

National Healthcare Quality Registries *in Sweden*



2007

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Graphic design and production: KLF Grafisk produktion

Cover photo: © Michael Betts /Matton

Printing: Edita, Stockholm 2007

English translation: Ron Gustafson, MedText International, Hörby

ISBN 978-91-7164-305-6

Foreword

The Swedish Association of Local Authorities and Regions (SALAR) and the National Board of Health and Welfare have collaborated for more than a decade to support the development and use of National Quality Registries. This collaboration takes place within the Executive Committee for National Quality Registries. The Committee also includes representatives from the Swedish Society of Medicine and the Swedish Society of Nursing.

Starting from 2007, the local authorities and regions (eg, county councils) have taken on the primary responsibility for the continuing operation, development, and financing of the registries. Given this more active role, the joint administration has been moved from the National Board of Health and Welfare to the Swedish Association of Local Authorities and Regions (SALAR), and now three county council directors serve on the Executive Committee.

The registries are being developed and managed by representatives of the professional groups that use them. From around 15 registries in the early 1990s, Sweden now has 56 registries that receive financial support via the Executive Committee.

Three competence centers for quality registries have been created. Several new registries and competence centers are requesting funding for 2008. This trend is gratifying and reflects the need for modern quality improvement systems in health care. It is also in line with the National Board of Health and Welfare's regulations on management systems for quality and patient safety (SOSFS 2005:12).

All National Quality Registries in Sweden contain individual-based data on problems or diagnoses, treatment interventions and outcomes. Hence, they are useful for multiple purposes. In addition to their applications at the local level, the registries are being used to a greater extent in general planning and management. The potential applications become even wider as increasingly more registries begin to move beyond medical data to include patient-perceived quality and quality of life. Internationally, the registries have achieved considerable attention, and it has been suggested that the Swedish registries provide a unique opportunity to monitor and continuously improve our health services. The registries play a key role as health services more extensively and openly report outcomes to meet the public's demand for transparency and freedom of choice.

It is now technically feasible, and for many reasons highly desirable, to integrate the National Quality Registries with the various patient record systems. Practical work in this area has begun within the framework of a national information technology (IT) strategy for health care and social services.

This document provides a status report of the situation in 2007. In addition to presenting the different registries and their applications in the quality improvement process, we also describe the central organization and the process for seeking financial support. Registry managers and websites are listed to give readers the tools to easily acquire additional information.

The managers of the registries and competence centers prepared the summary descriptions of their respective registries and centers. Tove Gemzell, Swedish Association of Local Authorities and Regions, managed the work of designing, compiling, and publishing this document. Other contributors were Bodil Klintberg and Jan-Erik Synnerman, Swedish Association of Local Authorities and Regions.

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Sweden and the Swedish Healthcare System

Facts

Area: 450 000 km², third largest country in Western Europe

Capital: Stockholm

Population: 9 million inhabitants

Form of government: Constitutional monarchy, parliamentary democracy

Life expectancy: women 83 years, men 79 years

Cost for health and medical care: Approximately 9% of GDP
(175 billion SEK or 25.4 billion USD)

Three Democratic Levels

Except for the Parliamentary level, Sweden is divided into municipalities (290) and counties/regions (20). There is no hierarchical relation between the municipalities and the counties/regions, and they all have their own self-governing local authorities. Municipalities are responsible for matters relating to the inhabitants of the municipality and their immediate environment. The main task of the county councils/regions is health care, which accounts for around 90% of the county councils' activities. However, they are also involved in other areas, such as culture and infrastructure.

Healthcare System

Everyone in Sweden has an equal right to healthcare services. With just over 5% of the population 80 years or older, Sweden has Europe's proportionally largest elder population.

Local taxes provide the funding base for health and medical care, which limits the options for economic expansion. Given such cost restrictions, it is necessary to optimize the use of existing resources. The county councils have considerable freedom in deciding how to plan and deliver health and medical care, leading to some regional variations in the services produced.

Municipalities are responsible for care of the elderly in their home or in specially adapted housing. This includes people with physical or psychological disabilities.

The role of central government is to establish principles and guidelines for care and to set the political agenda for health and medical care. This is achieved through laws and ordinances, or by reaching agreements with the Swedish Association of Local Authorities and Regions (SALAR), which represents the interests of government, professionals, and employers within Sweden's municipalities and county councils/regions.

National Quality Registries – An Overview

This chapter discusses the design of the National Quality Registries, the development of the registries and competence centers, and the management of activities supporting their development.

Need for National Quality Registries

Health and social services are developing and changing rapidly in Sweden, as in other nations. The organization and management of these services has been similar and stable for many years. At the general political and administrative level the focus has been on financial and staffing issues, ie, the framework for providing services. The content of health services has been determined mainly by the various groups of healthcare professionals, while the dynamics of change have been heavily influenced by new treatment options generated through research.

The traditions of health and social services explain why we have the types of management systems that we do. In health care, we have well-developed and functioning systems to monitor economic and human resource activities. Corresponding systems have not been developed for working with patients, although this is the actual core and the ultimate aim of provider organizations. The traditional patient record systems have not facilitated the compilation and analysis of data needed for quality improvement. Although increasingly more records are electronic, they essentially continue to be note pads that individual caregivers use for memory support in treating individual patients.

The National Quality Registries have been developed to fill the gap left by the lack of primary monitoring systems. The quality registries collect information on individual patient's problems, interventions, and outcomes of interventions in a way that allows the data to be compiled for all patients and analyzed at the unit level¹. Since the registries are national, the entire country is in agreement on what indicates good care. This also makes it possible to compare different units. Currently there are 56 national quality registries in health care, 55 of which receive funds from the Executive Committee for National Quality Registries. In the areas where National Quality Registries have been established, the tools are available for any unit that wants to participate to continuously monitor their effectiveness and the benefits that they create for patients.

The successful development of the Swedish National Quality Registries is explained largely by their decentralized nature. Caregivers that have the greatest use for the data also have the main responsibility for developing the system and its contents, and the databases are spread out among different clinical departments throughout Sweden. Registry content is continually validated in different ways by registry managers and units that use the registers. This is complemented by annual quality control, represented by the annual reports and grant applications submitted for central funding. Data quality in the National Quality Registries is sufficient for use in clinical research.

¹ In this document, the term unit is used as a synonym for department or clinic.

Areas of Development

Despite positive advancements in the National Quality Registries in recent years, several important fields in health care cannot yet be monitored, including:

- Psychiatry
- Primary care
- Elder care
- Dentistry

Although a few registries have been successfully established and continue to develop in these fields, additional registries need to be created in the near future.

Generally, compared to inpatient somatic (acute) care, the areas mentioned represent a higher level of complexity and require more resources to create functioning and fully developed quality registries. The level of difficulty is influenced, eg, by the number of units and patients that the registry covers, the length of the continuum of care or the care episode, the size of the participating units, and the need for such registries to cover services delivered by county councils, municipalities, and the private sector.

In several of the developmental areas mentioned, there are needs to create organizational environments that, similar to large hospital departments, can harbor and support the development of registries. Competence centers for quality registries (see next section) could exemplify such environments, and further competence centers may need to be established in the near future.

Information Technology Issues

In quality registries it is essential that data entry, retrieval, and analysis can be done in a manner that is as simple and user friendly as possible. Staff in departments and care units are burdened by many administrative duties that divert time from patient care. A prioritized area for development aims at saving as much work time as possible through avoiding duplicate entries in journals and quality registries. Utilization in general should be simplified and made as efficient as possible, eg, through fewer and more uniform interfacing in data entry and through user-friendly analytical and presentation modules to support continuous quality improvement efforts in the departments.

Since information technology (IT) systems in health care have been introduced at different points in time and with little or no coordination, their design is not standardized, and they are not adapted to communicate with each other. Hence, the information cannot be stored, searched, and transferred among the different systems in an efficient way, nor can they be used collectively by different users and for different important purposes.

Sweden adopted a national IT strategy for health care and social services in 2006. Aims of the national IT strategy include the creation of a uniform information structure and a developed technical infrastructure to enable efficient and secure information transfer between systems. As an initial step for quality registries, a pilot project (the IFK Project) was conducted in 2006 to create a common information structure for quality registries. This project is used as input in other national projects in the area. Further work with this will be a priority area for quality registries even in the future.

A substantial percentage of the funding available to the registries in recent years has been used to create modern, internet-based IT platforms. New quality registries and registries that need to develop and modernize their IT support, should primarily choose among the IT platforms already in use by the competence centers or other registries.

Other Types of Registries

In addition to the National Quality Registries, several other important types of registries in health care enable monitoring of quality and treatment outcomes. Three of these are discussed briefly below.

Local and regional quality registries

In many instances, individual departments, county councils, and regions have created quality registries (or corresponding) to enable them to monitor only their own activities. In some cases these systems are integrated with local patient record systems. These local and regional quality registries have yet to be inventoried from a central level. However, several county councils have conducted such inventories within their own organizations, in many instances identifying registries they had not previously been aware of.

If a local or regional registry is successfully operated and helps the concerned organizations to carry out measurement-based, patient-focused, and more effective quality improvement efforts it is obviously desirable to disseminate the registry to similar organizations throughout the country. Several of the current National Quality Registries in Health Care started as local or regional registries.

The disadvantage of local and regional registries is that, unlike the national registries, they do not contribute toward creating equal and comparable health services throughout the country. This is the reason why central funding is provided only to the National Quality Registries in Health Care.

Other national quality registries

Some national quality registries do not request central funding and hence are not included in this document. Such registries, at different stages of development, are in operation, eg, in neurosurgery and cancer care. Regarding the latter, the Swedish Cancer Society performed an inventory in 2007 and identified 18 national cancer registries, 6 of which are included in this document. A total inventory of the other registry areas is not currently available.

Several reasons suggest that all national quality registries should seek central funding. In addition to the enhanced resources associated with central funding, the information about a registry, eg, purpose, content, and contact information for registry managers, should become searchable and generally accessible. The review and feedback that takes place in conjunction with the annual application process also guarantees the quality and utility of the registries.

Health data registers

Four health data registers are available. Information in these registers can be used only for generating statistics, some followup and assessment, and research. The aim is to improve the opportunities to prevent and treat diseases. Health data registers, in contrast to the National Quality Registries in Health Care, are regulated by law. Hence, the level of coverage is high. On the other hand they contain fewer information items, mainly addressing treatment interventions.

The Epidemiological Center (EpC) at the National Board of Health and Welfare is responsible for the following health data registers:

- Hospital Discharge Register, which covers all instances of hospital care in Sweden and, in recent years, some outpatient data
- Medical Birth Register, which includes all births in Sweden and information about the mother and child

- Cancer Register, which contains information about people registered in Sweden who are diagnosed with cancer or a cancer-like condition
- Prescribed Drug Register, which contains information about drugs, consumable articles, and foods dispensed under prescription (corresponding) at pharmacies since 1999. Personal ID numbers have been included in the register since July 2005.

Furthermore, EpC is responsible for:

- Cause of Death Register, used as a basis for the official cause of death statistics and contains data on cause-specific mortality for descriptions of the population's health.

In a quality registry context, these registers play an important role, eg, in validating data in the National Quality Registries in Health Care. Resources are available at EpC for registry managers needing statistical support or assistance with validation of this type. It is important to emphasize that these registries have been developed for reasons other than quality registries and are used in part for other purposes.

Transparency

As with patient records, the National Quality Registries in Health Care contain information based on personal ID numbers of individual patients, and are thereby protected by similar standards regarding confidentiality and data handling. In contrast to the patient records, however, the primary aim of the quality registries is to enable data to be collected and analyzed in a way that supports different users in continuous development and improvement efforts. The main users of the registries are the staff of departments and clinical units, and the annual reports by registry managers are designed primarily for these users.

There is also an important need to manage data from the quality registries to also benefit users other than healthcare staff, eg, hospital and county council executives, patients, the public, and public agencies. This type of development is under way at many registries and competence centers, but efforts need to be broadened and intensified in the coming years. This work demands greater discourse with new users, more resources for analysis and presentations, access to new distribution and information channels, etc. To a greater extent, it also implies a need to be able to observe what different clinics and county councils achieve, and use these transparent comparisons in ongoing development and continuous quality improvement efforts. Generally, it calls for a high degree of transparency and accessibility to registries and treatment results.

The need for different users to be able to utilize the National Quality Registries is often formulated as a demand for greater transparency. This generally covers many of the issues discussed above, ie, discourse, analysis, information, distribution, and transparent comparisons –all based on the needs of new users.

The expression transparency at the clinical level in this document represents a formal requirement on the analytical report that each registry compiles annually. From 2007 all registries, with the exception of new registries that do not yet have complete data, must specify the department name when reporting data by department. For further information on how the annual reports are designed, distributed, and how the results are generally disseminated to different users, one must inquire directly to the registry manager.

Competence Centers

Three special competence centers for the National Quality Registries have developed in recent years. As with quality registries, more competence centers are being planned in different areas. The concept of a “competence center” emerged from the Executive Committee and through discussions with various registry managers. In a competence center, several registries share the costs for staff and systems that a single registry could not bear. Hence, continued development of the registries could be assured within certain parameters without abandoning the decentralized model. Competence centers aim to promote the development of new registries, create synergy effects by collaboration among registries (eg, in technical operations, analytical work, and use of registry data to support clinical quality improvement), and helping to make registry data beneficial for different users. The competence centers also enter into special agreements, eg, to define the limits of treatment indications or develop national guidelines. Despite the emergence of competence centers, the registries continue to be managed independently by registry managers. However, many registries have turned to a competence center for collaboration on operational and analytical work. Several registries use a common information technology (IT) platform, financed through funds that the Executive Committee granted to operate a particular registry, but invoiced from the competence center used. The expertise profiles of competence centers have two main dimensions: a) one or more specialty areas, eg, orthopedics, cardiovascular disease, or eye-related care, and b) and registry know-how that covers everything from the technical operation, to scientific analysis, to methodology for quality improvement.

Executive Committee

Representatives from the Swedish Association of Local Authorities and Regions, the National Board of Health and Welfare, the Swedish Society of Medicine, and the Swedish Society of Nursing collaborate at the central level in the Executive Committee for National Quality Registries (see appendix) to jointly discuss and determine how to shape registry support. The group decides how funding for registries and competence centers should be allocated. In 2007, funds have been allocated mainly through agreements between the state and the county councils under an arrangement referred to as Dagmar funding as well as supplemental funds from the county councils and the National Board of Health and Welfare. Other financing sources also exist, and options for continued financing are being studied. Regardless of the sources of future financing, the quality assessment systems that have been created for the registries are intended to continue, ie, annual reports and applications from registries that are evaluated and selected by the Executive Committee and Scientific Advisory Committee.

Scientific Advisory Committee

The Executive Committee appoints a Scientific Advisory Committee (see appendix) to review the applications received each year and to present recommendations for decision-making. The Scientific Advisory Committee includes expertise in health services, but also in the fields of epidemiology, statistics, registry management, and clinical quality improvement. The Executive Committee and Scientific Advisory Committee meet jointly several times per year to assure that they use a common foundation on which to base their decisions and to fully utilize the experience of the Scientific Advisory Committee in planning for the future.

Ongoing Work at the Central Level

Since January 1, 2007, the Swedish Association of Local Authorities and Regions has managed all central administration of the quality registries. This involves the administration and handling of annual applications, the meetings of the Executive Committee and Scientific Advisory Committee, producing printed material, and arranging the annual quality registry conference. Also, three people at the Swedish Association of Local Authorities and Regions are continuously involved in the relatively extensive and varied work with the National Quality Registries. This involves participating in registry conferences and steering committee meetings of the competence centers, informational activities, supporting clinical quality improvement with registry data, providing staff support for the Executive Committee, etc.

Conferences and Meetings

In addition to arranging the steering committee meetings for their registries, more registry managers are arranging one or more registry meetings annually for all users. In addition to addressing operational questions, clinical improvement efforts, and research findings during the year, these meetings are often used to discuss transparency and the publication of results from specific departments. When consensus has been reached, the registry managers can make the appropriate changes in their annual report and registry website. In similar fashion, the competence centers arrange user meetings for the registry managers with whom they collaborate. They also arrange meetings for the steering committees and boards of the respective centers.

In October of every year, the Executive Committee sponsors a quality registry conference. The conference is a showplace for the National Quality Registries and aims at attracting a broad target group in the health services. These conferences have been held in Stockholm, Göteborg, Malmö, Halmstad, and Linköping.

UCR – Uppsala Clinical Research and Registry Center

<i>Address</i>	<i>Uppsala Clinical Research and Registry Center (UCR)</i>
<i>Phone</i>	<i>+46-(0) 18 - 611 95 04</i>
<i>E-mail</i>	<i>anita.ostrom@usr.uu.se</i>
<i>Website</i>	<i>www.ucr.uu.se</i>
<i>Director</i>	<i>Lars Wallentin, Professor, Cardiology</i>
<i>Year started</i>	<i>2002</i>
<i>Employees</i>	<i>Around 45 at UCR, whereof 20 are engaged mainly with registries</i>

Background

The Uppsala Clinical Research and Registry Center (UCR) started on July 1, 2001 and operates with support from both the School of Medicine at Uppsala University and the Uppsala University Hospital (Uppsala County Council). The primary aim of UCR is to provide services for clinical research focused on developing and improving health care. Main activities at the Center include the development and operation of National Quality Registries in health care, project management, monitoring of clinical trials, data management, IT support for quality registries and clinical trials, advice in biostatistics and epidemiology, analysis and quality control, and education in UCR's areas of responsibility. The Center also invests in research and development of methods related to registry activities and clinical trials, and offers education and supervision in these areas. During its development phase, the Registry Center focused particularly on cardiovascular diseases and cancer, the two dominant causes of morbidity and mortality in society today. The areas of interest expanded during the development phase and now include diseases within several areas.

Services

UCR offers its services to organizations involved in healthcare research and development. Concerning quality registries, the largest purchasers are the registry managers appointed by the county councils. UCR also provides services directly to hospitals, county councils, and safety monitoring registries for new drugs.

UCR specializes in consulting, protocols, and technical development and operation of quality registries. Here, UCR offers project management and methods for and development of Web-based information technology for interactive data entry and report retrieval via the Internet. UCR provides services in data management, data security, linking and matching with other databases, statistics, and epidemiological analyses and advice as well as the production of annual reports and scientific documents. Furthermore, UCR offers consulting services and educational support for quality improvement projects involving registry analysis and feedback. UCR also provides a wide range of methodological support for implementing clinical trials that use the registries as a starting point. Education, monitoring, and direct online support services are offered by UCR. Informational material and registry websites are developed on request.

Competence

UCR is located at the Uppsala Science Park close to Uppsala University Hospital, the Biomedical Center, and the Medical Products Agency. Three physician researchers with extensive scientific knowledge and experience in research and development related to registries are in charge of the UCR and its competence center for National Quality Registries. The competence center has a steering committee and contact network of registry managers that also represent extensive competence and experience in registry activities. Core resources at UCR include an IT group of nine system developers who develop and operate Web-based registries. A five-member methodology group includes statisticians and data managers to support feedback through basic and advanced reports and scientific analyses. An operational group of five to six people, including information and education specialists, quality control monitors, secretaries,

and economists work directly with purchasers, registry administrators, and participating units. The Center also has two individuals providing services in systematic quality improvement.

IT Solutions

UCR's IT solutions are completely Web-based, and all components in the system can be reached via each computer connected to the Internet or Sjunet¹. Registries are developed on the basis of protocols, minimum specifications, and terminology lists that are developed in close, ongoing collaboration with purchasers and users. The system is based on common platforms for data entry and data transmission for generating reports. The system uses open source code and works with encrypted data via the Web server and applications server as well as with Java/JSP programming for Web interface, MySQL as a relational database for entering data, and the SAS statistical program for analyses and report generation. The programs are set up and open for language adaptation and internationalization. There are direct links to the population registry, and the Swedish personal ID number (personnumret) directly yields other individual-related data and vital status. The system is flexible and constructed with the potential for individual users to add to, define, and name their own selected variables. Interactive help functions, including term definition and functionality, are built into the program.

System operation is assured through daily backup copies and monitoring of applications with alarms via SMS to the operations manager. Logging in and authorization to use the system is controlled through advanced password management. In addition, all activity in the system is logged, which gives the opportunity to track the access of each user and any changes in the database.

The goal of registry technology is to be able to give all users current reports at any time regarding their own organization and its development, and be able to compare these figures with other centers. At selected intervals (usually every night) data are transmitted from the entry database (MySQL) to the analytical database (SAS). Hence, current data are always available for the reports that generate statistics for the user. On special webpages, the user can specify the parameters that form the basis for processing statistics. For each analysis, the statistics can be converted to tables and graphs, including statistical tests on groups, as determined by the user. Reports in the platform are continually developed and tailored for each system by UCR's experienced statisticians and data managers.

Affiliated Registries

National Quality Registries in Health Care

UCR is responsible for the development, operation, and online analysis of all registries listed below. All use UCR Web-based registry platforms except for the Swedish Heart Surgery Registry and the National Registry for Catheter Ablation.

- RIKS-HIA – Registry on Cardiac Intensive Care [Register of Information and Knowledge about Swedish Heart Intensive care Admissions] (p 36)
- SEPHIA – Registry on Secondary Prevention in Cardiac Intensive Care [Secondary Prevention in Swedish Heart Intensive care Admissions] (p 43)
- Swedish Heart Surgery Registry (p 37)
- SCAAR – Swedish Coronary Angiography and Angioplasty Registry (p 36)
- Swedvasc – Vascular Registry in Sweden (p 41)
- RiksSvikt – National Heart Failure Registry (p 35)
- GUCH – Grown-Up Congenital Heart disease Registry (p 42)
- Swedevox – Respiratory Failure Registry (p 29)
- GallRiks – Swedish Quality Registry on Gallstone Surgery (p 50)
- SveDem – Swedish Dementia Registry (p 64)
- Auricula – Atrial Fibrillation Register (p 45)

² Sjunet connects the Swedish healthcare sector through a single private network for data communication.

- Webrehab Sweden – Quality Registry in Rehabilitation Medicine (p 63)
- Senior Alert – National Registry on Nutrition, Fall Prevention, and Pressure Sores (p 83)
- National Catheter Ablation Registry (p 44)

Other registries

UCR is responsible for the development, operation, and online analysis of the registries listed below. All use UCR Web-based registry platforms.

- Lung Cancer Registry. Contact: Regional Oncology Center in Uppsala-Örebro Region.
- Registry on Hydrocephalus and Arteriovenous Malformations in the Brain. Contact: Kristina Cesarini, Academic Hospital, Uppsala.
- Pulmonary Hypertension Registry. Contact: Björn Ekmehag, Lund.
- SITS – International Registry on Thrombosis in Stroke [Safe Implementation of Thrombosis in Stroke]. Contact: Nils-Gunnar Wahlgren, Karolinska University Hospital, Solna.
- EQUIP – International Registry on Cardiac Intensive Care. Contact: Bertil Lindahl, UCR, Uppsala.
- ERAS – International Registry on Colorectal Surgery – [Enhanced Recovery After Surgery]. Contact: Jonathan Hausel, Ersta Hospital, Stockholm.

Improvement Process Support

From 2003 and 2004, the competence centers have led the development of public reporting of healthcare interventions and outcomes at the regional, county, and hospital levels. This work has drawn public attention and contributed substantially toward increasing participation and improving quality in the registration and improvement of care delivered at many units.

The competence centers have initiated and implemented quality improvement projects for several registries with breakthrough methods, supported by Internet-based presentation of quality registry data and Internet-based education. A controlled trial (Quality Improvement in Cardiac Care – QUICC) has shown that the methods can achieve substantial improvement in care in the short term. The QUICC project has received major national and international attention. In cardiac care, several hospitals have requested QUICC, and consequently it has been developed as a service that UCR can offer to interested hospitals. Hence, a followup project called QUICC plus has been carried out, and another project on secondary prevention after myocardial infarction – QUICC-2nd – is under way at 12 hospitals. Currently, the competence center has two employees who can provide support to hospitals that want to pursue registry-supported quality improvement methodology.

Relevant Research

Registries affiliated with the competence center are used extensively in research and for several doctoral projects. The registries maintain a high profile and present new findings at national and international conferences. Every year, registry findings are used in papers published in international journals, as shown in the annual reports of the registries. Examples of notable findings in recent years include the variations in cardiovascular health services in relation to gender, age, diabetes, kidney function, and the hospital providing care. Research has also highlighted the outcomes of various treatment interventions in clinical practice, eg, blood thinning and thrombolytic therapy, cholesterol lowering treatment, and different types of catheter-borne and surgical procedures. Currently, a much needed assessment of new and expensive cardiovascular interventions, eg, drug-eluting stents for vascular stenosis, catheter therapy for atrial fibrillation, and primary balloon angioplasty compared to thrombolytic treatment in the ambulance for myocardial infarction. Research is also focusing on secondary prevention measures such as physical activity, smoking cessation, psychosocial situation,

quality of life, and the health economics of vascular disease. Using behavioral science methods, patient participation in making treatment decisions and patient satisfaction with health services are also being studied. Methods involving evidence based quality improvement, with efforts to systematically improve the interaction between continuous outcome measurement and interactive education via the Internet, are being scientifically assessed in recognized national and international randomized trials.

International Activities

Internationally, the competence center collaborates with registry centers in England, Germany, and the United States.

