



Development of a Regional Lymphoedema Service

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Why do we need a Network?

“The human question is not how many can possibly survive.....

but what kind of existence is possible for those who do survive.”

Frank Herbert

Lymphoedema – stages 0, 1, 2 and 3



2004 Report of the Lymphoedema Services Review Group



Background context: Report findings -

1. Ad hoc services across Province
2. Waiting times – up to 2 years
3. Minimal access for non-cancer lymphoedema
4. No clinical guidelines or standards
5. <10 specialist trained clinical and support staff
6. Lack of knowledge(referrer, generalist and specialist)
7. Low referral numbers and poor referral pathways
8. Lack of patient voice
9. No minimum data set or statistics

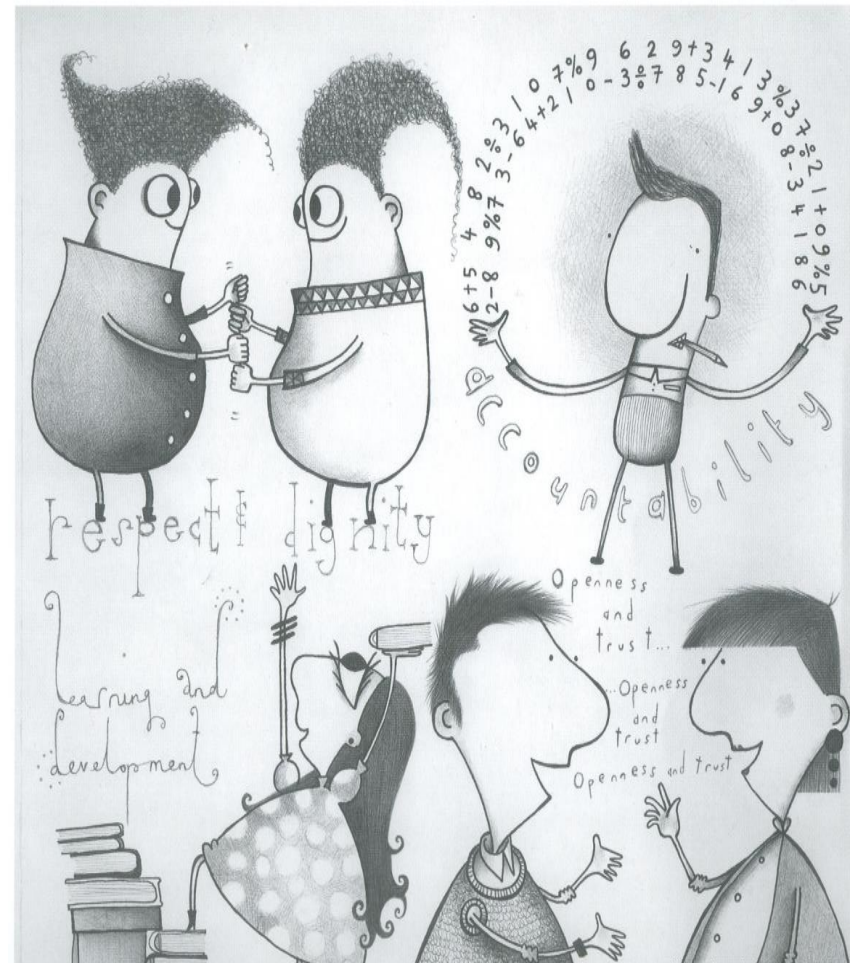
6 Key N.I. Lymphoedema Review recommendations

1. Develop CREST (similar to NICE/ SIGN) Lymphoedema Guidelines to standardise & improve practice
2. Develop lymphoedema services as a *managed clinical network* - Coordination, leadership and governance
3. Specialist lymphoedema practitioners leading Trust Lymphoedema Teams
4. Awareness education for other healthcare professionals
5. Develop an electronic lymphoedema data base for epidemiology & audit

Definition: A network facilitates equitable access and high quality care (provided by a well trained and motivated staff in modern surroundings)

