

Macmillan Greater Manchester Lymphoedema Programme

Gap Analysis Report

Revision History

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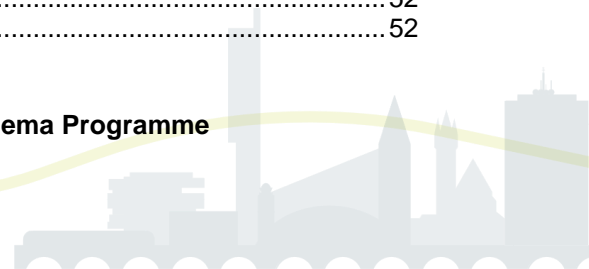
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1. Executive Summary

The Greater Manchester Cancer Macmillan GM Lymphoedema Programme objective is to undertake a detailed review of lymphoedema care for adults in Greater Manchester. The review will highlight areas of good practice, champion the benefits of optimal care for patients with lymphoedema, evidence the need for lymphoedema provision, and via the undertaking of a detailed gap analysis (as set out in detail this report) outline current provision and challenges faced in GM.

The aim is to use the information gathered by the project team to identify innovative, cost effective and sustainable solutions – at a GM and / or Locality level - to address the challenges identified and ultimately reduce variation in the outcomes for people at risk of / affected by lymphoedema. The project will aim to deliver improvements in risk reduction, provision & ongoing management and Learning & development as outlined in the graphic below.

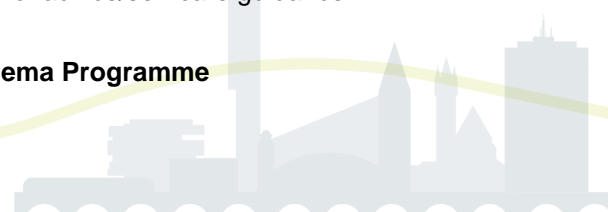
Risk Reduction	All relevant professionals provide risk reduction guidance: prevention & infection, weight management and exercise
	All patients suspected of lymphoedema are referred to a lymphoedema practitioner for diagnosis and appropriate treatment
	All people that are aware that they could develop lymphoedema reduce their risk through self-care (weight management, risk and infection and exercise)
Provision & Ongoing management	Greater Manchester standards for Lymphoedema treatment and care with agreed outcome measures
	A skill mix workforce for localities to provide appropriate treatment and support self-management for effective management of the condition.
	All lymphoedema patients are empowered to self-manage or are supported through self-management
	Greater Manchester standards for reporting lymphoedema treatment and auditable patient notes.
	Collaborative working between professionals for a person-centred approach to improve patient outcomes
	Greater Manchester to have a hosiery formulary for effective prescribing
Learning & Development	Streamline recording of incidence and prevalence within primary care data systems
	All relevant professionals know the signs & symptoms, self-care guidance and how to refer to a lymphoedema practitioner
	All people that are aware they could develop lymphoedema are educated in lymphoedema & self-care to reduce their risk.
	People affected by lymphoedema are educated and have access to information to self care to improve their quality of life.
	All relevant professionals have the national guidance competency levels for lymphoedema treatment and/or supported self-management

A gap analysis has been undertaken to understand the provision of lymphoedema within GM during 2019, utilising the 2015 Strategic Health Needs Assessment for lymphoedema as a baseline. The gap analysis will also utilise national guidance and how that compares to the current provision within GM.

Below is a summary of the key points identified via the gap analysis against the 3 focus areas of the project.

Prevention and Risk Reduction

- There is evidence that Cancer Clinical Nurse specialists in GM have good knowledge of the risk and signs & symptoms of lymphoedema. Breast Cancer CNSs are the most confident in providing guidance to patients on self-care to reduce the risk of developing the condition.
- There is evidence to suggest that people at risk of lymphoedema aren't always aware that they are at risk, and therefore not aware of the measures they could put in place to reduce the risk and ultimate severity of the condition.
- The programme has not evidenced a standardised pathway for people who have developed lymphoedema.
- There is reported variation in wider healthcare professionals' knowledge of lymphoedema risk factors, and therefore subsequent variation in the provision of advice/self-care guidance.



- There is reported variation in general practitioners' knowledge of lymphoedema risk factors, and variation in the provision of advice/self-care guidance
- There is scope for improvement in engagement, education and collaborative working between lymphoedema specialist practitioners and other health and social care professionals to support people at risk of lymphoedema e.g. cancer pathways, vascular, weight management, cellulitis, primary care, pharmacists and services reaching the older population.

Provision

Data

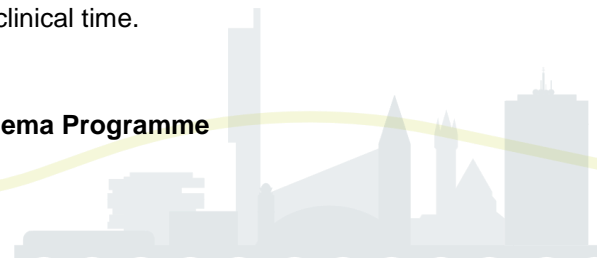
- Data on lymphoedema prevalence is variable depending on reports and studies. Based on prevalence within the National Lymphoedema Partnership (NLP) Commissioning Guidance for Lymphoedema Service for Adults in the United Kingdom – March 2019nUGreater Manchester prevalence is estimated to be around 11,000 – 18,000.
- Lymphoedema Network Wales was set up in April 2011 to implement the strategy for lymphoedema in Wales. This investment was to enable all lymphoedema patients access to the appropriate services at the right place, right time and with the right person regardless of whether their lymphoedema is related to cancer or not. From this investment they have demonstrated increase in prevalence from 2.4 to 6.4 per 1,000 population.
- There is variation in how lymphoedema practitioners record patient activity data and details of lymphoedema on their clinical management systems. It has not been possible within the gap analysis to fully understand the each's services capacity and demand.
- There is reported variation in how lymphoedema is recorded within Primary Care data systems. Not all GPs are aware of the READ codes/SNOWMED codes associated with lymphoedema.
- Inconsistent data completeness (primary care, acute and community services) makes it difficult to provide an accurate cost benefit analysis of additional investment in lymphoedema provision.

Service Models in Localities (commissioning and provision)

- There are many examples that people affected by lymphoedema, who have accessed lymphoedema services, stating their appreciation for the lymphoedema practitioners who provide high quality treatment and care.
- There is variation in how people are referred to a lymphoedema service and definite scope for improvement in the information available regarding current service provision and how this should be accessed for diagnosis and treatment/management.
- There is inequity across Greater Manchester for primary and secondary lymphoedema based on the services commissioned and their referral criteria.
- The commissioning of lymphoedema services in Greater Manchester is varied and complex. There are some services that have been developed by the provider rather than being formally commissioned.
- Not all services are working to a service specification or agreed set of standards.
- There is room for improvement in partnership working to make service provision improvements to reduce the challenges faced by people affected by lymphoedema.
- There are significant waiting times for some of the services in Greater Manchester and scope to improve how national guidelines are presented and monitored from a commissioning perspective.
- There are inconsistent standards and pathways for the prescribing of lymphoedema garments with evidence that there are opportunities for improvements and cost efficiencies.
- There is variation in the level of detail within service specifications and some services do not have a specification to follow.
- There is a lack of KPIs or outcome measures that services are required to follow to improve patients' outcomes.

Workforce

- Not all services have access to administrative support therefore some clinicians are completing their own administrative tasks, using valuable clinical time.



- There is a risk to the sustainability of services due to a lack of skill mix. Succession planning is challenging as there are minimal positions within Greater Manchester at band 4 and 5, for progression.
- There has been varied investment in lymphoedema provision in some localities within Greater Manchester. Recruitment and retention issues have been identified as challenges faced in some localities in Greater Manchester.
- Providers have reported an increase in complex patients requiring a significant number of clinic appointments for intense treatment. Lymphoedema practitioners are unable to provide the required treatment due to their capacity and caseload.
- Some services are only qualified to provide treatment for mild to moderate lymphoedema. There is an inequity of care for people with complex and severe lymphoedema.

Treatment and hosiery

- Shared experience from people affected by lymphoedema who wear their compression garments, receive appropriate treatment and provide self-care that their lymphoedema is managed with reduced swelling and a reduction in infections.
- As GM does not have a formulary for lymphoedema garments, there is variation in the prescribing of compression garments.
- There are a significant number of compression garments that are available and PrescQIPP Bulletin 192 (April 2019) state it can be difficult to identify intended products. In addition GPs have shared they feel they do not get appropriate information and do not find it easy to prescribe garments. People affected by lymphoedema have also shared experiences of receiving incorrect garments. The above can cause inaccuracy of prescriptions. Compression garments are costly and if they do not fit, the product is wasted or patients wearing incorrect garments could potentially exacerbate their condition including damage to the skin and tissue integrity.
- There is variation in lymphoedema services collaboratively working with other services for people with co-morbidities.
- Not all patients receive a treatment/care plan. Lymphoedema practitioners have shared that there are some patients who are not self-managing and therefore their condition is not improving. People affected by lymphoedema have shared that they would like access to expertise knowledge in-between appointments for supported self-managed.
- There is scope for improvement in relation to the discharge process from specialist services and for rapid re-access to service if the condition worsens.

Learning and Development

- **Patient learning and development:** The review has evidenced that patients require further education on how to reduce their risk of developing the condition and how to manage their condition if they develop lymphoedema.
- **Wider Healthcare professionals:** This review has evidenced that wider healthcare professionals including GPs would benefit from training on how to support people at risk and what information to provide for people at risk to self-care.
- **For lymphoedema practitioners:** There are accredited qualifications and non-accredited training available on the treatment of lymphoedema. However, Greater Manchester clinicians who would like to develop their skills in lymphoedema management would currently be required to travel long distances in order to obtain this training. This causes challenges in developing the lymphoedema workforce.
- **For wider healthcare professionals:** Current medical, nursing and AHP training does not include modules on lymphoedema. The International Lymphoedema Framework has provided Lymphoedema Education Benchmark Statements (LEBs). However, feedback from universities to the International Lymphoedema Framework is they would like course content. Therefore the gap will continue until course content is developed.
- Hosiery companies provide some form of training for wider healthcare professionals (e.g tissue viability nurses) to support the management of lymphoedema/chronic oedema but there is no consistency in how this is delivered across Greater Manchester.



Patient experience

- There is evidence that services and the lymphoedema specialists are valued by people attending them. They really value their skills and knowledge of the condition.
- People affected by lymphoedema reported different types of access being problematic when attending a service. Some mentioned how long it can take to be referred and be seen by a specialist.
- Some people feel certain treatment they require is not possible as services are too busy.
- Those people affected by lymphoedema that can loan equipment from services for lymphatic drainage express improvements to their conditions for the duration of the loan period.
- There have been people affected by lymphoedema who have advised that GPs have not referred them to a lymphoedema service until the condition deteriorated, therefore impacting on their quality of life.
- There is variation in the distances patients in GM travel to access specialist lymphoedema services.
- There is a lack of support groups for people to attend. There is evidence of people wanting to attend local support groups if available. This could reduce the social/psychological impact.
- People have information around the practicalities of living with lymphoedema. Information around what support.

Other Evidence

- The National Lymphoedema Partnership Commissioning Guidance for Lymphoedema Service for Adults in the United Kingdom provides further evidence from a national perspective of the gaps and variations in lymphoedema care. They provide recommendations and the sharing of good practice is within the guidance (appendix 1 – supporting documents).
- Lymphoedema Network Wales has evidenced good practice and the benefits in investing in lymphoedema provision. Their data recording tool LymCalc has provided a significant amount of data to provide a quality audit on the services within Wales.
- Surgery is becoming an option but is currently minimal within the NHS. The Christie NHS Foundation Trust has provided surgery to a small number of people who were not responding to traditional treatment to evaluate the effectiveness of surgery.
- The evidence used in the preparation of this report suggests that patients with cancer related lymphoedema have better access to services, even though services are available in Greater Manchester for non-cancer related lymphoedema. The data recording of 8 weeks of activity shows that 57% of the access was cancer related when only circa 24% of lymphoedema is cancer related.

The Benefits of Optimising Lymphoedema Prevention, Diagnosis and Management

The lymphoedema service for adults living with and beyond cancer – a template business case for commissioners cited within the national lymphoedema partnership commissioning guidance provides benefits in making changes to the provision of lymphoedema:

Group	Benefits
For patients	Improved information and self-management Improved quality of care Reduced progression of lymphoedema Reduced complications of lymphoedema (e.g. cellulitis, hospital admission) Improved patient experience and quality of life Reduced carer strain Reduced personal costs of hospital attendance
For primary care	Reduced GP attendances, urgent appointments and home visits Reduced complications of lymphoedema Skills development: improved non-specialist care of lymphoedema patients in primary care Improved clinical and cost effectiveness of prescribing
For providers	Reduced complications of lymphoedema

	Reduced emergency admissions Reduced pressure on outpatient clinic appointments Improved patient experience/outcomes
For commissioners	More effective use of secondary care resources Improved quality of care for local population Improved patient experience/outcomes Reduced variation/inequality Cost savings

This gap analysis will be shared with GM Cancer, Macmillan Cancer Support, the GM Clinical Commissioning Groups, NHS providers of lymphoedema services within GM, and people affected by lymphoedema. The evidence within the document will support the development of a set of GM standards and tools that can be used to make improvements for risk reduction, provision & ongoing management and learning & development. The project can also provide supporting evidence to each locality to recommend what measures they could put in place for an equitable provision for people at risk of/affected by lymphoedema.

2. Introduction

The Greater Manchester Macmillan Lymphoedema Programme commenced in January 2019 in response to the 2015 Lymphoedema Provision in Greater Manchester Strategic Health Needs Assessment and a partnership between Greater Manchester Cancer and Macmillan. The Health Needs Assessment identified:

- No pro-active measures to reduce risk/prevent lymphoedema
- Delays in the timeliness of referrals to appropriate services directly result in additional costly complex and severe cases (that are avoidable) impacting on patient quality of life and increased referrals to other health services
- Inconsistency of data recording across service providers to understand the provision needs
- Limited numbers of lymphoedema specialists and wider workforce
- Inequitable service provision across Greater Manchester to enable appropriate care (including education for self-management)
- Costly non-elective admissions for lymphoedema related health conditions (that may have been avoidable)
- Increased incidence and prevalence of lymphoedema. (2015 estimated 11,000 in Greater Manchester).
- Inadequate information systems leading to inaccurate lymphoedema incidence and prevalence data.

The objective of the gap analysis is to provide a current (2019) position of the provision of lymphoedema within Greater Manchester, utilising the previous scoping work as a baseline. The report draws conclusions on the effectiveness, outcomes, impact, efficiencies and sustainability of the current services by utilising:

1. Qualitative based evidence from services, people affected/at risk of lymphoedema, published documentation and results from surveys.
2. Quantitative based financial and patient level data

The data collected demonstrates:

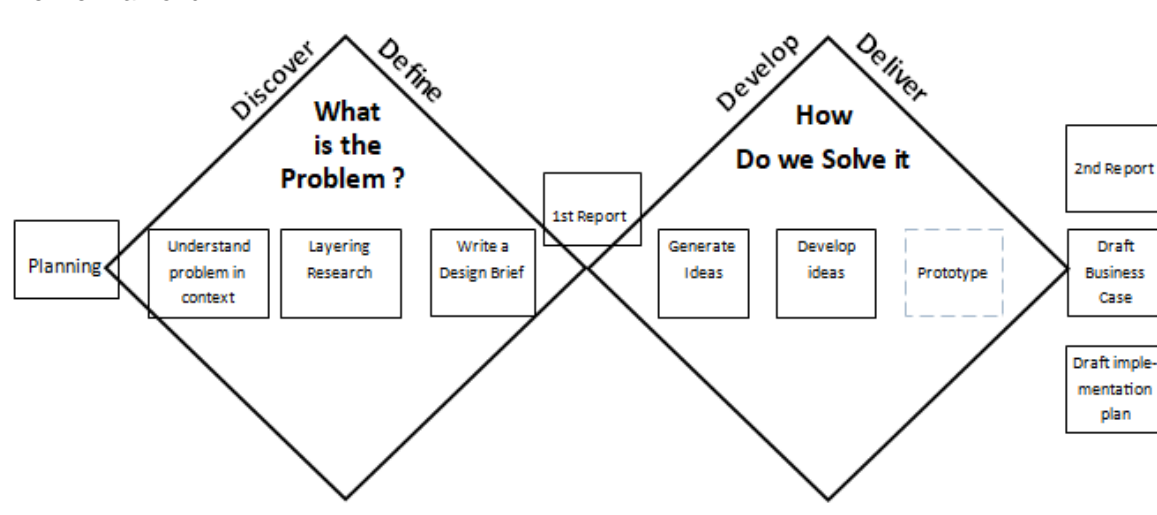
1. An overview of the current state of service provision and how this differed from 2015.
2. Specific variation within provision
3. the gap in patients receiving pro-active measures to reduce their risk of developing lymphoedema and recognising signs and symptoms for timely access services.
4. The resources required aligned to prevalence
5. Education requirements
6. The need for an equitable and cost effective provision



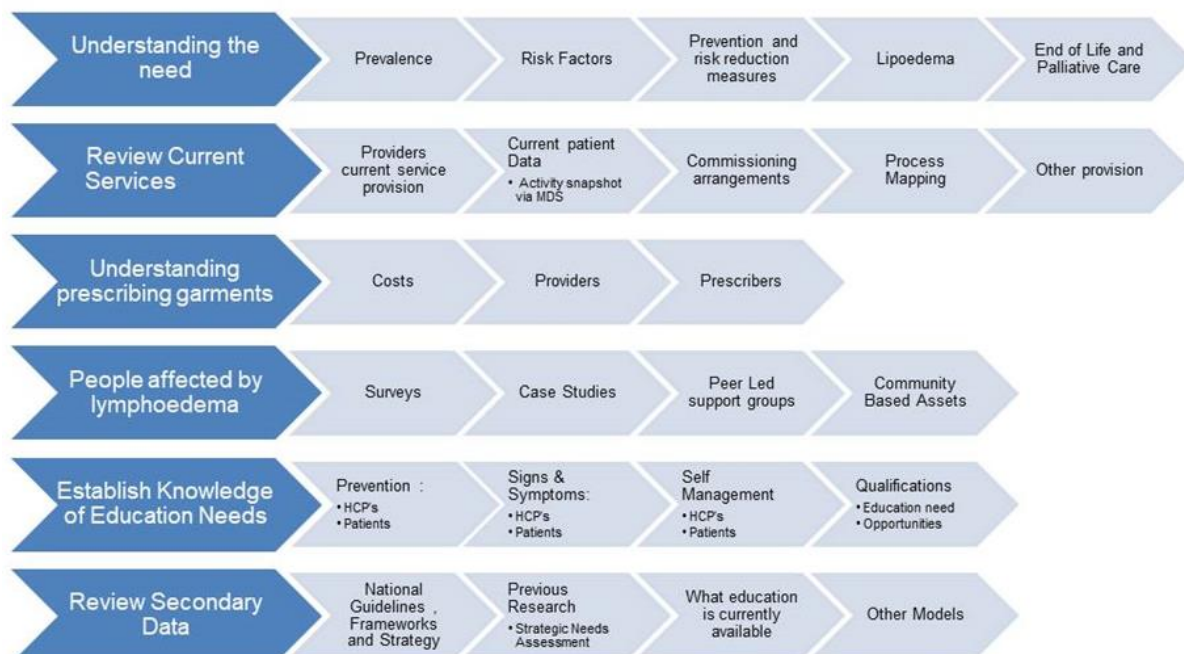
This report identifies the gaps, variations and other good practice. It will provide the evidence of what needs to be addressed for a Greater Manchester equitable and cost effective lymphoedema provision.

