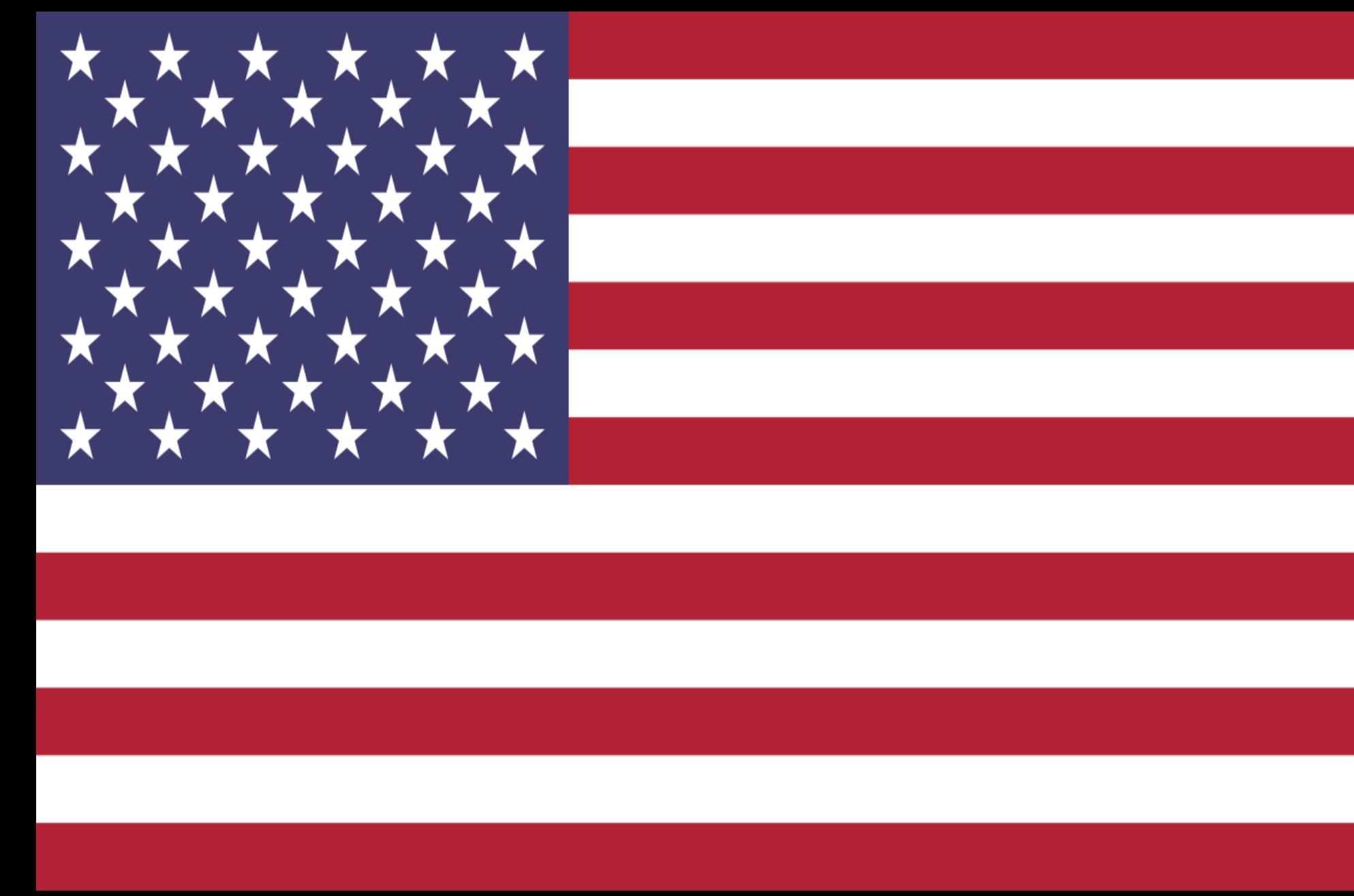


# ILF-COM reporting from American Lymphedema Framework Project University of Missouri Sinclair School of Nursing Columbia, MO, United States of America



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## BACKGROUND

- International Lymphoedema Framework (ILF) recognized challenges with international variation in chronic oedema/lymphoedema outcome measurements.
- Difficulties
  - Lack** of agreed standards
  - Lack** of validated measurement methods
  - Lack** of evidence=low awareness
  - Lack** of consistent assessment methods
  - Lack** of outcome consensus to guide providers
  - Lack** of definition for effective vs. ineffective treatment outcomes
  - Lack** of understanding patient vs. professional perceptions of outcome priorities

- GOAL**  
International outcome measure standard;  
Foundation with robust validation

## METHODS

### Project

- Scoping systematic review assessment methods
- Qualitative interviews with medical device industry stakeholders
- National framework survey developed
- 14 national frameworks enlisted
- Patient and health care professional focus

### Data

- Survey Monkey launched: December 2018-February 2019
- Analysis: March-May 2019
- Final report: May 2019

## REFERENCE

Moffatt, C. & Norregaard, S. (2018). Protocol for undertaking the Chronic Oedema Outcomes survey for National Frameworks on behalf of the ILF. Version 1.4, Nov. 6.

