

# International Lymphoedema Framework Australia — emerging issues and the way forward

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## Key words

Clients, knowledge gaps, lymphoedema, stakeholders

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## Abstract

Lymphoedema affects many Australians and considerably reduces quality of life for those who do not receive adequate treatment. It is a chronic condition that requires timely diagnosis and ongoing management. However, individuals working with lymphoedema continue to voice concerns about the imbalance between patient needs and available resources, as well as access inequity and a general lack of awareness about the condition by both patients and clinicians. The International Lymphoedema Framework Australia (ILFA) aims to improve lymphoedema management across Australia by developing a collaborative network of multidisciplinary service providers who work in tandem with patients to achieve a cost-effective and sustainable solution to a chronic problem. One of ILFA's primary goals is to clearly identify the issues faced by individuals living and working with lymphoedema, recognising this is the first step to positive change. In 2013, ILFA commissioned a Broad Consultation Survey to examine the scope of these issues. A thematic analysis revealed problems with education and public awareness, paucity and inconsistency of training for service providers, prohibitive costs of ongoing management, limited patient access to information and treatment, and inequity of service access in regional and rural communities. Acknowledging the current barriers facing lymphoedema treatment and management will help improve services in the future.

Lymphoedema affects more than 25,000 Australians (Medical Services Advisory Committee, 2004) and approximately 20% of cancer survivors (Cancer Council, 2012). This is possibly an underestimation due to the range of presenting and diagnostic criteria — i.e. swelling, skin disorders, vascular conditions and infections that can confound diagnosis. There are no formal reporting systems for lymphoedema and many individuals with milder forms of lymphoedema do not present at clinics.

Lymphoedema can present with complex symptoms, the neglect of which can result in significantly compromised patient wellbeing (Linnitt, 2005). Timely diagnosis and treatment is pivotal to management of the condition and quality of life. Unfortunately, despite recent advances in lymphology research, lymphoedema remains disproportionately overlooked in clinical settings (Moffat et al, 2003). Moreover, there is consensus among individuals

working with lymphoedema that resources and services currently available are inadequate to meet consumer needs (Lee, 2010).

It is an ongoing struggle to make lymphoedema care a priority on national healthcare agendas. This barrier to progress is compounded by limited awareness and understanding of lymphoedema among medical professionals, the general public and policymakers.

The International Lymphoedema Framework Australia (ILFA) is an organisation dedicated to introducing positive and proactive changes to the current system. By fostering collaborative efforts between lymphoedema stakeholders, including patients, service providers (such as physiotherapists, occupational therapists and nurses), medical practitioners from various disciplines (such as rehabilitation medicine, vascular medicine, wound care, surgery and oncology) and the

wider community, the ILFA seeks to improve lymphoedema management in Australia. More specifically, it aims to develop a long-term strategy for effective and sustainable lymphoedema service provision as facilitated by multidisciplinary conversations and resource pooling. In parallel, it seeks to improve quality of life for individuals living with lymphoedema via patient empowerment and access to support networks.

When negotiating the lymphoedema agenda, the ILFA presents a singular and strong voice. Although unified, this voice remains multi-faceted due to the diversity of ILFA's stakeholders, including an advisory board of experts within the field of lymphoedema, practitioners and clinicians, researchers, patients, advocacy groups, and industry affiliates. These individuals are responsible for envisioning positive solutions, and managing their evolution from conception to delivery. Importantly, the ILFA "does not replace

existing lymphoedema organisations but acts to create an opportunity to work together to drive change” (ILF, 2010).

Capitalising on this partnership, the ILFA aims to undertake the following (ILF, 2010):

- Assess the current system of care provision and identify its deficits.
- Identify problems related to access and payment of care for patients, as well as cost of training for practitioners.
- Involve all stakeholders in strategic planning.
- Adapt the *International Best Practice for Management of Lymphoedema* document (Lymphoedema Framework, 2006) to suit national requirements (garment use as advised in UK may differ for Australian users who live in hot and humid environments).
- Define appropriate models of care.
- Implement best practice model of care.
- Evaluate the success of new system of care using the ILF minimum dataset.