3. Methodology

The programme took the guidance of the Double Diamond Methodology within the Discover and Define Diamond:



Below is the framework that was developed to identify what primary and secondary data was required to understand the problem. Semi structured interviews/meetings with lymphoedema practitioners, commissioners and people affected by lymphoedema were conducted. The project also collected data through questionnaires, eight weeks of service's activity, published documents and reports evidencing good practice.



4. Understanding the need for lymphoedema

Below is a definition of lymphoedema from the National Lymphoedema Partnership (NLP) Commissioning Guidance for Lymphoedema Service for Adults in the United Kingdom – March 2019:

Lymphoedema is chronic swelling due to failure or incompetence of the lymphatic system. It most commonly affects the lower or upper limbs, but may also affect other areas including the head and neck, trunk, breast or genitalia. Chronic oedema is often used interchangeably with the term 'Lymphoedema'. Whilst chronic oedema may result from different pathologies it is important to note that ALL chronic oedema is in part a failure of the lymphatic drainage. The condition affects individuals of any age, gender or ethnicity.

Insufficiencies in the lymphatic system may be due to a congenital lymphatic abnormality (primary lymphoedema) or damage caused by cancer treatment, disease, infection, trauma, chronic venous insufficiency and other pathologies (secondary lymphoedema).

Lymphoedema/chronic oedema is staged according to the International Society of Lymphology staging from 0 to III, with 0 being a sub-clinical state and III being hard fibrotic tissues with skin changes, increased folds and overgrowths. The earlier the condition is treated the less likely it is to deteriorate to stage III.

The British Lymphology Society recognises 4 population groups:

1, People at risk, 2, People with mild uncomplicated oedema, 3, People with moderate to severe OR complicated oedema regardless of severity and 4, People with oedema and advanced malignancy.

The NHS Outcomes Framework (NHS OF) is a set of indicators developed by the Department of Health and Social Care to monitor the health outcomes of adults and children in England. The framework provides an overview of how the NHS is performing. The latest indicators were released in November 2019. There is synergy with these indicators and lymphoedema:

- 2.1 Proportion of people feeling supported to manage their condition
- 2.2 Employment of people with long-term conditions
- 2.4 Health-related quality of life for carers
- 3a Emergency admissions for acute conditions that should not usually require hospital admission
- 4.1 Patient experience of outpatient services
- 4a.i Patient experience of GP services

A link to these indicators for further details is available in Appendix 1 – supporting documents

4.1. Prevalence

4.1.1. National guidance

The Commissioning Guidance for Lymphoedema Services for Adults in the United Kingdom published in March 2019¹ has provided some guidelines on the likely prevalence per 1,000 population. The document used the examples from Derby's reported prevalence of 3.93 per 1,000 population. Lymphoedema Network Wales demonstrated an increase in prevalence post investment into lymphoedema provision. (2.6 to 6.4 per 1,000 of the population. These figures are based on those patients accessing services and therefore the NLP guide that these are likely to be conservative figures.

Below is a table showing the potential prevalence in Greater Manchester detailed within the British Lymphology Society's Calculator. This also includes the approximate practitioners based on a 250 caseload per practitioner:

Clinical Commissioning	Population:	Prevalence based on Derby's 3.93	Approximate no of WTE	Prevalence based on	Approximate no of WTE
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Group	Mid-2017 Population Estimates for Clinical Commissioning Groups (CCGs)	per 1000 Population	lymphoedema practitioners based on 250 caseload per practitioner	Wales's 6.4 per 1000 Population	lymphoedema practitioners based on 250 caseload per practitioner
GREATER MANCHESTER	2,832,133	11,130	44.5	18,126	72.5
NHS Bolton CCG	284,813	1,119	4.5	1,823	7.3
NHS Bury CCG	189,628	745	3	1,214	4.9
NHS HMR CCG	218,459	859	3.4	1,398	5.6
NHS Manchester CCG	545,501	2,144	8.6	3,491	14
NHS Oldham CCG	233,759	919	3.7	1,496	6
NHS Salford CCG	251,332	988	4	1,609	6.4
NHS Stockport CCG	291,045	1,144	4.6	1,863	7.5
NHS Tameside and Glossop CCG	257,453	1,012	4	1,648	6.6
NHS Trafford CCG	235,493	925	3.7	1,507	6
NHS Wigan Borough CCG	324,650	1,276	5.1	2,078	8.3

4.1.2. Greater Manchester primary care READ/SNOMED codes

It is possible to gain a local understanding of Greater Manchester prevalence based on primary care clinical data recording READ/SNOMED codes. Each code is assigned to a clinical term.

The project has obtained the current lymphoedema READ codes (appendix 2). Once this data has been retrieved, it will be possible to see a comparison of the known prevalence in Greater Manchester in comparison to National guidance. The codes relate to diagnosis (n16), diagnostic procedure (n2), operation and procedure (n12), therapeutic procedure (n2), admin (n2) and local code (n2). In addition to this there are also oedema codes within the system.

A GP questionnaire was completed where 90 GPs across Greater Manchester responded to how they record lymphoedema. 49% did not specifically record lymphoedema, 8% did not respond. 24% advised they put it as a READ code. The final 9% varied from "coding it as a 'problem'", "not sure", "would code it if could find the code". One GP shared that they did not specifically record "*as not always confident about diagnosis*".

The national lymphoedema commissioning guidelines have recommended that GPs are encouraged to use appropriate READ codes. The recommendation is for Scotland but the evidence above shows there is a potential gap within Greater Manchester that needs addressing.

5. Risk Factor and Reducing the Risk

Risk Factors

There are two types of lymphoedema, primary lymphoedema and secondary lymphoedema.

Primary lymphoedema occurs from a hereditary or congenital abnormality in the lymphatic system.

Secondary lymphoedema results from damage or a chronic venous overload. Cancer is a risk for developing lymphoedema, as are cancer treatments. Other risk factors include age, obesity, trauma,

immobility, damaged venous system and cellulitis. Further details of these risk factors are within the NLP commissioning lymphoedema guidance.

Reducing the Risk

Lymphoedema cannot be cured; early intervention, management and regular self-care can reduce the severity of oedema and the risk of repeated episodes of cellulitis. If people are informed that they are at risk of developing lymphoedema they can be taught what measures to put in place to reduce the risk. This education will enable people to recognise the signs and symptoms in order to access health professional support efficiently to reduce the severity of the condition.

Evidence within this gap analysis indicates that non-specialist staff and people affected by lymphoedema would benefit from improving their knowledge and learning what measures they can put in place to reduce the risk and severity.

A Greater Manchester prevention and risk reduction strategy for all risk factors could potentially reduce the incidence and prevalence. In turn this could improve people's quality of life, avoiding the need to manage a long term chronic condition.

Below are further details of the risk factors.

5.1. Cancer

There have been a number of studies into the estimated percentage of people who will develop lymphoedema due to cancer. A recent study by Rockson et al (2019) - Cancer-associated secondary lymphoedemaⁱⁱ, estimated that approximately 1 in 7 cancer patients will develop lymphoedema. Circa a quarter of lymphoedema is due to a cancer diagnosis.

Patient Quote:

I have lymphoedema in my left arm... This condition is for the rest of my life. Patients should be told of the fact they may develop lymphoedema after their operation. It was a shock to find out later. Female Breast Cancer, 5 years after diagnosisⁱⁱⁱ

5.1.1. How likely are you going to develop lymphoedema

The table below shows the differences in studies that were cited in the Lymphoedema provision in Greater Manchester Strategic Health Needs Assessment in 2015 to more recent studies that have been reviewed.

Tumour group	% of patients likely to be diagnosed with lymphoedema by tumour - cited in 2015 Strategic HNA	New cancer diagnosis Jan – Dec 2013 ^{iv}	Estimated annual lymphoedema incidence based on 2013 diagnosis	% of patients likely to be diagnosed with lymphoedema by tumour – updated resources	New cancer diagnosis Jan – Dec 2018	Estimated annual lymphoedema incidence based on 2018 diagnosis
Head & Neck	12% ^v	411	49	75% ^{vi}	439	329
Gynaecological	36% ^{vii}	427	153	36% ^{vi}	498	179
Melanoma	11% ^{viii}	1001	110	31% ^{vi}	1479	458
Sarcoma	10% ^{ix}	65	7	30% ^x	115	35
Urology	25% ^{xi}	593	148	25% ^{xi}	587	147
Breast	28% ^{xii}	1623	455	25% ^{vi}	1890	473

The table above indicates that:

- The most significant change from the Greater Manchester Strategic Health Needs Assessment in 2015 is the percentage increase of Head and Neck cancers; 12% to a more recent study of 75%. However it is not clear where the 12% figure was derived from.
- There is no recent evidence to inform the incident rates of urology related lymphoedema. 2003 is the latest research report found. There is no further evidence to inform whether there is an increase of lymphoedema incidences

- There table above evidences that there has been an increase in sarcoma related lymphoedema. It must be noted that the more recent study in 2011 was not a like for like of the 2003 report.
- The percentage for skin cancers has increased. However guidance from the Greater Manchester Skin Cancer pathway Board informed the project that treatment options are changing for skin cancer patients. It is likely that less skin cancer patients will be at risk of developing lymphoedema due receiving treatment that does not impact the lymphatic system.

5.1.2.Pathway Boards

Gaps have been identified in the tumour specific pathways.

- During a patient Holistic Needs Assessment swelling can be raised as a concern but data is unable to identify whether this is post-operative swelling, lymphoedema or other swelling.
- There were gaps in some of the standardised end of treatment summaries. Work has commenced to ensure that it has been included
- Data has not been fully captured to understand the exact points in the pathway of the risk of lymphoedema. It is clear there are variations and differences to how cancer patients are informed about lymphoedema as a consequence and how much education they are provided to reduce their risk of developing the condition.

Pathway	End of Treatment Summaries	Part of the pathway
Breast	Included	
Sarcoma	Included	
Gynaecological	To be confirmed	
Urology	Included	
Skin	To be confirmed	
Head and neck	Included	<p>A questionnaire was completed at a Greater Manchester Head and Neck event. 68 responded:</p> <ul style="list-style-type: none"> - 64% were not or not at all confident in providing lymphoedema prevention advice - 57% do not discuss lymphoedema as a consequence of head and neck cancer - Those that do discuss it as a consequence 7% was at diagnosis, 14% was at pre-op, 46% pre-treatment and 32% after the completion of treatment

London Cancer Alliance has published a lymphoedema management pathway for cancer-related lymphoedema and also provides clear guidelines of the expectation for non-specialist staff. This can be seen in appendix 3. A Greater Manchester lymphoedema management pathway for cancer-related lymphoedema would enable a clear pathway for all cancer related lymphoedema.

5.2. Obesity

The UK ranks as 5th among 31 developed nations for obesity and the problem of obesity is rising steadily in the UK despite national initiatives to address the problem.

Obesity will exacerbate any oedema, due to increased burden on the lymphatic system, increased cutaneous blood flow and long term skin changes, poor mobility and lack of physical activity combined with chronic venous insufficiency. In the super obese pressure exerted on lymphatic structures by abdominal apron and excess fatty tissue further compromises the circulatory system. Prevalence of lymphoedema in obesity variously measured at 33%- 74% (O'mally 2015, Fife 2008) Other comorbidities in obesity also have contributory factors i.e. diabetes, heart failure, sleep apnoea (Patients often sleep sitting up therefore increases dependency pressures and oedema).

Severe obesity can lead to massive localised lymphoedema (MLL) often found in the lower limbs which increase the problem of shape distortion, and recurrent infection. Genital oedema can also cause continence issues leading to further skin problems.

There have been many papers that discuss improvement in lymphoedema in weight loss particularly in breast cancer. It is important to remember true lymphoedema cannot be cured but a reduction in obesity related causal factors will relieve some of the execratory factors and therefore the lymphoedema will improve. This is not the case in the super obese and morbidly obese patients. The long term effect of such obesity causes irreversible tissue and structural changes which cannot be reversed even with massive weight loss as in those who have bariatric surgical intervention. These patients will have long term often severe problems with lymphoedema.

The increased risk of cellulitis is directly linked with obesity and the contributory factors described above. This is often poorly managed and recurring, leading to a deteriorating circle of oedema, immobility, poor skin, lymphorrhoea, low mood etc. Prevalence of cellulitis in a small study in Derby in obesity was 28% in overweight, 36% in obese and 51% in morbidly obese.

The British Lymphology Society (BLS) reviewed its guidelines for the management of patients with a BMI of over 40 in 2018 in a paper entitled Treatment Pathway for Lymphoedema Patients with a body Mass Index (BMI) equal or greater than 40kg/m². These guidelines promote patients receiving appropriate lymphoedema treatment providing that the patient is receiving weight management support, are actively engaging with weight loss and activity programmes. This is to ensure success of the lymphoedema specialist intervention. Failure to comply should result in discharge back to the care of the GP. However the morbidly obese and super obese patients should be engaging with bariatric services combined with good lymphoedema services, treatment and self-management will lead to improved outcomes.

A review of eight weeks of appointments within the Greater Manchester's lymphoedema services showed that 46% of the total patients were considered to be obese BMI 30 - >40. A third of those patients had a BMI >40.

5.2.1.Weight Manangement services in Greater Manchester

Bariatric Surgery Service

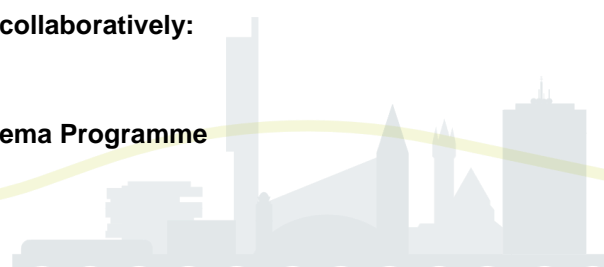
Engagement with the Salford Royal Foundation Trust's Greater Manchester Weight Management Service based at Salford (SRFT) in July 2019 confirmed that lymphoedema and chronic oedema is a big problem for some of their patients. The service receives approximately 1000 new patients per year and approximately 25% will go on to have bariatric surgery. The rest are followed up within their service and supported into medical and self-management. There are approximately 5000 people currently on their caseload.

Lymphoedema, massive localised lymphoedema and recurrent cellulitis are recognised problems in their patient group. There have been many attempts to refer to lymphoedema services within Greater Manchester but this has not been successful. This service then refer to dermatology services, vascular services, tissue viability, or back to the GP.

Tiered 3 Weight Management

A meeting with Morelife, the new tier 3 weight management service for 5 CCG areas in Greater Manchester advised they had little knowledge of lymphoedema. There is a clear education need for these professional to understand risk reduction, signs and symptoms and referrals for lymphoedema so they can inform and educate their patients to reduce them developing lymphoedema and timely access to lymphoedema provision.

Gaps in Greater Manchester Lymphoedema Services working collaboratively:



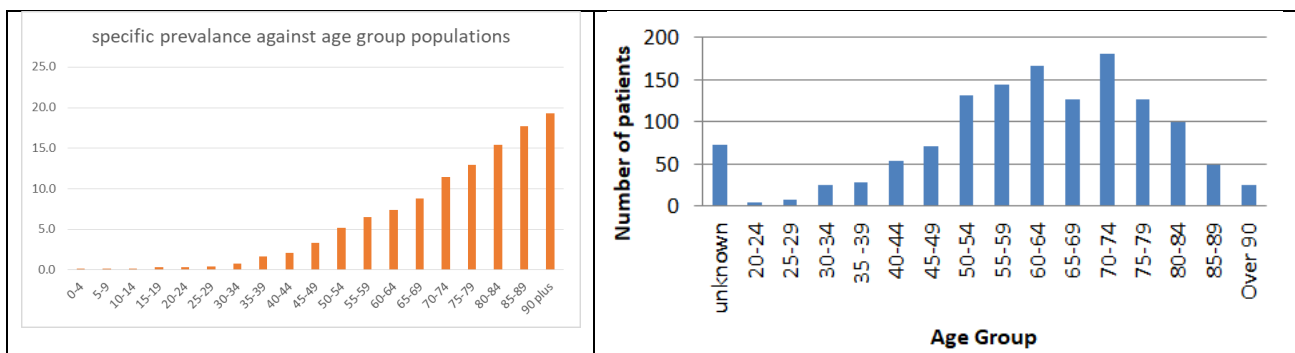
From the semi structured interviews with the lymphoedema practitioners, it evidenced there was variation in how the current lymphoedema services referred patients that required weight management services. Some services were aware of the tier 3 weight management services, others referred back to their GPs.

There are restrictions on the BMI within some of the lymphoedema service's referral criteria. They either do not accept patients over a certain BMI or assess by individual case. The project has evidenced that those services specifications that state each case will be assessed, is not always adhered to as referrals over a certain BMI have not been accepted.

The national commissioning guidance recommends that *"A holistic approach to the assessment also facilitates referral to other health disciplines to address other factors likely to affect treatment outcome"*. Early intervention, education and support will be key for this patient group as well as a multi-disciplinary specialist workforce that work collaboratively to address these complex issues.

5.3. Age

The Lymphoedema Support Network has provided the project with data they have collected indicating that the prevalence per 1,000 population increases by age. Below are two graphs. The first graph is showing the increase in prevalence by age using data from Lymphoedema Network Wales. The second graph is the age group of people when the services within Greater Manchester recorded all appointments during an eight week period in 2019.



Lymphoedema Network Wales are currently working on a programme to provide education in care homes to improve the risk reduction and the supported self-management.

5.4. Damaged venous system and chronic oedema

The term 'Chronic Oedema' is often used interchangeably with the term 'Lymphoedema'. Oedema results from an imbalance between capillary filtration into, and lymphatic drainage from the interstitial space. Chronic oedema is defined as oedema of at least 3 months duration which distinguishes them from acute causes of oedema. In every case of chronic oedema there will be some impairment of lymphatic drainage, either through an underlying abnormality, or through 'lymphatic failure' as a result of the capacity of the lymphatics being overloaded (NLP 2015^{xiii}). The site of oedema is commonly in the legs and feet and is exacerbated by obesity, venous disease, immobility and increasing age. This is significant as the population increases, although it is not solely prevalent in the elderly. Damage to the venous system, and dependency or gravitational oedema from trauma, neurological deficit and arthritis can also cause chronic oedematous changes.

Within Greater Manchester patients with chronic oedema/lymphoedema are often referred to one of several different community teams for diagnosis, treatment and on-going management. These referrals may be to district nursing, tissue viability or podiatry teams but there is variation in the access to professionals trained to provide lymphoedema treatment.

South and Central Manchester, Trafford, Stockport, Salford and Bolton's non- cancer lymphoedema provision is through St Ann's Hospice. The hospice has 1.45 WTE specialist lymphoedema practitioners and provides lymphoedema care for 6 CCGs in total. Tameside, HMR, Bury and Oldham community services do provide lymphoedema services for chronic oedema patients. The practitioners advised they are working with little or no support for administration, or cover for annual leave, sickness and training. These services have informed they do not always offer best practice Decongestive Lymphatic Therapy (DLT) and intensive phases of treatment due to time constraints and lack of staff.

There is a pilot lymphoedema service in North Manchester funded for 2 years (pilot end summer 2020) with staff currently in lymphoedema training which offers collaboration between district nursing, tissue viability nurses, podiatry and lymphoedema community teams. Collaborative working and a more joined up cohesive approach to managing complex chronic oedema patients has been evidenced by the Lymphoedema Network Wales and Cambridgeshire and Peterborough NHS Trust^{xiv} to offer the best evidence based treatment but more work needs to be done in Greater Manchester to bring these services together. The Lymphoedema Network Wales have published a Wet Leg Pathway (Appendix 4) that could be developed into a localised version to improve the pathway for these patients.

The Macmillan Greater Manchester lymphoedema programme has recently engaged with the Manchester Amputation Reduction Strategy (M.A.R.S.) project run by Mr Naseer Ahmad consultant Vascular Surgeon at Manchester Foundation Trust. The aim of M.A.R.S. is to reduce numbers of lower limb amputations and prevalence of leg ulcers across Greater Manchester and reduce the inequalities of service provision for lower limb wounds focusing on prevention, health and social care, and IT. M.A.R.S is proposing an integrated acute and community pathway that will include lymphoedema provision.

