



Macmillan Greater Manchester Lymphoedema Programme Final Report and Evaluation

January 2019 - December 2020

Funded by

MACMILLAN
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GM Macmillan Lymphoedema Programme

Greater
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Cancer

FOREWORD

Senior Responsible Officer for the programme

Adrian Hackey January 2019 – March 2020 and Ali Jones September 2019 – December 2020

Funders:

Macmillan Cancer Support – Thank you to Fran Mellor and Coral Higgins (MHCC) in developing the partnership application and agreement.

Programme Team:

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Laura Tickle – Macmillan User Involvement Facilitator
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Macmillan Clinical Lead, Karen Livingstone (January 2019 – January 2020)
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Macmillan Project Support Officer, Melissa Shaw (February 2019 – November 2019)

With special thanks to all the people affected by lymphoedema who have been involved in this programme and the lymphoedema practitioners. The outcomes of this programme would not have been achieved without your knowledge, expertise, experiences and commitment.

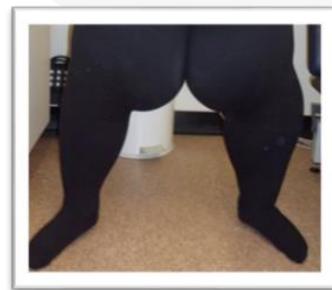
Fiona Sanderson, lymphoedema specialist, St. Ann’s Hospice
Julie Kenyon & Paula Williams, lymphoedema specialist, The Christie NHS Foundation Trust
Kathryn Taylor, lymphoedema specialist & Rebecca Williams, lymphoedema practitioner, MFT
Rachel Mayall, lymphoedema specialist, HMR INT Team
Jo Thorpe and Sally Ward, lymphoedema practitioners, Oldham service
Janet Dorey, lymphoedema specialist, Tameside and Glossop service

Thank you to Macmillan Cancer Support and GM Cancer for recognises the importance of this programme.

ANDREW'S STORY

Thank you to Macmillan Cancer Support for allowing the programme to look at all related lymphoedema. This story demonstrates that there is a need for upskilling the wider workforce, a need to work more collaboratively between services and providers in order to prevent chronic long term conditions. Andrew’s story is a reason why this programme was funded. Andrew was eventually referred to a lymphoedema service after 2 years of deterioration and healthcare professionals not knowing where to refer him . This is not a single case in Greater Manchester and this is why treatment for chronic oedema needs the right resource/upskilling to reduce the risk, identify early signs and treat appropriately

Andrew has lymphoedema in his legs. “Initially, my struggles were physical. I couldn’t walk without my legs bleeding. They were so large that they rubbed each other when I walked. I could hardly get downstairs, I couldn’t leave the house. My days consisted of sitting in my bedroom, sitting in my bedroom, sitting in my bedroom and sitting in my bedroom. Just as bad as the physical struggle was the mental struggle. Until this point I had never been out of work. I left school at 16, started work 3 months later and until October I had been working for the same company (over 22 years). It doesn’t feel good to have no reason to get up and it’s even worse when you can’t go anywhere no matter how much you want to”. *Full story in appendix 7*



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CONTENTS PAGE

Title	Page Number
Background	4
Programme Structure	5
Programme Governance	6
Communication & Engagement	7-9
Benefits & Outcomes	10
Information & Analysis	11
User Involvement	12
Co-Production	13-15
Model of Care	16-18
Learning & Development	19-21
Case for Change	22
Implementation Plan	23-27
Programme Evaluation	28, 34-37
Deliverables and Outcomes	29-31
Benefits and Outcomes	32-33
Appendix	38-44

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BACKGROUND

The Macmillan Greater Manchester (GM) Lymphoedema Programme was a two year programme from January 2019 until December 2020. A partnership between Macmillan Cancer Support and Greater Manchester Cancer to understand the health and social care provision for people at risk and affected by lymphoedema across GM and co-produce a Model of Care. GM covers the 10 CCG areas of Bolton, Bury, HMR (Heywood, Middleton & Rochdale), Manchester, Oldham, Salford, Stockport, Tameside & Glossop, Trafford and Wigan.

The partnership commenced based on the evidence and recommendations from the 2015 Scoping of Lymphoedema for the City of Manchester through Macmillan's Manchester Cancer Improvement Partnership and the GM Strategic Needs Assessment. The scoping document identified there were:

- No national commissioning guidance or standards,
- No pro-active measures to reduce risk/prevent lymphoedema,
- Delays in the timeliness of referrals to appropriate services directly resulting in additional costly complex and severe cases (that are avoidable). This impacts on patients quality of life.
- Inconsistency of data recording across service providers to understand the provision needs,
- Limited numbers of lymphoedema specialists and wider workforce skill mix,
- Deficiency of an equitable service provision across GM to enable appropriate care,
- Costly non-elective admissions for lymphoedema related health conditions (possibly avoidable),
- Increase of incidence and prevalence of lymphoedema. (estimated 11,000 – 18,126 population). Due to living longer, increase non-malignant causes and increase of cancer prevalence,
- Inadequate information systems leading inaccurate lymphoedema incidence and prevalence data.

Macmillan Cancer Support funded the programme, hosted by Greater Manchester Cancer to have a programme lead, clinical lead, user involvement facilitator, quality improvement facilitator and a project support officer. Alongside a grant for user involvement.

WHAT IS CHRONIC OEDEMA/LYMPHOEDEMA

A chronic swelling that can affect any area of the body but usually the arms and legs. This can have an impact on a person's physical, psychological and social wellbeing. The sooner you treat this, the better outcomes for the patient. There are two causes:

Primary Lymphoedema - Lymphoedema can be heredity/ congenital

Secondary lymphoedema - Overload, blockage or damage to lymphatic system in



THE VISION

Greater Manchester to have a cost effective, pro-active and sustainable provision that:

- Identifies people at risk, regardless of the cause of their lymphoedema
- Supports self- management
- Reduces co- morbidities caused by lymphoedema
- Provides timely assessment and treatment of their symptoms.

PROGRAMME STRUCTURE

The Macmillan GM Lymphoedema programme has worked collaboratively with commissioners, primary care, lymphoedema practitioners, their management teams, wider health & social care workforce and people affected by lymphoedema to:

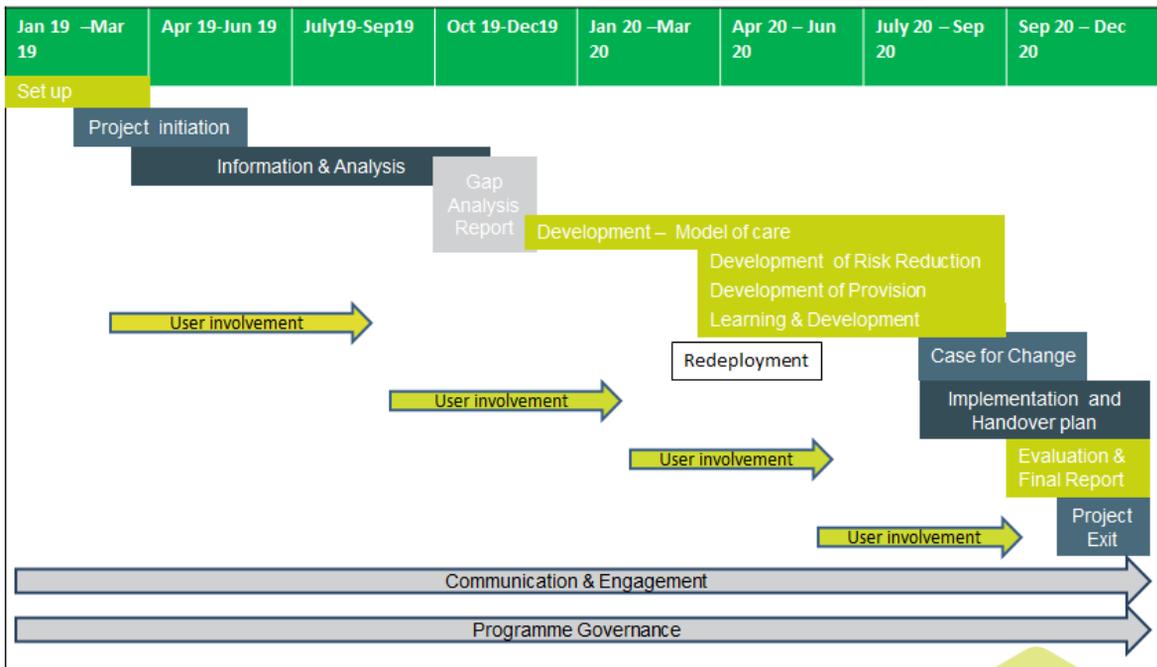
- Understand the problem,
- layer the research and evidence the variations and needs,
- develop ideas for improvements and reduction of variation,
- propose ideas for pro-active, equitable, cost effective and sustainable lymphoedema provision.

OBJECTIVES

- Scope provision and write a gap analysis report,
- embed User Involvement throughout the programme to follow a co-production model,
- develop a model of care that has
 - an effective risk reduction structure across the system within each risk factor,
 - a set of standards for an equitable model of care across GM,
- learning and development requirements,
- propose recommendations to commissioners and providers to progress either locally or through a GM network,
- develop a strategic plan of how the above vision and aims will be achieved.

TIMEFRAMES & KEY MILESTONES

The below road map provides a summary of how the Macmillan GM Lymphoedema programme delivered the above objectives. This road map was revised in January – March 2020. The changes accommodated the extension of the information and analysis work stream and the amendments from a business case, to a case for change due to key findings from the gap analysis report.



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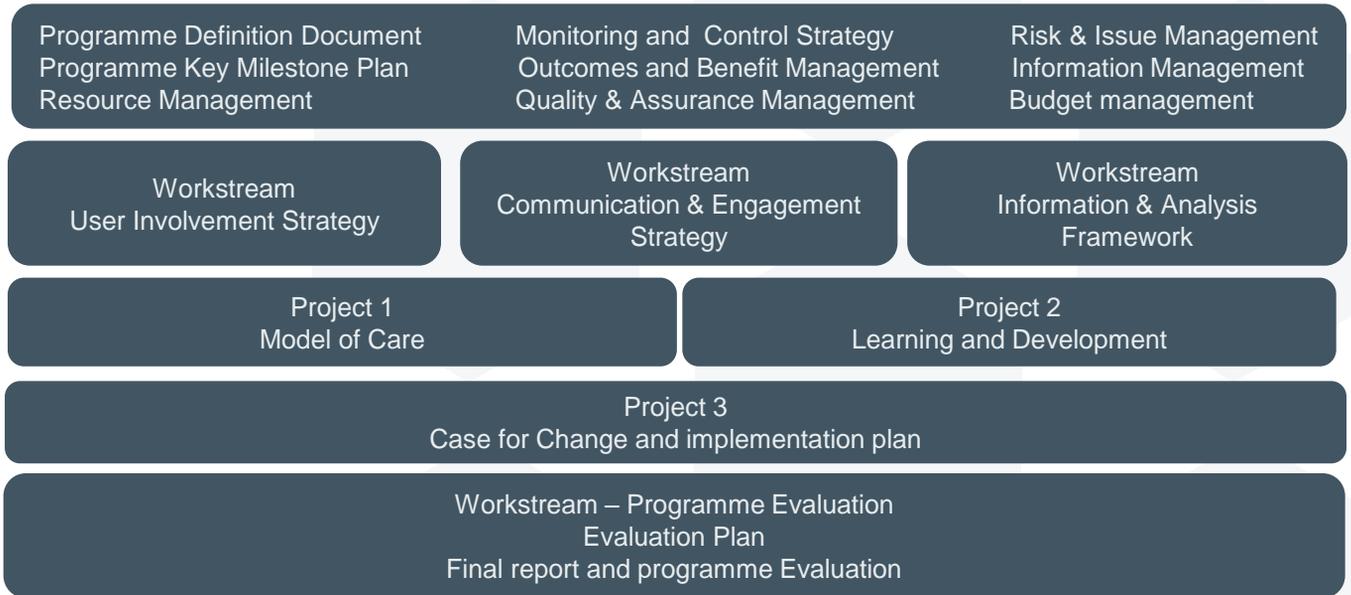
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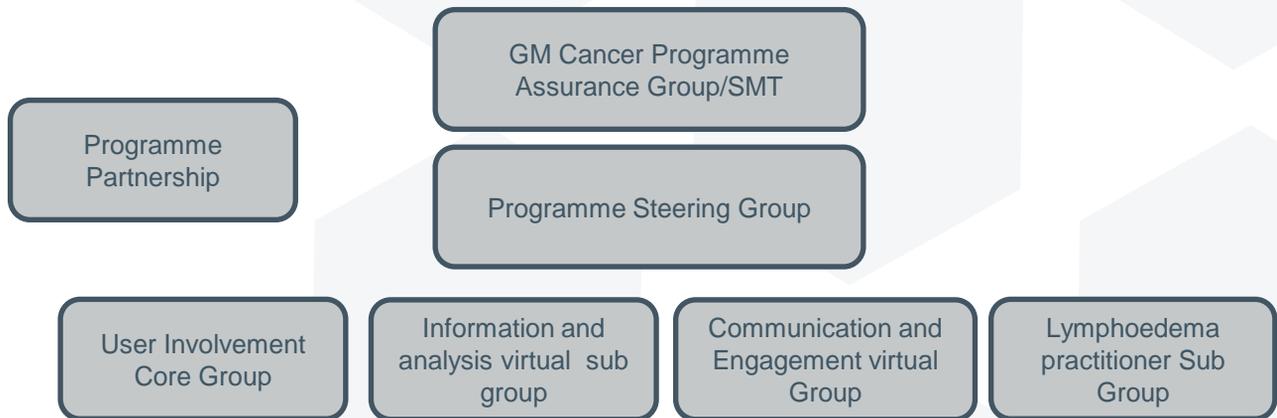
PROGRAMME GOVERNANCE

The Macmillan GM Lymphoedema programme utilised both Macmillan and GM Cancer's template documents that are based on Managing Successful Programmes. Below is the governance framework that was used:



The above strategy documents took circa 3 to 4 months to complete. This provided the detail and planning of the programme to ensure it was being managed to a high quality.

