National Healthcare Quality Registries in Sweden 2005

This book describes 57 National Quality Registries and three “competence centers” that serve the Swedish healthcare system. Also presented briefly are over twenty registries that applied for, but did not receive, public funding in 2005. The content and number of registries changes from year to year. This overview describes the situation in 2005.

The catalogue presents the aim, content, and coverage of current registries, and describes how outcomes are reported back to the users and applied in the quality improvement process. The book also describes the role of central organizations and the routines in applying for financial support to start up and operate a National Quality Registry.

Homepage addresses, e-mail addresses, telephone numbers, and other contact information are presented for each registry and competence center.

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National Healthcare Quality Registries in Sweden 2005
The Swedish Association of Local Authorities and Regions (SALAR) and the National Board of Health and Welfare have joined forces for over a decade to support the development and use of National Quality Registries in health care. 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. 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 57 registries that receive economic support through the Executive Committee. Three competence centers for quality registries have been created. Over 100 registries and several new competence centers are requesting funding for 2006.

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, making them 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 improve our health services. In coming years, registries will play a key role as health services begin more extensive and open reporting of 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. The practical work in this area has begun, as has a review of legislation to enable ongoing, positive development.

The aim of this overview is to describe the situation in 2005. Beyond presenting the different registries and their applications in the quality improvement process, the document also describes the central organization and the routines in seeking financial support. Registry managers and homepages are listed to give readers the tools to easily acquire further information themselves.

The managers of the registries and competence centers prepared the summary descriptions of their respective registries and centers. Bodil Persson, Swedish Association of Local Authorities and Regions, managed the work of designing, compiling, and publishing this document. Other contributors were Marianne Holmberg, National Board of Health and Welfare and Jan-Erik Synnerman, Swedish Association of Local Authorities and Regions.

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This chapter discusses the design of the National Quality Registries in health care, 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, i.e., 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 a well-developed and functioning system 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 level. 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, 57 national quality registries 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 largely explained by their decentralized character. 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. The contents of the registry are continuously validated in different ways by the registry managers and the units that use the registry. 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 also used as a synonym for a department or clinic.
Transparency

Generally, a high level of transparency is desired when presenting registry results. In this catalogue transparency at unit level refers to registries that present results and identify the reporting unit by name in their annual reports. This does not necessarily mean that the results from the annual reports are easily accessible to the public. Not all registries have homepages, and those that do often target only participating units.

Other Types of Registries

Several other important registries are available in health care in addition to the local and regional quality registries, research registries, etc. In particular, the national Health Data Registry should be mentioned. The Health Data Registry is regulated by law, in contrast to the National Quality Registries, and consequently the coverage is high. However, the information contained in the Health Data Registry is somewhat limited, particularly as regards treatment interventions.

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

- The Patient Registry, which covers all admissions to hospitals in Sweden, and in recent years also data from some outpatient services.
- The Medical Birth Registry, which includes all deliveries in Sweden and information about the mother and child.
- The Cancer Registry, which contains information on people registered as living in Sweden and diagnosed with a tumor or tumor-like condition.
- The Pharmaceutical Registry, which started in October 2005 and contains information on all prescriptions filled in Sweden.

Furthermore, the EpC is responsible for:

- The Cause of Death Registry, which provides a basis for official cause of death statistics and maintains data on cause-specific mortality for describing the health of the population.

In a quality registry context, these registries play an important role, e.g., in validating the data in the National Quality Registries. A person from EpC is available to the registry managers that need statistical support or assistance with validation of this type. Otherwise, it is important to note that these registries were created for different reasons, and are used for somewhat different purposes, than the quality registries.
Competence Centers

Three special competence centers for 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 manage. Hence, continued development of the registries could be assured 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. Competence centers have expertise profiled on two main dimensions; a) one or more specialty areas, eg, orthopedics, cardiovascular disease, or eye-related care, and b) “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. They decide on the allocation of financial resources to registries and competence centers. To date, funds have been allocated mainly through agreements between the state and the county councils under an arrangement referred to as “Dagmar funding”, but other financial sources exist or 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 decided on 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 manage-
ment, 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.

**Work Process at the Central Level**

Based on the agreement with the Swedish Association of Local Authorities and Regions, the National Board of Health and Welfare has served as the central administration for quality registries during most of the past decade. This mainly involves the administration and handling of annual applications and meetings of the Executive Committee and Scientific Advisory Committee. Other administrative activities, eg, producing printed material or arranging the annual quality registry conference, have been shared among the partners.

Two to three individuals at the Swedish Association of Local Authorities and Regions and the National Board of Health and Welfare are continuously involved in the relatively extensive and varied work with the National Quality Registries. This involves informational activities, participating in registry conferences and steering committee meetings of the competence centers, 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, research findings, and clinical improvement efforts during the year, these meetings are often used to discuss transparency and the publication of results from specific units. When consensus has been reached, the registry managers can make the appropriate changes in their annual report and registry homepage. 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, and Halmstad.
UCR – Uppsala Clinical Research and Registry Center

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Director: Lars Wallentin, Professor, Cardiology
Year started: 2002
Employees: Around 35 at UCR, whereof 18 are engaged mainly with registries

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 Sweden today. The areas of interest expanded during the development phase and now include diseases affecting other areas, eg, lungs, kidneys, gastrointestinal tract, neurology, and the musculoskeletal system. Other activities include health-oriented research, particularly concerning the effects of diet and functional food.

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. Competence centers have a steering committee and a 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 people that develop and operate web-based registries, ie, web programmers, system programmers, database programmers, and computer operation and security staff. A methodology group of six people, including statisticians and data managers, 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 staff, secretaries, and economists, work directly with purchasers, local registry administrators, and participating units. The center also has a group of two to three people providing services in systematic quality improvement.

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 help services are offered by UCR. Informational material and registry homepages are developed on request.

**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 Sjunet². 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, MIMER as a related 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 (personnummer) 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 (MIMER) to the analytical database (SAS). Hence, current data are always available for the reports that generate statistics for the user. On special web pages, 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.

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

The following registries are active in UCR:

- RIKS-HIA – Registry on Cardiac Intensive Care
- RIKS-HIA International – English version of RIKS-HIA
- SEPHIA – Registry on Secondary Prevention in Cardiac Intensive Care
- HKIR – National Registry for Heart Surgery
- SCAAR – Swedish Coronary Angiography and Angioplasty Registry
- SwedVasc – Vascular Registry in Sweden
- RiksSvikt – Heart Failure Registry
- GUCH – Grown-Up Congenital Heart disease Registry
- SWEDEVOX – Respiratory Failure Registry
- GallRiks – Swedish Quality Registry on Gallstone Surgery
- SweDem – Swedish Dementia Registry
- AuricuLA – Registry for Atrial Fibrillation and Anticoagulation
- Registry for Lung Cancer
- Registry for Hydrocephalus and Arteriovenous Deformity in the Brain
- NjuR – Registry for Kidney Diseases
- SITS – Safe Implementation of Thrombolysis in Stroke

Negotiations on collaboration to develop several other registries are under way, including the Swedish Registry for Active Uremia Care (SRAU), the Swedish Dental Implant Registry, the Registry for Palliative Care, and the Nursing Registry.

Current Activities

In addition to the development, improvement, and operation of new and old registries, UCR promotes and supports the use of registries for transparent reporting, systematic quality improvement, scientific reporting, and broad national and international collaboration.

Improvement Process and Outcomes

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 created public attention and contributed substantially toward increasing participation in and improving quality of registration and improving the 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. Randomized controlled trials have also shown that the methods can, in the short term, achieve substantial improvements in care. The QUICC (Quality Improvement in Cardiac Care) project has received major national and international attention. In cardiac care, QUICC has been requested by several hospitals and has consequently developed as a service that UCR can offer to interested hospitals. UCR also has developed competence and participated in similar improvement projects for other registries, eg, the diabetes registry.

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 is being carried out on new and expensive cardiovascular interventions such as 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, patients’ participation in making treatment decisions and patients’ satisfaction with health services is also being studied. A method promoted by UCR – systematic evidence based quality improvement in interaction with continuous outcome measurement and interactive education via the Internet – is being scientifically assessed in recognized national and international randomized trials.

Other Activities
Nationally, the competence centers have ongoing collaboration with all hospitals in Sweden and many specialties and specialty societies. Internationally, the competence centers collaborate with registry centers in England, Germany, and the United States. As regards research, UCR is collaborating with cardiovascular centers in Great Britain, Spain, France, Italy, and Poland to develop quality improvement processes supported by quality registries. In the global SITS Registry, UCR provides registry services to 31 nations on 4 continents.

UCR also participates in directing an EU project to standardize registry variables in Europe. The project has achieved EU Commission approval of the proposed Cardiology Audit Data Standards (CARD) 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 set up to be multilingual.

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 the implementation of new national guidelines. Presenting and discussing the results from the national guidelines comprise an important aspect of education on delivering cardiovascular care as presented in domestic and international textbooks and review articles on cardiovascular disease.

Future Plans
The general goal is to maintain and develop Internet-based registry methods and tools for evidence based development of health services, mainly in cardiovascular care. Efforts are focused on further development of interactive, Internet-based registration and direct transmission from electronic patient records and other databases, interactive statistical and reporting modules for quality control and quality improvement, and Internet portals for information, communication, education, and collaboration. The intent is also to develop Internet-based tools for decision support as a means to improve care and test multilingual versions for international collaboration. Planning also includes studying the utility of Internet-based tools in clinical practice to continuously improve and monitor care and its outcomes, and to identify and contribute toward solving problems in health care. To an increasing extent, the systems and databases will be used to assess new diagnostic and treatment methods in relation to patient benefit and costs in multidisciplinary collaboration among several national and international groups. The development of this methodology should contribute toward improving the efficiency and equity of care in Sweden and Europe. The National Board of Health and Welfare, the Swedish Association of Local Authorities and Regions, the Swedish Heart and Lung Fund, and the Swedish Foundation for Strategic Research support development of this high-profile area in Swedish quality improvement and research in health care.
EyeNet Sweden

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Director: Mats Lundström
Year started: 2003
Employees: 5

Background
EyeNet Sweden was formed on January 1, 2003 with the aim to serve as a competence center for quality registries. The Swedish National Cataract Registry with its extensive experience in data collection, clinical quality improvement, and research provided the foundation for developing a competence center. Furthermore, the Cataract Registry could offer expertise in the areas of patient benefit and cost effectiveness. During 2003, the field of public health was also included in the areas that EyeNet Sweden intended to develop. The Swedish National Cataract Registry was formed in 1992 and currently includes over 750,000 cataract operations.

From the outset, EyeNet Sweden affiliated itself with two established quality registries: the Swedish Corneal Transplant Registry and the Macula Registry. A childhood cataract registry was formed in 2003 since the disease and its treatment differ substantially from common cataracts. Refractive surgery is an expanding area in ophthalmology. A registry for assessing surgical methods to correct vision defects by changing the refraction in the eye has been under development since 2005, as has a registry on eye fundus changes in premature babies. A glaucoma registry is also under construction. Specialists in these fields within ophthalmology have created the registries mentioned.

Competence
Associates at EyeNet Sweden include:

Mats Lundström, Adjunct Professor in ophthalmology with many years of experience in the operation of national quality registries. Registry Manager of the Swedish National Cataract Registry since 1992. Chair of ECOS (European Cataract Outcome Study) and ES-CRS/ASCRS3. Past Director of the Department of Ophthalmology, Blekinge Hospital (1980–2003).


Kristin Svensson, Department Secretary with experience as an R&D secretary in Blekinge since 1995. Administers research methodology courses in collaboration with the Department of Social Medicine in Malmö.

3 European American Society of Cataract and Refractive Surgeons Outcome Study
Several external consultants in various fields participate in the development of EyeNet Sweden:

Clinical Epidemiology  
Tomas Troëng, Jonas Ranstam
Statistics  
Jonas Ranstam
Economics  
Pontus Roos, Rolf Färe
Ophthalmology  
Ulf Stenevi, William Thorburn, Kristina Tornqvist, Birgitta Bauer, Margareta Claesson, Gerd Holmström and Bo Andersén.
IT  
Department of Information Technology, Blekinge Hospital, Leif Fransson, IT Secretary, Profdoc Lab, Inc.

Services

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 by the profile that EyeNet Sweden established for itself. On request by registries or other interested parties, EyeNet Sweden can:

- Support the introduction of new registries in ophthalmology and other specialties by giving practical advice, education, and examples of web-based forms and reports.
- Manage, in return for financial remuneration, the construction and operation of National Quality Registries on the technical platform developed in collaboration with Profdoc Lab, Inc.
- Compile, analyze, and present registry data in a way that it is useful for different users, eg, for health planning, clinical quality improvement, and clinical research.
- Collaborate in national monitoring of healthcare quality and outcomes and, for example, in developing national guidelines.
- To furnish statistical information from the quality registries to further develop research in the area.

IT Solutions

EyeNet Sweden collaborates with Profdoc Lab AB, which constructs web-based forms for registry data and develops monitoring forms and reports according to user specifications. The administration and servers for EyeNet Sweden are located at the IT unit, Blekinge Hospital, Karlskrona, Sweden.

Affiliated Registries

The following registries are affiliated with EyeNet Sweden, which manages registry operations:

1. The Swedish National Cataract Registry was formed in 1992, and by 2004 it included 98% of all cataract surgeries performed in Sweden.
2. The Swedish Corneal Transplant Registry, a national registry, was formed in 1996 and covers corneal transplants performed in Sweden.
3. The Macula Registry started in 2003 and aims to assess the different methods available for treating diseases of the macula. Not currently web-based, but moving in that direction.
4. The Registry of Congenital Cataract was formed in 2003 and aims to design and assure quality treatment to achieve the best possible vision for affected children. In children, surgery at an early age is particularly important so that vision develops and functions normally.
5. The Registry of Refractive Surgery is under construction and covers different surgical methods to correct vision defects by changing the refraction in the eye. To promote good quality in refractive surgery, the registry aims to inventory methods that can be applied and assess the results.
In addition, the following registries are being developed or discussed:

6. A registry on eye changes in premature children is in the making, and experts in the field have decided to submit a registry application. Children born prematurely may have changes in the retina. If the changes are detected and treated, treatment can improve the child’s vision. The registry aims to assure quality of screening in premature children. A registry will also facilitate studies of, eg, national and regional incidence, the natural course, and risk factors. The registry will also collaborate with PNQ (Perinatal Quality Registry).

7. The Registry of Surgical Methods for Glaucoma is under construction and is intended to survey surgical methods and their outcomes in Sweden.

8. The European Cataract Registry has been administered from the Swedish National Cataract Registry in Karlskrona since 1995. Over 50 units in Europe and elsewhere in the world voluntarily participate in the registry. Since 2003, the registry has been affiliated with EyeNet Sweden.

Current Activities

EyeNet Sweden has chosen to prioritize the improvement process in ophthalmology, and from the outset has managed the national Q-reg project. The competence center also works to start and develop new registries within the specialty and in other disciplines. Existing registries need to be developed further. During 2004 and 2005, EyeNet Sweden developed a handbook on starting quality registries.

Improvement Process and Outcomes

EyeNet Sweden has managed a Q-reg project, involving 9 participating units in Sweden, that was initiated by the Swedish Association of Local Authorities and Regions in collaboration with Qulturum Educational Centre, Jönköping. The aim of the project has been to create a national indication model for cataract surgery that differentiates waiting times according to disease grade and subjective problems, and to create a process that considers waiting times from the patient’s first contact with health services for their disorder. The results include a patient questionnaire to assess subjective, cataract-related problems in daily activities, driving, and independent living. Questionnaire responses are compiled into an indication model known as NIKE (National Indication for Cataract Extraction) and complemented by visual acuity and surgical assessment of the patient’s cataract. A digital version of the questionnaire and NIKE is available. In addition to creating the indication model, some of the 9 participating units have reduced waiting times to surgery by directly calling patients with questionable cataracts (optician referrals) for preliminary examination prior to surgery.

EyeNet Sweden was commissioned by the Swedish Association of Local Authorities and Regions to develop a proposal for national indications for cataract surgery and a proposal on e-mail referral to prepare for the introduction of the national waiting time guarantee on November 1, 2005.
Research
Examples of research projects currently under way at EyeNet Sweden are listed below.

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<td>Mats Lundström, Eva Wendel.</td>
<td>To study how long improved, self-rated vision is maintained after cataract surgery.</td>
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<td>A randomized trial of self-rated vision after concurrent bilateral cataract surgery compared to operating on one eye at a time.</td>
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Other Activities
Since the EyeNet Sweden competence center is in the development phase, its activities have expanded with time. Other activities that we have been engaged in since we started in 2003 include:

- EyeNet Sweden arranges annual development conferences for affiliates and planned registries.
- A handbook on starting quality registries was published in June 2005. The handbook is available in pdf format from www.eyenetsweden.se or through www.kvalitetsregister.se. It may also be ordered in print via eyenetsweden@ltblekinge.se.
- A European registry for refractive surgery and cataract surgery is being created, as commissioned by ESCRS (European Society for Cataract and Refractive Surgeons). A contract has been signed with ESCRS to promote quality improvement and create greater confidence in refractive surgery among patients and providers by raising the standards and making the procedure safer in Sweden and Europe. Web-based forms and report abstracts have been developed in collaboration with Profdoc LAB AB, an IT consulting company.
- Collaboration with primary care to develop a leg ulcer journal and early diagnosis of gastrointestinal cancer.
- User meetings for registries.
- Discussions are ongoing concerning national quality registries in palliative care.
- EyeNet Sweden provides “Improvement and Quality” education at “Leadership and Personal Development” courses for resident physicians.
Future Plans
For the future we envision greater opportunities to participate in clinical quality improvement in health services that use quality registries as a measurement tool. The quality improvement process is not research, but rather an approach to work that bridges the gap between evidence based knowledge and healthcare routines. Up to now, we have worked in our specialty areas, but the methodology is the same regardless of specialty.

