# The Swedish national quality Registry of Ulcer Treatment (RUT): How can 'RUT' inform outcome measurement for people diagnosed with venous leg ulcers in Australia?



Öien RF & Weller CD

#### **ABSTRACT**

Chronic venous disorders are increasingly being recognised as a health care priority in the Western world. The burden of venous ulceration is growing due to increased prevalence of venous disease, diabetes and obesity. A wide variety of health professional specialities are responsible for the prevention, diagnosis and treatment of venous leg ulcers (VLUs). Each discipline may have a different approach to preventing, diagnosing and treating venous disease depending on their practice, experience and training. Best practice treatment of VLUs is a firm compression bandage to aid venous return. Variability in clinical practice and variable quality of care as well as lack of standard guideline implementation and compliance can affect VLU healing outcomes. Monitoring patterns and quality of care for people diagnosed with VLUs with a national quality registry has been shown to improve quality outcomes for people in Sweden. This article outlines the positive healing outcomes from the Swedish Registry of Ulcer Treatment (RUT) and offers some reflections about how this learning can be applied to the Australian setting.

#### NATIONAL REGISTRIES IN SWEDEN

A system of national quality registries has been established in the Swedish health and medical services in the last decades. The registries

### Dr Rut F Öien\*

General Practitioner, B.A. M.D., PhD. Registry manager of RUT, Blekinge Wound Healing Centre, Blekinge Centre of Competence, SE 371 81 Karlskrona, Sweden Email: rut.oien@ltblekinge.se

#### Dr Carolina D Weller\*

PhD

NHMRC Postdoctoral Research Fellow, Senior Research Fellow, Department of Epidemiology & Preventive Medicine, School of Public Health & Preventive Medicine, Level 6, The Alfred Centre, 99 Commercial Road, Melbourne VIC 3004

\* Corresponding authors

cover different areas of medicine such as diabetes mellitus (NRD) and dementia (SweDEM). There are currently 81 registries which receive central funding from Salar, the Swedish authorities (www.skl.se), an organisation that publishes reports from national registries to enable the participant clinics to compare their outcome results with other clinics to optimise medical care.

## CLINICAL PRACTICE AND RESEARCH IN WOUND MANAGEMENT IN BLEKINGE, SWEDEN

Blekinge county in Sweden has 25 years' experience of quality improvement and clinical research within the field of wound management<sup>1</sup>. The research resulted in the establishment of Blekinge Wound Healing Centre (BWHC) in 2003. The centre is a GP-led (RFÖ), primary care-based specialist centre to treat and follow up the majority of ulcer patients in the whole county (population 150,000).

The majority of patients are referred to the centre by district nurses (52%), general practitioners (15%) or community nurses (8%). Some patients/relatives call for an appointment themselves (17%) or are referred from hospital colleagues (8%). BWHC offers a structured team management of ulcer care with emphasis on diagnosis, documentation and treatment. Every patient treated at BWHC is registered in the national quality registry.

### RUT — REGISTRY OF ULCER TREATMENT, THE SWEDISH NATIONAL OUALITY REGISTRY FOR **HARD-TO-HEAL ULCERS**

The need for a web-based, quality registry became obvious when establishing the BWHC, which is why a quality registry for hardto-heal leg, foot and pressure ulcers was initiated by RFÖ. The registry was introduced as a tool with a checklist in clinical practice to assess adequate diagnosis, suggest treatment strategies and follow every patient to ulcer healing. Registrations started in Blekinge but slowly spread throughout the country. In 2009 RUT was introduced nationally and is today used daily and nationwide. The registry holds data for over 2,240 patients with hard-to-heal ulcers, that is, approximately 10% of every patient in this group in Sweden. Eighty per cent of those patients (1794/2240) have completed follow-up, where 80% had achieved complete healing and 20% had either died or had some level of amputation.

