

# ACHIEVING CONSENSUS IN LYMPHOEDEMA CARE

Philip Morgan, Christine Moffatt, Debra Doherty

The Lymphoedema Framework Project is a national initiative aimed at developing and evaluating integrated, primary care-based, specialist-led lymphoedema services in a number of participating primary care trusts around the country. The aims of the project are to make available appropriate care to patients no matter what the cause of their lymphoedema, and to raise the profile of lymphoedema as a major health priority. Underpinning the project is partnership and consensus. This article provides an overview of how consensus was used to develop the key documents for national guidance for the management of lymphoedema.

## Key Words

Lymphoedema Framework  
Partnership  
Consensus  
Best practice  
Integrated primary  
care-based service

The Lymphoedema Framework Project (LFP) is a major initiative that originated from an epidemiology study undertaken in south-west London and which identified that lymphoedema is under-recognised, under-treated and under-resourced (Moffatt et al, 2003). In response to these findings, the ultimate aim of the LFP is to provide evidence that the treatment of lymphoedema needs national guidelines and more resources.

In addition, the project focuses on supporting the development and evaluation of integrated primary-care based lymphoedema services

Philip Morgan is Post-doctoral Research Fellow, Christine Moffatt is Professor of Nursing and Co-director, and Debra Doherty is Senior Lecturer, Centre for Research and Implementation of Clinical Practice at Thames Valley University, London

in a number of participating primary care trusts (PCTs) around the country. The development of services is informed by a set of national standards that help ensure early recognition, appropriate treatment, ongoing care and access to specialist services no matter what the cause of lymphoedema. Both the national standards and the best practice document are the product of a partnership approach and a rigorous process of consensus that form the foundation of the LFP as a whole.

## Partnership

The LFP is led by the Centre for Research and Implementation of Clinical Practice (CRICP) at Thames Valley University, London. Working with CRICP are four groups of partners:

- ▶▶ Patients
- ▶▶ Organisations
- ▶▶ Professionals
- ▶▶ Industry (Figure 1).

The Lymphoedema Support Network (LSN) has been involved from the earliest stages and provides an essential perspective of the needs of patients with lymphoedema. Participating PCTs provide an organisational view that is critical to the development of lymphoedema services in today's changing NHS, and a wealth of professional experience

and expertise is made available from the British Lymphology Society (BLS). The wound care and compression industry are involved to ensure that the most appropriate products are developed and made available to patients.

## Agreeing the way forward

The consensus dimension of the LFP stemmed from a national consensus conference held in April 2002. The conference brought together 130 people from a diverse range of backgrounds from within the 'lymphoedema community', and its aims were to build a shared picture of what was happening with lymphoedema at that time, to map out what good primary care services might look like, and to set an agenda for the way forward.

From this agenda, four working groups were developed:

- ▶▶ The clinical/service development group
- ▶▶ The consultation group
- ▶▶ The outcome group
- ▶▶ The education group.

Each member of the working groups was nominated by their respective partner organisation. The membership of the working groups comprised patients, researchers, doctors, specialist lymphoedema

