

Quality registries in Sweden: The national agreement between the government and SALAR

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Disclosure Statement of Financial Interest

I, Lars Backlund, DO NOT have a financial interest/arrangement or affiliation with one or more organizations that could be perceived as a real or apparent conflict of interest in the context of the subject of this presentation.



Quality registries:

- 73 National Quality Registries (+ 27 registry candidates) and 7 Competence Centers with central funding in Sweden
- 1975 knee replacement surgery
- Initiated by the medical professionals
- Purposes
 - Quality improvement
 - Research
 - Follow-up, comparisons

QR: definition and properties

- Contain individualized data concerning patient problems, medical interventions, and outcomes after treatment; within all health care production
- Annually monitored and approved for financial support by an Executive Committee administered by SALAR
- Can be based on diagnostic groups, interventions, level of care



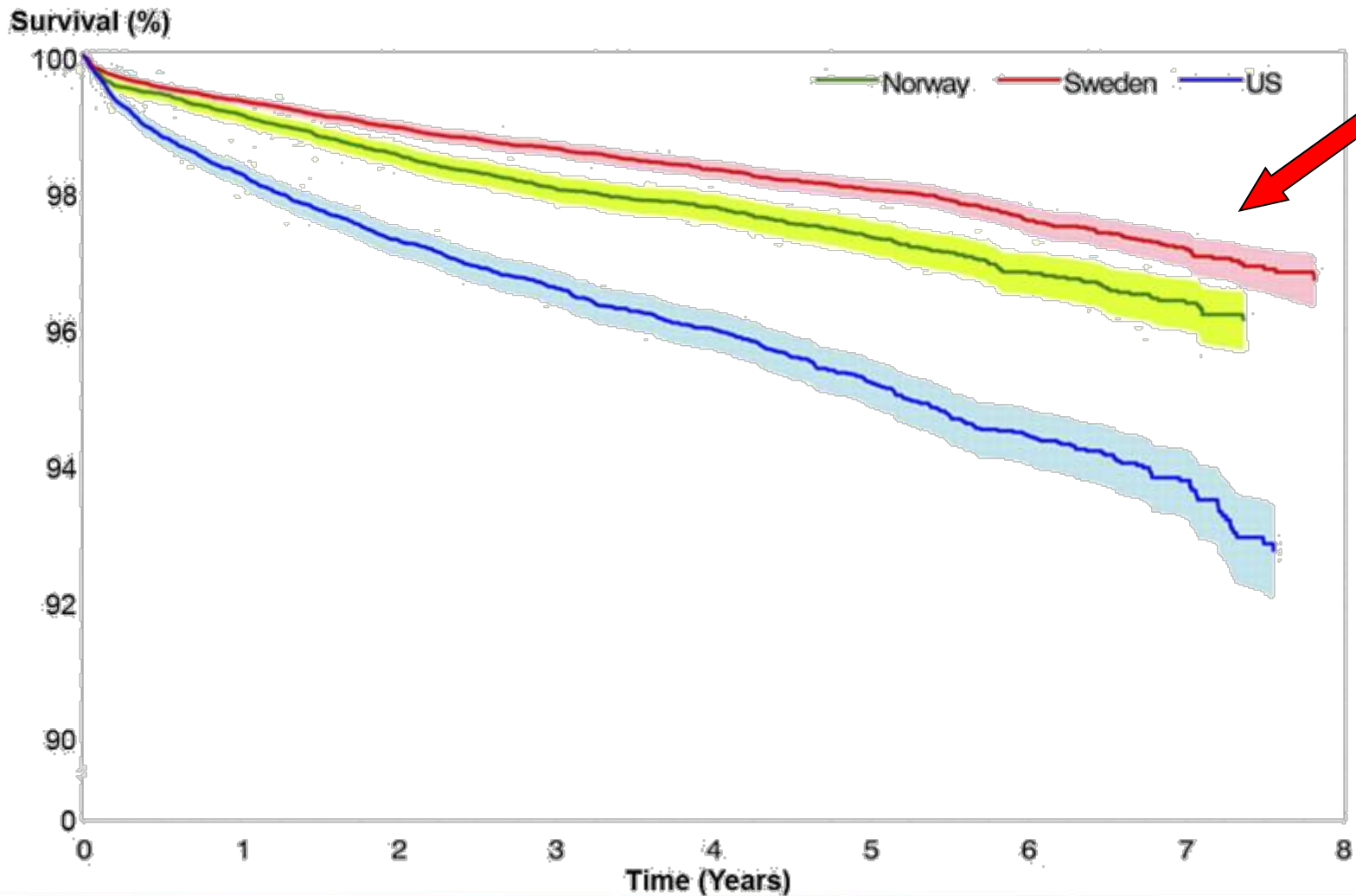
Vision

- The National Quality Registries are actively used by, and integrated in, Swedish health-care for continuous learning, improvement, research and knowledge management with the purpose to achieve best possible care in alliance with the individual

