

IMPROVING LYMPHOEDEMA CARE IN AUSTRALIA – A STAKEHOLDERS' PERSPECTIVE

FINDINGS FROM CONSUMER-LED WORKSHOPS HOSTED BY
FLINDERS LYMPHOEDEMA WORKING GROUP

OCTOBER 2023

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BACKGROUND

In July 2023, we brought together consumers, clinicians, NGOs, and researchers for a broad consultation process. We wanted to identify first, consumer experiences and barriers to lymphoedema care locally in Adelaide, and how it is nationally as well. This report describes what we learnt, and the priority solution areas as discussed with all our stakeholders.

To ensure that the discussion was consumer-centred, we used a co-design approach which allowed the consumer voice to set the scene for discussions on solutions. We hope this report will assist others to see the big picture and bring others to work together in co-designing research, services, and policy priorities.

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AIMS & METHODS

AIMS

The aims of this project were to identify key priorities to advance cancer-related lymphoedema care in Australia. To do this, it is crucial to be brought through the current lymphoedema care experience, through the consumers' lens. By understanding their perspectives first, discussions around solutions for lymphoedema care will more naturally centre around the consumers' needs.

METHODS

1 - Local SA Workshop

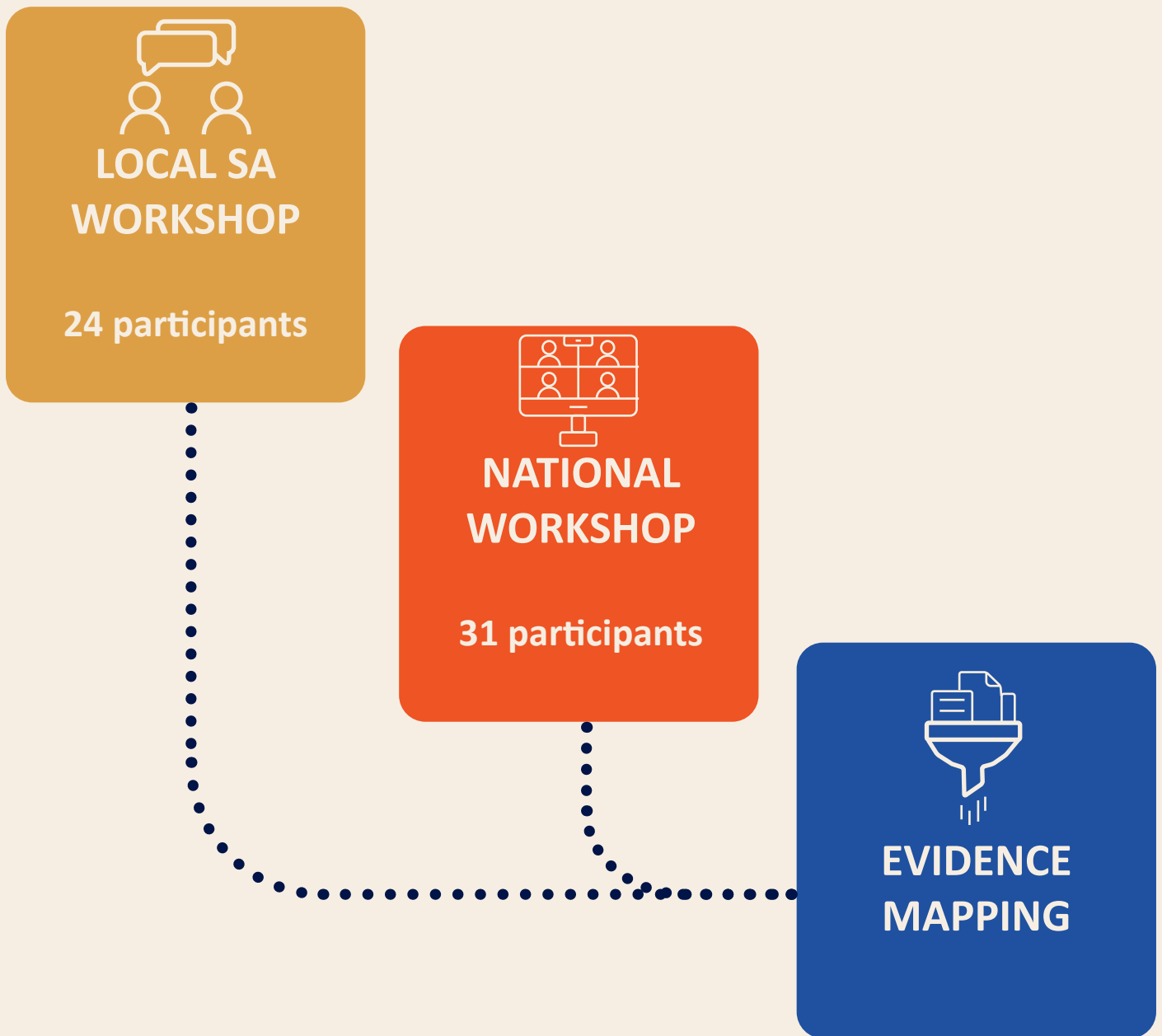
We invited people within South Australia and able to meet in Adelaide to an in-person workshop to tell us their experience of lymphoedema care (i.e., either obtaining or providing care) to better understand what are the key priorities and possible solutions at a metro and rural level within the state.