5.5. Primary Lymphoedema

Primary lymphoedema is due to a genetic fault in the development of the lymphatic system resulting in poor formation or function of the lymphatic system.

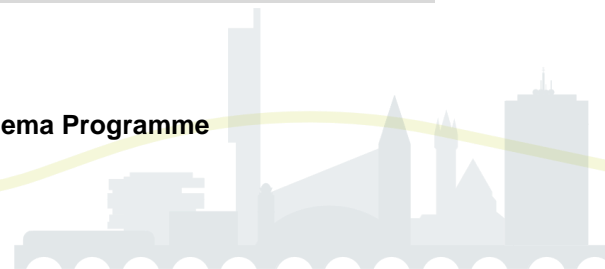
Primary Lymphoedema is thought to be relatively rare, affecting 1:6000 people. (Mortimer & Rockson 2014)^{xv} It may develop from birth or infancy but may not develop until adolescence or early adulthood. Several types of primary lymphoedema have now had their genetic mutation identified, such as Milroy's Disease and Lymphoedema-Distichiasis. There are now at least 7 mutations known to cause lymphoedema.

Chronic swelling in babies and children is diagnosed by a paediatrician but as there are no paediatric lymphoedema services within Greater Manchester these patients will be referred for accurate diagnosis and treatment to services in Leeds, Derby or London.

Investigations in primary lymphoedema aim to confirm a diagnosis and exclude other reasons for oedema.

Primary lymphoedema may not become apparent or symptomatic until adolescence or early adult hood and is often missed and not diagnosed until a subsequent event or cellulitis brings it to the attention of medical services. Below is a case study from a male that has been involved in the programme:

At around age 7 or 8 I was admitted to hospital for an infection, possibly for cellulitis. At around 20 years of age I went into hospital again for cellulitis. In my mid 20s I was prescribed compression hosiery. Since then I have had many episodes of cellulitis, some leading to sepsis. Around 5 years ago I was referred to the tissue viability service in Tameside. MLD is not recommended by Tameside unless it's for secondary lymphoedema.
Stephen, 38.



Within Greater Manchester primary lymphoedema is treated by community and hospice services. Full details of what services will accept primary lymphoedema is detailed in Section 6 - Greater Manchester Lymphoedema provision section.

Other tests that may be used are genetic screening and blood tests. Advances in genomics and genotyping in the future may well enable earlier diagnosis and therefore early access to treatment of primary lymphoedema.

5.6. Cellulitis

Cellulitis is a risk to lymphoedema and can be a complication with lymphoedema.

If a patient has had more than one episode of cellulitis in a limb, there is almost certainly some failure of lymphatic drainage. In 2013-2014, there were 104,598 recorded cases of cellulitis treated in secondary care in the UK, of which 69,229 hospital admissions involved a mean and median bed stay of 6.2 and 3 days, respectively. The actual incidence is much higher because many cases are treated in primary care.

An audit was completed on the number of non-elective cellulitis admissions in Greater Manchester by CCG in 2014-2015 fiscal year; in the 2015 lymphoedema provision in Greater Manchester Strategic Health Needs Assessment. It evidence that there were 7002 patients that had 12,343 inpatient episodes with a total of 77,162 bed days. Average cost per episode being £962. There were non-elective lymphoedema admissions of 4910 bed days at a cost of £831 per episode.

Patients have shared with lymphoedema services that instead of them being admitted to hospital for their cellulitis they are receiving IV Therapy at home. If the IV antibiotics are to be administered twice daily community nursing are able to do this. This is potentially reducing the non-elective admissions for cellulitis. Empowerment of self-management could reduce the risk of patients developing such infections reducing the need for antibiotics and IV therapy.

A patient that attended a Patient Education and Engagement event in November 2019 advised that since he has found the right garment and wearing it; he had noticed that his episodes of cellulitis are not so frequent.

5.7. Other conditions and considerations

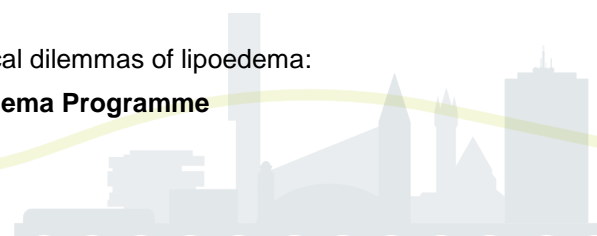
5.7.1. Lipoedema

Lipoedema is a chronic condition of abnormal accumulation fat cells which cause symmetrical swelling mainly affecting the legs and thighs, but also in buttocks and less commonly arms. In the UK, the minimum prevalence of lipoedema has been estimated to be 1 in 72,000 (Child et al, 2010)^{xvi}. However this is thought to be an underestimate; in Germany, the prevalence of lipoedema has been estimated to be 11% of women (Szél et al, 2014)^{xvii}

Lipoedema patients may indeed go on to develop a secondary lymphoedema if the build-up of fats affect lymph drainage and is then known as lipo-lymphoedema. Delay in diagnosis often results in late presentation, complexity and combined with a high BMI.

Treatment of lipoedema is to alleviate symptoms most commonly pain and discomfort and to attempt to maintain a good limb shape. Compression hosiery, mainly flat knit made to measure, can help support and reduce discomfort and may also involve MLD techniques, exercise, and psychosocial support. There is variation across Greater Manchester in whether someone with lipoedema can access a lymphoedema service.

Further information on lipoedema can be found – Pathophysiological dilemmas of lipoedema:



Med Hypotheses 83(5): 599–60. doi: <https://doi.org/10.1016/j.mehy.2014.08.011> Crossref, Google Scholar

5.7.2. Palliative and End of Life Care

North London Cancer Network/Derby & Burton Cancer Network 2006/2010 stated: 5-10% of all lymphoedema referrals are due to the presence of palliative Lymphoedema. The British Lymphology Society recognises four population groups with lymphoedema. Group 4 is People with oedema and advanced malignancy.

The International Lymphoedema Framework has a published document for the management of lymphoedema in advanced cancer and oedema at the end of life - <https://www.lympho.org/wp-content/uploads/2016/03/Palliative-Document.pdf>

This document is advocating that oedema is part of the holistic assessment that palliative care and end of life patients receive as part of the holistic assessment. This would enable clinicians to decide if a referral to a lymphoedema service for treatment/management is appropriate.

Box 1: Principles of care for the patient with end of life oedema

- The patient is at the centre of oedema assessment and treatment plan - what appears to be problematic to the health care professional may not be the patients overwhelming concern
- Assessment of oedema is part of the overall specialist palliative care assessment. Referrals are made for physical, psychological and social support as required
- Specialist palliative care health care professionals can assess and treat non complex oedema at the end of life after appropriate training in adapted multi layered bandaging
- Therapy aims to relieve symptoms, improve quality of life and reduce risk associated with the oedema
- Family and caregivers should be involved in simple adapted treatments where necessary and desirable
- Reassess regularly to identify contra-indications, assess the benefit of treatment, and changes in clinical condition

Greater Manchester

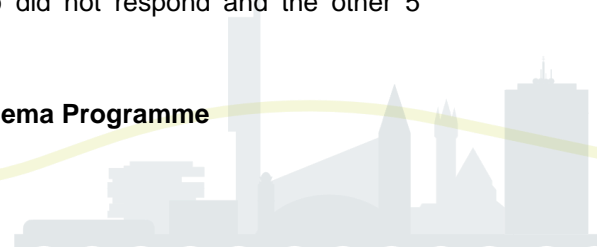
Engagement with palliative care and end of life services across Greater Manchester confirmed these guidelines are not included in their services. Further discussions are going to be held at the next Greater Manchester East Cheshire Palliative Care Advisory Group in December 2019.

As part of the review for lymphoedema provision; two questionnaires were developed and shared. One questionnaire to cancer clinical nurse specialists (CNS) and the second to wider healthcare professionals. Palliative care professionals responded to the two questionnaires.

In the CNS, 10 palliative care nurses responded. Wigan (n3), Manchester (1), HMR (n1), Tameside & Glossop (n.1), Oldham (n.1) Bolton (n1) and Stockport (n2). In the wider healthcare professional there were 7 respondents Trafford (n1), Bolton (n4), Manchester (n1) and Wigan (n1). 4 were nurses and 3 were consultants.

In both questionnaires:

- They were asked how confident they were to recognise lymphoedema symptoms. 10 were confident and 7 were not so confident/reasonably confident
- 15 of the respondents felt they had medium/average knowledge on the risk factors, where 2 said they had a little knowledge.
- 15 respondents advised they would refer to a lymphoedema service. The wider healthcare professional questionnaire was a free text answer. Two did not respond and the other 5 stated specific services.



- In the wider healthcare professional questionnaire they were asked if they were supported by a lymphoedema team 6 of the 7 respondents stated no. The respondent from Wigan stated yes.
- 15 of the 17 respondents stated they would benefit from training. The 2 that said training wouldn't benefit their role 1 was a consultant and evidence their knowledge in their responses within the questionnaire and the last respondent was already a lymphoedema key worker level trained.
- Below is a table of what advice these professional would provide. There is likely to be a gap in Greater Manchester of this group of patients being well informed about their chronic oedema/lymphoedema.

Type of Advice	Result
Encourage to obtain leaflets	1
Generic advice and referral	1
I do not provide information to patients	8
Lymphoedema leaflet	4
Tailored advice	3
Grand Total	17

6. Greater Manchester lymphoedema provision

This section presents an overview of lymphoedema services within Greater Manchester and any variation to the services identified in the 2015 Health Needs Assessment.

6.1. NHS services

A review of adult lymphoedema services commenced February 2019 by way of semi-structured interview to explore what provision each service provided including referral criteria, resources, activity and potential risks to the service. Over the review period there have been various changes to the workforce. Below is a reflection of the data as at 28th November 2019.

There are 10/11 services providing lymphoedema treatments across the 10 CCGs in Greater Manchester that are funded by the NHS. The services are based in a variety of settings including community (n= 5) four cover their full CCG's GP registered patient, one covers a partial area of their CCG's GP registered patients, acute hospitals (n=2), tertiary hospital (n = 1), hospices (n=1) that accepts referrals from six CCG's GP registered patients within Greater Manchester. The 10th/11th service is a collaborative service between an Integrated Care Trust and a local hospice. All the community and hospice services have specific commissioning and contracting arrangements.

In summary, 5 of the 11 services accept primary lymphoedema referrals; 9 of 11 accept secondary cancer referrals, of which 4 are cancer related only services; 7 of 11 accept secondary non-cancer referrals. Only 3 services, St Ann's, Oldham and Tameside & Glossop accept referrals for all causes of lymphoedema (primary, secondary cancer and non-cancer). Some exceptions apply to the above services. Appendix 5 provides a table with details of the services. There is no service in the whole of Greater Manchester for children and teenagers under the age of 18.

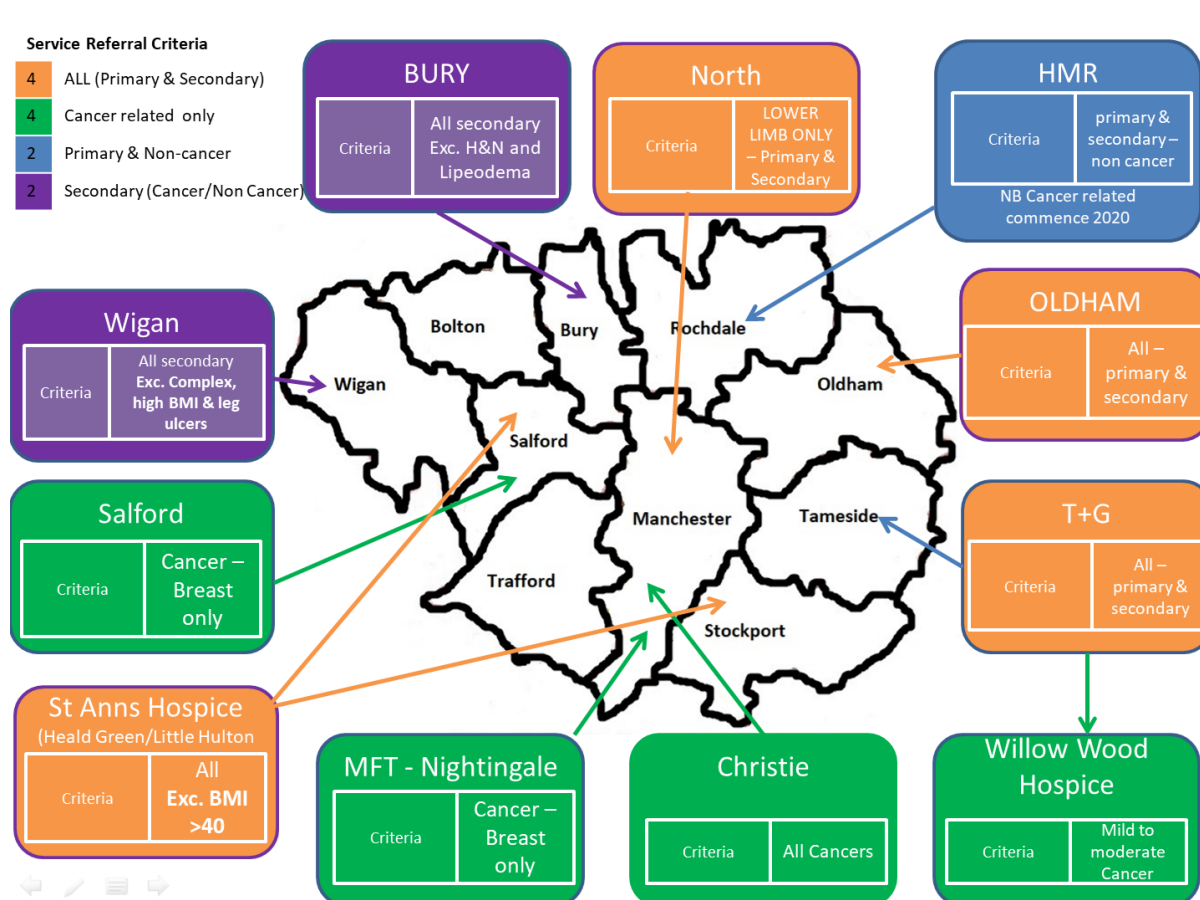
The 2015 Greater Manchester Lymphoedema Provision Strategic Health Needs Assessment stated that most lymphoedema services were for patients affected by cancer. This review has identified the provision in Greater Manchester is not primarily for cancer related lymphoedema.

There are four different types of services:

1. Hospice
2. Part of the cancer pathway
3. A combined tissue viability and lymphoedema community based service
4. A lymphoedema community based service



Below is a map illustrating the services and referral criteria:



The map highlights the breadth of people that can access the St. Ann's Hospice service. MFT and Christie are not locality specific.

HMR services will also accept cancer lymphoedema from 2020.

6.1.1. Workforce and caseload

As at 28 November 2019, the services have the following clinical resources:

Service	No. Staff	Clinical Workforce WTE	Caseload	Case per based staff on WTE	Variation/Observations
Bury TV & L*	1	0.42	222	529	2015 HNA was not aware of this service.
North Manchester	3	3.00	259	129	Pilot awaiting decision on sustainable funding. 1.00 WTE band 4 currently vacant
Oldham	1	1.00	129	129	Service initially trained 4 tissue viability nurses. May 2019 service decreased to 2 staff and now decreased to 1 trained staff member. Service looking to re-train new tissue viability nurses and service lead.
Rochdale	1	1.00	186	186	Part-time keyworker to commence

					January 2020 to include cancer related lymphoedema
St Ann's Hospice	3	2.45	400	275 (not including new post)	<ul style="list-style-type: none"> • One WTE Assistant is a new post that commenced quarter 3 2019/2020 • There has been a gap in workforce due to recruitment of one of the specialists • Since 2015 their caseload has doubled.
Tameside & Glossop	2	1.48	600	405	0.48 keyworker has been on long term sickness during the review period
Wigan	4	2.80	No data		0.2 WTE specialist has left.
Salford Physio and lymphoedema	2	1.47	75	Circa 51	The 2 staff members offer both physio and lymphoedema. The WTE just for lymphoedema is not clear.
Willow Wood	2	0.4	104	260	0.2 WTE staff member is due to retire.
Christie	6	3.31	700	211	Since 2015 this service workforce has increased by 1.51 WTE and caseload 387
MFT (Wythenshawe)	3	2.43	575	237	MFT staff have increased by 1.8 WTE but caseload has dropped by 225. Due to increase in staff they are able to follow up and discharge that they were not doing in 2015.
Total Clinical staff	28	18.76			

**Tissue Viability and Lymphoedema*

Administration is extremely low within only 4 services that have informed of dedicated administrative support totalling to 1.49 WTE. Appendix 5 provides the data of staff levels and administrative support. The clinical staff has informed they spend time completing administrative tasks that impacts on the amount of clinical time they can allocate to treat patients.

Four services are operated by a single healthcare professional or have one or less whole time equivalent (WTE) staff. This causes an impact to the accessibility of the lymphoedema provision when the specialist staff are not available.

Caseload per staff

The National Lymphoedema Partnership Commissioning Guidance¹ have shared “with a suitable skill mix a 1 whole time equivalent lymphoedema therapist to hold a case load of 220 and 250 patients with supporting assistant staff”. A higher caseload than this recommendation may impact on how much treatment patients may receive. There are three services that are above this recommendation.

The guidelines do not provide the severity of lymphoedema by caseload. The more complex lymphoedema requires a higher level of treatment compared to those with mild to moderate lymphoedema. The review of lymphoedema provision does analyse 8 weeks of activity from 10 of the services. This records the severity of the conditions for those patients who access the service during that period. Details of the results are within section 6.1.2. It would be beneficial if each service completed a full audit on their caseload. The service would be able to evidence the current demand for the service and whether it is able to provide the recommended treatment for each patient. Consistent auditable data recording would support services gaining this evidence.

Lymphoedema Network Wales have a standard data recording requirements across the services in Wales that enables Lymphoedema Network Wales to provide detailed Audit report in 2019. By having consistent and accurate data they have been able to evidence caseload, severity of staging, performance data, an outcome analysis, breaches and evidence safe staffing levels in comparison to the NHS Wales Lymphoedema Strategy. The services across Wales have the same data recording requirements using Lymcalc.

The British Lymphology Society have published a professional roles in the care of lymphoedema that outlines 1) lymphoedema professional roles and responsibilities, 2) the level of educational attainment needed to perform each lymphoedema professional role. A copy of this document is available in Appendix 1 – supporting documents.

6.1.2. Service Specifications

Six of the 11 provider service specifications have been received. These have been reviewed to understand if there is any variation in the provision within the locality versus the service specification, the standard between the service specification and the commissioning guidance's recommended service specification. It is acknowledged that some of these documents are beyond their review period, others are just KPIs rather than a service specification. It is likely that those services that have not shared a service specification do not have one.

Below provides some observations to the difference between what services have informed compared to the service specification:

- St Ann's – the information obtained states that referrals are not accepted for people with BMI greater than 40. The service specification states, *Patients with a BMI above 40 will be assessed on a case by case basis as to whether treatment would be effective.*
- Rochdale – the only apparent variation from the information obtained is people with a BMI above 35 should be referred to a weight management service prior to referring to the lymphoedema service. Not aware if this is currently happening.
- Oldham – There is no significant variation noted, although the recent departure of their specialist will impact the service in relation to severe cases where intensive treatment is required. This however may be a temporary issue. The service specification highlights that routine referrals should be 20 working days (4 weeks) and that the service is available 7 days per week. The information received from the service advised that routine referral time is 6 weeks, which highlights the workforce issues are impacting on delivering the service.
- Tameside – confirms this is a collaborative service with Willow Wood Hospice.
- Willow Wood Hospice – the specification details *the lymphoedema clinic provides keyworker advice, support and care to patients with primary and secondary lymphoedema.* Our programme has been advised that Willow Wood accepts referrals for people with secondary cancer related lymphoedema as per the Tameside service specification.
- Bury – There is variation to the operations of providing lymphoedema provision in comparison to a detailed service specification.