- Department of Health

- The best use of scarce specialist expertise, aiming to standardise care and improve services
- DHSSPS's "20 year vision for Health and Well being in N.I. 2005-2025" - creation of responsive and integrated services which cross boundaries of care



A Network's Strengths:

- Provides clinical leadership, accountability and focus
- Builds on existing services, drawing them together to improve user focus and local responsiveness
- Unconstrained by existing professional and health boundaries or interests of individual institutions i.e. transcends traditional boundaries



Lymphoedema Network Northern Ireland

Initial Objectives

1. 2008 Launch Lymphoedema Network Northern Ireland with a governing Board and robust action plan
2. 2008 Published CREST (GAIN) Lymphoedema Clinical Guidelines
3. 2011 Electronic Minimum Data Set initiated
– robust data collection
(2017 – over 5000 records held)





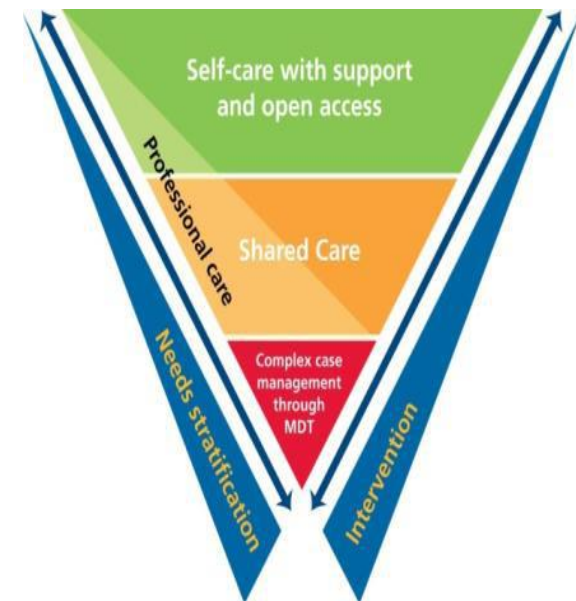
The Network's Vision

To change the emerging picture of the condition, reducing incidence rates and the number of chronic presentations

- Addressing access problems at either end of the condition pathway

- awareness/screening/immediate access
- complex conditions management
- long term condition model
- Survivorship
- the expert patient

- Supported by NHS regional Service Frameworks: cancer and cardio-vascular, TYC, Donaldson and Bengoa