The competence center will continue to actively support existing registries in ophthalmology and other specialties at the regional, national, and European levels. There are also plans to promote development in registry activities toward web-based entry of registry data to enable rapid feedback and analysis at the local level. EyeNet Sweden’s plan for the future is to continue promoting research in our profile areas of patient benefit, public health, and cost effectiveness. Recruitment of additional statisticians is part of our future plan.
NKO – National Swedish Competence Center of Musculoskeletal Disorders

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Homepage: www.nko.se
Directors: Center Director: Lars Lidgren, Operational Director: Jonas Ranstam
Year started: 2003
Employees: 4

Background
National quality registries for knee replacement, hip replacement, and 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 diseases. The development of registries offers considerable opportunities to improve care by identifying the methods, drugs, and medical 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 Göteborg 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 diseases.

The competence center is directed by a steering committee. Lars Lidgren, Lund is Chair and other members are: Peter Herberts, Göteborg, Ola Hägg, Göteborg, Olof Johnell, Malmö, Johan Kärrholm, Göteborg, and K-G Thorngren, Lund.

In addition, NKO has a reference group comprised of: Gunnar Németh, Stockholm, Olle Nilsson, Uppsala, Leif Ryd, Linköping, Olle Svensson, Umeå, and representatives of the National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions.

Competence

Acquiring new knowledge from a registry of health data is a task that becomes more complex with time. The volume of available data is growing. Since 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 skills in managing and analyzing data. By using advanced technology and modern methodology, the construction of databases, collection and analysis of data, and performance of biostatistical/epidemiological analysis become more effective, more reliable, and less expensive.

Hence, NKO is strengthening its professional resources in data management,

Services

NKO provides education and consulting services for established quality registries and new registries under development throughout Sweden. NKO offers expert advice in selecting data systems, planning new studies, and analyzing and reporting on collected data.

NKO also offers space for registries in a modern SQL database system and carries out studies under contract.
IT Solutions

NKO in collaboration with Inxl AB is 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 participating registries is based on delegation of responsibilities by the registry manager 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.

Avinova AB manages the practical operations of the registry system in a modern server facility where security is high: fire and break-in protection, reserve power, SMS surveillance, etc. Backup copies of the data are made daily.

Affiliated Registries

The NKO competence center has established a network for collaboration in the field of musculoskeletal diseases. The network includes the following registries, whereof some are established National Quality Registries with financial support from the Swedish Association of Local Authorities and Regions and the National Board of Health and Welfare (indicated by *) while other registries are being developed. Registries on the Internet can be reached via the NKO homepage.

The Swedish Knee Arthroplasty Register* was established in 1975 as the first quality registry in health care. It aimed at early detection of inadequate prosthetic models and techniques in knee arthroplasty. The registry is national in scope. In recent years, greater focus has been placed on monitoring patient satisfaction. Lars Lidgren, Lund, manages the registry.

The Swedish National Hip Arthroplasty Register* started in 1979. All units that provide hip replacement surgery participate. Peter Herberts, Johan Kärholm, and Göran Garellick from Göteborg manage the registry. The Swedish Orthopaedic Association appoints the board of the registry.

The Hemi-arthroplasty Registry started in January 2005. Since an increasing share of patients with cervical hip fractures receive hemi-arthroplasty, it was deemed important to monitor these cases separately and compare them with traditional fixation. The registry is managed by Cecila Rogmark, Malmö, and K-G Thorngren, Lund.


The Swedish Shoulder Arthroplasty Registry was established in 1999 by the Swedish Orthopaedic Association’s Shoulder and Elbow Section. The aim is to register all shoulder arthroplasties in Sweden, including primary surgery and revisions. Björn Salomonsson, Stockholm, is the contact person for the registry.

Quality Registry in Back Surgery* was organized by the Swedish Society of Spinal Surgeons. All units in Sweden that offer back surgery participate. The registry is web-based and administered by the Swedish Society of Spinal Surgeons’ Registry Group: Björn Strömqvist, Lund, Olle Hägg, Göteborg, and Peter Fritzell, Falun.

The Swedish Cruciate Ligament Registry developed through the collaboration of units in Sweden that provide cruciate ligament surgery. The aim is to compile data on surgical techniques and outcomes in a common database. Magnus Forsblad, Stockholm, is the contact person.

The Quality Registry for Children with Cerebral Palsy (CPUP)* is based on standardized national follow-up of children with cerebral palsy and aimed to assess old and new therapies. Gunnar Hägglund, Lund, manages the registry.
The Registry of the Scandinavian Sarcoma Group was founded in 1986 and aims to improve the diagnosis and treatment of sarcoma patients, provide a basis for treatment recommendations and clinical guidelines, and create the conditions for research and quality comparisons among sarcoma centers. Henrik Bauer, Stockholm, manages the registry.

The Registry of the Southern Sweden Arthritis Therapy Group (SSTAG) collects information on patients in the southern healthcare regions who are treated with biologic drugs for arthritic disease, usually rheumatoid arthritis, but also spondylarthitis and psoriatic arthritis. The registry includes outcome parameters and monitors side effects. Pierre Geborek, Lund, is the contact person.

The Rheumatic Surgery Registry started in 2004 and is a quality registry to monitor patients with inflammatory joint diseases in terms of function, activity grade, and quality of life. Anna Nilsson, Halmstad, manages the registry.

The Nordic Movement Analysis Registry was established in 2005 as the first coordinating registry for recording three-dimensional movement data. It enables, eg, analysis on how people walk before and after injury. The aim is to optimize and assess treatment of patients with orthopedic and neurological disorders. Bengt Söderberg, Lund, initiated and manages the registry.

For historic reasons, most of the registries currently manage their own operations. The Knee Arthroplasty Registry, the CPUP Registry, and the Nordic Movement Analysis Registry are now incorporated in the IT system of the competence center. Other registries partly utilize the competence center’s IT system for data analysis and reporting, and operational services are being planned for others. Medical interpretation and reporting are, however, managed by the registries themselves.

Current Activities

NKO participates in national efforts to improve accessibility to elective care. The project, initiated by the Swedish Association of Local Authorities and Regions, is partly in preparation for the waiting time guarantee that becomes effective in November 2005. NKO’s assignment is to develop clear and uniform indications for several orthopedic areas and make recommendations to follow up indications. Currently, a completed document addresses indications for knee and hip replacement, herniated disc, spinal stenosis, segmental pain, and meniscus and cruciate ligament injuries. The document is available on the homepage. NKO has also been assigned to develop indications for shoulder and foot surgery, estimated to be complete in January 2006. Additional work includes developing and testing the proposal for monitoring, which was submitted in the first document.

Improvement Process and Outcomes

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 underway 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 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 need 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 otherwise would be the case. Hence, it is important to identify problems early to limit patient suffering and cost.
Competence Centers

The knee and hip registries have been successful in warning 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. Nevertheless, it is important to continue the quality improvement process. New implants and surgeries are being continually introduced and require followup.

Research

The research activity at NKO focuses on projects grounded in existing registries and relevant to clinical quality improvement.

- Prosthesis survival (revision risk) and problems related to this are a natural aspect of followup in prosthesis registries.
- The association between surgical volumes and outcomes may have a substantial influence on the opportunities to improve clinical performance.
- The patient’s situation is illuminated by studies on general and disease-specific quality of life. Research on comorbidities and mortality is also under way.
- Registry information can offer good opportunities to illuminate factors of importance for the onset of disease. Genetic epidemiology is used to study the impact of hereditary and environmental factors on musculoskeletal diseases.

Other Activities

NKO collaborates with EyeNet Sweden and participates in international registry collaboration.

NKO also has taken the initiative to develop educational programs in registry administration. The first course is planned for February 2006.

In collaboration with rheumatologists, greater collaboration is planned with the early arthritis registries, eg, in southern Sweden. There are early arthritis cohorts in Lund (contact: Elisabeth Lindqvist) and Malmö (contact: Lennart Jacobsson). The units in Spenshult, Helsingborg, Kristianstad, SU/Mölndahl, and Karolinska University Hospital Huddinge are involved in the BARFOT Registry (contacts: Ingiäld 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 increasing collaboration concerning earlier arthritis 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 studying musculoskeletal pain from an epidemiologic perspective.

Future Plans

NKO plans to improve the opportunities to utilize registry information in clinical quality improvement through more extensive sharing of information by the different registries.

Plans also include development of new statistical and accounting functions in the NKO system to feed back information from the registry.
**Background and Aim**

Each year, for reasons unknown, increasingly more children at increasingly younger ages are being diagnosed with diabetes. SWEDIABKIDS makes it possible to monitor the content and outcome of care for childhood diabetes. Insulin pumps and other devices are becoming easier to use, even in treating the youngest children. New insulins are being introduced regularly. Such changes are best assessed at a national level. A comprehensive childhood diabetes registry also provides a base for other research. Diabetes complications can be observed already during childhood, but complications that require treatment are uncommon. Knowledge about the effects of diabetes during childhood is important if the patient later develops complications as a young adult.

**Coverage and Volume**

In Sweden, all children and adolescents (≤18 years of age) diagnosed with diabetes (over 700 children per year) are reported to SWEDIABKIDS. For 85% of Sweden’s 6400 children with diabetes, data are analyzed from each visit (>16 000 visits/year).

**Variables and Measures**

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. Over 90% of all units use the section’s data registry. All followup data are reported electronically. Twice per year, control lists are used to validate data on all new cases.

**Feedback Process**

The units can easily (push-button method) select and assess their own data. National data are divided into 1-year intervals and gender for analysis. A unit’s results are compared with the national average, and with results from other units, and are presented in an 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. HbA1c has improved successively in many places. Variations in outcomes have decreased among units. Blood sugar control, measured as HbA1c, is substantially better during the summer months than during the remainder of the year. SWEDIABKIDS shows that increasingly more children, even the youngest, use insulin pumps. The use of new insulin types is increasing, and the new, fast-acting analog insulins now dominate as mealtime insulin. It has become possible to give insulin on more occasions (mealtime insulin), even to the youngest children. Compliance with clinical guidelines is evident. It is now possible to introduce age-specific target values, and this is now being discussed.
Background and Aim
Obesity among children and adolescents is increasing rapidly in Sweden. Also, 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 registry can be used to assess the quality of local health services in relation to services in Sweden as a whole.

Coverage and Volume
Approximately 50,000 children in Sweden are estimated to have obesity that requires treatment. Earlier surveys have shown that fewer than 10% of Swedish children are treated within the health services. The registry is in a startup phase and began to register children in July 2005. Initially, children from four different units are being registered. It is projected that, within a year, 90% of pediatric units treating obesity in Sweden will be included in the registry. The target is to have 2000 children in the registry by the end of 2005.

Variables and Measures
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
At least once per year, the units report on children and adolescents treated for obesity. 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 will have the opportunity to add their own modules to analyze specific issues.

Feedback Process
The registry will report on its results annually. Participating units will also have full access to their own patient data online, and it will be possible to calculate data locally and compare it with the national average. In-depth analysis of specific issues will be possible when sufficient data have been collected.

Quality Improvement
Since the registry is in a start-up phase, improvement cannot be measured. The aim, however, is that the registry will contribute: a) toward improving the treatment of childhood obesity throughout Sweden, and b) toward eliminating the wide regional variations in access to care for childhood obesity.
PNQn – Perinatal Quality Registry / Neonatology

**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 follow-up of various risk groups, e.g., premature births. Here, it is particularly important to have feedback from longitudinal data on obstetric and neonatal outcomes. In Sweden, detailed, quality-related data on extremely premature births are being registered for 3 years. PNQn constitutes a database for the study. This database is expected to become permanent within the framework of PNQn.

**Coverage and Volume**

Since the registry began in its current form, there has been a strong increase in the number of admissions registered. During 2004, data on 5600 admissions were registered, corresponding to just over 50% of all neonatal admissions. When admissions from Region Skåne (southern Sweden) are added in 2005, the national registry will cover approximately 75% of the neonatal admissions in Sweden. With time, all units are expected to join the registry.

**Variables and Measures**

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 demographic data 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 ones) can be added to the registry.

**Reporting Process**

During the inpatient stay, data are captured on a special form and then registered in the database via the Internet – 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) and, at the latest, conclude at age 6 months if care has been continuous. In hospitals where the neonatal unit provides care for older children, the option exists to include these children until they reach 6 months of age.

**Feedback Process**

Feedback takes place via an Internet-based statistical module that allows all reported data to be searched, filtered, and presented online. A unit’s own data can be compared with the national average and the level of care. An automated annual report has been developed and became accessible in the autumn of 2005.

**Quality Improvement**

The registry has now reached the level where it is possible to study outcomes and compare different centers. During 2005, the steering committee is focusing on 3 follow-up projects that offer an opportunity to improve care routines. The steering committee intends to analyze the treatment of patent ductus arteriosus in premature children, antibiotic treatment during the neonatal period, and breastfeeding rates when discharged from neonatal care. Furthermore, the Swedish Medical Birth Register will be used in validating PNQ data.
Swedish Childhood Rheumatism Registry

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**Homepage:** www.blf.net/reumatologi

**Year started:** 2006  
**Public funding:** 2005  
**Governing body:** Uppsala County Council  
**Competence center:** Non-affiliated  
**Transparency, unit level:** No

### Background and Aim

Approximately 1800 patients in Sweden have juvenile idiopathic arthritis (JIA). Some of these children have severe disease and need antirheumatic medication of the same type used by adult patients, so-called biologic drugs. These are used when other drugs have been inadequate. Currently one of these drugs has been approved for use in severe multiple joint disease in children over 4 years of age, but the others have not been approved for children. Little is known about the long-term effects in children receiving biologic drugs. Short-term treatment shows that these drugs often yield good clinical improvement, while serious side effects are uncommon.

The aim is to identify the children that receive biologic drugs and follow them for effects and possible side effects.

### Coverage and Volume

After a startup phase, the goal is to include all departments of pediatrics in Sweden. Biologic agents are used to treat around 10% of the estimated 1800 children in Sweden with the disease.

### Variables and Measures

The variables we aim to follow are internationally accepted and validated clinical variables that describe the disease profile and its activity.

### Reporting Process

A secretary, or possibly a physician, at each unit will enter the data directly into the program or via a printed form.

The registry is web-based and will have its own platform in the Swedish Rheumatoid Arthritis Register.

### Feedback Process

At the unit level, the data can be analyzed for the unit’s own patients. The data will be analyzed continually via the Internet service of the registry and reported at least annually at the meeting of the Working Group on Pediatric Rheumatology (Swedish Pediatric Association).

### Quality Improvement

The registry offers major opportunities to monitor quality, draw comparisons within the entire patient group, and assess the treatment of individual patients. A prospective registry provides the opportunity to assess the benefits of the increasingly more expensive and powerful drugs used now and in the future.
Background and Aim

The volumes and costs of catheter-borne interventions (e.g., balloon dilatation) in treating coronary heart disease have increased substantially due to severity, high prevalence, changing indications, decentralization of services, and introduction of new interventional techniques.

This registry aims to monitor and improve catheter-borne interventions in terms of volumes, methods, and outcomes. The participating units can monitor trends and draw comparisons between their own hospitals and the nation as a whole.

The long-term goal is to achieve better, more effective diagnosis and treatment of patients with coronary heart disease – and thereby contribute toward lower morbidity and mortality and greater cost effectiveness in care.

Coverage and Volume

All 30 hospitals that provide PCI (percutaneous coronary angioplasty, or “balloon angioplasty”) and/or coronary angiography report to the registry. The level of reporting is 100% for PCI and 98.5% for coronary angiography.

Variables and Measures

Important variables include demographic data, risk factors, indications for intervention, vessel 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. It is also possible to register local variables based on the preference of the individual hospitals.

Reporting Process

Data are reported directly online via the Internet from the individual angiography/PCI laboratories.

Feedback Process

A published annual report presents background factors, outcomes at the national level, and comparisons among different hospitals and regions. The annual report also presents long-term outcomes regarding mortality, morbidity, and new interventions based on linking and matching data from the population registry, the healthcare registry, and the National Registry for Cardiac Intensive Care (RIKS-HIA).

Data are reported directly via the Internet, where each hospital can view its own production, and its own outcomes, and compare itself with the country as a whole. SCAAR’s web site publishes production data monthly for each center. The data are available to the public and accessible without a password.

Quality Improvement

Long-term outcomes vary widely, depending on whether or not drug-eluting stents are used. SCAAR has shown that the risk for restenosis after PCI is three times greater when drug-eluting stents are not used.

