

## **EULAR Scleroderma Health Professionals Network (EUSHNet)**

*A EULAR international collaborative network of Health Professionals working with people with Scleroderma/Systemic Sclerosis*

### **Terms of Reference**

#### **EUSHNET PURPOSE:**

**To improve non-pharmacological care and reduce inequity through an international network of health professionals working in SSc.**

#### **TERMS OF REFERENCE: BACKGROUND, SCOPE, OBJECTIVES AND GOVERNANCE OF THE EUSHNET NETWORK**

*The EUSHNet Network was initiated under the auspices of the EULAR standing committee for Health Professionals.*

*For the purposes of this document the definition of 'Health Professional' includes: dental hygienists, dieticians, nurses, occupational therapists, orthoptists, physiotherapists, podiatrists, psychologists, social workers, speech and language therapists and other relevant health professionals who are not medically qualified and are involved primarily in non-pharmacological health care and rehabilitation.*

This document was prepared by:

- Prof Anthony Redmond (UK)
- Dr Els van den Ende (NL)
- Mrs Ann Tyrrell-Kennedy (FESCA, IRL)

And approved by the EUSHNet steering committee on 25<sup>th</sup> April 2012

Version 1.0. 25/4/2012

## NETWORK TERMS OF REFERENCE

### BACKGROUND

Systemic Sclerosis (SSc)/scleroderma is a complex disease of unknown origin with heterogeneous manifestations. The disease has a significant impact on functioning and quality of life in the majority of patients. Non-pharmacological treatment is often provided as an adjunct to medical treatment, with the aim of supporting patients in living with the consequences of the disease. Health professionals, including nurses, psychologists, occupational therapists, physical therapists, podiatrists, and social workers play an important role in supporting patients with SSc to cope with their disease. However, so far research on the efficacy of non-pharmacological interventions is scanty and the body of knowledge regarding is limited.

Unmet health care and information needs are common among SSc patients. This might be explained by fragmented expertise among health professionals on non-pharmacological care, lack of knowledge among physicians and patients about available treatment modalities for SSc and restricted access to health services. Variations in the expertise, accessibility and dissemination of knowledge within and among countries may also lead to inappropriate variations in quality and equity of care. An international network of health professionals, collaborating with physicians and patients will contribute to the body of knowledge and the quality of care in systemic scleroderma by facilitating communication and exchange of knowledge among HPs and patients, by identifying gaps of knowledge and educational needs, by setting up campaigns to reduce undesirable variation in quality and access to care, by setting priorities regarding research and educational projects, by providing a framework for the collection and combining of data and by facilitating collaboration on specific projects.

### SCOPE

The EUSHNet network exists to improve non-pharmacological care and reduce inequity through an international network of health professionals working in SSc. The EUSHNet network is intended to complement the work of FESCA and the existing EUSTAR medical network in drawing together expert HPs with a specialist interest in the provision of, or development of, care for people with SSc and related conditions.

The network is affiliated to EULAR and EUSTAR and is a self-governing organization centering on the activities of HPs involved in the care of people with SSc and related conditions. EUSHNet will work with patient and medical groups to ensure commonality of purpose.

EUSHNet activities will be largely confined to the issues surrounding non-pharmacological care and as such will focus on physical, psychosocial and educational therapies, along with the associated need and impact. Where there may be potential for overlap with the activities of EUSTAR or other medically related groups this should occur only in partnership.

EUSHNet activities are intended to improve quality of care and reduce inequity internationally. As a general rule, priority will be given to activities that have the broadest impact over localized or specialized issues.

## OBJECTIVES

The main aim of the EUSHNet network is:

***To improve non-pharmacological care and rehabilitation, and reduce inequity through an international network of health professionals working in SSc.***

This aim will be achieved through the following objectives:

- I) To improve expertise of HPs through support for knowledge generation and better education
- II) To facilitate communication/ exchange between HPs to achieve clearly defined standards of care
- III) To establish standards of care and rehabilitation based on need, evidence and models of best practice

Activities guiding and falling within the terms of reference:

- a) Describing the current state of the art of HP practice in SSc to identify where we are in terms of research, practice and educational needs
- b) Identifying gaps in existing knowledge
- c) Setting an agenda for future projects
- d) Developing an inventory of existing knowledge and indicating resources available to disseminate where this exists
- e) Establishing a network of national champions to coordinate activities across member nations.
- f) Defining a core set of HP-relevant data including patient-reported outcomes for universal collection and pooling.
- g) Agreeing and facilitating a programme of work, aimed at rectifying poor or inequitable standards of care for people with SSC, and coordinated across nations.

## NETWORK ORGANIZATION

The EUSHNet Network consists of a steering committee (SC) and a network of national champions (NC) who will engage with and coordinate HP clinicians in the own countries in the conduct of the activities of EUSHNet.

### STEERING COMMITTEE

The Steering Committee is the decision-making body of the EUSHNet Network.

At inception it consists of seven representatives of the major professions constituting HPs in Europe and a cross-section of countries. The steering group is initially comprised of the three HPs and patient representatives involved in establishing the network, three further HPs and an *ex officio* representative of the medical EUSTAR network.

Once established the steering committee will, in perpetuity, comprise between six and eight members including fair representation of HP professions and relevant/contributing countries, one representative from FESCA or other relevant patient body and one representative from EUSTAR or other relevant medical body.