2 - National Workshop

We invited people across Australia to meet in an online workshop to tell us their experience of lymphoedema care (i.e., either obtaining or providing care) to better understand what are the key priorities and possible solutions at the national level. This workshop also offered an opportunity to identify the similarities and differences across the country.

3 - Evidence Mapping

Consumer priorities, current challenges, and possible future solutions to support lymphoedema care were coded which emerged from the two workshops.



PROJECT OUTPUTS:

- 5 consumer priorities important to their lymphoedema care experience
- 6 areas challenging supportive lymphoedema care across all stakeholders
- 3 levels of future solutions to improve cancer-related lymphoedema care in Australia

AND THE CONSUMERS SAY...

In both workshops, consumers shared their journeys and experiences with lymphoedema care throughout the years. Through their shared stories, discussions about the improvements, and what has remained unchanged in how they would like to obtain care emerged. From this, five consumer priorities were consistently raised and alluded to to achieve supportive lymphoedema care.

1. Awareness and Education

Addressing the lack of knowledge and misconceptions among both the public and healthcare professionals about lymphoedema. This involves educating and raising awareness about the condition.

2. Holistic Care Approach

Ensuring that lymphoedema care is integrated into the broader healthcare system, particularly at transition points in the cancer care continuum, to provide a more comprehensive approach for the consumer.

3. Workforce and Expertise

Building a workforce with specialised knowledge in lymphoedema and recognising the condition as a specific area of expertise within healthcare.

4. Patient Advocacy and Support

Empowering consumers to advocate for their own care, understand the importance of lymphoedema, and navigate the healthcare system effectively.

5. Resource Availability and Consistency

Ensuring that lymphoedema care resources, information, and subsidies are accessible and consistent for consumers across different regions and advocating for financial support when needed.

WHAT ARE WE WORKING WITH?

*“I say to people all the time,
cancer was the easy part.”*

With consumer priorities set as a precedent for discussions with all stakeholders relevant to lymphoedema care (e.g., healthcare professionals, advocacy groups, researchers, policymakers), reflecting on the current situation from a systems’ view is crucial to understand where barriers and bottlenecks may be. With the diversity of voices, we were able to distill six major areas challenging supportive lymphoedema care as follows:

- 1. The impact of lymphoedema on everyday life**
- 2. The inconsistency of information & awareness**
- 3. The inequity of lymphoedema care**
- 4. The inaccessibility to care & garments**
- 5. The lack of data/evidence**
- 6. The inefficiencies of policies & systems**

THE IMPACT OF LYMPHOEDEMA ON EVERYDAY LIFE

REFLECTION

- Across the range of well-managed and poorly managed lymphoedema, this condition affects consumers in how they see, feel, and think about themselves
- Consumers find they are needing to accommodate to their condition which impedes on everyday life and social norms
- Confronting lymphoedema as a chronic condition is overwhelming for consumers sometimes, especially when professional support is unevenly distributed
- Peer support groups are crucial when consumers feel a lack of easily digestible resources exist

CURRENT CHALLENGE

- Disbandment of support groups due to burnout/lack of funding

CURRENT ENABLER

- Having sustained peer support groups to turn to on various platforms (e.g., social media, in-person)

“Well, I’ve got through cancer, that’s fine, but this[Lymphoedema] is forever.”

“I didn’t see the importance of lymphoedema just not knowing anything about it because I was just let go [after cancer treatment].”

