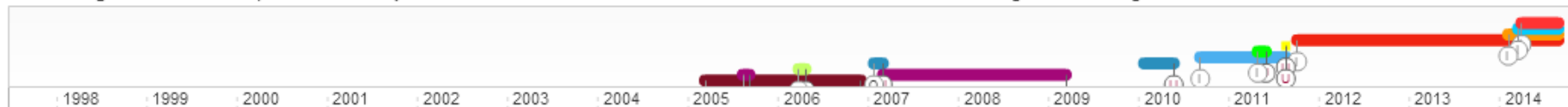
Översikt - MS MSSS-matris Funktionsklocka

Mätvärden ● EDSS ● MSSS ● SDMT ● S-Lymfocyter ● NeuroQol



S B M S B B M B B S B M S S S M S B S M B S B

Behandlingar ● Rebi ● Copa ● Mito ● Tysa ● Move ● Gile ● Mabt ● Avon ● Tecf ● Lemt ● Auba ● Ingen behandling



Tidsspänn: 1997-06-16 - 2014-10-26

Urvalsperiod: 6 månader 1 År 2 År Senaste året Samtliga

Skov 13 CSF 6 BMI 13 Studier Arbetsförmåga 31 FSMC 23 TSQ 28 NAbLab Biverkan Rehab Funktionsskalor **NeuroQol**

module settings

Vårdgivare EDSS-värde MSSS-score I allmänhet, skulle Du vilja säga att Din hälsa är

Conclusions / lessons learnt so far

- **Involve multiple stakeholders** at different levels in the early formulation of the approach in order to build a **sense of ownership**.
- **Limit the administrative burden**
- Ensure **data quality** and the use of **standards**
- Demonstrate **how to use the data for improvement** (health care and individual patients)
- Create a **trust environment** for building and maintaining registries
- Increase **transparency** to drive forward quality
- Encourage open access for **research**

Questions?

- How do we integrate item banking into decision making?
- Who should initiate the data collection – doctor or patient?
- How should we present the results to the doctor & patient?
- How do we share the results with other professionals?
- How do we train the people who administer the tests?
- How do we obtain PRO data from very young patients?
- How do we ensure the quality of the items/banks?