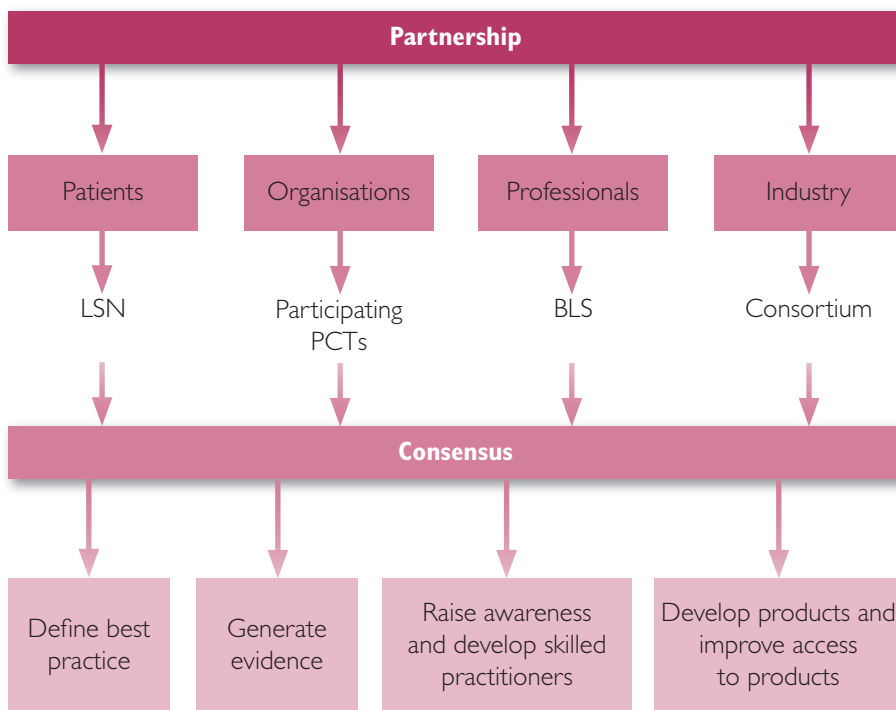


Figure 1. A partnership approach.

practitioners, therapists, pharmacists and nurse managers. These groups met regularly during the early stages of the project, and their work was disseminated widely for consultation. Table 1 gives an overview of the aims of each working group and their output. This article focuses on the work of the clinical/service development working group and the challenge of developing a best practice document using consensus methodology.

### A consensus approach

A consensus approach to the development of best practice guidance is recommended for measuring expert opinion where clinical trial literature is scant, conflicting or unclear (Kane et al, 2003). Systematic reviews conducted by Badger et al (2004a;b;c) demonstrated a lack of a traditional empirical evidence, in the form of randomised controlled trials, to support much of what is done in key areas of lymphoedema treatment and management.

However, while RCTs are considered as central to the development of practice, the point

has been made elsewhere that not all questions about treatment and management are answerable using a RCT methodology (West and Newton, 1997). Equally, for a variety of reasons, not all aspects of care and management will have been the subject of research and, where this is the case, ways must be found to make use of other sources of evidence, such as the expert opinion of professionals and patients (Rycroft-Malone, 2001).

There is a growing literature regarding the use of consensus methods to develop best practice guidance (Frances et al, 1998; Black et al, 1999; Hawryluck et al, 2002; Michie et al, 2005). Despite this, there is little formal guidance on the best way to combine expert opinion with what formal scientific evidence might exist (Shekelle and Schriger, 1993), and even less on how to effectively involve patient groups (Rycroft-Malone, 2001). With regard to the LFP, it was important that existing evidence informed the consensus process, and it was vital that the voice of the patient was clearly heard.

The three best known consensus methods are the Delphi process

(Bayley et al, 1994), the nominal group technique (Brown and Redman, 1995) and the consensus development conference (Jones and Hunter, 1995). Based on guidance from the Health Technology Assessment Programme (HTAP) (Murphy et al, 1998), a modified nominal group technique (NGT, RAND version) was adopted by the LFP. This approach was preferred because it allows for mailed questionnaires, it elicits private decisions and opinions, it facilitates face-to-face contact, and interaction is structured, which is important to allow all voices to be heard, not just the most dominant or eminent (Murphy et al, 1998).

### The process

#### The working group

To enhance credibility and aid eventual widespread adoption of the best practice document, it was important that the composition of the clinical/service development working group reflected the full range of people the document was intended to influence (Murphy et al, 1998). In addition, the resulting heterogeneity provided the variety of perspectives and views that aided the exploration of areas of contention and uncertainty, and promoted better group decision-making (Murphy et al, 1998). Researcher bias was minimised by ensuring that selection of the membership was the result of nomination by parent organisations, not by the LFP team. An overview of the consensus process is set out in Figure 2.

