

## Working with Populations to Treat Individuals: A Report from the Swedish Dermato-Epidemiological Network (SweDEN)

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### Introduction

In 1995, the European Dermato-Epidemiology Network (EDEN) was formed with the aim of expanding the role of epidemiology in dermatology (1). The Swedish Dermato-Epidemiology Network (SweDEN) was also started in the same year. National networks have also been established in other countries; for example, UK and Italy. We have previously described the SweDEN network after 3 years' work (2). We report here our experience after 17 years, reflecting especially on organisational forms for research and developmental work in an increasingly pressed professional situation.

### Why epidemiology?

Epidemiology is a tool for describing the distribution of health conditions in a population and the determinants of these conditions (3). Epidemiology is used for public health surveillance and for evaluation of interventions. It can be used to estimate burden of disease in populations. Such data are necessary for a properly prioritised allocation of resources within a healthcare service.

Epidemiological methods are important tools for scientific work. Understanding the proper use of these tools is necessary for critical reading of scientific literature, which is a pre-requisite for the application of evidence-based medicine, our compass in clinical decision-making. Epidemiology and evidence-based medicine are, however, only part of a spectrum of skills needed both in research and in the everyday practice of dermatology. There is competition for the time of both specialist trainees and practitioners.

### Educational needs in epidemiology

The process of education in epidemiology can be seen as a spiral of learning from the undergraduate level to residency, specialist training and continued medical education. In undergraduate and PhD education, the Bologna process (4) is an initiative aimed at strengthening the scientific basis of education. Epidemiology at these educational levels is a part of this process. Residency training programmes, specialist training and continuing medical education of specialists are

not covered by Bologna, but the need for a structure to ensure efficient delivery of knowledge in epidemiology is no less relevant. We envisage a role for SweDEN in this field.

### Why network?

Our network, SweDEN, aims at minimising bureaucratic routines in order to provide room for practical work with low costs for the organisation. The network is open to all persons with an interest in epidemiology within our discipline in Sweden. The physical network is merely a list of interested individuals. New names are added to the list as we come in contact with persons at our courses, workshops and other meetings. The network is organised by an idea group (steering group), which meets 2–3 times annually. The role of the steering group is to organize courses and workshops and to initiate/facilitate relevant research projects. In order to spread tasking to as many as possible, work-groups are formed for different projects. The steering group communicates with the network and others working in our discipline via a newsletter. The network form provides flexibility with low demands on financing and structure. The prerequisites for a well-functioning network at an individual participant level are interest, initiative, open-mindedness and an ability to interact positively with colleagues. Apart from a personal interest in participation, support at departmental level for the participating individual is crucial.

### Has the network made a difference?

The period during which SweDEN was established was an exciting time in the development of our knowledge of the extent of common dermatoses, such as contact dermatitis and atopic eczema. Previously the classical use of epidemiology had been in the study of infectious diseases including venereological diseases and skin cancer. The original members in the group were especially interested in eczema in the broader sense. A recurring "Linköping" workshop (now advertising its 15<sup>th</sup> event for 2013 as "The Linköping/Vadstena Workshop") was



the main forum for discussion. As work progressed, concepts such as evidence-based medicine were introduced and interest in these areas led to a wider role for the network, aiming at higher levels of competence in the care of eczema. A logical focus was on the development of the tools necessary for continued research, work that continued in small “*ad hoc*” groups with a specific task (5–8). Tools for the dermatological parts of public health questionnaires were validated (9), both for use in individual studies and national public health surveys (10). These validated questions have had good penetration in the field. The data gathered in national surveys has been evaluated and reported (11). The use of validated questions over time has allowed surveillance of common skin diseases (12). These results have been presented at relevant scientific meetings both nationally and internationally.

It became apparent that the Linköping Workshop was an important forum for the development of new skills on the part of interested individuals. A total of 14 workshops have been held. Table I shows the dates and themes of these meetings. Workshop themes have followed conceptual development in our discipline. In order to find time for all the areas needing coverage, courses other than the Linköping/Vadstena workshop have also been organised; a total of 11 such courses to date (Table II). Since 2007, special 3-day epidemiological courses have been held 4 times. The programme covers basic epidemiological principles, study design, data management through a combination of lectures and practical exercises in data analysis. In order to stimulate interest over a broader

Table I. *Linköping/Vadstena Workshops in Dermatological Epidemiology organised by the Swedish Dermato-Epidemiology Network (SweDEN). At all the workshops presentation and discussion of on-going projects from the participants were held in addition to the main theme*

Year	Topic
1995	Contact dermatitis
1996	Hand eczema questionnaire and psoriasis
1998	Evidence-based medicine and Cochrane Collaboration projects
1999	Meta-analysis and critical reading of clinical experimental articles
2001	Evaluation of interventional projects and the use of registers
2002	Health economics
2004	Inter-disciplinary research
2005	Intervention studies
2006	Scoring systems in dermatology – clinics, laboratory and statistics
2007	How to assess patient information – qualitative research methodology
2009	How to manage different types of processes
2010	Risk assessment
2011	Epigenetics
2012	Comorbidity

