Digital community of practice in lymphoedema care: a perspective piece

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Key words

Community of practice, digital health, eLearning, eHealth, digital community.

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Abstract

Professional groups and communities of practice play an essential role in the advancement of knowledge, innovation, and professional development across various fields. Health related groups in particular provide a structured forum for health professionals to engage in meaningful exchanges about current and future trends, challenges, and practices. This paper details the history, technology, governance and utilisation of the digital Australian Lymphoedema Professional Google Group, successfully initiated and administered for over twenty years by an Australian occupational therapist. This paper examines how the group functions as a digital community of practice, broadly describing its impact on professional development, knowledge sharing, and the collective advocacy efforts of its members.

Communities of practice can be defined as "groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise by interacting on an ongoing basis"(Noar et al, 2023). Communities of practice can be used for learning, exchanging information and knowledge and improving clinical practice for the implementation of evidence-based practice (Ranmuthugala et al, 2011).

A Google Group is an online forum where members can communicate through email or a web interface (Google, 2024). Users can start discussions by posting messages, which are then emailed to all group members or accessible via the group's webpage. Members can respond directly from their email inboxes or through the group interface, facilitating a continuous and interactive dialogue.

The group administrator can customise settings, such as whether to moderate posts, manage membership approvals, and decide who can view or contribute to the discussions. This platform supports a variety of uses, from simple information sharing to more complex collaborative efforts among its members.

The Australian Lymphoedema Professionals Google Group began as an initiative of Australian occupational therapist, Brenda Svensson-Florida (group administrator and owner, Australasian Lymphology Association accredited lymphoedema practitioner). She recognised the need for a dedicated free digital platform where health professionals with an interest in lymphoedema can exchange knowledge, share clinical experiences, and discuss advancements in treatment methodologies.

The group was originally founded in 2004, with the aim of bridging the distance between rural and metropolitan Australian occupational therapy lymphoedema-related services. From 2007 to 2024, the group evolved to bridge gaps between research, training, advocacy and provide a platform to seek advice or opinion to enhance clinical intervention , enabling therapists from various backgrounds (such as medicine, physiotherapy, occupational therapy, nursing, massage therapy and other allied health services) to collaborate and enhance their clinical skills and knowledge.

Most members are lymphoedema practitioners; however, some are researchers, medical practitioners and other health professionals with a special interest in lymphoedema.

Initially starting with a small group of nine healthcare professionals in 2004 and the group quickly grew as the value of shared expertise and support became evident, attracting a wider membership that spans multiple disciplines involved in management, education and research. The membership has grown to approximately 450, with membership across Australia, New Zealand and the UK.

Method

Administration of the Australian Lymphoedema Professionals Google Group is managed by the group owner, who retains the responsible for maintaining the integrity and purpose of the group. Membership is restricted to health professionals, with membership achieved through completion of a membership application that is emailed to the group owner.

The group owner has the authority to adjust settings that control membership, posting privileges, and visibility of discussions. This includes approving or denying membership requests, moderation of posts to limit inappropriate content, and set guidelines for discussions to ensure they remain productive and respectful. All new members are provided with instructions regarding how to interact with the group, change their membership settings and the need to provide disclosures regarding interests.

Users of the group are identified by their email address or Google account nickname name. To address potential challenges and provide some clarity around conflicts of interest and bias, the owner has implemented clear guidelines that require members to disclose any potential interests or biases when posting about products, services, or research.

Members are required declare interests at the top of applicable emails in a form similar to "Nothing to declare" or "Declaration: I have…". This transparency helps to promote integrity in the discussions and ensures that advice or information shared is not unduly influenced by personal or commercial interests.

All conversations and topics are allowed to promote free speech and open discussion. To prevent disruptive behaviour, such as unproductive complaining, the administrator also enforces a code of conduct that promotes professionalism and courtesy. Discussions that veer off-topic or become contentious, result in reminders of the group's purpose and the expectations for respectful communication.