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## RESULTS

- United States responses: N=555
- Workplace reported by professionals:
  - Public: 71% (n=217)
  - Hospital: 47% (n=145)
  - Other: 37% (n=38)
- Treatment outcome measured:
  - Yes: 52% (n=261)
  - Sometimes: 25% (n=127)
  - No: 10% (n=52)
- Outcome measure guidelines in U.S.:
  - Do not know: 61% (n=306)
  - National: 19% (n=97)
  - No: 15% (75)
- Insurance coverage:
  - Some aspects: 75% (n=358)
  - Do not know: 14% (n=65)
  - No funding: 10% (n=48)
- See Figures 1, 2, 3 for further details.

Figure 1.  
Professional Demographics

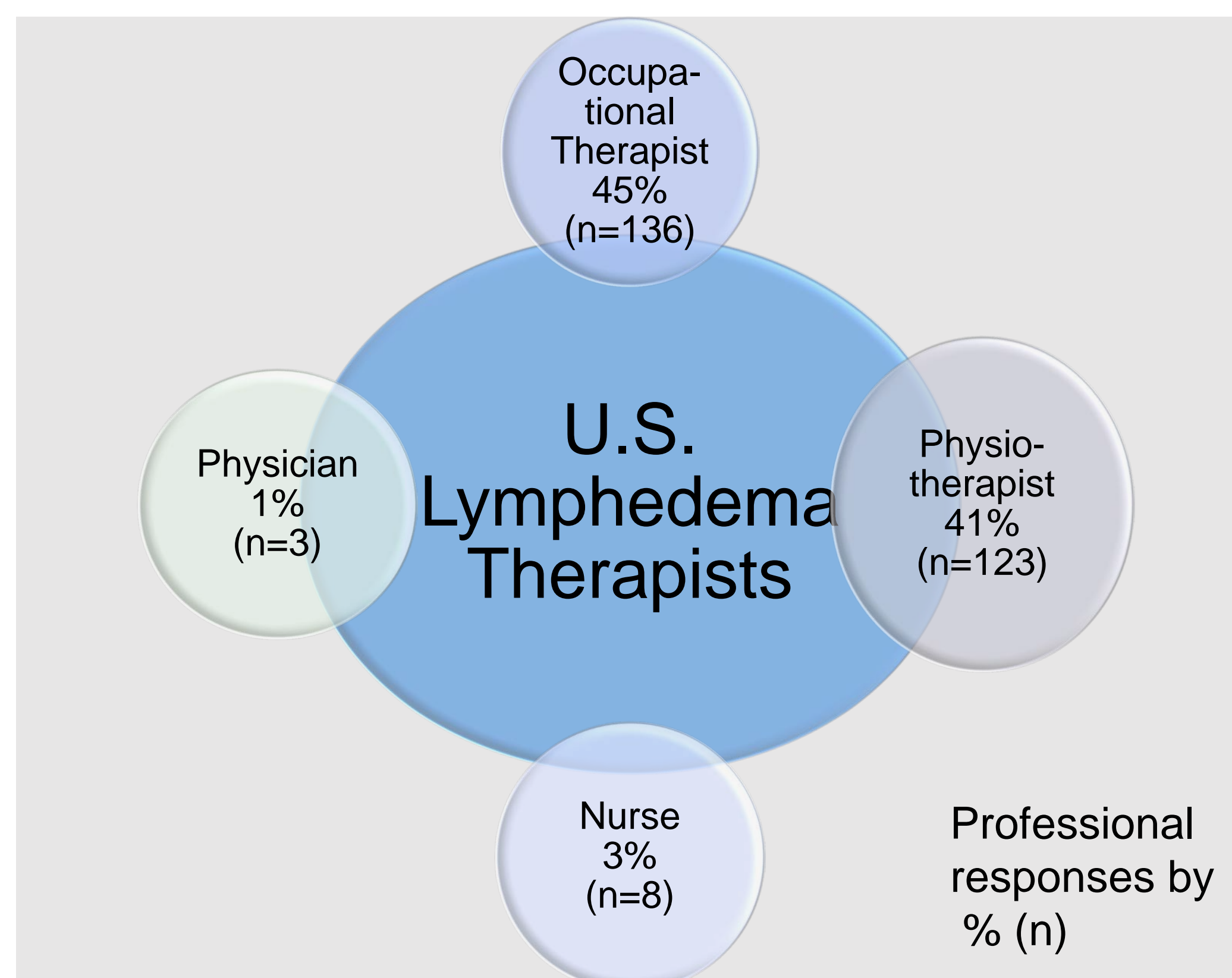
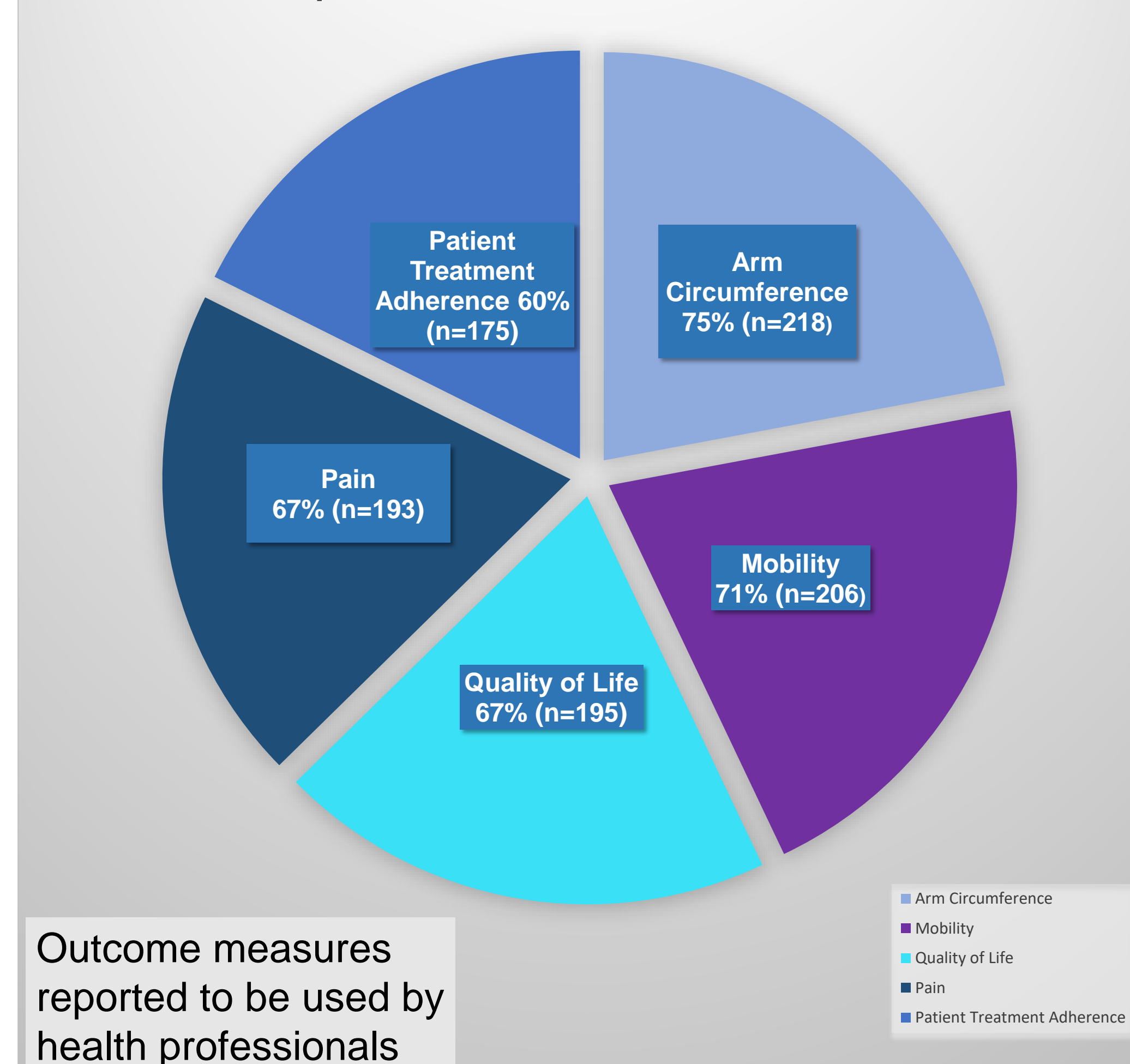


Figure 2.  
Reported Outcome Measures



## DISCUSSION

- ILF board to develop recommendations for oedema/lymphoedema outcome measures
- Identify country similarities and variations
- Responses demonstrate successful international survey strategies

## RECOMMENDATIONS

- Increase awareness national and international standards for oedema/lymphoedema care/outcomes
- Opportunity to improve oedema/lymphoedema care guided by action plan. See Figure 4.