On the research front, UCR is collaborating with the Clinical Trials and Evaluation Unit at the Royal Brompton Hospital in London to conduct a study (EQUIP) of registry-supported quality improvement among cardiovascular centers in Great Britain, Spain, France, Italy, and Poland. The study began in September 2007.

Through the global SITS Registry, UCR provides registry services to 31 countries on four continents. UCR has also constructed and manages the European Registry for Colorectal Surgery ERAS (Enhanced Recovery After Surgery).

UCR also participates in directing the EU project to standardize registry variables in Europe. The project received EU Commission approval for the proposed Cardiology Audit Data Standards (CARDS) for acute coronary heart disease, coronary heart interventions, and arrhythmias. The competence center's new version of the registry, developed in 2004 and 2005, is adapted to these variables and is also designed to be multilingual.

Other Activities

UCR managers are responsible for the factual documentation in the national guidelines for coronary care, where registry data forms part of the information base. UCR is also instrumental in providing statistical analysis to assess implementation of the new national guidelines. Presenting and discussing the results from national guidelines is a key component of education on the delivery of cardiovascular care, as presented in domestic and international textbooks and review articles on cardiovascular disease.

EyeNet Sweden

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<i>Director</i>	<i>Mats Lundström</i>
<i>Year started</i>	<i>2003</i>
<i>Employees</i>	<i>5</i>

Background

EyeNet Sweden was formed on January 1, 2003 at the request of the National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions (SALAR) for the purpose of serving as a competence center for quality registries. The Swedish National Cataract Register with its extensive experience in data collection, clinical quality improvement, and research in cataract surgery, provided the foundation for developing a competence center. Over the years, research areas have included public health, patient benefits, and cost effectiveness. The Swedish National Cataract Register was formed in 1992 and currently includes 880 000 cataract operations.

At the outset, two established quality registries – the Swedish Corneal Transplant Register (started 1996) and the Macula Register (started 2003) – affiliated themselves with EyeNet Sweden. The Registry of Pediatric Cataract was formed in 2003 as a subunit to the Swedish National Cataract Register, since pediatric cataracts and their treatment differ substantially from common cataracts. Refractive surgery is an expanding area in ophthalmology, and in 2005 an international registry was developed (RSOIS – Refractive Surgery Outcomes Information System) to assess surgical methods of correcting vision defects by changing refraction in the eye. During 2006, a regional registry – the Computerized Patient Record on Leg Ulcers – was developed, and an agreement has been signed between SDIR (Swedish Dental Implant Register) and EyeNet Sweden. Discussions are under way with dental services to develop a registry for edentulism and caries.

Experts within the respective fields created the registers mentioned above. In 2004, EyeNet Sweden in collaboration with the National Board of Health and Welfare and SALAR developed a handbook for starting quality registries. The Swedish handbook was published in 2005, and an English version followed in 2006.

Services

Within EyeNet Sweden's organization, there is extensive experience in operating national quality registries and how one uses registry data in clinical quality improvement. The main purpose is to start, develop, operate, and improve the National Quality Registries in Health Care and enhance analysis and reporting from these registries. Research is being conducted within the fields of public health, patient benefit, and cost-effectiveness. The services offered by EyeNet Sweden are determined partly by the core mission based on the agreement with the Executive Committee of National Quality Registries, and partly on the profile that EyeNet Sweden has created for itself. On request by registries and other interested parties, EyeNet Sweden can:

- Support the introduction/development of new quality registers in ophthalmology and other specialties
- Manage and support current quality registries
- Develop the role of quality registries in clinical quality improvement
- Participate in making registry data usable for other users
- Participate in developing national guidelines
- Further develop research in the field
- Create synergy effects in collaboration with different registries in analytical work and technical operation
- Provide education and practical advice

Competence

EyeNet Sweden is governed by an executive committee with representatives from SALAR, associated national registries, the Swedish Ophthalmological Society, and the management team of EyeNet Sweden. The management team includes:

Mats Lundström, Adjunct Professor in ophthalmology with many years of experience in managing National Quality Registries. Registry Manager of the Swedish National Cataract Register since 1992. Chair of ECOS (European Cataract Outcome Study) and ESCRS/ASCRS Outcome Study. Past Director of the Department of Ophthalmology, Blekinge Hospital (1980-2003).

Susanne Albrecht, Ophthalmology Nurse since 1986 with education in research, sociology, and organizational theory. Project Manager in breakthrough methodology. Leadership experience.

Eva Wendel, Ophthalmology Nurse since 1980 with education in research and public health. Project Manager in breakthrough methodology. Leadership experience.

Irene Serring, Network Technician and System Administrator for registries associated with EyeNet Sweden. Registry Secretary for the Swedish National Cataract Register.

Kristin Svensson, Research Secretary with experience as R&D Secretary in Blekinge since 1995. Primary responsibility for EyeNet Sweden's secretariat. Administers the course Basic research methodology in Blekinge (Faculty of Medicine, Lund University).

Development and support of information technology (IT) is managed by consulting firms. EyeNet Sweden has two long-term contracts with the IT Department, Blekinge County Council, regarding the technical platform, services, and support of the system. EyeNet Sweden also has a long-term contract with Profdoc Lab AB for the development of existing and new Web-based systems for data registration and reporting. Several external consultants in different fields collaborate in the development of EyeNet Sweden's services, eg, within the fields of clinical epidemiology, statistics, economics, and public health.

IT Solutions

EyeNet Sweden offers broad technical support, including system development, system operation, system security, and monitoring systems for statistics, accounting, communication, service, and support. A modern computer facility is available with its own reserve power, cooling system, alarms for break-ins, temperature, and humidity, fire extinguishing, video monitoring, passage security, etc. IT development and support is managed with the help of consulting firms, eg, the IT Department of Blekinge County Council manages technical platforms, service, and support of systems and Profdoc LAB AB manages development of current and new Web-based systems for data registering and reporting.

Affiliated Registries

The following registries have been developed and are operational within EyeNet Sweden

National Quality Registries

- Swedish National Cataract Register – Web-based since 2003 (p 73)
- Swedish Corneal Transplant Register – Web-based since 2006 (p 74)
- Macula Register – Web-based version under construction (p 75)
- Swedish Quality Registry for Caries and Periodontitis (SKaPa) – under construction (p 81)

Other registries

- SDIR – Swedish Dental Implant Register – A quality registry on dental implants is under construction. Aims at surveying the scope of implant treatment, and registering patient satisfaction, chewing function, implant loss, and other complications. Registry Manager: Björn Klinge, Karolinska Institutet.
- SWEDROP – Swedish National Registry on Retinopathy in Prematurity. Aims at quality assurance of screening of children born prematurely. SWEDROP is part of the PNQ-Registry but collaborates with EyeNet Sweden.
- Registry of Pediatric Cataract– Formed in 2003 and is a subunit of the Swedish National Cataract Register. The registry aims at optimizing screening strategies and more effective treatment of pediatric cataracts. In children, it is important to perform surgery at an early age to achieve normal sight development. Web-based since 2006. Registry Manager: Kristina Tornqvist.
- Leg Ulcer Registry – Computerized Patient Record on Leg Ulcers – Was developed 2006 and has been operational since spring 2007. The purpose and goal of the registry is to form a national basis for diagnostics and treatment of hard-to-heal ulcers and form a national basis for quality assurance and promote quality improvement in ulcer care. Registry Manger: Rut Öien.
- Registry of Refractive Surgery includes various surgical methods to correct vision defects by changing the refraction in the eye. The registry aims to inventory methods that can be applied, and assess the results to promote good quality in refractive surgery. The registry is included in RSOIS (see below). Registry Manager: Mats Lundström.
- ECOS – European Cataract Outcome Study – European registry on cataracts has been administered by the Swedish National Cataract register in Karlskrona since 1995. The registry has had voluntary participation from around 90 units in Europe and elsewhere around the world. Since 2003, the registry has been associated with EyeNet Sweden. Registry Manager: Mats Lundström.
- RSOIS – Refractive Surgery Outcomes Information Systems – In 2005, EyeNet Sweden reached a long-term agreement with the European Society of Cataract and Refractive Surgeons concerning the operation and support of a Web-based registry for refractive and cataract surgery. Registry Manager: Mary D Ardis, ESCRS, Dublin.

Improvement Process Support

Although EyeNet Sweden addresses development, improvement, and operation of old and new registries in all specialties, it has chosen to prioritize quality improvement in ophthalmology. From the outset, EyeNet Sweden has worked with a national Q-reg project that included development of a national model for surgical indications – the NIKE indication instrument. A revision of NIKE started during the spring of 2007 and involves ophthalmologists from around Sweden. The intent is to simplify and refine the instrument for clinical practice. During 2004, EyeNet Sweden in collaboration with the National Board of Health and Welfare and SALAR developed a handbook for starting quality registries. The handbook was published in Swedish in 2005 and in English in 2006. In 2007, Swedish and English versions of an information sheet were published. During the spring of 2007, NKO, UCR, and EyeNet Sweden began collaborating, eg, to develop a model contract for quality registries. During 2006 and 2007 EyeNet Sweden participated in a SALAR project to design an information structure for quality registries (The IFK Project).

Several projects have been initiated since EyeNet Sweden started in 2003, eg, studying the effects of simultaneous bilateral cataract surgery, determining the duration of positive effects from cataract surgery, and attempting to describe the benefits of slowing the course of a chronic eye disease. In the autumn of 2004, two research projects were started. One project, “Simultaneous Bilateral Cataract Surgery in Sweden 2003-2004”, analyzed rates and demographics and studied surgeons’ reasons for choosing, or not choosing, to perform bilateral cataract surgery on the same day. The other project, “Absence of Improved Vision After Cataract Surgery – Reality or Measurement Error”, surveyed and analyzed patient opinions regarding surgical outcomes. These projects have been completed and concluded.

A project focusing on the public health effects of cataract surgery on one or two eyes is under way. Three new projects were initiated in the spring of 2006. The project, "Health Economic Perspective of Simultaneous Bilateral Cataract Surgery", aims at describing how resources can be optimized in surgery, and the project "Health Economic Perspective on Long-term Effects of Cataract Surgery" will show how living standards are affected in a population. The third project, a national project involving 10 ophthalmology departments, is being conducted in collaboration with the Swedish National Cataract Register. It addresses the complications of cataract surgery in terms of loss of vitreous body in the eye. The intent is both scientific and practical, since it aims at implementing clinical improvement at a later stage via a so-called Q-reg project.

A major review was concluded in the autumn of 2006, and is presented in an article on diagnostic-specific and generic patient questionnaires in ophthalmology. Also planned is a revision of Catquest, a cataract questionnaire that the Swedish National Cataract Register developed and has used for several years.

A national quality improvement project involving nine ophthalmology departments in Sweden started in the winter of 2003 and aimed to create common indicators for cataract surgery. The project concluded in May 2004 and generated a national indication instrument NIKE. The instrument was validated in autumn 2004 through spring 2005 and is used nationally in the so-called maximum waiting time guarantee, introduced in November 2005. The instrument was assessed during the spring of 2007, and revision has been initiated to improve the instrument and facilitate its use in routine medical services.

Relevant Research

Research and development is focused mainly on the areas of surgery, patient benefits, and cost-effectiveness. Since its inception, EyeNet has initiated several research projects in health economics and patient benefits. Completed or ongoing projects include:

- *Health economic perspectives on simultaneous bilateral cataract surgery*
Aims to describe how to optimize resources in cataract surgery.
- *Markov model to describe the effects of cataract surgery*
Aims to describe the effects of different cataract surgery strategies on a population, by using a Markov model.
- *Index model to estimate the benefits of delayed deterioration in chronic progressive disease*
Aims to use an index model to describe the benefits of delaying a chronic, deteriorating course in three different eye diseases.
- *Duration of self-assessed benefit of cataract extraction – a long-term study*
Aimed at studying how long, on average, the positive effects of cataract surgery endure. The first part of the project has concluded, with results published in the British Journal of Ophthalmology 2005. The second part of the project will survey the potential causes of poor outcomes and address economic aspects.
- *Optimizing cataract surgery*
Aims to use a model to describe how cataract surgery can be performed with optimum efficiency. The foundation of the study is EyeNet Sweden's previous work on costs of cataract surgery and patient benefits of simultaneous bilateral surgery versus operating on one eye at the time.
- *Capsule rupture during cataract surgery – risk analysis and survey of functional outcome*
Aims at a risk analysis concerning capsule rupture during cataract surgery and to study how different management affects final outcome.
- *Validating the registration of complications* in the National Cataract Registry is planned to begin in autumn 2007.

International Activities

EyeNet Sweden has participated, eg, with presentations and educational programs, in several international conferences. An educational program on quality improvement methods focusing on measuring, analyzing, and improving outcomes was presented for European eye surgeons at the ESCRS conference in London (2006) and the ESCRS conference in Stockholm (autumn 2007). Several international scientific publications have been completed.

The European Cataract Outcomes Study (ECOS) is a European cataract registry that has been managed through the National Cataract Register in Karlskrona since 1995 and has been affiliated with EyeNet Sweden since 2003. The ECOS has voluntary participation by more than 90 units in Europe and elsewhere in the world. Since 2006 it has used a Web-based data entry form developed by EyeNet Sweden for ESCRS – RSOIS.

Refractive surgery is an expanding area in ophthalmology. In 2005, EyeNet Sweden in collaboration with Swedish refractive surgeons and ESCRS (European Society of Cataract and Refractive Surgery) developed an international registry, RSOIS (Refractive Surgery Outcomes Information System), to evaluate surgical methods for correcting vision defects by adjusting refraction in the eye. EyeNet Sweden provides development and support services, and EyeNet Sweden's server holds the database. The registry is available to surgeons worldwide who are affiliated with ESCRS.

Other Activities

EyeNet Sweden has arranged /participated in other activities, including:

- Annual meeting (EyeNet Sweden Days) with all registries affiliated with EyeNet Sweden.
- Handbook on starting quality registries, published June 2005. The handbook is available as a pdf file from www.eyenetsweden.se or www.kvalitetsregister.se. Printed copies may be ordered via www.eyenetsweden@ltblekinge.se. Swedish and English versions of the handbook are available.
- Several new registries have received practical and financial support.
- Discussions concerning appropriate variables and the design of standard reports.
- Meetings for registry users.
- Collaboration between NKO, UCR, and EyeNet Sweden started in the spring of 2007. A model contract for the startup and operation of quality registries will be developed.
- Several EyeNet Sweden research projects have been conducted and reported on at national and international conferences and meetings.
- An educational program, "Organizational Development and Quality Improvement in Practice" for resident physicians has been conducted on two occasions.
- An educational program on quality improvement methods focusing on measuring, analyzing, and improving outcomes was held for European eye surgeons in London (2006) and Stockholm (2007).
- A project, Information Structure for Quality Registries (IFK Project), aims to enable information to be supplied to patient record systems and the National Quality Registries without double entry, and also that different record systems and different National Quality Registries need to be adapted only once to become integrated.

NKO – Swedish National Competence Centre for Musculoskeletal Disorders

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<i>Directors</i>	<i>Center Director: Lars Lidgren, Operational Director: Jonas Ranstam</i>
<i>Year started</i>	<i>2003</i>
<i>Employees</i>	<i>8</i>

Background

National quality registries for knee and hip replacement, and for hip fractures have been active in Sweden for nearly 25 years. New registries have been, and continue to be, established in more areas related to musculoskeletal disorders.

Registry development provides major opportunities to improve care by identifying methods, drugs, and biomedical devices that offer the best treatment outcomes. This promotes rational distribution of healthcare resources and leads to improved quality of care.

NKO was established in 2003 in Gothenburg as a resource center for orthopedic quality registries, but moved to Lund in the autumn of 2004. In 2005, collaboration was established with rheumatologists and family practitioners to achieve broader coverage of musculoskeletal disorders. Also, NKO has started to collaborate more with registries in other, closely related fields, eg, surgery.

The competence center is governed by a steering committee comprised of Lars Lidgren, Lund (Chair); Johan Kärrholm, Göteborg; K-G Thorngren, Lund; Gunnar Nemeth, Stockholm; Olle Nilsson, Uppsala; Olle Svensson, Umeå; Magnus Karlsson, Malmö; and representatives from Sweden's local authorities and regions (SALAR).

Services

NKO is a national educational and consulting resource for both established quality registries and new registries being developed. NKO offers technical advice in constructing registries, methodological advice in planning registry studies, and practical assistance in analyzing and reporting on collected data.

Furthermore, NKO offers permanent space for quality registries in a modern Internet-based, database system and carries out studies under contract.

Competence

Acquiring new knowledge from a registry of health data is a task that becomes more complex with time. The volume of available data continues to grow, and the phenomena that can be studied are becoming more complex; increasingly difficult questions can be answered.

A well functioning registry places considerable demands on professional management and analysis of data. By drawing on advancements in technology and methodology, the construction of databases, collection and analysis of data, and performance of biostatistical/epidemiological analyses, etc can be more effective, more reliable, and less expensive.

Hence, NKO is strengthening its professional resources in data management, programming, biostatistical/epidemiological methodology, and health economics.

IT Solutions

NKO and Avensia Innovation are jointly developing a general, dynamic database system to collect data via the Internet. The system is based on modern, relation database technology and encrypted data communication. New registries can be constructed flexibly without the need for programming.

Administration of the participating registries is based on the registry manager delegating responsibility to, eg, data entry staff, unit managers, and analysts.

The system also includes an integrated reporting module with statistical calculations performed via a central server and an external program library with validated programs for statistical calculations using SAS, SPSS, STATA, R, and other necessary software.

Technical operation of the registry system takes place in a secure server facility with fire and break-in protection, reserve power, SMS surveillance, etc. Backup copies of the data are made daily.

Affiliated Registries

Registries marked with an asterisk (*) use the full NKO technical registry platform. Other registries can use parts of the registry platform. NKO also participates in operating some registries on its own registry platforms. NKO collaborates with other registries concerning issues involving assessment of registered data, central data management, methodology questions related to data analysis, registry development, etc.

National Quality Registries

- CPUP – Quality Registry for Children with Cerebral Palsy* (p 62)
- Quality Registry in Back Surgery (p 57)
- RIKSHÖFT – National Hip Fracture Registry* (P 52)
- Scandinavian Quality Register for Thyroid and Parathyroid Surgery (p 47)
- Swedish Shoulder and Elbow Registry* (includes two registers: pp 58,60)
- Swedish Quality Registry on Ventral Hernia* (p 51)
- Swedish Cruciate Ligament Registry (p 59)
- Swedish National Hip Arthroplasty Register (p 53)
- Swedish Knee Arthroplasty Register (p 54)

Other registries

- The Partial Arthroplasty Registry started January 1, 2005. Since an increasing percentage of patients with cervical hip fractures are receiving partial hip replacement, it is important to monitor these patients separately and compare the procedures with traditional fixation. Registry managers: Cecilia Rogmark, Malmö and KG Thorngren, Lund.
- The Hand Prosthesis Registry* started in 2006. Registry manager: Philippe Kopylov, Lund.
- The Indications Registry* is included in one of the NKO studies concerning the maximum waiting time guarantee in Sweden, with particular focus on indications for hip and knee arthroplasty.
- The Vasculitis Register* is a new registry constructed for information on pharmacotherapy and other treatment, quality of life, associated diseases/events in patients with vasculitis. Registry manager: Anders Jönsson, Lund.
- NKOISR (NKO Intervention Study Registry) is a meta-registry of intervention studies that NKO has registered and updates in international trial registries in accordance with requirements.
- The Nordic Gait Analysis Register* was established in 2005 as the first coordinated registry on three-dimensional motion data. This enables, eg, gait analysis before and after treatment or injury. The registry aims to optimize and assess treatment of patients with orthopedic and neurological disorders. Registry manager: Bengt Söderberg, Lund.

- The Rheumasurgery Register started in 2004, and is a quality registry to follow patients with inflammatory joint disorders regarding function, activity level, and quality of life. Registry manager: Anna Nilsdotter, Halmstad.
- The Scandinavian Sarcoma Group Registry was founded in 1986, and aims at improving diagnostics and treatment of sarcoma patients, provide evidence for treatment recommendations and clinical protocols, and create opportunities for research and quality comparisons among sarcoma centers. Registry manager: Henrik Bauer, Stockholm.
- The Scleroderma Registry* is a registry that is included in the epidemiological study of scleroderma.
- The Swedish National JIA Register* aims at identifying which children receive biological medications and survey long-term effects and possible side effects. Registry manager: Lillemor Berntson, Stockholm.
- The SSATG Register collects information about patients in the health services region of southern Sweden who are treated with biological medications for arthritic disease, mainly rheumatoid arthritis, but also spondylarthritis and psoriatic arthritis. The register includes effect parameters and followup of side effects. Registry manager: Pierre Geborek, Lund.
- STAR-ETIC* is a registry in a European project involving Sweden, Norway, Denmark, and the Netherlands, and aims to create a base for registering team-care interventions of patients with arthritic disease and examine various aspects of structure, process, and outcomes of services at hospitals and rehabilitation units in Europe.
- A Swedish Arthroplasty Register* is a registry of ankle prostheses. Registry manager: Anne Skoog, Stockholm.

Improvement Process Support

Registry data enables continuous quality improvement through a learning process where the focus is on developing surgical methods and total patient care, including rehabilitation. Furthermore, the ongoing development of registering patient-perceived health, which has been under way for several years, is directly related to the need for more detailed documentation and improvement of total patient care. An instrument for calculating the cost-benefits of an intervention would be included.

During 2003, no less than 8320 primary interventions were performed on the knee alone. A growing demand for surgery is predicted in coming decades: an annual increase of 5% can be attributed, eg, to changes in the age structure.

The direct costs for every primary procedure depends mainly on the costs of the implant, length of hospital stay, and followup. Between 5% and 10% of these primary prosthesis will require revision within 10 years due to loosening, mechanical complications, infections, etc. The need for reoperation varies, and for unsatisfactory implants and methods can be substantially greater than what would otherwise be the case. Hence, it is important to identify problems early to limit patient suffering and costs.

The knee and hip registries have been successful in cautioning about deficient technology and implants, and have encouraged departments and surgeons to improve their routines. This has led to a reduction in revision rates in Sweden, which from an international perspective are low.

In spite of the improvements achieved it is important to continue the quality improvement process. New implants and surgeries are being introduced regularly and require followup.

Relevant Research

NKO's research activities focus on assessing registry data.

- Prosthesis survival (revision risk) and related questions/problems are clearly important aspects in assessing prosthesis registry data.
- Patient comorbidities and mortality are important in assessing treatment, secondary prevention, and quality of life.
- Studies of general and disease-specific quality of life also provide information concerning the patient's situation.
- The association between surgical volume and outcome could be of substantial importance in identifying opportunities to improve clinical practice.
- Registry information can provide good opportunities for epidemiological studies aimed at illuminating issues concerning the origins of disease.
- Many methodology problems arise in registry research. Assessing the appropriateness of various analytical methods is an important aspect of continuous quality improvement.

International Activities

Several of the registers under NKO are multinational. NKO collaborates with other international registries and participates in Nordic and worldwide collaborating groups. NKO staff actively participate in relevant international scientific conferences as part of their continuing education to update competence and skills.

Other Activities

NKO has initiated a series of national seminars on the problems and possibilities of quality registers. The first seminar was held in February 2006, and the second in May 2007. A third seminar is planned for May 2008.

Greater collaboration with rheumatologists has been initiated concerning the early arthritis registries, eg, in southern Sweden. There is an early arthritis cohort in Lund (contact: Elisabeth Lindqvist) and in Malmö (contact: Lennart Jacobsson). Units in Spenshult, Helsingborg, Kristianstad, SU/Mölndahl, and Karolinska University Hospital in Huddinge are involved in the BARFOT Registry (contacts: Ingiöld Hafström, Huddinge, and Ingemar Petersson, Spenshult), which is part of the Swedish RA Registry. The BARFOT Registry started in 1991 as a structured monitoring system for patients with new rheumatoid arthritis, but also to study prognoses and pharmacotherapy.

There is also greater collaboration concerning the early osteoarthritis cohorts in Spenshult (contact: Ingemar Petersson) and meniscus cohorts in Lund (contacts: Ewa Roos and Stefan Lomander).

The EPIPAIN Registry (contact: Stefan Bergman, Spenshult) is being used in studying musculoskeletal pain from an epidemiological perspective.

Swedevox – Respiratory Failure Registry

<i>Registry Manager</i>	<i>Kerstin Ström (through 2007), Bengt Midgren Lung Section, Blekinge Hospital Pulmonary Medicine, Lund University Hospital</i>
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<i>Website</i>	<i>www.ucr.uu.se/swedevox</i>
<i>Year started</i>	<i>2004 (merger of two registries that started in 1987 and 1996)</i>
<i>Public funding</i>	<i>1992-2007</i>
<i>Governing body</i>	<i>Blekinge County Council (through 2007), Region Skåne</i>
<i>Competence center</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>For relevant quality indicators</i>

Background and Aim

Chronic obstructive pulmonary disease (COPD) induced by smoking is the most common cause of respiratory failure. COPD causes a deficiency in oxygen (hypoxia). Appropriate home oxygen therapy for severe chronic hypoxia doubles survival. Respiratory failure can also result from neuromuscular disease, deformed thorax, or morbid obesity, and is dominated by underventilation and the inability to adequately exhale carbon dioxide. Home respirators have a life saving effect in treating this type of respiratory failure. There are no national or international guidelines for home respirator therapy, and the lack of scientific studies is striking. Access to, and the quality of, treatment in Sweden varies among county councils. An increase in both types of therapy is apparent. The registry aims to assure the quality of home oxygen or home respirator therapy in chronic lung failure. Another aim is to acquire greater knowledge about the factors leading to respiratory failure and the most effective treatment options.