In achieving these goals, it is anticipated that the ILFA will:

- Raise the profile of lymphoedema in Australia.
- Improve access to financial assistance for service providers and consumers.
- Provide a higher standard of service provision based on evidence-based medicine, clinical research, and comprehensive best practise protocols.
- Address issues of service inequity, especially between metropolitan and remotely based consumers.

ILFA's goals are shared by the International Lymphoedema Framework (ILF), a UK charity established in 2009, as outlined in its focus document (ILF, 2010). This document suggests that a successful strategy will need to address current problems of resource inequity, barriers to lobbying for appropriate funding, and inadequate community awareness about lymphoedema. These issues appear to be instrumental in improving lymphoedema care, but how relevant are they to the Australian demographic? Moreover, how differently do the various stakeholders

approach these issues? This article will provide an overview to the current state of care and support of lymphoedema in Australia as determined by a national survey completed by the ILFA in 2012.

The ILFA recognised that a key step in the process of change is the identification of key issues experienced by stakeholders. Nuanced and multidimensional insight was needed to design services and protocols that best accommodate patient needs in a sensitive, relevant and cost efficient manner. Internationally, focus groups have been used to ascertain these needs and gaps in lymphoedema support.

The ILFA decided to run a national survey in 2013 — the Broad Consultation Survey (BCS) — because, given the vast distances in Australia, focus groups could be biased by the necessity of travelling to attend. Many patient stakeholders struggle with problems of mobility and travelling to focus groups may make attendance prohibitive and consequently encourage bias.

The methodology used to capture the main issues was thematic analysis. This is one of the most commonly employed forms of qualitative analysis (Howitt and Cramer, 2005), and is oriented towards describing and categorising unbounded textual data, such as that seen in open-ended survey responses. At its core, thematic analysis is concerned with extracting key patterns of ideas, while preserving the richness inherent in data related to human experience.

Although thematic analysis has been criticised for its lack of prescriptive methodological structure, it being a fluid process, it adheres to the principles of ‘grounded theory’. This requires researchers to be deeply immersed in the data, participating in both data transcription and coding, so they develop a familiarity with the data. In doing so, theoretical concepts, or key themes, will emerge from the data (Glaser and Strauss, 1967). This is in contrast to the tenets of quantitative research which supposes that a preliminary speculative theory is needed to drive data analysis, namely, hypothesis testing (Pelham and Blanton, 2003).

Thematic analysis is more explorative and allows researchers to participate in cycles of coding, theme definition and labelling, and recoding (Braun and

Clarke, 2006), as the data are digested into a cohesive, clearly delineated narrative. Ultimately, the analysis should yield a limited number of themes, or ideas, that accurately capture the gist of the textual data. Although this technique is qualitative, many researchers give numerical indications of the incidence and prevalence of each theme in their data, as will be the case in this article.

## Methods

### Recruitment

Lymphoedema stakeholders across all states and territories in Australia were invited to participate in an open-ended survey about their experience of living or working with lymphoedema. Invitations to participate in the survey were emailed to all lymphoedema support and service groups identified via the ALA and ILFA and online searches, as well as clinicians registered with Australian Lymphoedema Association (ALA) and lymphoedema patients on the national ALA database. In addition, related medical colleges, service providers, unions, clinics, state hospitals, oncology units and oncology support group, plus rural and indigenous health, education and support groups were contacted.

To optimise the number of participants, those emailed were encouraged to contact professional or personal associates about the survey and encourage participation. The stakeholders were given the option of completing the survey online via Survey Monkey, or on a hard copy posted to them upon request.

The survey contained demographic questions (i.e. gender, age, address, profession) and instructions to participants to list issues they personally experience regarding lymphoedema. Stakeholders that responded included patients/consumers, educators, medical professionals (e.g. GPs, medical specialists, nurses), allied healthcare providers (e.g. occupational therapists, physiotherapist, remedial massage therapists, dietitians and podiatrists), social workers, researchers, members of industry, and a few whose role spanned multiple categories (listed as ‘others’). The preliminary processes of survey design, stakeholder identification, dissemination and data collation was overseen by an external organisation, Pavilion Consulting Pty Ltd.

