

Initial Results from the LIMPRINT study

All Ireland Conference

November 15th 2017

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ILF Chair

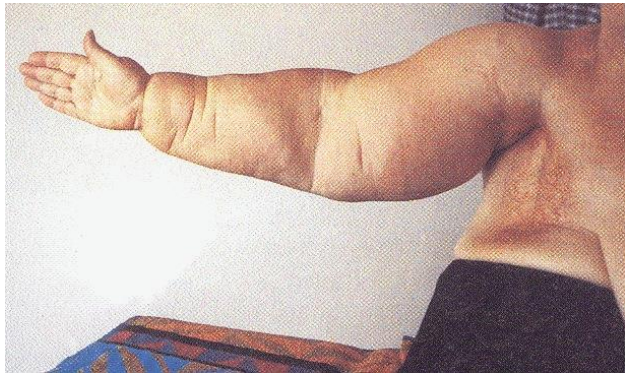


Outline of presentation :

- The development of the LIMPRINT methodology
- Initial analysis of data from
 - The current combined dataset
 - Community nursing services in the UK
 - Acute hospital prevalence studies in Europe, Scandinavia and Australia
 - Specialist chronic oedema services

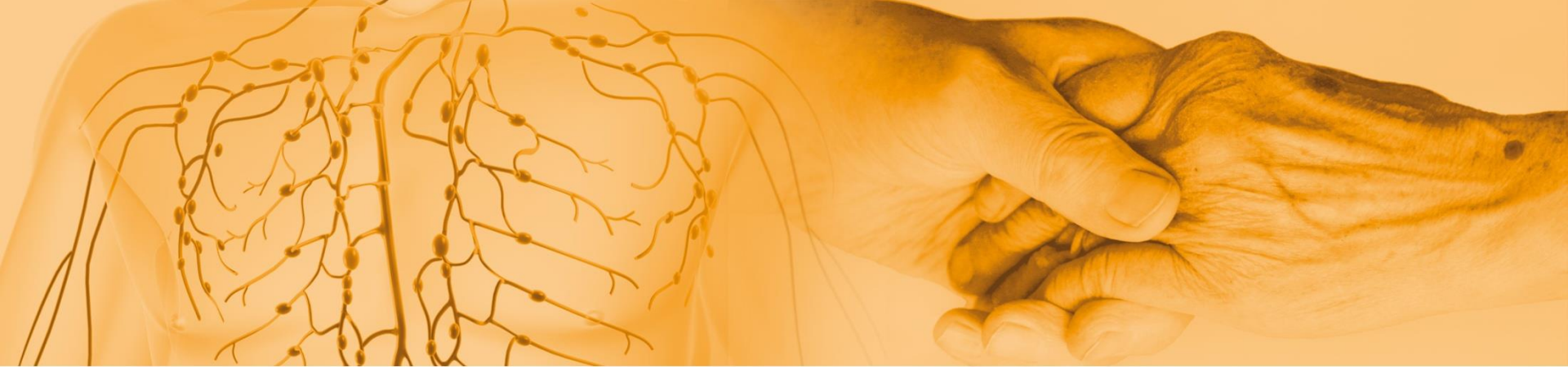


The Humanitarian Story of LIMPRINT



Lack of international data

- Lack of information to establish the size and impact of chronic oedema on health services
- Different methodologies used
- Focus on specific patient groups rather than all patients with chronic oedema
- Opportunity for international collaboration
- Urgent need to show the public health burden



INTERNATIONAL
LYMPHOEDEMA
FRAMEWORK

LIMPRINT STUDY (2014-2017)

- Lymphoedema Impact and Prevalence – International Lymphoedema Framework

Belong  Together



Primary Aim

To develop and validate an international prevalence methodology with an electronic system to assess the number of patients with chronic oedema and wounds its impact on individuals and health services



Secondary Aims

- To define the prevalence of chronic oedema in different health care settings
- To describe the profile of patients within specialist chronic oedema services
- To identify the quality of life impact on patients
- To identify the risk factor profile