Furthermore, earlier findings showed differences in antithrombotic treatment in acute situations. Quality improvement efforts are under way in both of these areas and clearly show general improvement across the country. The important work of following up complications has also improved.
RIKS-HIA – Registry on Cardiac Intensive Care

Background and Aim
Acute myocardial infarction is the single most common cause of death in both men and women, accounting for 16% and 11%, respectively, of all mortality in Sweden. Acute cardiovascular disease is the most common reason for hospitalization. It has increased by 12% during the past 10 years, and now 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. Cardiovascular disease accounts for 8% of permanent and temporary disability pensions, placing it as the third most common disorder.

The aim of RIKS-HIA is to support the development of evidence based care for acute coronary heart disease by providing continuous information on care needs, treatment, and treatment outcomes, and to support continuous improvement among all participating units. 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 2004, the registry included 73 of the 76 hospitals that provide intensive coronary care in Sweden. Hence, over 95% of these patients are included in the registry.

Variables and Measures
RIKS-HIA registers 100 variables related to medical history, risk factors, clinical findings, interventions, investigations, complications, outcomes, drugs, care planning, and diagnosis at discharge. The variables are the same for all of Europe. Re-admissions and survival are followed up by linking and matching the data from other hospital registries. The SEPHIA Registry monitors secondary prevention.

Reporting Process
Nurses and physicians register the data directly online via RIKS-HIA’s web-based program that meets all requirements for Internet data security. Hospitals with electronic patient records have the possibility to export their data to RIKS-HIA.

Feedback Process
Any individual who has the right to register data in RIKS-HIA may also access online reports and analyses. Options are available for advanced analysis, or to use preprogrammed analytical packages directly via menu options in the web program. An annual report is published and includes comments from the registry managers regarding the findings. The annual report is also available in pdf format via the homepage. Transparency of information applies to all units.

Quality Improvement
RIKS-HIA has identified regional variations in intensive coronary care and is working to reduce 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. These modules have contributed 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 lower complication and morbidity rates and shorter lengths of stay.
Circulatory Diseases

SEPHIA – Registry on Secondary Prevention in Cardiac Intensive Care

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 that 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-lowering interventions that are adapted to, and accepted by, patients and that are supported throughout the continuum of care. SEPHIA supports local and national assessment and development of interventions for secondary prevention after myocardial infarction.

Coverage and Volume
The first hospital began reporting in December 2004. Several hospitals joined during the spring of 2005, and currently 37 of the 76 that receive emergent heart patients participate in SEPHIA.

Variables and Measures
Variables include health-related quality of life as measured by 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), medication (compliance), perception of health care, 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 via the Internet. The registry is linked to RIKS-HIA. Hence, patients registered in RIKS-HIA and discharged with a diagnosis of acute myocardial infarction are placed automatically in SEPHIA for followup in both instances.

Feedback Process
Interactive reports are accessible via the Internet for all registered users. The data are presented in graphs and tables by hospital and for the country. Reporting functions are being expanded continually. Data from respective hospitals can be exported in Excel format for analysis in local statistical programs. The results are also presented in annual reports.

Quality Improvement
Since the registry is new, no findings on improvement are yet available. Step one is to describe secondary prevention in Sweden and the results achieved by current activities. The opportunity to measure results should allow many hospitals to institute immediate changes in their secondary prevention efforts. Step two will be to start an ambitious national project for systematic improvement (with “breakthrough methodology”) supported by SEPHIA, QUICC-2nd, planned to commence during 2006 and continue for 3 years. Planning for QUICC-2nd is under way.
Background and Aim
Since 1992, the Swedish Heart Surgery Registry has recorded all heart operations performed on children and adults in Sweden. Heart surgery is an effective form of treatment, but can involve risks for serious complications. Hence, to improve the quality of care, information on the procedures and their outcomes needs to 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 9000 heart interventions are performed annually. Around 120,000 surgeries have been registered. All heart surgery units in Sweden have participated since the start in 1992. The number of units providing these services has ranged from 13 in 1994 to 8 in 2005.

Variables and Measures
The information registered includes type of procedure, coronary artery grafts and heart valves, prevalence of diabetes and complications after surgery (e.g., infection, renal failure, stroke), and the need for circulatory assistance. Personal identification numbers show age and sex. Early and 1-year mortality are reported after the first heart operation and for those who have undergone an earlier heart intervention. Euroscore estimates the surgical risk based on a patient profile involving 17 factors.

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

Feedback Process
When UCR has entered the data, it can be returned to the units if further information and clarification are needed. Participating units have Internet access to their own data for further analysis. The annual report is available on the registry’s homepage, which also shows how the units report 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
Registration of surgical outcomes in all of Sweden and comparisons among the units are important for quality assurance – to minimize risks and costs and maximize health benefits for individuals and society. Waiting time and length of stay can be compared among units. Definitions of variables and options to improve and enhance the data are discussed regularly. Direct quality-of-life measures showing the benefits of heart surgery are being planned, but are not yet available. The intent is to further improve the care of heart patients and optimize resource utilization. The registry should promote further improvement in the quality and the effectiveness of safe cardiac care.
Background and Aim
The number of adults with congenital heart disorders is increasing as a result of successful treatment for congenital heart disorders in children. Children who otherwise would have died now survive to become adults. 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, e.g., 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 (>16 years) with congenital heart disease that are managed at one of the special units for adults (GUCH=Grown-Up Congenital Heart disease) located at seven university hospitals in Sweden. All patients (currently more than 4000) are registered. Nationally, the coverage level is high (nearly 100%) for complicated heart defects, simple heart defects with serious complications, catheter-borne treatment, and heart surgery. The coverage level is not as high for simple heart defects without complications.

Variables and Measures
The registry is longitudinal, follows patients throughout their lives, and therefore shows changes over time. Included are vital status, functional status, quality of life (EQ-5D), basic social variables, results of cardiology examinations, pharmacological treatment, outcomes and complications from catheter-borne therapies, maternal complications in pregnancy, and the prevalence of congenital heart disease 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
An analytical component is being designed. Predetermined, continually updated analyses of local and national 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 question can be obtained on request. National data are also presented in annual reports, which have been published since 1999. A steering committee determines the contents and design.

Quality Improvement
Probable undertreatment of impaired heart function following surgery for complicated heart defects (transposition) was identified, and treatment patterns have changed accordingly toward improvement.

Registry data have highlighted the prognostic importance of an ECG variable (QRS duration) in relation to severe rhythm disorders following surgery for Fallot defect.

Since registry data reflect the collective experience, the information has had direct clinical value in managing uncommon types of heart defects. For example, in pregnancy the information is valuable in predicting the risks to mother and child and possibly preventing these risks.

Quality assessment of catheter-borne therapies is being planned, and the adequacy of antihypertensive treatment given for certain heart disorders is being analyzed.
Background and Aim
The registry identifies factors related 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 60% 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 40,000 cases and, along with the Scottish Cardiac Arrest Registry, is the largest in the world.

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

Reporting Process
Data are reported via data forms. Some centers submit their data via text files, which usually involves exporting the data from a patient record system. The data sheets are given to a secretary who enters the information, which is then processed by a computer programmer. Hopefully, the registry will become Internet-based starting in 2006.

Feedback Process
An annual report provides feedback, showing the overall results for Sweden and informing the reader about distribution, average values, and trends. The participating centers receive their own results for the past year and previous years (average value). These are compared with outcomes for the country as a whole. Hence, every ambulance organization can compare itself to the national average.

Quality Improvement
An increasing percentage of patients are receiving CPR prior to ambulance arrival (confirming the mass education in CPR that has taken place in society). An increasing percentage of patients also receive drugs. However, both the time lapse before the alarm call and the ambulance response time remain unchanged (the latter has tended to increase, which is a major concern).
The percentage of patients admitted alive to the hospital has increased. However, the percentage of patients who are alive after one month remains unchanged. Given the higher age of patients and the lower percentage who need to be defibrillated on ambulance arrival, the results should be interpreted positively, ie, showing that the capabilities of first responders and ambulance teams have increased over the years.
RiksSvikt – Heart Failure Registry

**Background and Aim**
Heart failure is currently the single most common diagnosis in the departments of medicine in Sweden. Costs are high for the care of patients with heart failure. Studies show that the annual direct healthcare costs 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. The number of patients is steadily growing due to longer average life expectancy and improved care for myocardial infarction. RiksSvikt is in a developmental phase. Sixty hospitals have expressed interest in the registry. As of autumn 2005, 39 hospitals and 5 primary care centers participate in the registry, reporting on over 2700 patients (2785 admissions). The work to involve interested hospitals and primary care centers is continuing.

**Variables and Measures**
RiksSvikt registers marital status, living conditions, ECG, cardiac ultrasound, cardiopulmonary radiography, earlier or current diseases, interventions received, current medications, blood tests, patient’s quality of life, followup, and other examinations related to diagnosing cardiac failure.

One year after the initial registration date, the patient is followed up and asked to answer a questionnaire on their current functional class, medications, and quality of life.

**Reporting Process**
Forms are filled in by staff at participating hospital departments/clinics and primary care centers. Data are collected directly via the Internet or from computerized patient records. The data are collected and analyzed at UCR. Users can directly access the data via the Internet.

**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 view data in comparison to the national average. More extensive statistical analysis is done once per year and reported to all participating hospitals and primary care centers.

**Quality Improvement**
RiksSvikt is in a developmental phase and representative data are not yet available to show how heart failure is diagnosed or treated in Sweden. By 2008, RiksSvikt aims to have representative data on managing heart failure in Sweden. Already today some hospitals, (e.g., Linköping University Hospital) 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. Hence, a continuous improvement process is under way, although it is more intense at some hospitals. Goal: More than 90% of the patients diagnosed and treated according to national guidelines.
# National Catheter Ablation Registry

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**Year started:** 2004  
**Public funding:** 2004–2005  
**Governing body:** Östergötland County Council  
**Competence center:** Non-affiliated  
**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 2 to 4 electrode catheters inserted via blood vessels in the groin. Initially, this method was used on a small scale, mainly in treating patients with the following 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, the causes of which are not known in detail. 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 is intended 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.

The registry developed in 2004 and also presented its first annual report for 2004. Feedback to participating units, through collaboration with UCR, will begin in the autumn of 2005.

## Coverage and Volume

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

## Variables and Measures

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 and followup data on complications and treatment outcomes 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

The 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 being developed, and earliest opportunity to see improvement will coincide with the annual report for 2005. The long-term potential for improving the quality of catheter ablation services is good, and the potential value of direct feedback is considerable.
Background and Aim
Peripheral vascular surgery addresses diseases and injuries of the arteries and veins, except in the heart and brain. Approximately 25% of the interventions involve catheter-borne procedures at radiology departments or similar facilities, while the 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
According to the Acute Care Registry at the National Board of Health and Welfare, annually about 30 hospitals in Sweden perform over 9000 vascular procedures. Swedvasc registers approximately 90% of these interventions.

Variables and Measures
The registry includes causes for the intervention, risk factors, care level prior to intervention, blood pressure at arm and ankle levels, surgical date, admission and discharge dates, surgery, surgical code, surgical anatomy, surgical type, graft type, and manufacturer.

Followup date, function of the reconstruction, followup method, care level, arm and ankle pressure, and complications are registered at followup 30 days after the procedure.

Followup date, function in the reconstruction, followup method, care level, arm and ankle pressure, graft infection, date of death, date of occlusion, date of reoperation, date of amputation are registered at followup one year after the procedure.

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 following the procedure. The vascular surgeons themselves usually fill in the form, but at some hospitals specially trained nurses are responsible for this task.

Feedback Process
Locally authorized personnel have online access to the web registry where they can find analyses of results and national comparisons. A unit can also download its own data for local review and analysis. An annual report is released in May.

By applying to the steering committee, participating surgeons can access more data that can be used in research or special analysis.

Quality Improvement
A special committee has, for several years, studied complications from procedures for occlusions in carotid arteries (carotid stenosis). These reviews have identified several complication mechanisms that can be traced back to the surgeons. During the same period, the complication rate has shown a clear downward trend.

Mortality has been high regarding interventions for acute circulatory disorders in the arms and legs. It is possible to document a change in the interventions with an increasing percentage of catheter-borne methods, which has resulted in decreasing mortality.

Locally, as shown by the registry, systematic quality improvement efforts have sharply reduced waiting times for carotid stenosis surgery at several participating units. Waiting times for surgery have a major impact on stroke events. Furthermore, introducing quality variables and threshold values has promoted greater centralization, thereby reducing complications.
Riks-Stroke – National Quality Registry for Stroke

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Public funding: 1992–2005
Governing body: Västerbotten County Council
Competence center: Non-affiliated
Transparency, unit level: Yes

Background and Aim
Stroke is one of the major health problems in Sweden, annually affecting about 30 000 people, whereof 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 SEK annually. The aim of the registry is to contribute toward providing high-quality, equitable stroke care throughout the country. 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 2004, over 23 000 admissions from 83 hospitals were reported, corresponding to an estimated coverage exceeding 80%. The database currently contains approximately 190 000 admissions. 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 outcomes of health care. Epidemiologically, the level of coverage has been calculated on 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. Studies found the data quality to be good.

Variables and Measures
Registered variables include the acute onset and a followup 3 months after onset. The variables were chosen to reflect structure, process, and outcomes and include data on patient experience and most of the quality-related areas. The variables have expanded in recent 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 and graphic modules, hospitals may continually compare their data with 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 homepage. Teaching seminars for contact persons were conducted throughout Sweden during 2003 and 2004.

Quality Improvement
Interest in stroke care has increased dramatically in recent decades. Riks-Stroke has contributed to this trend by reporting on stroke care and by data processing and feedback related to process and outcome measures. Through continuous communication with stroke caregivers, Riks-Stroke has been a catalyst in this positive trend. Examples of improvement are: over 75% 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.
Swedish Quality Registry for General Thoracic Surgery

Background and Aim

General thoracic surgery includes surgical interventions in the airways, lungs, pleura, mediastinum, and chest wall. These comprise 15% to 20% of the total volume of thoracic surgery, the remainder being cardiovascular interventions. Surgery for lung cancer dominates in general thoracic surgery. Lung cancer causes the most cancer deaths in Sweden, and there is an increasing trend among women regarding lung cancer incidence and mortality. Of lung cancer patients, 20% to 25% undergo surgery. This corresponds to about half of the total volume of general thoracic surgery (over 1600 interventions in 2003). Curative treatment for lung cancer increasingly involves more complicated surgery with greater risks for complications during and after the operation. The aim is to acquire more knowledge about the surgical interventions performed and assess the outcomes. The registry aims to serve as a foundation for quality control, support medical advancements, and create a base for developing national guidelines on general thoracic surgery. In the future, the registry may also be used for research purposes.

Coverage and Volume

The registry will contain data from all eight departments of thoracic surgery in Sweden. Since relatively few surgeons (1 to 3) serve each department that offers general thoracic surgery, and since each has a representative on the steering committee the potential for comprehensive data registration is good.

Variables and Measures

Data on preoperative risk factors, postoperative complications, early and late mortality, and health-related quality of life would be continuously registered.

Reporting Process

The surgeons that perform the operations will enter the data on a web-based platform at the Uppsala Clinical Research Center (UCR).

Feedback Process

Feedback will be provided in standardized reports 2 to 3 times per year and via the opportunity for participating units to obtain their results online and compare them with the national average.

Quality Improvement

Since the registry is not yet active there are no results to report.
Background and Aim
Diabetes is a disease that is reaching nearly epidemic proportions in the world. Now, 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 created in 1996 in response to the goals of the Saint Vincent Declaration on quality documentation in diabetes care. Participating units can use the registry to compare their results with the national average, and measure goal achievement in relation to national guidelines.

Coverage and Volume
In Sweden, an estimated 350 000 to 400 000 individuals have diabetes. In 2004, the diabetes registry included 104 000 patients, ie, approximately 25% of all diabetes patients in Sweden. Reports from all county councils are submitted to the registry. Data are registered from around 90% of all departments of medicine and around 60% of all primary care centers.

Variables and Measures
The registry includes registration date, caregiver code, personal identification number, year of onset, diabetes type, diabetes treatment, body weight, height, abdominal circumference, HbA1c, blood lipids and blood pressure, s-creatinine, physical activity, and ten yes/no questions on smoking, blood pressure lipid reduction and ASA treatment, micro albuminuria, manifest kidney disease, eye fundus examination, retinopathy, and experience of stroke, myocardial infarction, foot examination, or amputation.

Reporting Process
Since 2002, registration has been electronic via the homepage, at least once per year per patient. Regarding registration, 54% takes place online, 35% are placed on the web via mailed files, and 10% are directly transmitted from electronic patient record systems. The system includes a mandatory section and an optional section.

Feedback Process
Via the web, every caregiver has 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 and their own selected criteria and categories. Annual reports that show outcomes as cross-sectional analyses for each year are prepared by the NDR data output group and are available on the registry's homepage.