### Data analysis

The majority of the data were inputted into Survey Monkey directly by the respondent. However, the responses of the participants who completed a paper questionnaire were manually entered verbatim onto Survey Monkey by two researchers. One researcher was responsible for generating a preliminary set of codes based on their transcription of pilot surveys ( $n=61$ ) and 40 of the BCS responses. The second researcher familiarised herself with this code. The second researcher also coded the remainder of the participant responses to ensure consistency and compliance with the grounded theory of thematic analysis. Data analysis was then initiated by rereading through all the survey responses, and adapting the original set of codes to better capture the complexities in the data. As is common in thematic analysis, these codes were further delineated into subcodes for more detailed interpretation. A 10% data check (ILF, 2010) was conducted to ensure consistent and appropriate coding by both researchers. On completion of data coding, the researchers subjected the coded categories to linear analysis. This allowed the researchers to identify which issues were more frequently commented upon, and by which demographic.

## Results

### Respondent demographics

Of the 641 individuals who responded to the survey, the largest proportion of responses came from individuals living with lymphoedema (patients;  $n=262$ ). Within this group, individuals were sampled from metropolitan, regional and remote areas of Australia, with the strongest representation from New South Wales, Queensland and Victoria.

Among those healthcare providers surveyed, primary and allied nurses contributed most prolifically ( $n=128$ ), closely followed by physiotherapists ( $n=102$ ), presumably because both professions regularly work with lymphoedema patients. Note, however, that the majority of nurses surveyed were wound care specialists, without lymphoedema care qualifications. Occupational therapists ( $n=42$ ) and remedial massage therapists ( $n=39$ ) were also well represented. Although slightly

fewer doctors ( $n=19$ ) and specialists ( $n=23$ ) responded, their responses were detailed enough to yield important insights and critical commentary about their experience of working with lymphoedema in Australia.

Unfortunately, not all medical specialisations were equally represented as some colleges approached were unable to invite their members to participate in this BCS. Other contributors included educators ( $n=23$ ), members of industry ( $n=31$ ), dieticians ( $n=12$ ), podiatrists ( $n=5$ ), social workers ( $n=5$ ), researchers ( $n=5$ ), and individuals with unspecified roles involving lymphoedema ( $n=6$ ). Interestingly, while the majority of contributing physiotherapists and occupational therapists work in public hospitals, most of the doctors and specialists did not belong to the public domain, working either in private clinics or hospitals. Similarly, the remedial massage therapists worked almost exclusively in private practice, often as sole practitioners.

### Key themes

A number of themes emerged from the BCS, and provide insight into the contemporary challenges to quality care, consumer and service provider needs, and existing gaps in lymphoedema care and support.

### Education and guidance

Spanning the various demographic groups, education was an issue raised by 59% of respondents. Overall, there is perceived inadequacy of education for medical and allied health professionals, as well as the wider community, about lymphoedema. Many consumers commented that doctors, surgeons and nursing staff often lacked awareness about lymphoedema — e.g. what it is, how to make a correct diagnosis, how to refer onto lymphoedema specialists who can provide correct treatment and care, and what precautions should be taken for individuals with lymphoedema.

A total of 42% of respondents indicated that GPs and surgeons need supplemental education in order to provide acceptable levels of care. Surgeons, in particular, were identified as lacking the skills and knowledge to provide patients with adequate

information about lymphoedema risk, necessary for informed consent, prior to their surgery.

Common throughout the responses of patients was overwhelming frustration that lymphoedema is not recognised as a 'legitimate' illness. Unfortunately, many also reported experiences of societal disrespect due to damaging misconceptions about lymphoedematous patients as being 'lazy' and 'obese', as well as the insensitivity with which they are treated in daily interactions, such as boarding public transport.

Guidance was a theme that emerged in conjunction with the need for education was guidance. However, whereas education described a need for more formal instructions, guidance pertained to the growing patient need for access to information about lymphoedema via informal methods. This was an issue raised primarily by consumers (28%), who expressed a consistent lack of reliable resources surrounding lymphoedema care and management.

Many patients wanted brochures and clear, jargon-free guidelines about how to live with their lymphoedema. Instructions for how to treat their lymphoedema — either through self-care or through the services of qualified lymphoedema therapists in their vicinity — was most frequently requested.

