

# Lymphedema Research Priorities in Canada:

## A Delphi Study By Roanne Thomas

Lymphedema is a chronic condition, most commonly manifesting as swelling of one or more limbs. Other areas affected by swelling include the head and neck, trunk, breast, and genitalia. Lymphedema is categorized as primary or secondary, the latter of which in North America is thought to be primarily associated with cancer and/or its treatments. The accumulation of lymphatic fluid in secondary lymphedema after cancer results from damage to the lymphatic vessels and/or nodes (e.g., as a result of surgery or radiotherapy). Swelling often results in pain and discomfort as well as physical and psychological morbidity, including poor

At the request of the Canadian Lymphedema Framework Advisory Board, the Research Working Group agreed to initiate a process to identify lymphedema research priorities.

body image and issues with mobility. People with lymphedema may also be susceptible to acute cellulitis, which requires the frequent use of antibiotics, may require hospitalization, and can be life threatening. In comparison to other chronic illnesses and conditions, both primary and secondary lymphedema are under-researched.



**Roanne Thomas, PhD** is a Canada Research Chair in Qualitative Health Research with Marginalized Populations and Professor in the Faculty of Health Sciences at the University of Ottawa. Her program of research includes studies of psychosocial aspects of secondary lymphedema after cancer. She is also Co-Chair of the CLF Research Working Group.

One of the roles of the Canadian Lymphedema Framework (CLF) is to facilitate research connections. The CLF is a collaboration of medical academics, lymphedema



therapists, patient advocates, and interested others, and is part of an international initiative to promote research, best practice guidelines, and lymphedema clinical development worldwide.



The Canadian Lymphedema Framework (CLF) recently collected and published its second repository about current Canadian research (*Pathways* Winter 2015). The current topics

of research are: information needs, treatment studies, laboratory research, surgery, and the impact of lymphedema. Summaries provided by researchers were published and more information can be found online ([www.canadalymph.ca](http://www.canadalymph.ca)). Further to this work, the CLF wished to identify lymphedema research priorities which could be promoted as a Canadian Lymphedema Research Agenda and also support grant applications for funding.

At the request of the Canadian Lymphedema Framework Advisory Board, the Research Working Group agreed to initiate a process to identify lymphedema research priorities. A sub-committee drafted an initial list, based on the national lymphedema stakeholders meeting held in 2009 (published in *Current Oncology*: Vol.18 no.6).

The Delphi technique, utilized in this study, is used to generate consensus among people who are experts in a certain topic. It is a cost effective approach to determining or ranking priorities with multiples stages of prioritization, as consensus can be reached without actually meeting in one room. In this case, the survey was used to generate consensus on priorities for research in lymphedema in Canada.

The sub-committee members were:

- Cathy McPherson, Manager/Administrator of the Lymphovenous Canada website
- Bev Lanning, RN, Lymphedema Registered Nurse
- Pamela Hodgson, MSc, Research Associate, McGill University Health Centre
- Anna Towers, MD, Director, Lymphedema Support Centre of the Quebec Breast Cancer Foundation, McGill University Health Centre
- Roanne Thomas, PhD, Professor/Canada Research Chair, University of Ottawa

The sub-committee chose potential respondents who would represent a variety of perspectives, including researchers, patients, advocates,

and health professionals. Respondents were also chosen for national representation and to achieve a reasonable response rate, allowing for attrition. The list was refined and edited via teleconference by the sub-committee. A survey was then drafted, circulated for feedback, revised, and sent via email to the identified, potential respondents.

### Round one of the Delphi study survey

Opened on November 19th 2014 and closed on December 3rd 2014. Thirty-three people responded out of the 42 people to whom the survey was sent (78.6% response rate). Respondents were asked to rank lymphedema research topics in order of their priority. Below are the rankings of the topics, ordered by a weighted score):

**1** Effectiveness of treatment modalities (e.g. including standardization of

definitions, measurement & assessment tools, etc.)

- 2** Incidence and prevalence (e.g. cancer-related, non-cancer related, primary, trauma)
- 3** Risk reduction (e.g. prevention post cancer, non-cancer, trauma, obesity, chronic edema)
- 4** Scientific (laboratory) research (e.g. lymphatic laboratory research, drug therapy, lymph node transfers, etc.)
- 5** Quality of life (e.g. social impact on work, home and leisure activities, etc.)
- 6** Economic impact (e.g. cost of treatment, personal loss, cost-benefit analysis etc.)
- 7** Self-care programs (e.g. patient-centered care)
- 8** Obesity and lymphedema/chronic edema
- 9** Children and lymphedema
- 10** Cellulitis (e.g. wound care, medication, etc.)

### Round two of the Delphi study survey

Respondents were asked to prioritize the top six topics from the results of the first survey. The subsequent survey was sent out on December 11th 2014 and closed January 9th 2015.

Twenty-six people responded out of the 33 people to whom the survey was sent (78.8% response rate). Comments from the first round of the Delphi survey were taken into consideration.

**Here are the final results:**

- 1. Effectiveness of treatment modalities**
- 2. Incidence and prevalence**
- 3. Risk reduction**
- 4. Quality of life**
- 5. Scientific (laboratory) research**
- 6. Economic impact**



**REGISTER NOW!**

# Academy of Lymphatic Studies



We offer both Certification Courses and Seminars.

## Courses in Manual Lymph Drainage (MLD) and Complete Decongestive Therapy (CDT)

### Lymphedema Management Seminar (31 hours)\* \$895

This 4-day course serves as an introduction to the management of uncomplicated lymphedema affecting the upper and lower extremities, using Manual Lymph Drainage (Vodder Technique) and Complete Decongestive Therapy.

