ALFP: IDENTIFYING ISSUES IN LYMPHOEDEMA IN THE US

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The American Lymphedema Framework Project (ALFP) is a national initiative introduced in 2008 to improve the management of lymphoedema (LE) and related disorders in the United States. A National Stakeholders Conference was held in March 2009 to share perspectives on the current state of LE, establish priority issues, and recommend actions to move the field forward.

Key words

Lymphoedema Best Practice Open Space Partnership

he American Lymphedema
Framework Project (ALFP) is a
national initiative established in
2008 as a collaboration of healthcare
providers, researchers, patients, and
industry representatives. The goal of ALFP
is to address the need for healthcare
standards, policy initiatives, education,
and research to impact and advance
the quality of lymphedema care in the
United States. Lymphoedema is an under-

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recognised, life-long condition, estimated to impact 22–66% of the 2.4 million breast cancer survivors in the US within two to 11 years of diagnosis (Petrek and Heelan, 1998; Armer and Ridner, 2007; Cormier et al, 2008; Norman et al, 2009). The ALFP was formed in partnership with the International Lymphoedema Framework (ILF), a United Kingdom-based charity which has made tremendous strides in raising the profile of lymphoedema and improving the standards of care in Great Britain (Morgan and Moffatt, 2006).

In the US, independent lymphoedema-related organisations have made progress over the last two decades to improve awareness in the medical and public domains and to define standards of care. However, there has been little opportunity or incentive for these stakeholders to collaborate. While not well documented, it is the perception of stakeholders that progress in improving outcomes for those suffering from lymphoedema (LE) is hindered in the US by a multitude of concerns. Healthcare coverage for lymphoedema in the US is fraught with access and reimbursement barriers not only resulting in poor and fragmented care, but essentially preventing an optimal standard of care from being implemented. Access to care is limited, in part due to the absence of medical professional education in this area, leading to delayed diagnosis, misdiagnosis, and inappropriate treatment. Education in the anatomy, physiology, and pathophysiology of the lymphatic system is deficient across medical disciplines and supplemental continuing education opportunities addressing lymphoedema and lymphatic disorders are not widely available. Insufficient reimbursement for necessary treatment and medical supplies inhibits optimal care and further confounds the problem.

In response to these needs, the American Lymphedema Framework Project (ALFP) was developed to enable partnerships across disciplines and among stakeholders to develop lymphoedema best practice initiatives in clinical care. health policy, education, and research. An initial goal of the ALFP was to amass input from a wide scope of stakeholders in the field of lymphoedema and obtain input on how to address these needs. The ALFP National Stakeholders Conference. described here, was the initial event for this collaborative input and culminated in proposals, action plans, and targeted goals that will drive the ALFP initiatives ahead. This report summarises the proceedings from the stakeholders meeting and outlines the next steps for the project.

Methods

The ALFP National Stakeholders Conference, sponsored by a grant from the American Cancer Society (ACS), was held in Glenview, Illinois, on 16 March, 2009. The ALFP meeting included patients, therapists, advocates, educators, physicians, nurses, researchers, industry representatives, and other parties interested in the field of lymphoedema. To enable the broadest scope of stakeholder attendance, the ALFP steering committee suggested participants and methods for reaching out to all potential stakeholders. This included calls for participation through direct mailings from ALFP to industry representatives, professionals, and patient support groups. Web-based advertisements were also used. Figure I details the process for inviting conference attendees.

The theme for the meeting was 'What can we do to improve the management of lymphoedema and lymphatic system disorders in the United States?'The Open Space method, as described by Owen and Stadler (1999) and successfully utilised for the ILF Stakeholders Conference, was chosen as the meeting format during the planning process. Open space meetings have been defined as a 'process that is appropriate when there is a need to deal with complex issues, where there is divergence of opinion, passion, and a potential for conflict and a decision time of yesterday' (Owen and Stadler, 1999).

Open Space method

The Open Space method consists of self-managed work groups where leadership is shared, diversity is encouraged, and personal empowerment is achieved (Owen and Stadler, 1999). This method capitalises on the group members' collective experiences and enables timely decisions in order to address complex issues utilising a highly diverse group of stakeholders with various and sometimes competing interests. The Open Space structure is not pre-imposed or controlled, but rather emerges from the group as appropriate to the people, task, and environment (Owen and Stadler, 1999).