Quality Improvement
Data from NDR show that from 1996 to 2004 the quality of diabetes care in Sweden steadily improved with regard to risk factors, and the county councils moved toward greater uniformity. NDR aims to promote more active use of registry data and is running a project in collaboration with the Swedish Association of Local Authorities and Regions (SALAR) and Qulturum in Jönköping where primary care units and medical departments are learning to use quality registry data in systematically improving quality in patient focused care. The participants analyze their own results, establish improvement goals, and analyze what is needed to achieve these goals. Hence, the team takes a more outcome-driven approach. Preliminary assessment has already shown substantial improvement in outcomes. For example, the departments of medicine reported that patients achieving their goals had increased from 29% to 37% for HbA1c, from 34% to 47% for ASA, and from 45% to 53% for antihypertensive treatment.
SOReg – Swedish Obesity Surgery Registry

Background and Aim
Obesity surgery is the fastest 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.

The registry is being developed and is projected to begin at the end of 2005.

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
Somewhat less than 1000 operations are performed at approximately 20 participating units in Sweden. The plan is for all units to participate in the registry.

Variables and Measures
The registry follows outcomes, primarily weight changes that are closely linked with effects of obesity comorbidities, and quality of life measured by SF-36, OP-9 forms. Data on indications and technical aspects of surgery are reported in conjunction with the operation. Complications related to surgery are reported 1 to 2 months postoperatively.

Weight loss, 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 will take place via the Internet. The quality of life forms received by post will be scanned centrally.

Feedback Process
An annual report will provide feedback. The data will also be discussed when the registry meeting is held in conjunction with the annual “Surgery Week” in August.

Participating units can also retrieve their current outcomes via automated standard reports and statistical functions. Outcomes from other units are available, but units are not identified.

Quality Improvement
Quality improvement cannot be assessed since the registry is still being developed.
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 3500 to 4000 thyroid interventions and about 1000 interventions for parathyroid disease are performed annually in Sweden. The aim of the registry is to improve the quality of diagnosis, surgery, and followup in thyroid and parathyroid surgery.

The registry is supported by the Swedish Association of Endocrine Surgeons and the Swedish Association of Otorhinolaryngology, Head and Neck Surgery.

Coverage and Volume

All units in Sweden that offer this type of surgery are invited to participate. The registry tries to use a similar platform for registration as other departments/units in Scandinavia so that eventually it will be possible to analyze data among Scandinavian countries. Sweden currently has 15 participating units. Over 1000 interventions have been registered as of this printing.

Variables and Measures

In addition to patient data, the registry also includes information specific to the units, eg, routines, staff, surgical skills, and ancillary resources. Patient data include age, sex, and disease. Other data registered include preoperative investigation, 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 to manage patients’ personal data. The 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. 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. The registry is directed by a steering committee selected by the users. 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 homepage.

Quality Improvement

The registry started only recently. The first data analysis, for 2004, was presented at the registry’s first annual meeting on September 22, 2005 in Lund.
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 also some functional improvement. Similar to hip and knee replacement surgery, there are risks for short-term and long-term complications.

In 1999, the Swedish Shoulder and Elbow Section (SSAS) 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 to date only 2 hospitals do not participate in the registry. In a comparison with the National Board of Health and Welfare’s diagnostic registry for 1999–2003, coverage is estimated to exceed 90%. Approximately 500 to 600 procedures are performed annually in Sweden, and the number is increasing.

Variables and Measures
The registry contains information about the departments/units, date of surgery, and patient data, e.g., personal identification 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 have started to survey (by post) 5-year followup of patients receiving surgery in 1999–2000. The survey uses 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 is still voluntary, and followup for the first year is under way.

Reporting Process
The registry is based on reporting, via a printed form, of all shoulder joint replacement operations. This year, when NKO inaugurates a web-based entry system and database, we will consider the possibility of moving there in the coming year.

Feedback Process
Units participating in the registry have received an annual report on the number and type of operations. They have been able to check their data against the registry. When uncertainties appear, 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 participating units for possible adjustment. Annual reports have been given to the participants, to SSAS, and are now available on the homepage.

Quality Improvement
Since the registry has existed only 5 years, we only recently started to perform limited analyses of the material. Although the data are limited, some variations can be observed. A self-evaluation score is being used to assess patients’ perceptions of the outcomes so that hopefully, despite relatively small patient groups, variations might be detected early.
Musculoskeletal Diseases

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Background and Aim
Hip fractures, including rehabilitation, cost 1.5 billion SEK annually in Sweden. The risk at age 50 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
Over 50 hospitals in Sweden offer surgery for hip fracture. Of these, 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.

Variables and Measures
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. 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 reoperation. It is possible to include other questions. One of these concerns quality indicators involving pressure sores that are reported on admission, during the care episode, and on discharge.

Reporting Process
Mainly nurses and department staff enter the information on a form. If needed, physicians are asked about surgical procedures and fracture type. Other parameters concern nursing services. The data are registered via a special program, encrypted, and sent by e-mail. 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. An online opportunity for web-based reporting and online calculating will soon be available for feedback of participant’s own data compared with 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 has also promoted selection of optimum surgical methods. This type of information will grow as the analytical work on surgical outcomes intensifies.
Swedish National Hip Arthroplasty Register

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**Year started:** 1979  
**Public funding:** 1991–2005  
**Governing body:** Västra Götaland Region  
**Competence center:** NKO  
**Transparency, unit level:** Yes, since 1999

**Background and Aim**

Total hip replacement, i.e., surgery to implant artificial hip joints, is the most common of the major orthopedic elective procedures in Sweden. The main aim of the registry is to acquire the information that provides individual patients with the best surgical method and implant type.

**Coverage and Volume**

The registry includes all units that offer total hip replacement, and all procedures are reported. The number of procedures per year in Sweden has increased gradually and now exceeds 13,000. This corresponds to 120 operations per 100,000 population and year.

**Variables and Measures**

Patient demography, implant type, and surgical method are reported for each primary operation. Personal identification 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 Kaplan-Meier methods are mainly used to present survival statistics. Failure is defined as the exchange or resection of all or part of the prosthesis. The revision burden, RB (revisions/[primary procedure + revisions]) is the key measure used to compare national and international data.

**Reporting Process**

The registry became web-based in 1999 and since that time reporting takes place via the registry’s homepage. All participating units use web applications in reporting. Copies of patient records from reoperations are sent to the registry regularly during the year. They are necessary for analysis and further studies. Most departments use a touch screen linked to the registry’s homepage to collect preoperative, patient-related variables like 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 departments, the National Board of Health and Welfare, the Swedish Association of Local Authorities and Regions (SALAR), and to the owner and purchaser organizations in health care. Annual reports are translated into English and published on the homepage.

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 reduced suffering for patients.
Swedish Knee Arthroplasty Register

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 feed back 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 83) that offer prosthetic knee interventions participate in the project. Since the start, the number of surgeries reported annually has increased steadily. Only 1075 operations were reported in 1997, but in 2004 the figure was 9680. Validation of the registry shows that approximately 95% of all operations are reported.

Variables and Measures
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 to assess patient satisfaction and health.

Reporting Process
The knee registry recommends that reporting be done in the operating room on a special reporting sheet with space to attach special stickers (product number, etc) that accompany the prosthesis package. 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 epicrises 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 participated in the “quality registry days” sponsored by the National Board of Health and Welfare and the Federation of Swedish County Councils where administrators and decision makers were informed 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.
Swedish Rheumatoid Arthritis Registry

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Year started: 1996  
Public funding: 1997–2005  
Governing body: Stockholm County Council  
Competence center: Non-affiliated  
Transparency, unit level: No

Background and Aim

Inflammatory joint diseases, mainly rheumatoid arthritis (RA), cost 3 billion Swedish kronor (SEK) per year. Every year, many people contract these lifelong, function-impairing diseases. Since curative treatment is not available, continuous monitoring of care is required for quality assurance. To relieve more patients of unnecessary pain and disability, and to improve their functioning and quality of life in a measurable way, the RA registry aims to close the gap between existing clinical guidelines and the actual delivery of health services.

Coverage and Volume

The registry includes all of Sweden and currently follows 11,751 chronically ill patients, an estimated one half of all who require specialized care for severe RA. These patients had 11,790 quality assured visits in 2004, an increase of 32% over the previous year. During the year, 2051 new patients were added to the registry, approximately two thirds of all new cases were included.

Variables and Measures

The basic data are the inclusion date, year and month of disease onset, diagnostic criteria, radiographic changes, and previous treatment with cortisone and antirheumatics.

The following are registered at every visit: pain (VAS), functional questionnaire (HAQ), disease sensation (VAS), work ability, swollen and tender joints, SR, CRP, the physician’s activity assessment, and prescribed drugs. Followup gives special attention to biologic drugs.

Reporting Process

The data are registered directly via the Internet during the physician visit at 3 university and 2 county district hospitals. Prior to the visit, patients have access to the homepage to report pain, quality of life, daily function, joint swelling, and joint tenderness. Physicians later make their own assessment of the joints and disease activity. They register this information and the agreed-on treatment, and give the patient a printout of the data. Some units collect data by having the patient and physician each complete a form during the visit and then submit the data via the Internet.

The patients are registered at their first visit to a rheumatologist following onset, or when biologic drugs are started. Systematic followup of all patients occurs during return visits.

Feedback Process

After entry, the data become accessible for feedback on the Internet for registered users at participating units. Data can be presented for each patient, compiled for the unit’s patient group, and viewed in diagrams of county, regional, and international comparisons. The registry also includes a special reporting generator that can search and deliver the compiled data in lists or Excel files. Feedback at national, regional, and local meetings is an important aspect of clinical improvement activities.

Quality Improvement

The starting point in the RA registry is that clinical improvement efforts are most effective at the point of care – the interaction between the patient and the caregiver. In planning care and measuring its outcome, the physician and patient together can use Internet services during the visit to proactively support decisions.

At the general level, the registry shows differences in treatment by hospital type, eg, in treating new cases. There is now better compliance with clinical guidelines. Although, since 1995, new patients seeking care have presented with more severe disease at the first visit, the outcomes have steadily improved after 6 and 12 months of treatment.
Background and Aim
In recent decades, surgical treatment of lower back diseases has increased considerably. This is not attributed to epidemiological changes in the disease panorama, but to the availability of improved diagnostic techniques (eg, CT and MRI), improved surgical options, and possibly to expanding indications. No consensus has been reached on indications and assessment of results. The aim of the registry is to assess the indications for, and the results of, surgical intervention for degenerative lower back diseases, with particular 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). Approximately 45 units in Sweden offer back surgery, whereof around 40 participate in the registry. Participation has been increasing since 1998.

Variables and Measures
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, EQ-SD, and the Oswestry back function score.

Perioperative data: Length of stay, diagnosis for surgery, interventions performed, complications, reoperation.

Postoperative data: Followup after 1, 2, 5, and 10 years including the same data as preoperatively and self-rated patient experience of surgical outcomes and general satisfaction.

Reporting Process
Since 2003, data are collected regularly via the web.

Feedback Process
An annual written report is provided to all registered units, and an oral presentation is given to members of the Swedish Society of Spinal Surgeons at their annual meeting. Furthermore, data on outcomes at participating units are compiled and fed back to the units. In the web version, the units can have constant access to their own results and compare these with aggregated data from the country as a whole. A supplement to Acta Orthopaedica was published in 2005.

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 over 3 years for spinal stenosis. Most of the patients are satisfied with the effects of surgery, but surgical treatment for herniated disc and spondylolisthesis yields better results than lateral spinal stenosis and segmental pain in movement. The registry on complications has identified several types of interventions with high complication rates, which require further analysis. The registry has gained substantial recognition internationally and participates in Scandinavian and major international societies for back diseases (ISSLE, SSE, and NASS). The registry offers a unique base for studies on the short- and long-term effects of back surgery on health status.
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, and is treated mainly by primary care centers, private physicians, specialty physicians, and occupational health services.

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 85% of the rehabilitation departments/units in Sweden. In 2004 the database increased by 2998 patients and now includes 11 631 patients.

Variables and Measures

Standardized forms cover demographic data, educational level, work status and belief in the future, psychometrics (MPI, HAD, MSPQ), pain intensity (VAS), activity (DRI), and life satisfaction (LiSat-11). 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

Patients complete the forms or enter the data directly on assessment. A special computer program processes the data immediately, and the results are presented in an assessment file and used clinically as a basis for team assessment. Followup data are collected on conclusion of rehabilitation and 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 in tables and graphs to participating units (to contact persons, department heads, and those responsible for medical care). Representatives from the units meet regularly to interpret the results, exchange experiences, and discuss quality improvement and further development of registry functions.

Quality Improvement

Introduction of a self-rating profile to support the assessments was received positively by the participating units and has probably contributed to the low data dropout rate.

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 pain.
Background and Aim

Bipolar affective disorder (manic-depressive disease) type I, where disease progression involves distinct manic episodes, has a lifetime prevalence of 1.5%. Type II bipolar conditions involve less pronounced hypomanic episodes and are even more common (particularly if one includes short-term episodes), raising the combined estimated lifetime prevalence to 5%. Depressive episodes occur more often than mania/hypomania in both types of bipolar disease. The care of patients in these disease groups varies, as does the ability to identify bipolar disorders. The conditions have a serious prognosis, and the more frequent the episodes, the greater the risk for a worse prognosis. The risk for suicide is greatest during the depressive phases, but is high in both type I and type II syndromes. Although treatment is well known in psychiatric care, studies show an increased risk for suicide in more recent cohorts of bipolar patients. Treatment varies in different areas, and prescriptions for lithium vary regionally.

New mood stabilizing drugs and psycho-pedagogical treatment methods have been introduced and need to be assessed in naturalistic cases. A quality registry is needed and is being coordinated with planned psychiatric quality registries. Special units and general psychiatric units need to assess diagnosis, treatment, and outcomes of interventions, which the registry aims to do.

Coverage and Volume

Since 2004, BipoläR has registered patients at the first two special units for affective disorders in Stockholm County. Units in Skåne, Västra Götaland, and other areas began to participate in the registry in 2005. Several specialized treatment units have been started and want to participate in the registry.

During the first year, 120 patients were registered at the Affective Disorder Center in Stockholm. This corresponds to 30% of the patient group at the clinic. The figure is projected to increase during the year, and by the end of 2005 the registry is estimated to include 50% of the patients.

Variables and Measures

The Collaboration on Quality Registries in Psychiatric Care (KPV) resulted in a set of basic variables. They describe the patient from a social and psychiatric perspective, the treatment interventions performed, and treatment outcomes. Furthermore, some variables describe the units and their activities. Diagnosis-specific variables are also included.

Reporting Process

During the visit, patients are informed about BipoläR and are asked for their consent. Information is entered via the Internet, and annual followup is presented via e-mail. The patients receive questionnaires on treatment satisfaction and symptoms, and they may respond either via a return envelope or the Internet.

Feedback Process

The Internet application includes a report generator to prepare reports based on the participating unit’s own data and other data in the registry.

Quality Improvement

A quality registry is being introduced for several units that wish to participate during the coming months. One-year followup has begun for the initial participating units. There are good opportunities to use the data in quality improvement efforts that can advance when results from the registry become available.
Background and Aim

In children and adolescents up to 18 years of age, 2% to 5% have AD/HD (approximately 1% have a severe type). Studies show that central stimulants (CS) have good effects on the core symptoms. Behavioral therapy at home and school, as well as special education are important, particularly in comorbidities such as acting out behavior, contact disorders, learning disorders, and motor problems. Knowledge about long-term clinical effects and side effects is deficient. Medications can be abused at higher doses, and pharmacotherapy for AD/HD remains controversial. Knowledge about other, non-pharmaceutical forms of treatment for AD/HD and its comorbidities are rapidly growing. Diagnostic and treatment resources are unevenly distributed, and uniform guidelines for AD/HD treatment are lacking. Followup and support in adults is often difficult due to insufficient resources. Hence, a national quality registry is urgently needed as a knowledge base to develop guidelines, to improve quality, and to increase the cost effectiveness of care.

Coverage and Volume

Active participants in the registry include local units and four university hospital units, covering about 13% of the Swedish population. Improvement efforts within the framework of KPV (the Collaboration on Quality Registries in Psychiatric Care) have delayed active registration. Nevertheless, registration is under way and there is an ongoing effort to increase the number of participating units.

Variables and Measures

KPV has developed a set of base variables. They describe the patient (from a social and psychiatric perspective), treatment interventions, and treatment outcomes. Furthermore, a set of variables also describes the treatment units and their activities. Diagnosis-specific variables for BUSA will be added.

Reporting Process

Patients are informed about BUSA during new treatment episodes and are asked for consent to enter their data in the registry. Data are entered via the Internet, and activity is continuously logged. Annual followup is reported via e-mail. Each year, patients receive a questionnaire on treatment satisfaction and symptoms, and they may respond either via a return envelope or the Internet.

Feedback Process

The Internet application includes a report generator to prepare reports based on the participating unit’s own data and other data in the registry. There are plans to distribute regular reports on the use of applications by participating units.

Quality Improvement

Starting in September 2005, the opportunities to use registry data in prioritizing care and to enhance quality and efficiency have been discussed at regional and local information/training sessions by BUSA and within the framework of the KPV collaboration. The aim is to promote participation in the registry, to improve coverage at the participating units, and to use the data as described above.
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 eating disorders (without further specification) 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.