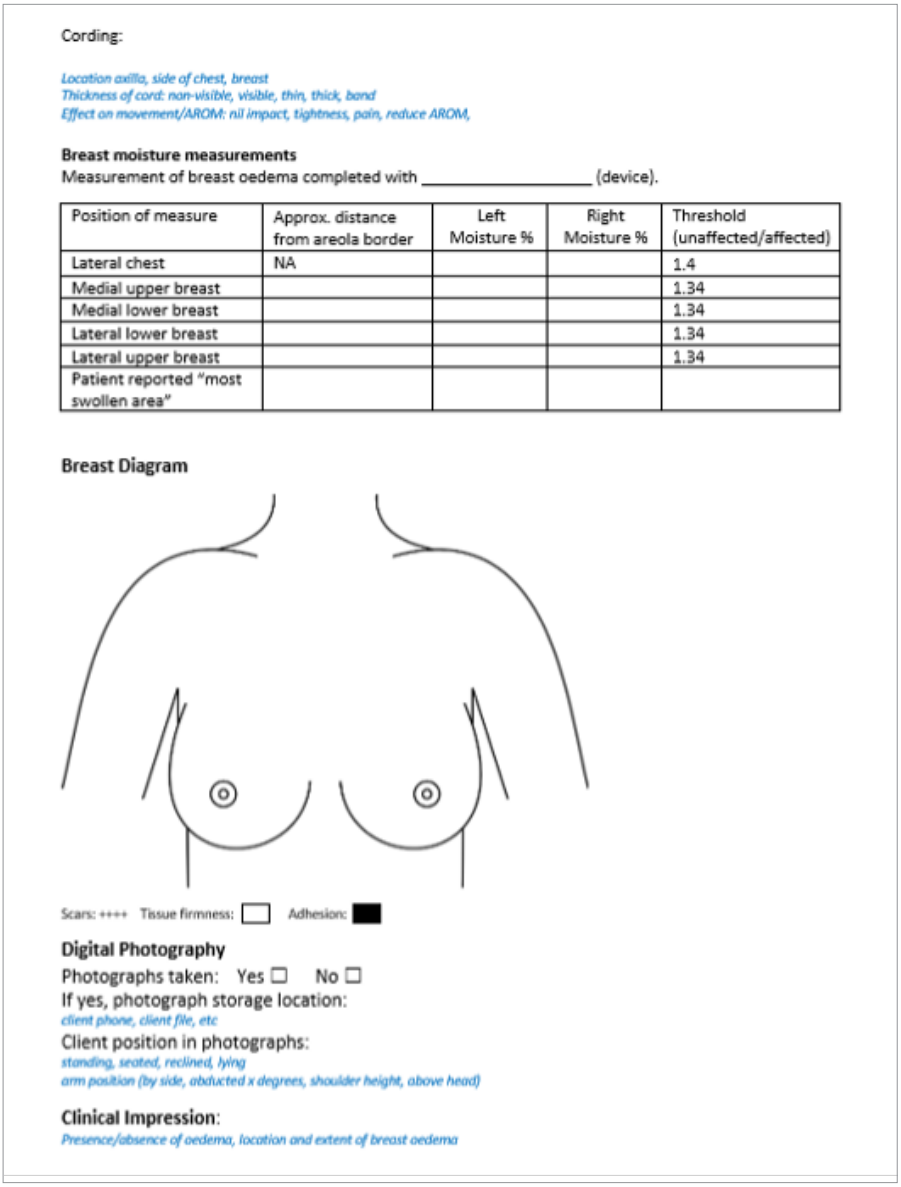
Results

The group has an average of 111 emails per month, with 123 in February 2024, 128 emails in March and 83 in April. Most emails are posed as clinical questions to the group.

One example of a clinical query, inclusive of brief clinical case history, was "Dear all. I am hoping to get some guidance. I have a lovely 50-year-old lady who is now 2 years on from lumpectomy with sentinel node biopsy/radiation/chemo. She is complaining of on/off stabbing pain in her breast (right under her scar line). On ultrasound (US) there is a visible seroma there and the lymph scanner measures a very low-grade difference (52% compared to 45% on the other side). There is no palpable pitting. There is some deep scar tissue palpated. Her function and range of movement (ROM) are perfect. I have done some laser on her and manual lymphatic drainage (MLD), nothing has helped with the pain. Is there anything else anyone can suggest?"

Four responses to this query were received from the group and included ideas such as targeting scar tissue release around the seroma and scaring, considering muscular adhesions in muscles such as pectoralis major and rib cage mobility exercises as well as lymphoedema and neuromuscular taping. Responses were received within four business days, with the author posting gratitude for the group's high-quality collective input. Such responses then allow lymphoedema practitioners to seek further assistance, continue or modify assessments and treatments with confidence based on feedback.

The group also develops or improves shared assessment or patient education resources. Expressions of interest for development of a particular resource is sent to the group, then members volunteer to participate in working groups to work on the project. Resources are then shared for the benefit of the entire group through Google Drive. One example of developed resources is a comprehensive four-page Breast Lymphoedema Assessment form (*Figure 1*; Australian Lymphoedema Professionals Google Group, 2023).



Cording:

Location axilla, side of chest, breast
Thickness of cord: non-visible, visible, thin, thick, band
Effect on movement/AROM: nil impact, tightness, pain, reduce AROM,

Breast moisture measurements
Measurement of breast oedema completed with _____ (device).

Position of measure	Approx. distance from areola border	Left Moisture %	Right Moisture %	Threshold (unaffected/affected)
Lateral chest	NA			1.4
Medial upper breast				1.34
Medial lower breast				1.34
Lateral lower breast				1.34
Lateral upper breast				1.34
Patient reported "most swollen area"				

Breast Diagram

Scars: ++++ Tissue firmness: ☐ Adhesion: ■

Digital Photography
Photographs taken: Yes ☐ No ☐
If yes, photograph storage location:
client phone, client file, etc
Client position in photographs:
standing, seated, reclined, lying
arm position (by side, abducted x degrees, shoulder height, above head)

Clinical Impression:
Presence/absence of oedema, location and extent of breast oedema

Figure 1. The third page of the Breast Lymphoedema Assessment form, showing areas where clinicians can document information on cording, fluid levels, scar tissue and clinical impression notes.

Conclusion

The Australian Lymphoedema Professionals Google Group represents an effective and well administered digital community of practice. The free group allows members to stay connected with other lymphoedema practitioners across Australia, NZ and the UK and share advancements in advocacy efforts, technology, treatment and best practice for the care of their patients.

References

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