There are four principles and one law of the Open Space method:

- >> Whoever comes is the right people
- Whatever happens is the only thing that could happen
- >> When it starts is the right time
- >> When it's over, it's over
- >> The 'Law of two feet' or personal



Figure 1. The process for inviting participants for the ALFP Stakeholders Conference included nomination from ad hoc committee members, external publicity from partners, and personal invitations.

initiative says to stand up for what you believe, and if you feel you are neither contributing nor learning where you are, use your two feet and go somewhere else.

National Stakeholders Conference

Seventy-two lymphoedema stakeholders attended the conference from a diverse range of backgrounds: lymphoedema therapists (27%), industry representatives (18%), researchers or professors (16%), lymphoedema patients and advocates (15%), physicians (9%), nurses (4%) and 'others' (11%) (Figure 2).

The conference began by meeting facilitators introducing the principles and law of Open Space meetings. The first and third sessions began by framing a question to initially focus participants and allow for open, creative imagination in developing solutions. Throughout the conference, groups emerged and were self-selected based on a topic interest. Summary input sheets were also distributed and collected over the course of the day to provide a

voice (anonymous or identified) for each individual. These forms were electronically collated and distributed in the preliminary proceedings within 24 hours of the completion of the conference (available for download at: www.ALFRorg).

The format of the ALFP meeting was broadly divided into three sessions, as described in Figure 3. The theme of the first session was 'What are the priority issues and barriers in the field of lymphoedema?'The first principle activity (activity A) consisted of four-person interdisciplinary groups, collaboratively addressing the issue over a set period of time. At the end of activity A, each individual completed an input sheet, which was later analysed for broad topics. This activity was followed by collapsing into progressively larger groups to collectively build on common ideas (activity B). Activity B involved creating small multidisciplinary working groups that developed the main topic areas or themes discussed during activity A. Themes identified from activity B included (in no particular order):

- >> Establish the credibility of the ALFP
- >> Create lymphoedema awareness
- ▶ Develop research to refine diagnostic standards and treatment
- ► Enhance patient education, support, and self-management
- Establish criteria for health-provider education
- Promote evidence-based lymphoedema management
- >> Improve reimbursement.

The second session consisted of a 'market place' in which individuals moved throughout the room examining and discussing the themes in an open forum, and ultimately choosing a topic-based work group for the third session in accordance with their interests.

The third session converged on individual topics by asking the members: 'How should these issues be addressed?' Groups brainstormed about potential solutions and resources required. Action plans were developed for each topic. In this forum, the groups completed written forms providing specific recommendations and potential methods for achieving these results for the ALFP. Reports from the third session were orally presented to all meeting participants at the end of the afternoon, in addition to being included in the

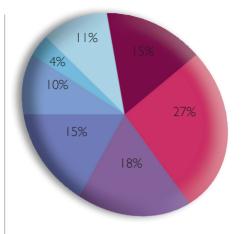
preliminary proceedings (available for download at ALFP.org).

Results

The ALFP Steering Committee carefully reviewed the documents produced by the afternoon working groups and formatted the following summary of conference findings. The following themes were identified as priority issues in the field of lymphoedema (*Table 1*).

Establish the credibility of the ALFP

Integrity will be obtained by fostering a positive political environment in which a broad scope of stakeholders are represented and actively participate in a transparent process of project development. Interested stakeholders should be encouraged to enter into participation at any time in the best practice development process, Every effort should be made, through marketing materials and announcements, to recruit and engage participants, encouraging liaisons from professional organisations, patient groups and industry. Furthermore, ALFP must produce deliverables that are consistent with its mission, including best practice documents, a research agenda, and a minimum data set. Credibility will lend itself to increased recognition across medical disciplines, among medical professional associations, patients,



Lymphoedema patient/advocate

Lymphoedema therapist

Industry

Professor/researcher

Medical doctor

Nurse

Other

Figure 2. Details of ALFP stakeholders conference attendance by self-identified area of primary responsibility.

reimbursement sources, and the general public.