Coverage and Volume

All units in Sweden that arrange either type of therapy for more than a few patients with respiratory failure participate in the registry. Coverage is 85% for oxygen therapy patients and 90% for home respirator patients. Approximately 1800 (1500 oxygen therapy) patients are added to the registry each year, and in total the registry includes 16 000 (13 500 oxygen therapy) patients.

Key Variables

Demographic data, smoking anamnesis, blood gas values, pulmonary function, WHO performance status, possible maintenance treatment with cortisone tablets, and information about oxygen or home respirator treatment. Quality of life is monitored with EQ-5D for oxygen therapy patients.

A quality-of life-questionnaire for chronic lung failure is being translated from German and will be validated.

Reporting Process

Data are entered via a Web-based form. Oxygen therapy patients are followed up by reporting after 1 year, and home respirator patients after 1 and 3 years.

Feedback Process

Each participating unit can generate, via the Web, their own data and information using the register's quality indicators to compare to the country as a whole for a time period of the user's choice. Annual reports, and presentations at the annual registry meetings, describe the trends, quality of treatments, and outcomes, eg, in terms of survival. Analyses are performed with the help of statisticians, controlling for confounders such as age and gender.

Quality Improvement

Ten quality indicators are currently used regarding home oxygen treatment. Since 1987 there has been gradual improvement in eight of these (access to treatment, different aspects of patient selection, concurrent treatment, and survival). For example, access as measured by the number of patients starting home oxygen treatment per year, has increased five-fold while the differences between the different county councils has declined by three fourths. The annual report presents clinical-level information on the relevant quality indicators.

Swedish Quality Register of Otorhinolaryngology

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Year started	1997
Public funding	1997-2007
Governing body	Stockholm County Council
Competence center	-
Transparency, unit level	Planned 2007

Background and Aim

Ear, nose and throat (ENT) specialists began a quality improvement initiative at the national level in 1994. To reflect the diversified scope of the specialty, eg, different ages and surgical and medical interventions, a registry center was established from the outset and involved several interventions/diagnoses. Initially these included: malignant tumors in the ENT region; myringoplasty (eardrum repair); septumplasty (surgery of the nasal septum); intubation of children with recurring secretory media otitis and recurring acute media otitis; and tonsillectomy. During 2006, another ear surgery/hearing improvement intervention was added, otosclerosis surgery (surgery of fixated bones/stirrup). Another two diagnoses in the area of chronic disease/rehabilitation are on their way to the registry: severe hearing impairment in people of working age, and hearing impairment in children. The aim of the registry is to continually measure quality indicators in a large part of our activities and manage ongoing quality improvement work based on registry data. The effects of quality improvement efforts can also be followed in the registry.

Coverage and Volume

All ENT units in Sweden participate in one or more of the registries. Validation studies have focused, for example, on dropout in reporting at the unit level. The level of coverage for the different registers varies among diagnosis/intervention and among the participating units. Greater compliance is expected as reporting becomes transparent.

Key Variables

Lead times for addressing malignancy, waiting time to first visit and waiting time to intervention, surgical method, per- and post-operative complications, length of stay, and time on sick-leave are

some of the key variables. Focus is also placed on patient experienced benefit/degree of satisfaction with the intervention, which is collected via questionnaires.

Reporting Process

Since 2003, the ENT departments continually register their results on-line via a website.

Feedback Process

Data/outcomes are fed back dynamically and immediately via the registry's website. Reports are also presented at annual user days and regular national meetings of the ENT association and unit directors.

Quality Improvement

The registry informs about aspects of the ENT specialty with regard to quality differences and quality deficiencies. This provides continuous, valuable discussion for quality improvement work in special reference groups formed for the registry during 2007. The reference groups are a means for the registry to analyze results, initiate quality improvement, and propose standards. The management group is the strategic group that directs the development and marketing of the quality registry.

During 2006, national guidelines/clinical protocols and patient information were developed for septumplasty where the results in several places are unsatisfactory. Another example of quality improvement concerns tonsillectomy, where the percent of unplanned return visits is 3 times higher than expected, according to the specialty association. The reason for the high rate of unplanned return visits has been surveyed via an interview study, using special expertise from Borås University College.

BORIS – Childhood Obesity Registry in Sweden

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<i>Year started</i>	<i>2005</i>
<i>Public funding</i>	<i>2003, 2005-2007</i>
<i>Governing body</i>	<i>Stockholm County Council</i>
<i>Competence center</i>	<i>-</i>
<i>Transparency, unit level</i>	<i>No, planned 2008</i>

Background and Aim

Approximately 20% to 25% of 10-year-old children in Sweden are overweight, and just over 3% are obese. The prognosis for overweight children becoming normal weight adults is growing worse. Currently, 80% of obese 6- to 7-year-olds become obese 17- to 19-year-olds. The association between obesity and different types of morbidity is becoming increasingly obvious. The fundamental aim of the registry is long-term monitoring of treatment for childhood obesity in Sweden. A national quality register can be used to assess the quality of local health services in relation to services in Sweden as a whole.

Coverage and Volume

Currently, 17 of the approximate 40 pediatric departments (42%) in Sweden indicate that they would like to participate in the registry. Of these, 7 departments (17%) have started to register patients. The goal for 2007 is to have 14 active departments (30%) and that 10 departments which have expressed interest, but requested more information, will also participate.

By June 30, 2007 nearly 1300 patients had been registered. Since epidemiological data suggest that Sweden has between 50 000 and 60 000 obese children, approximately 2% to 3% of all Swedish children with obesity are currently in the registry. Only a small percentage of obese children in Sweden are subject to treatment by the health services.

Key Variables

Data in the registry include age, sex, weight, height, BMI, BMI SDS, time of first contact, referrals, earlier treatment, ongoing treatment, type of caregivers, visit frequency, and involvement of other caregivers. The time and cause of dropout/discontinuation is also registered. Other voluntary information may be reported if relevant.

Reporting Process

The units report on children and adolescents treated for obesity, normally once per year and patient. The registry is Web-based. Some information is obligatory for participation, and some information is added by the caregiver based on availability of the data. Users have the option to add their own modules to analyze specific issues.

Feedback Process

Participating units will have full access to their own patient data online. The departments will be able to take out groups that match their own patient material (eg, start of treatment, age, sex) to compare treatment outcomes.

Quality Improvement

To date, BORIS has contributed to local quality improvement in care at the departments which have participated longest in the registry. Routines and formats for physician visits have enabled the collection of more complete and comparable data. Parameters important for determining future morbidity, eg, waist circumference, are usually measured. A report that did not show satisfactory results from obesity treatment in teenagers has resulted in a pilot project in Stockholm to establish a clinic for obese young people aged 15 to 25 years.

SWEDIABKIDS – The Swedish Childhood Diabetes Registry

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<i>Year started</i>	<i>2000</i>
<i>Public funding</i>	<i>2000-2007</i>
<i>Governing body</i>	<i>Västra Götaland Region</i>
<i>Competence center</i>	<i>-</i>
<i>Transparency, unit level</i>	<i>Yes, from 2005</i>

Background and Aim

Each year, for reasons unknown, increasingly more children at increasingly younger ages are being diagnosed with diabetes. National quality improvement regarding diabetes in children started in the early 1990s and has been done at the individual level since 2000 via SWEDIABKIDS. Insulin pumps, new insulins, and assistive devices, etc are being introduced regularly. These changes are best assessed at the national level. The register of diabetes in children also provides a foundation for other research. Diabetes complications can be observed already during childhood. Knowledge about the outcome of diabetes during childhood is important when/if the patient later develops complications as a young adult.

Coverage and Volume

In Sweden, all of the around 750 children and adolescents (≤ 18 years of age) diagnosed with diabetes each year are reported to SWEDIABKIDS. For 95% of Sweden's 7000 children with diabetes, data are analyzed from each visit during the year ($> 22\ 000$ visits/year).

Key Variables

SWEDIABKIDS is a national quality registry that is used as a tool in day-to-day health services. The registry contains all measures needed in providing diabetes care, including personal information, genetic predisposition for diabetes, disease intensity at onset, height, weight, BMI, HbA1c, insulin types and all insulin doses during the day, puberty, regular screening for renal disease, eye fundus changes, hypertension, smoking, ketoacidosis or severe hypoglycemia, lipid levels, annual screening for thyroid function, and celiac disease.

Reporting Process

Diabetes nurses enter the data from their own units. All followup data are reported electronically. Starting in 2008, a new Web-based program will be used to enter data.

Feedback Process

The units can easily select and assess their own data. National data are analyzed according to 1-year intervals and gender. A unit's results are compared with the national average and with results from other units, and are presented in the annual report. Registry data are discussed during the spring and fall meetings of the section for endocrinology and diabetes of the Swedish Pediatric Society.

Quality Improvement

The registry has simplified diabetes care. Blood sugar control, measured as mean HbA1c, has improved successively at most departments, on average - 0.37 percentage points. Marked improvement, up to one percentage point, has been reported in recent years. Differences in the results among different clinics have declined. SWEDIABKIDS has shown that increasingly more patients use insulin pumps, and the increase is clear even among the youngest children. New types of insulin are used to a greater extent. Compliance with clinical protocols is clearly demonstrated.

PNQn – Perinatal Quality Registry/Neonatology

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<i>Year started</i>	<i>2000</i>
<i>Public funding</i>	<i>1997-2001, 2003-2007</i>
<i>Governing body</i>	<i>Västerbotten County Council</i>
<i>Competence center</i>	<i>-</i>
<i>Transparency, unit level</i>	<i>Yes, since 2007</i>

Background and Aim

PNQn was initiated to enable national assessment of the quality of care for newborns. During the 1990s, local registries were established at all of the larger neonatal care units. Coordination of registry variables was viewed to be desirable and necessary to assess differences in outcomes and care routines. PNQn was designed by a national steering committee representing the different health service regions and relevant professions. One aim is to establish a database to serve as a basis for long-term followup of various risk groups, eg, premature births. Here, it is particularly important to have feedback from longitudinal data on obstetric and neonatal outcomes. For 3 years, detailed perinatal data have been registered on extremely premature births, ie before gestational week 27. PNQn has been used as a database for the study, the results of which are now being analyzed. SWEDROP, a quality registry on eye damage that could appear in premature births has become affiliated with PNQn.

Coverage and Volume

Currently, around 32 000 admissions are registered. Starting in 2007, the registry has national coverage, and the number of admissions is estimated to increase by 10 000 per year.

Key Variables

PNQn contains basic obstetric background data about maternal health, current pregnancy, and delivery. Detailed information about the child and its progress are recorded, as are diagnoses and interventions during the inpatient stay. Information is reported at the unit level and contains information on the mother's residence to be able to monitor referral patterns and complex care processes, particularly in regard to subspecialty services. In addition to the standard list of variables, local variables – including searchable variables – can be added to the registry.

Reporting Process

Data are captured on a special form and then registered in the database via the Internet. This is done during the inpatient stay or, at the latest, when the child is discharged from the unit. Transmitted data are encrypted, and the registry requires special identification to login and retrieve the data. PNQn should register children admitted for care during the neonatal period (day 0–27). Units also have the option to register all children who they treat, even those older than 4 weeks of age on admission.

Feedback Process

Feedback takes place via an Internet-based statistical module that allows all reported data to be searched, filtered, and presented on-line. A unit's own data can be compared with the national average and the level of care. Open comparisons based on the hospital and the mother's residence can be performed. Statistical modules have been developed so that standardized annual reports can be obtained.

Quality Improvement

With national coverage, the registry can give detailed information on the outcomes of neonatal care. The steering committee compares the variables important at the county council and hospital levels (eg, respiratory support, antibiotic use, and breast-feeding routines) and is planning a program with clinical visits to assess different routines and outcomes for the purpose of learning from the units reporting the best results.

SÖK – National Registry of Suspected/Confirmed Sexual Abuse in Children and Adolescents

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<i>Year started</i>	<i>2006</i>
<i>Public funding</i>	<i>2006-2007</i>
<i>Governing body</i>	<i>Östergötland County Council</i>
<i>Competence center</i>	<i>Resource Center KPV</i>
<i>Transparency, unit level</i>	<i>Planned 2008</i>

Background and Aim

Many research reports show a strong association between being a victim of sexual abuse in childhood and mental and physical functional disorders in later childhood/adolescence and as adults. A Swedish prevalence study reported that 12% of girls and 4% of boys had been victims of sexual abuse/harassment. The National Board of Health and Welfare's expert report shows that, according to international studies, the prevalence among children using childhood and adolescence psychiatric clinics was approximately 30%. The same report showed that prevalence among adult psychiatric patients ranged between 24% and 64%.

Since multifactorial causes underlie sexual abuse, care must be delivered in collaboration with other sectors of society, such as social services and the judicial system.

The overriding aim of the registry is to assure quality throughout the continuum of care. A quality register that includes comprehensive information about the life situation of children and their family is a prerequisite for well-documented care decisions and assessments. It is also important to collect information regarding collaboration among authorities on addressing problems and how quickly the different authorities act, which includes initial interaction and waiting times. This enables assessment of the hypothesis that extensive collaboration and early intervention yields better outcomes for users. All of the factors mentioned above probably vary nation-wide, and better knowledge can, in the long run, lead to more appropriate and equitable care.

The quality registry has been implemented at the 3 specialized units that are now collecting data on all new cases. In the second phase, scheduled to begin in spring 2008, SÖK will be offered to other child and adolescent psychiatric clinics having specialized expertise. This creates the conditions for

higher quality, even at units with lower volumes and less specialization. The registry also addresses questions concerning the benefits and quality of treatment as perceived by patients. Greater knowledge about quality indicators in the area of sexual abuse and dissemination of an assessment culture, along with the SÖK reporting per se can also provide structural support for the individual caregiver so that she/he is reminded about important areas to cover in meeting and treating patients and their family members. In other words, we think that SÖK's method of helping caregivers describe what they do is a way to encourage and develop evidence-based methodology within the field.

Coverage and Volume

All patients who gave their consent at the 3 special child and adolescent psychiatric clinics in Sweden are included, starting from May 2007. Starting in 2008, other units will be invited to participate.

Key Variables

Background data, collaboration and input from other authorities involved, interaction/crisis support/crisis treatment, and assessment of treatment needs, trauma-focused treatment, assessment of completed interventions.

Reporting Process

Currently using paper forms. Web-based solutions are planned.

Feedback Process

Continual feedback to the 3 specialized units.

Improvement Process

Not yet applicable.

RiksSvikt – Heart Failure Registry

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<i>Year started</i>	<i>2003</i>
<i>Public funding</i>	<i>2003-2007</i>
<i>Governing body</i>	<i>Östergötland County Council</i>
<i>Competence center</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>No</i>

Background and Aim

Heart failure is currently the single most common diagnosis in the departments of medicine in Sweden. The number of patients is steadily growing due to longer average life expectancy and advancements in the care of myocardial infarction. Studies show that the annual direct costs for patient care exceed 3 billion Swedish kronor (SEK), or approximately 2% of the entire healthcare budget. RiksSvikt aims to improve the management of patients with chronic heart failure by providing a basis for comparison, showing good examples, and enabling analysis of different outcomes at the national level.

Coverage and Volume

At least 200 000 patients in Sweden are estimated to suffer from symptomatic heart failure. Sixty hospitals have expressed interest in the registry. As of autumn 2007, 47 hospitals and 18 primary care centers participate in the registry, reporting on over 10 834 patients (13 822 admissions). The work to involve interested hospitals and primary care centers is ongoing. Based on data from the epidemiology center, there is currently a 40% level of coverage in the participating hospitals.

Key Variables

RiksSvikt registers 70 variables concerning underlying diseases and interventions performed, EKG and echocardiography, medical treatment, calculated target dose, blood tests, patient self-rating of quality of life, and planned followup. Patients are followed up one year after the date of initial registration and answer a questionnaire to report on their current functional class in terms of tiredness and shortness of breath, medication, and quality of life.

Reporting Process

Staff report via the RiksSvikt Web-based program, which meets all standards for data security on the Internet. It is possible to export data to RiksSvikt from hospitals with electronic patient records. The data are collected and processed at UCR.

Feedback Process

Hospitals and primary care centers have access to online information regarding diagnostics, medical treatment, mortality, morbidity, quality of life, and other parameters. It is also possible to review data in comparison to the national average. More extensive statistical analysis is performed once per year and reported to all participating hospitals and primary care centers. The annual reports are available via the Internet in pdf format.

Quality Improvement

By 2010, RiksSvikt aims to have representative data on managing heart failure in Sweden. Already today some hospitals, (eg, University Hospital in Linköping) use the findings of the registry in quality analysis and determine the key targets for improvement. Since comparisons with the national average are always available online in the registry, participating hospitals are encouraged to make changes that improve care. The annual report and discussions at the annual meeting clearly encourage quality improvement activities. Goal: Over 90% of the patients are diagnosed and treated in compliance with national guidelines.

SCAAR – Swedish Coronary Angiography and Angioplasty Registry

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<i>Year started</i>	<i>1998</i>
<i>Public funding</i>	<i>1998-2007</i>
<i>Governing body</i>	<i>Värmland County Council</i>
<i>Competence center</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>Yes, since 1998</i>

Background and Aim

The number of patients who undergo coronary angiography and/or PCI continues to increase year after year, both in Sweden and internationally. As in past years, patients with major acute myocardial infarctions, where direct PCI is used instead of anticoagulation therapy, account for the greatest increase. SCAAR is a procedure-related registry, the main purpose of which is to collect relevant information about interventions in all procedures performed. Linking and matching with other registers enables long-term followup of outcomes, mortality, relapse, and complications, thereby contributing toward better quality of care.

Coverage and Volume

In 2006, coronary angiographies were performed at 30 hospitals, 27 of which also performed PCI. All PCI and coronary angiographies are included in SCAAR with the exception of the hospital in Skövde, which does not yet register coronary angiographies. Since 2006, Iceland has participated fully in SCAAR.

Key Variables

Important variables include demographic data, risk factors, indications for intervention, puncture site, angiography findings, primary decision after coronary angiography, complications, and clinician performing the procedure.

Stenosis characteristics and type of stent are registered for PCI. Procedure-related data such as transillumination time, number and type of x-ray contrast agents, and antithrombotic treatment during the procedure are also registered.

Reporting Process

Since 2001, all reporting has been done on-line over the Internet. The database is located at UCR in Uppsala. Every reporting unit has continuous access to analyses and reports that are updated daily.

Feedback Process

Feedback includes the continually updated and comprehensive written reports where users can compare their data with national data. Users also have immediate access to tables and graphic presentations of statistical analyses for selected time intervals for patient groups and for all registered variables. The management team produces a summarized annual report in print that is also available on the websites of SCAAR and the National Board of Health and Welfare.

Quality Improvement

An obvious example is the use of drug eluting stents. The aim of this device is to prevent restenosis in the coronary artery. SCAAR could publish data in the most well-respected international journal which associated a small but elevated risk for mortality with the use of drug eluting stents. The National Board of Health and Welfare, the Medical Products Agency, and the Swedish Society of Cardiology then issued strong recommendations for reduced utilization. In Sweden, utilization decreased from 60% to 15%. Internationally, the use of drug eluting stents has also decreased.

Swedish Heart Surgery Registry

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<i>Year started</i>	<i>1992</i>
<i>Public funding</i>	<i>1992-2007</i>
<i>Governing body</i>	<i>Stockholm County Council</i>
<i>Competence center</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>Yes, since 1992</i>

Background and Aim

The Swedish Heart Surgery Registry has recorded all heart operations performed on children and adults in Sweden since 1992. Heart surgery is an effective form of treatment, but may involve risks for serious complications. Hence, to improve the quality of care, information on the procedures and their outcomes must be collected, compared, and discussed. The registry makes it possible to monitor trends in the distribution of various interventions, risk profiles of patients, and outcomes. Given the current rapid expansion of catheter-borne methods in treating heart disease, it is essential to monitor the trends in open heart surgery.

Coverage and Volume

The registry is national and complete. Approximately 8000 heart interventions are performed annually. Around 130 000 surgeries have been registered. All heart surgery units in Sweden have participated since the outset in 1992. The number of units providing these services has ranged from 13 in 1994 to 8 in 2007.

Key Variables

Age and sex are indicated by the patient's personal ID number (personnummer). Waiting times, length of stay, and county of residence are shown. The information registered includes type of procedure, prevalence of diabetes and certain complications after surgery (eg, infection, renal failure, stroke, and the need for mechanical circulatory assistance). Mortality after a procedure is presented by sex and age group, categorized by type of procedure and Euroscore (a method to estimate surgical risk based on a patient profile involving 17 factors).

Reporting Process

The departments report 4 times per year to the Uppsala Clinical Research Center (UCR) via magnetic disk from the data system at the unit. UCR has certain control functions to verify data.

Feedback Process

UCR reviews the data and reports back to the units if further information and clarification are needed. Participating units have direct Internet access to their own data (Excel file) for further analysis. The annual report is available on the register's website, which also shows how individual units reported their data. In addition to annual reports, the information is reported to health services at meetings and symposia. The registry report presents transparent data on surgical outcomes at the unit level, allowing users to view how their hospital compares with others. The registry is searchable by surgical intervention and diagnosis.

Quality Improvement

The registry shows trends in heart surgery since the early 1990s in Sweden. It clearly indicates that all departments are operating on increasingly elderly patients, while at the same time the risk of death within 1 month after surgery tends to decline. Waiting times at the different units are presented, showing a trend that all patients should be able to receive surgery within the 3-month maximum waiting time guarantee. Transparent reporting of certain complications after surgery has led to a conscious effort to further improvement of care and reduce complications that prolong the postsurgical course and make it more expensive.

RIKS-HIA – Registry on Cardiac Intensive Care

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Year started	1995
Public funding	1995-2007
Governing body	Uppsala County Council
Competence center	UCR
Transparency, unit level	Yes, since 2003

Background and Aim

Acute myocardial infarction is the single most common cause of death in both men (16%) and women (11%). Acute cardiovascular disease is the most common reason for hospitalization and accounts for approximately 16% of hospital services. Annually, around 60 000 patients receive care for acute coronary heart disease, which consumes 570 000 patient days at a cost of 2 billion Swedish kronor (SEK). In addition, the costs for coronary artery interventions and drugs are SEK 5.2 billion SEK. Cardiovascular disease accounts for 8% of permanent and temporary disability pensions, placing it as the third most common disorder.

RIKS-HIA aims to support continuous quality improvement in the care of acute coronary heart disease at all participating units by providing continual information on care needs, treatment, and treatment outcomes. Long-term goals are to contribute toward reducing mortality and morbidity in patients and to increase the cost effectiveness of care.

Coverage and Volume

Hospitals participating in RIKS-HIA report on all patients that receive intensive care for acute coronary heart disease. In 2006, the registry included 72 of the 75 hospitals that provide intensive coronary care in Sweden. Hence, over 95% of these patients are included in the registry. In total, 58 410 admissions were registered in 2006.

Key Variables

RIKS-HIA registers 100 variables related to medical history, risk factors, clinical findings, interventions, investigations, complications, and outcomes. Drugs, care planning, and diagnosis at discharge are registered. The variables are the same throughout Europe. Readmissions and survival are followed up by linking and matching the data from other hospital registries. The SEPHIA Registry monitors secondary prevention.

Reporting Process

Data are registered directly online via RIKS-HIA's web-based program that meets all standards for Internet data security. Hospitals with electronic patient records have the option to export their data to RIKS-HIA.

Feedback Process

All RIKS-HIA users can retrieve advanced analyses or use on-line, pre-programmed analytical packages. Furthermore, every second month, a quality report is sent via e-mail to several people involved in the registry at each participating hospital. This report compares the hospital's compliance with the national guidelines to the 20 best hospitals in Sweden. A transparent annual report covering all participating departments includes comments from registry managers concerning the findings. The annual report is distributed in print and is available in pdf format via the website.

Quality Improvement

RIKS-HIA has identified regional variations in intensive coronary care and contributes toward reducing these differences. Shortcomings such as delay time have been addressed, and corrective actions are being taken. RIKS-HIA contains quality modules that analyze the extent to which units treat patients in accordance with national clinical guidelines and the status of the individual patient. The modules contribute significantly toward improving intensive coronary care in Sweden. The registry has also been used to assess different treatment strategies. Through scientific reports published in international journals, the registry has helped improve coronary care worldwide. Improvement is reflected by trends toward lower complication and morbidity rates and shorter lengths of stay.

National Registry on Out-of-Hospital Cardiac Arrest

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Year started	1990
Public funding	1993-2007
Governing body	Västra Götaland Region
Competence center	-
Transparency, unit level	No

Background and Aim

The registry identifies factors relative to out-of-hospital cardiac arrest, mainly where cardiopulmonary resuscitation (CPR) has been started either by responders who intervene before the ambulance arrives or by ambulance staff. One aim is to study the factors important to survival and how these factors, and survival itself, change over time. Another important aim is to share experiences among all of the ambulance organizations in Sweden.

Coverage and Volume

Approximately 70% of the ambulance organizations in Sweden participate in the registry. It is estimated that missing cases vary from 0% to 30% at the different centers. Annual volumes vary between 2000 to 3000 cases per year. The registry contains over 50 000 cases and, along with the Scottish Cardiac Arrest Registry, is the largest in the world.