LIMPRINT : Strategic Plan

- International requirement for epidemiology
- International partnership with key academic/clinical partners
- Development of research methods and data collection tools (ecrf)
- Validation of methods (inter-rater reliability studies)
- **Undertaken in Japan through validation of pitting test**
- Development of quality mechanisms
- Implementation of studies in each country
- Analysis and publication programme
- **Policy strategy for each country**




Definition of chronic oedema

- Chronic oedema present for > 3 months affecting any site of the body irrespective of the underlying aetiology or concurrent co-morbidities
- (Moffatt et al 2003 QJM)



The Core Tool

 Core Tool		Page 1			
Date: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>		Site Number <input type="text"/> <input type="text"/>			
Day Month Year		Patient Number <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>			
Facility Number <input type="text"/> <input type="text"/> <input type="text"/>					
Type of Facility (check one)					
<input type="checkbox"/> General practitioner	<input type="checkbox"/> Nursing home				
<input type="checkbox"/> Community nursing / Home care service	<input type="checkbox"/> Elderly care residential home				
<input type="checkbox"/> Acute hospital (check type of patient)	<input type="checkbox"/> Specialist Lymphoedema service				
<input type="checkbox"/> In-patient <input type="checkbox"/> Out-patient	<input type="checkbox"/> Other (specify) _____				
Demographics					
Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female	Age: <input type="text"/> <input type="text"/> <input type="text"/>				
Level of Obesity (check one)					
<input type="checkbox"/> Under weight	<input type="checkbox"/> Normal weight	<input type="checkbox"/> Obese <input type="checkbox"/> Morbidly obese			
Mobility					
Lower body (check one)	Upper body (check one)				
<input type="checkbox"/> Bed bound	<input type="checkbox"/> Full range of movement				
<input type="checkbox"/> Chair bound	<input type="checkbox"/> Limited range of movement				
<input type="checkbox"/> Walks with aid	<input type="checkbox"/> No function				
<input type="checkbox"/> Walks unaided					
Relevant Co-morbidities (check all that apply)					
<input type="checkbox"/> Diabetes Mellitus	<input type="checkbox"/> Heart failure / Ischaemic heart disease				
<input type="checkbox"/> Neurological disorder	<input type="checkbox"/> Peripheral arterial disease				
Classification of Lymphoedema (check one)					
<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary				
If Secondary, swelling due to: <input type="checkbox"/> Cancer <input type="checkbox"/> Non Cancer					
(check one and fill out appropriate section below)					
If Cancer: (check all that apply)		If Non Cancer: (check all that apply)			
<input type="checkbox"/> Treatment related	<input type="checkbox"/> Venous	<input type="checkbox"/> Immobility	<input type="checkbox"/> Obesity	<input type="checkbox"/> Lymphatic Filariasis	
<input type="checkbox"/> Metastatic lymphatic obstruction	<input type="checkbox"/> Other (specify) _____				
Lymphoedema History (check one)					
Estimate the duration of the lymphoedema:					
<input type="checkbox"/> <6 months	<input type="checkbox"/> 6 months – 1 year	<input type="checkbox"/> 1-2 years	<input type="checkbox"/> 2-5 years	<input type="checkbox"/> 5-10 years	<input type="checkbox"/> >10 years
Cellulitis					
Has the patient ever had cellulitis? <input type="checkbox"/> Yes <input type="checkbox"/> No					
In the past year, has the patient had an acute infection in the affected areas due to the swelling?					
<input type="checkbox"/> Yes	<input type="checkbox"/> No	If yes, How many times: <input type="text"/> <input type="text"/>			
In the past year, has the patient been admitted to hospital as a result of this infection?					
<input type="checkbox"/> Yes	<input type="checkbox"/> No	If yes, How many times: <input type="text"/> <input type="text"/>			
Rev. 2013-11-08					



Undertaking the clinical assessment

- Procedure undertaken using an agreed format and procedure (including the pitting test)
- Chronic oedema (CO) assessed and recorded using a body map
- Classification of type of chronic oedema completed by specialist lymphologist assigned to the team
 - Staging of chronic oedema (ISL staging) and circumference measurements completed
- Types of wounds and treatments recorded
- Mobility status and co-morbidities clarified with staff and medical notes





