

ILF-COM survey findings report

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The recent evidence from the LIMPRINT project [1] highlighted the size and impact of chronic oedema or lymphoedema on health services internationally. However, there remains a lack of clarity of outcome measures for this cohort of people with chronic oedema or lymphoedema. A lack of validated and standardised chronic oedema outcome measures leads to difficulty in benchmarking health care service and research outcomes impacting on service delivery and resource funding for services. Hence, the International Lymphoedema Framework-Chronic oedema Outcome Measures (ILF-COM) is an international project that aims to address this issue. Therefore, a series of steps were initiated in Denmark 2018. These were (1) a scoping systematic review (ongoing); (2) a qualitative survey about reimbursement issues with medical industry partners (ongoing) and finally (3) an international survey was undertaken to identify stakeholders' perspectives.

Consequently, the Australian ILF-COM committee was formed in November 2018 for the purpose of fulfilling Step (3). These comprised of three volunteers: Linda Khong (W.A.); Gillian Buckley (VIC) and Sally James (VIC). The international survey was disseminated mainly through informal state-wide therapist networks, social media and medical industry partners in a snowball approach.

A total of 12 frameworks took part with over 8000 (n=8014) respondents from 61 countries participated in the ILF-COM survey monkey that ran from December 2018 till end March 2019. Each framework reported their [ILF-COM findings via posters](#) at the ILF 2019 Conference in Chicago 13-15 June 2019. For Australia [2], 688 people took part in the survey. Half (54%) were patients. Majority of the healthcare professionals (266 respondents) who took part were physiotherapists (42%). Overall, the survey's international respondents demonstrated that patients and healthcare professionals viewed Limb Volume, Quality of Life status and Mobility Status as three most important outcome measures as well deemed successful outcomes. In comparison, circumferential measures and mobility status were top two frequently used outcome measures in Australian clinical practice. Quality of Life status measures were used less frequently as an outcome measure. Papers on these findings will be reported. The next step agreed at the conference framework stakeholders' meetings were to

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consider developing a clinically meaningful outcome measure through a consensus model and to validate them through frameworks.

Similar to other ILF-COM framework committee members I met in Chicago, we (the three volunteers) were amazed with the unexpected impressive results collated in less than four months. It was only possible with the strength of social media in reaching the hard-to-reach cohort at the grassroots level and medical industry partners' support. We would like to express our heartfelt appreciation to everyone involved.

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References

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2. Khong, L., Buckley, G., James, S. (2019). *International Lymphoedema Framework: Chronic Oedema Outcome Measures. Reporting of survey findings from Australia.* Poster presented at the 9th International Lymphoedema Framework Conference, Chicago, USA. <http://doi.org/10.13140/RG.2.2.20924.69761>. (Poster)