Table II. *Courses organised by the Swedish Dermato-Epidemiology Network (SweDEN)*

Year	Place	Topic
1998	Umeå	Sample size
1999	Borås	Critical reading of scientific papers
2000	Lund	Health economics
2001	Stockholm	Qualitative research methods
2002	Eskilstuna	Clinical trials
2003	Linköping	From a questionnaire to an article
2005	Göteborg	How to read a scientific paper
2007	Hemavan	Dermato-venereological epidemiology (level 1)
2008	Hemavan	Dermato-venereological epidemiology (level 1)
2010	Stockholm	Dermato-venereological epidemiology (level 1)
2011	Hemavan	Dermato-venereological epidemiology (level 2)

public, reports of Workshops and Course have been printed in *Bladet*, our newsletter published in *Forum for Nordic Dermato-Venereology*. Thus, information about SweDEN has reached a larger proportion of dermatologists than the 35% of Swedish Society of Dermato-Venereology (SSDV) members who have participated in either workshops or courses.

The Linköping/Vadstena Workshop has been a meeting place and a fixed point in the Swedish dermatological firmament. We have used this forum to introduce new concepts and to recruit the best help in the field to acquire new skills. An important part of the workshop has been a platform for the presentation of research projects in planning or analysis phases for a critical discussion on epidemiological and methodological issues. Over the years more than 30 projects, with a considerable number of resulting publications, have been presented and, according to reports, have benefitted from this service.

## Sustainability

The network as a method of organisation has advantages over more rigid group formations, but still relies on well-functioning group dynamics. Against a theoretical background on group dynamics we feel that, although the steering group has functioned without written rules and regulations, a solid consensus on what we wanted to achieve in a general sense has been achieved. An important feature has been that the “productive phase”, i.e. the phase leading up to a workshop or an article, has never been considered the end of the group process, but rather as a point in the continuing cycle of the network. It seems that the absence of strict rules and regulations has facilitated the natural change in the constitution and work of the group. Individual members, or constellations of members, up to and including the whole steering group, have worked, when necessary, in “production mode”, but the group has always cycled further, returning to “orientation” or “getting to know you” phases as new projects materialize and concepts of epidemiology and best practice develop and mature.

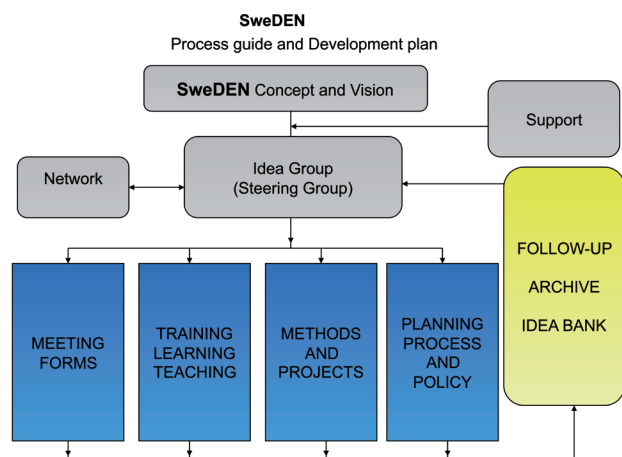


Fig. 1. Description of process-orientation in the Swedish Dermato-Epidemiology Network (SweDEN).

If an attempt were to be made to summarise the group's structure and processes, it might look like Fig. 1, which demonstrates that an idea group with support from existing dermato-venereological structures and a network of interested "shareholders" (from a personal to an organisational level) organise activities in the form of meetings and other training/research forums, endeavour to develop and make available dermato-epidemiological competencies and interact as appropriate in matters relevant to the pursuit of the networks vision – "Evidence-based dermato-venereological healthcare from population to individual; dermato-venereological public health work from individual to population". Whatever a more detailed analysis of the group dynamics might show, we, in the steering group, feel that after 17 years we can recommend the networking method.

### The future

There will be continued demands on the efficient use of time and funding within our discipline. We see our main task in the network to be to foster dermato-epidemiological principles within our discipline at a national level. However, we also foresee the need for cooperation with other national networks in multi-centre studies and in developing guidelines and educational curricula. We consider the network form to be especially attractive at a national level and will try to develop this work at an organisational level further. Our activities also need to be sustainable. Our work will rely on enthusiastic individuals, but there should be sufficient depth in the network to not solely rely on them. Of the meeting forms that already exist within SweDEN, interactive, net-based resources are in most need of development.

### Conclusion

Dermato-epidemiology has improved our knowledge in common dermatoses and is an important part of continuing

development of dermato-venereology. SweDEN aims to link basic epidemiological undergraduate training to specialist training, addresses the need for continuing medical education for specialists and provides, through specific events and networking, a forum for discussion and collaboration so that the individual patients we treat can benefit from knowledge of disease gained at a population level.

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