Data collection – Module tools

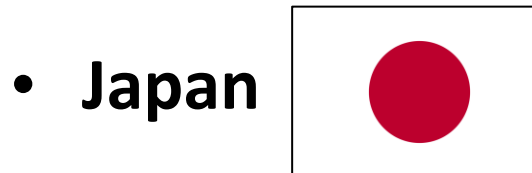
- **Module tools:**
- These tools assess the impact on the patient. There are five module tools:
 - ❑ Demographics and disability (including WHODAS short form)
 - ❑ Quality of life (EQ5D. LYMQOL)
 - ❑ Details of swelling (Limb volume and ISL staging)
 - ❑ Wounds (types of wound , site and treatment)
 - ❑ Cancer (types of cancer and treatments)



Quality management procedures

- International Steering Group (including statisticians/ health economists/ patients and a data management group)
- Project manager for all studies
- Centralised project management systems
- Quality mechanisms for data collection in all settings
- International Protocol for use in all countries
- Robust electronic data system to prevent errors in data entry

Participation: N= 14,000 +

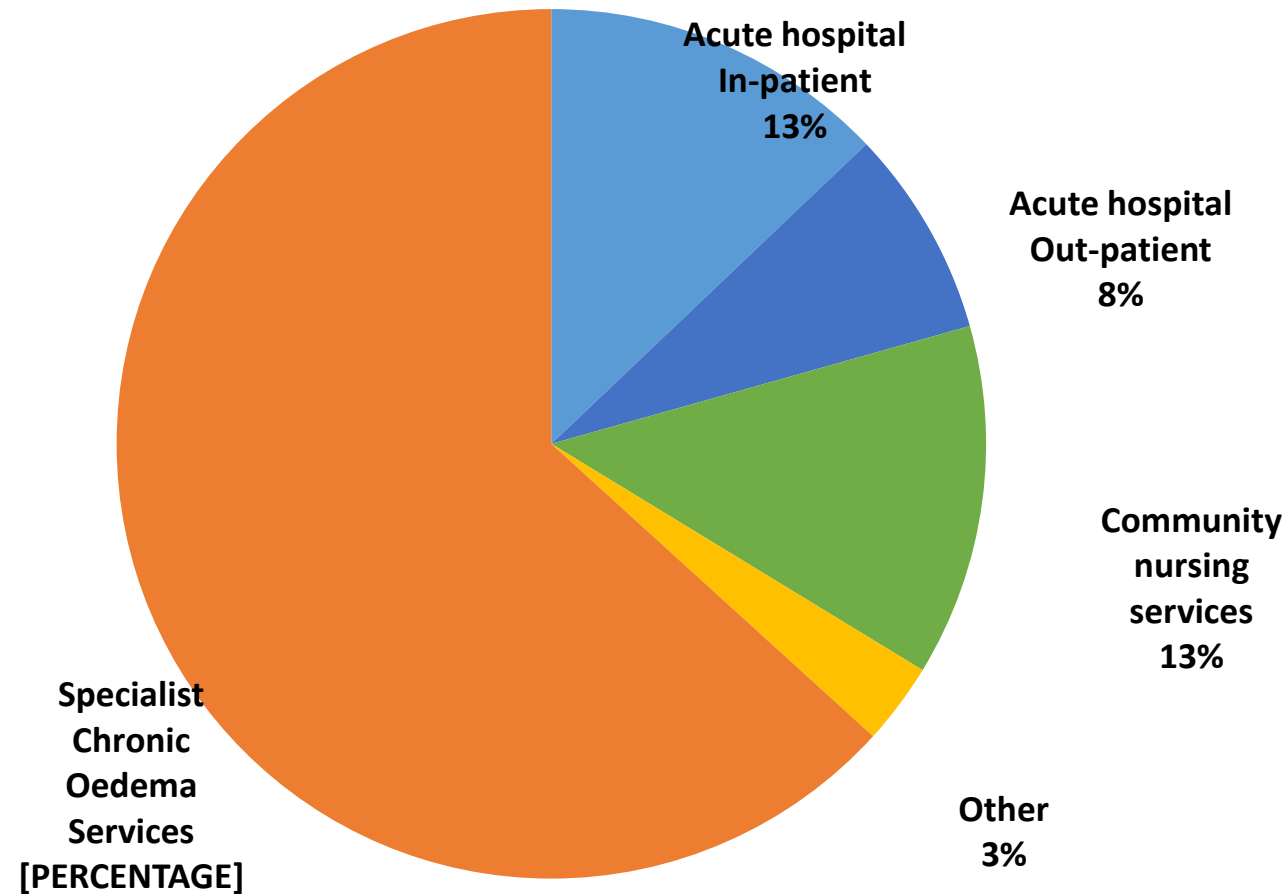


40 sites

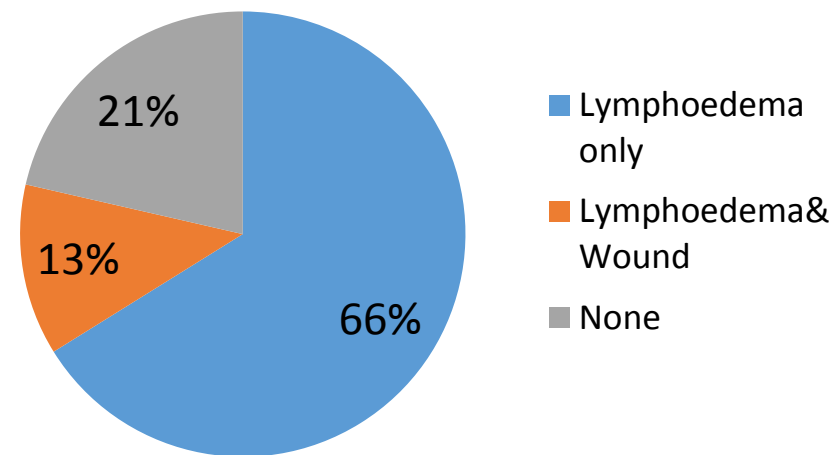
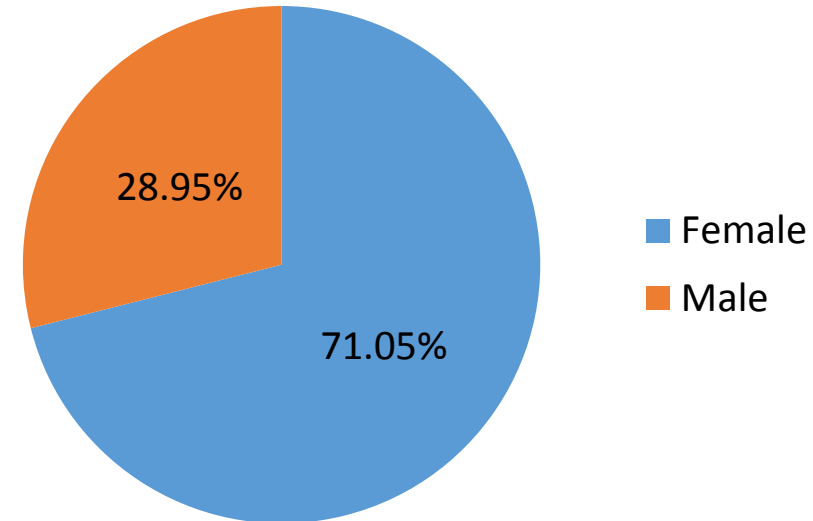
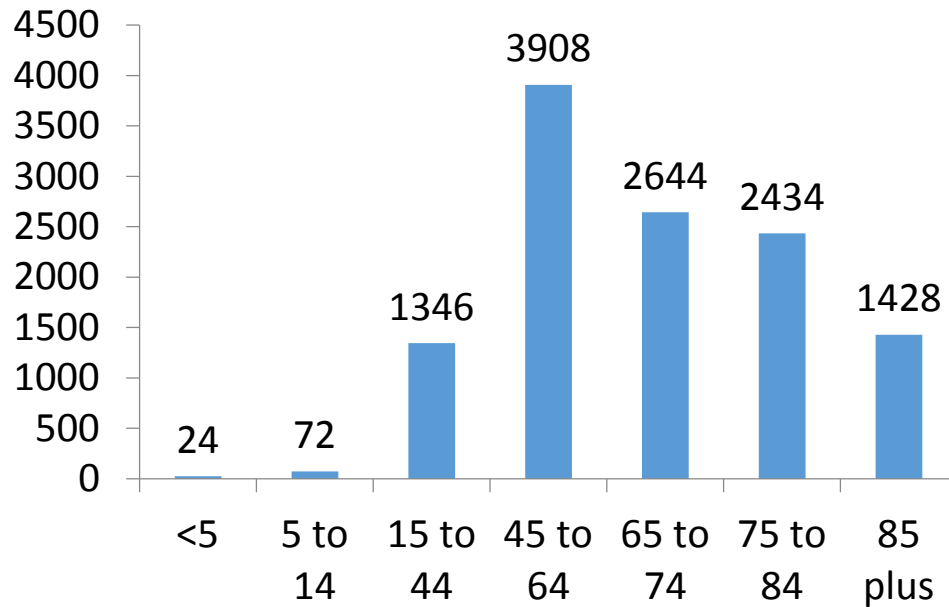
Highlights of Initial Analysis