The programme followed the below reporting structure



The reporting structure slightly changed in Year due to COVID. The main change was that the GM Cancer Assurance Group dissolved and instead of quarterly reports in went to GM Cancer's SMT on a by exception basis.

Two of the work streams were via a virtual sub group to tap into expertise on adhoc basis for guidance. This worked extremely well as it was possible to obtain a breadth of information from various expertise that become key stakeholders for the success of the project. For example GM have a shared service for primary care data that would have not joined a working group but have been vital on the known prevalence.

Full details of the budget review and residual risk can be found in appendix 1

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COMMUNICATION AND ENGAGEMENT

A communication and engagement plan was developed at the start of the programme. This enabled the programme team to have a clear structure of key stakeholders through a stakeholder mapping exercise. It also identified the level of communication the programme team would provide, when and to whom. This document also evidenced how the programme team would embed co-production into the two years. It recognised co-production should involve a number of individuals and these have been grouped into seven areas:



This programme recognised there are steps in order to achieve full co-production and followed Sherry Arnstein, 1969 ladder of participation:

Stepping towards full participation



Arnstein, Sherry R. (1969) 'A ladder of Citizen Participation', Journal of the America Planning Association, 35: 4, 216 -224

COMMUNICATION PLAN

The communication plan utilised the below to identify what communication was required and how best to deliver that communication:

Communication item / Event	Stakeholder Group	Description/ Purpose	Frequency	Delivery Method	Date/ Deadline	Responsible	Desired Outcome
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ENGAGEMENT PLAN

The engagement plan enabled the programme team to identify all key stakeholders and how they would be involved. At the different stages of the programme (start, information and analysis, model of care, case for change and handover). Each stakeholder was identified and assessed using the below structure:

1.Stakeholder Group	2. Nature of Involvement	3. Why are they being engaged	4.Engagement Required:	5.What we want them to do	6 Engagement Method	7.Engagement Timeframe	8 Outcome required
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Then the below process was used to ensure the right stakeholders had been identified and the programme was engaging with them in a meaningful and appropriate way to obtain the outcomes required.



The programme has been very successful in engaging with wider stakeholders to raise the profile of the importance of risk reduction and early identification due to linking with areas of high agenda including cancer, obesity, vascular, cellulitis and end of life & palliative care.

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COMMUNICATION AND ENGAGEMENT

The programme had over 21 communication methods. Below are examples

National Lymphoedema Awareness week	Commissioning Guidelines Launch	GM Cancer Annual Report	Steering Group Meetings	Programme Team meetings	GM Cancer's Website	Monthly Progress Report
Recruitment of workforce to complete surveys	Milestone and work plans	Recruitment of User Involvement	Focus Groups	Stakeholder Newsletter	User Involvement Newsletters	Legs Matters Week
Patient Case Studies	Social Media	Exception reports	Locality meetings	project working groups	Evaluation	Final Report

Programme Launch



The programme launched in March 2019 in alignment to the launch of the National Lymphoedema Partnership's Commissioning Guidelines. As part of the launch the Macmillan Clinical Lead wrote a letter to all GM MPs to advise them of the launch of the commissioning and the vision of the GM programme. In addition to this the team took part in the awareness week with odd socks and asked for support from GM Macmillan's GPs. The programme team also went to different Macmillan Information and Support Centres and set up stands to start recruiting people affected by lymphoedema and speak to healthcare professionals. The programme developed an information poster (appendix 3) To clearly communicate with the wider stakeholders for example GM Cancer Pathway Boards.

Monthly Programme Updates

The programme produced a monthly update circulated via email to all stakeholders Core and Non-Core Steering Group members. This update covered key areas of work, risk/issues, user involvement, budget, updates on outcomes and any upcoming work that was being prepared. In mid 2019, it was recognised that a similar update was required for the lymphoedema services to also share with their management team. In 2019 this was quarterly and moved to monthly during the development and case for change phase.

Steering group meetings

Steering group meetings have been 8 weekly. Core members were GM Cancer, Macmillan, commissioners, user involvement, lymphoedema service managers for hospice and cancer related. It was identified that the programme was missing representatives from community related lymphoedema services and they were invited. The steering group had representatives from every locality within GM. All key pieces of work and outcomes have been brought to the steering group for feedback and sign off. The steering group reviewed the responses from the questionnaires to retrieve key themes, they reviewed and made amendments to the gap analysis report, reviewed the set of standards statements and system approach. The 16 key priorities for year 2 of the programme was another key piece of work the group provided guidance on.

100% of respondents to our evaluation survey noted that the programme team has been visible and approachable throughout the programme. 90% noted that we provided a good amount of updates throughout the programme.

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COMMUNICATION AND ENGAGEMENT

Lymphoedema service meetings

In 2019 the Macmillan Clinical Lead attended the 3 yearly Lymphoedema Network meetings. These meetings are half day where they discuss service development and offer peer review. From these meetings it was decided to have a sub group to deliver a GM Patient Education and Engagement event that took place late November 2019.

In early March 2020, the programme set up a separate lymphoedema service meeting that also invited the managers. Seven lymphoedema practitioners attended and we looked at the 16 key priorities of work to support the system approach and set of standard's statements. Since then these meetings have been bi monthly and have been open to all lymphoedema practitioners and their managers. These meetings provided a forum for the programme to gain clinical expertise from a hospice, community and cancer related perspective. A core group of clinicians have been integral to the success of the second year of this programme.



User Involvement – Core Group



The User Involvement Facilitator developed various opportunities for people affected by lymphoedema to be involved in the programme in alignment with the ladder of participation. One of those opportunities was to be involved in the core group that took place every two months. In these meetings they looked at topics raised by the core group at the beginning of the programme e.g. self management and education. For a full overview of the user involvement work stream of this programme please go to the appendix for a copy of the full report.

Social Media – Twitter

It was agreed in May 2019 that the programme team would develop it's own Twitter page. Taking into account the risk of a social media page for a time limited programme. Since May 2019 the page has 244 followers. The page has tweeted 453 times included tweets about the programme and re-tweeting information about lymphoedema and other GM Cancer related tweets. The Twitter page was initially set up to recruit people affected by lymphoedema and connect with other lymphoedema services and organisations to understand what was happening elsewhere.

In March 2020 it was lymphoedema awareness week, where the programme delivered a week of social media activity that the User Involvement Facilitator planned tweets throughout the week with some days having more than one tweet. The tweets promoted what the team were working on, support groups and photos of our odd socks. The team retweeted other lymphoedema services that were also supporting lymphoedema awareness week. During the week the teams twitter account received over 30 more followers. The number of engagements on twitter was 282, including 21 retweets and over 60 likes of tweets sent; the impressions made were 6667. The programme shared the first version of the system approach via social media. Feedback was retrieved and incorporated into the final version.

The first #GLOSSOP
#Lymphoedema support group
agreed 16 March venue TBC #SockIt
#EverybodyCan
@dawnmummyhockey



Macmillan GM Lymph... 08/03/2020 ...
We have highlighted in our gap analysis report, a system level approach is needed to reduce peoples risk of developing #lymphoedema or if people have #lymphoedema, it getting worse #EverybodyCan #SockIt



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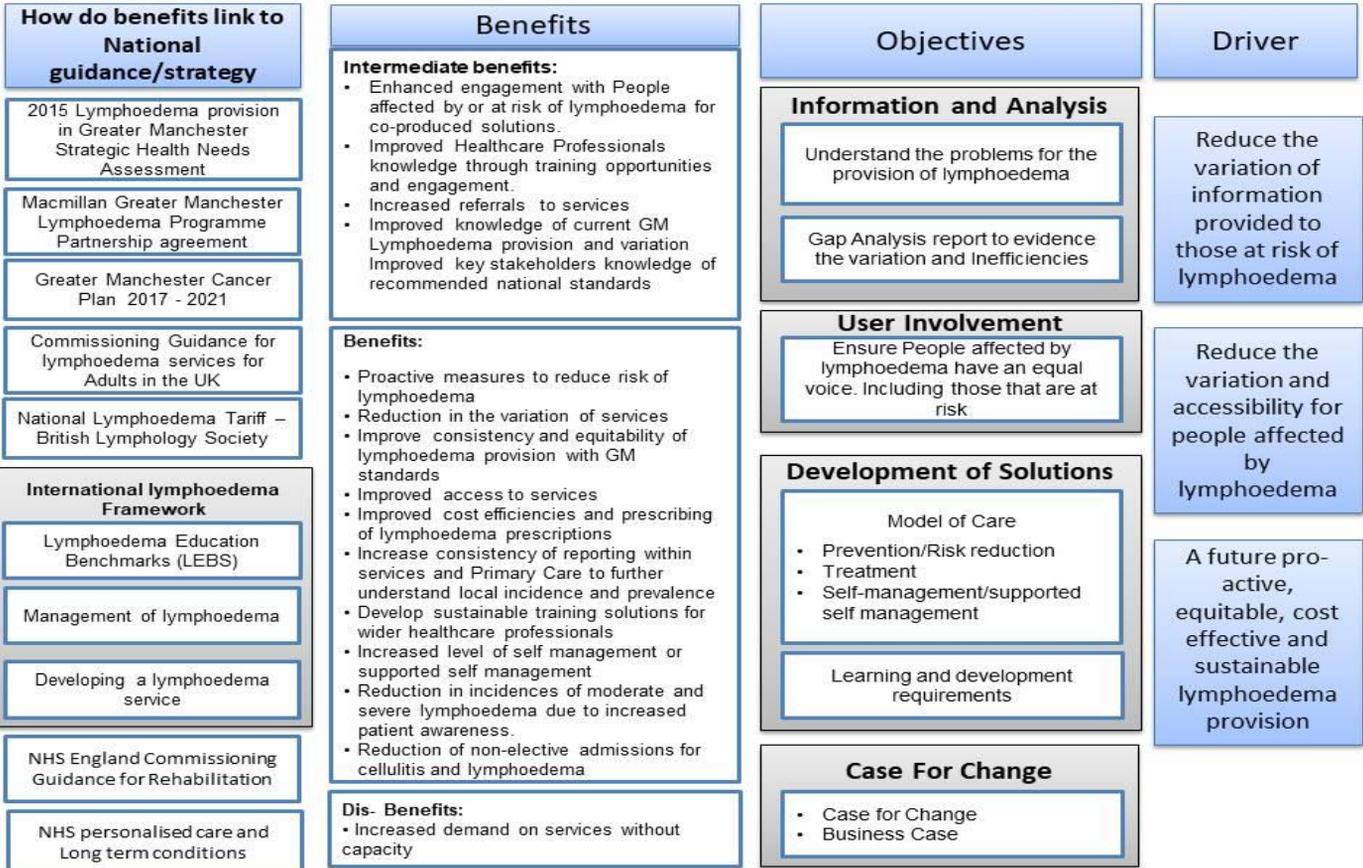
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BENEFITS AND OUTCOMES

The benefits and outcomes management provided clarity to the key stakeholders of the target benefits and outcomes of the programme and the aspired benefits and outcome for the provision of lymphoedema in the long term. The benefits maps aligned to the programme's drivers, strategic objectives and links to national strategy and other guidance. The benefit map shows the relationship between activities and project outputs and the benefits.

BENEFITS MAP



BENEFITS REALISATION PLAN

From the map the programme developed a benefit realisation plan that:

- Identified the stakeholders that will be affected by each identified benefit,
- Identified the outcomes and enablers required for each benefit realisation,
- Determined how the programme would measure whether a particular benefit has been realised,
- Allocated responsibility for delivery of the benefits,
- Identified dates for expected delivery of the benefits.

Below are the headers of the plan that the programme used against each benefit. This plan was then utilised when developing the evaluation plan to support the evaluation of the programme.

Desired benefit	Stakeholders impacted	Enablers required to realise benefit	Outcomes	Current baseline measure	Current positions	Who is responsible	Target date
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A copy of the plan can be found in Appendix 6

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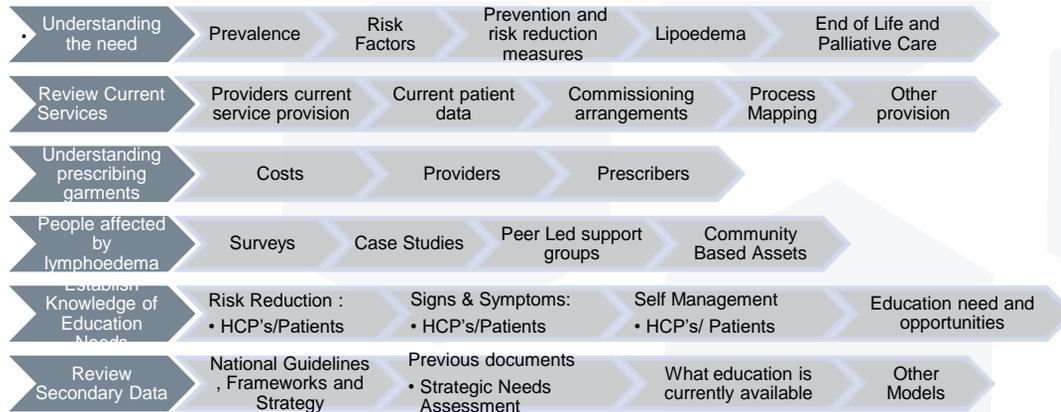
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PROGRAMME OBJECTIVES INFORMATION AND ANALYSIS

An Information and Analysis Framework was developed during the set up of the programme to understand data required for a robust gap analysis. The steering group signed off the framework and request to extend the milestone deadline for this piece of work due to the breadth of information that needed to be obtained. Retrieving the majority of information took around 6 months to obtain and a further 3 months to collate and analyse. Further information has been continuously retrieved throughout the two years.