Key Variables

1. Patient characteristics: age, sex.
2. Conditions related to onset: whether cardiac arrest was witnessed, location of cardiac arrest, cause, and rhythm when ambulance staff intervened.
3. Treatment aspects: if anyone had started CPR prior to ambulance arrival, and if so, when and who; defibrillation, drugs, intubation, and number of shocks delivered.
4. Time lapse between cardiac arrest and alarm call, time from alarm to ambulance arrival, and time from alarm to defibrillation.
5. Number of patients that regained pulse rhythm, had pulse rhythm on arrival to the hospital, and were alive after 1 month.

Reporting Process

Reporting takes place via on-line entry and via text files, which often involves using an export function from an existing patient record system. Programmers handle the data. We hope to be using a web-based register within 1 year.

Feedback Process

Feedback takes place via an annual report that provides an overview of nationwide outcomes in terms of distribution, mean values, and trends. Centers receive their own results, which can be compared to the national average and to previous results.

Quality Improvement

An increasing percentage of patients are receiving cardiopulmonary resuscitation prior to arrival of an ambulance (a reflection of the mass education on CPR in society) and delivery of drugs. The percentage of patients admitted alive to hospitals has increased from 15.3% in 1992 to 21.7% in 2005. At the same time, the percentage of patients alive 1 month after cardiac arrest has increased from 4.8% in 1992 to 7.3% in 2005. One reason for the increase in survival is probably the increasing percentage of cardiac arrest patients who receive life-saving intervention prior to ambulance arrival. This percentage has increased from 31% in 1992 to 49% in 2005. These results are impressive, given the fact that patients are older and the percentage of arrhythmias that can be defibrillated on ambulance arrival has decreased. We believe that the feedback achieved through this National Quality Registry is a contributing factor to the improved survival rate after out-of-hospital cardiac arrest.

Riks-Stroke – National Quality Register for Stroke

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Website	www.riks-stroke.org
Year started	1994
Public funding	1992 - 2007
Governing body	Västerbotten County Council
Competence center	-
Transparency, unit level	Yes, since 2003

Background and Aim

Stroke is one of the major health problems in Sweden, annually affecting about 30 000 people, 20 000 for the first time. The numbers in Sweden are expected to increase substantially as the percentage of elderly increases. Stroke is the disorder that accounts for most patient days in hospitals and institutions, and is the third most common cause of death. Costs for stroke are estimated to reach 14 billion Swedish kronor annually. The registry aims to contribute toward providing high-quality, equitable stroke care throughout Sweden. Riks-Stroke is a tool for continuous quality improvement in hospitals and an instrument by which the National Board of Health and Welfare can monitor national guidelines for stroke services.

Coverage and Volume

The number of reported admissions has more than doubled since the start of the registry in 1994. During 2006, there were 24 633 admissions from 80 hospitals, corresponding to an estimated coverage exceeding 90%. The database currently contains approximately 247 472 admissions (2006). All hospitals that care for stroke patients in the acute phase participate in Riks-Stroke, but the level of coverage varies among hospitals. In recent years, 3-month followup has been carried out for nearly 90% of the admissions reported, which gives a profile on the course of stroke with the possibility to assess the outcome of care. The level of coverage has been calculated epidemiologically, showing an estimated incidence of 250 to 300 stroke cases per 100 000 population. Coverage has also been estimated by matching the figures with inpatient registries (PAR). Studies found the data quality to be good.

Key Variables

Registered variables include the acute onset and a followup 3 months after onset. The variables were chosen to reflect structure, process, and outcome. The data include patient experiences, and represent most areas of quality. The variables have been expanded in the past years to more fully reflect medical practice. Hence, the registry can serve as a followup instrument for the National Board of Health and Welfare's national stroke guidelines.

Reporting Process

Data are reported via the Internet.

Feedback Process

Participating units have online access to their own data. Using statistical modules and a graphic model, hospitals may continually compare their own data against national data. A national compilation of the data, with comments on each participating unit, is prepared annually as is an analytical report that is sent to the unit directors and contact persons and placed on the website. Teaching seminars for contact persons were conducted throughout Sweden during 2003 and 2004. Teaching seminars have begun and are planned for 2007 and 2008.

Quality Improvement

Interest in stroke care has increased dramatically in recent decades. Riks-Stroke has contributed this trend by reporting on stroke care and by data processing and feedback related to process and outcome measures. By continuous communication with stroke caregivers, Riks-Stroke has been a catalyst in this positive trend. Examples of improvement include: over 80% of stroke patients receive care at a stroke unit, 98% of stroke patients in Sweden receive computed tomography, and over 90% receive some type of antithrombotic therapy on discharge.

Swedvasc –Vascular Registry in Sweden

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Year started	1987
Public funding	1990-2007
Governing body	Örebro County Council
Competence center	UCR
Transparency, unit level	Yes, since 2004

Background and Aim

Peripheral vascular surgery addresses diseases and injuries of the arteries and veins, except in the heart and brain. Approximately 40% of the interventions involve catheter-borne procedures while remainder involve open surgery. The most important areas include interventions for stenosis of the carotid arteries, rupture of the aorta, and circulatory disorders in the legs. In addition to serving these patient groups, surgical services are used rather extensively by dialysis units.

Registration of these procedures aims at measuring outcomes to improve care and serve as a base for research.

Coverage and Volume

Around 35 hospitals in Sweden perform just over 10 000 vascular procedures annually, according to the acute care register of the National Board of Health and Welfare. Swedvasc registers approximately 95% of these interventions.

Key Variables

The registry includes the reason for intervention, risk factors, care level prior to intervention, surgical anatomy, type of surgery, type of graft, and manufacturer.

Registered at followup 30 days after the procedure are: function in the reconstruction, whether improvement or deterioration has occurred, the level of care, and complications.

Registered at followup one year after the procedure are: function in the reconstruction, care level, graft infection, date of reoperation, and date of amputation.

A new version of the registry with more diagnostic- and intervention-specific variables is being developed.

Reporting Process

Since 2003, data have been reported directly via the Internet. Staff members fill in the information prior to the procedure, after the procedure, and 30 days and one year after the procedure. Vascular surgeons usually fill in the form, but at some hospitals specially trained nurses perform this task.

Feedback Process

Locally authorized personnel have online access to the Web registry where they can find analyses of results and national comparisons. Unit staff may download their own data for local review and analysis. An annual report is released in May.

Participating surgeons may apply to the steering committee for access to more data that can be used in research or special analyses.

Quality Improvement

High mortality has been reported for interventions against acute circulatory disorders in the arms and legs. We have been able to document a shift in practice toward an increasing share of catheter-borne methods, which has led to declining mortality. Local quality improvement efforts based on registry data have enabled several departments to sharply reduce waiting times for carotid stenosis surgery. Waiting times for surgery have a considerable impact on stroke. The registry revealed wide regional variations in access to stroke-preventing surgery. Feedback of this information to leaders in the region is expected to improve access to surgery regardless of where the patient lives. Also, the introduction of quality variables and threshold values has promoted greater centralization, with fewer complications as a result.

GUCH – Grown-Up Congenital Heart Disease Registry

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Year started	1998
Public funding	1998-2007
Governing body	Region Skåne
Competence center	UCR
Transparency, unit level	Yes, since 2005

Background and Aim

Because of the highly successful treatment of congenital heart disorders in children, most now survive to become adults. Hence, this group of patients is becoming larger. Although most feel healthy, the course is not necessarily without problems, and complications are common for some types of heart disorders. The registry aims to assure quality in care for adults with congenital heart problems, not least as regards new treatment methods, eg, catheter-borne therapies. The registry should provide feedback to pediatric cardiology/heart surgery through long-term followup. The registry also aims to describe patient groups that did not exist previously and should be able to identify groups at risk for future complications.

Coverage and Volume

The registry is limited to adult patients (older than 16 years) with congenital heart disease that is managed at one of the special units for adults (GUCH=Grown-Up Congenital Heart disease) located at 7 university hospitals in Sweden. The number registered exceeds 5500. Including all levels of severity, Sweden has an estimated 20 000 adults with congenital heart disease. The coverage level is high (nearly 100%) for complicated heart defects, simple heart defects with serious complications, catheter-borne treatment, and heart surgery, but lower for simple heart defects without complications. The integration of pediatric cardiology into the registry is under way and will increase the level of coverage even for simple heart defects.

Key Variables

The registry is longitudinal, ie, it follows patients throughout their lives, and therefore observes-changes over time. Included are vital status, functional status, quality of life (EQ-5D), basic social variables, results of different cardiology exami-

nations, pharmacotherapy, outcomes and complications of catheter-borne therapies, maternal complications in pregnancy, and the prevalence of congenital heart defects in offspring.

Reporting Process

Reporting is Web-based, and data are submitted either directly or on forms completed by physicians, nurses, or secretaries with registry training.

Feedback Process

Continually updated, predetermined analyses of local-unit and national level data are available on the Web. Participating units may choose to perform estimates and analyses based on their own data. National data concerning a particular issue can be obtained on request. National data are also presented in annual reports, which have been published since 1999. A steering committee determines content and design.

Quality Improvement

Deficient measurement of blood pressure in the arm and leg was shown following surgery for stenosis in the aorta (coarctatio aortae). This led to more stringent routines (from 2005 to 2006 the best center increased from 66% to 81% and the worst from 0% to 11%). Undertreatment of elevated blood pressure was identified, but it is too early to tell whether the situation has improved. Registry data have highlighted the prognostic importance of an ECG variable (QRS duration) in relation to severe rhythm disorders following surgery for Fallot defect. Catheter-borne therapy and heart surgery have been analyzed and show very good treatment results and a low incidence of complications, ie, quality is good. Registry data reflect collective experience and has had direct clinical value in managing uncommon types of heart defects.

SEPHIA – Registry on Secondary Prevention in Cardiac Intensive Care

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<i>Year started</i>	<i>2004</i>
<i>Public funding</i>	<i>2004-2007</i>
<i>Governing body</i>	<i>Uppsala County Council</i>
<i>Competence center</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>Yes, since 2006</i>

Background and Aim

Emergency treatment of myocardial infarction has improved dramatically during the past decade and has resulted in reducing 30-day mortality by approximately 30%. Nevertheless, long-term survival among those who survived the first month has not changed substantially. Interventions to lower the risk for reinfarction are of utmost importance. Scientific studies and national and international guidelines are well established and address interventions in secondary prevention that reduce the risk for reinfarction and death and improve quality of life. The long-term challenge is to successfully introduce and maintain risk-reducing interventions that are adapted to, and accepted by, patients and that are supported throughout the continuum of care. The registry aims to provide strong support for the local and national assessment and development of interventions for secondary prevention after myocardial infarction.

Coverage and Volume

Currently, 64% of hospitals that admit emergent heart patients participate. During 2006, the registry recorded 3025 patients at the first followup after 6 to 10 weeks and 2737 patients at the second followup after 12 to 14 months.

Key Variables

Variables include: health-related quality of life (EQ-5D), heart symptoms (angina and respiratory distress), employment (including sick leave), readmissions (due to heart disease, stroke, or hemorrhage complications), risk factors (smoking, physical activity, weight), secondary prevention activity (eg, heart school, cooking, exercise, stress management, smoking cessation), medications, and measurement of blood pressure, blood lipids, p-glucose, HbA1c, and cardiac rhythm (ECG).

Reporting Process

Data on all patients under 75 years of age are registered directly during a visit to a physician or coronary care nurse at 6 to 10 weeks and 12 to 14 months, respectively, after myocardial infarction. Data can also be obtained via telephone interviews at corresponding times. Data are entered in the registry online. The registry is linked to RIKS-HIA, which means that patients discharged with a diagnosis of acute myocardial infarction, are placed automatically in SEPHIA for followup at both times.

Feedback Process

Interactive reports are accessible via the Internet for all users. The data are presented in graphs and tables by hospital and for the nation. Reporting functions are continually expanding. Data from the respective hospitals can be exported in Excel format for analysis in the local statistical programs. Furthermore, hospital-level results are presented in an annual report.

Quality Improvement

During 2006, a project (QUICC-2nd) started at 12 hospitals throughout Sweden and will continue for 3 years. Using systematic quality improvement (breakthrough methodology) supported by SEPHIA, the project focuses mainly on substantially increasing the percentage of patients that achieve secondary prevention goals in smoking cessation, physical activity, pharmacotherapy with ACE inhibitors/ARB, systolic blood pressure level, cholesterol level, and return to work. Initial findings are encouraging. SEPHIA will also provide important support to a national project (SOFT) that started in 2007. SOFT aims to improve individual patient education and motivation to comply with necessary lifestyle changes. Furthermore, many local initiatives use SEPIA in their efforts to improve secondary prevention services.

National Catheter Ablation Registry

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Year started	2004
Public funding	2004-2007
Governing body	Östergötland County Council
Competence center	UCR
Transparency, unit level	No

Background and Aim

Catheter ablation was introduced in Sweden in May 1991. The method is intended to diagnose and treat several types of arrhythmias by using electrode catheters inserted via blood vessels in the groin. Initially, this method was used on a small scale, mainly in treating patients with two diagnoses: (1) WPW syndrome, where an extra conduction pathway exists between the atria and ventricles of the heart, and (2) AV nodal reentrant tachycardia, which is the most common form of rapid, regular heart rate. With time, more arrhythmia types were identified for curative treatment through catheter ablation, eg, focal atrial tachycardia, atrial flutter, and relatively recently ventricular tachycardia and atrial fibrillation.

The registry aims to be a tool for quality improvement in a rapidly expanding field. Indications have been established for some types of arrhythmias, but indications are less well-established for others.

Catheter ablation of atrial fibrillation has been performed since 2001, and the number of procedures has increased strongly, mainly during the past 2 years. Special focus is directed at this type of arrhythmia diagnosis.

The registry developed in 2004 and presented its first annual report in 2005. Feedback to participating units, through collaboration with UCR, started in the autumn of 2005. The system was tested in spring 2007.

Coverage and Volume

All units report to the registry, and all catheter ablations are registered. The level of coverage at followup after 6 to 12 months remains unconfirmed.

Key Variables

Important variables include demographic data, symptoms caused by heart arrhythmias, and important quality parameters in technical data related to treatment, eg, procedure time, transillumination time, and estimated radiation dose to the patient. Procedure-related complications are reported. Followup data on delayed onset of complications and the final outcomes of treatment are also registered.

Reporting Process

Five centers report procedure-related data, directly in conjunction with the procedure itself, via secure transmission to a database physically located at Linköping University Hospital. Other units report to the same database, eg, weekly. Followup data at 6 to 12 months after the procedure are reported in the same way, with questionnaires mailed to patients when followup data are missing.

Feedback Process

Data are compiled at Linköping University Hospital and analyzed in collaboration with UCR in Uppsala. Quality parameters, eg, complications, procedure time, radiation exposure time, estimated radiation dose, and the percent of patients followed up, will be fed back to the participating units and presented in relation to the national average.

Quality Improvement

The registry is still being developed. The earliest opportunity to observe improvement will coincide with the annual report for 2006, when the trends for some of the participating centers can be assessed using several quality parameters. The long-term potential for improving the quality of catheter ablation services is good, and the potential value of direct feedback is considerable.

AuriculA – National Registry of Atrial Fibrillation and Anticoagulation

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<i>Year started</i>	<i>2007</i>
<i>Public funding</i>	
<i>Governing body</i>	<i>Stockholm County Council</i>
<i>Competence centre</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>Yes, since 2007</i>

Background and Aim

In Sweden, atrial fibrillation (AF) is the most common type of arrhythmia and is found in about 150 000 people. Currently about 2 million PT/INR tests are used as a base for as many warfarin prescriptions per year, whereof 1 – 1.5 million are intended to prevent stroke in this patient group. New treatment methods for AF are accompanied by the need for followup and assessment. The risks associated with anticoagulants create a need to simplify and structure routines.

AuriculA offers a simple solution to both needs. The quality of treatment in patients with atrial fibrillation can be improved, and warfarin dosing can be simplified while safety is improved through process support.

Coverage and Volume

The target group is comprised of patients with atrial fibrillation and those on warfarin treatment regardless of indication. Approximately 2600 patients are currently registered, and approximately 30 000 doses of warfarin have been delivered. Around 10 units are currently in operation. The goal is for AuriculA to become a nationwide registry.

Key Variables

The most important variables in AF are: type of fibrillation, demographic data, stroke risk factors, medications, interventions, and cardiovascular events. Key variables regarding dosing support are: demographic data, observations (details about patients and their disease), relevant medications, PT results, indications for treatment period, and registration of complications including severe hemorrhaging and mortality related to warfarin.

Reporting Process

Reporting is Web-based and direct. Regarding AF, information can be entered on a form and registered later. It is also possible to export data to the register.

Feedback Process

Individual hospitals and community health centers or units can access information online, eg, regarding diagnostics, pharmacotherapy, or data for comparing with the national average.

Daily work routines are supported through time savings and quality assurance. The registry will contain an internal quality system to assure quality of the data collected and simultaneously enable direct feedback on site.

Once per year a more comprehensive statistical analysis will be reported to all participating hospitals, community health centers, and/or units.

Quality Improvement

AuriculA is in a development phase, following a pilot phase in 2006, and the system is being marketed to several county councils.

Preliminary data on the AF aspect of the study suggest that warfarin treatment continues to be underutilized among elderly and women having multiple risk factors for stroke.

Dosing support will markedly influence the way in which warfarin treatment is delivered by relieving some burden on the units that fully use the system.

The goal is for the registry to contribute key data about trends in services and health care, and to assure quality in routines involving anticoagulants.

NDR – National Diabetes Registry

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Website	www.ndr.nu
Year started	1996
Public funding	1996-2007
Governing body	Västra Götaland Region
Competence center	-
Transparency, unit level	At hospital and county council levels, and community health centers on request

Background and Aim

Diabetes is a disease that is reaching nearly epidemic proportions in the world. Already, diabetes care is estimated to consume approximately 10% of all healthcare expenditures. Good diabetes care is cost effective and helps prevent long-term development of complications. NDR was formed in 1996 and is used to compare the outcomes of a unit with the national average, and to measure goal achievement in relation to national guidelines.

Coverage and Volume

In Sweden, an estimated 350 000 to 400 000 individuals have diabetes. In 2006, the diabetes registry included 156 000 patients, ie, approximately 45% of all diabetes patients in Sweden. All county councils report to the registry. Data are registered from about 95% of all departments of medicine and about 75% of all primary care centers.

Key Variables

In addition to registration date, caregiver code, and personal identification number, the registry includes year of onset, diabetes type, diabetes treatment, body weight, height, abdominal circumference, HbA1c, blood lipids and blood pressure, s-creatinine, physical activity, and yes/no questions on: blood pressure lipid reduction and ASA treatment, micro- and macroalbuminuria, eye fundus examination, retinopathy, smoking, and prevalence of stroke, myocardial infarction, foot examination, or amputation.

Reporting Process

Since 2002, registration has been electronic via the website, and takes place at least once per year per patient. Regarding registration, 70% takes place online, 15% are placed on the Web via mailed files, and 17% are directly transmitted from electronic patient record systems.

Feedback Process

Via the Web, all caregivers have immediate access to their own results and comparative national statistics. Hence, individual caregivers can quickly and easily register their own patient data, and analyses can be performed that generate extensive statistics based on the individual unit's data. Annual reports show outcomes as cross-sectional analyses transparently on the registry's website.

Quality Improvement

The Departments of Medicine and the primary care centers in Sweden have improved quality of diabetes care in terms of target values for different risk factors since 1996. There has been a continuing rise in the use of lipid reducing drugs and acetylsalicylic acid, particularly for heart disease. However, differences remain among hospitals and among primary care in different county councils.

For the second year, NDR presents a quality index, county council score, based on national guidelines for diabetes care. This index shows which county councils have the highest quality of care and which county councils have a higher level of reporting to NDR. Based on the index, the 3 county councils rated highest this year are Östergötland, Västerbotten, and Kronoberg. The transparent and published annual report should contribute to ongoing quality improvement in diabetes care.

In 2003, NDR was invited to collaborate with SALAR and Qulturum in Jönköping to conduct a project on quality improvement in diabetes care, NDR-IQ. The project included an educational phase and a followup phase of 6 and 12 months respectively. The improvement results in many cases are striking. The new NDR-IQ project is scheduled to start in the autumn/winter of 2007-2008.

Scandinavian Quality Register for Thyroid and Parathyroid Surgery

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Year started	2004
Public funding	2004-2007
Governing body	Region Skåne
Competence center	-
Transparency, unit level	No, planned within 2 years

Background and Aim

The departments of surgery at all university and county hospitals in Sweden offer thyroid and parathyroid surgery (surgery for diseases in the thyroid and parathyroid glands). Surgery departments/units at county district hospitals and several ear nose and throat (ENT) units also offer thyroid surgery. An estimated 2500 thyroid interventions and about 1300 interventions for parathyroid disease are performed annually in Sweden. The registry aims to improve the quality of diagnosis, surgery, and followup in thyroid and parathyroid surgery.

The registry receives support from the Swedish Association of Endocrine Surgeons and the Swedish Association of Otorhinolaryngology (Head and Neck Surgery).

Coverage and Volume

In 2005, the registry included 39% of the surgical units and 66% of the procedures. During 2006, additional units were added. Currently (June 2007), 25 departments of surgery and ENT participate in the register. Eight Danish departments also use the same platform.

Key Variables

The registry includes information specific to the units, eg, routines, staff, surgical skills, and ancillary resources. It also includes patient, eg, age, sex, and disease. Other data registered include preoperative studies, type of intervention, histological diagnosis, type of followup, peri- and postoperative complications, and cured disease.

Reporting Process

The quality registry is an Internet-based database, with a local, hospital-based, Web-server that manages patients' personal data. Participating units

register the data continually throughout the year. Schematically, the data are registered in two blocks: Block I includes baseline data, preoperative data, surgical and short-term followup (less than 6 weeks). Block II includes long-term followup (6 to 12 months postoperatively). All patients with post-surgical complications should be followed up after 6 months. Also, all patients receiving surgery for parathyroid disease should be followed up after 6 months due to the potential for relapse.

Feedback Process

The registry issues several standard reports, in text and graphic form. Users have online access to the reports, allowing them to see their own data and aggregate data for all participating units. Users can also export their data in Excel format for further statistical analysis as needed. Datascript is programmed for annual uni- and multivariate analysis of selected key variables. The results are disseminated via the website. A steering committee selected by the users directs the registry. The user group meets once per year. In conjunction with this meeting, further data analyses are presented. The date and time of the user meeting, information from the steering committee, and other news are communicated via the registry's website.

Quality Improvement

The registry reveals the effects/risks of treatment methods at a national level, which have not been possible to observe at the unit level. Examples include the increased risk for complications such as re-bleeding after goiter surgery, which clearly is related to higher age, and the increased risk for infection that is observed following surgery for certain types of thyroid cancer. This type of knowledge can then be fed back to local units for preventive actions.

SOReg – Swedish Obesity Surgery Registry

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Year started	2005
Public funding	2005-2007
Governing body	Örebro County Council
Competence center	-
Transparency, unit level	Planned for 2008

Background and Aim

Obesity surgery is the most rapidly growing area in gastrointestinal surgery. During the 1990s, the Swedish Obese Subjects study reported on quality and outcomes of Swedish obesity surgery. Most departments that offered this type of surgery participated. A registry promotes improvement of results and quality. The specialty can assess whether the results of a new method, eg, laparoscopic techniques, or changes in indications, correspond to the results achieved when the changes were tested in a research context. Since obesity surgery is also growing rapidly internationally, the registry is Nordic with plans to affiliate with Norway, Iceland, and Denmark.

Reporting of data to SOReg began in May 2007 in Sweden. Norway and Iceland are next in line.

A steering committee appointed by the Swedish Association for Upper Abdominal Surgery within the Swedish Surgical Society is taking the lead to develop the registry.

Coverage and Volume

Approximately 1500 operations annually are being provided at over 30 units in Sweden. By May 2007, agreements had been reached with virtually all departments that perform obesity surgery. Norway does not permit obesity surgery to be performed at units that are not affiliated with a quality registry.

Key Variables

The registry monitors outcomes, primarily weight change, that are closely linked with effects of obesity comorbidities, and quality of life measured by SF-36 and OP-9 forms. Data on indications and technical aspects of surgery are reported in con-

junction with the operation. Early postoperative complications are registered 6 weeks postoperatively. Weight loss, complications, reoperation, and quality of life are measured 1, 2, and 5 years postoperatively. Each participating unit can also enter data from additional followups.

Reporting Process

Reporting takes place via the Web. The quality of life forms are scanned centrally.

Feedback Process

An annual report will provide feedback. Furthermore, registry meetings will be held and data will be discussed in conjunction with the annual "Surgery Week" in August. Outcomes will also be regularly placed on the website. (An open-access website is being constructed).

Each department may obtain their own current results at any time through automated standard reports and statistical functions. These results are compared to the results in the entire registry.

Quality Improvement

This cannot yet be determined since data have been entered in the register only since May 2007. However, affiliation with the registry has already led to a discussion about optimum lead-time registration and learning processes in the transition to laparoscopic surgery.