#### Developing a first draft

Two related approaches were used to explore practice and generate recommendations for an agreed best practice approach. Clinical vignettes were prepared and the group was asked how the patient described should be managed in a primary care setting. The working group was also asked to address a set of questions about key areas of practice (Figure 3 shows the full sequence of steps). Each vignette and set of questions was supported by the best available literature, systematic reviews and

Table 1

The aims of the partnership working groups

Aims	Outputs
<p><i>The clinical/service development working group</i></p> <ul style="list-style-type: none"> <li>Define the clinical practice required for the treatment of all patients with lymphoedema</li> <li>Define best practice drawing on published literature, systematic reviews and consensus opinion</li> <li>Define the service framework for the PCT model</li> </ul>	<ul style="list-style-type: none"> <li>National standards of care</li> <li>A service model of care</li> <li>UK and international best practice documents</li> <li>Focus documents and templates for practice series on specific areas of practice, such as lymphoedema bandaging and hosiery</li> </ul>
<p><i>The outcome working group</i></p> <ul style="list-style-type: none"> <li>Define effective evaluation outcome measures for the project</li> <li>Work with the Lymphoedema Support Network to evaluate the patient's experience throughout the project</li> <li>Define the research methods to be used</li> <li>Develop a core minimum data set</li> </ul>	<ul style="list-style-type: none"> <li>Identified patient and professional outcomes of care</li> <li>A study to investigate common proforma for prevalence</li> <li>Data collection tools</li> <li>Common data set and appropriate software</li> </ul>
<p><i>The education working group</i></p> <ul style="list-style-type: none"> <li>Assess the educational needs of practitioners required by the implementation of standards of care</li> <li>Develop a tailored education programme for lymphoedema</li> <li>Ensure the educational strategy takes account of the future national needs for lymphoedema services</li> </ul>	<ul style="list-style-type: none"> <li>Designed, piloted and implemented educational needs analysis</li> <li>Developed and validated educational programmes based on the needs analysis to meet the needs of the new service</li> <li>Developed specialist educational pathways diploma and degree levels</li> <li>Working towards e-learning programmes</li> </ul>
<p><i>The consultation working group</i></p> <ul style="list-style-type: none"> <li>Design and implement a consultation framework</li> <li>Incorporate the views of patients, varying local and national professional groups and organisations in designing and evaluating the new service</li> <li>Communicate developments within the project and disseminate recommendations to relevant agencies</li> <li>Lobby parliament for a change in policy with a view to national service provision</li> </ul>	<ul style="list-style-type: none"> <li>Regular newsletters on progress of project</li> <li>Regular updates for professional journals</li> <li>Forge partnerships with journals to focus on lymphoedema</li> <li>Acceptance of compression garments onto UK Drug Tariff</li> <li>Wider European and international consultation and documentation</li> </ul>

national and international guidelines where they existed (Tables 2 and 3). This was considered important to avoid over-reliance on opinion and dogma (Fink et al, 1984), and to reinforce the view that this was a research exercise and not one totally reliant on opinion and personal experiences (Murphy et al, 1998).

An important element of this process was that discussion by the group was conducted face to face, which enabled exploration, clarification and dispute to take place. The first draft of the best practice document was written from this process. To

assist the review of the document, levels of evidence supporting the guidance included in the first draft was graded using a system based on the Health Technology Assessment Model (Murphy et al, 1998) (Table 4). This first draft was then reviewed by the total membership of all the working groups and, following this wide review, it was further scrutinised by two commissioned 'experts in the field', following which a second draft was produced.

**Electronic appraisal of the second draft**

Members of all the working groups were sent the second draft of the

best practice document and asked to consider 138 statements about aspects of care and management within the document that had been highlighted for clarification by the clinical/service development working group. Each statement was rated on a four-point Likert scale, where the member could record that they strongly agreed, agreed, disagreed or strongly disagreed with the statement. For convenience, speed and privacy, this part of the process was conducted online and the responses entered immediately into a database ready for analysis. This opportunity for private consideration and response away from the group