The Framework structure



Data Collection

Risk Reduction and early identification – The programme team researched information to understand the risks and requirements for early identification. This included the March 2019 Commissioning Guidance and British Lymphology Society (BLS) documentation. From this, three questionnaires were developed (primary care, wider healthcare professionals & cancer CNSs) to understand their competencies and what information they provide to patients to support risk reduction.

Provision - An initial mapping exercise was completed to understand what services were available compared to the 2015 GM Strategic Health Needs assessment. The programme met with each service to collate key information. In addition to this; desktop based research was completed to understand what private practice was available. From the initial mapping exercise it was clear that caseload data collection was minimal to understand the true capacity and demand. Nine out of the ten services agreed to record 8 weeks of patient activity against the BLS minimum dataset that provided the programme a snapshot of how the services were working.

Learning and Development – Desktop based research was completed to understand what courses were available across the country. No lymphoedema specific courses that offered a qualification were local to GM. Hosiery companies have a comprehensive education offer on garments, risk reduction and early identification mainly accessed by community teams. It was not clear if undergraduate courses and post graduate courses incorporated chronic oedema and lymphoedema into their modules. The International Lymphoedema Framework and BLS have education framework and competencies guidelines that can be utilised. This was further explored across the two years of the programme and engagement with local universities have developed initial relationships for potential outcomes in the future.

User Involvement – The User Involvement Facilitator developed a questionnaire and met with a number of people affected by lymphoedema to listen to their experiences. This was incorporated into the Gap Analysis Report.

Gap Analysis Report

In December 2019 a GM Gap Analysis Report was shared to the programme's key stakeholders show the variations in lymphoedema provision across Greater Manchester, identify the competency levels of the wider workforce and understand good practice in GM and nationally. A multi-stakeholder meeting took place in December 2019 to initiate the co-production of the Model of Care. A copy of the report is available on the GM Cancer Website.

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CO-PRODUCTION

The New Economic Foundation (NEF) has defined co-production as:

'The relationship where **professionals and citizens share power to design, plan, assess and deliver support together**. It recognises that everyone has a vital contribution to make in order to improve quality of life for people and communities'. (Commissioning for outcomes and co-production – A practical guide for local authorities)

The programme informed, consulted and engaged with lymphoedema services, commissioners, people affected by lymphoedema and lymphoedema practitioners across the country who have driven change and the wider health care workforce to write a robust gap analysis report. This report was shared with GM lymphoedema services, people affected by lymphoedema, Commissioners, GM Cancer and Macmillan. Then taken to the key stakeholders for their review and commenced the co-design and co-production of the Greater Manchester Model of Care for lymphoedema.

MULTI STAKEHOLDER EVENT – 10TH DECEMBER 2019

All GM key stakeholders were invited to an event so the programme could build upon the gap analysis report to bring together ideas for the Model of Care.

Purpose Multi Stakeholder Meeting

- To understand the gaps and inconsistencies across GM lymphoedema provision through the gap analysis report
- To understand the recommendations for improvement from capturing good practice from services, strategy, frameworks and guidance.
- To understand the identified education needs evidenced through the programme collating appropriate data
- Understanding the current challenges the current services face
- Understanding the current challenges people affected by lymphoedema face
- To look and discuss ideas that have been developed from the Macmillan Lymphoedema Programme team through the collation of information to assist in the development:
- Agree priorities for the Macmillan Lymphoedema Programme for 2020
 - The priorities of the programme team
 - The commitments from the key stakeholders

Macmillan GM Lymphoedema Programme

Gaps and Next Steps

10th December 2019



Below is the agenda for the event and feedback from the attendees

Unity of lymphoedema practitioners to improve practice and services

A greater understanding of lymphoedema and its impact on pts and NHS

A better understanding of lymphoedema and the impact on patients

There is a lot of knowledge/skills/expertise in GM area

Need for joined up approaches across localities

Agenda item

Session 1 - Looking at the Gap Analysis Report

- Group 1 – Risk Factors and Risk Reduction
- Group 2 - Provision for people living with lymphoedema
- Group 3 – Learning and Development

Session 2

- Part 1 - The life of a lymphoedema practitioner – Presentation
- Part 2 - Two Case Studies - People affected by lymphoedema

Session 3 – Developing ideas

- Group 1 – Risk Factors and Risk Reduction
- Group 2 - Provision for people living with lymphoedema
- Group 3 – Learning and Development

A lot of work to do to improve provisions of lymphoedema services

Will raise further discussion about how to improve communication and support between services

What a huge and difficult challenge improving lymphoedema services is, CCGs have to get on board

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Still variation

My voice has been heard

It's a challenge

Greater Manchester Cancer

CO-PRODUCTION

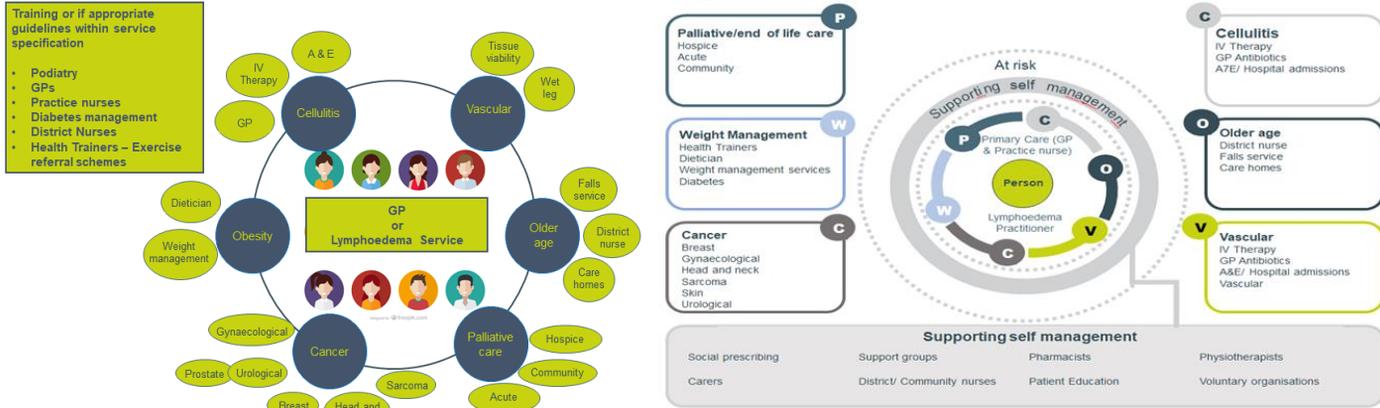
THE SYSTEM APPROACH

The multi-stakeholder event re-confirmed that there needed to be a system approach to support risk reduction, provision and supported self-management. From this the programme started to develop a visual to show the requirement of a system approach. Below is the process that the programme took to get to the final version:

First draft – shared on Twitter – March 2020

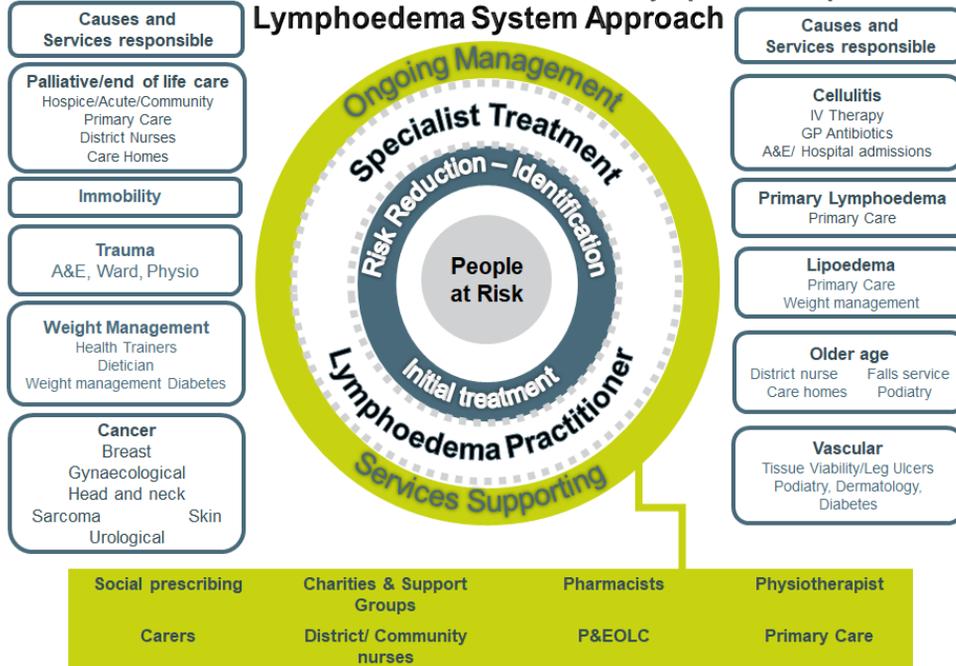


Second draft – updated post feedback



Final Version based on feedback from lymphoedema practitioners

Lymphoedema System Approach



The GM lymphoedema system approach identifies the causes of lymphoedema and services responsible for providing risk reduction guidance and supporting the care and ongoing management for lymphoedema.

Alongside the System Approach is a Set of Standards Statements that can be found in Appendix 5

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CO-PRODUCTION

16 Work priorities were developed based on the information gathered at the multi-stakeholder event.

From this the programme went back to the main stakeholders with the request to advise what they felt were the priorities that the programme needed to focus on in 2020. Commissioners and Macmillan Cancer Support informed the programme of what their top priorities were. People affected by Lymphoedema and the Lymphoedema practitioners looked at the priorities in a group session and used the MoSCoW prioritization categories



Must have: Non-negotiable needs, that are mandatory for the programme



Should have: Important initiatives that are not vital, but add significant value



Could have: Nice to have initiatives that will have a small impact if left out.



Will not have: Initiatives that are not a priority for this specific time frame.

All priorities were collated and analysed and shared with the programme Steering Group highlighting which were the top priorities across all the stakeholders.

The programme continued to address all priorities but due to staff levels reducing the Learning & development priorities were impacted

The pathway and standards was part of the original scope of the programme. All other priorities the programme delivered were additional outcomes that would provide some important long term benefits for lymphoedema patients.

16 WORK PRIORITIES



RISK REDUCTION

- A GM standardised lymphoedema pathway
- Cancer end of treatment summary templates to have lymphoedema and risk reduction information as a consequence of cancer
- Resource List in how patients can self-care
- Provide a list of Lymphoedema services in GM.

PROVISION

- GM Lymphoedema - Set of Standards
- GM Hosiery guidelines for effective ordering of garments
- Develop standards and tools for Health and Social Care workforce to support risk reduction and management.
- Develop an agreed list of Primary Care SNOMed codes for prevalence and diagnosis letters to GPs



LEARNING & DEVELOPMENT

For People Affected by Lymphoedema

- A set of guidelines for a care plan to support patients to self manage effectively
- Peer to Peer Support Opportunities

For Wider Workforce

- Gateway C – provide lymphoedema expertise in late effects module
- Skin care film – Support patients to give advice on skin care
- Work with Manchester Amputation Reduction Strategy on pathways and competency framework
- Cancer professionals competency framework and training opportunities

For Lymphoedema Practitioners

- Develop a directory of courses currently available for Lymphoedema
- Develop standardised training material for practitioners to use in each locality for both patients and professionals



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MODEL OF CARE

RISK REDUCATION

This section will address the 16 work priorities and detail the position of where they are up to and if not completed how and who will continue the work to gain the outcomes.

A GM Standard Lymphoedema Pathway

The programme reviewed different pathways from across England and GM services. The pathways were either just cancer related or vascular related and were very specific to referrals into lymphoedema services and not linked to the importance of risk reduction guidance and supporting self management. The project drafted a GM Lymphoedema pathway then embedded good practice from other pathways. It ensured early identification, risk reduction and referral to lymphoedema services was incorporated into the pathway. The pathway covers the wider workforce's responsibility to understand the risk of chronic oedema and lymphoedema and to refer into the lymphoedema service in a timely manner. The second half of the pathway is to demonstrate good practice of triage, treatment on ongoing self-management. The document was shared with key stakeholders for comment. There were some clinical amendments made and the document was shared with the steering group for final sign off. This is a strategic document. The importance is to embed chronic oedema/lymphoedema into current practice, tools, pathways and policies for the wider healthcare workforce. For example community nurses, ambulatory care pathway for cellulitis, templates in cancer pathways, vascular pathways and guidelines/checklists for end of life and palliative. A copy of the pathway is on GM Cancer's website.

Cancer - end of treatment summary templates



Personalised Care Interventions for Cancer has four main areas that the healthcare system is required to embed: 1. Personalised Care and Support Planning based on an Holistic Needs Assessment, 2. End of Treatment Summary, 3. Health and Information and Support, 4. Primary Care - Cancer Care Review. GM Cancer are delivering a programme to ensure consistency of embedding these 4 areas in alignment with NHS England's guidance.

The end of treatment summaries provide clear information about consequences of treatment and it is imperative to ensure the right information about risk of lymphoedema, early identification and self-management to reduce the risk of developing lymphoedema is embedded into the GM templates, for patients to be better informed.

The end of treatment summary templates were reviewed by lymphoedema practitioners to ensure that lymphoedema or swelling was mentioned as a consequence of cancer and its treatment for the relevant tumour groups. It was felt that the information in the templates were not clear enough to empower the patient to self-manage the key components to reduce the risks of developing the condition.

GM Cancer's transforming aftercare and personalised care programme are now completing a quality assurance audit. Breast Cancer, Colorectal and Genealogical templates have either been completed or are in the process. The GM Cancer team now have access to the lymphoedema practitioners to ensure the wording is accurate in each updated templates.