Swedish Hernia Registry

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Year started	1992
Public funding	1992-2007
Governing body	Jämtland County Council
Competence center	-
Transparency, unit level	Yes, since 2006 (including county council level)

Background and Aim

Surgery for inguinal hernia is the most common procedure in general surgery, with nearly 20 000 procedures annually. A successful operation is an uncomplicated intervention that requires approximately one week of sick leave, followed by alleviation of the problem. However, it can also lead to recurrence of hernia, severe chronic pain, and in rare cases mortality. Previously, relapse affected around 20% of all patients receiving surgery. Modern methods and material have substantially reduced the relapse rate. Epidemiological studies, eg, based in part on the Swedish Hernia Registry, have shown that several percent of all surgeries 1 to 2 years postoperatively report severe or moderately severe pain that limits the quality of life. Quality assurance of inguinal hernia surgery is therefore of considerable medical and economic importance, particularly since hernia surgery is often performed by surgeons at an early stage of education.

Coverage and Volume

The registry started in 1992, initially with 8 departments of surgery, and has continuously expanded to include 96 departments. Hence, nearly 100% of all hernia surgery is included. A database has been created with detailed information on over 150 000 registered operations.

Key Variables

For every hernia surgery, 38 different quality variables are registered. These include; waiting time, percentage of acute operations, ASA, BMI, surgical methods, anesthesia method, surgical material, surgical time, antibiotics, percent of re-operations, peri- and postoperative complications, percentage of day surgery, chronic pain, mortality, etc. The most important outcome variables are re-

operation rates due to relapse, severe pain, and infection. Also, surgical methods, material, surgeons, and choice of anesthesia are studied in relation to outcomes in terms of complications, relapse, and chronic pain.

Reporting Process

Data are reported to the registry continually throughout the year, 30 days after the registered operation. Data input and control for all participating units is Web-based. The surgical units and surgeons have immediate access to information on their own performance. Major emphasis is placed on entering complete and accurate data in the registry.

Feedback Process

Feedback to participating units takes place during April and May the following year via annual reports and department/unit reports (accessible only to the respective units). Also, a website is open to the public where results from the respective participating units and county councils can be compared.

Quality Improvement

Comparing the reoperation incidence in hospitals that have participated in the registry for 3 years or longer versus hospitals that have recently joined shows that the former group improved their results more quickly than the latter group. The percentage of operations for relapse continues to decline slowly. In 2006, relapse accounted for 10% for all surgeries compared to approximately 17% a decade earlier. Participating units receive the results and adapt surgical methods, material, etc. Monitoring the data over time shows that the method with the best results is now used in 75% of the operations, in contrast to only a few percent a decade ago.

GallRiks – Swedish Quality Registry on Gallstone Surgery

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Year started	2004
Public funding	2004-2007
Governing body	Jönköping County Council
Competence center	UCR
Transparency, unit level	Yes, to some extent in the 2006 annual report, but increasing thereafter

Background and Aim

Gallstones are a common disorder in Sweden, and the gallbladder is removed in more than 12 000 patients annually due to gallstone problems. Treatment for stones in bile duct is also common, and approximately 6000 endoscopic examinations of the bile duct are performed annually. In gallbladder surgery and endoscopic treatment for stones in the bile duct, 5% to 10% of the cases face a risk for some type of postoperative complication. Serious problems related to biliary surgery that damages the bile duct, or causes death, affects 0.5% to 1% of the cases. However, nearly 80% of the patients are relieved of the problems that surgery that was intended to cure. GallRiks aims to assure optimal quality in this high-volume service in Sweden.

Coverage and Volume

GallRiks started on May 1, 2005 and continues to grow. By the end of 2006, over 85% of the hospitals treating gallstones in Sweden (51 hospitals) participated. During 2006, GallRiks registered 7340 biliary surgeries and 4006 endoscopic examinations of the bile duct. This corresponds to approximately 55% of all biliary surgeries and between 50% and 90% of all endoscopic examinations performed in Sweden in 2006.

Key Variables

The registry collects information on surgical interventions and the postoperative course for all patients. For patients with stones in the gall bladder, where surgery is being considered, quality of life is measured with SF36 before and after surgery.

Reporting Process

The registry is Web-based and data are reported in conjunction with intervention or examination of the patient. Patient questionnaires are answered on paper and registered by a local coordinator who also registers followup variables at 30 days and at 6 to 9 months postoperatively, upon automatic notification from the registry.

Feedback Process

Participating units receive automatic, standardized online reports of their own data and national data for comparison. In the same way, individual surgeons receive their own data and the unit's combined data for comparison. Annual reports are public information and published on the registry website and in a Swedish journal of surgery (Svensk Kirurgi). A national annual conference for users is held in March to present the previous year's results and analyses.

Quality Improvement

The first annual report from GallRiks (2006) showed that the units vary widely (0% to 100%) in providing antibiotics to prevent postoperative infection in elective biliary surgery. In comparing units with high versus low use of preventive antibiotics, no association was found between use rates and postoperative infection rates. Hence, antibiotics for preventive purposes should be avoided in elective biliary surgery.

Swedish Quality Registry for Ventral Hernia

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Year started	2007
Public funding	2007
Governing body	<i>Region Skåne</i>
Competence Center	NKO
Transparency, unit level	<i>Planned for 2009</i>

Background and Aim

Ventral hernia refers to a tear or bulge in the abdominal wall that allows abdominal organs to push through. Ventral hernias are divided into primary and incisional hernias. Primary hernias are most common, but often of lesser clinical value. The most common are navel hernias and epigastric hernias (above the navel). Incisional hernia appears following previous abdominal surgery where the incision site ruptures. This causes substantial trouble for the patient and expensive consequences for society when the patient cannot return to normal working life. Inguinal hernia is not usually included since it is anatomically and surgically distinct, requiring a special technique.

Swedish hospitals annually report approximately 3000 operations for anterior ventral hernias, which consume approximately 10 500 patient days. In addition, many primary minor hernias are treated by ambulatory surgery.

Since previous surgical methods have not been successful (with relapse rates as high as 80%), numerous techniques have developed. Mesh implantation is the foundation of modern treatment of incisional hernia, while the methods for other hernias vary widely.

Registration of the surgical methods used for different types of hernias and complications aim at supporting quality improvement both at the local and national levels. During the past decade, attention has been directed at the need for optimum treatment of the abdominal wall in abdominal surgery.

Long-term results provide insight on the optimum method for treating various types of hernia (tailored methods).

Coverage and Volume

The registry is in a start-up phase and has not yet formed affiliations with the surgical units. Interest within the profession is strong. Initial data collection at ten units began during 2007 to assess the practical aspects of collecting data prior to full-scale implementation.

Participation by all surgical units in Sweden is the goal.

Key Variables

At the national and local levels: patient structure, interventions related to hernia type, surgical method, mesh utilization, fixation method, pharmacological prophylaxis, etc.

Likewise, results can be assessed for: 3-month healing rate, reoperation rate, early and delayed complications, and frequency and outcome of emergent interventions.

The registry also intends to implement measure for quality of life.

Reporting Process

The intent is to register data over the Internet in a Web-based interface. Data can be collected using a questionnaire for reporting that should include 6-month postoperative followup.

Feedback Process

Aggregated information will be presented at different levels, nationally and at the unit level, and eventually at the regional level. Transparent reporting is being planned in the long term.

Quality Improvement

Recent studies conducted in Sweden indicate a major potential for improvement in abdominal wall surgery, particularly as regards incisional hernia surgery.

RIKSHÖFT – National Hip Fracture Registry

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<i>Year started</i>	<i>1988</i>
<i>Public funding</i>	<i>1990-2007</i>
<i>Governing body</i>	<i>Region Skåne</i>
<i>Competence center</i>	<i>NKO</i>
<i>Transparency, unit level</i>	<i>Yes, since 2005</i>

Background and Aim

Hip fractures, including rehabilitation, cost 1.5 billion SEK annually in Sweden. In people 50 years of age, the risk for hip fracture at some point during one's lifetime is 23% for women and 11% for men. The National Hip Fracture Registry aims to report and compare outcomes to achieve equitable, high-quality care in Sweden. Close collaboration among hospital services, primary care, and municipal nursing services expedites discharge to the home of these patients, who have traditionally experienced a long continuum of care that involves rehabilitation in institutions and convalescent homes.

Coverage and Volume

Nearly 50 hospitals in Sweden offer surgery for hip fracture. Of these units, 80% participate in the registry, and most of the others intend to start when the newly developed Web-reporting system is established. Approximately 18 000 hip fractures occur annually in Sweden according to estimates from the National Board of Health and Welfare's diagnosis registry. The number of patients has increased in pace with the aging population.

Key Variables

Variables include time from fracture to hospital arrival, time to surgery, fracture type related to surgical method, sex, age, living alone, disease grade based on ASA, and length of stay in relation to percentage of patients discharged to their residence before fracture. Other variables include walking ability and assistive devices on followup in relation to the patient's ability prior to fracture, pressure sores, etc. After 4 months, treatment outcomes are assessed in relation to how far the patient has advanced in the continuum of care and walking ability, assistive walking devices, reported hip pain, and quality of life based on EQ-5D. Surgical methods are continuously related to complications and reoperations. It is possible to include other questions.

One of these concerns quality indicators involving pressure sores reported on admission, during the care episode, and on discharge.

Reporting Process

Care staff, mainly nurses, enter information on a form. If needed, physicians are asked about surgical procedures and fracture type. Other parameters concern nursing services. Web-based reporting began in January 2005.

Feedback Process

The current reporting program allows participating units to perform calculations and develop diagrams from their own data. They have the possibility to access the data online for feedback of their own data compared to the national average and other appropriate comparative groups. Information is provided via annual reports to department heads and those responsible for the registry at the unit where the data are presented and analyzed. On request, departments receive special feedback of analyzed data.

Quality Improvement

The registry has contributed toward optimizing the care of hip fracture in Sweden, eg, by reducing length of stay and increasing discharge rates to original residence, which improves the effectiveness of acute care and reduces the use of rehabilitation resources. The registry is used in local healthcare quality improvement projects. For example, reporting of pressure sores has led to a reduction in this serious complication. The registry promotes choosing the optimum surgical methods. Interest in reporting on hip fractures is increasing internationally, and there is extensive international collaboration based on RIKSHÖFT.

Swedish National Hip Arthroplasty Register

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Year started	1979
Public funding	1991-2007
Governing body	Västra Götaland Region
Competence center	NKO
Transparency, unit level	Yes, since 1999

Background and Aim

The registry covers total hip arthroplasty and partial arthroplasty. Total hip arthroplasty involves replacing the entire joint with an artificial joint. In partial arthroplasty, only the upper portion of the femur is replaced since the socket is undamaged. A partial prosthesis is used only in certain cases to treat fractures of the femur neck. The registry aims to enhance knowledge, optimize the choice of surgical method and implant, and form the basis for continuous quality improvement.

Coverage and Volume

The register includes all units that perform total hip replacement, and all operations are registered. The number of arthroplasty operations is increasing. Approximately 14 000 first-time total arthroplasties and approximately 4000 partial arthroplasties are performed annually. The number of total arthroplasties corresponds to 120 operations per 100 000 inhabitants and year.

Key Variables

Patient demographics, implant type, and surgical method are reported for each primary operation. Personal ID number and side of implant are unique variables. Preoperatively, VAS is the instrument used to report on patient pain, and EQ-5D is used to self-rate health-related quality of life. Patients are followed up by surveys on pain relief, satisfaction, and EQ-5D, which enable an individualized cost-benefit analysis.

All reoperations are reported, and the results are presented with survival statistics. Failure is defined as the exchange or removal of all or part of the prosthesis. Outcome variables such as 2-, 5-, and 10-year survival rates are used as indicators of the unit's quality. The variables are related to patient factors to compensate for the patient's general health and the operation's level of difficulty.

Reporting Process

The registry became Web-based in 1999, and since that time data are reported via the registry's website. All participating units use Web applications in reporting. Copies of patient records from reoperations are sent to the registry regularly during the year and are necessary for analysis and further studies. Most departments use a touch screen linked to the registry's website to collect preoperative, patient-related variables such as EQ-5D. Surveys are used in followup.

Feedback Process

All publications and annual reports are presented via the registry's website. Furthermore, every annual report is printed and distributed to all units, the National Board of Health and Welfare, the Swedish Association of Local Authorities and Regions (SALAR), and to owner and purchaser organizations in health care. Annual reports are translated into English and published on the website.

Contact physicians from all participating units meet annually at a registry conference in Stockholm.

Quality Improvement

Annual feedback from the registry to participating units has led to continuous improvement in national long-term outcomes after hip replacement surgery. Sweden currently has the lowest reoperation rate in the world. Economic analysis comparing national revision rates and the cost for revision surgery shows that the registry has saved Swedish citizens between 1.5 billion and 1.8 billion SEK (in direct costs) in the past 15 years.

The main objective of the registry is to contribute toward continuous clinical quality improvement – the figures above clearly show that this objective has been achieved, resulting in a substantial savings for society and less suffering for patients.

Swedish Knee Arthroplasty Register

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Year started	1975
Public funding	1989-2007
Governing body	Region Skåne
Competence center	NKO
Transparency, unit level	Yes, since 2005

Background and Aim

In 1975, the Swedish Orthopaedic Association introduced a registry for artificial knees. The registry was started because this new type of surgery was disseminating rapidly across Sweden and involved a wide range of implants that were regularly changing. The literature did not provide adequate information, and orthopedic surgeons realized that it would be impossible for individual surgeons to select the most appropriate implant and surgical method based solely on their own experience. The aim was to collect, analyze, and feedback information that could warn about deficient methods and inappropriate implants, stimulate departments/units and surgeons to improve their routines, and report on regional differences in needs, treatment, etc.

Coverage and Volume

All departments/units (currently 78) that offer prosthetic knee interventions participate in the project. From the start, the number of surgeries reported annually has increased steadily. Only 1075 operations were reported in 1997, but by 2005 the figure had risen to 10 338. Validation of the registry shows that approximately 95% of all operations are reported.

Key Variables

To maximize coverage and complement reporting, only a minimum data set is collected in conjunction with the primary operation. It contains information on identity, age, basic disease, where the operation was performed, the implant, and cementing. Patients are followed up to identify unsuccessful procedures, ie, revisions. Additional information is acquired from questionnaires targeted to assess patient satisfaction and health.

Reporting Process

The knee registry recommends that reporting be done in the operating room on a special reporting form (A4 format) with space to attach special stickers (product number, etc) that accompany the prosthesis packages. Reports are sent regularly to the registry office at Lund University Hospital where final registration takes place. In cases of revision, the registry also requests copies of discharge notes and surgical reports. Since a functioning platform for computerized reading and control of prosthesis information is lacking, the registry does not yet enter data via the Internet.

Feedback Process

Users report to the registry in several ways; orally, on paper, and electronically. Recent information on volume and research results is disseminated at annual meetings with the contact physicians from participating units. Every unit receives its own data and can compare its results with the national average. Information from the registry is disseminated to the profession and other interested parties via annual reports and scientific articles, and through participation in national and international meetings. The registry often participates in the quality registry days sponsored by the National Board of Health and Welfare and the Federation of Swedish County Councils to inform administrators and decision makers about the registry.

Quality Improvement

The registry continually advises surgeons on implants, methods, and patient selection. Patients can be given more accurate information on what they can expect from surgery, why some methods are viewed to be appropriate, and if and when it is appropriate to operate. Decision makers are given information about treatment indications, patient benefits, and cost benefits of procedures, trends in treatment results, and future needs.

National Pain Rehabilitation Registry

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Year started	1998
Public funding	1997-2007
Governing body	Västerbotten County Council
Competence center	-
Transparency, unit level	Starting in 2007

Background and Aim

Long-term musculoskeletal pain causes suffering in many patients and limits their activities. Well-functioning, evidence based rehabilitation is needed for these conditions. Controlled studies show that cognitive-behavior-oriented interdisciplinary rehabilitation has a positive effect on function and activity, but return-to-work varies. Assessment is difficult due to patient heterogeneity. Since 1998, the National Pain Rehabilitation Registry, owned by the Swedish Association for Rehabilitation and Physical Medicine, has collected data for describing patients found to need pain rehabilitation. The aim of the registry is to enable comparison of patient groups at different rehabilitation units and the effectiveness of programs regarding changes in pain intensity, emotions, self-control, activities, and return to work.

Coverage and Volume

Long-term musculoskeletal pain is included under various syndrome descriptions and diagnoses.

The registry assesses and improves quality of rehabilitation services that cover patients with complex functional limitations that provide coordinated multidimensional rehabilitation. The registry covers an estimated 80% of the rehabilitation departments/units in Sweden. In 2006 the database increased by 2651 patients and now includes 17 171 patients.

Key Variables

Standardized forms cover demographic data, educational level, work status and belief in the future, psychometrics (MPI, HAD), pain intensity (VAS), activity (DRI), and life satisfaction (LiSat-II). The data on sickness absence is obtained from the Swedish Social Service Administration's central database before, and 1 and 2 years after rehabilitation.

Reporting Process

Questionnaire responses are entered in the local databases at the units. A special computer program processes the data immediately, and the results are presented in a self-rating profile. The profile also includes outcome-related reference and probability values. Followup data are compiled on conclusion of rehabilitation and again 1 year later. The data are reported to the registry once per year for analysis of the results.

Feedback Process

Several times per year, registry data are fed back electronically as tables and graphs to the units. Representatives from the units meet regularly to interpret and compare results, exchange experiences, and to discuss quality improvement in pain rehabilitation and further development of registry functions.

Quality Improvement

Introduction of a self-rating profile to support team evaluation has received a positive response by the participating units and has probably contributed to the low data dropout rate. The structure and quality of the investigative methods used for evaluation have improved.

National results from the registry, and results from local analysis of the data, are used in assessment and development at the units, leading to improved quality in rehabilitation of patients with long-term musculoskeletal pain.

Swedish Rheumatoid Arthritis Registry

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Year started	1996
Public funding	1997-2007
Governing body	Stockholm County Council
Competence center	-
Transparency, unit level	Yes, since 2004

Background and Aim

Inflammatory joint diseases, mainly rheumatoid arthritis (RA), cost 3 billion Swedish kronor (SEK) per year. Since curative treatment is not available, continuous monitoring of care is required for quality assurance. The RA registry aims to improve the health of everyone with rheumatoid arthritis in Sweden through continuous feedback of treatment results to patients and caregivers directly during the visit.

Coverage and Volume

The RA registry has national coverage since all rheumatology departments in every county council, as well as private practitioners, participate. The registry monitors just over 20 000 chronically ill patients, with 100 000 quality assured visits. The level of coverage is increasing about 35% per year, and in 2007 the registry contained more than half of all RA patients in Sweden.

Key Variables

Inclusion data cover disease onset, diagnostic criteria, and previous treatment with cortisone and antirheumatics. The following are registered at every visit: pain, (VAS scale), disease sensation (VAS), functional impairment (HAQ), work capacity, swollen and tender joints, SR, CRP, physician's activity assessment, and prescription drugs. Biological drugs and their side effects are given particular attention in followup.

Reporting Process

Internet services can be used by the patient and physician for proactive decision support during the visit. At many units, also during the visit, patients themselves register their pain, disease sensation, daily functional impairments, and swollen and ten-

der joints. Later during the visit, physicians make their own assessment of the joints and disease activity and print out an individualized overview for the patient. Some units collect data by having the patient and the physician complete forms during the visit and then submit the data to the registry. Side effects from new biological drugs are reported to the registry via the Internet and then forwarded directly to the Swedish Medical Products Agency.

Feedback Process

In addition to the immediate feedback during the visit, all registered users have access to an Internet service that makes the data available directly after entry. Diagrams are updated every night, showing information about patient groups, eg, each physician's or unit's patient group, and diagrams comparing the county, region, and nation. The registry also has a report generator that can search and deliver the compiled data requested. Feedback is an important aspect of the clinical improvement process nationally, regionally, and locally.

Quality Improvement

A basic assumption of the RA registry is that the clinical improvement process is most effective at the point of care (ie, in the interaction between patient and caregiver). This is facilitated by using the RA register online at increasingly more visits (4417 visits during 2006). Already during the first visit, when patients receive their diagnosis, 90% of the patients are treated according to the guidelines. Ongoing followup of the disease course in every patient has led to better results each year since the registry started. The RA registry has played an important role in nationwide dissemination of the new biological therapies developed in rheumatology, enabling these agents to be used quickly, efficiently, and equitably throughout the country.

Followup in Back Surgery

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<i>Year started</i>	<i>1992</i>
<i>Public funding</i>	<i>1992-1999, 2001-2007</i>
<i>Governing body</i>	<i>Jönköping County Council</i>
<i>Competence center</i>	<i>NKO</i>
<i>Transparency, unit level</i>	<i>Yes, since 2006 for production data and accessibility, but not transparent for outcome variables</i>

Background and Aim

In recent decades, surgical treatment of lower back disorders has increased markedly. This is attributed to the availability of improved diagnostic techniques (eg, CT and MRI), improved surgical options, and possibly to expanding indications. Consensus has not been reached on indications and assessment of results. The registry aims to assess the indications for, and the outcomes of, surgical intervention for degenerative lower back diseases, with emphasis on changing indications, the health effects of new surgical methods, and the registration of complications.

Coverage and Volume

The registry includes approximately 85% of the patients receiving surgery for degenerative lower back disorders in Sweden (herniated disc, central and lateral spinal stenosis, spondylolisthesis, and segmental pain). Around 45 units in Sweden offer back surgery, whereof around 40 participate in the registry. Participation has been increasing since 1998. Starting in 2007, the registry includes cervical, thoracic, and lumbar operations and also fractures, tumors, infections, and deformities.

Key Variables

Preoperative data: demographics, pain duration, analgesic consumption, walking distance, and walking ability. Pain is rated according to the VAS scale for back and leg pain, SF 36, EuroQol, and the Oswestry back function score. Perioperative data: Length of stay, diagnosis for surgery, interventions performed, complications, and reoperation. Postoperative data: Followup after 1, 2, 5, and 10 years including the same data as preoperative and self-rated patient experience of surgical outcomes and general satisfaction. There are disease-specific parameters for the new diagnostic entities mentioned above.

Reporting Process

Since 2003, data are collected regularly via the Web.

Feedback Process

An annual report is sent to all registered units, and an oral presentation is given to members of the Swedish Society of Spinal Surgeons at their annual meeting. Data on outcomes at the individual units are compiled and fed back. In the Web version, the units have continuous access to their results and can compare these with national aggregate data. A supplement to Acta Orthopædica describing a large body of registry data was published in 2005 (2005;76:1-24).

Quality Improvement

The back registry aims to influence practice mainly through good examples. It documents that indications are correct and that patients who receive surgery for degenerative back disorders in Sweden have, on average, a long duration of pain, eg, nearly 1 year for herniated disc, and around 3 years for spinal stenosis. Most patients are satisfied with the outcome of surgery. Surgical treatment for herniated disc and spondylolisthesis yields better results than lateral spinal stenosis and segmental pain in movement. Surgical outcomes for herniated disc are gender-related (better outcomes in men than women) and appear to vary by hospital type. These facts are being analyzed. The complications register has identified several types of interventions with high complication rates, which require further analysis. The registry has gained substantial recognition internationally and is presented at Scandinavian and major international societies for back disorders (ISSLE, SSE, NASS). The registry offers a unique base for studies on the short- and long-term effects of back surgery on health status.

Swedish Shoulder Arthroplasty Registry

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<i>Year started</i>	<i>1999</i>
<i>Public funding</i>	<i>2005-2007</i>
<i>Governing body</i>	<i>Stockholm County Council</i>
<i>Competence center</i>	<i>NKO</i>
<i>Transparency, unit level</i>	<i>No, possibly in 2008</i>

Background and Aim

Shoulder joint replacement surgery (arthroplasty) is an increasingly common intervention. Typically, it is used in patients diagnosed with osteoarthritis or rheumatoid arthritis. Arthroplasty is also appropriate in treating fractures in the upper part of the upper arm, currently the most common cause. Clinically, these procedures are shown to yield good results in pain alleviation and some functional improvement. Similar to hip and knee arthroplasty, there are risks for short- and long-term complications.

In 1999, the Swedish Shoulder and Elbow Section (SSAS) of the Swedish Orthopaedic Association established a national arthroplasty registry to report on these shoulder operations so that quality parameters could be analyzed.

Coverage and Volume

Shoulder replacement is offered by approximately 45 to 50 hospitals in Sweden, and only 2 hospitals do not participate in the registry. Coverage is estimated to exceed 90% based on a comparison with the National Board of Health and Welfare's diagnostic registry for 1999-2003. Approximately 600 procedures involving joint arthroplasty are performed annually in Sweden, and the number is increasing.

Key Variables

The registry contains information about the departments/units, date of surgery, and patient data, eg, personal ID number and diagnosis. Implantation and certain surgical variables are noted. Reoperation of the shoulder replacement implant is used as the primary endpoint for prostheses survival. Since these reoperations are relatively rare, we also note all other subsequent surgeries in the shoulder joint from previous shoulder replacements. Furthermore, we conduct a postal survey in 5-year followup of all patients with a self-evaluation score (WOOS) that is a diagnosis-specific shoulder score on quality of life. Similar to the hip registry and several other registries, we also use EQ-5D for diagnosis-independent comparisons. Since 2004, the same scores have also been used in the shoulder registry preoperatively to compare with 1-year followup. However, participation by the departments remains voluntary, and followup for the first year is under way.

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Reporting Process

The registry has used printed forms in reporting. In 2007, when we join NKO and change to the platform for the database, we will be able to offer Web-based reporting.

Feedback Process

Units participating in the registry receive an annual report on the number and type of operations. They can check that their data corresponds to the registry. When uncertainties arise, more detailed data can be compared. Furthermore, the National Board of Health and Welfare's diagnostic registry is compared annually, and the results are reported to the units for possible adjustment. Annual reports are presented to participating units, SSAS, and via the registry's website and will be further developed via the reporting module in the new NKO platform.