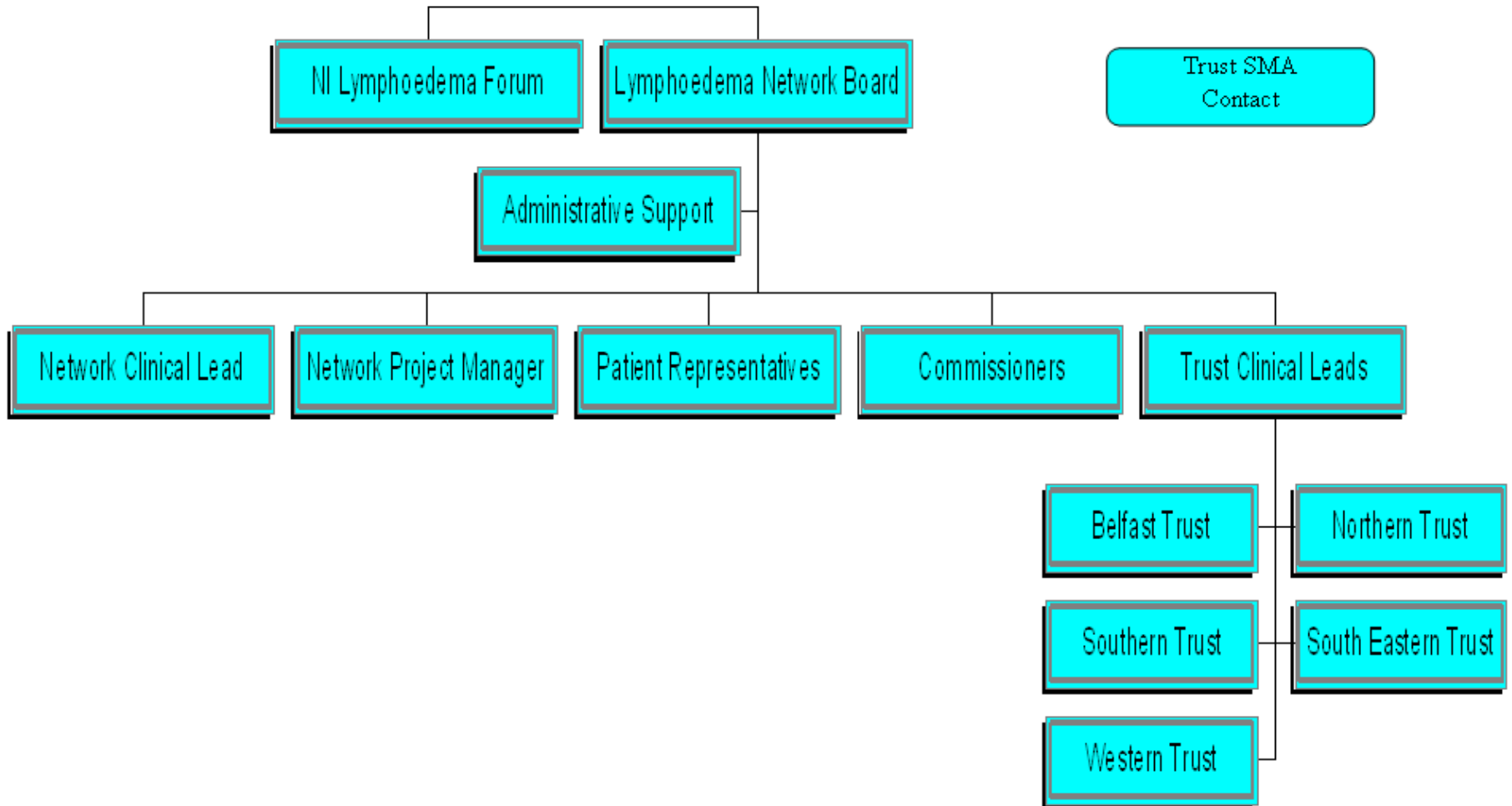


Risk Stratified Model of Care



The Network Structure

Northern Ireland Clinical Lymphoedema Network





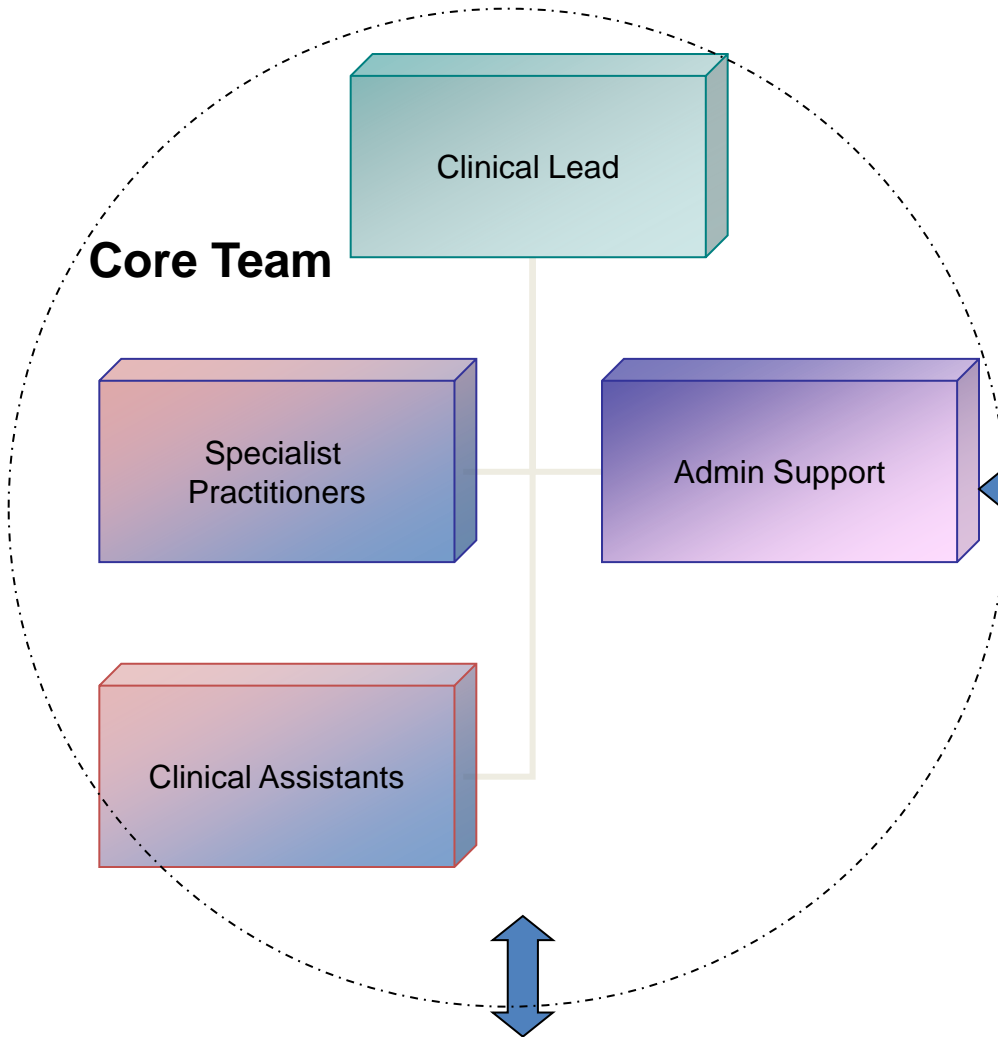
The LNNI Network Board

Role: to guide the network and be responsible for addressing the principles underpinning the network development.

- Members:
 - 5 Patient representatives
 - 5 Trust Lymphoedema Leads
 - Primary care
 - Regional Network Lead
 - Public Health Agency representative (Chair)
 - Department of Health
 - Health and Social Care Board



Support by Wider Trust Lymphoedema Team



- Vascular
- Dermatology
- Genetics
- Palliative Care
- Oncology
- Tissue Viability
- Community Nursing
- Primary Care
- Complementary Therapy
- AHPs
- Clinical Psychology
- Paediatrics

Lymphoedema Network




4th Key Objective: LNNI education strategy

- Accessible, specialist, high quality care
- General health promotion, screening , early diagnosis and self-care/awareness for patients
- Improved referral practice: diagnosis and access into service
- Undergraduate engagement
- The empowerment of “At risk” patient groups – prevention and aid for early self-referral
- Current patients to improve self-management as per long term conditions model

LNNI Education Resources

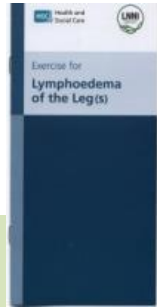
- Website: www.lnni.org
- Posters
- Leaflets

HSC Health and Social Care | Lymphoedema Network Northern Ireland | 4 Key Self-Management Messages




- 1. Wear your garment every day**
Apply first thing in the morning and remove at bedtime. Always compare any new garments with your old ones to make sure they are the same (if ordered as a repeat prescription). If you have any problems or concerns contact your lymphoedema therapist as soon as possible.
- 2. Take good care of your skin**
Wash and moisturise your limb daily using a cream to keep your skin in good condition and to reduce the risk of infection.
- 3. Be active!**
Sitting/standing in one position (particularly with the limb hanging down) will make the swelling worse; just padding the feet, getting up and walking around the room/going up and down one step a few times will improve the movement of fluid.
- 4. Think about your weight**
Reduce or keep your weight within normal limits using a healthy eating plan and regular exercise as this will have positive benefits on your lymphoedema management.