Resource list – patient self care

The four key components to self-management is exercise, skincare, lymphatic drainage and hosiery. There is a breadth of information available from Lymphoedema Support Network, British Lymphoedema Society, Macmillan Cancer Support, NHS, Cancer Research, other lymphoedema services website. As part of the pathway a list of available resources has been provided that will be shared with cancer workforce, primary care workforce, wider community healthcare workforce and end of life and palliative care workforce. This will also be included on the GM Cancer website. The lymphoedema services can also utilise this list to share with their patients

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MODEL OF CARE

RISK REDUCATION

List of Lymphoedema Services in GM

At the beginning of the programme all services in GM were identified and engaged with. A semi structured interview was developed to understand their service including referral criteria, staff levels, case load and commissioning arrangements. This was then put in a map and then table formatted to evidence the variation across GM. All services have reviewed the table to ensure accuracy. The list can be found on GM Cancer Website and has been incorporated into documents for end of life and palliative care. The aim is also to have a similar tool for the cancer workforce. It has also been shared with the lymphoedema support network and British Lymphology Society (BLS) for their websites.

PROVISION

Greater Manchester Lymphoedema Set of Standards

The national commissioning guidance for the provision of adult lymphoedema launched in March 2019. This was an essential document for the programme to understand the national objectives. This document incorporated the work of London's cancer related lymphoedema service specification and business case. A number of the GM services had well structured service specifications. In addition to this Wales, Scotland and Northern Ireland had also produced documents of good practice. The BLS tariff guidelines have been utilised in the document to evidence if lymphoedema is identified at the mild stage, treatment is significantly less and the impact to patients is minimal in comparison to if the patient's condition is not treated until it is very complex (as detailed in the tables). The programme took all the good practice and produced the GM Lymphoedema Set of Standards that covers risk reduction, early intervention, treatment, ongoing self management and learning and development. A sub working group of lymphoedema practitioners was established to review the standards. Amendments were made and the revised version was shared with the steering group for final sign off and then shared with GM Cancer. A copy of the standards are available on GM Cancer's website.

Next Steps

The standards have been shared with all CCGs and Lymphoedema services. There are elements of the standards that needed developing including:

- GP diagnosis template letter to improve the recording of lymphoedema in primary care,
- Tools such as top tips for community nursing teams, primary cancer and cancer workforce,
- Getting lymphoedema representatives in GM initiatives and structures for example Cancer Pathway Boards, GM Active and Adult Social Care.

Further details of the next steps can be found in the implementation plan section of this report.

BLS tariff document

This table has broken down the tariff to the average amount of time for treatment. This is clinical time and not additional time for clinicians to complete non clinic facing work. This is based on **one** oedema site.

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Simple/Mild (ILF Stage I)		
Year 1	Direct clinical time (Clinic Slot Required)	Indirect Time (Paperwork, Clinical Governance, training)
First Assessment	60 minutes	30 mins
Tx schedule	40 minutes	20 mins
3 Follow up	40 minutes x 3	20 minutes x 3
Total Time	220 minutes or 3 hours 40 minutes	140 minutes or 2 hours, 20 minutes
Yearly Ongoing*		
2 Follow ups	40 minutes x 2	20 minutes x 2
Total Time	80 minutes	40 minutes

*until stable for discharge/back to non- specialised service.

Very Complex (ILF Stage III)		
Year 1	Direct clinical time (Clinic Slot Required)	Indirect Time (Paperwork, Clinical Governance, training)
First Assessment	60 minutes	30 mins
Tx schedule First tx	40 minutes	20 mins
DLT per oedema site	40 minutes x 200	20 minutes x 200
Follow up	To be negotiated	
Total time	At least 8,100 minutes or 135 hours	At Least 4,050 minutes or 67 hours and 30 mins
Yearly Ongoing*		
Follow ups	To be negotiated	

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MODEL OF CARE PROVISION

Greater Manchester Hosiery Guidelines

Compression

- Wear hosiery daily
- Wash hosiery daily
- Ensure moisturiser is absorbed before wearing hosiery
- Follow care instructions

Information that was collated identified there are inconsistent standards and pathways for the prescribing of lymphoedema garments. With evidence that there are opportunities for improvements and cost efficiencies. The programme recommended a lymphoedema hosiery formulary or guidelines for all lymphoedema garments. Lymphoedema compression garments are an essential part of the treatment to reduce swelling, reduce infection and improve the person's quality of life. A compression garment is required to be accurate otherwise treatment will not be as effective and could exacerbate the condition. There is evidence of wastage when the lymphoedema practitioner is not a non-medical prescriber. PrescQIPP Bulletin 192 (April 2019) state it can be difficult to identify intended products.



Cellulitis and prophylaxis - If patients are not compliant in wearing their or have the wrong compression garment they are at a higher risk of developing skin infections and cellulitis.

An audit - A local audit evidence that the wider workforce are prescribing lymphoedema garments for patients that are unlikely to have lymphoedema and have another form of swelling or have lymphoedema but have not been referred to a service that is appropriately qualified to prescribe the most accurate garment for patients outcomes.

A project scoping document was submitted to Greater Manchester Medicines Management Group (GMMMG) recommending a tiered approach and a central costing structure.

Outcome – Further information on cost efficiencies has been requested. A further task and finish group was set up with clinicians, CCG representatives, hosiery companies & medicines management team to establish how to continue to drive this forward post the programme. A way to progress this, is to develop a tiered approach and pilot it in one geographical area to prove the concept and evidence the patient outcomes, reduction on pressures to other services, reduction of antibiotics and reduction in wastage and incorrect prescribing of garments.

Develop standards and tools for wider workforce

The programme sent a survey out to the healthcare workforce in cancer and community. Through the responses from the questionnaire there was a clear gap that professionals were not providing risk reduction advice and early identification for treatment/referral. The system approach provides a clear structure to who is responsible and therefore needs upskilling. Standards were incorporated in the GM set of standards and pathway. As part of the implementation plan a sub group of lymphoedema practitioners have worked with the programme team to develop tools to support primary care, end of life and palliative care, cellulitis, community nurses and vascular.

Primary Care data - SNOMed Codes

The national commissioning guidance made recommendations around effective recording of primary care data. There are a number of diagnosis and treatment codes for lymphoedema in primary care. The programme reviewed these with clinicians to understand what codes were relevant. From this a report was requested to look at total lymphoedema diagnosis, number of diagnosis in 2 years, up to 5 years ago. Evidencing known prevalence and how that varied in comparison to the studies on prevalence evidenced variation. The programme has commenced some analysis of this data against the GP practices and have broken it down to primary network level for one CCG area to see if some targeted work could be completed by the lymphoedema service.

This work has also enabled development of a standardised GP diagnosis letter to support more accurate recording and developing an algorithm for a flagging system within the EMIS system so GPs can retrieve guidance and links immediately

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LEARNING AND DEVELOPMENT

Patient care plan

Patient compliance was a theme that was brought up by some lymphoedema practitioners. In addition to this it was evident from user involvement and patient experience as detailed in the User Involvement final report that patients wanted to be empowered to self-manage their condition and have the information and guidance that fitted them as a person. For consistency across GM it was agreed that a care plan template would be developed. Based on a number of sub group meetings it was clear that the lymphoedema services would prefer GM guidelines for a care plan to follow to enable them to deliver personalised care but to a specific standard. The guidelines have been produced based on a personalised care approach and have been shared with all the services to embed into their practice. It would be beneficial if management of services completed adhoc quality assurance audits/focus groups with their patients to understand if patients are receiving a personalised care offer and have the guidance they require to empower them to self-manage for better patient outcomes.

Peer to Peer Support Opportunities

The User Involvement Facilitator has worked with a couple of lymphoedema patients to start peer to peer support groups in two areas within Greater Manchester. Due to COVID19 this has been put on hold as the patients have wanted to have face to face support. Full details on this work can be found in the User Involvement report.

Gateway C – Managing Physical Effects

The screenshot shows the Gateway C course page for 'Managing Physical Effects'. It includes a header with the Gateway C logo and 'Health Education England' branding. Below the header is a photo of a man and the course title. The page is divided into several sections: 'Overview', 'Who is it for?', 'This course will support you to:', 'Specialist interviews', 'Feedback', and 'To access the course register for a GatewayC account: www.gatewayc.org.uk/register'. The 'Overview' section states: 'This course aims to help in the identification and management of some of the common long-term effects of cancer and its treatments, such as peripheral neuropathy and lymphoedema. It also provides information on how to support optimal bone and cardiovascular health after treatment for cancer.' The 'Who is it for?' section says: 'FREE to all primary care professionals across NHS England, including GPs and practice nurses.' The 'This course will support you to:' section lists: 'Understand different types of cancer treatments and their short- and long-term side effects', 'Explore how to support patients living with peripheral neuropathy', 'Explore how to support patients living with lymphoedema', and 'Understand the impact of cancer treatment on cardiac and bone health and how to monitor this in primary care'. The 'Specialist interviews' section lists: 'Dr Pauline Leonard, Consultant Medical Oncologist, discusses types of cancer treatments and their side effects', 'Dr Vivek Misra, Clinical Consultant Oncologist, outlines peripheral neuropathy and discusses methods to prevent and manage this', 'Karen Livingstone, Clinical Specialist in Physiotherapy and Lymphoedema, describes methods to treat lymphoedema', and 'Dr Ashling Lillis, Consultant in Acute Medicine, discusses cardiovascular disease and bone health in patients that have had cancer treatments.'

The screenshot shows the Gateway C course page for 'Improving cancer outcomes through early diagnosis'. It includes a header with the Gateway C logo and 'Health Education England' branding. Below the header is the course title and a '1 CPD hour available' badge. The page is divided into several sections: 'This course aims to help in the identification and management of some of the common long-term effects of cancer and its treatments, including:', 'The course includes specialist interviews from:', and 'To access the course register for a GatewayC account: www.gatewayc.org.uk/register'. The 'This course aims to help...' section lists: 'Peripheral neuropathy', 'Lymphoedema', and 'Cardiac and bone health'. The 'The course includes specialist interviews from:' section lists: 'Dr Pauline Leonard, Consultant Medical Oncologist', 'Dr Vivek Misra, Clinical Consultant Oncologist', 'Karen Livingstone, GMC's Lymphoedema Project', and 'Dr Ashling Lillis, Consultant in Acute Medicine.'

Karen Livingstone, the Macmillan Clinical Lead for the programme during 2019 and a Clinical Specialist in Physiotherapy and Lymphoedema was interviewed in how to support patients living with lymphoedema. This is a central element of the Managing Physical Effects course in GatewayC.

GatewayC is a free online cancer education platform for primary care professionals.

Register here: www.gatewayc.org.uk/register

GM Cancer Education - skin care films

The Lymphoedema programme worked with GM Cancer Education programme on a sustainable education offer. The education programme agreed to develop short films on how to deliver appropriate skin care management and a section on cellulitis. The cellulitis films has been embedded into the GM Acute Oncology e-learning for Trust's Emergency Care team to understand the role of acute oncology. This will reach a significant number of the acute workforce to improve their knowledge of cellulitis and lymphoedema.

The clips have been circulated to the lymphoedema services, primary care, GM Cancer's Education twitter page and is available on GM Cancer website. The programme has received excellent feedback via social media and key stakeholders

“Skin care video is a fantastic resource”



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LEARNING AND DEVELOPMENT

Wider workforce – competency framework

MARS Pathway – Community teams

The programme has worked with Manchester Amputation Reduction Strategy (MARS) to ensure that lymphoedema is incorporated where necessary within MARS. This is linked to the national wound care and diabetic foot strategies. A lymphoedema, red leg and wet leg pathway have been incorporated into the pathways that are being developed. The competency framework project led by MFT and GM Health Social Care partnership is looking at all community staff competency levels for lower limb. This has been put on hold due to COVID19 and looking to commence early 2021. Fiona Sanderson, Lymphoedema Specialist St. Ann's Hospice and Kathryn Taylor, Lymphoedema Specialist, North Manchester MFT will be part of this group to ensure the competencies of lymphoedema are included. MARS is piloting their framework in Manchester and Trafford, evaluating the outcomes to be adopted across GM.

End of Life and Palliative Care (EOL&PC)

The programme and a representative for hospices developed communication to see if the hospices would commit to their staff having the appropriate competencies to support the management of chronic oedema and lymphoedema. This piece of work was shared with the GM & East Cheshire EOL&PC Clinical Network. The network fed back, although it was complicated, they recognised it was a gap and willing to provide resources to improve the knowledge. Fiona Sanderson, Lymphoedema Specialist, St. Ann's Hospice is now working with the Medical Director to pilot a guide.



Lymphoedema in Advanced Disease and End of Life

1. Causes of Lymphoedema
2. Assessment
3. Drug treatment
4. Emergency and reversible situations
5. Cellulitis and Red Legs
6. Additional Treatments
7. Genital and Head and Neck Oedema
8. Frequently asked questions by patients
9. GM Lymphoedema services
10. Useful links

MFT's End of Life and Palliative Care Educator have utilised a learning outcomes framework that was developed as part of the Vanguard's funding. They have piloted this with a small group of staff and are in the process of evaluating it. They will be presenting their evaluation to GM & East Cheshire EOL&PC Clinical Network. Paula Williams & Julie Kenyon, Lymphoedema Specialists, The Christie and Fiona Sanderson, Lymphoedema Specialist, St. Ann's Hospice have agreed to work on this post December 2020 and will provide education material for the MFT's End of Life and Palliative Care education.

Cancer workforce – Competency Framework

12. Lymphoedema

Learning outcomes	Self assessment	Action plan	Evidence of Success	Review date
The practitioner will be able to:				
12.1 Identify the sites and contributing factors (systemic or non-systemic) for lymphoedema and describe the pathophysiology of lymphoedema (LACE) and describe the difference between primary and secondary lymphoedema.				
12.2 Describe the signs and symptoms of lymphoedema and measure of limb oedema and interventions, including one-on-one assessment/management, alongside other oedema.				
12.3 Outline the appropriate treatments when they are indicated (e.g. systemic, compression garments) and self-care lymphoedema strategies.				
12.4 Describe the signs, symptoms and management of cellulitis and red legs and describe the difference between cellulitis and lymphoedema.				
Practice-based skills and competencies				
The practitioner will be able to:				
12.5 Provide information on evidence-based practice and research that underpins the care of lymphoedema and its complications.				
12.6 Provide information on evidence-based practice and research that underpins the care of lymphoedema and its complications, and advice for practitioners, including the impact on lymphoedema.				
12.7 Demonstrate basic assessment and care of lymphoedema, to include measurement of limb oedema, use of compression garments, and care and use of compression garments.				
12.8 Recognise and provide support to patients with lymphoedema and its complications and describe the management which is currently scheduled.				

