



ILF-COM update March 2019

We have been amazed at the interest in the ILF-COM survey. Thank you for all your help in getting it disseminated to so many places and people. As of this morning 4891 people have accessed the SurveyMonkey site with 2484 completing the questionnaire in February. And these figures show that although 12 National Frameworks agreed to be part of the study, in fact we have had responses from people in 51 countries. The power of the internet is huge. The data we will have is so important to having more evidence for this often-neglected condition in each of your countries and internationally

Some countries have only recently joined the survey and it has been decided that it will stay 'live' until 31st March 2019. This, in fact, coincides with Lymphoedema Awareness Week from 3rd to 9th March and World Lymphoedema Day on 6th March. We know that many of you are involved in activities promoting better care, reimbursement, and a much greater awareness of the condition during this week but could we ask you to give one more big push to the survey so that patients, professionals, and those working in the medical device industry who have not yet accessed it may have the opportunity to do so if they want.

If you are a National Framework receiving this update, we will over the next couple of weeks be sending you the template for your poster and some information around your design. We are asking that the poster will be sent electronically to the ILF Secretariat, CAP, who will then download and print the poster. It will, of course, be yours to take home after the Chicago Conference.

The Literature search is ongoing and is so much larger than originally presumed. But it is happening!

We have one more interview to have with an industry partner looking at the challenges around measurements and outcomes, the cost of care, and, of great importance, the problems surrounding reimbursement. These interviews will then be analysed and should give us much needed information and hopefully ammunition in the quest for setting standards measuring outcomes that are understandable internationally to patients, professionals, and those that hold the purse strings.

Again, our thanks to you all. This could not have happened without you.

With our best wishes

Susie Murray on behalf of Christine Moffatt and Susan Noerregaard