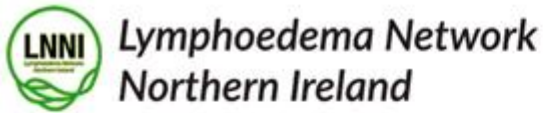
Lymphoedema Network Northern Ireland | www.lnni.org | June 2015



HSC Health and Social Care | LNNI



Advice for patients at risk of developing lymphoedema




Part of the NI Health & Social Care Board

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Lymphoedema



Prevention of Lymphoedema:
 - Avoid injury to limbs
 - Avoid insect bites
 - Avoid skin infections
 - Avoid tight clothing
 - Avoid prolonged standing
 - Avoid strenuous exercise
 - Avoid sunburn
 - Avoid cuts and scratches
 - Avoid burns and scalds
 - Avoid heavy lifting
 - Avoid repetitive strain

Recommended Treatment:
 - Compression therapy (stockings, bandages)
 - Exercise
 - Skin care
 - Weight management
 - Lymphatic drainage (manual or mechanical)
 - Surgery (in some cases)



What is lymphoedema?

Lymphoedema is a chronic (long-term) condition that causes swelling in the body's tissues. It can affect any part of the body, but

Teamwork is essential to help in achieving long-term management of lymphoedema



Teamwork is essential to help in achieving long-term management of lymphoedema

Management of lymphoedema involves a multi-disciplinary team approach. The team may include:

- General Practitioner (GP)
- Physiotherapist
- Lymphoedema Therapist
- Podiatrist
- Wound Care Specialist
- Psychologist
- Occupational Therapist
- Speech and Language Therapist
- Community Nurse
- Healthcare Assistant
- Pharmacist
- Physiotherapist
- Podiatrist
- Wound Care Specialist
- Psychologist
- Occupational Therapist
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- Community Nurse
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- Pharmacist



Complex Condition Management

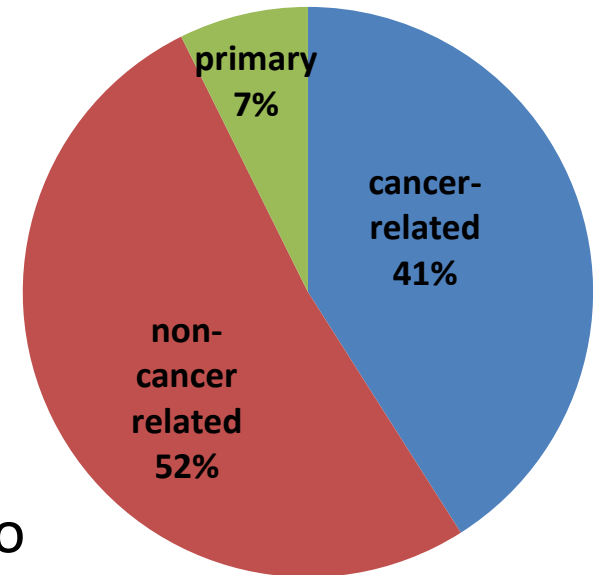
- 2008 Plan for consultant (palliative care, dermatology and vascular) led complex lymphoedema clinics
 - 4 per year (funded by LNNI)
 - > up-skilling of trust lymphoedema leads
- Gradual move to 1 clinic every 2 years which also includes consideration for specialist lymphoedema liposuction surgery (vascular surgical representation)



Impact Against Initial Deficits

1. Ad hoc services modernised into a coordinated, influential and effective network with robust governance arrangements to monitor service
2. 2 year waiting times reduced to meet regional AHP access targets: 13 weeks for routine, 1 for urgent
3. Inequity of cancer-related lymphoedema versus non-cancer lymphoedema access resolved
4. Lack of patient voice dramatically altered to be integral at all levels (Board and trust) via direct engagement

2017 Caseload Division





Impact Against Initial Deficits

5. Satisfaction questionnaires demonstrated:
 - 80% of patients rated their treatment as very good
 - 17.6% as good
 - 2.4% as satisfactory
7. Quality of Intervention:
 - 95% offered optimal, tailored treatment
 - 5% treatment modified due to lack of resources
8. Increased referral rates:
 - 2010: 869 new patients;
 - 2017: 1624 new patients (extrapolated based on 10 months)



