The Swedish Quality Registries and Primary Health Care

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A system of national quality registries has been established in the Swedish health and medical services in the last decades. There are about 73 registries and seven competence centres that receive central funding in Sweden. All national quality registries contain individualised data concerning patient problems, medical interventions, and outcomes after treatment and aggregated the data can be used with the purpose of continuous learning, quality improvement and management.

Definition of quality registers in Sweden
A national quality registry contains individualised data concerning patient problems, medical interventions, and outcomes after treatment; within all healthcare production. It is annually monitored and approved for financial support by an Executive Committee.

Vision
The vision for the quality registries and the competence centres is to constitute an over-all knowledge system that is actively used on all levels for continuous learning, quality improvement and management of all healthcare services.

A catalogue that describes the National Healthcare Quality Registries in Sweden was published 2007. The catalouge also describes the organization of the Quality Registries and the Swedish healthcare system.

Competence centres
Seven competence centers for the National Quality Registries has been established. In a competence center, several registries share the costs for staff and systems that a single registry could not bear. Hence, a continued development of the registries can be assured although the system follows a decentralized model, i.e. each register is governed by a professional collaboration.

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.

EyeNet
One of the very first centers is Eyenet,
EyeNet Sweden was instituted January 2003 as a centre of competence within the field of quality registries. The Swedish National Cataract Register, NCR, with its long experience of data collection and research, formed the framework of this new developing centre. EyeNet Sweden now works with and supports registries from all parts of health care, including dental care.

EyeNet Sweden is located in Blekinge Hospital in Karlskrona Sweden close connected to Blekinge Centre of Competence, LP of the ImPrim project.
The principal recipients of the feedback of processed and analyzed data from the National Quality registries are the local profession and the units that participate in the registry. It is there that they best can analyse data as well as take measures for improvement. In pace with the increasingly open reporting of results by the registries, other interested parties have also arisen such as patients/the public and politicians as well as client organizations. A Handbook for establishing quality registries was published by EyeNet and will be accessible on the web.

Primary Health Care and Quality registries
In PHC the value of quality registries has been lively discussed. The arguments against have been that the management of old patients with co-morbidity seldom will follow guidelines. However there are general practitioners who have developed quality registries for PHC. One of these are Rut F Öien, MD PhD, coordinator of the national quality registry Rikssår or RUT (Registry of Ulcer Treatment). She started this work 15 years ago and is now the coordinator on national level.

Her description of this register follows;

Registering Ulcer Treatment through a national quality registry: RUT – a winning concept for both patients and the health care sector
Rut F Öien

RUT (Registry of Ulcer Treatment) is a web-based national quality registry on hard-to-heal ulcers developed to meet the demands of modern ulcer care in providing reliable diagnosis, adequate strategies for ulcer care and a structured follow up to ulcer healing. RUT was the first primary care quality registry in Sweden initiated by a general practitioner, Rut F Öien, since most leg ulcers patients are treated in primary or community care in Sweden. RFÖ is also the registry manager.

National registries
A system of national quality registers has been established in the Swedish health and medical services in the last decades. RUT (Registry of Ulcer Treatment) has been running since May 1st, 2009. The Swedish national registers cover different areas of medicine such as diabetes mellitus (NRD), dementia (SweDEM), Swedish intensive care (SIR) and acute coronary care (RIKS-HIA). There are currently 73 registers and 27 registry candidates that receive central funding from Salar, the Swedish Association of Local Authorities and Regions www.skl.se. Salar publishes reports from the registers to enable the participant clinics to compare their outcome results with other clinics in Sweden for optimising medical care.

RUT was developed in cooperation with EyeNet Sweden www.eyenetsweden.se, one of the competence centres (1) and is also the first primary care register in Sweden initiated by a general practitioner Rut F Öien (RFÖ).

Research in wound management
In Blekinge county there are 150,000 inhabitants and we have 25 years’ experience of quality improvement and clinical research within the field of wound management (2, 3) resulting in the establishment of Blekinge Wound Healing Centre in 2003. The Centre is a GP-led (RFÖ), primary care based specialist centre covering the treatment and follow up of the majority of ulcer patients in the whole county. Ten per cent of the patients treated at the Centre are referred from physicians at the hospital.
When the need for a web-based quality register became obvious, RUT was developed to meet the demands of modern ulcer care. Introducing a structured team management of ulcer care with the emphasis on diagnosis and documentation and treatment was the key to success for an improved wound management programme. Over the last years, RUT has been adjusted and evaluated at Blekinge Wound Healing Centre in order to determine the clinical parameters. RUT has been operational since May 1st, 2009.
Registrations in RUT

Patients with hard-to-heal leg, foot and pressure ulcers are registered at two occasions. The first registration, assessment of the ulcer, is to guarantee the diagnosis. The second registration is at follow up, i.e. at ulcer healing.

It should be noted that all patients with a non-healed ulcer remain on the register until the ulcer is healed no matter how long this takes. Therefore, at follow up the patient can either have a healed ulcer, be deceased, have had an amputation and thus no longer an ulcer, moved to another geographical area or no longer wishes to stay on the register.

At the first registration the following parameters are noted: patient’s social security number, which is linked and matched to the Population Statistics at The Council for Official Statistics of Sweden; gender; age; date of diagnosis; profession or former profession; smoking habits; civil status; number of children; mobility; exercises habits and Body Mass Index.