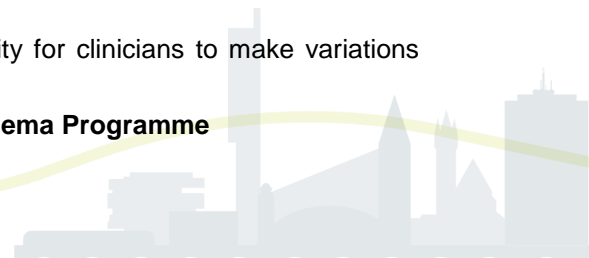
From above it is clear there are differences to what is happening operationally to what has been commissioned.

Difference between national guidelines to current service specifications

In general the service specifications are minimal in comparison to the breadth of national guidelines that are available.

A specification or a set standards of care and treatment would provide a consistent approach across Greater Manchester. It would enable lymphoedema practitioners to work towards a set of agreed standards that would provide clarification of what is expected of them. For example

- KPIs on referral times,
- Quality of life metrics and outcome measures,
- Guidance on standards for treatment plans with the ability for clinicians to make variations based on clinical decisions,



- Reporting requirement standards.

6.1.3. Referral times and appointment slots

The British Lymphology Society has developed a tariff guidance documents for commissioners^{xviii}. This documents recommends the below referral times:

Urgent referrals (palliative patients) – 2 weeks
Routine referrals 6- 10 weeks

Current referral times across the services vary from 1-16 weeks. Below illustrates the variation between the services:

Service	Referral Time	Caseload	First appointment average clinic time	Follow up appoint average clinic time
Bury	4 weeks	222	60 minutes	40 minutes
Christie	4 weeks	700	60 minutes	30-60 minutes
HMR	6 weeks	186	90 minutes	60 minutes
MFT	4-6 weeks	575	60 minutes	45 minutes
North Manchester	1 week	259	90-120 minutes	60 minutes
Oldham	6 weeks	129	60-90 minutes	60 minutes
Salford	1 week	75	60 minutes	60 minutes
St Ann's Hospice	Cancer - 2 week Non Cancer 12 - 16 weeks	400	60 minutes	30-60 minutes
Tameside and Glossop	12 weeks	600	60-90 minutes	60 minutes
Wigan	16 weeks	<i>No data</i>	60 minutes	60 minutes
Willow Wood Hospice	16 weeks	104	60 -90 minutes	60 minutes

The British Lymphology guidelines recommend first assessment should be 60 minutes direct clinical time with 30 minutes indirect clinical time.

All further treatment should be in blocks of 40 minutes direct clinical and 20 minutes indirect clinical. The Greater Manchester services are close to the recommendations but there are inconsistencies. The semi-structure interview questions were developed prior to the review of these guidelines and therefore it is not clear if the services allocated time include both direct and non-direct or just direct clinical time.

6.1.4. Risks and known issues to services

Retirement

There are a number of specialists and keyworkers across the services due to retire within the next 12-36 months. There is a potential risk to the service if no succession planning is put in place.

- Willow Wood – Keyworker due to retire January 2020
- Tameside and Glossop ICFT – Specialist potential to retire within next 3 years.
- MFT – Keyworker (0.93 WTE) retiring January 2020, potential opportunity to return on temporary contract (0.4WTE). Specialist (0.5 WTE) is due to retire within next 2 years.
- The Christie Foundation Trust - 1.8 WTE potential to retire in next 3 years

Risk of long term sickness

Those services which have single staff services, increasing or heavy workloads, or where there is minimal trained staff to cover annual leave, sickness and training.

Challenges with Mentorship

In the semi structured interview some staff raised they found it a challenge to find a local mentorship to support them as part of their qualification. Specialist level lymphoedema staff in Greater Manchester also find it a challenge to have the capacity to provide the relevant mentorship for newly qualified practitioner.

Staff retention

The staff that have left their lymphoedema service are moving into a different speciality such primary care, palliative & end of life care and physiotherapy. The reasons were a lack of support, workload, managerial support and career progression to why they did not staying within the speciality of lymphoedema. This is a potential risk as other practitioners may move away from lymphoedema due to the same reasons.

Increase in demand for service

Due to the Macmillan Greater Manchester Lymphoedema programme raising awareness of lymphoedema as a condition; the services may have an increase in referrals. This is a risk to those services specifically who already have longer referral to first appointment waiting times.

6.1.5.Variation from 2015 Strategic Health Needs assessment

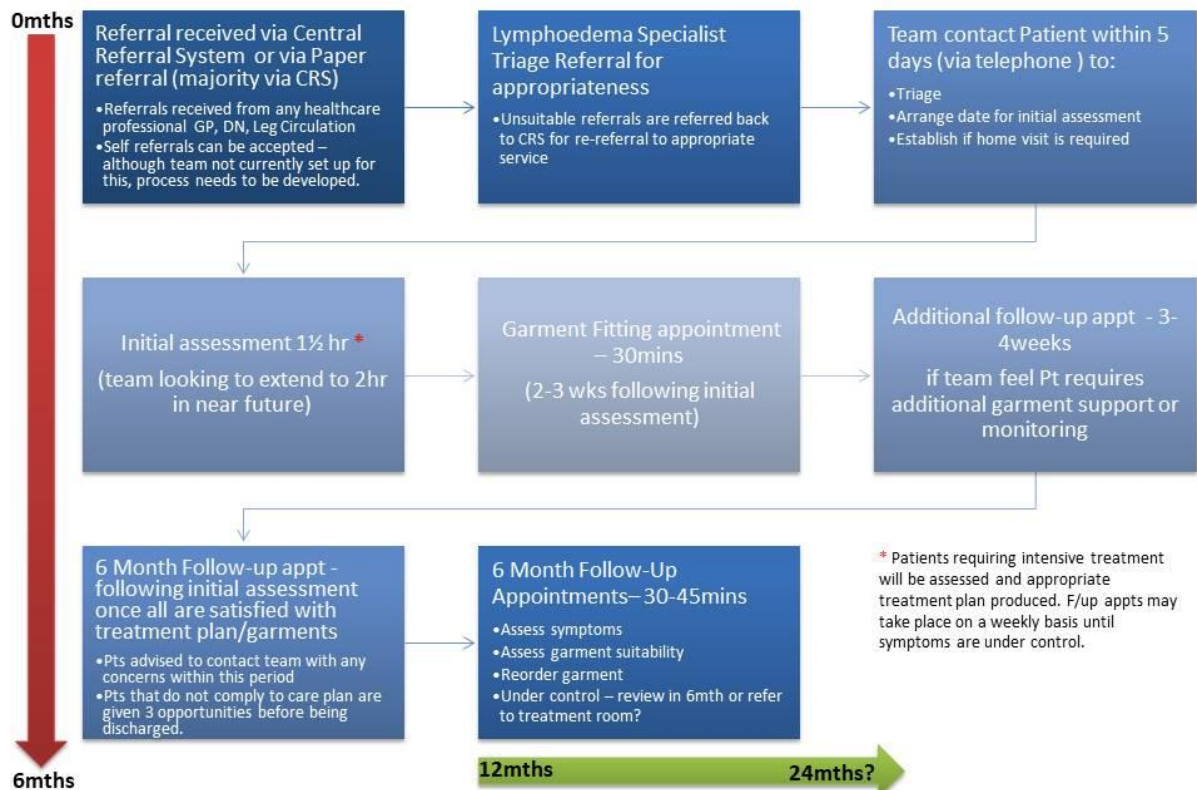
- Salford Tissue Viability service offered a key worker level service with approximate 400 people on their caseload. The current service does not have any lymphoedema specific trained staff but offers basic bandaging.
- Pennine Acute Breast Cancer 0.2 WTE. 2 breasts CNSs covering half a day clinic. Both CNS has retired and there is no longer a clinic. In 2015 they had 105 patients on their caseload.
- Stepping Hill Hospital Breast Service provided a key worker led service that is no longer. In 2015 it was reported to have a caseload of 860
- Bolton Hospice had a key worker level service but since the commencement of the Christie's outreach clinic at Bolton Hospice there has been a steady decline in the demand for the hospice staff lower level lymphoedema support to patients. The hospice staff that are trained will provide low level support if asked.
- Springhill Hospice cancer service 1 day a week was decommissioned but this has now been re-commissioned as part of the lymphoedema HMR community service and hours have increased.
- Dr Kershaws Hospice had a key worker led service that is now more of a support group due to the commissioning of the Oldham Community tissue viability and lymphoedema service.
- The Christie at Oldham Satellite service has a physiotherapist that is keyworker level trained and offered a small provision to breast cancer patients that uses the satellite facility.

6.1.6.Process Mapping

North Manchester Lymphoedema service was mapped out in its process for uncomplicated lymphoedema. Due to constraints it was not possible to complete this with all services. From discussions with the clinicians it is likely there will be variation across Greater Manchester. An agreed process map for all service would provide consistency.



North Manchester Lymphoedema Service – New Patient Pathway (not requiring intensive treatment)



6.1.7. Minimum dataset

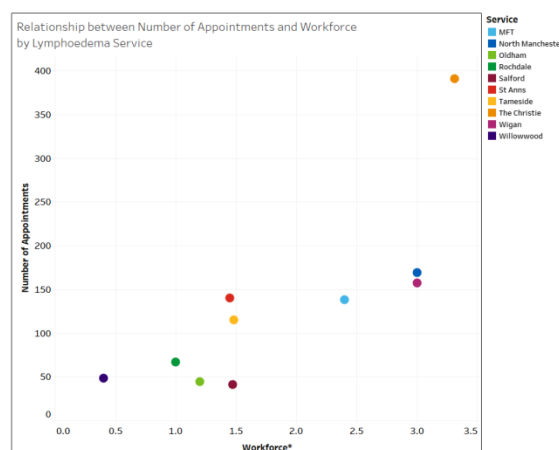
It was identified that services record their patient activity in various formats and some data still collated in a paper based format. The variations made constraints to understand the services capacity and demand.

The British Lymphology Society minimum dataset acknowledge by the International Lymphoedema Framework provides some data recording consistency. Appendix 5 provides graph results of the minimum dataset. The recording sheet provided demographics, level of obesity, mobility, cause of lymphoedema and if they were a palliative patient, severity based on the ISL staging, Length of time prior to assessment, cellulitis, site of oedema and wounds. The template does not provide details of treatment plans, length of time at the service or length of time within appointment.

10 out of the 11 services submitted an eight weeks of activity to provide a snapshot. The period of time was during the summer so external factors needs to take into consideration such as annual leave and services not providing intense treatment to patients due to the heat. There was also some sickness during the period that reduced the number of clinic appointments.

A total of 1310 appointments were recorded. Two of the services advised that 11 of their patients had additional appointments totalling to 32 more appointments during the eight weeks for intensive treatment. 57% were cancer related lymphoedema. Considering only circa a quarter of lymphoedema is due to a cancer diagnosis; based on this activity cancer patients have better reach in to services in Greater Manchester than non-cancer patients. The data evidence from the number of breast cancer patients have better access to a lymphoedema service due to the breast cancer only lymphoedema services. However if you look at the figures from a basic percentage against tumour groups; the percentage of breast patients having treatment during this eight weeks is only slightly higher than what the average percentage should be.

The chart shows the relationship between the numbers of appointments compared to workforce. It does not take into consideration the length of time for appointments and other external factors including some workforce have a combined role so their WTE included other appointments such as physiotherapy or wound care, sickness, annual leave and study leave. The referral details evidence variation to the length of time for new appointments and follows up which does not make the table below very accurate.



6.1.7.1. Comparison to national tariff guidelines

The national tariff guidelines advises that a clinician time should be split by two thirds face to face clinical time and one third non-clinical time e.g. supervision, travel to home visits etc. NHS capacity and demand modelling calculate capacity by 42 weeks of the year (80%) to take into consideration annual leave etc.

One service had a lymphoedema practitioner off for 21 days out of the 40 days due to annual leave and sickness leave. There was an impact to this service of 21 days (157.5 hours). This is more than the recommendation of an 80% capacity.

Based on the minimum dataset and national guidelines, basic calculation indicates some services do have capacity to see more patients. There are other services that they are at their maximum capacity based on circumstances for example long term sickness. There are multiple factors that need to be taken into consideration e.g. the caseload of complex and severe cases that require more treatment, length of time it takes clinicians to complete administration.

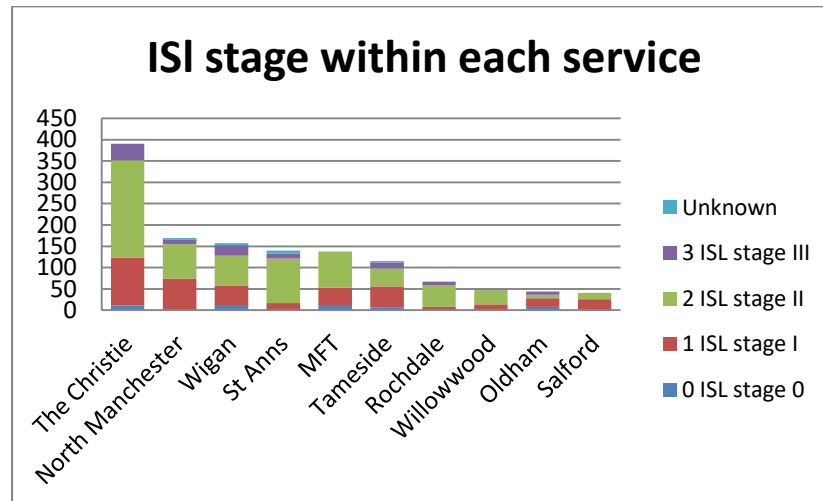
6.1.7.2. New appointments

There is no consistency in the ratio of new appointments allocated. It varies from 10% to 25%. The national tariff guidelines recommend 6-10 weeks routine referrals. You can see from the below table there are some services that are not able to achieve this. There are likely to a number of reasons for such variation such as workforce, length of appointments, treatment requirements for example those services that are keyworker led will be providing less treatment time compare to those specialist practitioners. Another reason is there does not seem to be standard practice in allocating a certain percentage of appointments for new appointments.

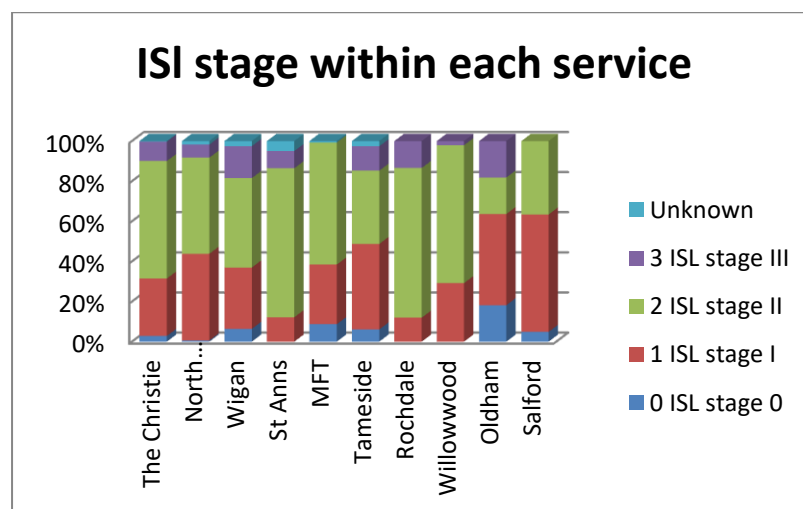
Service	Percentage of new appointments	Ave Referral to 1st Appt. (weeks)	Known caseload
Oldham	25%	6	129
Wigan	24%	16	no data
Tameside	23%	12	600
Rochdale (HMR)	16%	6	186
MFT	16%	6	500
North Manchester	13%	1	186
Christie	11%	4	700
Willow Wood	10%	16	104
St Ann's	10%	16	400
Salford	10%	1	75

6.1.7.3. Number of patients and the severity of their condition

Below illustrates the total number of patients recorded in each service and the percentage of patients recorded in each service by their severity of their condition during the eight week period. Even though the Christie's have seen the most amounts of people it does not take into consideration workforce, length of appointments. For example Salford Breast service is a combined physiotherapy and lymphoedema service. Therefore they may have a higher physiotherapy workload.



The percentage graph illustrates that most services have a higher caseload of stage ii that requires more treatment in year one compare to stage i based on the national tariff guidelines.



6.1.7.4. Obesity and Lymphoedema

As detailed in the risk factors there is a relationship between obesity and lymphoedema. The minimum dataset shows this coloration with 46% of the total patients during the eight weeks were considered to be obese BMI 30 - >40. A third of those patients had a BMI >40. The minimum data evidenced a higher percentage of people being obese if their lymphoedema was more severe:

- 72% of those patient with **stage iii** lymphoedema were obese BMI 30 - >40. 55% of these patients had a BMI>40.
- 48% of those patient with **stage ii** lymphoedema were obese BMI 30 - >40. 31% of these patients had a BMI>40.

- 38 % of those patient with **stage i** lymphoedema were obese BMI 30 - >40. 22% of these patients had a BMI>40.
- 18 % of those patient with **stage 0** lymphoedema were obese BMI 30 - >40. 33% of these patients had a BMI>40.

6.1.7.5. Cellulitis

433 patients were recorded to have had a history of cellulitis. 213 of those were shown to have had a history of cellulitis due to their swelling.

Over the eight week period, 65 out of the 1310 patients had a hospital admission due to their cellulitis in the past year. In total there were 84 hospital admissions. The Strategic Health Needs Assessment reported that in 2014 to 2015 the non-elective cellulitis admissions in Greater Manchester for each CCG had an average cost of £962. Based on the average cost the above 65 patients costed the NHS £80,808 for a 12 month period for non-elective cellulitis admission.

Factors to consider:

- There is also the costs of those patient that have cellulitis and non-elective hospital admissions that are a patient to one of these services but did not have an appointment over the eight week period.
- There are also those people that may have lymphoedema that are not diagnosed and not accessing services that are also developing cellulitis with non-elective hospital admission, IV Therapy or antibiotics.

It is possible for non-elective admission costs to be reduced if people were managing their lymphoedema more effectively and reducing their risk of developing an infection.

6.1.8. Medicine Optimisation – Garments and IV Therapy

A hosiery company has provided 12 months of data showing the number of garments ordered across Greater Manchester for a 12 month period. The data showed that there were 1013 different type of hosiery products ordered. This data does not separate lymphoedema and vascular related ordering. However it provides an overview of the breadth of garments that are available to order.

There are no standards or a local formulary for prescriptions. The PrescQIPP Bulletin 192 – April 2019 recommends Clinical Commissioning Groups (CCGs) should develop, implement and review local pathways for the use of lymphoedema compression garments.

Abstract from the PrescQIPP Bulletin 192 – April 2019

Nationally £19.9 million is spent annually on the prescribing of lymphoedema compression garments (ePACT October to December 2018). These garments do have Dictionary of Medicines and Devices (dm+d) codes, but there are a wide range of products available, and GP prescribing systems do not recognise these codes so it can be difficult to identify the intended product. It is not possible to tell what proportion of this annual spend is due to the incorrect item being prescribed and dispensed leading to wastage and the need for another prescription. This bulletin provides the rationale for ensuring they are used as part of a local pathway that incorporates an ordering process which ensures the correct items are selected to avoid waste.

Bury CCG have completed an initial audit on their garments and this can be found in appendix 6.

The conclusion of the report:

“Work with the Macmillan GM Lymphoedema Programme to develop a lymphoedema garment formulary would be welcomed locally; however expert input would be required due the large variety of lymphoedema garments available.



A formulary of this nature would need to consider both the cost-effective use of resources but also the quality and variety of products available on the market to meet the needs of patients."