Resilience required...LNNI timeline:

- 1995 Campaign started – “lack of regional services”
- 2002 MSc Project->influencing CMO
- 2002 DHSSPSNI agreement for regional review
- 2004 Publication of review and recommendations
- 2006 funding and implementation group agreed
- 2008 Regional Guidelines and Network launched
- 2010 BMJ patient information award
- 2011 Health Minister commendation visit
- 2012 Runners up in UK Advancing Healthcare Awards and BJN Awards!
- 2016 Winners at the British Lymphology Society national awards 😊!



Transforming Your Lymphoedema Care

KEY: Lymphoedema is a long term condition requiring partnership between patient and therapist

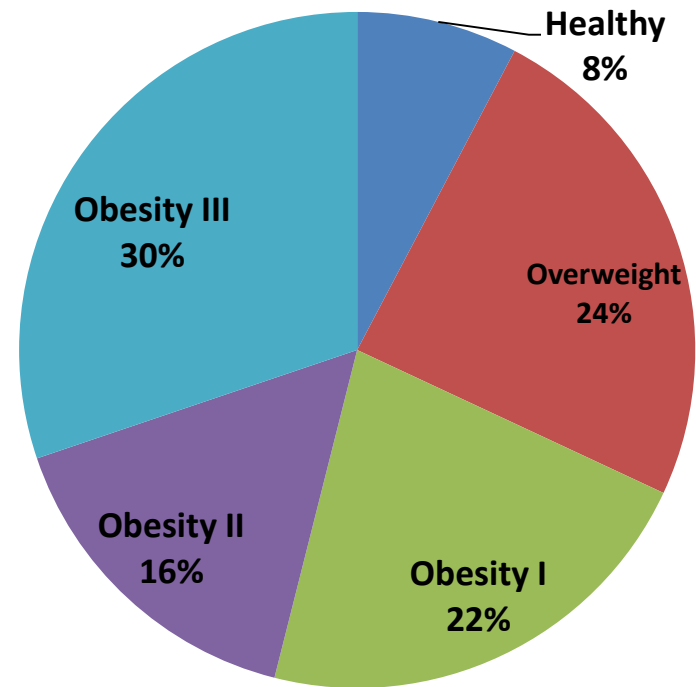
- Focus on increasing self-management, competence, confidence and independence
 - Choice of “Opt-in” review for patients including telephone reviews -> Discharge to care of GP with fast access back into system if required
 - Emphasis on core health skills – activity and diet
 - New pilots: “Healthy Legs” and aqua therapy
- > Impact on Review attendances:
- 2013 – 4517 review patients
 - 2015 – 2901 review patients