The Royal College of Nursing launched a Breast Cancer CNS competency framework that included a section on the competency levels for lymphoedema. This has been shared with all GM Lead Cancer Nurses for distribution. It has also been shared with GM's breast cancer pathway Board, the GM Cancer's education programme and workforce lead. The workforce lead has secured funding from Health Education England to develop and pilot a NW cancer CNS competency / capability and career framework. This commissioned piece of work will be led by Skills for Health and will be commencing in January 2021. During phase two (developing a competency framework) competencies relating to late effects (including lymphoedema) will be considered.

University of Manchester and School of Oncology post-graduate courses.

Lymphoedema is currently provided as part of the MSc Specialist Practice (Cancer) - Course unit - Principles and Practice of Breast Care Nursing. This unit included a section on lymphoedema that Paula Williams, Macmillan Lymphoedema Specialist, The Christie's delivers. Course content is being revised and this is something that Paula will complete with the University of Manchester. Also the University of Manchester are going to look at other current courses that require lymphoedema, new courses they are looking to develop and also the development of a stand alone lymphoedema module.

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LEARNING AND DEVELOPMENT

Lymphoedema courses

The programme completed a desk based research exercise to identify key post graduated and CPD accredited courses for lymphoedema. Appendix 5 details the courses identified. The programme has shared this information with a member of the British Lymphology Society (BLS) to see if the information could be shared with the BLS network for review and then look at adding all the courses onto their directory of training courses.

The programme has also contacted the compression garment companies to understand their training offer and how this can be split against the different levels/workforces. Potentially, this could support lymphoedema practitioners when working with the wider workforce of what training is available.

This priority was considered as one of the least important by the key stakeholders for the programme to focus on and minimal work has been completed. The GM transformation network for lymphoedema will be able to review the table and agree how to utilise it post December 2020.

Standardised training material

People affected by lymphoedema

The lymphoedema practitioners developed training material for the patient education and engagement event that took place in November 2019. The sessions were filmed through a Macmillan grant. It is recommended for the GM transformation network for lymphoedema to review the materials and agree how to utilise them in the future.

Training material for wider workforce

The lymphoedema practitioners are working in small groups to look at how they can educate the wider workforce. In addition to the education work for the cancer workforce, end of life & palliative care and MARS below are some of the additional areas:

Acute Oncology and Emergency care

Lymphoedema and cellulitis are covered in the newly developed e-learning that will be accessible for all urgent care staff to understand the role of the Acute Oncology service.

GM Active

A small group of lymphoedema practitioners will be working with GM Active regarding training material to be embed into 2 new modules as part of their GM Active College to upskill the GM Active workforce.

Care Homes and Adult Social Care

A small group of lymphoedema practitioners have had a couple of meetings to look at how we can educated the adult social care workforce on risk reduction, recognising early signs and symptoms and supporting self management. The programme has connected the small working group to GM Health & Social Care Partnership's Adult Social Care Transformation programme.

Obesity

A small group of lymphoedema practitioners are looking to connect with GM weight management services. Including training Tiered 3 weight management team for 5 out of the 10 locality areas in GM. This will cover overview of chronic oedema/lymphoedema, risk reduction guidance, recognising early signs and symptoms and early referrals. In addition to this look at a collaborative way of working for personalised care.

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CASE FOR CHANGE

Locality Meetings

Based on the findings in the gap analysis report, a business case was not appropriate because six out of the ten localities had commissioned community services that accepted all type of lymphoedema. Therefore it was deemed more appropriate to develop ten case for change to enable each CCG and provider to understand their needs to achieve the GM Standards and pathway from chronic oedema/lymphoedema.

The programme team developed ten locality documents in alignment to the standards and pathway. They provided the known lymphoedema prevalence within the area. This was based on primary care report against lymphoedema coding. The programme team compared the known prevalence to the predicted prevalence from the commissioning guidance based on populations. From September 2020 the programme met with each GM locality (Bolton, Bury, HMR (Heywood, Middleton & Rochdale), Manchester, Oldham, Salford, Stockport, Tameside & Glossop, Trafford and Wigan).

The GM lymphoedema system approach enabled the programme to identify key stakeholders to be invited to attend the meeting. This included the cancer commissioner, the CCG's medicine management team, Macmillan GP, lead cancer nurse, management of community teams, commissioner of community services, IV therapy lead, tissue viability, the lymphoedema services and their management team, people affected by lymphoedema.

The purpose of the meeting was to provide context to what the programme had discovered within the gap analysis report, how the programme developed the



An example of a locality document can be found on GM Cancer's website

standards and pathway. The meeting advised how the standards addressed reducing the gap and variation and what actions were specific to each locality. The risk reduction element was vital to evidence the responsibility of the wider workforce. The programme team utilised the Leg Matter's story of Dennis from GM. Dennis' story evidence the need for change within the system. [Legs matter week - Dennis story](#). This story alongside other patient case study raised the profile of how impactful lymphoedema can be on someone's life if not treated accurately and in a timely manner.

Action Plan

Each locality had an action plan post the meeting. This covered specific locality actions but also actions that the programme team could commence. Recommendations included utilising the primary care records system to flag important messages, look into their local effective use of resource's policy and local audits on compression garments for hosiery. The main action was how to address the system approach in their locality.

Business Case

Three of the locality meetings identified a need to either expand the service or develop a new service. For two of the areas lymphoedema will be considered in the locality Long Term Conditions Transformation programme to have equity of care across their locality. Another area has created links between a number of services who will be able to build a business case. Upskilling current workforce was a requirement.

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IMPLEMENTATION PLAN

One of the key deliverables for the programme was to develop a strategic implementation plan against the proposed business case. This deliverable has significantly changed with the programme not writing a GM business case and is aligned to the 16 work priorities and case for change. The implementation plan provides a clear work plan post 2020 covering what, who and how the transformation work for chronic oedema/lymphoedema will be delivered. This implementation plan will guide how the network can achieve the GM lymphoedema system approach and the long term outcomes that were set for this programme. There are three elements to this implementation plan and they are. GM initiatives, locality initiatives and service alignments. Below is a graph outlining the work that has taken place in the programme and will continue post 2020:

GM Lymphoedema System Approach Healthcare System responsible for Risk Reduction, Early Identification, Supporting Ongoing Management						
Outcomes and Current Position (guidelines and education)						
Palliative & End of Life	Cancer	Cellulitis & Trauma	Vascular	Primary Lymphoedema & Lipoedema	Obesity High BMIs	Older Age & Immobility
<p>Guide for consultants (St. Ann's Hospice developing with EOL&PC Advisory Board)</p>	<p>A lymphoedema representative at all relevant GM Pathway Boards that will be reporting back into their network</p>	<p>Ambulatory Care Pathways – Cellulitis</p> <p>IV Therapy Leads</p> <p>Lymphoedema practitioners to build relationship and arrange working groups to amend ambulatory care –cellulitis pathway</p>	<p>Lymphoedema, Red Leg, Wet leg incorporated into MARS Pathway.</p> <p>Lymphoedema practitioner's network to look at incorporating these pathways into their locality</p>	<p>Primary Care Working with GM Shared service primary care data team. GM lymphoedema practitioners will be working on an algorithm to provide instant messages within the EMIS system to provide guidance and sustainable education</p>	<p>GM Active: -Mapping appropriate services in each locality. -Modules to Upskills Health Trainers</p>	<p>Educations for Adult Social Care</p> <p>Oldham and HMR lymphoedema services are going to lead this project and develop a consistent model for all GM</p>
<p>Review how to embed guidance for all EOL&PC workforce including St. Ann's checklist to be utilised.</p>	<p>Personalised Care for Cancer programme completing a full review of all End of Treatment summaries and will ensure lymphoedema as a consequence of cancer is included in a meaningful way.</p>	<p>Acute Oncology E-Learning for Urgent Care workforce with 3 slides on Lymphoedema and Cellulitis</p>	<p>The MARS programme is looking to implement the new pathways and evaluate with the aim to implement across Greater Manchester in the future</p>	<p>Diagnosis Letters</p> <p>GM lymphoedema services have agreed to send a diagnosis letter to GP. A template letter with primary care coding has been developed by the lymphoedema practitioners</p>	<p>Weight Management</p> <p>GM specialist weight management service have a best practice meeting.</p>	<p>A top tips poster to help risk reduction, early identification and supporting self management</p>
<p>Manchester Foundation Trust's competency Framework – Working with this service on their pilot and course content.</p> <p>The pilot is being</p>	<p>GM Cancer's Cancer competency based framework. A newly funded piece of work to scope, develop and pilot a cancer competency and career framework in GM.</p>		<p>MARS competency based framework.</p> <p>A project within MARS is to look at the community workforce competency Levels including chronic oedema/ lymphoedema</p>	<p>GM lymphoedema services have agreed to send a diagnosis letter to GP. A template letter with primary care coding has been developed by the lymphoedema practitioners</p> <p>A top tips one page document with clear guidance has been developed.</p>	<p>North Manchester is going to lead this piece of work alongside Oldham, HMR and Wigan</p> <p>One of the Tiered 3 weight management service covering 5 GM localities has requested a training session</p>	

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IMPLEMENTATION PLAN

GM INITIATIVES

Lymphoedema representation on cancer pathway boards

There will be a lymphoedema practitioner representative on the relevant cancer pathway boards at GM Cancer, where lymphoedema is a consequence of cancer and its treatment. It is imperative for the lymphoedema practitioners to raise questions, seek opportunities to improve risk reduction and early identification and work with the pathway board managers and clinical leads for those opportunities. The GM lymphoedema network of practitioners will be kept updated and will have the opportunity to flag any queries to the representative.

End of life and palliative care

Greater Manchester Health and Social Care partnership End of Life and Palliative Care programme for GM and the Clinical network have agreed to improve patient outcomes, care and quality of life by improving competency and practice for chronic oedema/lymphoedema. Fiona Sanderson, lymphoedema specialist, St. Ann's Hospice is leading this piece of work that will go GM wide for all end of life and palliative care specialist services across acute, community and hospice. This piece of work will also help these services to refer into a lymphoedema service in a timely manner.

“End of life & palliative care pathway is a invaluable resource that will help signposting for both patients and professionals”

Development of a standardised diagnosis letter to GPs

Late 2020 a co-produced letter has been designed to ensure consistency across GM. This will be implemented in 2021 to improve guidance for GPs on their patients treatment for their long term chronic condition and assist with more accurate data coding (SNOMed codes) . This will enable each locality to complete a prevalence report within the CCG and compare with the reports in September 2020. GM Cancer's website will have a list of all the relevant SNOMed codes for lymphoedema, cellulitis relating to lymphoedema, chronic oedema, wet leg and codes relating to red leg diagnosis. This will be available in 2021. The template letter has been shared with Macmillan GPs in GM for their feedback where all of them approached felt it was clear, concise and useful letter.

GM transformation work's network for lymphoedema

The lymphoedema practitioners along with some of their managers and tissue viability services have agreed to be part of a network to continue with the transformation work that the programme has commenced. Seven out of the ten lymphoedema services have agreed representation to this network. This network will drive forward the changes required to reach a consistent GM approach. They will meet eight weekly and utilise the implementation plan as a work plan. The network will also be taking over the programme's twitter account to enable the 246 followers to continue to receive updates of the transformation work.

Undergraduate and Post Graduate courses

The programme has approach the University of Manchester to review their course content for the undergraduate nursing degree, post graduate cancer related courses and to look at stand alone lymphoedema modules. The programme has recommended for the University of Manchester to attend the first network meeting in January 2021 to discuss a work plan, a lead for this piece of work and engaging with other local universities.

Upskilling current workforce

The previous page outlines how the GM lymphoedema network will develop education tools to upskill the current workforce under each risk category. The education will need adapting to suit the audience needs and levels but will ensure overview of lymphoedema, risk reduction guidance, early signs and systems and referrals to specialist services

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IMPLEMENTATION PLAN

GM INITIATIVES

Top Tips Information Poster (Community Nursing, GP and Cancer workforce)

St. Ann's Hospice drafted and worked with Bury's service on a top tips information poster for community nurses. This was based on discussions held at the Stockport locality meeting. The programme has put this in a one page format. Feedback has been that the document is clear, concise and easy to read. This template has then been utilised for primary care. A Macmillan GP has reviewed the template and provided guidance on how to amend it for the audience.

Algorithm for Primary Care Systems

The lymphoedema practitioners are working with a primary care data lead within GM Shared services. The programme requested all SNOMed codes relating to lymphoedema, chronic oedema, wet legs, cellulitis and diagnosis of red legs. In December 2020, the lymphoedema practitioner started to review all codes to decide what codes to use to offer guidance and links for GPs and other primary care practitioners. For example the algorithm could state if a patient has had 2 episodes of cellulitis in the last 12 months then a note will be flagged on that patient's record that the GP should consider a referral to the lymphoedema service. Each code and ruling will have an agreed short message and relevant links to access additional information.

Compression guidelines

The programme will provide a handover document to HMR CCG who have agreed to lead on this piece of work. The programme is proposing that a small group should develop guidelines for community teams to follow and deliver a pilot in one or two localities. An audit specification needs to be developed in order for the pilot site to gain a baseline, agree the timeframe for the pilot and have an evaluation plan. This piece of work needs to evidence that having a formulary/tiered approach guidelines for chronic oedema/mild lymphoedema will

1. help to prescribe appropriate garments within primary care and community nursing teams,
2. gain patient outcomes,
3. demonstrate that there is a reduction in costs on garments and if not, evidence that appropriate garments are being used with better patient outcomes,
4. reduction in antibiotics for cellulitis,
5. reduction of access to the IV Therapy service and admissions to hospital.