Current Study Population (N=13, 909)

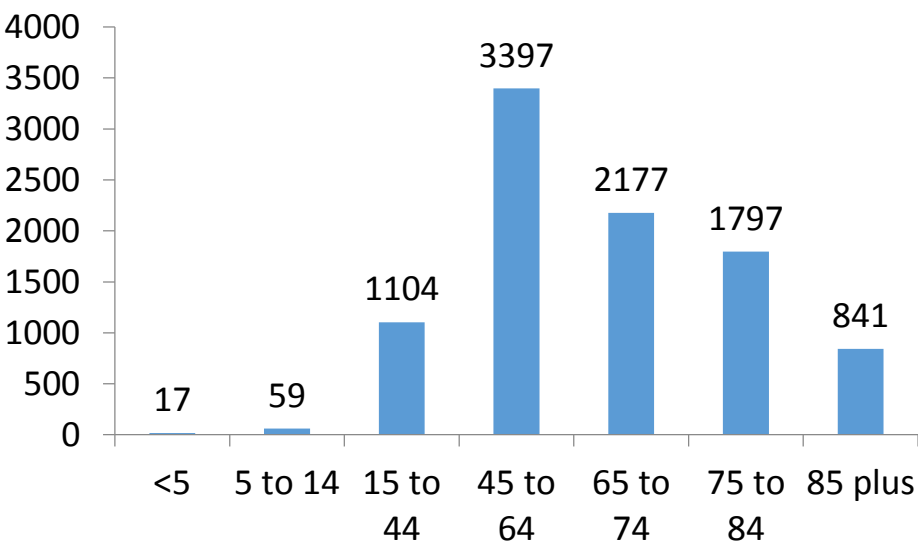
Country	N
Australia	222
Canada	44
Denmark	900
Ireland	152
Italy	1622
Japan	1000 +
France	1,311
Turkey	951
UK	7,707



• Initial analysis **(n=11,856)**



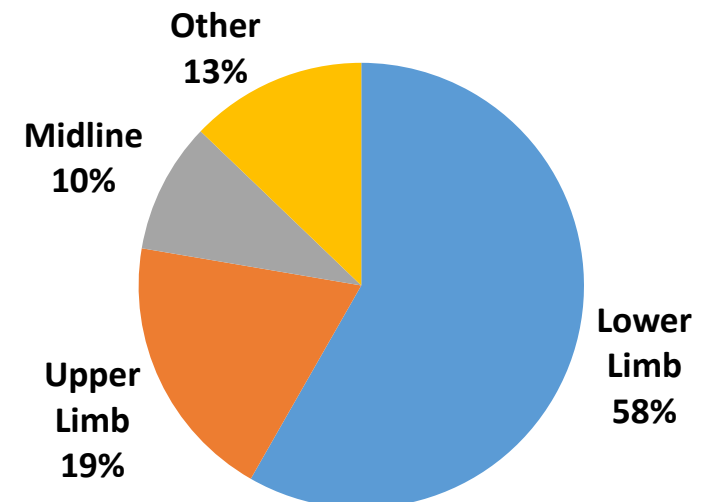
• Patients with Chronic Oedema (n= 9,391)