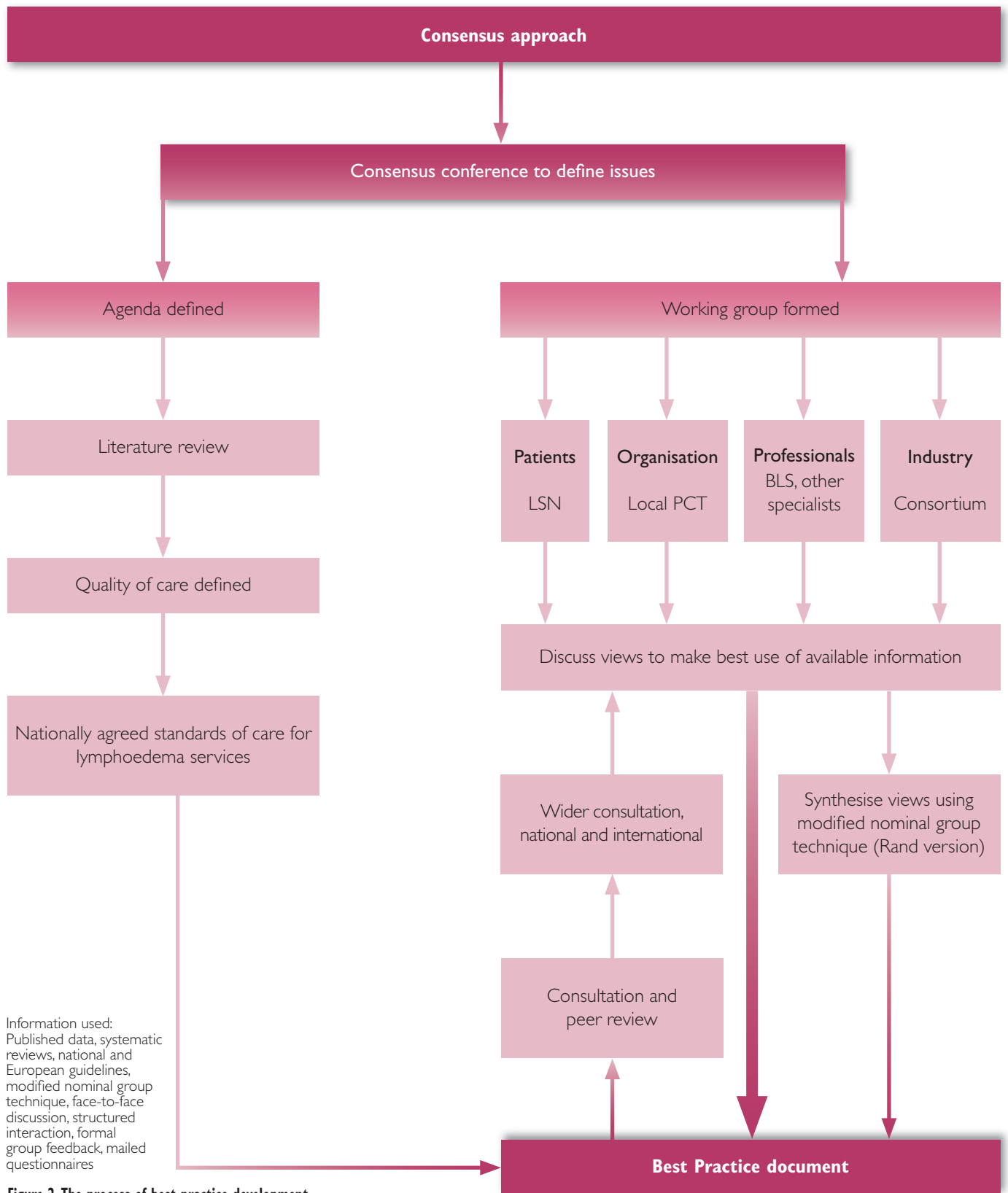


Figure 2. The process of best practice development.

was important as it provided time for quiet reflection of the issues, as well as mitigating the effects of status and dominance by more vocal members (Murphy et al, 1998).

A 95% agreement rate for each item was considered an acceptable level for inclusion in the next draft. The ground rules for this part of the process asked that any disagreement

with a statement had to be justified by the member concerned so as to facilitate redrafting. In the event, 20 statements failed to achieve 95% agreement and were redrafted.