There is a possibility that hosiery companies can support this pilot to provide the data and analytics of the data.

Social Prescribing

All localities in Greater Manchester have a social prescribing scheme. It is essential that the social prescribers are aware of this long term chronic condition. Social prescribers will be key to help empower patient to self manage by looking at what it is in the community to help them move more, peer to peer support etc. This links with the piece of work the User Involvement Facilitator completed for November 2019 GM Cancer Conference's reviewing patients knowledge of community based assets.

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GM Macmillan Lymphoedema Programme

Are community assets available for people living with lymphoedema?
 Authors: Laura Tickle¹, Debra Allcock¹
 Affiliations: Macmillan and Greater Manchester Cancer¹ As part of the Macmillan Greater Manchester Lymphoedema Programme

1) Introduction
 When people have good social support networks and are included and valued in their community, they experience better health (Wilson, 2016). We explored service users' experiences of their local community and how community assets may benefit people affected by lymphoedema.

2) Method
 23 service users that have been affected by lymphoedema were emailed to complete an online survey comprising of qualitative questions. Qualitative data was analysed using Interpretive Phenomenological Analysis (IPA).

Figures 1. Lymphoedema word cloud
 This word cloud was developed using common words that patients used in their survey responses.

3) Themes
 7 themes were identified from the 8 patients that responded, one over the phone, all use lymphoedema services in Greater Manchester:

- 1) Access to a lymphoedema service therefore is vital
- 2) Lack of awareness to get out of the regions that we are just overwhelmed
- 3) Variation of support there are no support groups* there are too many that are
- 4) Only person with lymphoedema I don't know anyone else where I live that has it
- 5) Control over condition staff taught me techniques to manage it
- 6) Community assets to support condition (usually - compression garments, are terrible in the heat) there are events held to give information
- 7) Skills that could improve things (public speaking or social media)

4) Outcomes
 Patients are reliant on their existing lymphoedema service. They do, however feel able to manage their lymphoedema in their own community sharing accessible drop in clinics, tailored exercise groups, and medical devices available to borrow would be beneficial. Health professionals and the community being made aware of lymphoedema could reduce the isolation and stigma felt by people.

References
 1. Wilson, C (2016). Co-production and community development - a primer
 2. Icons made by "https://www.flaticon.com/authors/freemix"

Twitter: @GM_Cancer @MGM_LYMPH



IMPLEMENTATION PLAN

LOCALITY INITIATIVES

CCGs and Lymphoedema services need to work together on the locality initiatives. Identifying the key stakeholders and developing working parties. It will be imperative for the leads of the GM initiatives to keep all key stakeholders involved in their progress. Each GM initiative needs to be delivered at a locality level but will have the GM consistent approach. Below are a list the locality initiatives that need to be looked at during 2021

Cellulitis – Ambulatory care pathway

It was identified that there are gaps between healthcare professionals and inconsistencies within policies in how to treat lymphoedema and cellulitis. The programme has initiated meetings with four out of the ten localities with the IV therapy leads to access their ambulatory care pathway for cellulitis. There have been four different responses:

Locality 1 – Happy to amend the pathway to include referral of lymphoedema service but concerned about the BLS position document for cellulitis as it does not take into consideration local guidelines and antibiotic stewardship.

Locality 2 - Agreed to have a staff member to work with the lymphoedema practitioners to agree appropriate amendments.

Locality 3– Felt their knowledge on lymphoedema was minimal. They recommended initiating a meeting with the pharmacist, microbiologist, IV therapy team, commissioner and the lymphoedema service to develop a working group.

“ I think your work will be invaluable in preventing unnecessary antibiotic treatment by offering another differential diagnosis potential ”

Locality 4 – Agrees there is a gap that needs addressing and willing to be part of a working group

As part of the locality handover documents the programme will be recommending for each locality to identify their provider pharmacist, microbiologist, IV therapy team, commissioner and arrange a working group party to overcome the variances and work towards an agreed pathway and guidelines to improve patient outcomes.

Business Case and/or support from provider's management or corporate services

As part of the handover documents the programme will recommend those localities that need to consider a business case and develop a local working party to pull the evidence together.

Some localities will require support from management, senior management and corporate services such as transformation programme teams to help support improve competency levels, achieve the standards and system approach. Where possible the programme team has initiated communication with other programmes and senior management teams asking for their support. The localities need to continue the communication to gain the support.

The User Involvement Facilitator from the programme team has worked extremely closely with the lymphoedema practitioners to reach out to people affected by lymphoedema. Andrew's story (available within the appendix) provides the clear evidence to why there is a need to change to stop avoidable chronic conditions from developing, and accessing service for appropriate treatment in a timely manner and not having people lose their jobs and live in their bed all day when lymphoedema is treatable. In addition to this the UI Evaluation report provides a significant amount of detail from a person affected by lymphoedema's perspective.

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IMPLEMENTATION PLAN

LYMPHOEDEMA SERVICE ALIGNMENTS

There are two main areas that the programme is recommending the lymphoedema service to complete in order to align their services to the system approach and standards. Below are the two key headers. Each service will have an individualised handover document

Work with management team to communicate, engage and develop working relationships to improve patient outcomes

- Continue to build meaningful relationships between lymphoedema service, MSK physios & Frailty physios,
- Continue to build relationships between social prescribing teams in each primary care network so they understand the needs of lymphoedema patients
- Link with weight management services within each locality
- Link in with the daily huddles utilising link workers or establishing lymphoedema champions
- Implementation of programme documents to help the wider workforce including '10 top tips'
- Engage and build relationships with the lead cancer nurse, personalised care for cancer programme manager, information and support centres and tumour specific teams,
- Set up a working group with IV therapy lead, microbiologist, pharmacist to overcome antibiotic stewardship for cellulitis and lymphoedema
- Engage with vascular consultants to embed pathway for lymphocitigraphy

Work towards the System Approach and Set of Standards Statements

- **Completion of the GP template letter** including diagnosis code commitment to send a diagnosis letter to GP's for each patient. Utilising the GM template, clearly stating which SNOMed codes are relevant for that patient to enable accurate recording in primary care.
- **KPIs** – Look at how the services can evidence against the proposed KPIs and outcomes
- **Reporting Standards** - Work with business intelligence team to embed reporting requirements into your system. This will enable service data to be auditable for capacity and demand.
- **Audit caseload** - to see if there are gaps in patients attending service. Each low obesity related lymphoedema. Build those connections with appropriate services
- **Support the CCG Primary Education Lead** - educate primary care on a regular basis utilising resources
- **Treatment of patients**
 - Align and monitor referrals to first appointment with standards,
 - align treatment plans to standards (linked to tariff guidelines) – unless there is an exception for individual patients,
 - follow the GM Lymphoedema pathway,
 - provide a personalised care plan to each patient on paper so the patients are empowered to self-manage in between treatment appointments. Utilising the Care Plan Guidelines,
 - commit to the develop of compression guidelines for a consistent GM approach in decision making for prescribed garments.

Surgery

A consultant at the Christie Foundation Trust is interested in developing surgical treatments for patients not responding to conservative treatment. The programme has recommended to engage with the Effective Use of Resource's Greater Manchester Team to look at developing a GM policy

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PROGRAMME EVALUATION

This section of the report will summarise

- The deliverables achieved and not achieved and the reason/s,
- outcomes of the programme that were planned within the programme initiation document,
- further outcomes achieved or outputs that will develop further outcomes post the programme ending,
- a summary of the UI evaluation and final report,
- a summary of the impact and benefits from this programme to our key stakeholders.

DELIVERABLES

The programme had eight deliverables that were identified in the partnership agreement and within the programme definition document. They were:

- Programme Governance
- Information and Analysis workstream – with Gap Analysis report
- Ensure people affected by lymphoedema had an equal voice on this programme of work
- Developed a co-produced GM model of care for risk reduction, early identification, treatment and management of condition
- Identify the learning and development requirements
- Business case/Case For Change locality documents
- Strategic implementation Plan
- Exit Strategy

This section will provide a summary of those deliverables.

LOGIC MODEL

The programme utilised the logic model using the below headings.

Outcomes	Rationale	Inputs	Activities	Outputs	Impact
show the specific changes that the programme brings about.	outlines the problem or opportunity you are addressing.	outline the resources required for your intervention, including human, financial, organisational and in-kind	outline what will be carried out based on the inputs for the intervention or programme.	outline the directly measurable results that the intervention or programme delivered.	outlines the ultimate change your intervention or programme is contributing to.

Below are the programme identified outcomes:

- A robust gap analysis to produce an evidenced based report.
- A model that has been co-produced.
- An agreed proposed model
- A Strong Business Case completed
- A realistic Implementation Plan
- Outcomes and Benefits Ownership Handed over
- A robust exit Strategy

MEL FRAMEWORK

The MEL Framework is to plan how the programme will monitor, evaluate and learn. For all the planned outcomes the programme completed this table. The table was utilised to develop a series of questionnaires for a survey to all the key stakeholders:

Outcome	How we will Measure	How we will know	When will we collect	What will it Tell

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DELIVERABLES AND OUTCOMES

DELIVERABLES ACHIEVED

This section will provide details of the deliverables and outcomes achieved. This will be split into three tables, deliverables achieved, not achieved and outcomes.

Description of deliverable	Describe the extent of how the deliverable meets the expected quality?	Are further activities needed to transition into business as usual – if so, what?	Completion accepted by
Programme Governance	The programme team wrote and maintained all the strategy documents. All documents were shared with the steering group for formal approval and then added to a version log for version control.	No. The programme team will ensure that all elements of the programme are within the strategy documents are finalised.	December 2020
Information and Analysis workstream – with Gap Analysis report	The programme developed an Information and Analysis framework to gather the information that was required for the gap analysis report. This deliverable was a key element of Year 1 of the programme.	The Gap Analysis Report can provide a baseline for GM. Services are recommended to record extensive data in an audible format as this will provide further evidence that this programme was unable to retrieve specifically around capacity and demand	December 2019
Ensure people affected by lymphoedema had an equal voice on this programme of work	The User Involvement Strategy was signed off by Macmillan engagement team and the programme steering group. This enable the programme to follow a robust process to achieve understanding patient's lived experience through case studies, focus groups, involvement in work streams and patient films, Lymphoedema Support Network. Patients have attended meetings and also feedback on pieces of work to ensure everything was developed collaboratively, taking all points of view and gaining a middle ground.	User Involvement representatives offered other opportunities both with GM Cancer, Macmillan Cancer Support and other local initiatives. Lymphoedema practitioners to continue engagement with patients for future developments	December 2020
Developed a co-produced GM model of care for risk reduction, early identification, treatment and management of condition	The 10th December 2019 commenced the conversations of how to achieve a model of care. This meeting had representation from all key stakeholders. The model of care was developed based on this session and then was shared with key stakeholders for feedback to enable any amendments. All work has been split into risk reduction and treatment to ensure the outcomes of a model considered these to areas.	The implementation plan and handover documents to each locality will enable the model of care to be utilised in business as usual and for each locality to works towards what is required of them to reach the GM Standards.	December 2020

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DELIVERABLES AND OUTCOMES

DELIVERABLES ACHIEVED

This section will provide details of the deliverables and outcomes achieved. This will be split into 3 tables, deliverables achieved, not achieved and outcomes from achieving those deliverables.

Description of deliverable	Describe the extent of how the deliverable meets the expected quality?	Are further activities needed to transition into business as usual – if so, what?	Completion accepted by
Identified the Learning and Development requirements	<p>Learning & Development was part of the Information and Analysis Framework. The programme was able to retrieve the education all practitioners had received and would like to receive.</p> <p>Survey's enabled the programme to retrieve a general knowledge of wider workforce needs.</p> <p>In addition to this desktop research was completed to understand the known course available including from higher education and from hosiery companies.</p> <p>The User Involvement Facilitator also obtained what patients needed to learn how to better self manage. This supported the development of the care plan within the 16 work priorities</p>	<p>From the identified learning and development requirement eight work priorities was set under learning and development. Four out of the eight have been completed and the requirement is for people to utilise them.</p> <p>The other four will be part of transformation network for lymphoedema group.</p>	December 2019
Produced 10 Case For Change locality documents	This deliverable was amended from a business case to case for change. This was recognising not all localities gap was a business case. Macmillan Cancer Support fed back on a number of occasions to the programme the impact of the case for change documents and the localities meetings that ensure key stakeholders understood their local need to gain better patient outcomes.	This work has been transferred into a locality action plan and handover document	October 2020
Strategic implementation Plan & Exit Strategy	<p>The programme looked at how the work could be transitioned into business as usual and what could be closed down. There were elements of the 16 work priorities not completed or that had driven further outputs that the programme commenced with lymphoedema practitioners including the primary care flagging system.</p> <p>User Involvement needed to ensure all consent were in place for stories and an offer of other opportunities provided.</p>	<p>This deliverable has achieved:</p> <ul style="list-style-type: none"> - 10 locality handover documents and emails to all key stakeholders - A work plan for the transformation network for lymphoedema. A group that is meeting 8 weekly and will be leading on elements of the work to gain further outcomes. - A hosiery handover document to HMR CCG as the lead 	December 2020