Below is a list of the hosiery companies the services use

Service	Sigvaris	Juzo	Medi UK	Haddenham	Essity	Jobst	Elinar	Other
Total	9	9	7	7	7	4	2	3
Bury	1		1	1		1	1	
HMR		1			1	1		
MFT - Nightingale Centre	1	1	1		1			
North Manchester - Lymphoedema Service	1	1		1	1	1		
Oldham	1	1	1			1		Predom
Salford	1	1	1	1	1			
St Anns		1	1	1	1		1	Venostan
Tameside & Glossop ICFT	1	1		1	1			Thusane
The Christie	1	1	1					
Wigan and Leigh	1	1		1	1			
Willow wood	1		1	1				

The cost of cellulitis non-elective admissions and IV therapy treatment also needs to be taken into consideration when looking at garments. There is a potential that an increase in provision would mean an increase in hosiery costs. Never the less this could decrease the costs on non-elective cellulitis admissions and IV therapy treatment.

6.2. Other provision

6.2.1. Surgery

Over the last twenty years, there has been resurgence in interest in surgery for lymphoedema. In general, the options are divided into reconstructive surgery (that tries to enhance the remaining function of the lymphatic system), and de-bulking surgery (that accepts the lymphatic system is too damaged to recover, and treats the consequences of lymphoedema). Currently, there is limited access to surgery for lymphoedema on the NHS. Most procedures need to be undertaken privately or with special individual funding arrangements. (BLS 2018^{xix}). Surgery is not a cure for lymphoedema but may help to manage symptoms and improve quality of life. The surgical team should always work collaboratively with lymphoedema practitioners prior to and following surgery to provide a seamless experience to the patient.

Lymphatic Liposuction

Liposuction aims to remove excess adipose tissue from the affected limb(s). This effects volume reduction with the aim of reduction of limb distortion and an improvement in the shape of the limb. However it is vitally important that the patient wears effective compression hosiery continuously and diligently following this procedure to prevent recurrence. Specialist lymphoedema follow up and replacement of garments will continue therefore surgery continues to impact on Lymphoedema service provision. The Christie Foundation Trust has funded a minimal number of patients for this procedure. The Christie's Lymphoedema service is looking for NHS investment to increase the numbers of patients.

Lymphaticovenular anastomosis (LVA) and Lymph Node Transfer (LNT)

These surgical procedures attempt to improve the swelling but do rely on there being a good remaining lymphatic function available elsewhere in the body. The aim is to redistribute lymphatic fluid either to the remaining circulation via the venous system or to transplant lymph nodes from an unaffected area to bypass any damaged tissues and over time improve lymphatic flow. LNT can rarely cause lymphoedema in the drainage area from the donor site. These patients will continue to need specialist services and monitoring following surgery.

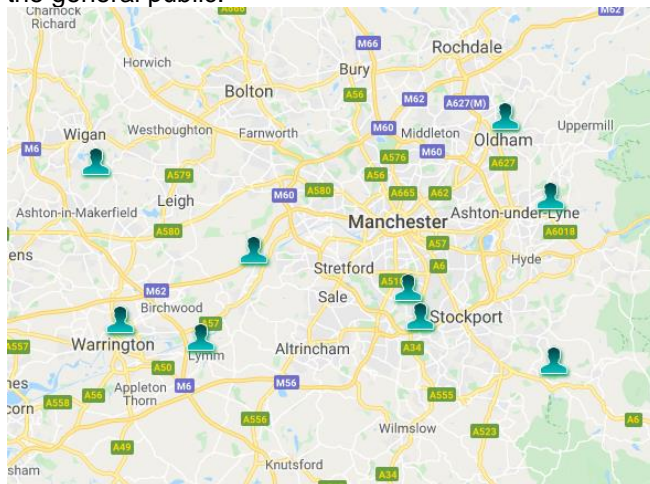
In September 2015, the Welsh Health Specialist Services Committee (WHSSC) supported LVA surgery for 42 patients per annum, funded by Wales NHS. Wales is still the only country in the UK to offer this surgery on the NHS for cancer and non-cancer lymphoedema patients^{xx} but the numbers remain low comparable to the need.

6.2.2. Palliative care and end of life

There are palliative care and end of life nurses that are trained at keyworker level lymphoedema. There are also other end of life and palliative care clinician that will have received training modules on lymphoedema. Even though these staff are unlikely to be providing treatment they will be providing some support on self-management.

6.2.3. Private

Below is a map of private practitioners that are registered with MLDUK and will accept enquiries from the general public.



MLDUK is a company limited by guarantee who publishes a register of MLD practitioners including their professional qualifications. There is evidence from the user involvement/patient experience section within the gap analysis report that patients who access the NHS services also attend private appointments for treatment.

6.2.4. Private Complementary Therapist

There are also private complementary therapists advertising lymphoedema treatment. A brief review of some of these treatment offers indicates the therapists are offering complementary therapy rather than competent lymphoedema treatment.

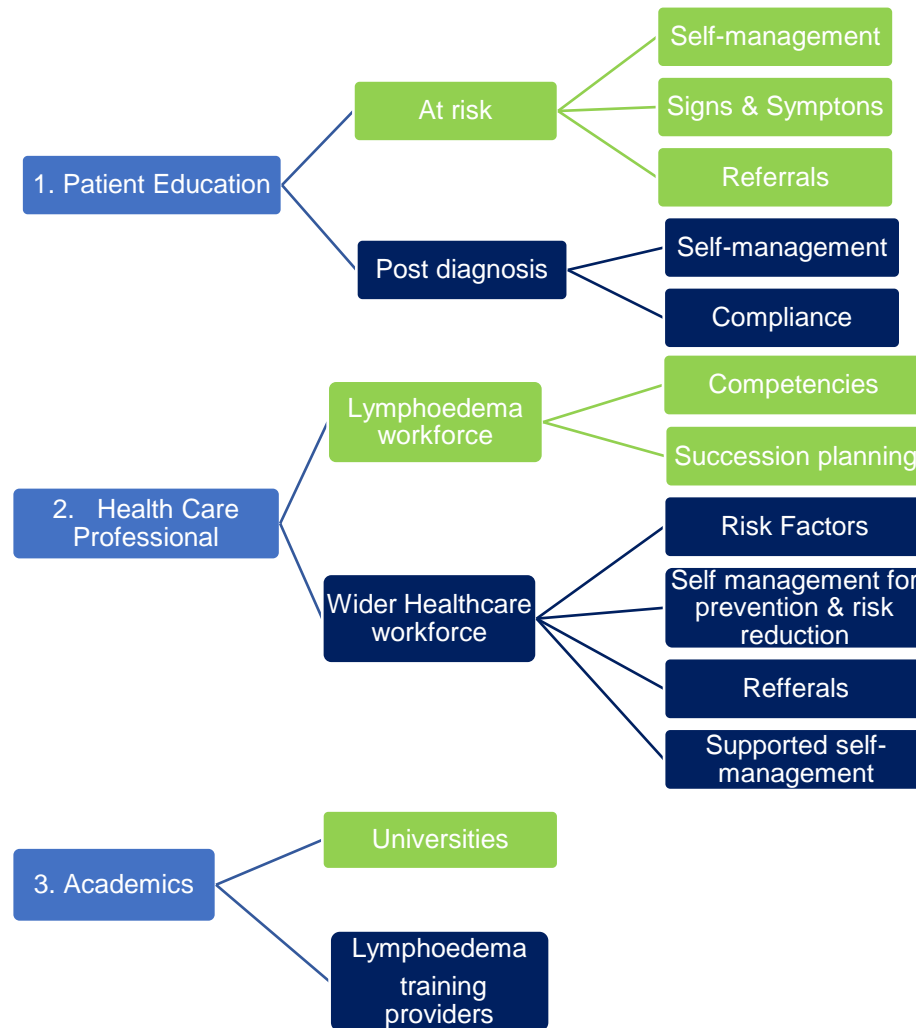
6.2.5. Support Groups

- Oldham Dr Kershaw's support group
- Rochdale service has a support group
- North Manchester lymphoedema service's support group

- Two of the programme's user involvement representatives are working with the Macmillan User Involvement Facilitator and Macmillan to set up two support groups
- Lymphoedema Support Network is a charity that offers membership and over the phone and social media support to people affected by lymphoedema.

7. Learning and Development

As part of the review; the programme was required to look at learning and development needs. This was split into three sections as detailed below. The method was Questionnaires, semi-structure interviews and review of secondary documentation.



7.1. Patient Education

The Patient Experience section 7.1 will demonstrate the findings from patients about their education needs. In addition to this other information that the programme has gathered is detailed below.

Cancer Patients – Living with and Beyond Health and Well-being events

Across Greater Manchester Cancer Clinical teams are delivering Health and Well-being events. This is an opportunity for lymphoedema specialist services to educate people at risk of lymphoedema due to their cancer treatment about self-care and signs and symptoms to re-inforce the message. There is not a clear structure for lymphoedema to be included in these events.

Patient Education event

The Christie's Lymphoedema service held a large patient education event circa 3 years previously. The Greater Manchester lymphoedema Clinical Network wanted to develop a first Greater Manchester patient education event in 2019. The aim was to deliver an event along similar lines but to include the whole of Greater Manchester Lymphoedema services working together collaboratively for all types of adult lymphoedema patients. This took place in November 2019. This event delivered an engagement session in which patients were in table groups and facilitated to cover different topics including self-management.

Evaluation of the event showed that the majority of patients that responded were moderate in their knowledge prior to the event.

What was your level of knowledge about lymphoedema before this event?	
Did not respond	2
Low - 1	0
2	8
3	38
4	22
High - 5	7
Grand Total	77

What was your level of knowledge about lymphoedema after this event?	
Did not respond	7
Low - 1	
2	
3	7
4	34
High - 5	29
Grand Total	77

55% of attendees' knowledge increased by one, 13% knowledge increased by two and 2% knowledge increased by three. 16% knowledge was the same. 14% didn't complete the questions fully.

Patient Feedback

More emphasis needed from Macmillan nurses about owning your own body when having first lymph node clearance (breast cancer)

A lot to take in all at once, but informative and useful. A stepping stone to self-management with a degree of confidence.

Macmillan should be commended in raising profile of lymphoedema which acknowledged and truly am grateful for that a push has been made in educating not just patients but clinicians who care for us as their patients

They were all very good but as I have had lymphoedema for 17 years only some things were new. It was great to have an update especially on what is available

I felt a little uncomfortable as I have the condition but not from cancer and I felt it was more tailored to this. I also have lipoedema, I feel this should also be addressed the two combined would be helpful.

I didn't think there was enough awareness of none cancerous lymphoedema, commonly lipo lymphoedema. Also most of my problem has been legs very little on this.

Very useful information - particularly regarding exercise

A lot I already knew, but there was still a couple of things I learnt, I also am a member of the LSN and receive a magazine every few months which is useful too.

Learnt so much from the exercise so helpful, handy tips for moisturiser, very informative on treatments, very helpful and light hearted but got to the point across without using the serious side

Brilliant sessions and very informative, wish I had the opportunity to learn more when first diagnosed

I have developed lymphoedema due to a road accident damaging the system in my right leg. I know it will never improve these sessions have been useful.

The feedback from this event confirms there are clear outcomes of increased patient knowledge and a gap in patient's knowledge. This event was for over 100 people where there are over 3,000 on the current caseload and a potential 11,000 to 17,000 people with lymphoedema. Local sustainable options need to be considered to enable more patients to access such education.

7.2. Healthcare Professionals – Lymphoedema workforce

The British Lymphoedema Society has published professional's roles in the care of lymphoedema (copy in Appendix 1 – supporting documents). This recommends the required education level for healthcare professionals and the lymphoedema specific courses required for the different levels of practice.

Current Lymphoedema Staff

In the semi-structured interviews with the services it was noted that a number of practitioners are upskilling and undertaking training:

In-training

Four practitioners are either undertaking or working towards qualifying as a lymphoedema specialist.

Salford – Both Keyworkers undertaking Specialist training, expected completion January 2020, this will allow the team to provide specialist breast service and could potentially extend the service to other cancers i.e. Head and Neck, although current commissioning of the service is for a lymphoedema and physio breast service only

North Manchester – Keyworker is undertaking specialist training with Tissue Viability Nurse undertaking keyworker training which aims to be completed mid-2020. This could potentially extend service to accept upper body and cancer, however this will be dependent on commissioning provision.

Wigan – have a keyworker development post currently, which will increase capacity of their service. There is obviously need for further trained lymphoedema staff if the region aims to develop and improve the overall provision and align with the BLS recommendations.

Training Needs

There is another development post that will be looking to qualify as a specialist in the future. Other training recorded was for Fluoroscopy, Manual Lymphatic Drainage (MLD), Kinesiotaping (a form of treatment), Oncology training and psychology.

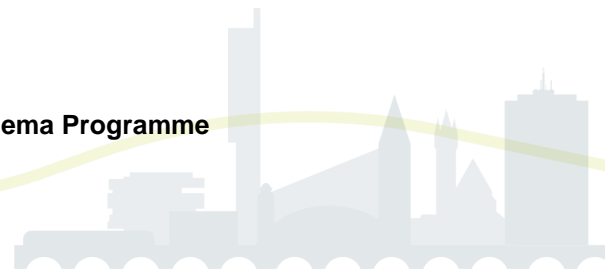
7.3. Healthcare Professionals – Wider Healthcare workforce

Three questionnaires were developed to understand the knowledge of Cancer Clinical Nurse Specialists, GPs and wider healthcare professionals (District Nurses, Tissue Viability Nurses, Palliative Care and End of Life specialists, Allied Health Professionals) practitioners understanding and knowledge of lymphoedema. These practitioners are likely to be in frequent contact with those patients at risk of lymphoedema as well as those with a diagnosis, who often have complex co-morbidities. These practitioners are likely to be in contact with those people at risk and those people who are diagnosed within lymphoedema and have co-morbidities. These questionnaires enabled to understand what the gaps and needs are within Greater Manchester.

7.3.1. Key Themes from Questionnaires

Key Themes from Cancer Clinical Nurse Specialist:

- Knowledge of risk was high but some educational needs
- Increase the confidence in recognising symptoms
- A need for education in prevention advice
- Training would benefit their role



Key Themes from Primary Care:

- GPs knowledge on risk, prevention and stages of lymphoedema is low
- Good ability to recognise symptoms of lymphoedema
- Gaps in knowledge in where to refer
- Challenges in communication between lymphoedema services and GP on prescribing of garments

Key Themes for wider healthcare professionals:

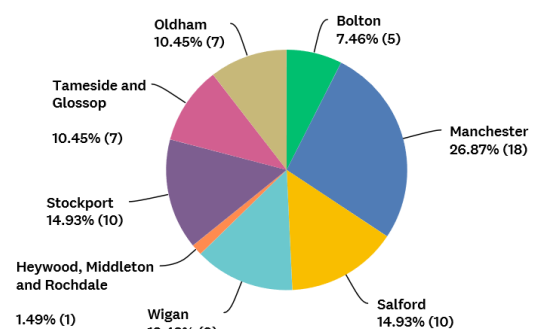
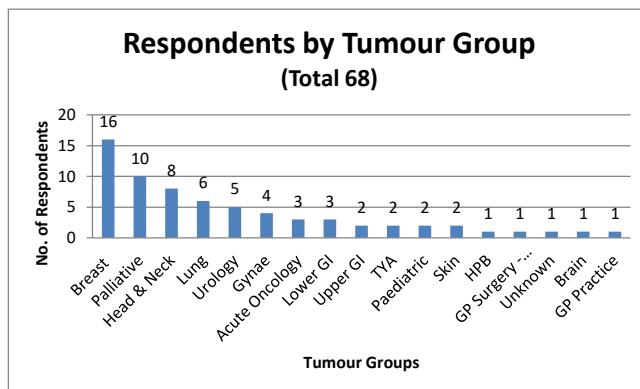
- High percentage of respondents have little knowledge on risk factors and causes of lymphoedema
- They had better knowledge of lymphoedema symptoms
- People at Risk of Lymphoedema are not provided guidance to reduce their risk
- Professional supporting the treatment of lymphoedema (bandaging) knowledge is average to little knowledge
- Training would benefit their role
- Lack of collaborative working and links with the different specialities

7.3.2.Clinical Nurse Specialists questionnaire

The questionnaire was sent to all CNS's in each Acute Trust via Lead Cancer Nurses to gain an understanding of knowledge regarding risk, symptoms and prevention of lymphoedema, in addition to identifying education requirements.

We received 68 responses and whilst the results provide us with a valuable insight of the current landscape, the programme acknowledges that the results obtained are a small sample and may not reflect the whole GM CNS population.

The information below provides a breakdown of the respondent's locality and which tumour groups they predominantly worked in.



Knowledge of Risk

The programme obtained information from published studies of research that shows tumour groups who are at an increased risk of lymphoedema as detailed in section 5.1 and percentages provide below:

Tumour Group	Head Neck	& Gynae	Skin	Sarcoma	Breast	Urology
Risk %	55-75%	36%	11-31%	30%	25%	25%

Other tumour groups do have a risk of developing lymphoedema, although this is a significantly lower percentage.

The survey asked CNS's if they were aware of the risk of lymphoedema in their tumour groups by categorising their risk.

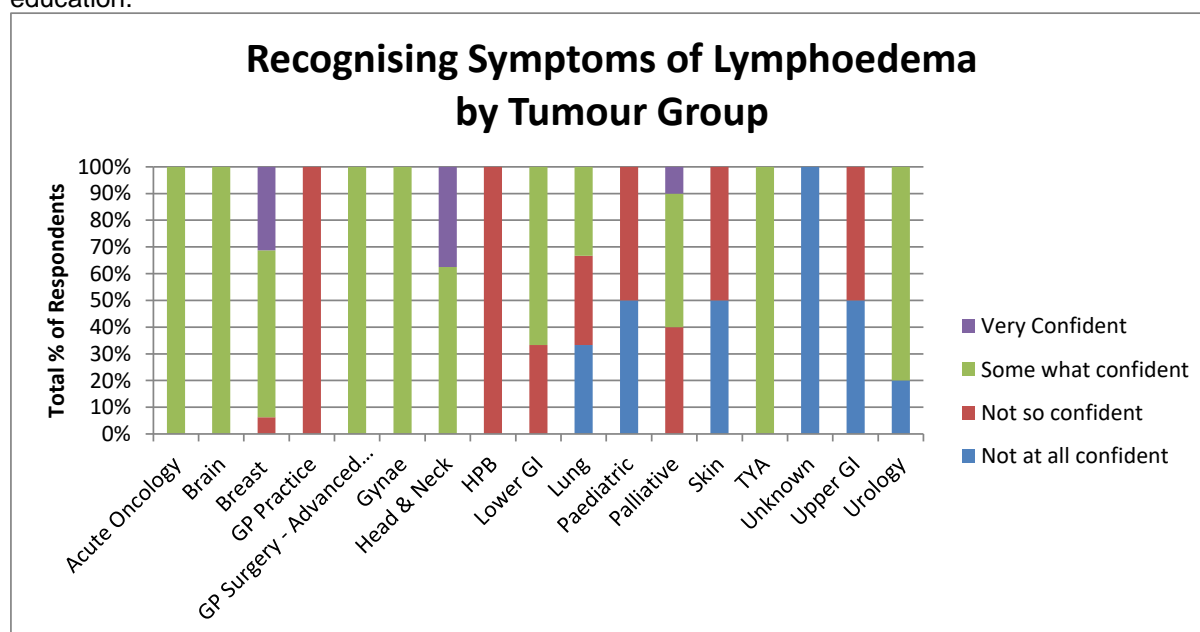
Respondents by Tumour Group (risk %)	High >50%	Med 10-50 %	Low <10%	Grand Total
Breast (25%)		13	3	16
Head & Neck (55-75%)	5	2	1	8
Gynae (36%)	1	3		4
Urology (25%)		3	2	5
Skin (11% - 31%)			2	2
Sarcoma (30%)			No Respondents	

The results show the majority of CNS's were aware of the risk for their tumour groups. Over 80% of Breast and 75% of Gynae CNS's were aware of the risk. However, it does highlight the need for further education as 100% (2) of Skin CNS's believed the risk for their tumour group was low, along with over 37% of Head and Neck CNS's stating the risk was medium or low, when this tumour group is high risk.