The roles of the steering group are:

1. To establish and maintain the EUSHNet network
2. To establish the constitution and operating framework of the EUSHNet network and ensure its observance
3. To deliver the initial setup project to time and on budget
4. To attempt to establish a sustainable model through which the activities of the EUSHNet network can be continued
5. To survey and report on the existing state of the art
6. To coordinate a network of National Champions able to undertake activity within their own geographical regions
7. To develop a mechanism to prioritise a series of topics for 'campaign type' activity
8. To facilitate and support the conduct of the campaigns
9. To approve and deliver a plan for publications and dissemination of knowledge/ results
10. To establish a standard operating procedure (SOP) for the development of EULAR HP networks in other disease areas

---

## NATIONAL CHAMPIONS (NC)

At the heart of the proposed programme of work is a coordinated network of NCs drawn from the body of HPs in each participating country. The strength of the EUSHnet network lies in the coordinated activity of small numbers of practitioners in large numbers of EU member states. The champions will be the interface between EULAR and their own national agendas and will be aided by the EUSHNet network in engaging with their own domestic SSc community in an organized and coordinated manner.

National Champions roles may include the following:

1. to receive and cascade the suggestions of the SC to HPs in their own geographical region
2. to make efforts to meet and engage with other HPs from varying backgrounds
3. coordination and management of the Network activities within individual member states
4. to provide a brief of annual working plan
5. evaluation of recommendations elaborated by the steering group and contributing to action plans as appropriate
6. timely collection of data and, with the support of the SC, preparation and development of Network deliverables
7. distribution of any documents and information connected with the Network activities
8. contribution to EUSHNet reports/ publication plan and results dissemination plan
9. conducting regular review of the network operation and local activities against its objectives
10. ongoing contribution to the dissemination of the results, deliverables and outcome of the Network activities.

Annual cycle: an annually defined set of activities will be coordinated by the steering group based on priorities defined in conjunction with medical and patient representatives. National Champions will be tasked with specific activities mapped onto these agreed priorities.

To coincide with this cycle an annual meeting of existing and prospective NCs, along with all interested parties will be held, for instance in conjunction with the EULAR congress..

National champions will be nominated to countries according to need and availability. In the first instance it is envisaged that a maximum of three NCs per country would be required, with the named NCs acting as a coordinator to cascade information to other active HPs within each nation. Numbers in the various roles will be subject to ongoing guidance from the steering committee as the network develops.

## CONSTITUTION AND GOVERNANCE

The overarching activities of the EUSHNet network are accountable through the Steering Committee to the EULAR standing committee for HPs.

## ROLES AND TERMS OF OFFICE

Members of the Steering Committee will serve for terms of three years and may stand for two consecutive terms. Election will be through self-nomination, and in the event that more nominations are received than places are available, a ballot will be conducted within the constituency of existing steering group members and national champions. Normally, the two longest serving members will stand -down at the end of each year. Where there is a tie in durations served, lots will be drawn to decide those to stand down. (Note in the period 2011 -2014 these arrangements will be suspended to allow establishment of the network and continuity of roles).

The steering committee will elect from within its membership by ballot (secret ballot if necessary) one member to act in the role of Chairperson and one in the role of a secretary for a term of three years. The chair may stand for a further (third) term if the retirement point is reached within the period of tenure as chair.

Network champions will normally be appointed through a process of self-nomination and approval as appropriate by the steering committee. It is intended to have at least one network champion per country. Where appropriate to local geography or to professional scope of practice, more than one network champion per country is entirely acceptable and will be facilitated by the steering committee.

## REVIEW

Network champions will be subject to review by the steering committee on an annual cycle depending on activities. Criteria for successful review will include:

- Contribution to EUSHNet campaign activities
- Contribution to dissemination and publication activities as appropriate
- Attendance at planning/ review meetings or maintenance of ongoing communication with the steering committee and other champions as required.

## EUSHNET ACTIVITIES

Once the EUSHNet network is established the steering group will:

1. Approve, annually, the working program for the following year, with clear objectives, tasks, activities, associated deliverables and responsibilities
2. Review the execution of tasks, ensuring that they are carried out in line with the objectives laid down in the terms of reference and providing guidance to the national champions
3. Provide help for the technical and logistical arrangements for the execution of the activities
4. Publish and actively disseminate the outcomes of any work and ensure its translation into improved clinical care
5. Monitor the effectiveness of national champions and work to maintain an active network of champions representative of the EU constituency of HPs.

## MEETINGS

### STEERING COMMITTEE

The steering committee will normally meet, either in person or using electronic communications, at least once per year. The Chairperson of the SC will propose an agenda to all the members not less than 14 days in advance of the relevant SC meeting. Minutes of the SC meetings will be the responsibility of the chair or a designated alternate and will be submitted to all partners without delay.

### NETWORK CHAMPIONS

Due to the larger number and geographical spread of potential network champions there will be no expectation of fixed period meetings. Meetings may be called as appropriate to task and available funding on an ad hoc basis. Where possible, SC and NC meetings will be aligned with larger international meetings and congresses.

## WORKING LANGUAGES

The working language of EUSHNet Network is English. The additional costs related to the use of other European languages for meetings, proceedings, publications, etc. will be borne by particular members who might wish to use other languages.

## DURATION OF THE TERMS OF REFERENCE

The validity of the text of the present Terms of Reference is not limited. Any amendments to this text may be introduced by the Steering Committee upon the request of a two thirds majority of EUSHNet SC members.