Supplementary Information 7: Preliminary findings presented to participants

Theme/subtheme	***Key points***
Treatment provided as 'usual' care	• Self-treatment, focus on hosiery • Women and practitioners report treatment variation mostly relates to hosiery • Hosiery often provided through GP/pharmacy
Intensive treatment is not 'usual' care	• Course of treatment with bandaging and MLD • All practitioners delivered intensive-DLT but rationed to those with greatest need/severity of swelling • Considered optimal treatment by women and practitioners • Few women had received any form of intensive treatment
Information and education	• Provided 1-1 or group session as 'usual' care • Women want more information about lymphoedema, treatment options, how to recognise and respond to changes, long-term implications • Women want *written* information about their treatment and what is happening to them, to better self-treat BCRL
Terminology	• What is treatment? • Variable words used to describe treatment • Checking patients and practitioners mean same thing with same words, e.g. exercise–what type of exercise?
Treatment decisions	• Influenced by resources/capacity • Use of clinical criteria and waiting lists to ration treatment, particularly intensive-DLT • Practitioners frustrated by resource constraints
Challenges of hosiery	• Hospital versus GP/pharmacy provision • Delays and incorrect garments affect swelling control • Practitioners issue disclaimers to GP • Keeping garments clean, having enough items
Measurement/ outcomes	• Monitoring size-tangible • Uncertain whether HRQOL tools are useful • Patients unclear what issues should be monitored by PROMS, especially identifying LO-related issues
Expectations of treatment and goal-setting	• Control versus swelling reduction • What is a good outcome? • What can be achieved with self-treatment?
Discharge	• Different service policies • Patients generally not keen to be discharged; they want ongoing monitoring of symptoms/progress
Offering intensive-DLT at early stage	• Varying views of practitioners: expectations of outcome, capacity, varying hosiery to reduce swelling, psychological aspects • Window of opportunity to affect swelling while mild • Burden of treatment • Is BCRL priority? Focus on getting on with life • Modified DLT may be more acceptable, e.g. ICPT

Title: Women's and practitioners' views of early intensive decongestive lymphoedema treatment for breast cancer-related arm lymphoedema: a focus group study.
Journal of Cancer Survivorship.
Authors: Jeffs E, Ream E, Chang YS, Taylor C, Bick D. corresponding author: Jeffs E. King's College London and Guy's & St Thomas' NHS Foundation Trust. Eunice.jeffs@kcl.ac.uk; Tel: 07557325642