**Table 2**

**Examples of vignettes**

A 61-year-old woman has had a mastectomy and axillary node clearance for left breast cancer. She has had a previous thrombosis and has type 2 diabetes which is controlled by oral medication. She has developed lymphoedema of the left arm and is very obese. She is housebound and ambulance staff say she is too large to get into an ambulance, so she is unable to attend clinic appointments. Her main carer is her daughter who has chronic back pain.

**How should this patient be managed in the community?**

A 60-year-old man has metastatic disease of the left femur and lungs. He had venous lymphatic obstruction, secondary to a deep vein thrombosis of the left leg, and was prescribed warfarin. He currently has lymphoedema of the left leg extending to the groin and is immobile in bed. There are lymph blisters now developing on this leg and lymphorrhoea from the toes.

**How should this patient be managed in the community?**

Further consultation was conducted until agreement was reached.

**National and international review and endorsement**

The final stage of the consensus process was the review of the best practice document by an international panel of lymphoedema experts. This was vital because the international perspective has not only extended the document's scope and relevance, but has also enriched its content, perspective and influence. It is a reflection of the rigorous process of consensus outlined here that the document has received endorsement from all international lymphology societies.

**Discussion**

The use of a consensus approach to develop a best practice document for the management of lymphoedema was necessary because of the lack of empirical evidence to support many aspects of practice. The use of such an approach will inevitably raise concerns about best practice being the result of a composite of subjective judgements and opinion, rather than hard scientific evidence. However, Murphy et al (1998) point out that consensus is concerned with making policy decisions; it is not a scientific method of creating new knowledge. The best that can be done is to ensure that, as part of the consensus process, a balance is achieved between the research evidence that does exist and the collective knowledge and expertise of those contributing. As part of this it is, of course, vital that the process is a dynamic one and that the

**Table 3**

**Examples of questions used to explore key issues of lymphoedema management**

**Intensive treatment**

- What do professionals mean by intensive treatment (definition, duration, frequency)?
- What should intensive treatment consist of?
- What is the evidence to support the form intensive treatment should take?
- What is the criteria for deciding whether intensive treatment is necessary?
- How should the transition between intensive treatment and maintenance treatment be managed?

**Skin care**

- What types of emollients are advisable for skin hygiene?
- What types of emollients are advisable for moisturising skin?
- How should emollients be applied?
- What is the protocol for the treatment of tinea pedis?
- What treatment should be used to manage hyperkeratosis?

**Manual lymph drainage (MLD)**

- When should MLD be used?
- Should MLD always be used during intensive treatment?
- How frequently should MLD be used during the transition phase of treatment?
- What determines when MLD will be used during the maintenance phase of treatment?

**Table 4**

**Grading of supporting evidence in the best practice document**

A	Clear research evidence
B	Limited supporting research evidence
C	Experienced common-sense judgement