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DELIVERABLES AND OUTCOMES

DELIVERABLES NOT ACHIEVED

Summary of the deliverable still to be realised	Description of how it will be delivered after the project close	Who is the owner?	Describe how this will be followed up
<p>Business Case. It was agreed that the programme would amend this objective,</p> <p>The findings from the Gap Analysis report evidenced some services had been commissioned appropriately but</p> <ul style="list-style-type: none"> - Some services are not delivering what is commissioned - Or - Not delivering against the prosed standards <p>Therefore a case for change to each locality was more appropriate and would enable each locality to agree if a Business Case was required in the future.</p>	<p>Bolton – CCG, Bolton FT’s Tissue Viability & Community, St. Ann’s Hospice and The Christie FT are working in collaboration to retrieve the evidence required and look at a business case. Bolton has a EUR for lymphoedema and this needs to be used more to evidence the need.</p>	Partnership	<p>The GM Cancer, Cancer Commissioner’s meeting will have a quarterly agenda item on lymphoedema.</p> <p>The Lymphoedema practitioners will be meeting 8 weekly to look at the transformation work</p>
	<p>Bury – Programme has engaged with the care organisation’s Directors to look at supporting the service through transformation or quality improvement teams. With the recommendation of upskilling all the wound care service. An internal business case may be required for education.</p>	Bury Care Organisation	
	<p>HMR – A business case is currently not required. The cancer commissioner will continue to work with the service to implement all transformation work</p>	HMR cancer commissioner	
	<p>Manchester and Trafford – Inequity of service across the locality. Trafford and Manchester Local Care Organisation under the long terms condition work stream as vascular is a priority. MARS incorporates lymphoedema (lower limb). Possible of inequity of other limb lymphoedema</p>	LTC Condition work stream & MARS	
	<p>Oldham – A business case is not required. A new Tissue Viability and Lymphoedema lead is commencing in January 2021 and will be working with the new innovative team. Also looking to upskilling their TVN workforce in the future</p>	Lead Tissue Viability and Lymphoedema Nurse	
	<p>Salford – The programme have recommended Salford CCG to address the gap of lymphoedema workforce in their tissue viability service with Salford Care Organisation. In addition Lymphoedema will be an agenda item in the St. Ann’s Hospice general contract meeting.</p>	Partnership of key stakeholders	
	<p>Stockport - Lymphoedema will be an agenda item in the St. Ann’s Hospice general contract meeting with Stockport CCG. A partnership between Tissue Viability, IV Therapy Lead, St. Ann’s Hospice and the CCG have formed to implement system approach</p>	Commissioner	
	<p>Tameside & Glossop - The Tissue Viability and Lymphoedema Lead will continue to work with the service to implement all transformation work</p>	Service Lead	
	<p>Wigan - An internal business case from the service lead to the Trust has been submitted due staff retiring. Also will continue to work with the service to implement all transformation work</p>	Service Lead	

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BENEFITS AND OUTCOMES

PLANNED OUTCOMES

Outcomes	How the programme measured	How will the programme know	Evidence of how the outcome was achieved
A robust gap analysis to produce an evidenced based report	<p>Full understanding of the provision, improvements and variation for lymphoedema in Greater Manchester.</p> <p>Follow the Information and analysis Framework</p>	<p>All information is collated aligned to the Information and analysis framework</p> <p>Steering Group members confirm that the information was robust</p> <p>Feedback regarding report</p>	<p>The majority of information was collated in alignment to the framework and where data was not retrieved it provided evidence of gaps that needed to be addressed.</p> <p>The steering group signed off the gap analysis report as a robust report.</p> <p>Key stakeholders who received the report fed back in December 2019 how robust and informative it was.</p>
A model that has been co-produced.	<p>The UI Strategy</p> <p>Evidence the programme has delivered the communication plan.</p> <p>Evidence what and how stakeholders have been involved in the programme</p>	<p>Evidence of the UI work and UI Evaluation report</p> <p>Evidencing how the programme has delivered the communication and engagement plan</p> <p>Feedback from key stakeholders</p>	<p>This final report provide key information of the work from people affected by lymphoedema. A UI evaluation report will evidence how the programme has ensure outcomes from the programme aligned with this.</p> <p>This report evidences the breadth of communication and engagement. The programme has continually analysed their key stakeholders and provided target communication in order to ensure the model was co-produced.</p> <p>A survey sent to all key stakeholders responded that they all (13) understood why they had been involved in the programme, 11/13 said the programme had the right stakeholder representation. The other 2 did not provide any further information .</p>
An agreed proposed model	<p>Model is signed off</p> <p>Key stakeholders agree to sign up to implementing the model</p>	<p>Key stakeholders to agree to take ownership of certain projects for sustainability</p> <p>Locality meetings - stakeholders to agree to actions within the locality action plan and ownership of action plan post project ending</p>	<p>The steering group signed off the system approach and set of standard statements in January 2019.</p> <p>This developed a the GM Standards and GM pathway. The pathway has been deemed complicated but this evidenced how complicated lymphoedema is, especially in the risk reduction and early identification stage.</p> <p>There are a number of key stakeholders in each locality that have agreed to take ownership on the implementation and handover documents to ensure the implementation of the model. However it would be recommended to evaluate the implementation to see if the programme initiated the long term vision</p>
A Strong Business Case completed	<p>Steering group sign off the business case</p>	<p>All Cancer Commissioners to agree to submit the business case through their governance structure</p>	<p>This was not achieved. This was an informed decision the programme took and amended the deliverable for a case for change.</p>
A realistic Implementation Plan	<p>An implementation plan that key stakeholders have agreed and signed up to</p>	<p>By key stakeholders providing agreement and commitment to the implementation plan</p>	<p>seven out of the ten services have agreed to be part of the transformation network for lymphoedema. This covers nine out of the ten areas. The one area that is not covered, the service is gaining support from management and might be able to join at a later date.</p>
Outcomes and Benefits Ownership Handed over	<p>Handover document</p>	<p>Final report evidencing all the benefits</p>	<p>Appendix 6 provides all the identified benefits and what has been handed over</p> <p>In the key stakeholder survey 12/13 said they are aware of their role post December 2020 in continuation of the programmes work streams</p>
A robust exit Strategy	<p>Steering Group to sign off as robust exit strategy</p>	<p>The programme team will provide assurance that all elements of the programme will be appropriately closed or transferred for sustainability</p>	<p>November Steering Group the programme provided an overview of the aims for the exit strategy. All members were happy with the plans. Regular update to the responsible officer of the programme provided assurance to the direction on the exit of the programme.</p>

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BENEFITS AND OUTCOMES

FURTHER OUTCOMES AND BENEFITS

The programme has enabled the facilitation role for Lymphoedema practitioners working collaboratively together on transformation work.

Increased referral of Head and Neck patients into Christie service and to trial within Salford Cancer service. Potential links to attending an event for Head and Neck cancer pathway

Cancer - End of Treatment summaries
All templates have swelling or lymphoedema. The personalised care programme will improve this as each template is being updated. Breast, Gynae and Colorectal templates ensure patients are empowered to ask for guidance on risk reduction

GM Lymphoedema practitioners worked collaborative to deliver a GM patient education and engagement event

Locality meetings has enabled lymphoedema practitioners to build relationship with the services linked to risk reduction

The programme has raised the profile of Lymphoedema and connecting it to Chronic Oedema

National representatives of lymphoedema have congratulated the programme of its work and has recommended it to be published

Initiated meetings to discuss course content in higher education
And other training within the core risk groups

NHS England Personalised Care for Cancer Programme Lead has agreed to share this report to all Cancer Alliance's Personalised Care Programme Leads

London Lymphoedema Community of Practice has requested our work plan
"As you can imagine we were impressed"

Initiated meeting with IV therapy Leads, microbiologist and pharmacist to discuss the difference between local policy and BLS document to agree a outcome to improve patient outcomes

Top Tips for Community Nursing to improve knowledge and help them to identify patients earlier

Patient Stories evidencing why there is a need for change

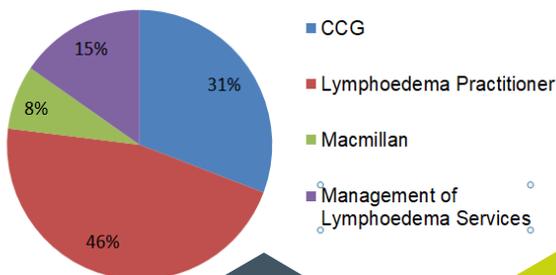
Top Tips for Primary Care to improve knowledge and help them to identify patients earlier

PROGRAMME EVALUATION

EVALUATION SURVEY

As part of the evaluation plan, the programme team devised an evaluation survey and sent it to the key stakeholders – commissioners, lymphoedema practitioners and their managers, Macmillan Cancer Support. 13 people responded out of 80 people (16%). Below is an analysis of the responses back from the survey

Stakeholder



12 understood why they were involved in the project from the beginning.

100% said the project team has been visible and approachable throughout the project

69% were very satisfied with the opportunities that have been involved in

2 lymphoedema practitioners did not feel the project had enabled to enhance working relationships

The impact of the Project quotes:

84% felt that the right stakeholder representation throughout the project

“ I feel there has been great work done during the project, Hoping to reduce cost to the CCG, reduce incidence of cellulitis, have an impact on training needs within care homes ”

“ I have learned so much and the insight has been invaluable. It has also enabled me to build relationships and networks, especially being new to the CCG. ”

“ raised the serious nature of lymphoedema as a consequence of a cancer diagnosis and also highlighted non-cancer lymphoedema The benefits of awareness and early management, and how patients can be supported to manage their own condition Great work - well done to all ”

“ Better understanding of lymphoedema services and provision for people who have chronic oedema not related to cancer. ”

“ Collaborative working with other services ”

“ Improved links with other services ”

“ Increased my awareness and supported me to further promote the service within my trust. ”

“ provided an opportunity to fully understand the complexities of lymphoedema and the difficulties for its practitioners in both raising its profile and securing the correct funding opportunities ”

“ I have been able to network with my peers. ”

In your opinion do you feel that the project has raised the profile of lymphoedema?

10 a lot

3 CCG, 4 lymphoedema practitioners, 3 management of services and 1 Macmillan

3 a little

1 was from CCG and 2 lymphoedema practitioners

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PROGRAMME EVALUATION

Please indicate below which aspects of the project you have found most / least useful

Project strategies	Project governance documents	Gap Analysis report	December's Multi Stakeholder	16 work ideas priorities	Locality meetings	Steering Group Meetings	Monthly reports
least - 3	least - 3	least - 1	least - 2	least - 3	least - 2	least - 2	least - 3
most - 6	most - 8	most - 11	most - 8	most - 8	most - 9	most - 9	most - 9
did not respond - 4	did not respond - 2	did not respond - 1	did not respond - 3	did not respond - 2	did not respond - 2	did not respond - 2	did not respond - 1

How could we have improved on the least useful?

I feel that the team have provided an excellent opportunity for this discussion. the conflicts for healthcare this year I feel have impacted on its work, but this has been unavoidable.

I wasn't able to attend many of the regular meetings due to my working days

Make it less complicated

Unsure/Not Sure/Nothing

What piece of work have you done on the project that has made you feel proud?

Being involved in working groups and hopefully going to make a difference and raise awareness in care homes

Patient Education day

Networking locally

No one specific area. I don't actually feel proud

Currently I am working on a business case to increase the WTE within the team. Information received will assist me with this business case

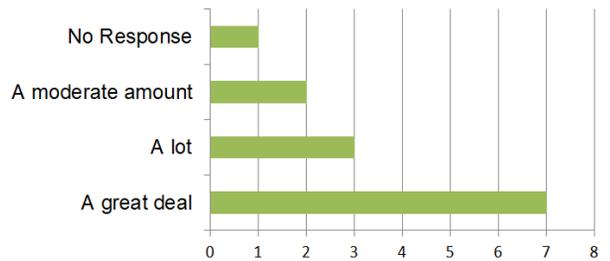
To have built relationships with Deb and Molly, they are so knowledgeable and have helped me to understand the project.

Appointing Deb & Laura and then appointing Molly

Helping to invest in the programme

Raising awareness of lymphoedema

Did project provide clear updates throughout the 2 years



What is the biggest success of the project?

- Raising the profile of lymphoedema and providing it a platform
- Pathway
- Clear documentation to make improvements
- Locality documents
- Hosiery

77% developed a set of standards & Pathway that is Proactive, cost effective, equitable, sustainable

12 people understand what their role is in the continuation of the project priorities

12 are willing to commit their time in sustaining the work from the project

What do you feel has been missing or least helpful of the project?

- Nothing
- Lack of Funding
- Timing
- Competing priorities
- Remit too big
- Capacity and demand data
- Involvement from others

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PROGRAMME EVALUATION

Lessons Learnt

The evaluation plan was completed retrospectively towards the end of the programme. Completing this plan at the beginning would have been beneficial to understand how the programme was going to obtain its deliverables and outcomes.

The first 6 months of the programme had not engaged with the management of lymphoedema services. This was recognised and engagement work commenced.

It was clear that the monthly reports needed amending for effective communication. The programme to constructive feedback and amended them to align to the work plan.

The wider workforce use the word chronic oedema and true lymphoedema. It is key that the correct wording is used to the audiences. The programme was able to make lymphoedema relevant to those stakeholders by changing the language to chronic oedema.

It was vital to have engaged with the workforce associated with the risk categories at an earlier stage of the programme. If this had been completed, localities would be further forward than they are now.

It is important to raise change requests against the original partnership agreement and for the partnership to be flexible and make those changes if evidence demonstrates a need. Changing the deliverable from business case to case for change was certainly right. Even though some services are disappointed in not getting extra funding for more staff. Improvements need to be made in collating data and working with the wider workforce for risk reduction.

Early Outcomes/successes

The programme was able to quickly deliver a launch of the programme in alignment with the launch of the National Commissioning Guidance of Adult Lymphoedema services. This enabled the programme to engage with identified key stakeholders.

The programme's Information poster was an early success, as it enabled the programme to clearly explain the structure of the programme. The programme received positive feedback from all the cancer pathway boards that it attended

The GM patient education and engagement day provided an excellent outcome for the programme and assisted in gaining significant data for the gap analysis report.

Impact on programme due to COVID19

Positive Impact – It enabled key stakeholders to attend meetings that they may have not been able to attend due to the positive benefit of video conferencing and no travel times.

