

RESEARCH FEATURE

Dragging lymphoedema into the digital age

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Innovations such as telehealth, wearable devices, artificial intelligence, and precision medicine are transforming health systems. ¹ While aware of this revolution, it has very much felt as if it is happening somewhere else, as I flick through garment catalogues and subtract numbers in my head. Like me, you may have imagined practice enhancements in the form of a shared patient record, analysis and display of limb changes, or perhaps the use of clinic data for building our knowledge base through research. Admittedly, we are now seeing widespread uptake in electronic medical record (eMR) systems, clinic management systems, and My Health Record. These systems have provided administrative support and information access, but they have not been the solution many of us hoped for. In many ways, the digitisation of the health record has merely translated a paper record to the screen without reimagining the opportunities that digital technologies provide.

Lymphoedema is somewhat unique in its reliance on objective and subjective outcomes. Patient reported outcomes, particularly symptom report, treatment acceptance and quality of life measures are essential for understanding whether the treatment being offered is having a positive result from the patient's perspective. However, our patients cannot estimate the amount of fluid or tissue change present, and in many cases are not reliable in reporting size changes. ² Furthermore, while other specialties may be able to determine



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severity or map progression with a scan or blood test, we struggle to 'know' what changes have occurred because we are not mapping a single parameter. As lymphoedema is multifactorial, a range of outcome assessments are reported. Volume (or size change), palpation, dermal changes and patient-reported symptoms are used together to estimate what physiological changes are occurring.³

In more recent times, novel techniques have been developed, often deployed initially in research, assessing dermal thickness, adipose hypertrophy, and extracellular fluid volume and flow. In the clinic, however, a suite of objective and subjective assessment tools are used to evaluate progression, and/or treatment success, each contributing in their own way to our understanding. In



Figure 1: A Learning Health System

addition to being time consuming, the subsequent data set can be unwieldy, and limited in its relevance to our patient's understanding of their condition.

The field of health informatics offers some useful frameworks that could enable us, as lymphoedema therapists, to work smarter, not harder. The most promising and all-encompassing, perhaps, is the learning health system (LHS). The LHS describes a digital platform in which patient experience is made available, in the form of large de-identified data sets, providing real world data for monitoring outcomes over a long time period, and to conduct comparative effectiveness studies ⁴. In addition, best practice knowledge is embedded at point-of-care within the platform to support clinical decision-making (clinical decision support) ⁵. It is where clinical care and research meet, with clinical data the bedrock of this system ⁶ (Figure 1). As such, determining a data set that is representative of the changes that occur in lymphoedema, and acceptable to potential users without being onerous, is a necessary first step in creating a LHS.

Waiting for someone else to build a platform for lymphoedema did not bear fruit and so we set out on a path of research (Figure 2) to build our own LHS for lymphoedema, through the research program that made up my PhD. Fortunately, several leaders from a range of disciplines brought their experience to bear in the fields of lymphoedema (Prof S Kilbreath and Dr E Dylke), information systems (A/Prof S Poon) and translational medicine (Prof T Shaw). We initially

outcomes and language used to report change in lymphoedema. Current practice (specifically upper limb lymphoedema in the first instance) was investigated in the literature, through a systematic review ⁷, and in the clinic via an observational study ⁸ and semi-structured interviews ³.

A lack of consistency was evident at all stages of the assessment process, including which assessments were selected, measurement protocols followed, as well as how data were analysed and reported. In the literature the outcome of size change was reported in absolute (cm and ml) and relative terms (percentage and ratio), unilateral or interlimb difference, pre- and post-intervention or as change over time. In the conversion of circumference to volume, five different equations were cited in the literature reviewed.⁷ There were 37 terms in total used to describe the changes seen and palpated in upper limb lymphoedema.⁹ Furthermore, variation in assessment selection was evident, and for clinicians, was determined by the purpose of the visit, patient preference, and resources and time available.

The reliability and replicability of lymphoedema assessment is not inconsequential as these are used to detect and monitor lymphoedema, to estimate the tissue changes present, to understand the patient experience, to evaluate treatment response and inform treatment plans. ³ While current methods of data analysis facilitate between appointment comparisons, a review of change over time is frequently absent ⁸, which is not ideal for a chronic condition. To determine how to best represent lymphoedema presentation and change over time, a process of consensus was

sought using an international Delphi study to inform the data set (n=40). Delphi is an iterative survey process whereby expert consensus is sought. This two-round process required that 70% of the experts (lymphoedema clinicians and researchers) agree that an outcome or term should be included in a data set to represent change in lymphoedema. For example, this process narrowed the number of terms representing visible and palpated change from 37 to 18. Interlimb difference as a percentage for monitoring unilateral limb lymphoedema, and limb volumes for monitoring bilateral limb lymphoedema, represented by a line graph, were the preferred outcomes to represent change in limb size over time. ⁹

