

## **Appendix 1.**

### **Questions from Stakeholders Group Meeting: Toronto, November 2019**

#### **Prevention/ Risk reduction**

1. What is the effect of Radiotherapy?
2. What are the differences in risk based on surgical techniques?
3. What is the value of new surgeries aimed at prevention of BCRL?
4. Is there an impact from breast reconstruction?
5. What is the effect of Chemotherapy protocols and effects of chemotherapy?
6. What is the impact of other impairments (i.e. shoulder dysfunction)?
7. What is the impact of other comorbid diseases?
8. Can lymphedema be prevented?
9. What is the value of prophylactic measures (i.e. compression sleeve)?
10. What is the value of self-monitoring?

#### **Risk Reduction**

11. When should we be introducing risk reduction strategies?
12. What are the risks associated with taking blood pressure, venipuncture, and medical procedures involving the 'at risk' arm or region?
13. Should patients be advised to wear a garment for travel?
14. Should advice be tailored by varying degree of risk?
15. What is the critical time for surveillance of lymphedema?
16. What is the importance of weight control / management?
17. What should we advise re: exercise parameters: restrictions – what is safe?
18. What is the impact of cellulitis? What is the value of infection prevention strategies?
19. What is the value of nutrition counseling?
20. Are there considerations related to the work environment?

#### **Diagnosis/ Assessment – Best practices related to lymphedema diagnosis?**

21. When is there a need to rule out sinister causes? What percent/symptoms may be related to recurrence?
22. What is the best diagnostic method to diagnose LE?
23. Is there a gold standard of measurement/assessment protocol: Percentage, cm, Pitting? Stemmer?
24. What is the role of bioimpedance in the diagnosis of lymphedema?
25. Is there a universal definition of LE – percent/ volume? Is there a critical cut-point?
26. What is the value of self-reported sensory changes?
27. Is there value in limb segment assessment?
28. Is there value in obtaining pre-operative measures?
29. Is there a simple questionnaire for early identification of LE?

#### **Assessment: other**

30. What are the important variables related to lymphedema: onset, extent?
31. What is the value of ROM and strength measures?
32. What is the significance of scar tissue, fibrosis -association with lymphedema

33. What key symptoms, quality of life, functional scales – should be captured? What value do they add? (e.g. body mass index, axillary web syndrome, exercise levels, function, cellulitis assessment)
34. What is the importance of capturing the patient's goals of treatment/ care?

**Management:**

35. What is the value of surgery for existing lymphedema?
36. What is the value of medications for existing lymphedema?
37. What is the gold standard for conservative treatment?
  - a. What are the key components of treatment?
  - b. What is evidence of: timing/timelines of treatments?
  - c. What is the evidence on the needed frequency of treatment in acute phase?
38. What are the personal lifestyle factors that impact LE?
39. Evidence behind skin care advice/treatment?
40. What is the evidence on?
  - a. Manual lymph drainage
  - b. Compression therapies, how do you decide type of garment (e.g. flat knit, circular knit), and compression level? When do you need to replace sleeves?
  - c. Compression bandaging: initiation when? Criteria for appropriateness?
  - d. Lymphedema pumps
  - e. Kinesiotaping
  - f. Laser therapy and modalities
  - g. Exercise: divided by stage of healing
  - h. Evidence for aquatic therapy
  - i. Night-time compression: what is the evidence?
41. What is available from industry commercially?
42. Can we better deliver care by using technology – assessment/ standardized reporting?

**Outcomes:**

43. What is the needed frequency of follow-up/surveillance?
44. How do we promote self-management, self-monitoring?
45. How do we support a patient centred approach (e.g. rural patients, disease status)?
46. Should outcomes be based on patient goals?
47. What is different for those with malignant/palliative LE outcomes and treatment?
48. What are the best measurements?
  - a. What are the recommended questionnaires? How often should they be administered?
  - b. What about other measures (e.g. strength, psychosocial impact, adherence, function, quality of life)?
49. What constitutes a significant clinically meaningful improvement, stable, progression (worsening) of lymphedema?