There was also interest in lymphoedema prevention among breast cancer patients, as well as a general demand for accurate, evidence-based information concerning diet, exercise, management of concomitant problems (e.g. obesity and wound care), and therapeutic options. Most importantly, there is a need for specific and standardised guidelines detailing correct protocol with regards to venepuncture (including blood draws and cannulation) and application of blood pressure cuffs on lymphoedematous limbs. This information needs to be available to both consumers and healthcare providers, as many consumers reported feeling deeply anxious about disease aggravation when doctors and nurses ignored their requests to use non-lymphoedematous limbs for medical interventions.

Finally, there is a growing patient interest in receiving information about up-to-date lymphoedema research, either to inform their daily management of

lymphoedema or as basis for exploring alternative treatment options, as reflected by the 13% of respondents who commented on this issue.

### Training

Comments about training (34%) were raised mainly by service providers, including remedial massage therapist, physiotherapists and nurses. A need for training and accreditation was revealed, which is both affordable and nationally recognised. Courses that are currently available are either cost and time prohibitive for individuals seeking to become service providers, or fail to provide attendees with qualifications that are sufficiently well reimbursed by the Medicare Benefits Schedule rebates to make the service viable.

These shortfalls culminate in a shortage of service providers to meet the patient demand for affordable and effective lymphoedema care, as well as decreasing interest in allied health professionals to invest in lymphoedema specialisation. For lymphoedema practitioners who are currently practising, this service shortage poses a serious risk of professional isolation, being overwhelmed and overworked, as was captured in some survey responses.

### Service provision

There is widespread concern that lymphoedema services are severely lacking across Australia. This was an issue commented on by 54% of respondents, many of which were consumers. For individuals living with lymphoedema in rural communities, the problem is even more pronounced and represents a huge barrier to effective disease management. The shortage of lymphoedema clinics and lymphoedema therapists in non-metropolitan areas means that individuals are forced to either forgo treatment, leading to poorer quality of life, or that they must commute long distances to access metropolitan services. This was perceived as an unfair imposition, being both time-consuming and costly. Moreover, commuting is often impractical as lymphoedema can impair mobility and make long distance travel uncomfortable or impossible.

For metropolitan consumers, concerns were raised about the quality of available

services. Thirty four per cent commented on their difficulties in accessing timely and appropriate diagnosis, treatment and support. This is in large part due to poor communication between doctors, nurses and lymphoedema care providers, as identified by 12% of respondents. Furthermore, as many lymphoedema therapists practise privately, public hospitals were viewed as lacking adequate services, especially with regards to early intervention of lymphoedema.

Finally, service inequity was identified as a major problem, especially between the Department of Veterans' Affairs and public patients. Patients with congenital lymphoedema also expressed frustration about their perceived disadvantage in accessing services, as they believed more resources were available to people with cancer-related lymphoedema.

### Cost of treatment

Forty-two per cent of respondents commented on the lack of government funding for lymphoedema care, including both patients and service providers. While Medicare in Australia reimburses allied health workers for a limited number of half-hour sessions per patient per annum, patient expenditure vastly exceeds these reimbursements if appropriate lymphoedema management is to be achieved. Many patients considered lymphoedema treatments prohibitively expensive, especially when compounded by additional expenses for garments, bandages, skin care, exercise programmes, psychosocial services, pain management and disability care. Although some consumers owned private health insurance, the majority did not think they received adequate coverage or reimbursements that made long-term service use fiscally feasible. Twelve per cent of respondents stated that health insurance was inadequate, inconsistent and costly.

### Compression garments

The use of compression garments is essential to proper lymphoedema management. Concerns over garments were raised by 46% of respondents. Many consumers expressed difficulties in accessing correctly fitted garments in a timely manner (due to cost and availability), as well as difficulties

with putting garments on among older people or mobility-impaired individuals. In addition, for individuals living in hot and humid parts of Australia, wearing compression garments can be uncomfortable, especially if they are poorly fitted.

Garments need to be replaced frequently to remain therapeutic, as they loosen with continued wear. The cost of purchasing compression garments further detracts from their appeal, and was the most commonly reported garment-related grievance.

### Discussion

The BCS revealed important gaps in existing lymphoedema services and challenges to quality lymphoedema care. It captured patient and service provider concerns about education, training, services and costs, all of which need to be addressed to improve quality of life for individuals with lymphoedema.