**Coverage and Volume**

Approximately 2600 treatments have been registered since 1999, with 820 new registrations in 2004. Of the 30 specialized eating disorder units in Sweden, 29 participate in RIKSÄT. The percentage of teams in general psychiatry that specialize in eating disorder services is unknown, but is probably relatively small (<1/3).

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**Variables and Measures**

The Collaboration on Quality Registries in Psychiatric Care (KPV) developed a set of basic variables. They describe the patient from a social and psychiatric perspective, the treatment interventions performed, and treatment outcomes. Other variables describe the treatment units and their activities. Diagnosis-specific variables are also included.

**Reporting Process**

During the visit, patients are informed about RIKSÄT and are asked for their consent. Information is entered via the Internet, and annual followup is presented via e-mail. The patients receive questionnaires on treatment satisfaction and symptoms, and they may respond either via a return envelope or the Internet.

**Feedback Process**

The Internet application contains a report generator for developing reports using the unit’s own data and other registry data. Monthly reports are sent out regarding use of the registry.

**Quality Improvement**

Opportunities to analyze collected data are underutilized, and training sessions were started in September 2005. The level of motivation for working with clinical quality improvement is high, but few within the departments are experienced in this type of work. The training sessions have the dual purpose of promoting use of the data and motivating a greater level of coverage.
Schizophrenia is one of the most serious psychiatric diseases. It usually debuts during one’s 20s, and over half of the individuals affected will have substantial problems with the disease for the remainder of their lives. The risk of a schizophrenic episode at some point in life is less than 1%, and approximately 0.5% of the population have the disease at any given point in time.

Although schizophrenia often has a chronic course, many people with the disease live a good life if they receive adequate care and support. Frequently, they require support from several different levels of care. In Sweden, the municipalities and county councils often provide services for many years.

Schizophrenia is a disease with major consequences for society, and causes considerable suffering for the individual patients and their families. Although the disease has a long history, basic knowledge is lacking about how to provide care and which methods yield the best results.

The registry was formed to find ways to effectively treat and support individuals affected by schizophrenia. The aim is to use resources as efficiently as possible and help people achieve the highest possible quality of life.

**Background and Aim**

Schizophrenia is one of the most serious psychiatric diseases. It usually debuts during one’s 20s, and over half of the individuals affected will have substantial problems with the disease for the remainder of their lives. The risk of a schizophrenic episode at some point in life is less than 1%, and approximately 0.5% of the population have the disease at any given point in time.

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**Variables and Measures**

The Collaboration on Quality Registries in Psychiatric Care (KPV) developed a set of basic variables. They describe the patient from a social and psychiatric perspective, the treatment interventions performed, and treatment outcomes. Other variables describe the treatment units and their activities. Diagnosis-specific variables are also included.

**Reporting Process**

In conjunction with newly diagnosed schizophrenia, the patient is informed about the disease and is asked for his/her consent to enter data in the registry. The information is entered via the Internet. All use is continually logged. Annual follow-ups are carried out by e-mail. The patient receives annual questionnaires on treatment satisfaction and symptoms and may respond by using a return envelope or the Internet.

**Feedback Process**

The Internet application contains a report generator for developing reports using the unit’s own data and other registry data. Monthly reports are sent out regarding use of the application.

**Quality Improvement**

Opportunities to analyze collected data are underutilized, and training sessions were started in September 2005. The level of motivation for working with clinical quality improvement is high, but few within the departments are experienced in this type of work. The training sessions have the dual purpose of promoting use of the data and motivating a greater level of coverage.
Quality Registry for Dependency Care

Background and Aim
Dependency (mainly involving alcohol, narcotics, and medication) is a common disorder. These disorders are increasing and affect between 300,000 and 500,000 people in Sweden. They increase the risk for other diseases, are often chronic, and account for a large part of health service utilization. The total annual costs in Sweden have been estimated to exceed 100 billion SEK, whereof 20% to 25% are care costs. In Stockholm county, over 17,000 individuals received dependency care in 2003, which involved 6000 hospital admissions and approximately 260,000 primary care visits. Approximately 4000 alcohol and narcotic-related deaths occur annually in Sweden.

Scientific knowledge about treating alcohol and narcotic dependency has increased in recent years, but little is known about the practical effects of treatment and its results. The care registry contains information about diagnosis and the length of stay for inpatients, but little information is available about diagnoses in primary care. A quality registry would create a foundation for improving care by providing knowledge about the diagnostic panorama and mixed abuse in primary care settings (where most patients appear), social situations, alcohol and drug habits, treatment at different treatment units for patients with various problems, and the outcomes of treatment.

Coverage and Volume
Approximately 15,500 patients were treated at the Center for Dependency in 2003. There were 170,000 contacts in inpatient and outpatient services. The registry is new and started on a small scale with the goal to become national.

Variables and Measures
Registration at the initial visit, and on admission to and discharge from hospital includes several parts. Personal information includes, eg, children, housing, employment, sick-leave status, and contacts with social services. Substance abuse anamnesis describes the age of debut in alcohol and narcotic abuse, the daily use of sedatives/hypnotics, current use of alcohol and narcotics (including prescription drugs classified as narcotics), and alcohol- and narcotic-related medical and social consequences. Care information includes methods of contact, previous care from health services, social services, and institutions, other diseases and related treatment, current psychiatric problems (past 30 days based on Addiction Severity Index), and any allergies. Laboratory tests, diagnoses, and treatment are also reported.

Reporting Process
A patient administrative system (PVS) has been introduced in dependency services and is used at all 60 units within the departments. Computerized patient records are used at half of the departments, but work is under way to include the rest. The aim is for the quality registry to include anamnesis information from the patient record. Data entry via a web-based system is being planned in collaboration with KPV (Collaboration on Quality Registries in Psychiatric Care).

Feedback Process
Information will be regularly analyzed and compiled in easily accessible reports about patients, process measures, and outcomes. The reports will be presented, eg, at regular unit meetings with section chiefs and staff groups.

Quality Improvement
The main issue in working with the registry is how the units should improve in relation to the findings from the integrated feedback, which is intended to improve care.
Background and Aim

Cerebral palsy (CP) is the most common type of physical functional impairment in children affecting approximately 1 in 500. 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 the onset of hip luxation and severe contracture in children with CP by continuously registering data throughout the growing phase, monitoring the prevalence of CP, and assessing different treatment methods.

Coverage and Volume

By June 2005, 13 of the regions and county councils in Sweden had joined CPUP, covering 78% of the population. All other county councils have expressed a desire to participate and are planning to do so.

Variables and Measures

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

Reporting Process

A physiotherapist and occupational therapist examines the child and submits the reports. Most districts have a coordinator that transmits the information to the database, but in some districts the physiotherapist and occupational therapist register the data directly. Once per year, the data are transferred to the server in Lund for central compilation, analysis, and an annual report. Web-based reporting is being developed.

Feedback Process

Care teams receive reports from the local registry on a child’s development over time. Once per year, the county councils and regions receive reports from the central registry presenting local outcomes in relation to national outcomes.

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

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

Quality Improvement

Ten 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.

Findings from southern Sweden show:
- total prevention of hip luxation, which earlier affected 10%
- reduction in the number of severe contractures by 70%
- reduction in the onset of scoliosis by 60%.

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

Dementia diseases affect increasingly more people in Sweden as the population becomes increasingly older. An estimated 140,000 people in Sweden have some type 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 diseases.

The registry aims at early and interactive followup of trends in patient populations, diagnosis, treatments, and outcomes in health care related to dementia. Our goal is equitable and optimum treatment of patients with dementia.

Coverage and Volume

The registry is under construction. A national registry is the goal. Specialized clinicians that participate in the registry investigate approximately 2000 new patients per year. In the initial stage, hospital clinicians will register patients, and in the second stage the primary care units will register patients. The number of dementia investigations is estimated to be 17,000 to 20,000 per year. Coverage at the outset is approximately 15%.

Variables and Measures

Measures will be determined by a working group in conjunction with the specifications of the quality registry. The quality indicators will be clear, measurable, and will be grounded in clinical reality and standard definitions.

The quality indicators mainly address: 1) how the diagnosis is established, 2) how ongoing care is planned and delivered, and 3) how treatment and other interventions change over time.

Reporting Process

Every participating unit 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 the opportunity to download data from one’s own unit for further processing and analysis. In online reports via the web, the user will be able to select the variables to be presented, possibly shown in groups that are interesting to compare. The registry will also publish an annual report for the target groups of professionals, funding bodies, and political and administrative decision-makers.

Quality Improvement

Particular emphasis will be placed on the presentation of trends that support quality improvement activities. By having access to longitudinal data on quality indicators and variables, participating units can monitor the extent to which goals are met. It will also be possible to see whether variations decrease and value improves after the introduction of quality improvement programs.
SMS – Swedish Multiple Sclerosis Registry

**Background and Aim**

In Sweden, 12 000 people have multiple sclerosis (MS), a lifelong disease of the central nervous system that often debuts before the age of 40. In most cases, MS leads 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 care for MS that is equitably distributed.
- 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, 27 departments participate in the registry, and this year all but one county will be represented. Over 6000 people with MS are included in the registry, which corresponds to about half the MS patients in Sweden. The rate of increase in the number of patients was 30% during the past year.

**Variables and Measures**

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

**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**

As needed, participating units can go directly to the registry to acquire statistics on their own patients, treatments, etc, and use several predefined reporting formats to compare the figures with national statistics. The units can search for data on their own patients. Annual reports analyze and describe registry activity, and the information is distributed to participating units and presented at the annual meeting.

**Quality Improvement**

Disease modifying drugs have an effect mainly in younger patients and those with low-level disability. During the registry’s first year it was observed that this finding was not reflected in the existing treatment patterns. Registry users were informed about the situation at several meetings. It also received attention nationally and in the Journal of the Swedish Medical Association. By 2002 the situation had been corrected, and the percentage of treated patients with high-level disability decreased while treatment increased in the low-level group. The report in 2004 showed a continuation of the positive trend and a gradual increase in the total number of patients treated in Sweden.

The registry implemented a checklist of 7 common symptom complexes that caregivers should evaluate annually and report on any interventions. The aim is to achieve a direct, quality-enhancing effect via documentation requirements. The checklist is new, and the percentage of completed lists varies from 0% to 91%. In 2004, data were available for 1726 patients with 3864 identified problems, whereof 1068 (32%) had been treated.
Background and Aim
Annually, over 1100 people in Sweden contract life threatening chronic renal failure. Due to an organ shortage only a few patients receive transplants immediately, and dialysis is necessary. About 1100 people start dialysis treatment annually. Approximately one fourth are medically suitable for transplantation, but the shortage of kidneys requires patients to be treated by dialysis for several years first. Mortality in dialysis patients is high, 25% to 30% annually.

The dialysis population – which grows by 3% to 5% annually because of gradually improving survival rates in dialysis – is currently around 3300, whereof one fourth are treated at home, mainly with peritoneal dialysis (PD) and to a lesser extent with home hemodialysis (HHD). Three fourths receive hemodialysis (HD) at dialysis units. Many in the latter group are older and have multiple disorders.

The cost for one year of HD in a clinic is estimated to be 0.6 million Swedish kronor (SEK), while home treatment is 10% to 40% lower. Hence, the cost for treating dialysis patients in Sweden is 1.5 to 2.0 billion SEK.

The quality of dialysis treatment influences patients’ self-perceived health status, the need for hospitalization and other health services, and mortality.

An associated national quality registry, the Swedish Registry for Active Uremia Care (SRAU), registers prevalence and survival in active uremia care, dialysis, and transplantation. Comorbidities and possible changes in the type of treatment are also registered. SRAU has reliable data on uremia care outcomes, but does not show the quality of the various care components. Discussions are under way on how the registries can collaborate.

SDDB focuses specifically on measuring, presenting, assessing, and improving key parts of the various processes in dialysis care.

Coverage and Volume
Nearly 85% of the dialysis population in Sweden was included already during first year (2002), and in 2004 the registry included nearly 95%. All dialysis units in Sweden are expected to participate in the 2005 study.

Variables and Measures
SDDB registers variables that reflect dialysis prescription, relevant pharmacotherapy, a range of laboratory values, eg, blood, phosphate, thyroid hormone, measured dialysis dose, and blood pressure. Eventually we plan to use scientifically accepted instruments to measure health-related quality of life.

Data at the individual level – depending on the type of variable – are more or less uncertain. However, at the clinical level and higher, the average values and degree of goal attainment are stable and reliable.

Reporting Process
SDDB performs a cross-sectional study every autumn. During a specified period, participating units report on a set of values for each patient treated. Reporting takes place via the Internet using encrypted data transmission.

Feedback Process
The homepage shows the outcomes for each unit. Annual reports and analyses are published on the homepage and in print.

Quality Improvement
SDDB has not been active long enough to confirm specific improvements at the national level. International experience shows that the methodology works and that treatment quality improves.
Background and Aim

The National Quality Registry for Gynecological Surgery is an umbrella organization for 6 quality registries that cover the field of gynecological surgery. The registry includes hysterectomies (uterus), adnexa (ovaries and ovarian tubes), and endometrial ablations (surgery involving the uterus) and will, in the near future, begin to register incontinence, prolapse surgery, and cancer surgery.

The aim is to give participating units a tool to continuously monitor their quality improvement efforts and compare their results with other units.

Coverage and Volume

More than 70% of the units in Sweden participate, but the level of coverage varies among registries. Participation in the hysterectomy registry is 60%, but lower with the adnexa registry since the indicators for cancer surgery and benign surgery are unclear, and many interventions are performed on an emergency basis. Incontinence and prolapse surgery are new areas. Approximate annual volumes in Sweden are: 8000 hysterectomies, 8000 adnexa operations, 4000 prolapse operations, and 2000 incontinence operations.

If the survey forms are used as specified, the response rate for the reporting units is 98%.

Variables and Measures

Surgical time, surgical method, peri- and postoperative complications, length of stay, sick leave, time with disorder before intervention, and time before the patient returns to activities of daily living (ADL). Many of the findings are based on patient questionnaires since the patient’s self-perception of the problem is important in this type of surgery. The attending physician also renders an opinion.

Reporting Process

Surveys are sent to patients before and at 6 weeks and 1 year after surgery. Secretaries enter the data. The data on admissions, surgery, and discharge are captured directly by physician entry or by printed forms that are later transmitted. A short version of the registry is available to those who enter only the obligatory data.

Feedback Process

Feedback consists of four parts: reports 2 to 3 times per year on specific topics where analysis is more thorough, the report generator where the participating unit’s own quality parameters can be monitored, 3 meetings per year for registry physicians and secretaries, and site visits to the units are planned every second year to review quality improvement efforts, registry logistics, and validity.

Quality Improvement

The registry has contributed to greater cost effectiveness and care quality of care. Transparent comparisons at the unit level have reduced postoperative infections (due to increased use of perioperative antibiotics), and the length of stay after hysterectomy has been shortened. Without the registry, neither the wide variations among units nor the subsequent improvements could have been observed. Registry data were also used as a basis to discuss guidelines on preventing thrombosis. Unnecessary postoperative visits have been eliminated. Patients are followed up only as needed and in the way they prefer. Previously, it was assumed that all patients wanted a checkup, although 80% actually preferred to be followed up in another way. The registry has clarified differences in how patients and providers view complications, which has improved the information to patients regarding the normal recovery process.
Swedish Gyn-Oncology Registry

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**Year started:** Planned for 2006  
**Public funding:** 2005  
**Governing body:** Västra Götaland Region  
**Competence center:** Non-affiliated  
**Transparency, unit level:** No

**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, 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. The information should help identify problem areas and improve care processes. Monitoring of outcomes can lead to changes that reduce variations across the country.

**Coverage and Volume**
All gyn-oncology units in Sweden have representatives in the working group of 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.

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

**Reporting Process**
Data are reported to the registry as follows:
1. In conjunction with referral – clinical assessment of patients at gyn-oncology units
2. Following the conclusion of primary treatment
3. During followup after progression
4. After checking against the cancer registry
5. Date of death is obtained from the population registry
6. Cause of death is obtained via direct reporting and from the cause of the death registry.

Data are reported 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 (the units are not identified by name) will be transmitted to the FIGO international registry.

**Feedback Process**
The data will be analyzed in consultation with statistics experts from the oncology center. Some standardized statistics will be accessible via the homepage planned for the registry.

An annual report is planned. Regarding feedback, the plan is to return identified data to the respective units, and unidentified data will be generally available in the registry.

**Quality Improvement**
Since the registry is in the planning phase no outcomes are available.
Background and Aim

The Swedish Registry for Active Uremia Care (SRAU) registers everyone who needs dialysis and/or kidney transplantation due to chronically impaired kidney function. The underlying kidney diseases, treatment type, survival, cause of death, and other information are registered. The registry aims to help clinicians monitor their own units in relation to the national average and to use the findings in planning for future resource needs.

Coverage and Volume

All 65 units that provide dialysis and/or kidney transplantation services participate in the registry. Hence, coverage is 100%. The validity of reporting has been checked at several hospitals. Underreporting of 5% was found. This is a negligible figure in the statistical analysis since over 7000 living patients are registered. The registry includes data on over 20 000 patients, and approximately 1100 new patients are added each year.