Quality Improvement

The registry has started to analyze the content, but it is too early to provide solid findings. Our 5-year followup data will soon be extensive enough to permit more detailed analysis. Although the data are limited, some variations can be observed. A self-evaluation score is being used to assess patients' perceptions of outcomes, and despite relatively small patient groups, this will hopefully facilitate early detection of any variations.

Swedish Cruciate Ligament Registry – X-base

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<i>Year started</i>	<i>2005</i>
<i>Public funding</i>	<i>2007</i>
<i>Governing body</i>	<i>Stockholm County Council</i>
<i>Competence center</i>	<i>NKO</i>
<i>Transparency, unit level</i>	<i>Yes, since 2005</i>

Background and Aim

Anterior cruciate ligament injury is a serious knee injury that affects young patients (mean age 26 years). This damage often leads to early osteoarthritis in the knee. Many surgical methods can be used to treat the injury, but knowledge about the individual methods is weak.

The registry aims assess the outcomes of the different surgical methods at an early stage, thereby optimizing treatment of injured patients.

Coverage and Volume

The registry added 2352 anterior cruciate ligament reconstructions in 2006, and approximately 2700 primary cruciate ligament operations were performed in total.

Currently, 55 of Sweden's 72 orthopedic departments report their cruciate ligament operations. Many of the nonparticipating departments do not offer this type of surgery.

Key Variables

Patient-reported, subjective function score and quality of life score. Choice of transplant and fixation method. Prophylaxis for infection and thrombosis. Activity related to the injury and time from injury to surgery.

Reporting Process

A Web-based platform is used to register information on patients and health services. Patient information can also be registered by scanning printed forms.

Individual patients report on their quality of life and knee function using three Web-based questionnaires. Surgeons report on how they perform the operation, the transplant they choose and how it is fixated. Also reported are all knee-joint injuries and how they are treated, the type of activity performed during injury, and elapsed time between injury and surgery.

Feedback Process

Every clinic or orthopedist has access at any time to study the results of their department in relation to the total registry. Each year, information is compiled and fed back to the participating departments.

Quality Improvement

We observed an increasing rate in the use of tendon transplants, from 83% in 2005 to 87% in 2006. Patients show improved knee function with cruciate ligament reconstruction, and tendon transplants provide better knee function in all activity variables. Hence, tendon is recommended as the treatment of first choice in primary reconstruction of the anterior cruciate ligament.

Swedish National Elbow Arthroplasty Register (SAAR)

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Year started	1999
Public funding	2007
Governing body	Västmanland County Council
Competence center	NKO
Transparency, unit level	No, planned for 2008

Background and Aim

Prosthetic replacement of the elbow is an increasingly common surgical procedure. It is usually performed on patients diagnosed with rheumatoid arthritis, but it also appropriate for elbow fractures. Clinically, these procedures have yielded very good results in terms of function and pain alleviation.

Similar to hip and knee arthroplasty, there are short-term and long-term risks for complications.

In 1999, the Swedish Shoulder and Elbow Section (SSAS) of the Swedish Orthopaedic Association (SOF) established a national arthroplasty registry to report on these elbow operations so that quality parameters could be analyzed.

Coverage and Volume

Elbow arthroplasty is performed at about 10 to 15 hospitals in Sweden, and only one hospital has chosen not to participate in the register. Coverage is estimated to exceed 90% based on a comparison with the National Board of Health and Welfare's diagnostic registry for 1999-2003. Approximately 80 procedures are performed in Sweden annually, and the number is growing.

Key Variables

The registry contains information on departments, surgical dates, and patient data such as personal ID number and diagnosis. Implants and some surgical variables, ie previous surgery, are noted. We use reoperation of elbow arthroplasty implants as the primary endpoint for prosthesis survival. These reoperations are relatively rare, and we also note all other subsequent operations of the elbow from

previous elbow arthroplasty. Furthermore, we sent (by post) a 5-year followup, using a self-evaluation score (QuickDASH) of patients receiving surgery 1999-2000. Results have been reported at the annual meeting of the Swedish Orthopaedic Association.

Reporting Process

The registry is based on reporting all elbow arthroplasty procedures via a printed form. This year (2007) we planned to move the register to NKO's database, and during 2008 we hope to begin Web-based reporting.

Feedback Process

Each year, information from the registry has been accessible on the registry's website, which has been open to all participating units and to the public since 2003. Furthermore, results from the registry have been reported annually at SOF and SSAS annual meetings. Annually, data are compared with the National Board of Health and Welfare's diagnostic registry.

Quality Improvement

The registry has existed for 7 years. Hence, we have recently been able to start analyzing the material, although to a limited extent. For example, we have shown that the difference in prosthesis survival in the medium term between unconstrained and semiconstrained prostheses is small (not statistically significant).

SMS – Swedish Multiple Sclerosis Registry

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Year started	1996
Public funding	2000 - 2007
Governing body	Stockholm County Council
Competence center	-
Transparency, unit level	Yes, since 2006

Background and Aim

Around 12 000 people in Sweden suffer from multiple sclerosis (MS), a lifelong disease of the central nervous system that often debuts before 40 years of age, frequently leading to substantial functional impairment after a few years. The cost to society for MS has been estimated at 5 billion SEK, whereof pharmacotherapy represents approximately 10%.

The SMS Registry is intended to support patient-related work, but it also allows local units to manage quality control and improvement.

Aims of the SMS registry include:

- to contribute toward high-quality, equitably-distributed MS care in Sweden
- to assure that prevailing treatment indications for MS are followed
- to assess the long-term effects of modern drugs that modify the progression of MS.

Coverage and Volume

Currently, 40 departments/units participate in the registry, representing all counties in Sweden. The registry includes information on 8400 patients, ie, around 70% of the MS patients in Sweden. The annual rate of increase in the number of patients is around 12%.

Key Variables

- Demographic information
- Disease history (eg, age of debut, debut symptoms, type of progression, possible genetic predisposition)
- Diagnostic investigation involving MRI and spinal fluid testing
- Progression modifying treatment
- Checklist of symptom categories
- Rating scales for functional level, quality of life, tiredness, and cognition.

Reporting Process

The registry is Internet-based. Data are entered in the registry directly by a caregiver in conjunction with the patient's visit.

Feedback Process

Participating physicians can retrieve statistics, directly as needed from the registry, on their own patients and on all unit, county, or national patients via several predefined report formats. Furthermore, there are unlimited possibilities to search the data on one's own patients and on the unit's or the county's patients. National data are compiled annually and presented in the annual report and at the annual meeting.

Quality Improvement

Variations in the use of disease-modifying drugs in Sweden have narrowed since the registry has been in operation. In parallel, treatment has been focused on groups expected to realize the greatest benefits. A followup of 937 patients on disease-modifying drugs found that the rate of deterioration decreased by about half in comparison to untreated patients (Tedenholm H, et al, *Läkartidningen* 2007.) All patients in Sweden treated with a new (2006) disease-modifying drug, Tysabri, are registered continuously in accordance with a special, expanded protocol to assess risks and benefits. We are using a rating scale (MSIS-29) to register patient-perceived physical and psychological levels of function, which allows a broad assessment of short- and long-term interventions at the group level and for individual patients.

CPUP – Quality Registry for Children with Cerebral Palsy

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<i>Public funding</i>	<i>2005-2007</i>
<i>Governing body</i>	<i>Region Skåne</i>
<i>Competence center</i>	<i>NKO</i>
<i>Transparency, unit level</i>	<i>Yes, since 2006</i>

Background and Aim

Cerebral palsy (CP) is the most common type of physical functional impairment in children affecting approximately 1 in 400. Children with CP are at high risk for developing contracture (muscle rigidity), hip luxation (hip dislocation), and scoliosis (spinal curvature). These conditions often are accompanied by severe pain, impaired function, and a lower sense of wellbeing. After the onset of contracture, luxation, or scoliosis, the disorder is difficult to treat.

The aim of CPUP is to prevent hip dislocation and severe contracture in children and adolescents with CP by continuously registering data throughout the growing phase, monitoring the prevalence of CP, and assessing different treatment methods.

Coverage and Volume

Starting from 2007, all county councils and regions in Sweden participate in CPUP. For the age groups covered by all regions, over 90% of all children with CP are registered in CPUP.

Key Variables

Every child is followed up once or twice per year by reporting on over 100 variables related to function, mobility status in different joints, current treatment (physiotherapy, surgery, orthotics, treatment to reduce spasticity, etc). Furthermore, standard x-ray exams are given to check the child's hips and spine.

Reporting Process

The child's physiotherapist, occupational therapist, orthopedist, hand surgeon, and neuropsychiatrist conduct examinations and report on different aspects. Reporting has been Web-based since 2007 (3C-NKO).

Feedback Process

The team treating a child receives real-time feedback via Web 3C that indicates the child's development over time. Each county council/region receives an annual report with information showing local outcomes compared to national outcomes.

The registry is used in part as a tool for ongoing followup of the individual child, and in part for national quality assessment of aggregated information.

CPUP arranges an annual conference in Lund for reporting, education, and feedback of information.

Quality Improvement

Twelve years of experience in southern Sweden has shown that the CPUP registry can help prevent the development of severe complications of brain damage from CP. Standardized followup via the registry enables early identification of the children who can benefit from preventive intervention.

Briefly, the findings from southern Sweden show:

- total prevention of hip dislocation, which earlier affected 10%
- reduction in the number of severe contractures by 70%
- reduction in the incidence of scoliosis by 60%.

Along with these substantial improvements, we have been able to reduce the number of operations for contracture by 70%.

Data registered for areas in Sweden that have been affiliated with CPUP for several years show similar effects for hip dislocation and contractures.

Webrehab Sweden – Quality Registry in Rehabilitation Medicine

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<i>Year started</i>	<i>1998</i>
<i>Public funding</i>	<i>2004-2007</i>
<i>Governing body</i>	<i>Västra Götaland Region</i>
<i>Competence center</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>No</i>

Background and Aim

Rehabilitation is important to reduce the impact of disease or injury. Assessment is needed to monitor the effects of intervention on individual patients, to assess the intervention per se, and to assure quality. The DRG system has not been designed for rehabilitation processes and hence is seldom used in departments of geriatrics and rehabilitation medicine. In the United States, activity levels must be registered on admission and discharge for reimbursement. Similar ideas have been raised in NordDRG. For several years, Sweden has registered individuals in inpatient rehabilitation medicine units (entered on diskettes and printed out on paper). Different patient groups are represented, but brain injuries (stroke or trauma) are common as are peripheral nerve disorders (MS, Guillain-Barré) and multitrauma. Access to services is unevenly distributed across the country, as are the opportunities for a well functioning continuum of care in municipalities. Often it is the local organization that determines whether one receives care at a rehabilitation medicine or geriatric unit. Currently, no registry covers people rehabilitated at geriatric units in the country, where brain injury and post-prosthesis surgery are common reasons for admission.

Coverage and Volume

The registry mentioned above included 70% of Sweden's rehabilitation medicine units, and just over 80% of the inpatients. The new Webrehab (Web-based registry with online feedback) has raised the interest of many throughout Sweden, including units operated by county councils and services under contract. To date, 15 of Sweden's rehabilitation medicine units have joined, ie, just over 80% of the inpatients beds will be registered.

Key Variables

Webrehab Sweden will register rehabilitation resources (professional groups available to the client), whether a rehab plan has been established for the client, whether it has been followed (at followup), and the rehab interventions that the client received following discharge (followup).

- Function based on ICF (functional level)
- FIM (activity level)
- Complications (quality of care)
- EQ-5D (health-related quality of life)

Reporting Process

Online reporting is continuous.

Feedback Process

Feedback to the individual units is direct. Annual reports are sent to the participating units, and registry conferences are arranged.

Quality Improvement

Awareness has increased regarding care times. Discussions have been held at local development conferences to obtain feedback about outcomes, eg, if individual clients have been particularly care-demanding. Observations on the large share of stroke patients receiving care motivated several units to provide staff training focusing on stroke. The new Webrehab registry is viewed as user-friendly and motivating to work with since it offers immediate feedback of data.

SveDem – Swedish Dementia Registry

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<i>Year started</i>	<i>2005</i>
<i>Public funding</i>	<i>2005-2007</i>
<i>Governing body</i>	<i>Stockholm County Council</i>
<i>Competence center</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>No</i>

Background and Aim

As Sweden's population becomes increasingly older, dementia disorders affect increasingly more people. An estimated 140 000 people in Sweden have some form of dementia, whereof two thirds have Alzheimer's disease. Although dementia affects many people, the figures are uncertain since not all suspected cases are investigated. Furthermore, there are no national data on the investigation, treatment, and followup patients with dementia. The Swedish Dementia Registry is being constructed to meet the need for followup of dementia.

The registry aims to improve the quality of dementia care in Sweden by collecting data to monitor changes in patient populations, diagnoses, and treatment of dementia disorders.

Our goal is equitable and optimum treatment of patients with dementia.

Coverage and Volume

The registry was launched on May 1, 2007. A national registry is the goal. The clinicians that participate in the registry investigate approximately 2000 new patients annually.

In phase one the hospital clinicians will register patients, and in phase two the primary care units will register patients. The number of dementia investigations is estimated at 17 000 to 20 000 per year. Hence, initial coverage is approximately 15%.

Key Variables

Information registered includes; how the diagnosis is established, how continuing care is planned and delivered, and how treatment and other interventions change over time.

Reporting Process

All participating units will report their data to the registry via an Internet-based system.

Feedback Process

The system will provide Web-based access to reports on descriptive statistics, and provide users the opportunity to download data on their own unit for further processing and analysis. In online reports via the Web, users will be able to select the variables to be presented, possibly displayed in groups of interest for comparison. The registry will also publish an annual report for target groups of professionals, funding bodies, and political and administrative decision-makers.

Quality Improvement

Particular emphasis will be placed on presenting trends that support quality improvement activities. Given information based on their own data, participating departments/units can monitor the extent to which goals are met and whether variations in the variables decrease and value improves after quality improvement programs have been introduced.

Annual compilations of data in the registry will provide a national status report concerning dementia care in Sweden.

GYNOP – National Quality Registry for Gynecological Surgery

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Year started	1997
Public funding	1994, 1997-2007
Governing body	Västerbotten County Council
Competence center	-
Transparency, unit level	Yes, since 2003

Background and Aim

The National Quality Registry for Gynecological Surgery encompasses 6 independent registries that cover the broad field of gynecological surgery. The registry includes hysterectomies (uterus), adnexa (ovaries and ovarian tubes), incontinence/prolapse, and tumor operations as well as endometrial ablations (surgery in the uterus). The Swedish Society of Obstetrics and Gynecology (SFOG) supports and participates actively in the registry. The aim is to provide the departments with cost-effective tools for continuous monitoring of quality efforts over time and relative to other departments.

Coverage and Volume

Approximately 25 000 operations are performed annually in Sweden, which the registry intends to follow up. Of these, 8000 are hysterectomies, whereof approximately 60% are registered (2006). The hysterectomy register is the oldest (started in 1997). Three of the subregistries started in 2006. Of Sweden's approximately 55 surgical departments, 40 participate. Four plan to join in the autumn 2007.

Key Variables

Important variables include traditional medical variables collected during the care episode, and information the patients report themselves, ie, problems and expectations prior to surgery, complications, and postsurgical results. This information is gathered via patient questionnaires, with response to the patient's physician. Many of these operations are performed to alleviate problems the women experience. Hence, assessment of outcomes cannot be based on medical grounds alone.

Reporting Process

Questionnaires are sent to patients before, 8 weeks after, and one year after surgery. Mainly physicians collect data on admission, surgery, and discharge. The registry is completely integrated in 2 electronic patient record systems. Starting 2007, patients are invited to answer questionnaires via the Internet.

Feedback Process

- 1) Reports 4 to 6 times per year with thorough analysis of specific topics
- 2) Internet-based report generator where units can monitor their performance monthly
- 3) Meetings for physicians and secretaries 3 times per year
- 4) Clinical visits to support quality improvement, register logistics, and validity.

The results are transparent and accessible to the public via the registry website, www.gynop.org.

Quality Improvement

The registry has contributed to greater cost effectiveness and quality of care. For example, transparent comparisons have enabled units to reduce postoperative infections and shorten the length of stay following hysterectomy. Without the registry, neither the wide variations among units nor the subsequent improvements could have been observed. Registry data have also been used as a basis for guidelines for preventing thrombosis. Postoperative questionnaires provide a basis for targeted check-ups – return visit instead of no follow up. The questionnaires increase the focus on patients' assessment of care. The registry has clarified the disparities in how patients and providers view complications, which has improved the information to patients regarding the normal recovery process. The registry shows that the care reported from the participating units maintains very high quality in comparison to results reported internationally.

SRR – Swedish Renal Registry

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Year started	2007 (SRAU 1991, SDDDB 2002)
Public funding	1991-2007
Governing body	Jönköping County Council
Competence center	-
Transparency, unit level	Partial since 2006

Background and Aim

The Swedish Renal Registry resulted from the merger of the Swedish Registry for Active Uremia Care (SRAU, started in 1991) and the Swedish DialysisDataBas (SDDDB, started in 2002), and the local Kidney Registries in Stockholm County Council and Västra Götaland Region. Approximately 1100 people per year in Sweden are affected by chronic renal failure and start dialysis treatment, while approximately 350 to 380 patients receive a functioning kidney transplant. Approximately 3500 patients currently receive dialysis, and just over 4000 have a transplanted kidney. Annually, the number of patients receiving active uremia care increases by 3% to 4%. The registry aims to monitor trends regarding causes of renal disease and the number of patients needing dialysis and transplantation, eg, as a basis for projecting trends in active uremia care. Another aim is to measure, report on, and assess several quality variables in patients with advanced renal failure and receiving active uremia care to contribute toward improving key aspects of the various processes regarding dialysis and the care of renal failure.

Coverage and Volume

All departments (100%) that offer dialysis /kidney transplantation participate in the epidemiological aspect of the registry. Coverage of repeat examinations of dialysis effectiveness exceeds 95%. The renal failure aspect of the registry currently covers approximately 30% of the patients who have contact with health services due to severe renal failure. This part is expanding rapidly.

Key Variables

The epidemiological aspect of the registry includes the individual's age, sex, basic disease, possible contributing factors for disease, eg, heart disease, hypertension, diabetes, and malignancy, and changes in the patients treatment, possibly change of residence, and cause of death. As regards dialysis and care of renal failure, the registry includes relevant pharmacotherapy and laboratory values, eg, blood value, phosphate value, parathyroid hormone value, measured dialysis dose, and blood pressure. A module for measuring health-related quality of life is being developed.

Reporting Process

Web-based reporting began in autumn 2007, using encrypted data transmission. Every unit also has a contact person responsible for reporting. The central secretariat checks reported information for quality by contacting the units. The data are linked and matched with the cause of death register for additional quality control.

Feedback Process

The website presents the results from each unit. Each of the 65 participating units can compare themselves with each other and with a national average. Analytical reports are published on the website and in print. Most data are reported at the clinical level, but mortality data are reported at the county council level (starting autumn 2007).

Quality Improvement

Survival in active uremia care (under 16 years with SRAU) has successively improved. Annual mortality has been reduced by 6% in those receiving kidney transplants, with approximately half of that group on dialysis. The quality variables for dialysis tend to become more similar across departments over time.

National Prostate Cancer Registry

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Year started	1996
Public support	1996-2007
Governing body	Uppsala County Council
Competence center	-
Transparency, unit level	No

Background and Aim

The National Prostate Cancer Registry (NPCR) aims to monitor time trends and geographic differences within Sweden regarding the reason for initiating the investigation, diagnostic procedures, treatment, and tumor characteristics. Registration takes place at all units that diagnose and treat prostate cancer (PCa). The most important process measures are age-standardized measures of total incidence and incidence of PCa in different stages, and the use of curative and palliative treatments. The outcome measures of total-, relative-, and disease specific mortality are obtained through linking to the citizen/person register and the cause of death register.

Coverage and Volume

NPCR has a coverage of 97.5% compared to the Cancer Registry. All departments that diagnose and treat PCa report to NPCR. In 2005, the registry reported 9548 new cases of prostate cancer Sweden

Key Variables

Variables reported on since establishment of the registry are: TNM stage, local tumor stage, lymph node metastasis, skeletal metastasis, serum concentration of prostate specific antigen (PSA), and primary treatment within 6 months after diagnosis. The reason for the investigation leading to diagnosis has been reported since 2000. Since PCa diagnosis and treatment has changed dramatically in the past decade, NPCR began to collect further data in 2007. Registration is divided into 2 occasions, the first at diagnosis and the second at treatment. New variables at diagnosis are: prostate volume, number of medium needle biopsies, and number of biopsies showing cancer. Regarding treatment, additional

variables include: type of prostatectomy, information on nerve-preserving surgery, pathological stage, surgical radicality, and type of radiotherapy. Representatives for oncology and pathology were added to the steering committee in the autumn of 2006. Reporting of information about symptoms via patient questionnaires after curative treatment is planned, starting in 2008.

Reporting Process

To date, reporting has been based on sending printed forms to the respective oncology centers, no later than 6 months after diagnosis. In turn, they forward the data to the Regional Oncology Center in Uppsala. An Internet-based reporting method, INCA, is being introduced (2007).

Feedback Process

Oncology centers report annual, clinical-level data within the respective regions. Annually, a national report is compiled that presents transparent information at the county council level and is accessible via the website. In conjunction with placing the report on the Web, a newsletter is published that reports and comments on aspects of special interest. INCA opens new opportunities for feedback. Individual departments have direct online access to their data, which they can compare with national data.

Quality Improvement

Since the registry started, there has been a gradual trend toward standardization in diagnosis and treatment in Sweden. The new variables in the registry enable better quality assessment of care. NPCR enables assessment of the effects of the national healthcare guidelines on prostate cancer.

National Breast Cancer Registry

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Website	-
Year started	2007
Public funding	2007
Governing body	Stockholm County Council
Competence center	-
Transparency, unit level	Yes, since 2007

Background and Aim

Breast cancer is the most common type of cancer in women. Approximately 6000 individuals are diagnosed with breast cancer annually in Sweden. The age-standardized incidence has steadily increased since the Cancer Registry was formed in the late 1950s, but mortality has decreased. However, there are some geographic differences in survival.

The aim is primarily to monitor breast cancer from a clinical aspect, how it is detected, treated, and the outcomes of treatment, and to identify regional or local differences in treatment and methods of detection, and relate these to outcomes and the quality goals established by specialty societies. Secondly, the registry serves as a source of new knowledge concerning the association between tumor characteristics and treatment outcomes, and also changes in the nature of breast cancer over time, etc.

Coverage and Volume

The aim is to achieve full coverage, which has already been achieved in regional registries through close collaboration with the oncology centers.

Key Variables

The registry has focused on 2 goals; that it contain mandatory information required for cancer registration, and that it contain the quality parameters established by the National Board of Health and Welfare in collaboration with the steering committee. Furthermore, the registry has focused on lead times and description of diagnostics and treatment processes. There is also a followup aspect, reporting quality variables after surgery and any cancer relapse. The variables have been modified substantially after testing the registry in 5 departments. The registry contains information on preoperative diag-

nostics, tumor data, type of surgery, waiting-times for diagnosis and treatment, long- and short-term complications and relapse rates, and patient satisfaction, including cosmetics. The main outcome measures are survival, complication and relapse rates, and the percentage of satisfied patients.

Reporting Process

Four test units in Stockholm, Helsingborg, Lund, and Göteborg tried a test version of the registry for 2 years. Since 2007, Karolinska University Hospital Solna has reported. Web-based reporting started in May 2007, permitting all units in Sweden to report via their regional oncology center. The registry is one of the first to be established in the common electronic INCA platform used by Sweden's oncology centers.

Feedback Process

Web applications provide online feedback of aggregate and unit-level data in tables and figures, with the possibility to compare with national and regional data. The respective units can retrieve their data online for analysis. At the regional level, the oncology centers will handle data on request from the region's units. At the national level, the Stockholm-Gotland Oncology Center will compile a summary in collaboration with the registry's steering committee. Only a descriptive analysis will be possible during the initial years, but comparisons of survival and mortality in relation to variables in the registry will be possible in the future.

Quality Improvement

Not applicable since the registry is not fully operational.

National Quality Registry for Esophageal and Stomach Cancer

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<i>Public funding</i>	<i>2005-2007</i>
<i>Governing body</i>	<i>Region Skåne</i>
<i>Competence center</i>	<i>-</i>
<i>Transparency, unit level</i>	<i>No</i>

Background and Aim

The registry was formed by consolidating and further developing two well-established national registries for esophageal and stomach cancer surgery (SECC and SWEGIR), which had been part of the Swedish Association for Upper Abdominal Surgery (SFÖAK). The registry was constructed during 2005 and launched in January 2006.

Goals:

1. To become a registry with national coverage of all diagnosed esophageal and stomach cancer in Sweden, whether or not it is treated.
2. To register all resection surgery and some palliative interventions for diagnosed esophageal and stomach cancer in Sweden.
3. To register complications, survival, and quality of life after resection surgery.
4. To conduct health economic analyses and facilitate research.
5. To expand (in the near future) the register on cancer therapies.

Coverage and Volume

Currently (2007), 55 surgery, oncology, and ENT departments participate in the registry under written agreements between the unit directors and the registry. Data from 2006 had not been analyzed when this document went to press. When checked against the cancer registry, data processed manually indicate that just over 50% are registered.