THE INCONSISTENCY OF INFORMATION & AWARENESS

REFLECTION

- There is a varying level of awareness of lymphoedema across all stakeholders; though generally metro areas are better resourced than regional and rural areas
- While a lymphoedema care pathway has been created, it is not readily available to the public and sits behind a membership platform

CURRENT CHALLENGES

- There is a general lack of education about lymphoedema across health professionals and consumers as a result of limited evidence-based information and resources available on them
- Consumers are unsure about what care to get at what time in the cancer care continuum, so it is difficult to be empowered to self-advocate
- No clear pathway for health professionals to upskill in lymphoedema care
- There is an imbalance about lymphoedema care advice across different cancers; therefore advice that might for some may not be relevant for all

CURRENT ENABLERS

- Knowing key contacts within personal networks with expertise in lymphoedema helps consumers and health professionals navigate the information and healthcare system
- Health professionals having time to get training for lymphoedema care
- Consumers who come across health professionals who take steps to prep consumers about the risk of lymphoedema during or before cancer treatment

POINTS TO IMPROVE ON

- Well-timed doses of knowledge so consumers can get the right care at the right time
- Strategies need to be in place to help consumers build confidence and empower them to self-manage

THE INEQUITY OF LYMPHOEDEMA CARE

REFLECTION

- There is a general lack of consistency in policies from state to state, service provision metro versus rural, and access to lymphoedema care advice with different cancers
- Cities and metro areas tend to be more well-resourced than regional and remote areas, so perhaps there needs to be an identification of what roles and processes are needed for lymphoedema care and leverage what is already existing in different regions

CURRENT ENABLERS

- Particularly, breast care nurses have more awareness and knowledge of lymphoedema and will refer consumers to therapists to get baseline assessments (sometimes even before surgery/treatment occurs) which has better outcomes for the consumer

“Do I buy [my] children’s shoes or do I get a garment?”

“Constantly from our network, is about people forced to choose whether it’s accessing mental health support, lymphoedema therapies about elite health...”

THE INACCESSIBILITY TO CARE & GARMENTS

REFLECTION

- Consumers sometimes need to make a decision on their health because there is no Medicare funding for lymphoedema
- Overburdened therapists find it difficult to take on new patients because they are servicing large areas and are already inundated with the consumers they already have
- Garment subsidies now exist across Australia in various degrees
- There are varying degrees of ease in obtaining garments, whether it is to get the garment itself or accessing subsidies to procure garments

CURRENT CHALLENGES

- Health professions are in silos where lymphoedema demands a multidisciplinary approach, so it is difficult to keep up to date on which professionals work in a local region if turnover rate is high
- Health professionals are already generally time-poor and lymphoedema requires multidisciplinary coordination; the burden of which falls to the overwhelmed consumer because of lack of navigation resources
- Lack of workforce with expertise to manage lymphoedema particularly in regional and rural areas
- Consumers having long wait times to progress to the next step of lymphoedema management
- The subsidies for garments are inconsistent from state to state (i.e., some are more generous than others) and cover a fraction of the costs

CURRENT ENABLERS

- Consumers who come across health professionals who push consumers early and prepped with the knowledge of the risk of lymphoedema during or before cancer treatment
- Growing evidence for holistic multidisciplinary approach to lymphoedema care (i.e., exercise, garment, therapy)

POINTS TO IMPROVE ON

- Finding untapped workforce which can take on specific processes required for lymphoedema care (e.g., garment scheme to be trained to measure)
- Identify funding models that allow professionals to upskill and help to distribute service provision
- Using mentoring to ensure knowledge and expertise is passed onto younger professional counterparts before experienced professionals stop practicing
- Coordination of lymphoedema care; possibly could make use of nurse-led shared care models
- Having an equitable and consistent garment scheme available to consumers

“...because at the moment it’s just absolutely not enough to cover the breadth of comorbidities”

THE LACK OF DATA/EVIDENCE

REFLECTION

- Differences in lymphoedema care for different cancers and lymphoedema related chronic diseases mean that lymphoedema care is not formulaic

CURRENT CHALLENGE

- General lack of evidence-based and data on lymphoedema at a population level

CURRENT ENABLER

- Growing evidence for holistic multidisciplinary approach to lymphoedema care (i.e., exercise, garment, therapy)

POINT TO IMPROVE ON

- Leveraging different models of care already in existence for other successfully managed recognised chronic care conditions (e.g., diabetes)

“It’s this really continued problem where we with lymphoedema just simply don’t emerge out of the vast numbers of conditions [to the Government] and [Lymphoedema]’s not classified under any area.”