Good examples

- **Pediatric oncology**
 - 5-years survival rate for children with ALL increased from 10% to about 90% since the 1970s
- **National Cataract Register**
 - decrease in the number of postoperative infections by 80%
- **Swedish Hip Arthroplastic Registry**
 - discharging of poorly functioning prostheses- 10% reoperation rate

Fig. 4 Survivorship curves (with 95% confidence intervals) for total hip arthroplasty implants in the United States, Sweden, and Norway.



Kurtz S. M. et.al. J Bone Joint Surg 2007;89:144-151

Increased financial support

- Agreement between the government and SALAR about the development and financing between 2012 and 2016
- The Pharmaceutical Industry is not a part in financing
- Prioritized areas: Primary Care, Psychiatry, Dental Care, Social Services
- Background: Report ("Gold-mine in health-care") showing the unused potential

Agreement

- Around 320 million SEK each year 2012-2016
- 70% government, 30% regions/county councils
- Separate agreement on the relationship between pharmaceutical industry and SALAR
 - Legal aspects of access to data from QR
 - Economic issues

Organization

- **Steering Committee:** strategic decisions (government, county councils, local authorities, SALAR)
- **Executive Committee:** decisions about financial support for QR and competence centers
- **Reference groups:** input to steering and executive committees
 - Patients and clients
 - Producers of health care and social services
 - Researchers
- **Expert group:** judgement of applications

Supporting functions for QR

- Registry Centers (Competence Centers) (7)
 - Support the initiation of QR
 - Competence in statistics, epidemiology, informatics, legal issues
- Registry office at SALAR
 - Administration of economic applications
 - Support to QR
 - National conference
- National Registry Service at National Board of Health and Welfare
 - Support for researchers: which variables in which QR?
 - Methodological support for QR and RC

Some general goals

- Faster development of QR
- Better integration and use of information technology and informatics (National Information Structure, SnoMed)
- Better integration between the electronic patient record and QR (avoid "double registration")
- Clearer routines around patient integrity

Specific goals for follow-up

- Coverage
- Presenting on-line data to the clinics
- Public presentation of results
- Data from QR used by the clinic management for quality improvement
- Number of research projects supported by QR

At the end of 2013:

- 60% of the NQR will have a 80% coverage
- 95 % of NQR present data online to the clinics
- 100% of those with at least 80% coverage present data to the public
- 60% of NQR present outcome measures to the patients
- 50% of the clinic managements use QR for quality improvement
- Number of research projects based on QR data has increased with 100%

QR in Primary Care

- Prioritized field
- More than half of all doctor visits
- 8-10 existing QR with some use in PC
 - Diabetes, Heart failure, Dementia, COPD/Asthma
- Difficulties in implementation
 - More than one registry for one patient/visit
 - Extra work, "double registration"
 - Important PC problems and perspectives are lacking
 - Concerns about integrity

Financial support for a PC-QR 2012. Desirable properties:

- Developed by PC professionals
- Automatic retrieval of data from EPR
- All professional fields within PC
- Chain of care

PC-QR. Preliminary directions of the work in progress

- Data from EPR to Regional databases
- National portal to aggregate data
- Export to diagnosis specific QR
- In pipe-line from National Board of Health and Welfare: The Patient Registry is suggested to expand to include also Primary Care (identity, caregiver, diagnosis, interventions)
- Cover important areas: Chronic diseases, musculo-skeletal disorders, common mental disorders (depression, anxiety, sleep), acute infections

PC-QR. Some challenges

- Increased structure of information in EPR (rather than free text)
- Common definitions of variables
- Increased use of interdisciplinary terminology, e.g. Snomed
- Technical solution(s) to export from EPR to QR no quick-fix
- Patients' ability to accept or not