#### REGISTRY PROCESS

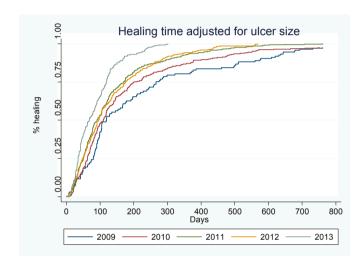
Patients with a hard-to-heal leg, foot or pressure ulcer are registered on two occasions. The first registration is to assess the ulcer diagnosis for optimal treatment and the second registration is at follow-up, that is, at ulcer healing or negative clinical event such as amputation or death. The registry holds 52 mandatory variables such as gender, age, diagnosis date, smoking habit, mobility, pain, ulcer size and location, sleeping pattern, ulcer recurrence, actual concomitant diseases and medication (www.rut-europe.eu).

It is documented if the patients has/has had a deep vein thrombosis (DVT), varicose veins, arterial or venous surgery. The clinical assessment includes Doppler measure of the arterial circulation. The following ulcer diagnoses are used: venous, arterial, venous-arterial, diabetic foot ulcer, pressure ulcer, traumatic ulcer, inflammatory vessel diseases such as vasculitis or skin tumours such as squamouscell or basal-cell carcinoma. Every user can at any time receive data online from their own unit, which can be used to compare the unit's quality of wound management with that of the whole country.

#### RESULTS FROM RUT 2009-2013

The median healing time for all ulcers, that is, leg ulcers, foot ulcers and pressure ulcers shows a significant reduction from 146 days in 2009 to 73 days in 2013 (Figure 1). The median age in 2013 was 81 years (ranging from 12 to 104 years), the majority of patients being

Figure 1: Healing time for leg, foot and pressure ulcers in RUT, from 2009 to 2013 (n=2022)



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women (59.5%). The median ulcer duration was 12 weeks (mean 117 weeks, ranging from 1 week to 46 years). The group of patients with ulcer duration for more than 1 year was 26.3% in 2009, compared with 16.9% in 2013.

As ulcer size has a negative impact on ulcer healing, it was found that median healing time in 2013 for smaller ulcers (<10 cm²) was 56 days compared with 88 days for larger ulcers (>10 cm²). The median ulcer size in 2013 was 3.25 cm² (mean 13.2 cm², ranging from 0.01 to 600 cm²). It has also shown a significant reduction in antibiotic treatment from 71% before registration to 29% at ulcer healing, possibly as a result of structured wound management with focus on continuity of care².³.

### INTERNATIONAL NETWORKS ON QUALITY REGISTRIES

The Swedish Hip Arthroplasty Register, http://www.shpr.se/en/, has a long experience of international cooperation with the goal of creating common research databases, and has created an international system of "early warnings" of newly introduced types of implants, and eventually poorly functioning implants. Interest throughout the world in harmonised and combined databases has increased as has the need for standardised statistics and processes of validation.

International cooperation using the Swedish national, quality registry for hard-to-heal ulcers has just started with participants from Germany, the German Wound Healing Society (DGfW), the Monash University, Melbourne, Australia, represented by Dr Carolina Weller (CDW) and the EWMA secretariat (European Wound Management Association). The aim of the cooperation is to establish an international collaborative consortium for health outcomes measurement for hard-to-heal ulcers. The consortium will focus in the first stage on VLUs and how to measure and report patient outcomes in a standardised way, the minimum data set (MDS) and what types of reports will be needed to compare different health outcomes in different clinical settings<sup>4</sup>.

Focus will be on harmonised variables, standardised statistics and validation. Experiences from RUT could certainly contribute to the development of this international registry.

The international group aims to use the standards of the International Consortium for Health Outcomes Measurement (ICHOM http://www.ichom.org/why-we-do-it/). ICHOM organises global teams of physician leaders, outcomes researchers and patient advocates defining standard sets of outcomes per medical condition, and then drives adoption to enable health care providers globally to compare, learn and improve. Outcomes are the ultimate measure of success in health care. When seeking treatment, patients want to know what their life will be like after treatment: will they return to work, will their symptoms improve and when will the wound heal<sup>4-6</sup>? The plan will be to work towards agreement with the proposed entry criteria and decide on which wound care outcomes should be prioritised. Issues about sharing de-indentified patient-level data, privacy or technical issues will be explored.