*“You’ve got to have the access as well.
But a lot of people just do not have that.”*

THE INEFFICIENCIES OF POLICIES & SYSTEMS

REFLECTION

- A model of care for lymphoedema which gives health professionals time to upskill; a concurrent systemic/governmental acknowledgement that cases of lymphoedema are only going to go up for a variety of factors (e.g., increasing population of cancer survivors, increasing ageing population, climate change)
- Because there is no summative evidence of the burden of lymphoedema at a population level, convincing the government that change needs to be made makes this a catch-22 situation
- Changes in the system/policies go hand in hand with evidence that exists

CURRENT CHALLENGE

- Governments come and go and so do their priorities, so action must be taken when the chance arrives
- Health professionals are not well-prepared for political negotiation despite their understanding of how dire health situations are
- No health profession has fully taken on responsibility of lymphoedema falling into their purview of work/responsibilities
- Governments tend to consult with external industry companies for economic analyses and do not include academic research in the consideration to these reports/projects

CURRENT ENABLER

- The AIHW report is a step forward in the right direction for lymphoedema care and shows that it is gaining traction at a government/systems level

HOW THINGS CAN BE BETTER

Across the two workshops, the diversity amongst participants allowed us to first discuss solutions that could within the local state of South Australia. We considered two questions:

- **How might lymphoedema care be improved at the metro (Adelaide) level?**
- **How might lymphoedema care be improve at the rural & remote state level?**

In the second workshop which included participants from across Australia, the solutions considered were then at a national level:

- **How might lymphoedema care be improved for all in Australia?**

This set the three levels of solutions considered (i.e., Metro - Adelaide, Rural - South Australia, and National). While some solutions were needed in both metro and rural areas to better support lymphoedema care, it was clear that solutions at all three levels needed to worked on simultaneously and continuously to exact positive change for all stakeholders

“I’m very lucky to have been diagnosed at the time that I live in.”

SOLUTION STRATEGIES

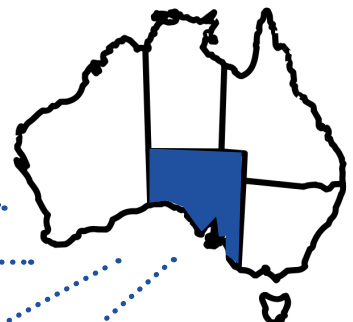
ACTION LEVEL

- STRATEGIC RESEARCH AGENDA
- NATIONAL REGISTRY FOR CONSUMERS
- COST ANALYSIS – HEALTH ECONOMICS OF LYPHOEDEMA
- CLEAR REFERRAL PATHWAYS
- RECOGNITION AS A CHRONIC CONDITION
- DEVELOP SUSTAINABLE TRAINING & SERVICE MODELS
- LEVERAGE TECH & CURRENT SUCCESSFUL CHRONIC CONDITION MODELS
- DETERMINE STRATEGIES FOR STAFF RECRUITMENT/ TRAINING/RETENTION
- UP TO DATE CLINICIAN REGISTRY FOR HEALTH PROFESSIONALS & CONSUMERS
- REVAMP EDUCATION GUIDELINES FOR ALLIED HEALTH & GPs TO INCLUDE LYMPHOEDEMA IN CURRICULA
- DETERMINE PRIVATE & PUBLIC COST OF LYMPHOEDEMA
- IDENTIFY MINIMUM MODEL OF CARE & OPTIMAL CARE PATHWAY
- CLINICIAN COLLABORATION TO OPTIMISE CONSUMER CARE

NATIONAL



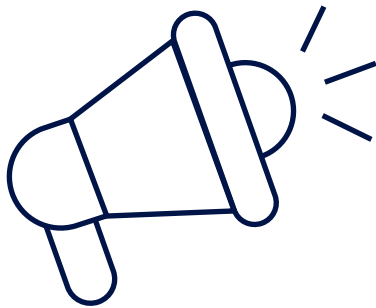
RURAL - SA



METRO - ADELAIDE



WHAT'S NEXT?



Advocacy

To stay in touch with what is going on in the lymphoedema advocacy space, please contact Ms Monique Bareham directly at lymphadvocate@gmail.com.



Research

To stay in touch with the Flinders Lymphoedema Working Group's progress and our other work, please contact Professor Bogda Koczwara directly at Bogda.Koczwara@flinders.edu.au.

ACKNOWLEDGEMENTS

This project was supported by the Flinders Lymphoedema Working Group. We gratefully acknowledge the facilitation at the workshops by Professor Bogda Koczwara and Ms Monique Bareham.

We are indebted to the people who made the time to come to the workshops and emailed in their ideas to share how lymphoedema care can be improved for the many – be it locally in Adelaide or for the whole Australia. All quotes within this report have come from consumers who have participated in the workshops.

And lastly, a heartfelt ‘thank you’ to Beryl Hayes for their donation and to the FHMRI Consumer & Community Involvement grant for supporting projects like these to progress lymphoedema research and care.