A learning health environment for lymphoedema. Laying the groundwork for digital transformation

Authors: Robyn Sierla, Senior lymphoedema therapist, Royal Prince Alfred Hospital, Sydney Local Health District, NSW, Australia; Associate Professor Elizabeth Dylke, Head of Physiotherapy, The University of Sydney; Associate Professor Simon Poon, School of Computer Science, The University of Sydney; Professor Tim Shaw, Director of Research in Implementation Science and eHealth (RISe), The University of Sydney; Professor Sharon Kilbreath (Emeritus), The University of Sydney

Introduction: A wealth of data is routinely collected by lymphoedema therapists at every patient session, but it is siloed and often paper based, limiting its usefulness. Digitisation of health information creates possibilities for new efficiencies, including analysis and display of circumference measures, and potential for a learning health environment for lymphoedema management. However, a digital record for the management of lymphoedema requires agreement of the necessary outcomes to be collected, the data set to describe these outcomes, and user-acceptance for this approach.

Aims: To determine consensus on a data set for reporting change in upper limb lymphoedema to inform a prototype platform to then test technology acceptance.

Method: Research by the authors determined the breadth of clinician reported outcomes for reporting change in upper limb lymphoedema. These studies included a systematic review to capture the outcomes reported in the literature; and observation and interviews with therapists.To narrow the dataset an international modified Delphi study (n=40) was used. Based on the agreed data set, a prototype clinical data system was built. The prototype was evaluated by experienced lymphoedema therapists (n=12) using a 'think aloud' protocol, followed by a questionnaire evaluating technology acceptance.

Results: Consensus from the Delphi study determined Interlimb difference expressed as a percentage tracked across time was preferred for reporting size change. The 37 terms used to describe visible and palpated change were narrowed to 18. Participants in the think aloud study confirmed suitability of the data set implemented, and there was full agreement that digitalisation is necessary and desirable. There was, however, concern about changing processes (n=5) and, for some, data flow and/or layout required revision. Outcomes beyond lymphoedema-specific assessment, such as BMI, were recommended. Intention to use the clinical data system was positive (75%) but interviews revealed this was influenced by what additional functionality was planned, with a desire for integration with practice management software, ability to upload photographs and forms and digital support for garment search and order processes expressed.

Conclusion: There was full agreement that a digital approach to lymphoedema outcome collection is desirable. However, therapists have long established bespoke assessment and reporting processes which created change resistance. Adapting processes to adopt a new system was viewed as a challenge for some. Adoption, in order to build a learning health environment, could be incentivised by addressing additional 'pain points' such as digitisation of the compression garment search.