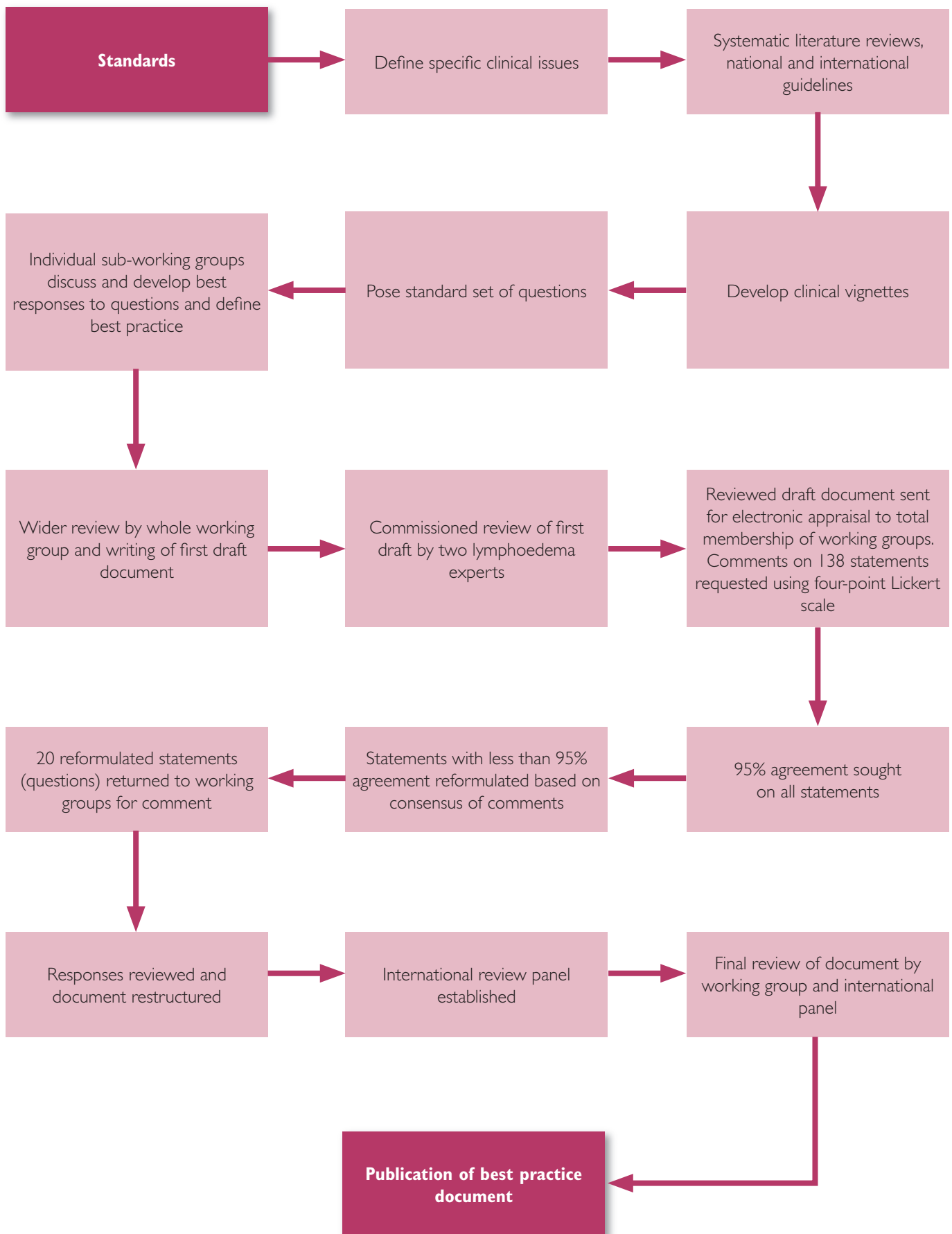


Figure 3. Steps of the consensus process.

## Key Points

- ▶▶ The Lymphoedema Framework Project is a national initiative to make available appropriate care to patients, no matter what the cause of their lymphoedema, and to raise the profile of lymphoedema as a major health priority.
- ▶▶ The project supports the development and evaluation of integrated primary-care based lymphoedema services in participating primary care trusts around the country.
- ▶▶ Integrated services and lymphoedema practice is guided by national standards and a Best Practice document.
- ▶▶ Both the national standards and the best practice document are the product of a partnership approach and a rigorous process of consensus that together form the foundation of the LFP as a whole.

Best Practice document is regularly reviewed and updated as new research emerges.

Of equal importance is the principle that all voices are heard. The power of group processes by which dogma and professional entrenchment can be perpetuated and therefore resist change are well-documented (Janis, 1982). This was a sensitive and challenging aspect of the process described here, simply because of the size of the undertaking, the complexity of the problems being addressed, and the professional commitment of those involved. The possible effects of the dominance of a particular group was allowed for in the private online rating phase of the process, as well as the positive inclusion of the patient's and carer's perspective and the diversity and heterogeneity of the group membership.