Create awareness of LE and related lymphatic system disorders

Expanded partnerships with external communities and with established

Session 1: What are the priority issues and barriers in the field of lymphedema?					
Activity A (stakeholder groups of four)					
Awareness/education	Standards	Research	Payment barriers	Treatment	

Activity B (stakeholder groups of 6–10)						
Establish the	Creating	Develop	Enhance patient	Establish	Promote	Improve
credibility of the	awareness of LE		education	criteria for	evidence-based	reimbursement
ALFP	and lymphatic	refine diagnostic		health provider	LE management	
	disorders	standards/		education		
		evidence-based				
		treatment				

Session 2: Market place

Individuals move around the room, discussing themes in an open format, then choose a topic-based working group for session 3

Session 3: How should these issues be addressed?

Small groups develop action plans to address the issues identified in session 1

Figure 3. The flow of an 'Open Space' meeting lacks structure by its definition, but the conference was broadly divided into three sessions.

lymphoedema organisations will serve to increase awareness of the scope of the problem among healthcare providers, patients, payers, and the public. Patient stakeholders interestingly reported a perceived lack of concern or 'indifference' to the condition on the part of their medical providers. Awareness campaign strategies included:

- ▶ Establishing a National Lymphoedema Education Awareness Day
- >> Identifying a national spokesperson
- >> Creating a recognisable logo
- Collaborating with various communities.

Develop research to refine diagnostic standards and provide evidence for effective treatment

Various types of research methodology, including basic, clinical, epidemiological, health service delivery, and patient-related, must be incorporated into the field of lymphoedema to enhance the current evidence base. The ALFP must create a mission-oriented approach to high priority research questions in areas such as aetiology, risk reduction, clinical predictive models, diagnostic criteria, classification, treatment outcomes, measurement techniques, chronic care, and diversity. All stakeholders should be included as partners in research. Funding sources beyond the traditional mechanisms should be considered including international collaboration, research networks, multisite collaborations, industry partnerships, educational foundations, and public health institutions. ALFP could serve as a conduit for these collaborations by facilitating networking capabilities through a research repository, funding information databank, and current ongoing research collaborations.

Enhance patient education, support and self-management

Patients who are at risk for lymphoedema should be educated to recognise physical changes associated with the onset of lymphoedema and to make the connection between 'swelling' and lymphoedema. Patients perceive that the gravity of their condition is misunderstood and ignored by their healthcare providers, bringing to light the significant issue pertaining to the lack of provider education which will be addressed in later portions of

this paper. Given the chronic nature of the condition and the associated decrements in quality of life, a life-long support system, both financial and social, is required. Even for individuals with insurance coverage, reimbursement is often limited, leading to a lifetime of expenses that a patient must accommodate. Solutions for patientfocused education through ALFP include encouraging a network of support groups and nurse navigators, and developing written materials for wide distribution and access. ALFP could host a patient-oriented national web-based resource centre to provide current and valid information. Participants also suggested online electronic forums for networking and support.

The current state of affairs undeniably paints an image of a 'chaotic patient journey' along the continuum of lymphoedema care, from the time of diagnosis (or misdiagnosis) to identifying and accessing quality treatment, to reimbursement and lifelong continued support and care.

Establish criteria for health provider education

Educational needs transcend the continuum of care and encompass all disciplines of healthcare providers. Additionally, and perhaps most underrecognised, is the need for educating legislative and healthcare reform policy stakeholders, as they are primary decision-makers regarding access to care and reimbursement for care. Education should encompass a standard nomenclature, establishment of best practices, and the implementation of optimal care across the continuum. Education that is driven by best practice standards and research can influence reimbursement and policy. Basic standards and accountability must also be established for educators. Currently, qualifications for clinical care providers differ between various schools. Best practice standards or competency

standards (however difficult to implement) may impact reimbursement. In the US, physicians are the gatekeepers of care for whom the knowledge must first be disseminated.