Further analysis shows Manchester locality appears to have the largest number of CNS's unaware of the correct risk factor for their tumour group, with 50% of Breast and Head & Neck CNS and 100% of Gynae, Urology and Skin CNS's unaware of the risk factor. Although Manchester respondents account for the largest locality response rate at 26% (16) and cover three large hospitals that provide cancer services. Nevertheless it highlights the need for further education.

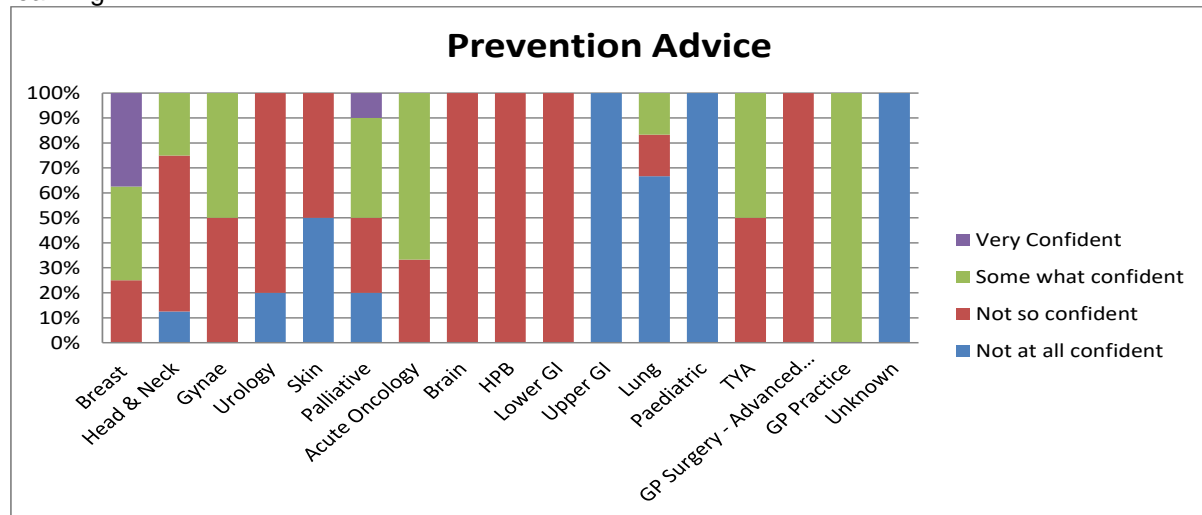
Symptoms

The survey asked how confident individuals were in recognising symptoms of lymphoedema. Overall the results show that 71% were somewhat or very confident, but 29% not so or not at all confident. Further analysis of the results shows tumour groups most confident include Head & Neck, Gynae, Acute Oncology, Brain, Breast and Urology who are between 80-100% somewhat or very confident. Results show that Skin CNS's who are both from different localities could benefit from additional education.



Prevention Advice

The survey asked how confident did individuals feel in providing lymphoedema prevention advice. Overall 62% of respondents stated that they were not so or not at all confident. Further analysis by tumour group highlighted with the exception of Breast and Acute Oncology, 50% or more of all tumour groups were not so or not at all confident in providing advice, again highlighting and opportunity for learning.



When asked what prevention advice did they provide results show:

- 35% do not give advice to their patients on lymphoedema.
- 29% provide a tumour specific leaflet
- 19% provide a leaflet on lymphoedema
- 16% provide tailored advice on lymphoedema

Referrals

The survey asked where respondents would refer patients with symptoms of lymphoedema. This question gave respondents categories to select. Over 82% stated to a specific lymphoedema service, 9% to information centres and 9% to other, which includes referring back to original consultants and one to a GP. Analysis shows those who would refer to information centres, lymphoedema services are available in there locality, therefore highlighting the need to communicate lymphoedema service provision across all GM localities.

As options were provided to the respondents it is unclear if they know what lymphoedema services are available to refer to or they just knew to refer to a lymphoedema service.

Education Needs

To help us understand education needs, the survey asked if specific training on lymphoedema would benefit their role and also which training method would be preferred. The results shown 87% felt training would benefit their role. The 13% that felt training would not benefit their roles; two thirds felt very or somewhat confident in their knowledge and did not feel it beneficial. The remaining third were lung CNS's who were not so confident, but possibly felt it was not beneficial due to small number of patients with lymphoedema they come into contact with. The preferred method of training was face to face with over 76% choosing a study day or ½ day learning session and 16% opting for an training module or e-learning.

Overall, the survey has showed that there is a significant desire for further education around lymphoedema and with exception to some tumour groups, who appear somewhat more information i.e. breast and gynae, there certainly is an opportunity to increase levels of knowledge relating to risk and symptoms in order to provide appropriate prevention/risk reduction advice, especially for the skin tumour group.

Details of the questionnaire and responses can be found in Appendix 8.

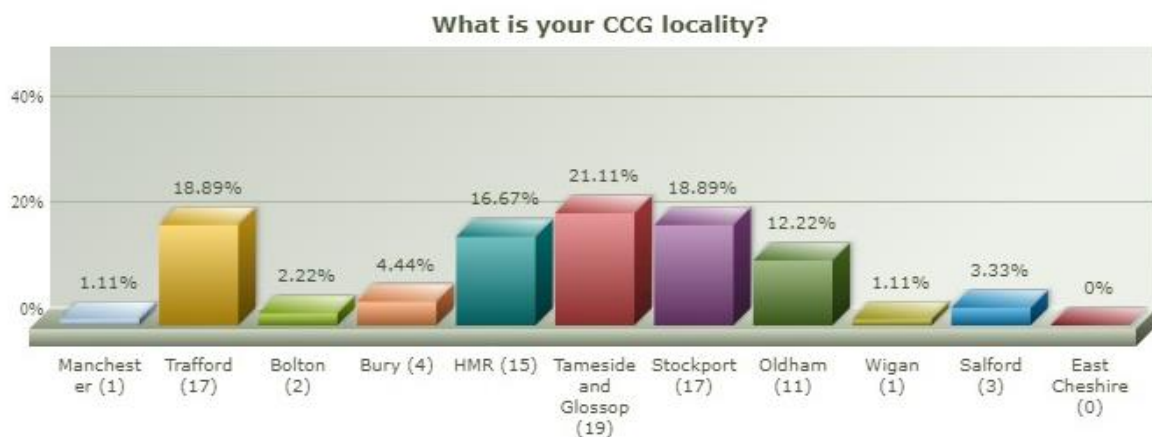
7.3.3. Primary Care Questionnaire analysis

The questionnaire was sent to GP's via CCG's Primary Care Communications teams to investigate their knowledge of lymphoedema in terms of: recognising risk factors, signs and symptoms, prescribing and referral processes.

The survey received a total of 90 responses. Key themes identified

- were lymphoedema knowledge,
- communication of service availability
- learning and education.

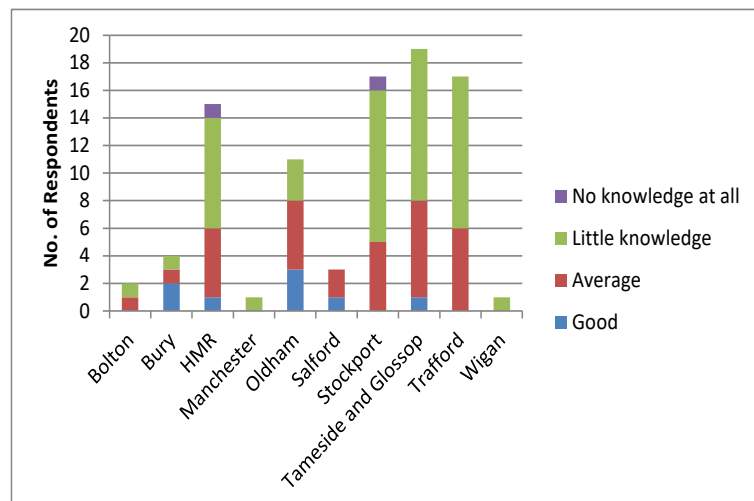
Details of which CCG our respondents represented are provided.



Lymphoedema Knowledge (Risk factors, Prevention and Stages)

The survey asked GPs how they would describe their knowledge of lymphoedema, which included risk factors, prevention, stages and treatments. The results show that **56%** of GPs report that they have **little to no knowledge** of being able to describe risk factors, prevention, stages of lymphoedema and its treatments.

Results broken down by geographical area, show that Salford, Bury and Oldham GPs feel they have good to average knowledge, whereas respondents from other areas i.e. Stockport, Trafford and HMR could benefit from further education.



Symptoms

GPs were asked how confident they felt in recognising the symptoms of lymphoedema?

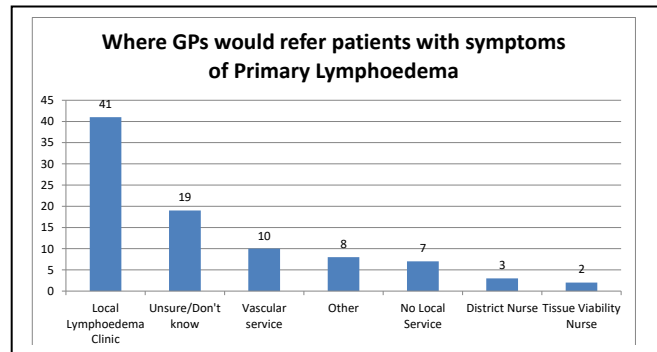
64% of GPs stated that they were **confident or reasonably confident in recognising the symptoms** of lymphoedema, despite over half of the respondents advising they had little or no knowledge of the risk or prevention of the condition. This may be interpreted that GPs feel less

confident in having a greater overall knowledge of lymphoedema (i.e. risk factors, treatments and staging), but confidence in their ability to recognise symptoms

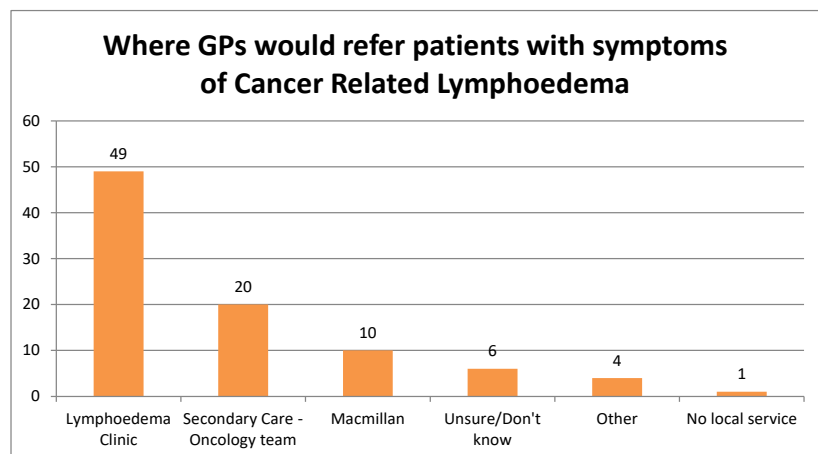
Referrals

The survey asked where would you refer patients presenting symptoms of lymphoedema in relation to the following groups:

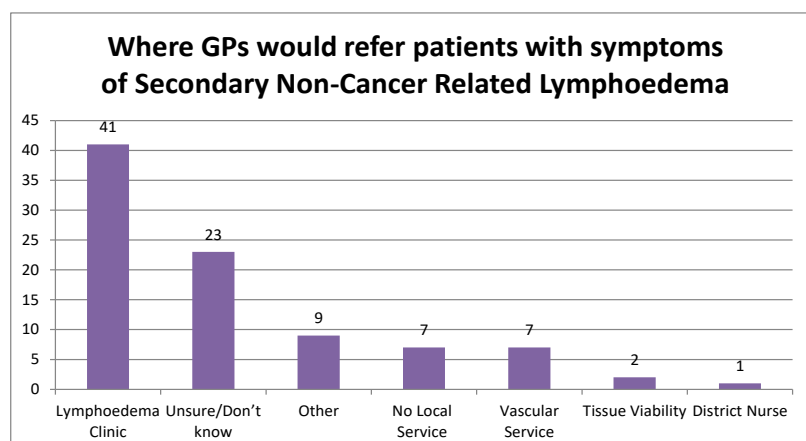
Primary Lymphoedema - the majority of respondents (45.6%) stated they would refer to a local lymphoedema clinic, of which 12% specified a lymphoedema service. However, 9% of those specified services (The Christie, Willow Wood and MFT) do not accept Primary Lymphoedema referrals. Over 20% were also unsure/not known or refer to lymphoedema clinic, with some referring to vascular. These results highlight that GPs would benefit from information regarding referral criteria for their local lymphoedema service.



Secondary Cancer - majority refer to lymphoedema clinic (54%) or via the patients cancer pathway (22%). A small number of respondents were unsure or thought there was no service available. Further analysis of the data shows that GPs with HMR have been impacted by the recent decommissioning of the cancer related lymphoedema service. However, the programme is aware that this service is looking to be recommissioned imminently.



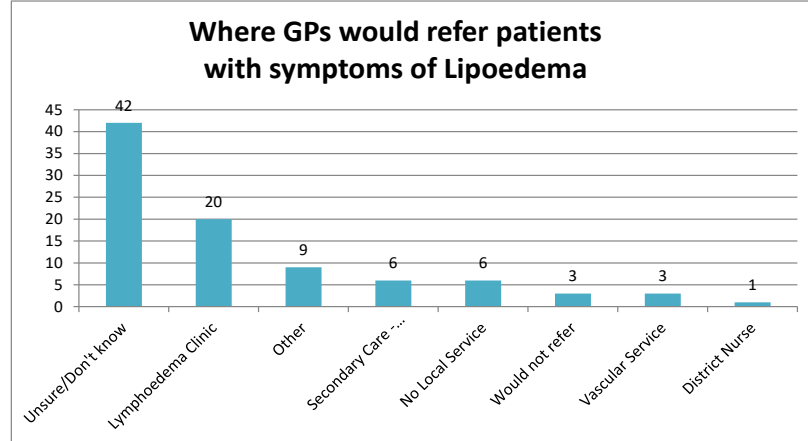
Secondary Non Cancer – as above, the majority of respondents (46%) stated they would refer to lymphoedema clinic, of which 10% specified a service that only accept cancer related referrals. A third of respondents stated they was no local service or unsure/not known where to refer. Further analysis shows services are available within the respondents localities, again highlighting the need for improved communication of lymphoedema services.



The information shows localities that would benefit from this information are HMR, Stockport, Trafford, Oldham and Tameside & Glossop.

Lipoedema - results indicated a significant lack of awareness relating to lipoedema, with approximately two thirds of respondents unsure where to refer and only a small number referring to the appropriate service.

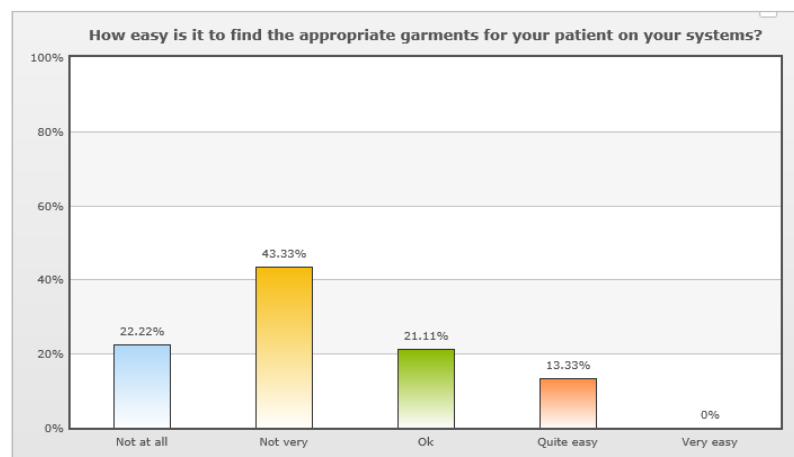
Overall, these results highlight that GPs would benefit from improved communication regarding the local lymphoedema service and referral criteria for their localities.



Prescribing

GPs were asked whether they felt the information provided by lymphoedema teams allows them to easily locate the appropriate prescription garments. The results show 52% did not feel the information they received was appropriate, highlighting an opportunity to improve communication and learning with GPs and lymphoedema teams.

The survey asked if it was easy to find the appropriate garments for the patient on their system. 66% of GPs reported that they found it not very to not at all easy to find prescribing the appropriate garment.



Education

The survey asked whether training on lymphoedema would benefit their role and the preferred method of training. Results also showed that **94%** of GPs reported that lymphoedema training would benefit their role. Face to face was more favourable (56%:- Lunch & Learn - 33%, ½ study day 23%), following closely by e-learning (30%).

A user involvement survey has also been carried out, which highlighted that patients had experienced lack of awareness from their GP.

'...I was advised to go through my gp who didn't have much understanding or information...'

'...I was advised to look online for information, as many GP's have only heard of the Lymphoedema, not the Lipoedema...'

'...I didn't realise it was lymphoedema, nor did my GP although I went to see him when my leg became swollen...'

Overall, the survey provided a valuable insight into the level of understanding from a GP perspective and highlighted the need to improve general lymphoedema knowledge, especially around the risk factors and the significant lack of knowledge around lipoedema. The results also shown the need for

improved communication of the local lymphoedema services and the referral criteria is apparent to ensure patients are referred to the appropriate services. Learning and development opportunities will support GPs with their overall knowledge.
Further details of the survey results can be found in Appendix 9.

Below is a list of the comments from GPs. These have not been amended in the wording. There is a strong case of need for investment in lymphoedema and training for primary care

A service would be extremely beneficial to our patients
as a GP and a user of this service, I feel we are very lucky to have such a good service locally but it is grossly under staffed
For some time we have had no significant service other than for breast cancer patients.
Loss of Lymphoedema services causes huge distress to patients. It tends to affect female patients more than male patients and as such cutting services is discriminatory.
I would suspect higher investment would result in fewer admissions with cellulitis/sepsis and fewer leg ulcers.
I would like to know who to refer to
I would prefer the garments to be prescribed by the service rather than gp. It would also be useful to know where we can send patients.
if anyone is available to provide a 90 minute training slot for Trafford GPs
Is there any e-learning packages too that we could use in the meantime?
IT is not clear exactly what lymphoedema services we have locally
maybe a session at a masterclass in stockport
No proper provision for patients with non-cancer lymphoedema or lipoedema. Occasionally Christie will see.
Please can we have a non-cancer related service
Please do let us know if there are any lymphoedema/lipodema services we can access for non cancer NHS, especially for lipodema.
please advise us of local lymphoedema services, thank-you for taking time to help us learn more. I am aware i need more knowledge in this area and would appreciate training.
This is an area of significant risk as there is not consistent provision of services
to inform us where is the appropriate service we can refer these patients to
updated referral information on available services and a self help flow chart would be very useful
We have struggled to access lymphoedema services in our locality and would appreciate improved service provision
We have TARGET on thursdays once monthly. can teach us about service then & there

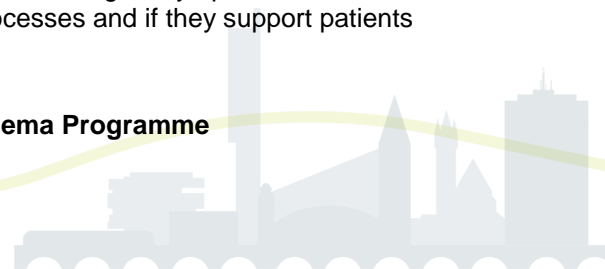
7.3.4. Wider Health Care Professional

Physical Health Trainers

Education events and meetings with Health Trainers as part of GM Active advised they would be interested in looking to support people within lymphoedema but would require training. In the patient survey (detailed below) there was a quote from a patient advising that a health trainer would not support them in exercise because of their lymphoedema. Exercise is a significant part of self-management. Collaboration between the two services is essential.