The final point to raise in this discussion is the question of the validity of the final document, and how this will be assessed. The difficulties with such an assessment are discussed elsewhere (Murphy et al, 1998, Rycroft-Malone, 2001). However, it is important to place the best practice document in context. It is the pivotal document in a national and international project of change in lymphoedema management. It is the central part of a methodology that includes an exhaustive evaluation of practice that is based on the recommendations and guidance it contains. As such, the review of this document will be as rigorous as its development.

## Conclusion

The aim of this paper has been to provide an overview of the partnership and consensus approach that forms such an important aspect of the LFP. In particular, it has focused on the development of the best practice document that guides practice within the integrated lymphoedema service model. The Best Practice document drives change and, thereby, the importance of the consensus that produced it is emphasised and underscored. Partnership and consensus remain fundamental to the LFP and, based on what has been learnt so far, will continue to underpin the work of the project and everyone involved. **JL**

## References:

- Badger C, Preston N, Seers K, Mortimer P (2004a) Benzo-pyrones for reducing and controlling lymphoedema of the limbs. *Cochrane Database Syst Rev* 2: CD003140
- Badger C, Preston N, Seers K, Mortimer P (2004b) Physical therapies for reducing and controlling lymphoedema of the limbs. *Cochrane Database Syst Rev* 2: CD003141
- Badger C, Seers K, Preston N, Mortimer P (2004c) Antibiotics/anti-inflammatories for reducing acute inflammatory episodes in lymphoedema of the limbs. *Cochrane Database Syst Rev* 2: CD003143
- Bayley EW, Richmond T, Noroian EL, Allen LR (1994) A Delphi study on research priorities for trauma nursing. *Am J Crit Care* 3: 208–16
- Black N, Murphy M, Lamping D, McKee M, Sanderson C, Askham J, Marteau T (1999) Consensus development methods: a review of best practice in creating clinical guidelines. *J Health Serv Res Policy* 4(4): 236–48
- Brown WJ, Redman S (1995) Setting targets: a three-stage model for determining priorities for health promotion. *Aust J Public Health* 19: 263–9
- Fink A, Kosecoff J, Chassin M, et al (1984) Consensus methods: characteristics and guidelines for use. *Am J Public Health* 74: 979–83
- Frances A, Kahn D, Carpenter D, Frances C, Doherty J (1998) A new method of developing expert consensus practice guidelines. *Am J Managed Care* 1(7): 1023–9
- Hawryluck LA, Harvey WRC, Lemieux-Charles L, Singer PA (2002) Consensus guidelines on analgesia and sedation in dying intensive care unit patients. *BMC Med Ethics* 3(3): 1–9
- Janis I (1982) *Groupthink*. 2nd edn. Houghton-Mifflin, Boston
- Jones J, Hunter D (1995) Qualitative research: consensus methods for medical and health services research. *Br Med J* 311: 376–80
- Kane JM, Leucht S, Carpenter D (2003) Expert consensus guidelines for optimizing pharmacologic treatment of psychotic disorders. *J Clin Psychiatry* 64(12): 95–7
- Michie S, Johnston M, Abraham C, Lawton R, Parker D, Walker A (2005) Making psychological theory useful for implementing evidence based practice: a consensus approach. *Qual Saf Health Care* 14: 26–33
- Moffatt CJ, Franks PJ, Doherty DC, Williams AF, Badger C, Jeffs E, Bosanquet N et al (2003) Lymphoedema: an underestimated health problem. *Q J Med* 96(10): 731–8
- Murphy MK, Black NA, Lamping DL, McKee CM, Sanderson CFB, Askham J, Marteau T (1998) Consensus development methods, and their use in clinical guideline development. *Health Technol Assess* 2(3): i–iv, 1–88
- Rycroft-Malone J (2001) Formal consensus: the development of a national clinical guideline. *Qual Health Care* 10: 238–44
- Shekelle PG, Schriger DL (1993) Using the Appropriateness Method in Clinical Practice Guideline Development. RAND, Santa Monica, CA
- West E, Newton J (1997) Clinical guidelines. An ambitious national strategy. *Br Med J* 315: 324