Curriculum standards for education in lymphoedema management are variable in the US and internationally. Access to lymphoedema education programmes is limited and ongoing competency of those treating lymphoedema is difficult to ensure. Furthermore, there is discrepancy in the field as to the level of education required to manage the condition at various stages and the different levels of acuity along the continuum of care. One possible solution is to create common minimum criteria for curriculum standards, supported by consistent ongoing competency skills testing. This would depend on the level of baseline education for the treating therapist and would be commensurate with their level of intervention with patients. Educational criteria will differ for those conducting more intense intervention, as compared to those working in a consultative capacity. A variety of resources are needed to achieve this goal, including academic curricula advisors, medical professionals, and reviewers. An immediate action that the ALFP could undertake would be to sponsor an awareness programme directed at healthcare professional schools, offering education and advice on integration of lymphoedema into curriculum.

Promote evidence-based practice for lymphoedema management

A best practice standard that is evidencebased is the ultimate goal of ALFP. Widest dissemination and promotion of this document will be vital to enhancing the delivery of care for lymphoedema and lymphatic disorders. The document should focus on diagnosis, treatment interventions, access to care, chronic implications of the condition, optimal points of provider intervention, patientassociated factors, and comorbidities. Additionally, emphasis should be placed on preventive strategies including risk-reduction, early diagnosis and intervention. Research integration is a critical component in the identification of effective and cost-effective interventions

in order to define the standards of care. Utilisation of cost modeling, comparative effectiveness, and outcomes studies should be encouraged through this initiative to establish a valid premise for altered reimbursement models.

Improve reimbursement

There is a dearth of readily accessible information on the topic of reimbursement for individuals with lymphoedema and lymphatic disorders. A strategic approach that links payment to proven best practice is needed and should be combined with robust efforts in lobbying and legislative advisement and education at all levels of government in all geographical regions. Existing databases may be helpful to examine current reimbursement trends for lymphoedema in the US. In addition, they may provide information on specific complications associated with lymphoedema, such as cellulitis, which can be costly, debilitating and recurrent. Economic modeling can be used to extrapolate and extend currently available data. For example, it is possible to project future expenses and dollars saved for lymphoedema conditions in circumstances in which complications are mitigated by early intervention and appropriate lymphoedema management.

Current lymphoedema reimbursement practices are dictated by the International Classification of Diseases, 9th Revision (ICD-9) codes which were developed by the Health Care Financing Administration to assist with the assignment of reimbursement amounts to providers by Medicare carriers. Numerous managed care and insurance companies base their reimbursements on these values established by the Center for Medicare and Medicaid Services (CMS). Currently, ICD-9 coding is limited for the condition of lymphoedema and not reflective of the many complexities of the condition. Current coding mechanisms are also inadequate to track inpatient hospital stays related to lymphoedema and related complications, making it difficult to track episodes of treatment, length of stay, and other important factors that contribute to cost analyses. Future diagnostic coding needs to be more

precise to identify case complexity and substantiate appropriate reimbursement models for various levels of treatment. The ALFP may seek collaborative efforts with payers such as CMS, the Veteran's Administration (VA), and other large third-party payers in order to make an impact on reimbursement coding and payment models. Other suggestions included the purchase of insurance datasets to perform analyses to examine lymphoedema outcomes for evidence to encourage state laws to mandate lymphoedema treatment and standardise professional qualifications.

Common themes

A number of common themes emerged across topic-based discussion groups. First, the current state of affairs undeniably paints an image of a 'chaotic patient journey' along the continuum of lymphoedema care, from the time of diagnosis (or misdiagnosis) to identifying and accessing quality treatment, to reimbursement and life-long continued support and care. This vulnerable population is poorly supported by the current medical system at all points in the healthcare spectrum. Second, credible and consistent mechanisms for healthcare provider education are vital and must be appropriate to the varying levels of medical intervention. Education and best practice must be mutually inclusive and work reciprocally to promote one another in order to directly impact clinical management. Education is a tool that can also impact other areas including research. reimbursement, and policy decisions. It is critical that target groups be identified and prioritised for contacts about funding, acknowledging that this involves a complex and interrelated set of players. Education, although vital at many points, must be a part of a larger concerted multi-modal approach to advancing the field.