Questionnaire to Health Care professionals

A questionnaire was sent to a variety of healthcare professionals including; Tissue Viability Nurses, Practice Nurses, District Nurses and AHP's via several mediums; provider and CCG Communications teams, Lead Nurses and Community Service teams to review their knowledge of lymphoedema in terms of; recognising risk factors, signs and symptoms, referral processes and if they support patients with lymphoedema.



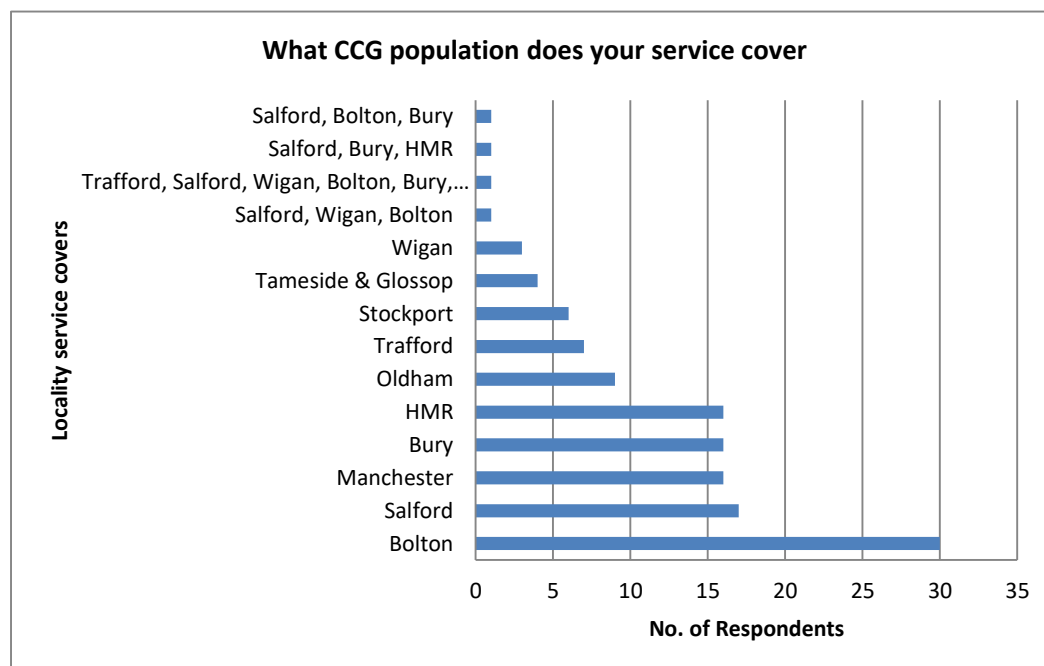
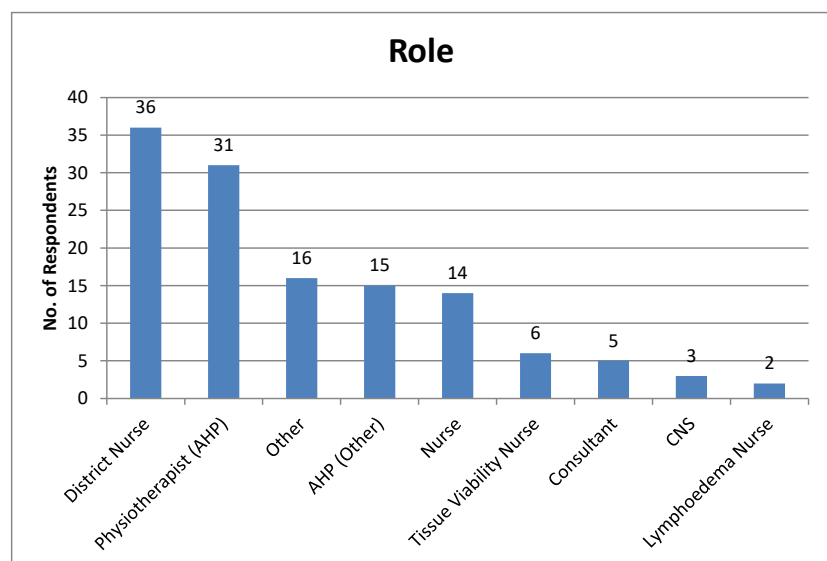
These professionals are likely to have contact with people who are at risk of the condition and also have contact with those that have lymphoedema due to co-morbidities.

The survey received a total of 128 responses. The key themes identified

- High percentage of respondents have little knowledge on risk factors and causes of lymphoedema
- They had better knowledge of lymphoedema symptoms
- People at Risk of Lymphoedema are not provided guidance to reduce their risk
- Professional supporting the treatment of lymphoedema (bandaging) knowledge is average to little knowledge
- Lack of collaborative working and links with the different specialities

Details of our respondents' roles are detailed below along with the CCG population their service covers:

As the results show we received the largest response 36% from AHP's (Physiotherapists 24% and Other AHP's 12%). Other AHP's include 9 podiatrist and 2 Occupational Therapists and 1 Dietitian, Therapy Instructor, Orthoptist and Exercise Physiologist. This is closely followed by District Nurses (28%). Details of those who responded 'Other' (16) include Health Visitors, Assistance Practitioners, clerical staff and service managers/team leaders plus a surgeon and palliative doctor. 1 Respondent did not state.



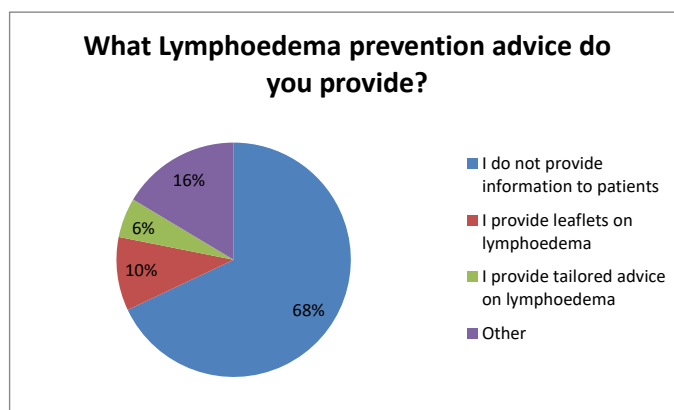
Lymphoedema Knowledge (Risk factors, Prevention and Stages)

The survey asked how you would describe your knowledge of lymphoedema, which included risk factors, prevention, stages and treatments. The results show that 60% of health care professionals reported that they had little to no knowledge of the risk factors, prevention, stages or treatment of lymphoedema. 30% reported they had an average knowledge of lymphoedema Whilst only 7% had a good knowledge of lymphoedema and 2% had a excellent knowledge.

Further analysis shows within the largest respondent groups (District Nurses and AHP's) there is a mix of knowledge. Of the 36 District Nurses who responded 47% described their knowledge as average to excellent, with the 53% stating they have little or no knowledge. Of the 46 AHP's; 78% stated they had little or no knowledge, highlighting the opportunity for education opportunities.

Healthcare professionals were asked how confident they felt in providing lymphoedema prevention advice. Results showed that over two thirds did not feel confident to discuss lymphoedema with their patients and 73% reported that they have little to no confidence in providing lymphoedema prevention advice to their patients.

The survey asked 'what prevention advice do you provide for lymphoedema patients'. The options were; do not provide advice; provide a lymphoedema leaflet; provide tailored advice or other. The results show that 68% of respondents do not provide prevention advice and only 6% provide tailored



advice. Of those who provided tailored advice, further analysis show that HMR, Manchester and Salford localities accounted for 87% (6) of these results, with District Nurses (2), Tissue Viability Nurses (2), Lymphoedema Nurse (1) and Physiotherapist (1) providing the advice.

The results of those who provided an 'other' response include sign posting to lymphoedema service, nurse, referring to GP. The gap in knowledge for GPs could mean that people are not provided effective prevention advice on how to self-care to reduce the risk of developing the condition.

Symptoms, Causes and referrals

Knowledge of symptoms

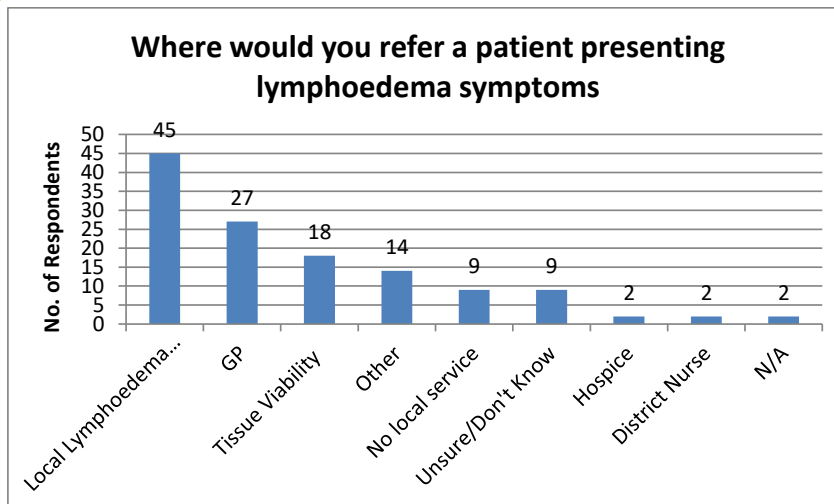
60% of respondents felt reasonably to very confident they could recognise symptoms of lymphoedema, despite 60% reporting they had little or no knowledge. This may be interpreted that the wider healthcare professionals feel less confident in having a greater overall knowledge of lymphoedema (i.e. risk factors, treatments and staging), but confidence in their ability to recognise symptoms.

Causes

The questionnaire asked how confident they felt in recognising the causes of secondary lymphoedema. Although survey showed that 60% felt confident in recognising symptoms of lymphoedema, 73% of HCP's stated that they have little to no confidence at all on recognising the **causes associated** with secondary lymphoedema.

Referrals

The survey asked where would you refer patients presenting symptoms of lymphoedema. Results are shown below.



It should also be acknowledged that findings also showed that almost a quarter (21%) of the wider health care professionals said they would refer a patient with a suspected lymphoedema to the GP. It should be noted that 56% of GPs reported in a survey that they have little to no knowledge of recognising risk factors, prevention, stages of lymphoedema or treatments.

Treatment and Hosiery

74% reported that they have little to no knowledge of the treatment and management options for patients with lymphoedema. 72% reported that they do not provide treatment.

Those who do provide treatment (28%) this is provided primarily by District Nurses from six of the 10 CCG localities. The treatment consists primarily of compression bandaging, with some providing skin care advice. Further analysis of this data show that of those healthcare professionals providing treatment 84% described their lymphoedema knowledge as average to little knowledge.

56% knew there was a high risk of cellulitis in a patient with lymphoedema with 44% either Medium or unsure.

Hosiery

34% informed they had a hosiery formulary to follow. This was mainly District Nurses and Tissue Viability/Wound Care. They were also asked if they were supported by a lymphoedema team. Out of the 34% - 33% said No. Mainly from Bolton and Manchester where the lymphoedema provision is not linked with community services. 65% said yes this was mainly HMR, Oldham and Bury where lymphoedema services are part of the wider community service offer and sits with the neighbourhoods.

36% informed that they did not have a hosiery formulary to follow. These were mainly physiotherapist, podiatrists, palliative care and included tissue viability and district nurses. Out of the 36%, 17% had support for lymphoedema service. This was across 5 CCG areas so a small sample. 70% advised they were not supported by a lymphoedema service. This was mainly physiotherapist, district nurses, palliative care. It also included IV Therapy Nurse and a Tissue Viability Nurse that is in a locality that the lymphoedema is part of the tissue viability service. The final 15% there were some that it was applicable to have support like a podiatrist and physiotherapist.

The remaining 30% stated that a hosiery formula was not applicable and out of those 77% of them did not think it was applicable to have support from a lymphoedema service. This was mainly physiotherapist that may have lymphoedema patients. There were other professionals that again support from a lymphoedema service maybe more applicable for them.

Training

Results also showed that 84% of felt that lymphoedema training would benefit their role. Face to face was more favourable 62% (½ study day 36%, Lunch and Learn 26%), following closely by online training 19%.

7.4. Academics

7.4.1. Universities – Undergraduates

The International Lymphoedema Framework has developed a set of 6 Benchmark statements. They have been developed as a teaching resource under the auspices of the International Lymphoedema Framework, a global umbrella organization, and registered UK charitable body. They have been developed through a process of expert panel consensus. These statements have been produced as guidance for any health care professional curriculum. Margaret Sneddon an Honorary Lymphoedema Specialist in NHS Forth Valley, Chair of the British Lymphology Society and a Director and Education Lead for the International Lymphoedema Framework (ILF); advised that feedback from universities was they needed module content alongside the benchmark statements. Further engagement work is required to see how they are nationally going to address this.

7.4.2. Training providers

Available Courses:

There are various training courses that are available. Some are accredited with universities such as Glasgow University, Wolverhampton University, University of East Anglia and University of Hertfordshire. There are other courses delivered by lymphoedema training academy and Lymphoedema Network Wales. There is also training for Manual Lymphatic Training (MLD) and courses are cited in the MLD UK website and Macmillan Lymphoedema Association.

The course costs vary but those that are accredited are over £1,000/£1500 for each module. Due to known retention issues, there is a risk for providers to invest in these courses. Courses are not local so there practitioners have to travel to travel distances involving overnight stays.

The programme has engaged with one university and there is a potential if an outcome of this programme is to train a higher volume of practitioners within Greater Manchester they would be willing to travel and the healthcare professionals would still gain a university accredited certificate.

Hosiery Companies:

There are some hosiery companies that provide training modules for the healthcare professionals in an adjacent field. A further review is required to gain a better understanding but there is no consistency or Greater Manchester approach to ensure the right staff are being training appropriately and effectively.

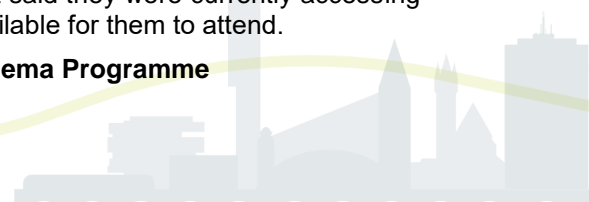
Online training

There are also online training modules that can be accessed for non-specialist lymphoedema staff. This review did not look at how these online courses are being access by Greater Manchester Healthcare professionals

8. People Affected by Lymphoedema

8.1. Quantitative Analysis

A paper based and online survey was distributed to lymphoedema patients across Greater Manchester. The survey consisted of 21 (18 closed and three open answer) questions. There were 6 men (including transmen) and 58 women (including transwomen) respondents 70% of which were of working age (18 to 64). When asked 48% of people did not consider themselves to have a disability, however 39% stated that their lymphoedema does prevent them from doing the things they would usually do. Figure 1 shows where in Greater Manchester respondents reside and where, if they are able to they attend a service. There were 81% of respondents that said they were currently accessing a lymphoedema service, 6% stated that there wasn't a service available for them to attend.



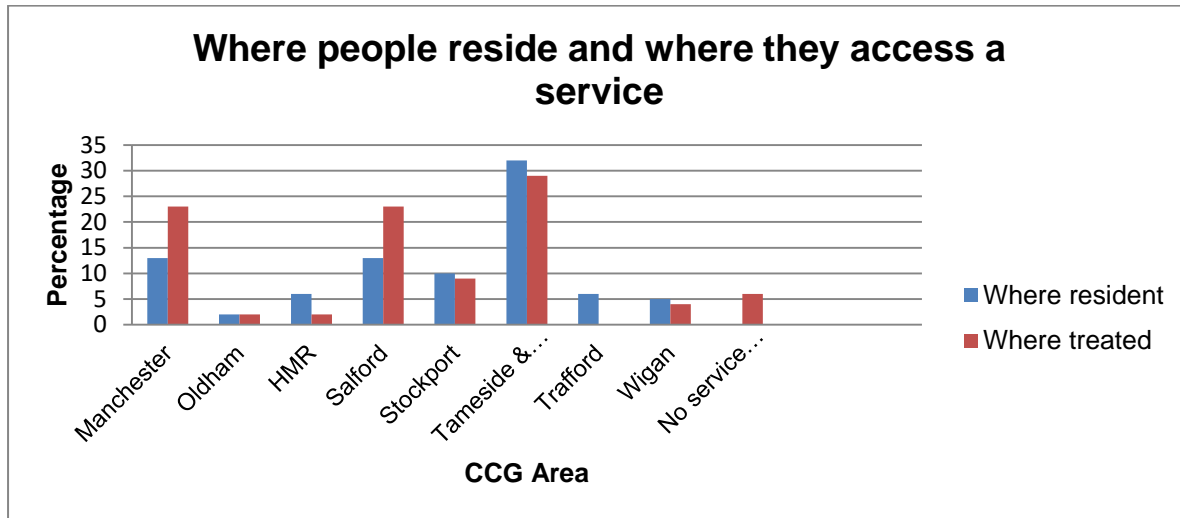


Figure 1. Residence and service access.

A large (74%) percentage of respondents said they have secondary lymphoedema as a result of cancer diagnosis, 16% have primary lymphoedema and 10% have secondary lymphoedema not cause by cancer. When asked about their risk of lymphoedema 55% said that they were unaware of being at risk of lymphoedema. Consultants and GPs were stated as being most likely to refer people to a lymphoedema service (Figure 2). When asked about when they were diagnosed with lymphoedema 28% of people felt they didn't have enough time to discuss the diagnosis and have their questions answered.

Referrer	Number
Consultant	22
GP	20
Lymphoedema Specialist	7
Nurse	6
Physio	3
There isn't a service in my area	3

Referrer	Number
Hospital registrar	1
Salford Hospital Leg Clinic	1
Macmillan - Dr Scott	1
Macmillan nurse	1
Speech and language therapy	1

Figure 2. Who referred you to a lymphoedema service?

The wait time from being referred to a service and having an appointment varied with 30% reporting only having to wait 1 to 4 weeks, whereas 59% reported having to wait between 1 and 5 months. Symptom change whilst waiting for an appointment was reported by 22% of respondents. The length of time people had lymphoedema symptoms before seeking help or advice from a health professional varied (figure 3). One respondent wrote about the impact of waiting and trying to pay for treatment - Woman aged 65-74 "I could only afford to self-finance in 2008 through a bank loan when I recognised the condition was getting worse. Immediately spoke to my local GP when I moved to Bolton, but on almost every visit to the surgery thereafter seemed to see a different doctor. I was encouraged to apply for funding from the local PCC, which I did and failed".

Length of wait	Number of people
Less than a week	5
1-2 weeks	8
2-4 weeks	1
1-2 months	7
2-4 months	5

Length of wait	Number of people
6 months	4
1 year	3
2-3 years	1
15 years	1
25 years	1

Figure 3 Length of time with lymphoedema symptoms before seeking help.

8.2. Qualitative analysis from a service user's perspective

Theme - Emotional wellbeing and support	
Sub theme – Body image	
Service and online forums have been a source of emotional support for people. People reported feelings of distress when they were diagnosed with lymphoedema and told that there isn't a cure. Feeling isolated and being unhappy with their body image was also reported as being an issue that people face daily.	
Female, 55 - 64	"Having access to a lymphoedema service was a life line to me as at the time I just wanted to have my leg cut off"
Female, 35 – 54	"accessed other resources...even just reading their stories gives me a better perspective and I feel less isolated"
Male, 35 – 54	"They care; they make me feel less of a freak."
Female, 35- 54	"At only 36 it has taken my confidence...I don't like going out because of the looks."
Recommendations	
Some services spend time providing emotional support for patients. There could be onward referral for people to receive emotional support from mental health services. Support groups, patient led or with service support that is online or face to face could be invaluable to help people feel less isolated. Support groups could remove some of the burden on services providing emotional support and allow larger numbers of people to talk through their concerns all at the same time rather than taking up clinical slots at a service.	