The proposed criteria for the international collaborative consortium for health outcomes measurement for hard-to-heal ulcers will be guided by two aspects:

- 1. the commitment to measure standard MDS within two years (if allowable within that country)
- 2. the ability to measure a prioritised set of outcomes by June 2016.

The MDS could include variables such as age, gender, ulcer size, ulcer duration, ulcer pain, treatment with antibiotics or antiseptics, assessment of arterial circulation, healing time, compression therapy or treatment with NPWT (negative pressure wound therapy).

## CAN LEARNING FROM THE SWEDISH RUT INFORM A QUALITY REGISTRY IN AUSTRALIA?

An estimated 400,000 Australians suffer from venous leg ulceration due to chronic venous insufficiency (CVI)<sup>4</sup>. In Australia VLUs are managed in a variety of settings including but not limited to primary care and community settings with reported variation in treatment and effectiveness<sup>4-7</sup>. Variation in treatment translated to health care costs in Australia of over \$3 billion when measured in 2010<sup>7</sup>. The burden is expected to rise with an ageing population and the growing epidemic of diabetes and obesity that will further increase health care costs in Australia<sup>4</sup>. Using the Swedish example, Australia could apply a similarly structured wound management clinical outcome approach and measure care time and costs. Other measurable outcomes that will be relevant from the Swedish model are health-related quality of life (HRQoL) and the potential to connect telemedicine with the wound registry.

There is an urgent need to address the many challenges to healing people with VLUs in Australia. Sweden has demonstrated that a structured team management of ulcer care with emphasis on diagnosis, documentation and treatment can positively impact on healing rates and ulcer recurrence.

Effort in changing health services to improve outcomes will require extensive infrastructure, costing time and money. It could be perceived as a major challenge to the large health care delivery system in Australia or it could be seen as an opportunity to make a major difference to improve the quality of care of people with VLUs in Australia. Sweden has paved the way and clearly shown that improvement is possible; not only in healing people in a more timely way with improved quality of life but also in economic terms8. Can Australia ignore the Swedish example and continue to care for people with VLUs in the same way as has been done for the past decades? It is planned to discuss this further when RFÖ and CDW lead the second Venous leg ulcer seminar in Melbourne Australia on Friday 15 August 2014. The seminar will be convened at Monash University as part of the annual seminar series "A call to action — Reducing venous leg ulcers by 50% in the next 10 years". Further information is available at: http://www.med.monash.edu.au/sphpm/creps/seminars. html

There will be an opportunity for an exchange of experiences with Australian wound care professionals, key health policy advisors to advocate for a national registry to treat patients with hard-to-heal ulcers.

#### **CONCLUSION**

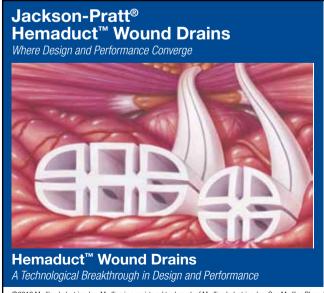
The results from the Swedish registry demonstrate the remarkable potential of RUT as a guarantee to improve health outcomes nationwide and internationally, namely in a significant reduction of healing time and health costs. Can Australia achieve the same? The task is huge but one that must at least be attempted so that meaningful comparisons of outcome data can one day lead to the best clinical practice in the delivery of wound care in Australia.

The Swedish RUT example has emphatically demonstrated outcomes measurement can have a powerful impact on health care delivery. On an individual scale, patients can expect clearer information about healing outcomes, and better care from health care professionals who are consistently evaluating their own practice. Outcomes measurement ensures that health care institutions are held accountable for delivering high-value care. People with hard-to-heal ulcers in Australia deserve nothing less.

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