Variables and Measures

The basic data registered include age, sex, primary disease, possible contributing disease states, e.g., heart disease, hypertension, diabetes, and malignancies. During the patient’s lifetime any changes in treatment and changes in residence, and eventually the cause of death are registered.

Reporting Process

At the outset, active uremia care is reported on a special form by the unit that begins the treatment. Every participating unit has a contact person that is responsible for reporting. Three to four times per year the central registry sends a list of names to the units to validate the information. The data are also checked against the cause of death registry since some individuals die at home and are not included in the data. Internet-based reporting has been discussed by contact persons at their annual meeting for several years, but will not commence until 2006.

Feedback Process

Every participating unit receives information on unit activities during the past year regarding the number of patients in active care, the number starting active uremia care, and other basic data. Other statistical information is not included, but all sex- and age-related data and statistical estimates are presented in the annual report from the central office. The compiled results and possible changes in registry reporting are discussed at the annual meeting as a basis for the coming year’s work and reports.

Transparency had been limited to the county level, but in 2005 it was expanded to include the unit level.

Quality Improvement

The extensive observation time (since 1991) enables statistical analysis that covers a long period. Survival, the most important quality parameter, has successively improved although mortality among dialysis patients remains alarmingly high, particularly at advanced ages. Annual survival has been worse than expected compared to the average population. Annual mortality among kidney transplant patients has been reduced by 6% compared to 2% in the dialysis population. However, new methods are expected to improve the outcomes.
Background and Aim
Breast cancer is the most common cancer among women in Sweden. Nearly 7000 women contract breast cancer annually. The age-standardized incidence has steadily increased since the cancer registry started in the late 1950s. Age-standardized mortality declined during the same period. There are several geographic differences in survival. Improved survival is a function of several related factors. The most important are probably:
1. Early detection of the disease by mammography screening, and also increased awareness.
3. Increasingly, subspecialized breast surgeons, working in multidisciplinary teams, manage breast cancer patients.
It is probable that by further optimizing the quality of operative care, surgery and subsequent treatment can further reduce mortality from breast cancer.

The registry aims to describe breast cancer care in Sweden and identify possible links between quality variables and relapse of the disease.

Coverage and Volume
Coverage by the registry will be high due to the long history of collaboration among clinical guideline groups and the established routines for reporting certain data in the registry. When the INCA (Information Network for Cancer Research) web portal for the oncology centers is launched in the autumn of 2005, the quality registry for breast cancer will be one of the first registries to be incorporated in the portal. Nearly 100% coverage is projected annually for patients that contract breast cancer. The foundation for compliance is that cancer reporting is also required by the oncology centers, and this will be joined with the quality registry. Hence, reporting will be checked within an existing organization.

Variables and Measures
The registry contains information on preoperative diagnostic safety, tumor data, type of operation, and number operations before treatment is finished, long- and short-term complications and relapse rates, waiting times for different steps in the diagnostic and treatment process, adjuvant cosmetic treatment, and reconstruction rate.

Reporting Process
Web-based reporting was started in the autumn of 2005. From 2002 to 2004 the registry was based on referral procedures of breast surgeons and oncology centers. In 2003, a test registry was initiated at the oncology center in Stockholm where 4 units reported every new case.

Feedback Process
Online feedback is included in the registry so that each department can view their data in comparison to the national average. Annual reports and analysis will be prepared and reported at specialist conferences, clinical guideline meetings, and throughout the continuum of care at the hospital. Annual reporting is expected to generate questions that require further study that can be initiated by the specialty society/steering committee.

Quality Improvement
The registry is new, and has not started to assess quality improvement.
National Quality Registry for Esophageal and Stomach Cancer

Background and Aim
The registry is a consolidation and further development of two well-established national registries for esophageal and stomach cancer surgery (SECC and SWEGIR). The registry has been constructed during 2005 and will become active in 2006.

Coverage and Volume
Goals:
1. To create a national registry for 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.
5. To register, at a later time, cancer therapies and details on palliative treatment.

Variables and Measures
The registry includes descriptive surgical data, tumor data, surgical and non-surgical complications, quality of life (using validated instruments), and survival analysis.

Reporting Process
The registry will be part of a national reporting system (INCA) that, for this registry, is administered by the Oncology Center in Umeå. Surgeons report data via a web-based reporting routine directly following an operation. Complications are reported in copies of discharge notes to regional oncology centers or via direct entry by the attending physician/nurse. To verify the surgeries performed, registry data will be linked and matched against data reported to the oncology centers in Sweden. Quality of life questionnaires are mailed out to patients 6 months after resection surgery. All data will be validated prior to acceptance by the national registry. Survival will be followed up via the population registry.

Feedback Processes
Participating units will have online access to their own outcome data for several variables, with national and regional averages for comparison. Annual reports will also be prepared.

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 wins professional support other treatment should also be registered. At the national level, multicenter studies can be facilitated and structured clinical improvement processes can be carried out.
National Prostate Cancer Registry

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Public funding: 1996–2005
Governing body: Örebro County Council
Competence center: Non-affiliated
Transparency, unit level: Yes

Background and Aim
Prostate cancer is the most common type of cancer in Sweden, and 9000 new cases are diagnosed annually. The incidence in recent years has increased by 10%. This trend is disturbing and raises several questions. The registry can follow trends and promote quality improvement by providing data for time trends and geographic comparisons. By linking and matching with the population and cause of death registries, the registry enables analysis of observed, disease-specific, and relative survival.

Coverage and Volume
Nationally, the registry covers 96% of all newly detected cases of prostate cancer. In 2003, coverage did not fall below 90% in any region.

Variables and Measures
In addition to regular cancer reporting, the registry contains the following variables; tumor stage based on TNM classification, PSA level, diagnostic method, malignancy grade of the tumor, pathway to diagnosis, and type of primary treatment. A special section on followup of early localization of prostate cancer in younger men includes local relapse, generalization, treatment complications, and survival measures.

Reporting Process
A printed form is used in reporting from all units that diagnose prostate cancer. A web-based form is being developed. Reports are filed no later than 6 months after diagnosis at the respective oncology centers, which then transmit unidentified data to the regional oncology center in Uppsala for national compilation.

Feedback Process
Annually, the oncology centers send regional reports to participating units in the respective regions. Feedback is completely transparent. A national report is compiled annually, presented openly at the county level, and placed on the homepage. In conjunction with placing the information on the Internet, a newsletter with comments on particularly interesting aspects is distributed.

Quality Improvement
The registry makes it possible to monitor the rapid increase in incidence that has occurred in recent years in Sweden and the wide regional variations. The increased incidence is largely a result of greater diagnostic activity involving the PSA (prostate specific antigen) blood test. Since the evidence base for early detection of prostate cancer is weak, there is an urgent need to monitor this trend. The use of different treatment interventions can also be analyzed. Since introduction of the registry, a gradual trend toward equity in diagnostics and treatment in Sweden has been observed.

Clinical quality improvement at the national level has involved histopathological grading of tumors in accordance with the internationally accepted Gleason grading scale. Distinct improvement can be observed.
Swedish Rectal Cancer Registry

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.

Variables and Measures
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. Postoperative 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. Starting in 2005, identifiable hospital data will be available that will enable comparison of all hospitals.

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.
Background and Aim
The National Quality Registry on Gynecologic Cancer Screening compiles information for all of Sweden on gynecologic cell testing to prevent cervical cancer, gynecologic tissue samples, and invitations to gynecologic cancer screening.

The county councils are in charge of gynecologic screening, and approximately 750 000 tests are conducted annually. National coordination and assessment of gynecologic screening has not been done previously.

The aim of the quality registry is to continuously monitor organized and opportunistic national and local cancer screening and to feed back the information directly to those responsible for assuring the quality of this activity in each county council. Women who have not been tested, or allow long intervals between testing, are those most likely to be affected by cervical cancer. National coordination is necessary to develop strategies that will increase participation in these groups. National coordination also offers an opportunity to continuously monitor the quality indicators that can eventually reveal deficiencies in the investigation, treatment, or followup of women with cell changes. The introduction of screening to detect HPV virus, and future vaccination against it, must be planned and assessed nationally to assure optimum quality and cost effectiveness.

Coverage and Volume
Gynecologic cell samples are analyzed and diagnosed at 32 pathology/cytology laboratories. All laboratories in Sweden participate in the quality registry. The registry includes 100% of the women that have cell tests, 100% of the women that have gynecological tissue tests, and 100% of the women invited for screening.

Variables and Measures
For cell testing: laboratory code, sample year, referral number, sample site, type of screening (organized/opportunistic), sample date, registration date, diagnostic code.

For tissue samples: laboratory code, sample year, agent number, sample date, registration date, histopathological diagnostic code.

For invitations to gynecologic screening: laboratory code, date, type of event (invitation, reminder, etc).

Reporting Process
Data are reported to a database from every laboratory via text files on CD or via FTP servers.

Feedback Process
Information is fed back to the oncology centers for regional reports, annual reports of gynecologic screening for individual laboratories, and for national conferences (with representatives from participating units) where national and regional/local reports are presented and discussed. A national report (intended for annual publication) is being prepared for the county councils and the laboratories.

Quality Improvement
In the spring of 2005, based on a uniform national classification scheme, the quality registry coded all diagnoses for gynecologic cancer screening in Sweden. The results have been sent to department heads, designated clinicians, and all pathology/cytology laboratories for review and comment. Similar work began in the autumn of 2005 for gynecologic tissue samples. There have been no previous attempts at uniform national classification.
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 long, taking approximately 2 years to achieve 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 2004 are in the registry. The 8 units in Sweden that perform corneal transplantation participate in the registry.

Variables and Measures

At the time of surgery, the patient’s sex, age, surgical indications, visual acuity, possible risk factors, surgical method are reported. The donor’s sex and age, and the corneal bank that deliver the donated cornea, are also noted.

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. The presence of other eyesight-impairing diseases is also reported.

Reporting Process

Printed forms from the two reporting times are sent to the registry manager who enters the data in a specially designed computer program (Access). The registry will soon be web-based.

Feedback Process

Participating surgeons may attend an annual user meeting where they receive reports compiled from the data. The meeting provides a forum for discussing the impact of the data in the clinical improvement process. When the registry becomes web-based, users will have access to standard reports that are generated automatically.

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 are 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 reported substantially lower postoperative astigmatism than other departments. A videotape was used to study the surgical technique at this department. Other departments modified their surgical technique accordingly, and eventually the registry data will show whether or not this has had an effect.
Swedish National Cataract Register

Background and Aim

Cataract surgery is the most common surgical procedure in Sweden. Around 80,000 operations are performed annually at a substantial cost to the health services. Methods in cataract surgery are developing rapidly. The registry promotes quality improvement by providing data for comparisons and to present good examples, to enable analysis of outliers at the national level, to assess the surgical benefits perceived by patients and thereby improve knowledge about appropriate indications, and to develop and expand knowledge about cataract disease.

Coverage and Volume

The participating units report 98.5% of all operations to the registry (2003), and total coverage is 95%. Since 2004, all local public (county council and municipal) and major private units participate in the registry.

Variables and Measures

Important variables include units, 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, and surgical incision. Measures also include planned and final refraction and whether the operation has healed 6 months after intervention. Special variables apply to congenital cataracts.

Reporting Process

Approximately 40 units report via the web. Secretaries usually enter the data from printed forms or patient records. Over 10 units submit data via text files and e-mail. A few units submit printed forms. Patient questionnaires are sent before and 6 months after surgery and include questions on 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 analysis, and time series. Particularly interesting aspects are also addressed at user meetings.

Since reporting is web-based, the units have access to automatically generated, standard reports at any time. These are also available in print for each contact person and department head 4 times per year. The standard report shows data for the units, and comparisons with other units regarding mean values and distribution. Results of patient questionnaires are presented in tables showing the responses by percent and outcomes by unit.

Quality Improvement

The registry has been important in technical improvements, eg, choosing the type of surgery and lens. In 1998, the registry began to report on severe postoperative infections. During the first year, antibiotic prophylaxis, sample taking, and treatment were discussed at several national meetings. All units later introduced uniform routines based on recommendations from the registry. Infections decreased by half, and Sweden now has a relatively low rate by international standards.

Clinical quality improvement at the national level, the so-called Q-reg project, has been implemented to reduce the percent of patients that do not experience benefits from cataract surgery. The results show that changing the surgical strategy in one or both eyes could reduce the percentage of patients with persisting problems. Another Q-reg project involving 9 units is under way and aims to improve continuity of care prior to cataract surgery, to make waiting time reporting more equitable, and to propose national indications for cataract surgery.
Macula Register

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Year started: 2003
Public funding: 2004–2005
Governing body: Uppsala County Council
Competence center: EyeNet Sweden
Transparency, unit level: No

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 more are expected within years. These methods are resource intensive and expensive.

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 influence treatment outcomes and thereby the opportunity to change treatment indications.

Coverage and Volume
Of all units that provide treatment, 94.4% participate in the registry. Reporting varies somewhat among the participating units. Several units register nearly 100% of the patients, while others experienced local problems in reporting.

Variables and Measures
The registry includes diagnosis, sex, age, symptom duration, visual acuity, nearsightedness, type of vascular membrane, position, size, angiography, optical coherence tomography (OCT), type of treatment, side effects, and subjective perception of treatment results.

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

Information is continually entered in a “local” data file at the units. Units submit their data twice per year to the coordinating center, to the “global” database, by e-mail or magnetic disc.

Units can continually monitor and analyze their treatment outcomes.

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 show data for the units and also comparisons with other units and the national average.

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

The registry has led to improved quality in diagnosing CNV, mainly the interpretation of angiographies, which has major importance for making treatment decisions for CNV. This has led to more uniform assessment and treatment policies for these patients.
Swedevox – Respiratory Failure Registry

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, characterized 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. A strong 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
Participating units in Sweden are those that prescribe therapy for adult patients with respiratory failure. Coverage is 85% for oxygen therapy patients and 90% for home respirator patients. The registry currently includes 11,655 oxygen patients and 2,018 respirator patients. Approximately 1000 home oxygen and 130 home respirator patients are added to the registry every year.

Variables and Measures
The registry includes demographic data, risk factors, diagnosis and conditions at the outset of treatment, blood gas values, pulmonary function, information on treatment with bronchodilators, vaccinations for influenza and pneumonia, and details about home oxygen and home respirator therapy.

Reporting Process
Over 60 units enter their data via the web, and have done so since late 2004. Some units submit printed forms. Oxygen therapy patients are followed up by reporting after 1 year, and home respirator patients after 1 and 3 years.

Feedback Process
Annual reports describe the patient groups by presenting time trends on various demographic and clinical data at the aggregate level. Other information includes trends in access to treatment in Sweden, the quality of treatment, and outcomes in terms of survival and utilization of inpatient services. All participating units receive statistics on their own data compared to Sweden as a whole. This information is also available on the web. The data are analyzed, controlling for confounders such as age and diagnosis, and later presented and discussed at annual user meetings.

Quality Improvement
Access to treatment has improved greatly in Sweden since the registry started, resulting in substantial reductions in variations among the county councils. The need for inpatient care after starting home oxygen therapy has declined by 75% since 1987 while age-adjusted survival remained the same. The quality of implementation has been enhanced, but there is also room for improvement. Vaccinations have increased by a factor of 2.5 and 4.0, respectively, since the information was first registered, which may have contributed to the reduced need for inpatient care. Utilization of individualized mobile oxygen equipment has increased, and is shown to improve the quality of life. Gaps in following up home respirator patients have been detected, which the participating units attribute to deficiencies in facilities and staff resources. These are important quality indicators and require further analysis.
Swedish Hernia Registry

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Year started: 1992
Public funding: 1992–2005
Governing body: Jämtland County Council
Competence center: Non-affiliated
Transparency, unit level: Planned for 2006

Background and Aim
Hernia surgery is the most common general surgery procedure in Sweden. A successful hernia operation is an uncomplicated intervention involving approximately 1 week of sick leave, followed by alleviation of the problem. Surgery could also lead to postoperative complications, e.g., recurrence of hernia and severe chronic pain. A registry with high-level validity can clarify the extent of such problems. The registry aims to monitor trends in Sweden on hernia surgery, including surgical method, waiting times, type of care, and outcomes. Also, the registry aims to create a reliable base for local assessment of treatment outcomes and facilitate joint epidemiological or prospective, randomized studies.

Coverage and Volume
The Swedish Hernia Registry (SBR) was created in 1992, initially with 8 surgical units. The registry has continued to grow and now includes 92 participating units. The registry covers about 95% of Swedish hernia surgery. Nearly 20,000 procedures are performed annually. A database including detailed information on just under 120,000 registered hernia operations has been developed.

Variables and Measures
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 reoperations, peri- and postoperative complications, percentage of day surgery, chronic pain, mortality, etc. The most important outcome variables are reoperation 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 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 performance. Emphasis is placed on entering complete and accurate data in the registry.

Feedback Process
Annual results are reported via the web site to the participating units in April or May the following year. Reports contain information about the performance of individual units and corresponding data aggregated for all units. The data are available to any unit at any time via the web site.