Co - morbidities	N	%
Diabetes Mellitus	1539	16%
Heart Failure / Ischaemic heart disease	1288	14%
Neurological disorder	703	8%
Peripheral arterial disease	286	3%
None of these	6347	68%

• Patients with Chronic Oedema (n=9,391)

	N	%
Primary lymphoedema	1413	15%
Secondary lymphoedema	7904	84%
Undefined	74	1%
Lymphoedema only	7842	84%
Lymphoedema & Wound	1475	16%
Morbidly obese	1609	18%
Obese	3124	34%
Normal weight	4166	46%
Under weight	189	2%
Cellulitis	3219	34%
Infection	1330	14%



Determinants of HRQoL (EQ5D)

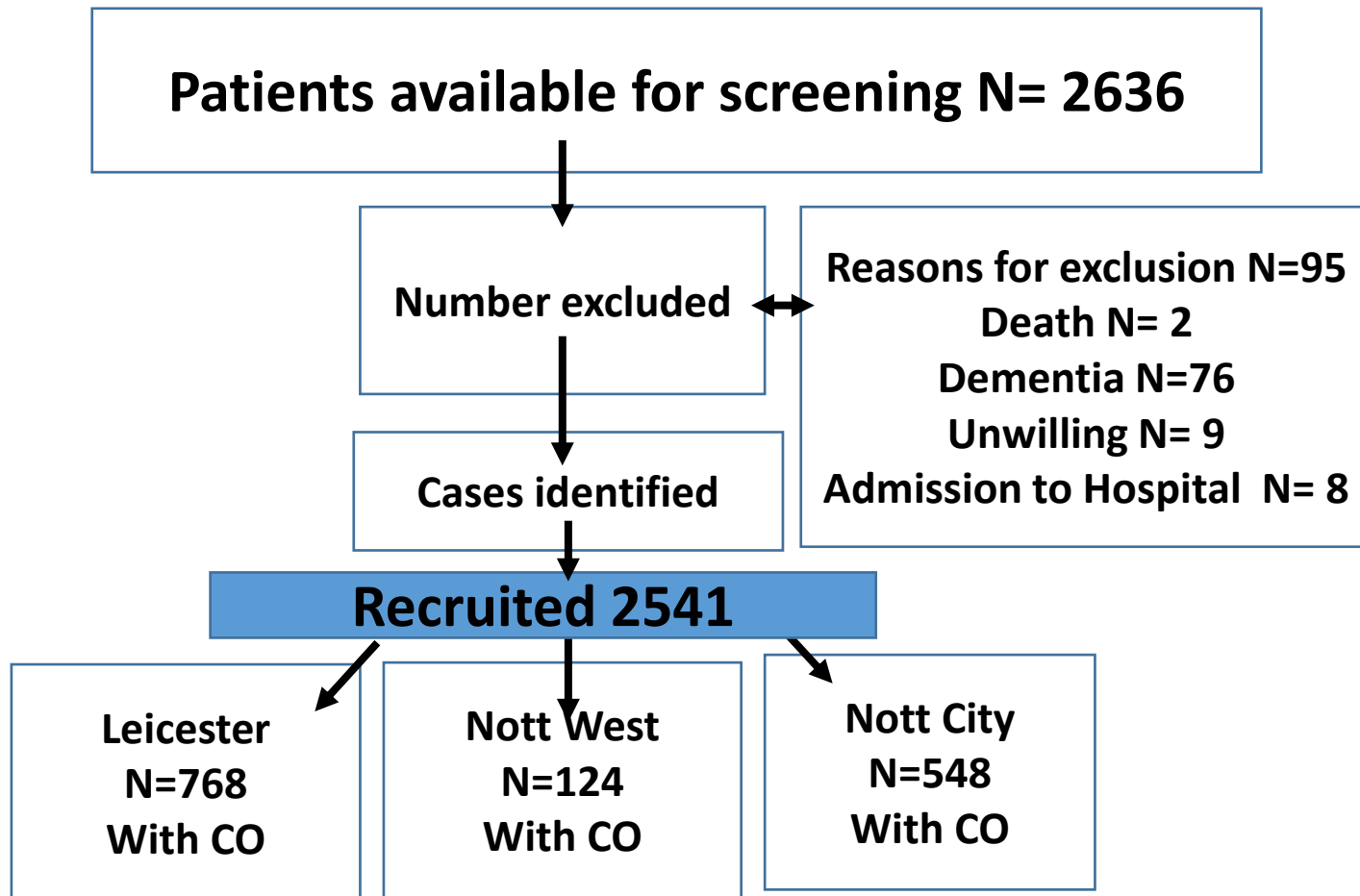
	n	Mean	SD	p
Female	761	63,6	20,0	0.001
Male	133	56,5	22,1	
Lymphoedema only	818	63,3	20,1	<.001
Lymphoedema & wound	76	53,9	23,0	
Morbidly obese	60	52,7	20,2	<.001
Obese	280	61,2	20,1	
Normal weight	528	64,6	20,2	
Under weight	25	56,3	22,1	
No cellulitis	672	63,9	20,3	<.001
Cellulitis	222	58,2	20,4	