Key Variables

Investigations and treatment delivered, complications, survival, and quality of life.

Reporting Process

Beyond reporting via printed forms, since May 2007 the registry has offered electronic Web-based reporting via the INCA platform – a Web-based portal for reporting cancer diseases. The Umeå Oncology Center manages the registry. Reporting takes place on three occasions to reflect investigation, treatment, and followup. Furthermore, quality of life is assessed prior to and 6 months following treatment. All data will be validated before being entered in the national registry. By linking and matching this data against data in the cancer registry, coverage can be checked, and any cases unreported to the registry may be requested from the oncology center.

Feedback Process

All reporting units will have full online access to their own data via the INCA platform. Unit directors that have signed contracts with the registry will receive a written compilation of the outcomes from their clinics. Annual reports at the national and regional levels will be public, but initially not at the clinical level.

Quality Improvement

The registry should be able to describe trends in treatment and complications in relevant diagnostic areas, provide a basis for analysis and clinical research (including health economics and quality of life), and provide support for local, regional, and national quality improvement efforts. Initially, the registry will focus on registering surgery and complications, but after it gains support from the professional community other treatment should also be registered. At the national level, multicenter studies can be facilitated and structured clinical improvement processes can be carried out.

Swedish Rectal Cancer Registry

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<i>Year started</i>	<i>1995</i>
<i>Public funding</i>	<i>1995-2007</i>
<i>Governing body</i>	<i>Uppsala County Council</i>
<i>Competence center</i>	<i>-</i>
<i>Transparency, unit level</i>	<i>Yes, from 2005</i>

Background and Aim

Rectal cancer is a common type of cancer in Sweden. The Swedish Rectal Cancer Registry was started as a means to address high morbidity and mortality in conjunction with surgery and the poor cancer outcomes (high local residual disease and many relapses) in the early 1980s. Concurrently, a new educational strategy for Swedish surgeons was also introduced. The registry aims at studying how rectal cancer surgery can develop further to improve the situation for patients.

Coverage and Volume

Every patient with rectal cancer is registered. All units participate, and coverage exceeds 99%. Registration is verified with the oncology centers in each region, where reporting is linked to the cancer registry. Hence, all rectal cancers are captured. Annually, around 1500 patients contract the disease.

Key Variables

The registry includes data on preoperative investigation, including colonoscopy, ultrasound, and MRI, and if the patient has received radiotherapy and/or chemotherapy. The choice of surgical method is registered as is radicality, extirpation of other organs, and technical details of surgery. Post-operative registration includes all cardiovascular-related complications and infections not directly related to surgery and all surgical complications, including reoperation rates and causes for reoperation. Tumor stage, based on TNM classification, is registered.

Followup includes registration of all oncological parameters, eg, local residuals and cancer survival. Quality of life parameters and side effects of treatment are also registered. The reports should be submitted annually. If reports are not submitted, the oncology center sends out reminders to the surgeons responsible.

Reporting Process

Every hospital in Sweden has a designated surgeon with the overall responsibility for reporting. A nurse often assists with reporting. The units continue to report all data to the oncology centers on printed forms. Designated surgeons are contacted if additional information is needed.

Feedback Process

Data from the registry, with interpretations of all parameters, are reported annually. The reports are sent to department heads and registry managers. Each hospital receives an identical report, where their own data can be compared with regional and national data. Since 2005, we have delivered identifiable hospital data to enable comparison of results by hospital.

Quality Improvement

The registry has helped Sweden achieve first place internationally in rectal cancer treatment. However, variations exist among hospitals and the data are being analyzed. This is a delicate task since consideration must be given to differences in patient mix in relation to tumor burden, age, etc in the different regions and hospitals. The goal is to use the identified quality parameters as guidelines for future care. Examples include postoperative mortality of 2%, a decrease in local residual disease rates from 50% to less than 10%, and an increase in cancer-specific survival from 45% to nearly 60%. The units with good results should strive to maintain or improve quality, and those with poorer results should strive to achieve guideline targets. Hence, there is the potential for long-term improvement of outcomes in Sweden.

Swedish Gyn-Oncology Registry

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Year started	2007
Public funding	2005-2007
Governing body	Västra Götaland Region
Competence center	-
Transparency, unit level	Yes

Background and Aim

Cancer care in general, and gynecological cancer care in particular, are subject to organizational changes that make it important to continuously register the quality of care. International comparisons show Sweden to be a leader in survival rates for gynecological cancer. We hope to retain this position. The registry was also designed to enable participation in the International Federation of Gynecology and Obstetrics (FIGO) database.

The registry aims to collect information on care processes (eg, diagnosis and investigation, treatment setting, the availability of and compliance with clinical guidelines, changes in waiting times, the use of centralized assessment/treatment planning) and outcomes (eg, surgical outcomes, survival, and cause of death).

Coverage and Volume

All gyn-oncology units in Sweden, oncology centers, and the Swedish Society of Obstetrics & Gynecology (SFOG) are represented in the working group for the registry. All participants have expressed strong interest in a comprehensive national registry. Issues concerning the level of coverage and missing patients can be addressed by checking against the cancer registry. Each year, around 3000 cases of gynecological cancer are reported to the cancer registry.

Key Variables

The registry includes the dates of important checkpoints in the continuum of care, surgical outcomes, survival data, type of treatment, and use of clinical guidelines.

Reporting Process

1. From women's clinics in conjunction with diagnosis and primary procedure
2. In conjunction with referral – clinical assessment of patients at gyn-oncology units
3. Following the conclusion of primary treatment
4. During followup after progression
5. After checking against the cancer registry
6. Time of death is obtained from the population registry
7. Cause of death is obtained via direct reporting and from the cause of the death registry.

Many women's clinics report surgical data via the GYNOP Registry, which transfers relevant data to the Swedish Gyn-Oncology Registry. Otherwise, data are reported via the INCA system primarily to regional oncology centers that check the data and match it against the regional cancer registry. The coordinating oncology center in Göteborg then collects the data and further analyzes the national data.

Later, the data (unidentifiable by unit) are transmitted to the FIGO international registry.

Feedback Process

The data will be analyzed in consultation with statisticians at the oncology center. Some standardized statistics will be accessible via the registry's planned website.

An annual report is being planned. The plan regarding feedback is to return identified data to the respective units, but unidentified registry data will be generally available.

Quality Improvement

Outcome data are not available since the registry is at an early stage.

Swedish Colon Cancer Registry

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Year started	2007
Public funding	2007
Governing body	Uppsala County Council
Competence center	-
Transparency, unit level	No

Background and Aim

Colon cancer, along with rectal cancer, is the third most common type of cancer in Sweden, and together with lung cancer, the most common cause of cancer mortality. As with the Rectal Cancer Registry, the aim of this registry is to improve not only surgery but also all other treatment options for patients with colon cancer.

Coverage and Volume

All patients with adenocarcinoma in the colon will be registered. This will be possible since all hospitals that offer colon cancer surgery have agreed to participate, and we can identify all cases through the Swedish Cancer Registry.

Key Variables

Preoperative diagnostic methods (colon radiography, colon CT, or colonoscopy), investigation of metastasis. Also registered are surgical methods, postoperative morbidity and mortality. We will also register access to oncology aftercare and cancer followup.

Reporting Process

Every department of surgery in Sweden that offers colon cancer surgery will have a physician responsible to report all cases to the registry. Reporting ta-

kes place via the regional oncology centers (ROC). Since the same centers are responsible for cancer registration in Sweden, all new cases will be identified. In the event that a hospital does not report a patient to the Colon Cancer Registry, ROC will check with the appropriate hospital for information on the patient.

Feedback Process

Annual reports will be sent to each hospital, where the hospital may compare their own data to national data. During the first 3 years, no unit-level data will be reported since the number of patients would be low, and comparative data among hospitals would be weak. Starting with the fourth or fifth year, hospital-specific data will be published in the same way as the Rectal Cancer Registry reports its data.

Quality Improvement

Since the registry started only recently, it is difficult to point to improved outcomes at this time. As with the Rectal Cancer Registry, we expect to see clearly improved outcomes with this type of quality control. We expect the registry data to reveal opportunities for addressing variations in the care of colon cancer in Sweden.

Swedish National Cataract Register

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Year started	1992
Public funding	1992-2007
Governing body	Blekinge County Council
Competence center	EyeNet Sweden
Transparency, unit level	Yes, as regards production data and accessibility since 2006, not transparent as regards outcome variables

Background and Aim

Cataract surgery is the most common surgical procedure in Sweden, with around 80 000 operations performed annually. Methods in cataract surgery are developing rapidly. The primary aims of the registry are: to encourage quality improvement by providing data for comparisons and presenting good examples, to enable analysis of outliers at the national level, to assess the surgical benefits perceived by patients, and to thereby improve knowledge about appropriate indications and develop and expand knowledge about cataract disease.

Coverage and Volume

The participating units report 97% of all operations to the registry (2006). All local public (county council and municipal) and major private units participate in the registry.

Key Variables

Important variables include: units/departments, demographic data, waiting time, vision at the time of surgery, previous cataract surgery, other eye disease, if both eyes are operated the same day, operation type, lens type, antibiotic prophylaxis during surgery, planned and final refraction, and whether the operation has healed 6 months after intervention. Special variables apply to congenital cataracts.

Reporting Process

Approximately 45 departments report via the Web. Over 10 units submit data via text files and e-mail, which usually involves using an export function from an existing patient record system. Patient questionnaires are sent before, and 6 months after, surgery and include questions on different types of perceived problems. Special forms are used for suspected endophthalmitis (infection).

Feedback Process

The annual report presents descriptive/analytical data, outcomes at the aggregate level, case mix, confounders, age- and gender-specific analyses, and time series. Particularly interesting aspects are also addressed at user meetings.

Units/departments have access to automatically generated, standard reports via the Web where they can compare themselves to other units. The results of patient questionnaires are presented in tables showing the responses by percent and outcomes by unit.

Quality Improvement

The registry has facilitated important technical improvements in terms of choosing the type of surgery and lens. The registry started reporting on severe postoperative infections in 1988. All units introduced uniform routines based on recommendations from the registry. Infections decreased by half, and Sweden now has a particularly low rate by international standards.

During 2003-2004, a Q-reg project was implemented aimed at improving the continuum of care prior to cataract surgery, make waiting times more equitable, and propose national indications for cataract surgery. The model was introduced at 85% of all units in Sweden, and has promoted a common view regarding when cataract surgery should be performed. A previous Q-reg project aimed to reduce the share of patients who did not experience benefits from cataract surgery. It found that the share of patients with persisting problems could be reduced by changing the operative strategy in one or both eyes.

During 2006, a project was initiated to survey the risks for functional outcomes following capsule complications during cataract surgery. All of the national improvement projects (concerning poor patient benefits, endophthalmitis prophylaxis, national indications, and capsule complications) can be viewed as preventive efforts.

Swedish Corneal Transplant Register

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Year started	1996
Public funding	2002, 2003, 2005-2007
Governing body	Västra Götaland Region
Competence center	EyeNet Sweden
Transparency, unit level	Yes, from start

Background and Aim

Corneal transplantation is the most common type of transplant procedure. In Sweden, 500 to 600 are performed annually. Rehabilitation after corneal transplantation is lengthy, taking about 2 years to obtain the final results. Many factors before, during, and after surgery affect the outcome. Outcome is measured in terms of visual acuity and/or freedom from pain. The Swedish Corneal Transplant Register was started to register these factors and then learn from the results, with the aim to improve outcomes. Using data compiled from the registry, patient information on treatment routines and surgical techniques can be improved. In some cases, the indications for surgery may also change.

Coverage and Volume

Approximately 90% of the corneal transplant patients in 2006 are in the registry. The 8 units/departments in Sweden that perform corneal transplantation participate in the registry.

Key Variables

At the time of surgery, the patient's sex, age, surgical indications, visual acuity, possible risk factors, surgical method are reported, as are the donor's sex and age, and the corneal bank that delivered the donated cornea. Data on followup 2 years after surgery include; if the transplant continues to function or if re-transplantation was needed, postoperative complications, visual acuity, refraction errors, and if refraction errors led to refractive surgery. Any other vision-impairing disorders are also reported.

Reporting Process

All participants register data via a special computer program. This Web-based reporting method replaces the printed forms previously used for the two reporting occasions.

Feedback Process

Participating surgeons may attend a user meeting once per year where they receive reports compiled from the data. This meeting offers a forum for discussing the impact of the data in the clinical improvement process. Feedback is Web-based, and starting in 2007 all participants will have access to automatically generated standard reports.

Quality Improvement

Since the registry is national, it offers a secure base for assessing the prognosis for different indications, the importance of different risk factors, etc, which means that patient information can be improved, that indications to some extent have changed, and that preoperative treatment is optimized. Being a national registry, it allows users to compare strategies and outcomes among participating units. For example, one department reports substantially lower postoperative astigmatism than other departments. We have initiated more intensive postoperative steroid treatment in all units to reduce the rejection risk. We have also introduced alternative treatment methods in a diagnostic group with a particularly poor prognosis after transplantation.

Macula Register

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<i>Year started</i>	<i>2003</i>
<i>Public funding</i>	<i>2004-2007</i>
<i>Governing body</i>	<i>Uppsala County Council</i>
<i>Competence center</i>	<i>EyeNet Sweden</i>
<i>Transparency, unit level</i>	<i>No</i>

Background and Aim

Throughout the western world, new vascularization (CNV) under the yellow spot (macula) of the retina is the most common cause of pronounced visual impairment ("social blindness") in people above 50 years of age.

The eye disease where CNV most frequently appears is the wet form of age-related macular degeneration (AMD). The wet form accounts for 90% of pronounced visual impairment from this disease.

Recently, new treatment methods have been adopted, and others have been introduced during the year. These methods are resource intensive and costly.

The registry aims to achieve uniform national followup, quality assurance, and assessment of treatment for CNV.

The registry includes measures of medical treatment and measures of patients' subjective experience regarding treatment outcomes. Hence, it is possible to see whether some parameters potentially affect treatment outcomes and hence the opportunity to change treatment indications.

Coverage and Volume

Eighteen of 20 departments that provide treatment participate in the registry. Reporting varies somewhat among the departments. Many departments register nearly 100% of their patients, while the others have had local problems with data entry. During 2007, several departments have started to treat macula degeneration with the new methods that have developed, and the goal is to also include these departments in the registry.

Key Variables

The most important variables are: diagnosis, sex, age, symptom duration, visual acuity, nearsightedness, type of vascular membrane, membrane position and size, type of treatment, side effects, and subjective perception of treatment results.

Reporting Process

Data are reported during treatment and at followup 3, 6, and 12 months after the conclusion of treatment.

Information is entered regularly in a local data file at the individual units. The units submit their data twice per year to the coordinating center, to the global database by e-mail or diskette.

Units can continually monitor and analyze their treatment outcomes. It is planned that the Macula Register will become Web-based in 2007.

Feedback Process

Twice per year, after the local data files are submitted to the global database, the data are analyzed and fed back to the participating units. Standard reports present data for the units and show comparisons with other units and the national average.

Twice per year, the Macula Register arranges meetings with participating units where the results are presented and discussed.

Quality Improvement

The registry has led to improved quality in diagnosing CNV, mainly regarding the interpretation of angiographies, which has a major impact on treatment decisions for CNV. In turn, this has led to more uniform assessment and treatment policies for these patients at the departments providing care in Sweden.

RIKSÄT – National Quality Registry for Specialized Treatment for Eating Disorders

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Year started	1998
Public funding	1998-1999, 2001-2002, 2004-2005, 2007
Governing body	Örebro County Council
Competence center	KPV Resource Center
Transparency, unit level	No

Background and Aim

Eating disorders often debut during teenage years and often involve repeated care episodes for a longer period. Anorexia nervosa (AN) or bulimia nervosa (BN) are prevalent in approximately 1.5% of teenage girls and younger women at any given point in time. Information on the prevalence of unspecified eating disorders is deficient, but the condition is assumed to be at least 3 to 4 times more common than AN and BN. The percent of the total eating disorder population that receives care through childhood and adolescent psychiatry, general psychiatry, or specialized eating disorder services is unknown, but is probably relatively small (<1/3). Eating disorders involve substantial suffering for the individual and a substantially higher mortality rate compared to most other psychiatric disorders. The extended disease process also has major consequences for the family and generates very high costs for society.

Knowledge about long-term treatment outcomes is limited. The registry aims to monitor specialized eating disorder treatment in regard to changes in, eg, treatment incidence, case mix, type and extent of treatment interventions, treatment outcomes, and satisfaction with treatment.

In this way it is also possible to increase the understanding for eating disorders and provide a tool that the units can use to assess themselves in relation to others in the registry.

Coverage and Volume

Between 1999 and April 2007, approximately 5400 treatments were registered. In recent years, the percentage of registered treatments has increased substantially (in 2006 nearly three times the average of past years), but remains at only around 50% of eating disorder patients in psychiatry. Nearly all of the 30 units specialized in eating disorders in Sweden participate in RIKSÄT. The percentage

of teams specialized in eating disorders in general psychiatry is less certain. However, there is no reason to believe that more than a few would not participate in RIKSÄT.

Key Variables

The variables describe the patient (socially and psychologically), the treatment and its outcome, the treatment units, and patient opinions about care and its results.

Reporting Process

Patients are informed about RIKSÄT and asked for their consent. The information is entered via the Internet. Annual followups are reported via e-mail. Patients receive annual questionnaires regarding satisfaction with treatment and appearance of symptoms, and can choose to report via a postal questionnaire or the Internet.

Feedback Process

Report generators produce reports about the participant's own unit and the others in the registry. Reports on registry utilization are also sent out.

Quality Improvement

The registry has clearly shown the need for complex measures to highlight treatment outcomes. For example, it has not been possible to confirm a positive association between subjective treatment satisfaction and treatment success expressed as symptom improvement. To date, the improvements that could be observed locally relate primarily to systematic collection of rather extensive data related to individual treatments. RIKSÄT plans to develop methods to promote development, both to increase the level of coverage and as a means to disseminate evidence-based findings.

SIR – Swedish Intensive Care Registry

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<i>Year started</i>	<i>2001</i>
<i>Public funding</i>	<i>2002-2007</i>
<i>Governing body</i>	<i>Värmland County Council</i>
<i>Competence center</i>	<i>-</i>
<i>Transparency, unit level</i>	<i>Yes, from 2005</i>

Background and Aim

The Swedish Intensive Care Registry (SIR) collects and compiles information to support local quality improvement efforts and encourage comparisons over time within and among the participating intensive care units. In capturing data, we focus on a set of important issues that reflect the activities of the units. Rapid feedback of a unit's own data, and comparisons with other units, can create incentives for change. The cost and resources required by intensive care, and high morbidity and mortality rates, make it essential to create a registry that covers all diagnoses for intensive care instead of single-diagnosis registries. The aim is to achieve the best medical and nursing outcomes with the least staff and material resources for all types and levels of disease, without complications.

Coverage and Volume

SIR includes 62 intensive care units (June 2007) with 126 410 intensive care admissions registered from 2001 to 2006 (27 811 during 2006). Coverage is 52% for county district hospitals, 96% for county hospitals, and 100% for regional hospitals. Coverage of pediatric intensive care is 100%, thoracic intensive care is 57%, and neurological intensive care is 50%.

Key Variables

Information about the reporting unit, data on individuals, data on general and intensive care, complications, care burden, diagnosis, interventions, and surgical code are registered. The variables used in reporting are available on the website.

Reporting Process

The ICUs transmit data once per month in a report format with attached validation programs. All raw data are saved, sorted, and labeled based on the quality of the particular entry. Mortality data from SPAR are updated each week.

Feedback Process

Data are published on the website within 6 hours of reporting. It is possible for units to access several predefined reporting profiles or analyze their own data in table format.

The annual report is published during Sept/Oct the following year and includes the midyear mortality figures.

Quality Improvement

SIR has established ten national quality indicators: 1) Follow up of quality of life and functional status after intensive care, 2) Swedish risk-adjusted 30-day mortality, 3) Isolation due to bacterial multiresistance detected in the ICU, 4) Ventilator associated pneumonia, 5) Central vein catheter-related infection, 6) Readmission to the same ICU within 72 hours, 7) Missed potential organ donor, 8) Discharge from ICU at night, 9) Refuse or discontinue medical treatment at ICU, and 10) Occupancy level.

Transparent reporting by unit has promoted internal control. For example, reporting of Swedish risk-adjusted 30-day mortality contributed toward systematic quality improvement to identify problem areas that were addressed later. In some cases, ICUs were phased out when it became obvious that basic quality standards could not be met. We now see (June 2007) an equalization of previous differences in risk-adjusted mortality.

PsoReg – Swedish Psoriasis Registry

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<i>Year started</i>	<i>2005</i>
<i>Public funding</i>	<i>2005-2007</i>
<i>Governing body</i>	<i>Västerbotten County Council</i>
<i>Competence center</i>	<i>-</i>
<i>Transparency, unit level</i>	<i>Yes, from 2007</i>

Background and Aim

Psoriasis is a common skin disease influenced by genetic and environmental factors. Sweden has a prevalence of 2.3%, one of the highest in the world. Psoriasis is viewed to be a systemic disease that increases the risk for cardiovascular disease and metabolic syndrome. Also, between 20% and 40% of psoriasis patients have inflammatory joint disorders. The care of patients with severe psoriasis requires systemic intervention, but there are no verified data showing what percent of psoriasis patients would be candidates for systemic therapy. All agents currently available, including the new biologic drugs, involve a risk for serious long-term side effects that must be considered in relation to the benefits. The new agents are expensive and have not been followed for any extended period. Each individual unit has limited experience with these agents, and uncommon side effects may be difficult to detect. Comparative studies with established forms of treatment are lacking. Furthermore, greater knowledge is needed on how different systemic drugs affect different types of skin psoriasis and psoriatic arthritis in different subpopulations, eg, gender.

Coverage and Volume

PsoReg started in spring 2007. The goal is to achieve 90% coverage of Sweden's publicly financed health services within 5 years. PsoReg has initiated collaboration with other European registries to improve the quality of psoriasis care in Europe.

Key Variables

PsoReg registers basic data on inclusion date, disease onset, diagnostic criteria, and earlier treatment. At every visit, the severity level of psoriasis is registered, as are quality life, drugs prescribed to the patient, and possible side effects (side effects can be reported via PsoReg directly to the Swedish Medical Products Agency).

Reporting Process

Data are entered via the Web. The webpage includes logic and control functions.

Reporting Process

Analytical data should show the association between different interventions and psoriasis subtypes, side effects, and outcome measures. Data from the registry are reported continually to the participating units so that local outcomes can be viewed in relation to national outcomes. Participating patients receive immediate feedback through abstracts of their own data in the registry.

Quality Improvement

The goal is for PsoReg to become an active tool in routine patient care, but also a planning and monitoring tool for the reporting units. The registry will also contribute toward increasing the quality of care at the national level, eg, by comparing the ways that units manage their patients. Given the time pressures in health services, there is a risk that physicians select a therapy without adequate critical appraisal, or are not fully informed of the drug's advantages and disadvantages. Since the registry requires active input of standardized and objective data, the decision-making process will become more informed and evidence based, enhancing the potential for individualized therapy. Patients' increased participation and responsibility in reporting data also enhances the potential for good self-care.

InfCare HIV

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Website	www.infcare.se (under construction)
Year started	2003
Public funding	2003-2007
Governing body	Stockholm County Council
Competence center	-
Transparency, unit level	Planned for 2008

Background and Aim

HIV treatment has drastically reduced morbidity and mortality. However, several problems remain, eg there is no curative treatment, long-term side effects are common, and there is greater psychosocial exposure. InfCare HIV aims to improve positive treatment outcomes, raise the quality of life for HIV-infected individuals, and equalize HIV care across Sweden, between sexes, and risk groups.

Coverage and Volume

Thirteen HIV units, including the 4 largest, participate. During the autumn another 19 units joined. These 32 units comprise 91% of all HIV units and care for 96% of all adults and 99% of all children with HIV. It is expected that 100% of all HIV departments will participate during 2008. A large Danish department is also affiliated.

Key Variables

The percentage that achieve the goal of nondetectable virus in blood are registered at each visit. Also reported is the percentage of patients not treated, even though they fulfill the treatment criteria for pronounced immune deficiency (<200 CD4+ T-lymphocytes). Also registered are incidence of the therapy failure, resistance development, and mortality. The patient's perceived quality of life is currently registered once per year. These data are correlated with base data such as sex, risk group, and age.

Reporting Process

Patients are registered at their first visit to the HIV unit after diagnosis. Systematic followup of all patients takes place on return visits. Nurses or physicians enter the data via a Web-interface. Certain data are transferred electronically from the laboratory directly to the database. Every unit's data is found in a subunit of the central database.

The registry has a steering committee with representatives from the larger units and from 2 smaller units. It includes 14 members representing physicians, nurses, and social workers/psychologists. Each unit compiles its own data on its own initiative several times during the year and compares these with the unit's previous data and annual national data. Once per year, national data are updated, and the quality goals for the coming year are defined.

Quality Improvement

Several times during the year, the respective HIV units check whether their treatment goals for key variables have been met. Care and treatment strategies for patients who do not meet the goals have been discussed during rounds. Care and treatment have been adjusted and the effects have been registered at the individual level and group level every second or third month. Hence, the results for central treatment goals have been met and even improved. The percentage of patients with nondetectable virus has improved, and now exceeds 90% after more than 5 years of treatment, a figure that leads the world. Previously observed variations among HIV units have been reduced.