Discussion

The enthusiasm among participants at this meeting was palpable throughout the day and the energy expended to achieve these outcomes was remarkable. Emphasis was repeatedly made concerning the arduous process that the ALFP will undertake in this endeavour

Key points

- Healthcare coverage for lymphoedema in the US is fraught with access and reimbursement barriers, that essentially prevent an optimal standard of care from being implemented. The American Lymphedema Framework Project (ALFP) initiative aims to eliminate barriers to care.
- The ALFP was developed to enable partnerships across disciplines and among stakeholders to develop lymphoedema best practice initiatives in clinical care, health policy, education, and research.
- The primary aim of the ALFP is to encourage a more robust evidence base to guide best practice while concomitantly defining current best practice standard of care.

and the importance of partnerships with all stakeholders to accomplish the goals of this project. Expectations for outcomes and turnaround of deliverables must be realistic, but also must be expediently addressed.

The Open Space method was an effective meeting format to solicit input from multiple constituencies. The Stakeholders Conference was a unique participatory opportunity undertaken to assure that:

- An exhaustive list of issues relevant to lymphoedema would be raised
- An opportunity for in-depth discussion ensued
- >> Related issues would be converged
- ▶ Responsibility would be taken for the recommended action steps.

It is clear from these proceedings that there is a quest to create a prioritised

research agenda. The duality of this task is to create a more robust evidence base to guide best practice while concomitantly defining current best practice. The best practice document that will be produced by the ALFP must be a dynamic document intended to inform current practice, as well as stimulate improvements and expansion in research endeavours.

The steering committee and project directors were able to glean substantial insight into the scope of the work that will need to be undertaken to assure success of this project. Ultimately, the National Stakeholders Conference provided guidance to enable the ALFP to achieve its mission to improve lymphoedema management in the US and globally.

Next steps

- ▶ Based on the common themes derived from this cohort of 72 attendees, the steering committee will survey constituents to assist with prioritisation of the identified issues.
- ➤ A web-based survey of practicing LE therapists will be administered to provide insight into current treatment trends in the field and to advise the formulation of a minimum data set. The dataset will eventually be housed in a central, national database to capture vital information about

- patients with lymphoedema and lymphatic disorders.
- ➤ A systematic review will be conducted to inform the research agenda which must be consistent with the mission of ALFP and work in concert with other aims of the project.
- We will develop a policy brief on lymphoedema and lymphatic disorders to promote education to legislative contacts, government agencies, and reimbursement entities.
- We will work in collaboration with the International Lymphoedema Framework (ILF) to promote international attention to the field of lymphoedema and lymphatic disorders. This includes developing strategies for international grant funding, promoting participation in the minimum data set data gathering, and supporting and advising in international publication strategies and translations of best practice documents.

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Table I
Summary of the stakeholders' identified issues and recommendations for solutions, needs, and action plans

Issues	Solutions	Needs	Action plans
Establish credibility of the ALFP	Foster a positive environment Maintain transparency Embrace a broad scope of stakeholders Facilitate and encourage stakeholders' active participation Produce deliverables consistent with ALFP mission, such as best practice documents, a research agenda, and a minimum data set	 Open door policy to encourage interested stakeholders to enter into participation at any time in the process of development Open process for decision-making Open access to meeting proceedings Taskforce for producing deliverables 	 Recruit and engage active participants Encourage liaisons from professional organisations, patient groups and industries Market materials and announcements Formulate taskforce for production of deliverables
Create awareness of LE and related lymphatic system disorders	 Expand partnerships among stakeholders with external communities Create and encourage collaborations among organisations and public communities Organise awareness campaigns Identify national spokespersons Create a recognisable logo 	 Open door policy of stakeholders Engagement of potential partners, such as healthcare providers, patients, payers, industries, and the public High-profile national and international spokespersons Identify other treatment-related conditions such as brachial plexopathy 	 Recruit a broad scope of partners from lymphoedema communities and external communities Establish a National Lymphoedema Education Awareness Day Organise a national walk for lymphoedema Identify and contact potential high-profile national and international spokespersons Call for logo

Table I Cont.