### Complete Lymphedema Certification (135 hours)\* \$3150

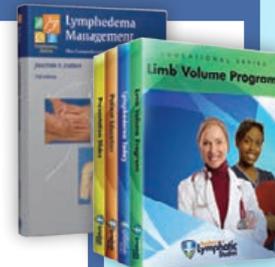
This course provides certification in Manual Lymph Drainage (Vodder Technique) and Complete Decongestive Therapy according to the rules and regulations set by the Lymphology Association of North America (LANA).

### Certification in Manual Lymph Drainage (40 hours) - NEW! \$1150

This 5-day course will certify therapists in the MLD Techniques developed by Emil Vodder, Ph.D. and will enable you to create treatment sequences for the management of edema including post-operative/post-traumatic edema and pathologies such as fibromyalgia, migraines, chronic fatigue and more.

**CEU's are available for all courses.**

**Call for dates and locations.**



\* Course registration includes educational CD-ROMs, textbook, posters, bandaging supplies and more.

**Early Registration Discounts and Financing Options Available.**

**Website** [www.acols.com](http://www.acols.com)

**Phone** 800.863.5935  
or 772.589.3355

Tuition in US dollars.

Quality of life research is emerging as an important topic of research as lymphedema awareness increases. Researchers in this area focus on coping and emotional well-being.

While recent research has increased knowledge about treatment modalities, its ranking at the top of the list reflects the potential impact of additional research on patients. Without data on prevalence, it is challenging for researchers and health professionals to establish the importance of their work. Like treatment, risk reduction research has direct impact on people at risk of developing or worsening lymphedema. Quality of life research is emerging as an important topic of research as lymphedema awareness increases. Researchers in this area focus on coping and emotional well-being. Basic, scientific or laboratory research will provide new knowledge about the lymphatic system that may help prevent lymphedema, lead to innovative ideas for treatment and be a possible step towards a cure.

	Rank by Weighted Score	# of Respondents Ranking as Top Priority
Effectiveness of treatment modalities	1	4
Incidence and prevalence	2	9
Risk reduction	3	5
Quality of life	4	2
Scientific (laboratory) research	5	5
Economic impact	6	1

Finally, economic analyses of the impact of lymphedema are also emerging, but more work in the area is required to establish costs for individuals, the health care system and to society at large. All six of these areas are connected and research in these domains is progressing.

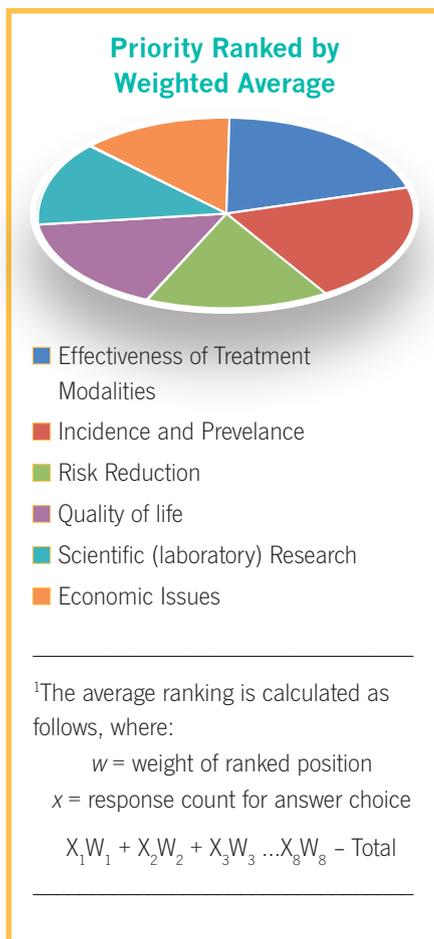
The table below provides more information about the ranking of research priorities. The table shows the rankings of topics by their weighted scores, but also by the number of respondents who ranked the topic as the top priority. While effectiveness of treatment ranks highest using weighted scores, it is interesting to note that incidence and prevalence was ranked as the highest priority by the most respondents (n=9).

The chart on the right also provides another way to understand the rankings. While the weighted scores ensure that priorities can be ranked in order, the chart shows that the actual scores are quite similar because all of the sections are comparable in size. This suggests that the priorities, although ranked, were all perceived as important by respondents.

The research priorities identified in this Delphi study are in alignment with the results of the Canadian Lymphedema Framework's 2009 meeting where stakeholders described a lack of research into the prevalence of lymphedema, effective treatment modalities, impact on quality of life, and cost analysis. Results of the stakeholder meeting are discussed in an article in *Current Oncology* ([www.current-oncology.com](http://www.current-oncology.com)). Lack of research in these areas means that

lymphedema advocacy with decision-makers and funders is often difficult and ineffective.

Granting agencies like to see that any research work being done responds to national research priorities in a given field. Once the above results are published, those interested in conducting lymphedema



researchers may refer to this Research Agenda in support of their grant applications. The CLF plans to publish a Research Report highlighting these lymphedema priorities, along with the current research currently being conducted in Canada. [L<sup>1</sup>](#)

### LIMPRINT

The CLF is participating in an international research study, called LIMPRINT (Lymphedema Impact and Prevalence International) which is a prevalence study to assess the number of patients with lymphedema/chronic edema and its impact on individuals and health services. The results of the study in Canada will be used to provide evidence for practise and as a support mechanism for reimbursement.