The BCS highlighted that changes must be made across all sectors; clinical practice, research, health policy and the ILFA will all be instrumental in identifying, designing, and coordinating the development of these improvements.

Some challenges have solutions that can be rapidly implemented with current resources, while others require innovative problem-solving, long-term planning, collaborative efforts and strategic campaigning for funding.

As such, the BCS was an important and necessary endeavour. It allowed the ILFA to involve a cross-section of its stakeholders to assess the current system of care provision and identify its deficits and needs. In generating a comprehensive snapshot of lymphoedema needs in Australia at present, the BCS permits interesting and informative comparisons to be made with other countries, as well as our future state of affairs. This affords us the opportunity to borrow successful strategies from overseas models where patterns of barriers or needs are similar to ours. It also provides a baseline, against which we can measure the fruits of our efforts, and to recalibrate where necessary to optimise service improvements. Of course, the data collected are experiential and subjective. However, the importance and validity of these voices must be acknowledged as

they represent the lived reality of those working with lymphoedema.

Given the simplicity of the BCS, it is a preliminary survey and will be followed by more goal-oriented surveying of stakeholders. However, its findings are robust and can be compared with those generated by the American Lymphoedema Framework Project (ALFP), which used a focus group for data collation. The ALFP held a national stakeholders meeting, involving 72 attendees, to brainstorm on issues. Using structured group activities, the groups worked to identify the priority issues and barriers. This led the ALFP to conclude that lymphoedema patients lack support by healthcare services at all points in the lymphoedema care continuum; lymphoedema healthcare provider education is critically needed and must be provided by credible and consistent educational programs; target groups must be identified to receive education; and further funding is needed to ensure adequate reimbursement for patients (Armer et al, 2009).

Evidently, there is large thematic overlap between the ALFP and the BCS findings, despite the methodological difference. Arguably, there are advantages in employing a survey as opposed to focus groups. It grants participation to more individuals, and is also democratising because it does not require people to travel to a meeting — this would have been prohibitive for many consumers who struggle with mobility or live remotely. Furthermore, anonymity encourages more truthful responses that can sometimes be compromised or stifled in group settings.

A comparison of our current BCS findings with those from previous survey studies in Australia (Lee, 2010) revealed that lymphoedema concerns and challenges remain largely unchanged. However, some improvements have been made. For example, the ALA has developed a National Lymphoedema Practitioners Register, which can now be easily accessed by any individual via the internet. For service providers, the National Breast and Ovarian Cancer Centre also runs secondary lymphoedema workshops for GPs.

Flinders University in Australia also offers a lymphoedema course, which is

grounded in evidence-based and holistic medicine, and aims to prepare students for diagnosing and designing care plans for lymphoedema patients, so the next generation of doctors will be better equipped to deliver quality care.

There has also been increased conversation among clinicians; especially information sharing about what factors support successful lymphoedema management. For instance, Bendigo Health is a hospital that has experienced success with implementing services that anticipate and accommodate the needs of lymphoedema patients living in nearby communities. This it shares with more remote practitioners in the Lower Mallee Region via bi-monthly videoconferences, which provide a forum for education and clinical support. Positive outcomes include the dissemination of consistent information, as well as more efficient referrals being made (McGowan and Deacon, 2010). This demonstrates a possible solution that may need only minor alterations to become suitable for broader coverage.

### Conclusion

Although this survey found significant gaps in the current system, healthcare professionals must not be discouraged. The authors recommend universities introduce modules in which future healthcare providers can learn about the lymphoedema. Similarly, professional development programmes should also be made mandatory to doctors, nurses, and allied health staff working in both public and private settings to ensure awareness of lymphoedema and competency in its management. This should be supplemented by written guidelines to dispel ambiguities in treatment.

Furthermore, an increase in the number of lymphoedema service providers is needed by providing nationally recognised and affordable training, and incentivising them to practise rurally. A platform for the interdisciplinary exchange of information is key to allow maximum expertise sharing, efficient referrals, and better-informed and more empowered consumers who can begin to take ownership of their self-care. More rigorous funding from the government and health insurance companies is also a necessity, perhaps through lobbying

efforts. Most of all, clinicians need to remain vocal about lymphoedema and advocate for a better future.

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