Develop research to refine diagnostic standards and provide evidence for effective treatments	Create a ALFP mission-oriented approach to high priority research questions Include all stakeholders as research partners Facilitate and encourage collaborative research Incorporate a variety of research methods Create a research repository Create government	 Establishment of ALFP leadership position Clear statement of a mission/purpose for ALFP Non-traditional research partners, such as healthcare insurance companies, government payers, patients, and industries A website to facilitate communication within and outside lymphoedema communities A website for easy access to researchers and up-dated studies High-profile national and international spokespersons 	 Develop and conduct a survey to identify priority research agenda Develop and conduct a survey to understand current state-of-art of lymphoedema services Establish a database serving as a searchengine for easy access to researchers and updated studies Establish minimum data set for practice and research Identify and contact potential high-profile spokespersons
Enhance patient education, support, and self-management	 Educate patients to recognise changes in their limb associated with the onset of lymphoedema to make the connection between 'swelling' and lymphoedema Campaign for a life-long financial and social support system for patients Encourage a network of support groups and nurse navigators Produce standardised educational materials Host a patient-oriented national web-based resource centre to provide valid information 	 Standardised patient education materials Consistent and full insurance coverage and reimbursement for risk reduction and self-management A life-long support system for patients, both financial and social Education for healthcare providers Open access to standardised provider and patient education materials 	Develop best practice documents for patient and provider education Establish a National Lymphoedema Education Awareness Day Organise a national walk for lymphoedema Host online electronic forums for provider and patient networking and support
Establish criteria for health provider education	Educate legislative and policy stakeholders who are the ultimate decision-makers for the standards of care, access to care, and reimbursement for care Establish educational programmes consisting of a standard nomenclature, establishment of best practices, and the implementation of optimal care across the continuum for education Educate physicians, gatekeepers of care in the US Establish standardised curriculum for lymphoedema education to ensure ongoing competency and accountability Create common minimum criteria for curriculum standards, supported by consistent competency skills testing for those who treat lymphoedema	Access to lymphoedema education programmes Standardised curriculum for lymphoedema education to ensure ongoing competency and accountability Established minimum criteria for curriculum standards, supported by consistent competency skills testing Academic curricula advisory committee to initiate and facilitate integration of lymphoedema education into curriculum standards	Identify and contact potential legislative and policy stakeholders Sponsor an awareness programme directed at healthcare professional schools to offer education and advice on integration of lymphoedema into curriculum standards
Promote evidence- based practice for lymphedema management	 Develop and create an evidence-based practice standard on risk-reduction, diagnosis, treatment, access to care, chronic implications, optimal points of intervention, patient associated factors, and comorbidities Disseminate and promote this document to enhance the delivery of care for lymphedema and lymphatic disorders Identify cost-effective interventions and define the standards of care based on updated research evidence Initiate and establish a valid premise for altered reimbursement models using cost modelling, comparative effectiveness, and outcomes studies 	Evidence-based practice standard documents on risk-reduction, diagnosis, treatment, access to care, chronic implications, optimal points of intervention, patient associated factors, and comorbidities Cost -ffective interventions and defined standards of care A valid premise for altered reimbursement models	Create an evidence-based practice document for lymphoedema management Establish a valid premise for altered reimbursement using cost modeling, comparative-effectiveness, and outcomes studies
Improve reimbursement	 Initiate robust efforts in lobbying and legislative advisement and education at all levels of government in all geographical regions Make an impact on reimbursement coding and payment models by seeking collaborative efforts with payers such as the Center for Medicare and Medicaid Services (CMS), the veterans administration (VA), and other third party payers Change current lymphoedema reimbursement practices that are dictated by the International Classification of Diseases, 9th Revision (ICD-9) codes 	 Accessible information on reimbursement for individuals with lymphoedema and lymphatic disorders More precise diagnostic coding that is reflective of complexities of lymphoedema condition More precise diagnostic coding to substantiate appropriate reimbursement models for various levels of treatment More precise coding to track episodes of treatment, inpatient hospital stays related to lymphoedema and related complications, and other important factors that contribute to cost analyses 	Purchase insurance datasets to perform analyses to examine lymphoedema outcomes for evidence to encourage state laws to mandate lymphoedema treatment and standardise professional qualifications Use economic modeling to extrapolate this data and recommend changes in projected expenses if these conditions are mitigated by early intervention and appropriate lymphoedema management