In addition, details are also taken regarding the nurse responsible for ulcer care; if the ulcer is a recurrent, new or traumatic ulcer; actual or earlier concomitant diseases; actual medication with particular interest in analgesics and antibiotics, and ulcer related pain. In the anamnesis (patient history) we focus on the following parameters: DVT (Deep Vein Thrombosis), varicose veins; arterial or venous surgery, history of recurrent leg ulcers, ulcer localisation: foot, leg, sacrum/hip and lateral or medial localisation. Ulcer size is also measured by digital planimeter (Visitrak®) and number of ulcers is noted.
During this evaluation we also assess patient circulation by means of palpation of *arteria dorsalis pedis* and *arteria tibialis posterior* as well as measuring the blood pressure by a hand-held Doppler, which is also used for measuring deep or superficial venous insufficiency (*vena saphena magna*, *vena saphena parva* and *vena poplitea*). The diagnosis is set by using these parameters together with the clinical examination. The following ulcer diagnoses are used: venous, arterial, venous-arterial, diabetic foot ulcer, pressure ulcer, traumatic ulcer, skin malignancy, hypostatic eczema or other diagnosis.

The strategy for wound management includes prescribed care for the skin surrounding the ulcer, the ulcer edges and the ulcer bed, as well as treatment for oedema. A photo gallery is linked to the register for visualizing the healing process.

Follow up at complete ulcer healing includes date of healing; time for healing (weeks); estimated number of weekly dressing changes to healing; compression therapy; treatment with antibiotics; pain relief; the most used dressing material, and if advice was given on smoking cessation, exercises and diet. Adverse events are recorded at follow-up i.e. amputation, venous or arterial surgery and death.

Every unit registers and has access to its own patients and visits. Registration can be done at any moment and follow-up can be carried out when all the mandatory parameters are registered.

Reports

Every unit or user can at any time receive data from their own unit which can be used to compare the unit’s quality of wound management to the whole country. Technical support is performed by EyeNet Sweden, www.eyenetsweden.se.
**Results 2009-2012**

An earlier study demonstrated a significant improvement in the care of hard-to-heal leg and foot ulcers in the county of Blekinge during the period 1994 to 2005 with reduction of treatment time, prevalence and significant cost savings (3). Treatment time decreased from 1.7 hours per patient per week in 1994 to 1.3 hours in 2005. Estimated prevalence of hard-to-heal leg and foot ulcers reduced from 0.22% in 1994 to 0.15% in 2005. These results led to a significant reduction of annual costs by SEK 6.96 million (approximately 1 million Euro) in the study area.

Another explanation for the improved results of leg and foot ulcer care is the more frequent use of compression therapy (71% in 1994 and 90% in 2005), a key to successful treatment of venous leg ulcers.

A further indicator of improved leg and foot ulcer care is the reduction in daily dressing changes (20% in 1994 to 10% in 2005) and the increase in weekly changes (12% in 1994 to 32% in 2005), which is also acknowledged in a recent Swedish study (4).

Basic data from the adjusted register in 2012 (n=1162) show a mean age of 73 years (13-97 years) with 60% women. Fifty-four percent of the patients suffered from heart disease and eleven percent had rheumatoid arthritis or other inflammatory disease.

![Ulcer healing per year](image)

Data from RUT show that in 2009 the median healing time was 135 days for ulcers of any etiology compared with 61 days in 2012.
Another result is the reduction of treatment with antibiotics from 78% in 2006 (5) compared with 24.6% in 2012.

RUT has been implemented regionally and is in use in primary, community and hospital care, namely dermatological departments, throughout the country. RUT has proved to be a guarantee for good clinical practice as well as for evaluation of quality, more participants are joining the register.

Discussion
The leg ulcer patient’s right to receive optimal treatment has been limited during the last decades due to lack of diagnosis by the physician and continuity of ulcer care to complete healing.(2,6,7) Dressing changes throughout weeks, months and even years have been carried out by the nurse often without a proper diagnosis.(2) The physician has often been absent in the team work around the patient, leading to missed diagnosis and hence the leg ulcer patient is not given optimal treatment for healing. It is well known that understanding the aetiology of leg ulceration is a prerequisite to systematic and sound clinical assessment and to planning and implementing appropriate wound management (8, 9). Furthermore research results have proven that hard-to-heal leg and foot ulcers, being symptoms of underlying chronic circulatory disease, have an adverse effect on the patients’ quality of life (10, 11).

RUT, as a diagnostic quality registry, provides information on both the outcome and process quality needed to provide high quality leg ulcer care. Several problem areas such as injuries caused by the health care sector can easily be identified in RUT leading to correction of treatment while also focusing on education of staff (12). Improvements in leg and foot ulcer care lead to a better quality of life and a reduction of pain in patients with ulcers (13-15). These aspects and the cost savings would be substantial if the quality register RUT were to be introduced in any department where ulcer care is given.

A shift in paradigm has occurred, where “ulcer care” with accurate diagnosis and effective treatment evolved to “ulcer healing”. A national quality registry has been found to be imperative in achieving better conditions for leg ulcer patients.

Hard-to-heal leg and foot ulcers have an adverse effect on the patients’ quality of life. Giving these patients an early and adequate diagnosis and hence more effective treatment will not only improve ulcer care but also reduce the costs for the health care sector. The success of wound management will be based on ensuring that the patient and staff have the knowledge and understanding of the ulcer’s aetiology and how specific types of treatment work.

RUT would appear to have the potential to improve the quality of care, ensure appropriate diagnosis and treatment, and eventually improve health outcomes nationwide.

Conclusion
To optimise treatment of hard-to-heal ulcers nationwide there is a need for a webbased quality registry to compare care, needs, costs and outcomes. RUT would appear to fulfill these demands and can also be used to identify problem areas such as injuries caused by the health care sector.

Acknowledgement:
Part of this article was published in EWMA journal
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