Quality Improvement
Units that participate in the registry have access to the results from analyzing registry data and adapt their surgical methods accordingly. Although the same surgical method might not be appropriate for all patients, by monitoring the data it might be possible to show, e.g., that the safest method is currently used in 60% of the operations versus 3% a decade ago. Usually, a very large number of operations are required to reveal the relatively small differences among the groups compared. Hence, a registry is necessary for this type of analysis.
**SDIR – Swedish Dental Implant Registry**

**Registry Manager:** Björn Klinge  
*Karolinska Institutet, Dept. of Odontology*  
**Phone:** +46 (0) 8-5248 8040  
**E-mail:** bjorn.klinge@ki.se  
**Homepage:** www.sdir.ki.se  
**Year started:** 2005  
**Public funding:** 2005  
**Governing body:** Stockholm County Council  
**Competence center:** Non-affiliated  
**Transparency, unit level:** When coverage permits

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**Background and Aim**

Dental services for the adult population are organized, managed, and financed in a much different way than health services. The Swedish Dental Implant Registry is the first in dentistry. There are major gaps in knowledge regarding long-term treatment outcomes and the incidence of complications from implant treatment. New implants and new treatment methods are introduced without any apparent systematic followup. The registry is being constructed to address this problem. The aim is to show long-term outcomes for different brands and types of implants in relation to the type of unit, the clinician, and the patient’s experience.

**Coverage and Volume**

There is no complete or verified information on the number of dental implants or the number of patients treated. An estimate from the Swedish Social Insurance Administration would suggest 100,000 implants annually on approximately 25,000 patients just in the group over 65 years of age. The cost to society per implant treatment in this age group is estimated to exceed 600 million SEK per year. Coverage is judged to be good based on information from specialty associations and professional dental organizations.

**Variables and Measures**

The registry will contain implant loss (end-point) as a measure of failure, patient experiences, implant position in the jaw, design of the prosthesis, type of material, smoking, general health, and medications.

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**Reporting Process**

Reporting will take place interactively via a web-based interface directly to the database. The support function with a help desk will be available.

**Feedback Process**

Feedback will take place interactively online via web-based interface directly with the reporting units. Annual reporting and user meetings will take place in conjunction with the annual national meeting of oral surgeons. Annual reports are planned for publication in the Journal of the Swedish Dental Association. The annual reports will contain descriptive and analytical data.

**Quality Improvement**

The registry is being constructed, so information on quality improvement is not yet available.
Background and Aim

Gallstones are a common disorder among the population. In Sweden, the gallbladder is removed in 11,500 patients per year due to gallstone disorders. Endoscopic interventions for stones in the bile duct are also common, with around 2,700 interventions per year.

In gallbladder surgery and endoscopic treatment for stones in the bile duct, postoperative complications appear in 5% to 10% of the cases. Serious complications on removing the gallbladder, such as damage to the bile duct, or death, occur in 0.5% to 1.0% of the cases. However, nearly 80% of the patients are relieved of the problems that surgery was intended to cure.

The number of gall operations varies over time and by geographic area, but these variations are not explained by differences in the prevalence of gallstones in the population. Hence, the aim of the registry is:

• to contribute toward uniform, evidence-based management of gallstone disorders as regards surgical indications and choice of surgical method.
• to identify patient benefits from gallstone treatment.
• to detect, at an early stage, unexpected negative effects of new gallstone treatment methods used in routine health care.
• to support local quality assurance efforts in gallstone surgery.
• to contribute toward expanding knowledge on gallstone disorders and their treatment.

Coverage and Volume

GallRiks started on May 1, 2005. The goal is to recruit 90% of the eligible departments as full participants in the registry by the end of 2005.
HIV Registry

<table>
<thead>
<tr>
<th>Registry Manager:</th>
<th>Åke Åkesson</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dept. of Infectious Disease, Karolinska University Hospital</td>
<td></td>
</tr>
<tr>
<td>Phone:</td>
<td>+46 (0) 8-5858 19 53</td>
</tr>
<tr>
<td>E-mail:</td>
<td><a href="mailto:ake.akesson@karolinska.se">ake.akesson@karolinska.se</a></td>
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<td>Non-affiliated</td>
</tr>
<tr>
<td>Transparency, unit level:</td>
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Background and Aim
The introduction of modern HIV treatment has led to a drastic decrease in morbidity and mortality. Since curative HIV treatment is not available, an ongoing registry of care is necessary for quality assurance. The HIV registry aims to verify and further improve the positive treatment outcomes in Sweden, and to create equitable care throughout the country between the genders and among risk groups, thereby providing HIV-infected patients in Sweden with good longevity and quality of life.

Coverage and Volume
Currently, the registry includes the 5 largest HIV units in Sweden and is considered to be national. The registry follows approximately 2600 patients, or about 70% of all HIV patients. On average, the patients made 3 confirmed visits in 2004. The percentage of new patients in 2004 increased approximately 9% compared with 2003.

Variables and Measures
The registry includes several basic demographic variables, eg, diagnosis date, age, sex, virus type, current and previous treatment. Registered at every visit are, eg, percent treated with HIV RNA <50 copies/ ml; percent treatment naive and percent treated with <200 CD4+ T lymphocytes respectively; incidence therapy failure at initial therapy; resistance evaluation on failure; registration of the most important and suspected new side effects; mortality/cause of death.

Reporting Process
Patients are registered at their first visit to an HIV unit after being diagnosed. All patients are systematically followed up during return visits. A secretary, nurse, and/or physician enters the demographic and laboratory data, drugs, and side effects at the initial visit and after each return visit. Depending on local conditions, the data are sent directly via the web to a central database or to a web-based local database where they are later transmitted to a central database.

Feedback Process
The registry has a steering committee including a registry manager and representatives from various collaborating partners. The Chair of the steering committee and the operative system manager have the responsibility to compile and analyze the data in accordance with decisions of the steering committee. Each participating unit, on its own initiative, compiles its own data and compares it with national data.

Quality Improvement
The HIV registry is based on the concept that clinical quality improvement should be decentralized to the patient units, and involve the interaction between caregivers and patients. During the visit, the physician and patient together use Internet services for proactive, pedagogical, decision support to plan care and measure its results. We believe that the registry, at the national level, will reveal potential differences in treatment among different HIV departments. New, national clinical guidelines for HIV treatment have been developed recently, and the registry should contribute toward better compliance with these guidelines.
National Quality Registry for Inflammatory Bowel Diseases

<table>
<thead>
<tr>
<th>Registry Managers:</th>
<th>Peter Andersson / Pär Myrelid</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dept. of Surgery, Linköping University Hospital</td>
</tr>
<tr>
<td>Phone:</td>
<td>+46 (0) 13-22 36 06 / 22 35 41</td>
</tr>
<tr>
<td>E-mail:</td>
<td><a href="mailto:peter.andersson@lio.se">peter.andersson@lio.se</a> / <a href="mailto:par.myrelid@lio.se">par.myrelid@lio.se</a></td>
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<td>Non-affiliated</td>
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<tr>
<td>Transparency, unit level:</td>
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</tbody>
</table>

Background and Aim

Chronic inflammatory intestinal diseases are a growing health problem. These disorders are found in 0.5% of the population, and the prevalence is expected to increase to 1% of the population before 2010. Causal treatment is not available, and the diseases require life-long surveillance and therapy. Patients with inflammatory bowel diseases (IBD) may receive advanced treatments that can have serious side effects, eg, drug side effects or surgical complications. The national registry that is being constructed will provide the opportunity to assess these undesirable effects in large patient groups. The registry also provides an opportunity for studies to recruit larger numbers of patients with particular subgroups of disease than what individual centers could recruit. The national registry will also provide a base for epidemiological studies.

Coverage and Volume

The registry is in a construction phase, and units engaged in caring for patients with IBD are being recruited. An estimated 40 000 individuals could be covered by the registry if all patients in Sweden were included.

Variables and Measures

The registry is divided into 3 levels. Participating units can choose levels based on their own needs. Level A is a minimum level involving annual registration of basic epidemiological data. Level B involves registering basic outcome parameters. Level C offers the opportunity to register detailed data on treatments and outcomes. Level C uses detailed prototype forms, but is not yet electronically linked to the rest of the registry.

Variables registered at levels A and B involve specific diagnoses (ulcerous colitis, Crohn’s Disease, undefined colitis, collagenous colitis, lymphocytic colitis, and other IBD), basic diagnostic data, previous surgery, outpatient or inpatient visits, abdominal or perianal surgery, pharmacotherapy, sick leave, quality of life based the Short Health Scale, and growth parameters in children and teenagers.

Reporting Process

The registry is accessible via the Internet. Local participating units are expected to register data continually by reporting to central units via Sju-net.

Feedback Process

Reporting back to the participating units and funding organizations is planned to occur annually. The data from a participating unit is fed back in identifiable form.

Quality Improvement

Since recruitment of units has just started, no improvement results are yet available. At the most basic level, the registry can provide information on variations in the number of cases in the different diagnostic categories in Sweden. Important epidemiological data can be obtained through the opportunity to link and match the data with other registries, eg, the cause of death registry and the cancer registry. National differences in medical and surgical treatment traditions can be detected. The information can be related to well being as measured by a validated index and sick leave rates, and could ultimately lead to changes in treatment patterns that benefit the patients. Likewise, information concerning the needs for inpatient care and the frequency of outpatient visits can reveal regional differences that could be a result of the treatment given.
SIR – Swedish Intensive Care Registry

Registry Manager: Carl-Johan Wickerts  
Dept. of Anesthesiology and Intensive Care, Danderyd Hospital  
Phone: +46 (0) 8-655 79 63  
E-mail: info@icuregswe.org  
Homepage: www.icuregswe.org  
Year started: 2001  
Public funding: 2002–2005  
Governing body: Non-affiliated.  
Transparency, unit level: Yes, from 2005

Background and Aim
The Swedish Intensive Care Registry (SIR) collects and compiles information to support local quality improvement efforts and encourage comparisons among the participating intensive care units. In capturing data, the focus is 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 registries that cover a single diagnosis. The aim is to achieve the best medical and nursing outcomes with the least staff and material resources for all types and degrees of disease without complications.

Coverage and Volume
SIR includes 50 intensive care units (June 2005) with 70,829 intensive care admissions registered from 2001 to 2004 (23,235 during 2004). Coverage is 49% for county district hospitals, 76% for county hospitals, and 78% for regional hospitals.

Variables and Measures
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 homepage.

In 2005, SIR established 9 national quality indicators: 1) followup of quality of life and functional status, 2) risk-adjusted mortality (mortality in relation to type of disorder and degree of severity), 3) bacterial multi-resistance, 4) ventilator-related pulmonary inflammation, 5) CVC-related infections, 6) readmission to ICU within 72 hours, 7) possible organ donors at ICU, 8) occupancy rate, and 9) patients discharged from ICU at night.

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

Feedback Process
Information is published on the intensive care registry homepage within 6 hours of reporting. It is possible to access several predefined reporting profiles or analyze one’s own data. The annual report is published in August of the following year and includes the midyear mortality figures.

Quality Improvement
Reports from the past 3 years have enabled the intensive care units to agree on 9 initial national quality indicators that the registry will follow. Other quality indicators are being discussed, and several other projects are underway:
• Discharge at night from the ICU as a risk factor for death (annual report 2004).
• Use and benefit of Mobile Intensive Care Groups.
• Discontinuation and refusal of treatment at the ICU.
• Are any potential organ donors being overlooked (special followup of deaths at the ICU)?
• Antibiotics and resistance development at ICUs (SIR and ICU-STRAMA have merged into SIR).
• Quality of life after intensive care.
Transparent and comparable information on the quality of care is an important quality improvement instrument, and it is SIR’s mission to present this in a uniform and standardized way.
Background and Aim

Interventions to monitor pregnancy play a major part in the good perinatal outcomes in Sweden. Maternal health services are usually a small entity in Swedish county councils, and there are no similar programs for local-level comparisons. Hence, a national system for quality assurance and quality improvement was created to promote equitable quality throughout Sweden. The registry can enhance knowledge about variations in resources, practice, patient mix, birthing methods, compliance with national recommendations, etc. These are studied in relation to outcomes such as inhibited growth, gestational diabetes, delivery method, breastfeeding, smoking, patient satisfaction, etc.

Coverage and Volume

Coverage is similar throughout Sweden. Private and public services, large and small units, large cities and small towns are all represented.

In 2003, the registry included 439 units (81% of all clinics) that reported 800 000 visits for 70 000 pregnant women (72% of all pregnancies).

Variables and Measures

A structure-related questionnaire addresses organization, resources, collaboration, range and scope of services offered, affiliation with gynecological cancer screening, etc.

Individual-based information provides data on, eg, smoking and use of snuff, growth inhibition, need for extra interventions, sick leave/maternal subsidies, percent with gestational diabetes, delivery method, breastfeeding, continuity, and patient satisfaction.

Reporting Process

Structure-related data are submitted via the Internet no later than April 30 every year.

A midwife submits individual-based information via the Internet in conjunction with a checkup after delivery. The data are entered directly into the database and can be fed back directly.

Feedback Process

Compiled data can be acquired at the unit, regional, and national levels at any time. As soon as the data for the year are entered, each unit can obtain a data file with their own raw data.

Once per year, the steering group compiles an annual report that is fed back to everyone involved and is later discussed at national conferences and local meetings.

Quality Improvement

The registry has helped provide a clearer image of the differences in organizations and resources. This is important since the National Board of Health and Welfare and the governing bodies (county councils and municipalities) establish requirements regarding the content of maternal health services. Before the registry was established, the national situation was not well understood. Now, each unit can show how well they meet the requirements and there can be a better discussion regarding goals and resources.

The registry has created greater awareness among the units about their own work and has increased the interest about issues addressed by the registry. Greater knowledge has been gained about compliance with existing national guidelines, which has led to an initiative to change these guidelines.
Neurorehabilitation Registry – Quality Registry in Rehabilitation Medicine

Background and Aim
The registry aims to monitor and assess the effects of rehabilitation interventions to improve the care of the individual patients over time, to enable assessment of activities at the unit level, and to compare individual participating units with other units. Another aim is to acquire information about the consequences of disease/injury on the individual, based on the ICF domain, and monitor changes within these parameters.

The units care for people of working age with different diseases/injuries (mainly stroke and traumatic brain damage) whereof neurological problems are the most common. The goal is that patients will return to their own homes.

Coverage and Volume
The registry includes around 750 inpatient admissions per year from 13 rehabilitation medicine units throughout Sweden, representing approximately three fourths of the available beds (all university departments and the large county hospitals participate).

Variables and Measures
The registry records demography, length of stay, diagnosis, lowest level of consciousness on arrival to the hospital, level of dependence on admission and discharge (determined by the Functional Independence Measure – FIM).

Reporting Process
Forms are filled in when patients arrive at the unit and when they are discharged from the hospital. Completed forms are entered on local computers at each hospital. Up to now, the data have been submitted on a magnetic disc to the operational manager. We hope to be able to enter data directly online and have online access to information on each patient cared for, reports, lists, tables and graphs, and statistics on care needs, interventions, and treatment outcomes for any time interval and patient group.

Feedback Process
Printed reports on the national registry have been sent to users annually. Also, once or twice per year, the information is presented orally at meetings of the Swedish Association for Rehabilitation and Physical Medicine.

Quality Improvement
In many cases, participating units have benefited from the data showing lengths of stay, diagnoses, and outcomes of the rehabilitation process (changes in FIM). It has also been valuable for units to compare themselves with the national average for Sweden. In some instances two departments, on their own request, have compared their data.
Background and Aim
Psoriasis is a common skin disease that affects people worldwide. The prevalence of psoriasis is influenced by genetic and environmental factors. Sweden has a prevalence of 2.3%, the highest in the world. Originally, psoriasis was considered to be solely a skin disease. Today, however, it is viewed as a systemic disease accompanied by an increased 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. For many years, individual units will acquire only limited experience with such agents. Hence, 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, e.g., gender.

Coverage and Volume
A test run of PsoReg is planned for autumn 2005. The goal is to achieve 90% coverage of Sweden’s publicly financed health services within 5 years. PsoReg has initiated collaboration with Denmark, Norway, and Finland to use PsoReg as the Nordic tool for quality improvement in psoriasis care.

Variables and Measures
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 is quality life, drugs prescribed to the patient, and possible side effects. Biologic drugs are monitored separately.

Reporting Process
Data are entered via the web. The web page includes logic and control functions.

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, e.g., by showing similarities and differences in the ways that units manage their patients. Given the time pressures facing health services, there is a risk that physicians select a systemic 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.
Background and Aim
Therapeutic home apheresis involves, eg, plasma exchange, photopheresis, immunoabsorption, and stem cell harvesting. Work with the registry has been steadily advancing. An annual report has been sent to all participating units and other interested parties, initially along with a report on Swedish blood supply and later as a freestanding report. 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 disease. Several different methods are used, involving different substitutions, with different fluids, including different plasma components. These multifaceted aspects require an ongoing registry for quality assurance. The apheresis registry aims at optimizing existing clinical guidelines and at surveying the effects of therapy and the risk for side effects from, and risks of, therapy. Furthermore, comparing treatment strategies among centers promotes optimization of quality in the country.