The results from this extensive consultation process fed into the development of a prototype lymphoedema assessment platform, developed by information technology students from the University of Sydney. The usability and technology acceptability of the platform was then tested with a group of lymphoedema clinicians. The data set determined from the Delphi study was confirmed through this process. It was clear, however, that clinicians' digital needs extended beyond the assessment of change. While we were looking to narrow the data set for usability, there were many 'add-ons', additional digital supports beyond the clinical data management system, that clinicians desired. The 'add-ons' suggested during the usability study included photography, body charts, schedule and clinic management systems (or integration with current systems) and a digital search for off the shelf garments. These ideas have been tabled for future iterations of Lymbase; apart from the garment search which has been prioritised in order to fund the platform development and sustainability. With a PhD completed and a goal of building a free and accessible platform incorporating user feedback received, investment was necessary for the redesign. Haddenham Healthcare,

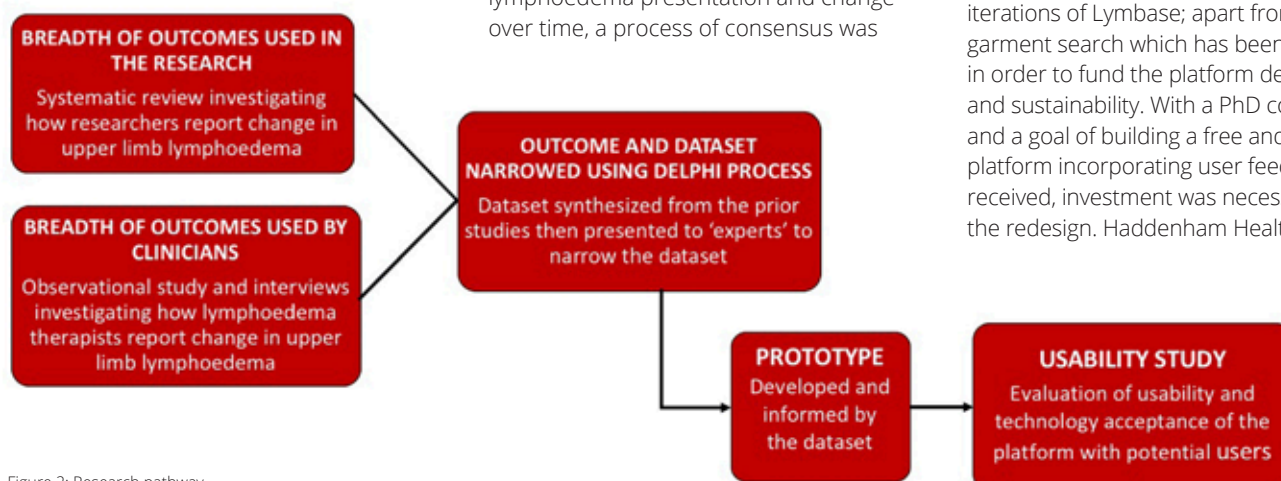


Figure 2: Research pathway

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with their history of supporting research and innovation, saw the potential benefits for patients and clinicians, and have generously provided the necessary initial investment and will contribute their specialist knowledge in the design of the garment search.

Lymbase™ is the name of the platform in development, abbreviated from lymphoedema database. Serendipity or design provided a co-founder, Mythili Baker, with extensive experience from a large data analytics firm and a series of consultants with expertise in software development, UI/UX design, data security and regulatory requirements. These resources, along with the investment from Haddenham, have enabled development to proceed with confidence that the data can be relied on to be safe and secure into perpetuity. User testing of the lower limb platform will soon begin with plans for release of Lymbase™ at the next ALA symposium in 2021. A walkthrough of the platform can be seen at www.lymbase.com and there is a contact form on the website if you have any questions or comments. We appreciate all feedback as Lymbase™ is a platform for lymphoedema therapists, created by lymphoedema therapists.

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(A very sincere thank you to all of you who have contributed to establishing the data set and user-testing of Lymbase™)

» *A walkthrough of the platform can be seen at www.lymbase.com and there is a contact form on the website if you have any questions or comments.*

The ALA and the Lymph Exchange pride themselves on supporting research on lymphoedema, particularly by early career and clinician researchers. To support the dissemination of this incredible work, we are proud to announce that from here forth, in each issue of the Lymph Exchange, one feature article will be written by an early career or clinician researcher in Australia and New Zealand. This special research feature article will give researchers the opportunity to share their work, alongside their journal articles, while allowing the Australasian lymphology community the chance to read about cutting edge research being conducted close to home.

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