Swedish Therapeutic Apheresis Registry

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<i>Year started</i>	<i>1992</i>
<i>Public funding</i>	<i>2004-2005, 2007</i>
<i>Governing body</i>	<i>Västerbotten County Council</i>
<i>Competence center</i>	<i>-</i>
<i>Transparency, unit level</i>	<i>No</i>

Background and Aim

The collection of data on therapeutic hemapheresis (eg, plasma exchange, photopheresis, immunoabsorption, and stem cell harvesting) began in 1992. The registry has progressed from paper-based to Internet-based. An annual report is sent to all participating units and other interested parties. In 1995, the registry started to collect data on the side effects of therapeutic apheresis. Treatment is often given as a last resort in life-sustaining therapy for severe, progressive diseases such as Guillain Barre, glomerulonephritis including vasculitis such as Wegeners Granulomatosis and Goodpasture syndrome, stem cell transplantations, and LDL absorption in homozygotic patients unable to eliminate LDL cholesterol. Five different methods are used (eg, centrifuge method, filter, absorbers). Substitution methods involve various fluids, including different plasma components (eg, albumin, stored, frozen or cryo-poor plasma). These multifaceted aspects require a registry for quality assurance. The registry aims to optimize existing treatment guidelines, in part by surveying prevalence of side effects/treatment risks, and the effects of the same, and by comparing treatment strategies among centers to optimize quality throughout the country. The registry also includes the outcomes of treatments.

Coverage and Volume

The registry is national, and approximately 90% of the treatments are registered (4500 treatments per year for acute and chronic patients). These patients require specialized care for their conditions, and treatment is centered at major hospitals (not in primary care). The treatment numbers have been relatively constant in recent years.

Key Variables

The basic data registered at every treatment are: patient identity, diagnoses, sex, age, access, treatment methods, technical equipment used, substitution

solutions used, the prevalence, degree, and type of side effects, and assessment of the patient's functional quality and treatment results.

Reporting Process

Six units at university hospitals report directly via the Internet. Others send in forms that are entered into the central databank. The data can be coordinated with the World Apheresis Association Registry. Registration of complete patient identity data enables linking and matching with other registries.

Feedback Process

The data (Excel files) can be requested at any time by the unit that entered it, and can be retrieved even after the end of the year. National data are analyzed by the steering committee and compiled into annual reports including improvement analyses, which are sent to all units. Comparisons of unit, regional, and national data are presented. Feedback is also presented at national, regional, and local meetings.

Quality Improvement

The registry enables users to see the effects of treatment methods at a national level. It would have been impossible to draw conclusions on these effects from the unit level. For example, the experiences from better clinics show that calcium infusion as prophylaxis and the choice of substitution solutions reduced the discomfort for patients even when followed at other clinics. Matching and linking with other registries is possible. Treatment policies have improved at the clinics. Patients have become aware of the possibilities and risks of therapeutic apheresis in Sweden. Outcomes are improving steadily.

SKaPa – Swedish Quality Register in Caries and Periodontitis

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<i>Year started</i>	<i>2007</i>
<i>Public funding</i>	<i>2007</i>
<i>Governing body</i>	<i>Värmland County Council</i>
<i>Competence center</i>	<i>EyeNet Sweden</i>
<i>Transparency, unit level</i>	<i>Registry under construction</i>

Background and Aim

The oral diseases of caries and periodontitis are common across Sweden. Although these diseases affect a large share of the population, there are very few followups and assessments aimed at improving oral health and further developing methods in general dentistry to treat caries and periodontitis. The lack of national assessment inhibits the advancement of methods in general dentistry. Followup is needed in both public and private dental services.

Currently, we have inadequate information about the percentage of the population examined and treated by dental services, and the type of care delivered. Caregivers need to assess and develop services to optimally adapt resources and achieve the best possible health for patients. In the future, patients will be more likely to ask for information on the outcomes of services.

Fundamental aims of the Swedish Quality Register in Caries and Periodontitis (SKaPa) are:

- to improve and develop the quality of care and treatment outcomes in prophylactic and reparative methods related to caries and periodontitis.
- to promote development of national guidelines.

Due to individual-specific information on diagnosis, treatment, and treatment outcomes, the quality registry can enable followup of treatment at the participating units and provide a basis for national followup.

Coverage and Volume

The registry is under construction.

Key Variables

Basic facts concerning patients and caregivers.

Caries and periodontitis:

- prevalence of healthy and diseased teeth and the spread of the diseases down to the tooth level and, in some cases, the surface level
- preventive and/or rehabilitative treatments, ie, codified interventions.

Reporting Process

Data should be reported by transferring electronic files from the dental health services to a database dedicated to the quality registry, which is now under construction.

Feedback Process

During the construction phase, the registry will feed back the analyzed, descriptive data regarding the patients health, treatment interventions, and visit patterns. Feedback will be quarterly, complemented with an annual report.

Quality Improvement

Due to the slow rate of change in dental diseases, it will take at least 3 years before assessment is possible.

Swedish National Registry of Palliative Care

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<i>Year started</i>	<i>2005</i>
<i>Public funding</i>	<i>2006-2007</i>
<i>Governing body</i>	<i>Kalmar County Council</i>
<i>Competence center</i>	<i>-</i>
<i>Transparency, unit level</i>	<i>Yes, 2006 at hospital/municipal level, 2007 at unit level</i>

Background and Aim

The Swedish Palliative Registry aims to successively improve care during the final phase of life, regardless of caregiver. Hence, the registry has started to study care during the last week of life in all cases of death. The intent is to expand the window of time to include a greater part of the final phase of life.

Coverage and Volume

Approximately 92 000 people die in Sweden annually. We estimate that 80% of these deaths are expected by the healthcare services. Hence, these cases can be identified for appropriate planning and care. Nearly 6% of all deaths were registered in 2006. During the first half of 2007 we have achieved 10%.

Based on our recommended classification, we estimate there are nearly 6000 caregivers in Sweden. Currently, (June 2007) over 700 units have applied. The registry is represented in all county councils and in one third of all municipalities.

Key Variables

According to a survey of units, the most important variables are documented routines and the availability of staff. The most important parameters during the final week of life include providing information about dying to the patient and family, freedom of choice regarding place where care is delivered, and care planning based on the known needs of the dying. The new module calls for, eg, patient opinions regarding certain symptoms, starting when the attending physician informs the patient that the medical staff perceives the patient to be dying.

It will also be possible for the individual units to add their own questions that are time-limited, eg, regarding the use of IV solutions, physiotherapy, and choice of medication and dose.

Reporting Process

The first two forms, which include information about the local unit, and information about the dying person's final week of life, are entered via an encrypted page on the Internet. A new form is being introduced in autumn 2007. This form may be reported via the Internet, but may also be included in the medical record system that is later forwarded through the encrypted xml.

Feedback Process

Data are validated at entry and stored in a primary database. Immediately afterward, a secondary database, adapted to feedback data, is created. Using this for support, both the staff and the public can directly see the results in standardized reports on the website. Users may select certain items. Further access can be granted by the steering committee following special evaluation.

Quality Improvement

The questionnaire itself helps units review their routines and work methods. Symptom control and personal satisfaction have improved at units that have been reporting at least 12 months.

The registry held its first annual conference in April 2007, where the data from 2006 were presented. Registry members are participating more in various types of meetings to help present and interpret information, thereby promoting continuous quality improvement.

Senior Alert – National Registry on Nutrition, Fall Prevention, and Pressure Sores

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<i>E-mail</i>	<i>joakim.edvinsson@lj.se</i>
<i>Website</i>	<i>www.ucr.uu.se/senioralert</i>
<i>Year started</i>	<i>2006</i>
<i>Public funding</i>	<i>2006-2007</i>
<i>Governing body</i>	<i>Jönköping County Council</i>
<i>Competence center</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>No</i>

Background and Aim

Nutrition, fall prevention, and pressure sores are important issues among patients 65 years of age and older – in health and social services and in primary care/home care and municipal elder care. Patients who contract pressure sores, become undernourished, or fall may face lifelong suffering.

Care recipients (clients) are covered by various services and types of clinical specialties, regardless of the payer organization (governing body).

Good infrastructure and systems are lacking, as are comparative studies of daily routines that could improve care and services for the client.

A shared national database creates the prerequisites in these areas to assess a client's care episode and compare the work of the different units in preventing injuries and treating clients.

The primary goal of the registry is to use captured data to help routine services improve the health of the client. The registry provides possibilities to design new working methods. It will offer facts about services and a new dimension to develop knowledge among healthcare and social service staff. The quality registry should also be a resource for research and economic assessment.

Coverage and Volume

The registry covers citizens aged 65 years and older with some type of contact with the health system. Data are collected from specialists, primary care, and home care within the Jönköping County Council and most of the county's municipalities. Västerbotten County Council along with Umeå and Skellefteå municipalities began to assess risks in May 2006. The Norrbotten County Council, along with Luleå and Kalix municipalities, started working with the registry during spring 2007. Other municipalities and county councils, and private providers intend to join.

Key Variables

Description of the number of clients at risk, and descriptions of interventions and their outcomes.

Another process measure is the association between the number of risk assessments conducted, the total number of clients that meet the inclusion criteria, and the percentage of clients receiving preventive interventions.

Description of the percentage of clients that actually avoided care-related injuries, ie, falls, pressure sores, or undernourishment during the period of care.

Reporting Process

Reporting takes place via a Web-based form. This function, with national coverage and Web-based forms, started in autumn 2007.

Feedback Process

The units participating in the registry receive feedback on their on work via Web-based outcome generators.

Quality Improvement

Analysis of the test in Jönköping County Council shows that systematic efforts in preventive care are increasing substantially. The data suggest that approximately 70% of clients aged 65 years and older have been assessed for risks related to falls, undernourishment, and pressure sores. The registry has confirmed that approximately 50% of clients at risk are receiving preventive services of some type. Previously, it was not possible to measure or assess this.

Quality studies, performed with the help of students, have indicated a reduction in the number of pressure sores. The registry has also facilitated collaboration along the continuum of care

Quality Registry for Emergent Care

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<i>Website</i>	<i>-</i>
<i>Year started</i>	<i>2007</i>
<i>Public support</i>	<i>2007</i>
<i>Governing body</i>	<i>Stockholm County Council</i>
<i>Competence center</i>	<i>UCR</i>
<i>Transparency, unit level</i>	<i>Planned for 2008</i>

Background and Aim

Currently, Sweden has no national quality registry that focuses on the initial phase emergent care, ie, prehospitalization, emergency room, and emergency medicine departments. Several departments of emergency medicine in Sweden are engaged in extensive restructuring, which involves emergency medicine physicians, triage, and integrated emergency medicine departments. The goal is to make the continuum of emergency care more unified, effective, and safe for the patient. A quality registry offers the opportunity for patients and families, and producers and purchasers, to monitor care outcomes and be assured that they meet the standards for evidence-based, goal-oriented, safe, patient-focused, equitable, effective, and timely care. The primary aim is to develop a registry that supports quality improvement in clinical practice and meet the demands listed above. Furthermore, this type of registry quickly generates large databases that can be used in research. The registry will primarily cover Stockholm, Uppsala, Region Skåne, and Göteborg. Nationwide expansion of the registry is being planned.

Key Variables

Age, sex, reason (symptoms) for seeking care, vital parameters (pulse, blood pressure, level of consciousness, respiratory rate, temperature) ambulance transport time, total waiting time at emergency department, discharge, waiting time for physician, mortality, return visit within 72 hours. These variables relate to the priority level at the emergency room.

Coverage and Volume

The registry will cover all patients seeking emergent care. The total annual volume of departments included in the first phase is uncertain since we do not know at this time whether prehospitalization activities will be included.

Reporting Process

During 2007, collaboration will be initiated with UCR to construct an IT-based system for automatic transmission of data from the patient record.

Feedback Process

Findings from the registry are compiled at the local and national levels for analysis and reporting in conjunction with quality improvement activities, education, and seminars aimed at professionals, purchasers, and patients.

Quality Improvement

Once the registry is established, we see opportunities to improve emergent care and its efficiency. The findings could also provide a foundation for research that would enable care to be based on higher-grade evidence.

Registry Applicants that Did Not Receive Funding in 2007

The introduction describes several types of registries (pages 12-13) that did not receive economic support from the Executive Committee for National Quality Registries. They are not described in this document, and hence are not classified as national quality registries. These include local and regional quality registers, other national quality registers, and also the health data registers and cause of death register maintained by the Centre for Epidemiology (EpC) at the National Board of Health and Welfare.

To help complete the overview of quality improvement activities in Sweden, applicants that did not receive financial support in this funding cycle are listed below. The addition of this list provides a more comprehensive view of Sweden's current and future activities in healthcare quality improvement than would be the case if only the funded registries were presented. It is likely that several of the unfunded registries will re-apply and could be granted funding after further development.

Obviously, limited economic resources make it necessary to prioritize among the applicants. Registries might be denied funding for a variety of reasons. However, the most common is that the registry is under construction and not sufficiently developed. The list might include applicants that do not meet the current definition of a National Quality Registry, or will not develop into a registry for other reasons. No attempt was made to shorten the list, or select particular unfunded applications. However, in some cases, applications that clearly did not focus on the start-up or operation of a registry were excluded.

Finally, it should be noted that during the year there were obviously some registry activities that did not result in an application, eg, many activities involving collaboration between the registry managers and other European countries. Increasingly more Swedish registries are being used in translated versions, or serve as models in the development of corresponding European registries. These activities are relatively extensive, but as with the local and regional registers they have not been inventoried.

Presented below is a brief overview (including contact information) of registries that applied for financial support in 2007, but for various reasons did not receive funding.

National Quality Registry for Bladder Cancer

Registry Manager	Staffan Jahnsson Department of Urology, Linköping University Hospital
Phone	+46 (0) 13-22 20 00
E-mail	staffan.jahnsson@lio.se
Website	-
Year started	1997
Funding, past 3 years	-
Governing body	Östergötland County Council

National Gynecological Cell Testing Register**– preventive examinations for uterine cancer**

Registry Manager	Pär Sparén Institution for Medical Epidemiology and Biostatistics, Karolinska Institutet
Phone	+46 (0)8-524 861 02
E-mail	par.sparen@ki.se
Website	-
Year started	2002
Funding, past 3 years	2004-2006
Governing body	Stockholm County Council

BUSA – National Register of Treatment Followup for Severe ADHD

Registry Manager	Gunilla Thernlund, Dept. of Child and Adolescent Psychiatry, Lund University Hospital
Phone	+46 (0)46-17 44 09
E-mail	busa@kpvcentrum.se
Website	www.kpvcentrum.se
Year started	2004
Funding, past 3 years	2005 and Coordinated Mental Health (Psyksamordning)
Governing body	Region Skåne

Bipolär – National Quality Register for Bipolar Affective Disorder

Registry Manager	Bo Runeson, Department of Clinical Neuroscience, Karolinska Institutet
Phone	+46 (0)8-672 24 94
E-mail	bipolar@kpvcentrum.se
Website	www.kpvcentrum.se
Year started	2004
Funding, past 3 years	2005 and Coordinated Mental Health (Psyksamordning)
Governing body	Stockholm County Council

Schizophrenia

Registry Manager	Ing-Marie Wieselgren, Psychosis- and Psychiatric Rehabilitation, Uppsala University Hospital
Phone	+46 (0)18-611 00 00
E-mail	schizofreny@kpvcentrum.se
Website	www.kpvcentrum.se
Year started	2004
Funding, past 3 years	2005 and Coordinated Mental Health (Psyksamordning)
Governing body	Uppsala County Council

Swedish Anesthesiology Registry

Registry Manager	Lars Wiklund, Dept. of Anesthesiology and Intensive Care, Uppsala University Hospital
Phone	+46 (0)18-611 48 51
E-mail	lars.wiklund@surgsci.uu.se
Website	noname.doneit.se/sfai/default/.php
Year started	1999
Funding, past 3 years	-
Governing body	Uppsala County Council

Swedish Dental Implant Register

Registry Manager Björn Klinge, Institute of Odontology, Karolinska Institutet
 Phone +46 (0)8-524 880 40
 E-mail bjorn.klinge@ki.se
 Website www.SDIR.ki.se
 Year started 2004
 Funding, past 3 years 2004-2006
 Governing body Stockholm County Council

Swedish Quality Register for General Thoracic Surgery

Registry Manager Ingemar Vanhanen, Ulf Hermansson, Dept. of Thoracic Surgery, Linköping University Hospital
 Phone +46 (0)13-22 20 00
 E-mail ingemar.vanhanen@lio.se
 Website -
 Year started 2007
 Funding, past 3 years -
 Governing body Östergötland County Council

National Register for In-Hospital Cardiac Arrest

Registry Manager Johan Herlitz, Department of Metabolism and Cardiovascular Research, Sahlgrenska University Hospital
 Phone +46 (0)31-342 10 00
 E-mail hlr-centrum.su@vgregion.se
 Website www1.sahlgrenska.se/default.asp?sid=85
 Year started 2005
 Funding, past 3 years -
 Governing body Västra Götaland Region

National Quality Register for IVF

Registry Manager Christina Bergh, Reproductive Medicine Unit, Sahlgrenska University Hospital
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 Website -
 Year started 2006
 Funding, past 3 years 2006
 Governing body Västra Götaland Region

ERAS – Enhanced Recovery After Surgery

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 E-mail eras@ucr.uu.se
 Website www.ucr.uu.se/eras
 Year started 2007
 Funding, past 3 years -
 Governing body Stockholm County Council

LAROS (Drug-assisted Rehabilitation of Opiate Dependence)

Registry Manager Tommy Strandberg, Dependency Center,
University Hospital Örebro
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Year started 2007
Funding, past 3 years -
Governing body Örebro County Council

Metabolic Effects of Antipsychotic Drug Treatment

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Year started 2007
Funding, past 3 years -
Governing body Norrbotten County Council

National Primary Care Database

Registry Manager Jan Sundquist, Institute for Primary Care Research,
Center for Family and Community Medicine (CeFAM)
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Website www.allmanmedicin.nu
Year started 2006
Funding, past 3 years -
Governing body Stockholm County Council

National Quality Registry for Primary Care

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Year started 2007
Funding, past 3 years -
Governing body Norrbotten County Council

Applying for Funding as a National Quality Registry

This section briefly describes the process of applying for funding as a National Quality Registry. Further information is available at www.kvalitetsregister.se where a handbook on starting a quality registry can be downloaded. The EyeNet competence center published the handbook in collaboration with other competence centers and the Executive Committee.

Application Process in Brief

Applicants for funding as a National Quality Registry submit applications electronically via the Internet. Registries that received grants in past years have an account where they can develop and work with their application online. Other applicants can create a new account on the website that they will also be able to use in the next grant application cycle. The application period is coordinated with the state's budget year. Applications are submitted in September, decisions are rendered in December, and funds are paid out at the beginning of the next year. Allocation of funds for the competence centers is also coordinated with the budget year, but handled in a different manner. Applicants that previously received financial support must submit two separate documents – an annual report and activity report from the previous year – via the Web-based application system. These reports are thoroughly evaluated in considering applications for continued funding. The Scientific Advisory Committee and the Executive Committee discuss each application. The Scientific Advisory Committee formulates a written statement that is finalized after possible revision by the Executive Committee.

General Principles for Funding

The applicant must describe the registry under 5 main headings. These headings, along with selected subheadings, include:

- Contact information
- Summary
- Registry formalities – Steering committee, competence, and support
- Contents – Relevance, aim, coverage, measures, data capture, analysis/feedback, and quality improvement.
- Financial need

The above information is used to assess the quality of the application according to the following principles for allocating funds:

- a) Relevance: The relevance of the registry in quality assurance from a national perspective; the severity, volume, and cost of the problem, and the need for quality assurance in the subject area.
- b) Design: The potential of the registry to generate relevant information that can be fed back to the health services with the probable effect being quality improvement; design (form, content, working methods), support, process and outcome measures, and level of coverage.
- c) Competence: The ability of the registry manager and other applicants to operate a quality registry.
- d) Analysis/feedback: Analysis, reporting, and feedback of information to the health services and the importance of the registry in clinical quality improvement.

To receive funding, the registry should:

- Contain individualized data on diagnosis/problem, medical and other interventions, and outcomes.
- Have support within the profession, eg, as demonstrated by involvement of specialist societies.
- Provide for contact conferences and feedback.
- Cover publicly financed organizations regardless of operational structure and, if possible, include privately financed health services.

Websites

The websites of the respective quality registries and competence centers are listed below. Not every National Quality Registry has a website. Often when a registry is affiliated with a Competence Center, information about the registry can be found on the Center's website.

SALAR's website for National Quality Registries

www.kvalitetsregister.se

Web-based Grant Application System

<http://ansok.net/skl>

National Healthcare Quality Registries in Sweden

Swedevox – Respiratory Failure Registry

www.ucr.uu.se/swedevox

BORIS – Childhood Obesity Registry in Sweden

www.e-boris.se

CPUP – Quality Registry for Children with Cerebral Palsy

www.cpup.se

GallRiks – Swedish Quality Registry on Gallstone Surgery

www.ucr.uu.se/gallriks/

GYNOP – National Quality Registry for Gynecological Surgery

www.gynop.com

Macula Register

www.eyenetsweden.se

Swedish National Cataract Register

www.cataractreg.com

National Prostate Cancer Registry

www.roc.se

National Quality Registry for Esophageal and Stomach Cancer (NREV)

www.incanet.se

Swedish Quality Register of Otorhinolaryngology

www.kvalitet.onh.nu

Auricula – National Registry of Atrial Fibrillation and Anticoagulation

www.ucr.uu.se/auricula

National Catheter Ablation Registry

www.ablationsregistret.se

NDR – National Diabetes Registry

www.ndr.nu

PNQn – Perinatal Quality Registry / Neonatology

www.pnq.se

PsoReg – Swedish Psoriasis Registry

www.psoreg.org

RIKS-HIA – Registry on Cardiac Intensive Care

www.riks-hia.se

RIKSHÖFT – National Hip Fracture Registry

www.rikshoft.se

Riks-Stroke – National Quality Register for Stroke

www.riks-stroke.org

RiksSvikt – Heart Failure Registry

www.ucr.uu.se/rikssvikt

RIKSÄT – National Quality Registry for Specialized Treatment for Eating Disorders

www.kpvcentrum.se

SCAAR – Swedish Coronary Angiography and Angioplasty Registry

www.ucr.uu.se/scaar

Senior Alert – National Registry on Nutrition, Fall Prevention, and Pressure Sores

www.ucr.uu.se/senioralert

SEPHIA – Registry on Secondary Prevention in Cardiac Intensive Care

www.ucr.uu.se/sephia

SIR – Swedish Intensive Care Registry

www.icuregswe.org

Scandinavian Quality Register for Thyroid and Parathyroid Surgery

www.thyroid-parathyroidsurgery.com

SRR – Swedish Renal Registry

www.snronline.se

SOReg – Swedish Obesity Surgery Registry

www.soreg.nu

SveDem – Swedish Dementia Registry

www.ucr.uu.se/svedem

Swedish National Elbow Arthroplasty Register (SAAR)

www.ssas.se

Swedish Shoulder Arthroplasty Registry

www.ssas.se/axel

Swedish Corneal Transplant Register

www.eyenetsweden.se

Swedish Heart Surgery Registry

www.ucr.uu.se/hjartkirurgi/index.htm

Swedish National Hip Arthroplasty Register

www.jru.orthop.gu.se

Swedish Knee Arthroplasty Register

www.ort.lu.se/knee

Swedish Cruciate Ligament Registry – X-base

www.aclregister.nu

SMS – Swedish Multiple Sclerosis Registry

www.msreg.net

Swedish National Registry of Palliative Care

www.palliativ.se

Swedish Rheumatoid Arthritis Registry

www.rareg.net

Swedish Hernia Registry

www.svensktbrackregister.se

SKaPa – Swedish Quality Register in Caries and Periodontitis

www.skapareg.se

Swedvasc –Vascular Registry in Sweden

www.karlkirurgi.com/swedvasc.aspx

Swedish Therapeutic Apheresis Registry

www.iml.umu.se/medicin

Followup in Back Surgery

www.4s.nu

WebRehab Sweden – Quality Registry in Rehabilitation Medicine

www.ucr.uu.se/webrehab/

Competence Centers**EyeNet Sweden**

www.eyenetsweden.se

NKO

www.nko.se

UCR

www.ucr.uu.se

Executive Committee and Scientific Advisory Committee for the National Quality Registries in Sweden, 2007

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National Healthcare Quality Registries in Sweden 2007

This document describes 56 National Quality Registries and three competence centers that serve the Swedish healthcare system. Also presented briefly are other types of registries and the quality registries that applied for, but did not receive, public funding in 2007. The contents and number of National Quality Registries vary from year to year. This overview describes the situation in 2007.

Also presented are the aims, contents, and coverage of current registries and a description of how outcomes are reported back to the users and applied in the quality improvement process. The document also describes the central organization, and how to apply for financial support to start and operate a National Quality Registry.

The website address, e-mail address, and phone number are given for each registry and competence center.

Documents published by the Swedish Association of Local Authorities and Regions may be ordered by phone +46 (0)20-31 32 30 or at www.skl.se

ISBN 978-91-7164-280-6

For more information on National Healthcare Quality Registries in Sweden, please visit our website: www.kvalitetsregister.se



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