



# Fine-Tuning Health Care

## – improved outcomes and cost efficiency using quality registries

Many health care systems are struggling today with rising costs, creating an urgent need to find new ways and systems to improve the quality of health care while also improving cost-efficiency. The high-level conference, hosted by the Swedish Ministry for Health and Social Affairs, addresses this challenge.

A variety of strategies are being implemented in different health care systems around the world. An approach offering great potential is the use of quality registries, also known as patient or disease registries. By using these registries, health care professionals can identify, implement and share best practices.

The quality registries also offer a great example of how patients can participate in a meaningful way in their own care. Effective use of quality registries can lead to better health outcomes and enhanced health care value.

### What is a Quality Registry?

Quality registries have in common that they collect comprehensive, high-quality data and follow outcomes of patients in a population with the same diagnosis or patients who have undergone the same medical procedure. Quality registries are also referred to as disease registries and patient registries.

### What is the purpose of Quality Registries?

Data from the quality registries enables clinicians in and across health care systems to identify, implement and share best practices for a given diagnosis or medical procedure. This allows for systematic quality improvement, leading to better health outcomes at a lower cost.

Making data transparent through open comparisons of results spurs a learning process between care units and often reduces the gap between high-performing and low-performing units, leading to better and more equal care for everyone. Furthermore, quality registries allow for unique real-life outcome research.

### Quality Registries in Sweden

A system of about 100 national quality registries has been established in the Swedish health and medical system in recent decades, with some dating back to the 1970s. They provide Swedish health care with a unique opportunity

to monitor the results and quality of health care services. Originally a resource reserved for a small group in the medical professions, the registries have now become one of the foremost tools for improvement efforts and quality follow-up within Swedish health care.

In 2006, transparent regional comparisons of health care quality and efficiency – public performance reports, also known as open comparisons – were also introduced. The aim was to ensure transparency for taxpayers and patients, to promote quality improvement and cost efficiency, and to share best practice. The national quality registries are an important source for the medical quality indicators/data in the regional comparisons.

### Initiatives to develop the registries

Since 1990, the Swedish Government and the county councils have allocated special funding to quality registries. In 2011, the Swedish Government decided together with the Swedish Association of Local Authorities and Regions (SALAR) to increase the funding to the quality registries substantially with the aim of increasing the quality of data as well as the percentage of patients participating. This is to create a system in which quality registries are the core in terms of measuring health outcomes, conducting research and improving the quality of care.

The Government and the Swedish Association of Local Authorities and Regions (SALAR) have signed an agreement on the development and financing of quality registries for the period 2012–2016. The agreement covers the financing of the registries, and the organisation and division of responsibility for them at national level.

This is a joint initiative between the state, the county councils and the regions. The parties are allocating SEK 1,5 billion for the period 2012–2016. The state is covering 70 per cent of the financing. The allocations are to be used to ensure improved data quality in registries and data depositories.

**Examples from the National Quality Registries in Sweden, see next page!**

# Examples from the National Quality Registries in Sweden

The National Quality Registries are important sources for research and development, leading to health care improvement. There are a number of good examples in which research based on the National Quality Registries has led to improved prevention, diagnosis and treatment in health care, both nationally and internationally.

## Hip surgery

The Swedish Hip Arthroplasty Register is one of the oldest registries, and one that shows remarkably good results. Through research and continuous monitoring, the registry has substantially improved care. Better surgical techniques and the elimination of poorly functioning implants have led to fewer reoperations. Thanks to many years of feedback to participating clinics, results have steadily improved. Sweden has today the lowest reported reoperation rate in the world.

## Stroke

The Stroke Registry (Riks-Stroke) has been used to identify the best organisational form for stroke care. The registry has shown that long-term stroke survival is significantly better for patients who have been treated in special stroke units. Patients admitted to the stroke units were also more satisfied with their care. Riks-Stroke has promoted increasingly rapid adherence to national guidelines for stroke, especially in terms of secondary prevention, i.e. interventions to prevent stroke recurrence.

## Cataract surgery

Through research and monitoring, the National Cataract Register has managed to identify risk factors and determine optimal prophylactic regimes for cataract surgery, leading to a decrease of approximately 80 per cent in the number of postoperative infections. The striking results have been noted internationally. In 1995 a European registry started with the same types of variables as in the Swedish system. Over the years, some 90 clinics from 25 countries have joined the registry.

## Rheumatology

The Swedish Rheumatology Quality Registers (SRQ) are national models of patient participation. The registers allow patients to present their own assessment of current

symptoms, everyday functionality and quality of life to their doctor online, before visiting the clinic. The doctor also enters data at the clinic and a time series of outcomes in relation to treatment over time is created instantly. Together, the patient and the doctor review outcomes of current treatment and benchmark against national outcome standards to decide on continued care. This brings better health and empowerment to the patient through increased knowledge and participation. Registry data on the safety and efficacy of new biologic drugs has also been useful for regulatory agencies like the FDA and EMA.

## Heart disease

There are many examples of how open comparisons of results have a quality-enhancing effect. In 2005, the heart attack registry created a quality index that showed compliance with national guidelines. Between 2005 and 2007, hospitals improved their quality index scores by an annual average of 13 per cent. Hospitals with below-average scores only achieved an improvement rate of 7 per cent, indicating that the gap between high and low performing hospitals was growing.

In 2006, quality index scores and patient survival rates for each hospital were made public. Between 2007 and 2009, after the data became public, the average annual improvement rate rose to 22 per cent, and the below-average hospitals improved their performance by up to 40 per cent per year, thereby significantly reducing the performance gap between high and low performing hospitals. The improved performance has led to a dramatic decrease in short and long term mortality after heart attacks in Sweden over the past decade.

## Care of the most ill elderly people

A major project has begun for better coordination of the care of the most ill elderly people. It involves four quality registries and two health care registries. The Government has introduced an incentives model to stimulate the development of these registries. Most of the 290 municipalities and all of the 21 county councils are now processing their own results for diagnosis, follow-up and end-of-life care for dementia. Risk analyses regarding nutrition, falling and pressure sores are being produced for patients at risk, followed by appropriate actions.

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**More about the National Quality Registries in Sweden:**  
[www.government.se/qualityregistries](http://www.government.se/qualityregistries)

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