UK Community Nursing Prevalence Studies

Methodology

- **Aim** to identify the prevalence of chronic oedema and wounds and to define the risk factors for patients treated within community nursing services in three cities in the UK
 - Leicester city community nursing service
 - Nottingham West community nursing service
 - Nottingham City community nursing services

Patient screening and inclusion



Community Nursing Prevalence and Risk Factors

	N	%
Nott City	548	51.6 %
Nott West	124	68.5 %
Leicester City	768	59.2 %

- **Clinical service ($p=0.024$)**
- **Age ($p<0.001$)**
- **Ethnicity ($p<0.001$)**
- **Obesity ($p<0.001$)**
- **Heart failure/ CHD ($p<0.001$)**
- **Wound ($p<0.001$)**

70% have a concurrent wound

Conclusion for Community Nursing

- Over 50% of patients have chronic oedema in community nursing services in the UK
- Complex heterogeneous population affected
- First robust prospective evaluation in nursing
- Concurrent leg ulceration is common (OR 4.3)
- Cellulitis is an underestimated problem
- Many patients have not received a diagnosis or treatment

Acute Hospital Prevalence Studies

Point prevalence

Facility code	Facility label	Chronic oedema patients	Database patients	Database Prevalence	Number of beds	Crude Prevalence
19	Montpellier 2	215	726	29,6%	1150	18,7%
30	Canberra AU	31	113	27,4%	113	27,4%
41	Ireland 2	8	76	10,5%	76	10,5%
15	QMC - UK	155	324	47,8%	634	24,4%
14	City hospital - UK	140	245	57,1%	490	28,6%
11	DK - Bispebjerg H	134	134	-	326	41,1%
12	DK - Frederiksberg H	43	43	-	126	34,1%
	Total	726	1661	43,7%	2915	24,9%

Conclusions of acute hospital prevalence in western populations

- A total of 1661 patients were included
- Chronic oedema is frequent in acute hospitals in western populations
- Predominantly affects the lower limbs
- Strongly associated with wounds
- Obesity and cellulitis are common