Theme - Supported self-management	
On the whole people do feel able to manage their condition. There was a sense of people requiring ad hoc support, such as between appointments was highlighted as a need. There was also concern about services discharging patients to self-manage and patients not having the support they require.	
Female, 65 - 74	"Helps you with keeping in control and help any time you have a problem or more swelling than normal"
Female, 35-54	"I'm conscious my 5yr anniversary is coming up...I may be signed off to completely self-manage...concerned...in the past I have had trouble with the ordering of tights through my GP"
Recommendations	
This ongoing support between appointments could also be facilitated with support groups. For people calling services with queries between appointments this could be a central helpline for all services, the helpline could answer brief FAQs for patients.	

Theme - Practical support and specialist equipment	
Sub theme - work	
There is a lack of information around the practicalities of living with lymphoedema. Information around what support such as financial support and access to aids to support living with this condition such as devices to help to put on compression garments is lacking. People also feel that finding clothes and shoes to fit is also very difficult as some people have one swollen leg or arm compared with the other so are unable to find clothes. People feel being sign posted to specialist equipment would be helpful. There are many people that are of working age and have changed jobs or find their lymphoedema impacts on their daily job, sometimes because of the garments, such as wearing a sleeve but needing to be bear below the elbow as working as a nurse.	
Female, 35- 54	"access to support, products, financial help all needs to be more readily available"
Female, 35 -54	"I've had a diagnosis of this which is lymphangioma, it's very demoralising. As i wear my compression, its firm of course, this is rubbing all the crutch area out of my jeans, other pants and my work trousers which is part of my uniform. I feel like a freak, I have a hard job where i am on my feet in excess of 9 hours per day, regardless of me wearing the compression the leg is solid"
Expectations of a service	
	"I've been given a compression garment and leaflet...the garment caused water

	blisters on my arm so I stopped using it and haven't been called back to clinic for a review"
	"I've been lucky I've access to a service"
Medical equipment and treatment	
Some services are able to borrow medical devices that help with treatment. This borrowing seems to happen only at some services and for some patients and not all. The treatment works while people are able to borrow the devices but cannot always be maintained by people to go and buy this equipment. People feel that they need to buy equipment or MLD in order to get the best treatment for them as the services aren't always able to provide what they require. Patients are concerned about the up keep of paying privately and being able to pay the large sums for medical equipment.	
Female, 35 - 54	"Bio compression pump...Great effect on my symptoms...enables me to do my job without pain, however at a cost of £1000 each; it is something I cannot afford".
Female, 65 - 74	"I was also lent a machine for a couple of weeks and there was improvement on my lower legs.
Female, 35-54	"Revolutionary...the taught me how to tape with kinesio tape which actually helps, book me in anytime to have the inflatable up blue legs on for 40 mins, constant source of support".
Female, 35 -54	"At my clinic I've been offered lipo suction but I need to lose weight. As I've been and done the menopause years ago I'm finding it harder to lose weight so I'm getting nowhere fast".
Pain and discomfort	
The amount of pain and discomfort felt by patients is not highlighted enough. People report that pain prevents them from doing much of their daily tasks from paid work, driving to work, shopping, gardening and physical activity. Sleep disturbance was frequently reported by patients resulting from pain.	
Female, 65 -74	"the overall improvement has been a decrease of pain killers during the day"
Female, 35 - 54	"pain, discomfort, impact on mobility, impact on lifestyle, ability. These things are overlooked"
Sex and Relationships	
Relationships have been reported to have been impacted by lymphoedema. Genital lymphoedema is a concern for patients and has impacted on some people's sex life. Such impact has led to feelings of depression. Patients with genital lymphoedema are anxious about the lack of information and because it is a sensitive subject people may not talk about it. People feel that the four cornerstones of care is not a benefit for people with genital lymphoedema.	
Female, 35 - 54	"The problem in my lower region was operated on where they removed these blisters, it was ok for 2 months and they came back again, my husband doesn't like the look of them and says it puts him off so there is no sexual contact.....absolutely doing wonders for my self-esteem"
Male, 65 - 74	"has had a massive impact on my relationship with my wife and has made me depressed"
Access	
Patients reported different types of access being problematic when attending a service. Some mentioned how long it can take to be referred and be seen by a specialist. Some said just being seen at a service can be a lengthy process. Others felt that they wished they could be seen more locally, as treatment can be painful so having to travel afterwards can cause discomfort. Access to different treatment is also different between services but also within a service, depending on time constraints".	
Male, 35 - 54	"I did also have lymph drainage...but now I have to pay for this service, as I am not a cancer patient"
Male, 65 - 74	"It has been time consuming just trying to access a service which has been heart breaking and debilitating"
Female, 55 - 64	"Unfortunately my outpatient clinical specialist is overworked with many patients and I see her each time often missing her lunch so she can fit people in and help as much as possible"

Theme - Value in service and specialists

Sub theme – Other medical conditions

Services and the lymphoedema specialists are valued by people attending them. They really value their skills and knowledge of the condition. People understand the ever changing world of medicine because of the advancements in treatments. They feel above a lot of health professionals, if they are at a service and the service doesn't know the answer they are happy to say so and to provide accurate information at a later date. The support around other medical conditions people suffer with is also important to people. They feel they are provided with good support and information about managing lymphoedema with other comorbidities, such as how to put garments on if you have arthritis in your hands.

Female, 35 - 54	"trust to do her best to support me"
Male, 55 - 64	"I could not imagine my life without these highly skilled experienced health professionals"

Theme - Health professional education

It is felt that more education is needed for health professionals that may encounter people with lymphoedema. This would help people to be referred to a specialist service more promptly. It is felt that when people have had a cancer diagnosis their risk of lymphoedema is not always highlighted to them, this can prevent people seeking advice if they start with a swelling. People that may support in the self-management of lymphoedema may need more education to prevent problems with hosiery measuring and ordering. Also people that could be seem to provide support by way of exercise and diet could have awareness training to help people with lymphoedema to maintain a healthy weight and keep mobile. Currently some services have turned patients away from exercise classes because they do not feel they have the knowledge to support them. Care staff in homes where people live with dementia have also been highlighted as a group that need education as it is those people rather than the patient that are managing the lymphoedema.

Female, 42	"GPs need educating and acknowledgment/recognition needs to be made for the issues that people with lymphoedema have to deal with."
Female, 55 -64	"My lymphoedema became worse due to doctors not understanding cellulitis which turned into grumbling cellulitis"
Female 35 - 54	"Even though they have my records they still automatically think I have had cancer to get lymphoedema".

Theme - System problems

Patients feel unsure about the system and whether they can self-manage without a specialist as the lack of awareness and knowledge has an impact on peoples treatment.

Female, 35 - 54	"in the past I have had trouble with the ordering of tights through my GP"
Female, 35 - 54	"I'm not sure that I get prescribed the right stockings half the time, not sure where it goes wrong in the chain from specialist to gp to pharmacy!"

Patients that are able to attend a service feel well cared for, although some feel the treatment they require isn't possible as services are too busy. There are some patients that can see the impact not having a service is having on them physically and emotionally. The difference in access and treatment available is variable and this is apparent in patient's responses. The impact of lymphoedema is great and not just physically. People require emotional support which could be offered away from a lymphoedema service. Highlighting lymphoedema in other professions would help with practical things like work and buying clothes, shoes hosiery and equipment. Also services that could support such as GPs and exercise classes and mental health services would benefit from better education about the condition so that they can better support in self-management so people can take better control of their condition.



9. Learnings from elsewhere

9.1. National Commissioning Guidance

The commissioning guidance and the programme summary of the commissioning guidance can be found in appendix 1 supporting documentation

The National Lymphoedema Partnership is asking all CCGs and Health Boards:

- to recognise and understand the local need for equitable access,
- understand the potential cost savings,
- utilise the British Lymphology Society and International Lymphoedema Framework guidance when agreeing to the requirements of the service. The latter recommends six standards for lymphoedema services that align with the NHS Outcomes Framework as well as the strategies/recommendations of all UK countries:

Standard 1: Identification of people at risk of or with lymphoedema
Standard 2: Empowerment of people at risk of or with lymphoedema
Standard 3: Provision of lymphoedema services that deliver high quality clinical care that is subject to continuous improvement and integrates community, hospital and hospice based services
Standard 4: Provision of high quality clinical care for people with cellulitis/erysipelas
Standard 5: Provision of compression garments for people with lymphoedema
Standard 6: Provision of multi-agency health and social care

- Utilise the BLS Tariff Advisory document a breakdown of comprehensive treatment as well as suggested staffing levels, (A summary of Tariff Guidelines also available)
- to utilise in the commissioning of services the Service specification and CQUIN from the Transforming Cancer Services Team,
- utilise the BLS 'Professional Roles in the Care of Lymphoedema',
- pre-qualified health professionals to include in undergraduate curricula utilising the Lymphoedema Education Benchmark statements (www.lympho.org/lebs) – The website evidence the need to include this as part of the undergraduate programme.
- Primary Care Education - allow earlier referrals and aid support of self-management

9.2. Wales

A meeting was held with the Lymphoedema Network Wales National Clinical Lead. Information was provided of how the provision of lymphoedema has developed since the commencement of the Network in 2011. Further documents have been shared and reviewed. Appendix 11 provides the governance structure and transformation/improvement projects

Wales has a similar population to Greater Manchester even though it is more rural and only has 7 Health Boards in comparison to 10 CCGs. The provision for lymphoedema staff in Wales in 2011 was very similar to the current provision in Greater Manchester.

Extract from Lymphoedema Value Based Business Case:

To help support people with lymphoedema, Lymphoedema Network Wales (LNW) was developed in 2011 to implement the Lymphoedema Strategy (2009). The £1 million recurrent funding was allocated across all the seven Welsh NHS Health Boards, enabling them to appoint lymphoedema staff and develop services. The allocation was based on the estimation that there would be 6,000 people with lymphoedema in Wales, (prevalence of two per 1,000).

The LNW service model included an overarching National Clinical Lead for Lymphoedema in Wales along with a National Education and Research post. Each of the seven Health Board lymphoedema services has a Clinical Lead with additional practitioners and support staff. Within the Lymphoedema Strategy (2009), it was recommended that each lymphoedema healthcare professional should carry a caseload of 150 to 220 patients if assistant/administration staff were also employed. The

lymphoedema service model was based on guidance from the International Lymphoedema Framework Best Practice for the management of Lymphoedema (2006).

(Appendix 1 – Supporting documents)

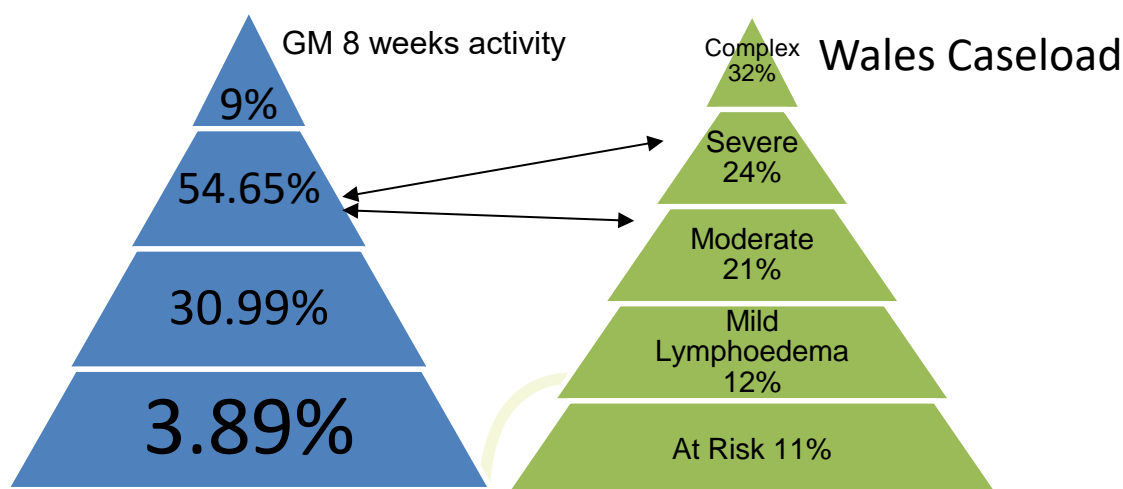
Since the services were established, the awareness of lymphoedema has improved and in 2018 over 20,000 people has been treated for lymphoedema in comparison to the 6,000 people it had planned for. Evidencing there was a larger need than expected.

Key findings from their review:

- 70% of people referred and treated for lymphoedema in Wales did not have a cancer history. In the Greater Manchester dataset 57% of appointments were cancer related lymphoedema.
- All Health Boards provides standardised assessment and treatment following agreed protocols
- Since 2011 prevalence was 2 per 1,000 to now 6.5 per 1,000 (it has risen each year since the funding was provided)
- In 2012 there were 9,069 patients on caseload as of March 2019 there was 18,324 on their caseload
- Workforce as of March 2019 was 55.99 WTE in comparison to Greater Manchester of 18.76 WTE
- Annual referral rates have escalated by 111% - 3512 in 2012 to 7414 in 2018
- Services are using data capturing systems - Myrddin, PAS and Lymcalc.
- All Wales Lymcalc database programme has evaluated to understand referrals and performance data (enables consistency). There is not a consistent approach in recording with Greater Manchester. From analysis of the Greater Manchester activity using the BLS minimum dataset. It evidence there are also additional information that is required such as length of clinic appointment,
- Complexity of cases had risen - 56% Severe/Complex

Table 1: All Wales Lymphoedema Severity Staging

Lymphoedema Severity Staging	Total Numbers of Patients on Caseload	%
At risk lymphoedema	2,006	11%
Mild lymphoedema	2,199	12%
Moderate lymphoedema	3,848	21%
Severe lymphoedema	4,398	24%
Complex lymphoedema	5,864	32%



Note Wales have split moderate and severe. The minimum dataset recording tool groups them together. There could be a cohort of people with complex lymphoedema in Greater Manchester that are not accessing a service.

Even though the Greater Manchester services have seen less 'At Risk' patients between these two data sets; there are significantly higher mild lymphoedema. It costs less for a lymphoedema professional to see 'At Risk' than Mild lymphoedema. If people were better informed in how to self-care and recognise signs there is a possibility that you can reduce the number of people developing lymphoedema and maintaining the condition as 'At Risk'. This would be cost effective to the system.

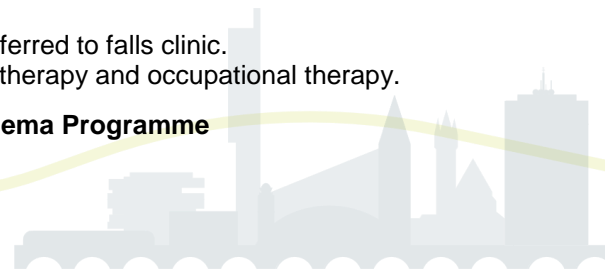
- Research published by Lymphoedema Network Wales in 2017 from a pilot evidence a decrease of cellulitis incidence by 82%
- Lymphoedema Network Wales has developed a Wet Leg pathway that supports the work between wound care and lymphoedema. This pathway could be localised to Greater Manchester to improve the provision for vascular lymphoedema patients.
- Lymphoedema Wales Network believes the provision of lymphoedema should be in a community setting.
- Lymphoedema Network Wales have made significant improvements. However in their May 2019 audit they raised
 - Still disparity across Wales
 - Not hitting their referral targets – 2 weeks palliative, 4 weeks urgent , 12 routine
 - A % of patients could be discharged
 - The provision still have a number of key challenges

<p>Demand:</p> <ul style="list-style-type: none"> • Understand demand versus capacity • Plan on waiting times and referrals if demand continues to rise by 20% • Understand current and future demands • Demonstrate value based approach to lymphoedema services by initiating the 'On the Ground Educators Project) • Increase capacity for intensive treatment
<p>Workforce:</p> <ul style="list-style-type: none"> • Review WTE • Ensure ratio of a therapist to patient meets the WG Lymphoedema Strategy 1:220 ratio • Continue to improve the awareness for education sessions/e-learning for wider workforce
<p>Management of Services</p> <ul style="list-style-type: none"> • Lymphoedema accommodation is suitable • Impact of safe delegation of patient from qualified to unregistered staff
<p>Quality</p> <ul style="list-style-type: none"> • All outcome codes are accurately entered of <u>lymcalc</u> • Robust performance quality measures are in place Impact of safe delegation of patient from qualified to unregistered staff

Value Based Patient Case Study

Below is a case study that Wales evidenced in their recent Value Based Business Case of the impact of a patient not being assessed within the 12-week target:

- Waiting 8 months to be seen by the lymphoedema service incurred costly consequences which could have been avoided if seen earlier.
- an 82 years old lady with heart problems, shortness of breath and decreased mobility.
- She has a history of bilateral swollen legs and repeated cellulitis.
- Her legs started swelling eighteen months ago and have in the last year broken down in numerous areas and leak lymphorrhoea.
- Whilst waiting for the appointment she suffered three episodes of cellulitis requiring admittance to hospital for 19 days.
- The district nurses had to attend daily and she was also referred to falls clinic.
- As the legs were so heavy she was also referred to physiotherapy and occupational therapy.



- The feet were also affected and she had to be measured for made to measure shoes from the Orthotic Department.

Table 1: Nancy's Story

	Sub optimal Pre lymphoedem a care over 1 year	Cost	Optimal Post lymphoedem a care	Cost	Difference
GP Visits	9	£36 x 9 = £324	2	£36 x 1 = £36	-£288
District Nurse visits	348	£26 x = £9,048	0	0	-£9,048
Lymphoedema clinic	0	0	12	£62 x 12=£744	+ £744
Dressings/compression garments	-	£3,560	-	£795	-£2,765
Physiotherapy/ Occupational therapy	16	£62 x 16= £992	0	0	-£992
Cellulitis episodes requiring admission	3	£2550 x 3= £7,650	0	0	-£7,650
Orthotics	1	£62 x 2= £124 Shoes = £550	0	0	0
Total	-	£22,248	-	£1,575	£20,673

(Costs based on NHS Reference costs 2015/2016)

9.3. Other Models

Huddersfield and Halifax – A&E with Cellulitis

The Macmillan Greater Manchester Lymphoedema programme visited the Lymphoedema Community Service in Halifax and Huddersfield. This service has undergone huge improvement in the past two years and is currently running a project with their vascular service to refer all patients attending A&E with cellulitis for lymphoedema assessment. A lymphoedema team is now based in the Adult Assessment Unit of Huddersfield Royal Infirmary. This approach is currently being evaluated and is awaiting the outcomes. This approach ensures early assessment and intervention to minimise the effects of lymphoedema but would be unable to be achieved on current staffing within GM.

Below is a snapshot of other commissioned models:

Kendal Lymphology is a private company that is commissioned by the local CCG based on the number of sessions for each staging. So patients are restricted to the number of appointments they are able to receive.

The Royal Derby Hospital – Consultant led with nurse/AHP. Derby have standardised pathways in place.

AccelerateCIC – A social enterprise working commissioned by the NHS. Specialist Care for those living with chronic wounds and lymphoedema. Specialist wound care (tissue viability) nurses, specialist lymphoedema nurses, a dermatologist, podiatrist, and clinical health psychologist. They work closely with GPs, practice nurses, district nurses and carers to ensure continuity of care.

University Hospital of North Midlands – A Nurse Led – Outpatient service. The Macmillan Advance Nurse Practitioner for Lymphoedema has put pathways in place and is looking at a programme of upskilling band 4s

Hertfordshire – Four CCGs commissioning 1 service with Hertfordshire Community Trust. Links with Age UK Champions for social prescribing and companionship.

10. Appendices

Please find appendices within MGM Lymphoedema – Gap Analysis Appendices

11. End Notes

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<https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcancerandits treatment.pdf>

^{iv} NHS Digital Cancer Waiting times

^v Lymphoedema Provision in Greater Manchester Strategic Health Needs Assessment

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