Coverage and Volume
The registry is national and includes approximately 4500 treatments per year in acute and chronic patients. These patients require specialized care for their conditions, and treatment is centered at major hospitals (not in primary care). The number of treatments have been relatively constant in recent years. Coverage is estimated at 94% of the units and more than 85% of the treatments.

Variables and Measures
The basic data registered at every treatment are: inclusion date, year and month of disease onset, diagnostic criteria, technical equipment, treatment principles/approach, side effects, and assessment of the patient’s functional quality.

Reporting Process
Five units at university hospitals report directly via the Internet. Others submit written reports/standard forms that are entered into the central database. The registry is linked to the World Apheresis Registry.

Through frequent and repeated treatments, most of the patients can be systematically followed up.

Feedback Process
After entry, the data become accessible on the Internet, but only for each registered user/unit (those who have entered the data). The data from all units are compiled at the end of the year into the national registry’s report. The annual reports are sent to all participating units and to the homepage of the National Board of Health and Welfare.

The units can use their data for internal statistics on production and quality. Regional and national comparative diagrams are available. Feedback is an important aspect of clinical quality improvement and involves national, regional, and local meetings.

Quality Improvement
The registry enables continuous, clinical quality improvement through more assessment of treatment effects and patient experiences.

The data increase the patient’s access to information on the benefits and risks of every treatment prior to starting it.

At the general level, the registry has revealed variations in treatment at different types of hospitals, eg, regarding treatments and risks. Better compliance with guidelines has been achieved, and outcomes have steadily improved.
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, e.g., 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
- eardrum repair – myringoplasty
- surgery of the nasal septum – septumplasty
- intubation of children with recurring secretory media otitis and recurring acute media otitis
- tonsillectomy.

In recent years, another ear surgery intervention has been added – otosclerosis surgery. Another diagnosis in the area of chronic disease/rehabilitation, i.e., severe hearing impairment among workers will soon be added to the registry.

The aim of the registry is to continually measure quality indicators in a large area 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. A reason for dropout was perceived to be a lack of motivation, and this has been addressed by information and education on a broad front. Data quality studies were also conducted and led to further evaluation of the material.

Variables and Measures

The registry includes surgical time, surgical method, peri- and postoperative complications, length of stay, time on sick leave, waiting time to first visit, and waiting time to intervention. Focus is also placed on patient-experienced outcomes, as surveyed in questionnaires.

Reporting Process

Since the spring of 2003, the ENT units have registered their data continuously via the Internet.

Feedback Process

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

During the past year, the ENT association started a process to create transparent registries. The plan includes reference groups for the different diagnoses, with the aim to strengthen the position of, and develop criteria for, a transparent registry.

Quality Improvement

The registry reveals the quality variations and quality deficiencies for much of the ENT specialty. This encourages ongoing, relevant discussions on improvement efforts in the special reference groups of the participating registries. During the year, national guidelines were established for nasal sputum surgery, where the outcomes in many units have not been satisfactory. Another example of quality improvement concerns tonsillectomy, where the percent of unplanned return visits is 3 times higher than acceptable, according to the specialty association. This issue is being addressed by a large interview study by experts from Borås University College.
Registry Applicants That Did Not Receive Funding in 2005

By presenting all applications that were submitted for funding, including the ones not approved, it is possible to gain a better total understanding of current and future activities related to quality registries in Sweden.

Obviously, limited economic resources make it necessary to prioritize among the applicants. The registries that did not receive funding might be under construction and are not sufficiently developed, or they may lack sufficient quality. 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. In presenting the following list, no attempt was made to “weed out” or select certain non-funded applications. However, in some cases, applications that clearly did not address 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. In addition to planning new registries, the collaboration with other European countries should be mentioned since increasingly more Swedish registries are being used in translated versions or are serving as models in the development of European registries. Hence, even though all applications have been listed, the description of registry activity is not totally complete.

The list presented below includes contact information and a brief overview of the registries that applied for funding in 2005, but, for various reasons, were not granted funds.

**National Quality Registry for Bladder Cancer**

*Registry Manager:* Staffan Jahnson, Dept. of Urology, Linköping University Hospital  
*Phone:* +46 (0) 13-22 20 00  
*E-mail:* saffan.jahnson@lio.se  
*Homepage:* None  
*Year started:* 1997  
*Funding, past 3 years:* 2002–2003  
*Governing body:* Östergötland County Council

**National Quality Registry for Malignant Melanoma**

*Registry Manager:* Kerstin Nordenskjöld, Oncology Center, Linköping University Hospital  
*Phone:* +46 (0) 13-22 20 16  
*E-mail:* chatarina.malm@lio.se  
*Homepage:* None  
*Year started:* 1999  
*Funding, past 3 years:* 2003  
*Governing body:* Östergötland County Council
National Registry of Acute Leukemia in Adults (Acute Leukemia Registry)
Registry Manager: Gunnar Juliusson, Hematology, Lund University Hospital
Phone: +46 (0) 46-17 13 15
E-mail: gunnar.juliusson@skane.se
Homepage: www.ocsyd.lu.se
Year started: 1997
Funding, past 3 years: 2003
Governing body: Region Skåne

Swedish Pacemaker and ICD Registry
Registry Manager: Fredrik Gadler, Dept. of Cardiology, Karolinska University Hospital
Phone: +46 (0) 8-517 758 77
E-mail: fredrik.gadler@ks.se
Homepage: www.pacemakerregistret.se
Year started: 1989
Funding, past 3 years: –
Governing body: Region Skåne

Quality Registry for Renal Medicine, NjuR
Registry Manager: Börje Haraldsson, Renal Medicine, Sahlgrenska University Hospital
Phone: +46 (0) 31-342 1701
E-mail: borge.haraldsson@kidney.med.gu.se
Homepage: www.NjuR.org
Year started: 2004
Funding, past 3 years: 2003–2004
Governing body: Västra Götaland Region

Swedish Anesthesiology Registry
Registry Manager: Lars Wiklund, Dept. of Anesthesiology, Uppsala University Hospital
Phone: +46 (0) 18-611 48 51
E-mail: lars.wiklund@akademiska.se
Homepage: noname.doneit.se/sfai/default.php
Year started: 2000
Funding, past 3 years: –
Governing body: Uppsala County Council

Nationellt Registry for Hydrocephalus Surgery
Registry Manager: Kristina G Cesarini, Dept. of Neurosurgery, Uppsala University Hospital
Phone: +46 (0) 18-611 49 86
E-mail: Kristina.Cesarini@neurokir.uu.se / Kristina.Cesarini@akademiska.se
Homepage: www.hydro.ucr.uu.se
Year started: 2004
Funding, past 3 years: 2003
Governing body: Uppsala County Council
KVITTRA (Quality Registry in Trauma Care)
Registry Manager: Per Örtewall, General Surgery and Transplantation, SU/Sahlgrenska University Hospital
Phone: +46 (0) 31-342 13 39
E-mail: per.ortenwall@vgregion.se
Homepage: None
Year started: 1998
Funding, past 3 years: –
Governing body: Västra Götaland Region

Quality Registry on Sex Reassignment
Registry Manager: Mikael Landén, Affective Center / Dept. of Psychiatry, St. Göran’s Hospital
Phone: +46 (0) 8-672 23 71
E-mail: mikael.landen@spo.sll.se
Homepage: None
Year started: 2005
Funding, past 3 years: –
Governing body: Stockholm County Council

Swedish Registry for Vagus Nerve Stimulation in Epilepsy
Registry Manager: Tove Hallböök, Neurology Section /Childrens Hospital, Lund University Hospital
Phone: +46 (0) 46-17 10 00
E-mail: tove.hallbook@skane.se
Homepage: www.svenskaepilepsisallskapet.c.se
Year started: 2005
Funding, past 3 years: –
Governing body: Region Skåne

Quality Registry for Primary Care
Registry Manager: Kjell Lindström, Primary Care R&D Unit, Qulturum
Phone: +46 (0) 36-325202
E-mail: None
Homepage: None
Year started: 2005
Funding, past 3 years: –
Governing body: Jönköping County Council

PRIS (Perioperative Registry in Sweden)
Registry Manager: Roland Andersson, Dept. of Surgery, Lund University Hospital
Phone: +46 (0) 46-17 23 59
E-mail: roland.andersson@kir.lu.se
Homepage: None
Year started: 2004
Funding, past 3 years: –
Governing body: Region Skåne
Joint Implants in the Hand and Wrist
Registry Manager: Christer Sollerman, Dept. of Hand Surgery, Sahlgrenska University Hospital
Phone: +46 (0) 31-342 30 95
E-mail: maria.knall@orthop.gu.se
Homepage: www.svls.se/sektioner/hk/
Year started: 2005
Funding, past 3 years: –
Governing body: Västra Götaland Region

Premature Infants With BPD, Bronchopulmonary Dysplasia
Registry Manager: Per Thunqvist, Sachsska Childrens Hospital, Söder Hospital
Phone: +46 (0) 8-616 40 46
E-mail: per.thunqvist@sos.sll.se
Homepage: None
Year started: 2005
Funding, past 3 years: –
Governing body: Stockholm County Council

Intraoral Devices for Oral-motor Treatment
Registry Manager: Jan Andersson-Norinder, Oral Health Center, Ågrenska Hospital
Phone: +46 (0) 31-750 92 00
E-mail: mun-h-center@vgregion.se
Homepage: www.mun-h-center.se
Year started: 2005
Funding, past 3 years: –
Governing body: Västra Götaland Region

Potential Nursing Variables in National Quality Registries
Registry Manager: Swedish Society of Nursing
Phone: +46 (0) 8-412 24 00
E-mail: torie.ernsater@swenur.se
Homepage: None
Year started: 2005
Funding, past 3 years: –
Governing body: Stockholm County Council

27-Week Registry – Extremely Premature Infants
Registry Manager: Karel Marsal, OB/GYN Dept., Lund University Hospital
Phone: +46 (0) 46-172550
E-mail: karel.marsal@gyn.lu.se
Homepage: www.medscinet.com/pnq27
Year started: 2004
Funding, past 3 years: –
Governing body: Västerbotten County Council
National Quality Registry for Emergency Medicine Riks-AKUT
Registry Manager: Bengt R Widgren, Emergency Medicine, Sahlgrenska University Hospital
Phone: +46 (0) 31-342 1163
E-mail: bengt.widgren@medic.gu.se
Homepage: None
Year started: 2005
Funding, past 3 years: –
Governing body: Västra Götaland Region

CNS Infections
Registry Manager: Jan Fohlman, Dept. of Infectious Disease, CLV
Phone: +46 (0) 470-58 82 80
E-mail: jan.fohlman@ltkronoberg.se
Homepage: www.cnsinfektioner.se
Year started: 2005
Funding, past 3 years: –
Governing body: Kronoberg County Council

National Quality Registry for Drug-Assisted Treatment for Opiate Dependence
Registry Manager: Leif Grönbladh, Methadone Program/ Dept. of Substance Dependency, Uppsala University Hospital
Phone: +46 (0) 18-611 21 52
E-mail: leif.grönblad@akademiska.se
Homepage: None
Year started: 2005
Funding, past 3 years: –
Governing body: Uppsala County Council

National CF Registry
Registry Manager: Lena Hjelte, Stockholm CF Center, Karolinska University Hospital Huddinge
Phone: +46 (0) 8-58587354
E-mail: lena.hjalte@karolinska.se
Homepage: None
Year started: 2005
Funding, past 3 years: –
Governing body: Stockholm County Council

Fracture Registry
Registry Manager: Hans Granhed, Dept. of Orthopedics, SU/Sahlgrenska
Phone: +46 (0) 31-3423410
E-mail: hans.granhed@vgregion.se
Homepage: None
Year started: 2005
Funding, past 3 years: –
Governing body: Västra Götaland Region
National Registry for In-Hospital Cardiac Arrest

Registry Manager: Johan Herlitz, Heart-Lung Dept., Sahlgrenska University Hospital
Phone: +46 (0) 31-821661
E-mail: hlr-centrum.su@vgregion.se
Homepage: None
Year started: 2005
Funding, past 3 years: –
Governing body: Västra Götaland Region

Swedish Registry for Gynecological Cancer Surgery

Registry Manager: Thomas Högberg, Dept. of Oncology, Linköping University Hospital
Phone: +46 (0) 13-22 20 71
E-mail: thomas.hogberg@ibk.liu.se
Homepage: None
Year started: 2004
Funding, past 3 years: 2004
Governing body: Östergötland 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. Additional information is available at www.kvalitetsregister.se or at www.socialstyrelsen.se. A handbook on starting a quality registry can be downloaded from the websites. The EyeNet competence center published the handbook in collaboration with other competence centers and the Executive Committee.

Application Process in Brief

Applicants for registry funds submit their applications electronically via the Internet. Registry managers that received grants in past years are sent login information at their contact address. Other applicants must contact the National Board of Health and Welfare to receive login information.

The National Board of Health and Welfare is responsible for handling the grant applications, compiling information for Executive Committee decisions, and paying out funds. 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 (via e-mail) two separate documents: an annual report and activity report for the previous year. 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

Five main headings are used in the application to describe a registry. 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.
- Budget
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, medical and other interventions, and outcomes.
- Have support within the profession, e.g., as demonstrated by involvement of specialist societies.
- Be responsible for contact conferences and feedback.
- Cover publicly financed organizations regardless of operational structure and, if possible, include privately financed health services.
- Have high, preferably national, coverage.
The homepages of the quality registries and competence centers are listed below. Not every registry has a homepage. In many cases, information about registries that are affiliated with a competence center can be found on the center’s homepage. The registries are presented below in the same order as listed in the catalogue.

**National Healthcare Quality Registries in Sweden**

PNQn – Perinatal Quality Registry / Neonatology
www.pnq.se

Swedish Childhood Rheumatism Registry
www.blf.net/reumatologi

SCAAR – Swedish Coronary Angiography and Angioplasty Registry
www.ucr.uu.se/scaar

RIKS-HIA – Registry on Cardiac Intensive Care
www.riks-hia.se

SEPHIA – Registry on Secondary Prevention in Cardiac Intensive Care
www.ucr.uu.se/sephia

Swedish Heart Surgery Registry
www.ucr.uu.se/hjartkirurgi

RiksSvikt – Heart Failure Registry
www.ucr.uu.se/rikssvikt

Swedvasc – Vascular Registry in Sweden
www.swedvasc.se

Riks-Stroke – National Quality Registry for Stroke
www.riks-stroke.org

NDR – National Diabetes Registry
www.ndr.nu

Scandinavian Quality Register for Thyroid and Parathyroid Surgery
www.thyroid-parathyroidsurgery.com

Swedish Shoulder Arthroplasty Registry
www.ssas.se/axel

RIKSHÖFT – National Hip Fracture Registry
www.sahfe.ort.lu.se

Swedish National Hip Arthroplasty Register
www.jru.orthop.gu.se

Swedish Knee Arthroplasty Register
www.ort.lu.se/knee

Swedish Rheumatoid Arthritis Registry
www.rareg.net
Followup in Back Surgery
www.4s.nu

SMS – Swedish Multiple Sclerosis Registry
www.msreg.net

SDDB – Swedish Dialysis Database
www.sddb.org

GYNOP – National Quality Registry for Gynecological Surgery
www.gynop.com

National Prostate Cancer Registry
www.roc.se

Swedish National Cataract Register
www.cataractreg.com/cataract

Swedish Hernia Registry
www.sbd.norrnod.se

SDIR – Swedish Dental Implant Registry
www.sdirki.se

GallRiks – Swedish Quality Registry on Gallstone Surgery
www.ucr.uu.se/gallriks

SIR – Swedish Intensive Care Registry
www.icuregswe.org

National Quality Registry for Maternal Health Services
www.sfog.se/mhvrapport

PsoReg – Swedish Psoriasis Registry
www.psoreg.org

Swedish Therapeutic Apheresis Registry
www.iml.umu.se/medicin

Swedish Quality Register of Otorhinolaryngology
www.kvalitet.onh.nu

Collaboration on Quality Registries on Psychiatric Care (KPV)
www.psykkval.nu.

Competence Centers
UCR – www.ucr.uu.se
Eyenet Sweden – www.eyenetsweden.se
NKO – www.nko.se
National Healthcare Quality Registries in Sweden
Executive Committee and Scientific Advisory Committee

Executive Committee of the National Healthcare Quality Registries

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Phone +46 (0) 480-840 90
E-mail: ragnhildh@ltkalmar.se

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Phone +46 (0) 8-555 53073
E-mail: marianne.holmberg@socialstyrelsen.se

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Phone +46 (0) 8-5555 3602
E-mail: bo.lindblom@socialstyrelsen.se

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National Healthcare Quality Registries in Sweden 2005

This book describes 57 National Quality Registries and three “competence centers” that serve the Swedish healthcare system. Also presented briefly are over twenty registries that applied for, but did not receive, public funding in 2005. The content and number of registries changes from year to year. This overview describes the situation in 2005.

The catalogue presents the aim, content, and coverage of current registries, and describes how outcomes are reported back to the users and applied in the quality improvement process. The book also describes the role of central organizations and the routines in applying for financial support to start up and operate a National Quality Registry.

Homepage addresses, e-mail addresses, telephone numbers, and other contact information are presented 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 fax +46 (0) 20-31 32 40.

ISBN 91-7164-096-7

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