Figure 4.  
Model to Move Forward in Outcomes

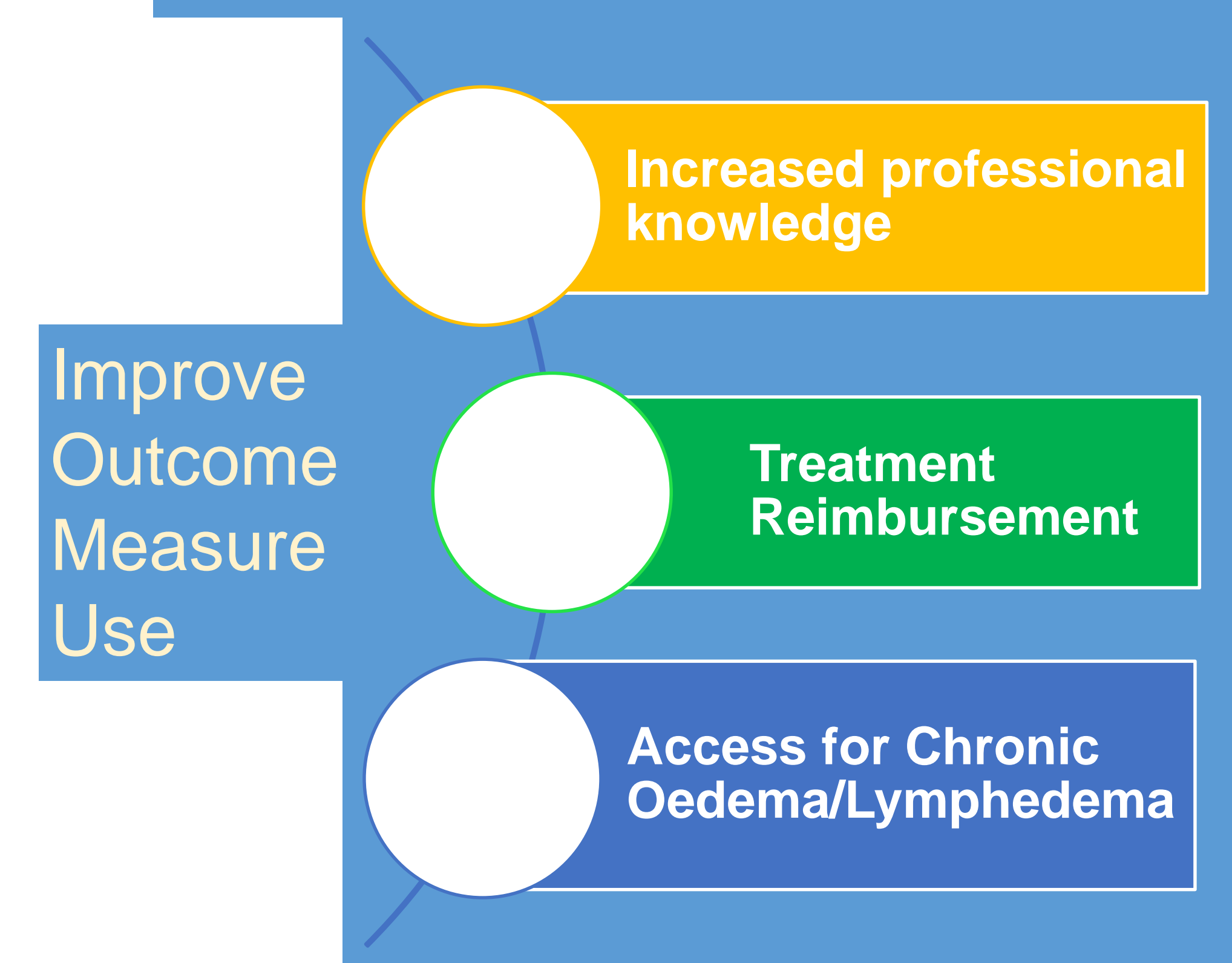


Figure 3.  
Successful Treatment Outcomes