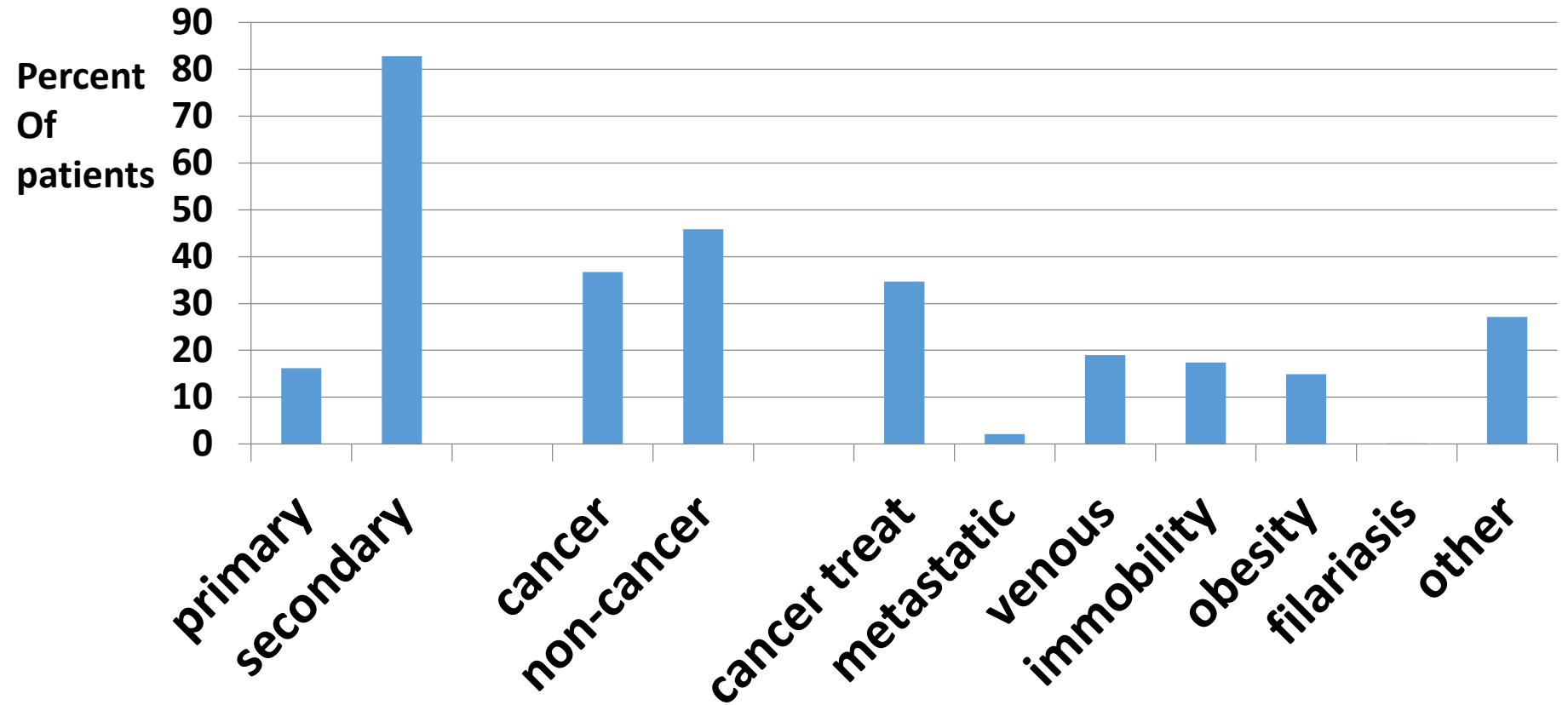
International profile of specialist services

Patients available N=7500

UK	5660
France	585
Italy	770
Turkey	476
Denmark	9

Patients in Specialist Services: Total group (N=7500)

Causes of Chronic Oedema



Early messages from LIMPRINT (1)

- Over 25% of acute hospitalized patients suffer with chronic oedema in western populations compared to a low prevalence in Japan.
- Primary lymphedema affects 15% of patients in general health care settings and specialist services
- Cancer related chronic oedema affects only 35% of patients with secondary chronic oedema

Early messages from LIMPRINT (2)

- Early risk factors associated with reduced quality of life :
being male; concurrent cellulitis; presence of a wound;
morbid obesity
- High prevalence > 51% in community nursing patients in the
UK (never defined before)
- Concurrent wounds present in 70% of community nursing
patients
- Cellulitis occurs in 34% of total chronic oedema population

Rotterdam, The Netherlands, 6-9 June 2018

8TH INTERNATIONAL LYMPHOEDEMA FRAMEWORK CONFERENCE



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on board!

NLNet
Netherlands Lymphoedema
Network

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PROGRAMME TOPICS:

- Lymphology
- Oncology
- Lipoedema
- REHAB
- Self-management
- Positive health
- Pediatric and primary lymphoedema
- Chronic care
- Outcome measures
- National guidelines

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Congratulations to Ireland for their enormous contribution to LIMPRINT and the work of ILF

Greetings from:

*International Lymphoedema
Framework (ILF)*