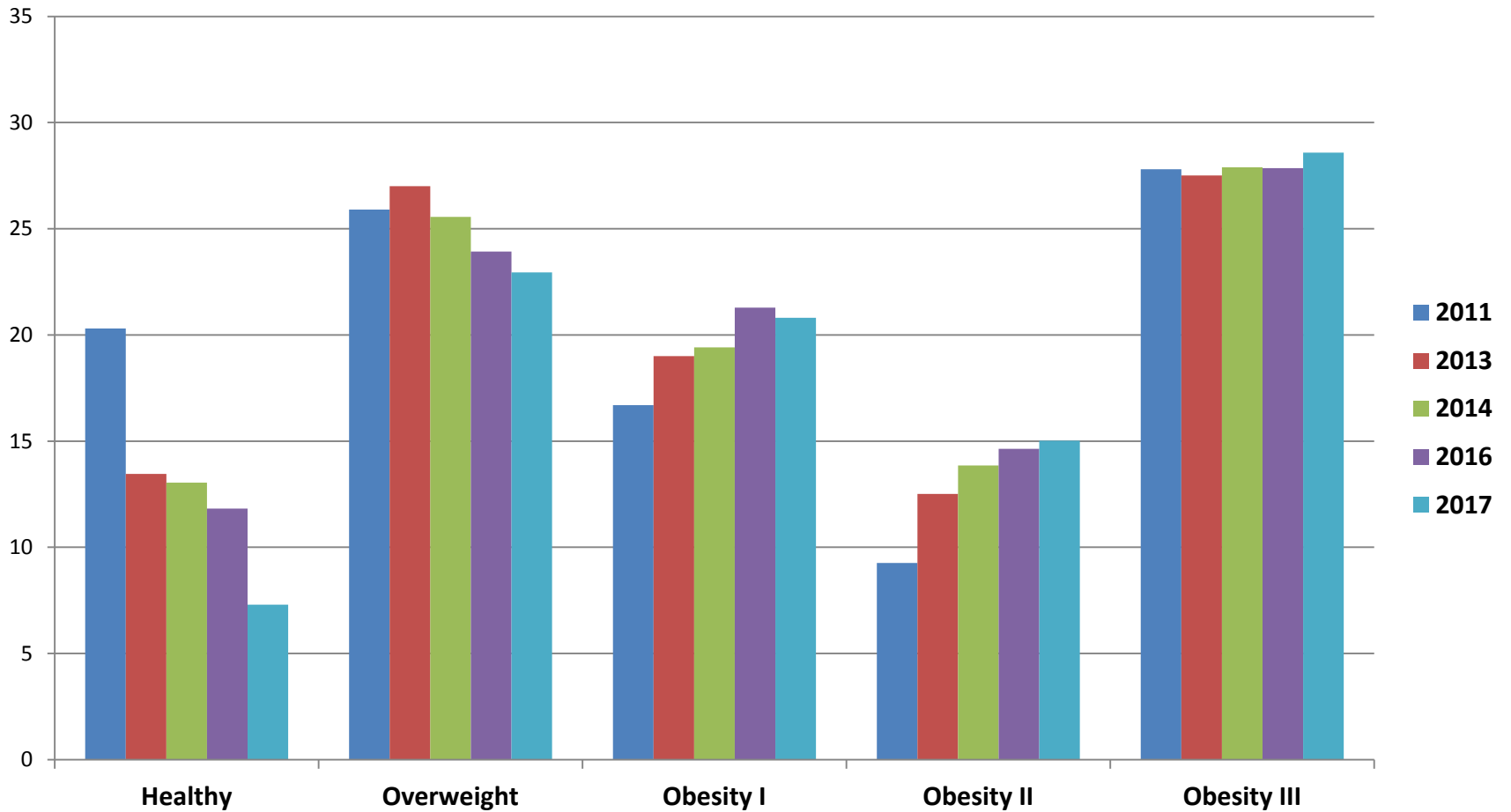
Further Need for Change....

- CREST Guidelines estimated prevalence to be 1.33 per 1000 population
- 2017 LNNI referral statistics show this to now be 4.83 per 1000 population
- Increasing obesity related lymphoedema
- Increasing chronic oedema and lipoedema referrals
- 3.2% annual increase in cancer survival rates

2017 LNNI BMI % Levels n=2537



Variation in BMI levels 2013-2017





2017 Referral Criteria

Lymphoedema and swelling (*associated with misshapen limbs*) and linked to the following predisposing risk factors:

- Trauma and tissue damage e.g. lymph node dissection, radiotherapy, vein surgery
- Malignant disease
- Venous disease e.g. recurrent ulceration, post DVT
- Infection e.g. recurrent cellulitis
- Inflammation e.g. RA, psoriatic arthritis
- Dependency e.g. obesity, immobility
- Primary e.g. hereditary, congenital syndromes



The Future

- Increasing number of babies diagnosed with lymphoedema -> management of the baby, child and adolescent (and carer implications)
- Associated conditions referrals e.g. chronic oedema and lipoedema
- Non-medical prescribing
- New technologies to support core services e.g. liposuction and negative pressure devices
- Impact of obesity -> public health issue for patients, and HCPs re safe handling i.e. skill mix review required
- Continued increasing prevalence and complexity beyond 2008 estimate -> constant modernisation required