Due to clinics closing down, lymphoedema practitioners had additional capacity to support the programme and enable the programme team to build close relationships with a number of lymphoedema practitioners who have been instrumental to the success of this programme

Negative Impact - The programme team was redeployed into priorities services within the Christies. This was certainly the right thing to do but it did impact the work of the programme for about three to 4 months. This was minimal compared to other projects and programmes.

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PROGRAMME EVALUATION USER INVOLVEMENT



Programme Learnings

Based on UI feedback, working virtually due to Covid-19 hasn't suited everyone. There are people that have chosen not be involved in the programme until face to face meetings can happen again. Other people have highlighted that they do not have the technology to be involved virtually "Covid-19 has meant that meetings can only be held on line and my computer skills are not adequate for this". The User Involvement Facilitator held a number of sessions to teach people the new technology and to hold virtual coffee mornings. This had very low uptake, but did allow one service user to attend some virtual meetings after a session on MS Teams "Thank you for your support and your help with educating me in the new technology. I would never have done it without your help"

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APPENDIX 1: PROGRAMME GOVERNANCE

Original Road Map

Jan19-Mar19	Apr19-Jun19	Jul19-Sep19	Oct19-Dec19	Jan20-Mar20	Apr20-Jun20	Jul20-Sep20	Oct20-Dec20
Programme Set up							
Discovery							
Gap analysis							
		Develop					
				Propose			
				Business case			
				Implementation plan			
						Commissioning Intentions	
						Programme Final Evaluation	
						Programme Close down	
		Report		Report			

Programme Governance

Information and
Analysis Framework



Info and Analysis
Framework

Communication and
Engagement Plan



Microsoft Word
Document

Gap Analysis report



Lymphoedema
Gap Analysis Report

Logic Model and MEL
Framework



MGM Lymph
Evaluation Framework

RESIDUAL RISKS AND ISSUES

Risk or issue description	Comment on Likelihood and Impact of risk occurring	Assigned owner	Describe how this risk will be followed up
If the transformation network group does not take ownership of the work plan Then addition outcomes and the long term vision may not be achieved	Likelihood – low Seven out of ten services have confirmed to join a working group and accepted to attend 8 weekly meetings that is being facilitated by Debra Allcock over a transition period		Debra Allcock can advise Macmillan Cancer Support and GM Cancer after six months of this network meeting to determine if still a risk
If HMR CCG does not lead on the hosiery work Then this work priority will not be completed and gain the anticipated outcomes	Likelihood – low Full handover provided to HMR CCG and within HMR CCG's governance structure agreeing to do this piece of work in HMR	Jan Teece	Jan Teece can keep GM Cancer informed through the cancer commissioner's meeting
If the localities do not act to make changes from the recommended handover documents Then there is likely to be no equity of care across GM for lymphoedema Funded by	Likelihood – medium Each locality has a key stakeholder willing to drive the changes. There is a hope that an individual will take leadership in each locality		Programme recommends that Macmillan or GM Cancer engage with each locality to understand their position

APPENDIX 2 - FEEDBACK

“Thank you to everyone for all the hard work and support you have given each other to produce some fantastic outcomes to support the future and sustainability of lymphoedema services across GM”

Below is feedback that the programme collated from comments and emails;

Juzo	A meeting with JUZO representative advised that the practitioners they had spoken to had felt that this was the first time they had been fully involved in looking at lymphoedema services
Steering Group Zoe Merchant - Prehab 4 Cancer	Meeting in May AOB - recognised for all that the project had achieved during COVID19 especially redeployment "Fantastic Resource" for Skin Care Video
Anne Marie Raferty Eol&PC	Many thanks for sharing what I am sure will be in invaluable resource that will help signposting for both patients and professionals.
User Involvement representative Susan Todd GM Cancer	Comment regarding Fiona Sanderson 'The Lymphoedema Specialist Fiona Anderson has been constant throughout Covid-19. She has contacted me to check on my lymphoedema and continued to liaise with me by phone and by consultations at St. Anne's Hospice' You've been super busy Debra J, huge well done for all you and your team have accomplished – you must be feeling very proud and happy!
Tim Humphreys Macmillan	Loving your work, Deb! And Molly and Laura are ace too!
Sharron Woods WWL	I just wanted to let you know that I found the meeting this week really helpful and informative. Also, generated a lot of discussion within the team, which is always good. I have discussed some of the issues raised with my manager and I am working on a business case to increase the wte within the Lymphoedema Team.
Nas Ahmed Vascular Consultant and Clinical Lead - MARS	There is huge opportunity here to achieve many of the LTC aims and Debra is a passionate and extremely intelligent advocate for the condition. She has helped shape my thoughts on the problem as well as helped incorporate the solution into the MARS pathways. I would wholeheartedly recommend a chat with her!
Coral Higgins MHCC	you should all be so proud of what you have achieved. Finally we are taking lymphoedema seriously and you have got us into a great position to really make some meaningful improvements. Its now down to all of us to carry things on and make things better for patients but thank you for setting us on the right path
Jan Teece HMR CCG	Totally second what Coral has said, you have been amazing and personally you have helped me so much in this role. I hope all works out well for you and Molly, thank you so much for your drive and commitment to the service and for everything you have done. I'm sure I'll see you knocking about Tameside. Take care
Fran Mellor Macmillan	I ditto all your comments Deb, Laura and Molly together with the lymphoedema therapists across GM have done an excellent job in the most difficult of circumstances, a pandemic and a subject that many people shy away from. Our professional awards have been suspended this year but there will be next year and most definitely, Tim and I will look for an opportunity to highlight the teams work.
Rachel Mcmillan St. Ann's Hospice Jane Nicklin Facilitator – London Lymphoedema COP	I'd just like to echo the feedback so far and you've done an amazing job despite of all the challenges we have faced this year. Thank you to everyone for all the hard work and support you have given each other to produce some fantastic outcomes to support the future and sustainability of lymphoedema services across GM. It was fascinating to hear how much detailed work you and your team have done; congratulations to you all. We certainly felt that we could learn a lot from your work and will bring it to the attention of our CoP and would like to keep the links going with GM. I have attached our TOR/ statement of purpose. Members of the CoP were clear that they wanted a framework but didn't want to get hung up on the detail of this.
Nicole Alkemedede Stockport Commissioner	Could you please pass on my compliments to your whole team. You have delivered absolutely fantastic work with the Lymphoedema programme! You can all be very proud on the massive positive difference you have made for patients and staff through the programme. Fantastic feedback and a great opportunity to network between two regions taking a solid stance on lymphoedema. Great work.
Darren Jennings Primary Care data Helen Wrench Personalised Care for Cancer	from my limited interaction with Molly and yourself I think you have done a great job and will be sorry to see you leave! This is amazing work , you should be very proud of the successful engagement with the various stakeholders and the production of such high quality material .Thank you so much for sharing !

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APPENDIX 3 - PROGRAMME INTRODUCTION

Macmillan GM Lymphoedema Programme

Programme Team: Debra Allcock (Programme Manager) Karen Livingstone (Macmillan Clinical Lead) Alison Reddican (Quality Improvement Facilitator) Laura Tickle (User Involvement Facilitator) Melissa Shaw (Macmillan Project Support Officer)

Background / Introduction

Greater Manchester Cancer and Macmillan Cancer Support have developed a two year partnership for this programme.

Lymphoedema is a chronic failure of the lymphatic drainage system resulting in persistent swelling which can affect any part of the body.

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 and cellulitis.

Lymphoedema cannot be cured; early intervention, management and regular self-care can reduce the risk of repeated infection and severity of cases.

Summary (Project Description)

Using a **co-production model** the programme will lead on understanding the problem, developing ideas for improvements and reduction of variation in access and availability that will be proposed to the Greater Manchester Network.

Model of Care

- 1) **Prevention & Early diagnosis** - An effective structure across the system to prevent & reduce incidences and increase earlier diagnosis.
- 2) **Service provision** - Propose a set of standards for an equitable model of care across Greater Manchester including referral, treatment and self-management.

Learning and Development

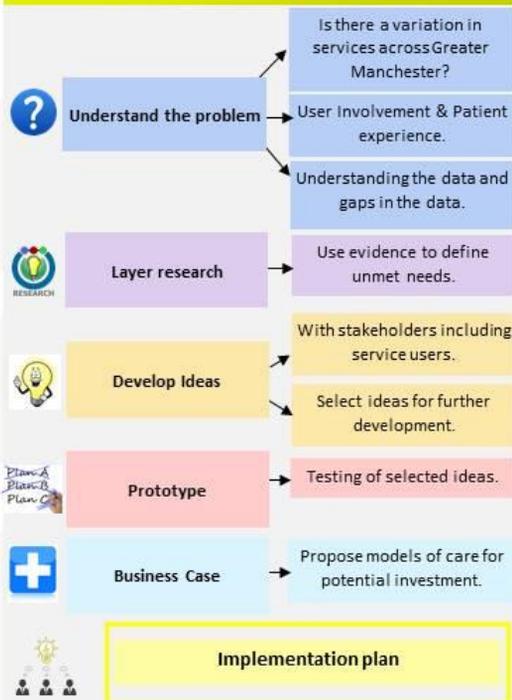
- 1) **Patients education** needs to identify signs, symptoms and promote self management.
- 2) **Education needs** for the wider healthcare professionals and lymphoedema workforce.
- 3) **Qualifications & training** for future healthcare professionals.

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Method



Expected Benefits/Outcomes

The recommendations for an equitable, cost-effective and sustainable provision of lymphoedema would enable:

- * Reduction in incidences of moderate and severe lymphoedema due to increased patient awareness.
- * Reduction in unplanned admissions and length of stay for severe lymphoedema and cellulitis.
- * Improvement to peoples' quality of life and independence.
- * Increased level of self care.



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APPENDIX 4 - STATEMENTS

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

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APPENDIX 5 - TRAINING MATERIAL

Below is a list of post graduate and CPD courses that have been identified by the programme

Educator	Course	Level
University of Hertfordshire	MSc Clinical Skin Integrity and Wound Management 30 credit module - Managing Chronic Oedema 30 credit module - Advanced Chronic Oedema	For Nursing, Vascular and TVNs -
University of Glasgow	1 week Online Introductory lymphoedema course Continuing Professional Development (CPD) certificate	Band 4/introduction
	Graduate Certificate in Lymphoedema Practice - 60 Credits aimed for band 5 lymphoedema practitioner	Low grade key worker
	Graduate Diploma in Specialist Lymphoedema Management (120 credits - all 4 courses) - Band 6 Lymphoedema Specialist Practitioner	Key worker
	A Postgraduate Certificate (12 months PT) in Advanced Lymphoedema Management (60 credits) - Band 7 Lymphoedema Advanced Practitioner	Specialist
UCLAN	AdvCERT - Introduction to Chronic Oedema Management (Keyworker level)	Key worker
The Royal Marsden	Introduction to Chronic Oedema Management AdvCert	Cancer only
	(BSc (Hons) in Cancer Practice and Graduate Diploma in Cancer Practice that provides lymphoedema management. East Anglia University • Principles of Breast Care Management • Principles of Gynaecological cancer care	Cancer only
Lymphoedema Training Academy	Essential Care in lymphoedema Advanced Management of Lymphoedema	1st is key worker and 2nd is specialist
University of Wolverhampton as part of Compton Care	- Contemporary Approaches to Lymphoedema Service Provision (6HW117) - Specialist Assessment and Management of Mild/Moderate Lymphoedema (6HW115) - Specialist Assessment and Management of Complex Lymphoedema (6HW116)	Each module is 20 Credits at Level 6
Birmingham University	Lymphoedema Fundamentals of Care 1 academic term: - already completed a basic course - If part of BSC hon's achieved 240 credits at least 120 at level 5 - If graduate certificate have achieved bachelors degree 360 credits (120 at level 6)	Various levels
RCGP – Lymphoedema	This course aims to educate GPs about the diagnosis and management of chronic oedema and lymphoedema.	Free for GPs or £25
BMJ	BMJ learning module	GPs and GP trainees
Macmillan	Macmillan Professionals online Manual Lymphatic Drainage	Various
K-taping		Lymphoedema practitioners
Fluoroscopy		
Casley-Smith Lymphoedema Education	Various courses - Casley-Smith MLD training Training courses in Casley Smith method of Manual Lymphatic Drainage, Casley Smith Exercises and Multi-Layer Lymphoedema Bandaging.	Lymphoedema practitioners

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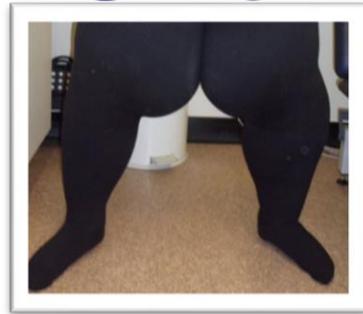
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APPENDIX 6 - BENEFITS

Desired benefit	Stakeholders impacted	Enablers required to realise benefit	Outcomes	Current baseline measure	Current positions	Who is responsible	Target date
Improved knowledge of current GM Lymphoedema provision and variation	Lymphoedema Services Commissioners GM Cancer Macmillan People affected by lymphoedema	Macmillan Lymphoedema Programme Team Services	Gap Analysis report detailing current provision and variation	Lymphoedema provision in GM Strategic Health Needs Assessment 2015	Gap Analysis report shared with key stakeholders. Locality Meetings Tools to inform wider workforce	Macmillan Clinical Lead Macmillan programme Manager	10 December 2020
Improved key stakeholders knowledge of recommended national standards	Commissioners Services Macmillan Macmillan Programme Team People affected by lymphoedema	National Lymphoedema Partnership International Lymphoedema Framework British Lymphology Society	Gap Analysis report detailing recommendations and evidencing good practice	Lymphoedema provision in GM Strategic Health Needs Assessment 2015	Multi Stakeholder event reviewing all evidence collated	Macmillan Programme Manager Macmillan Programme Team	10 December 2019
Improved knowledge of the health needs of people affected by lymphoedema	Commissioners Services Macmillan Macmillan Programme Team People affected by lymphoedema	Macmillan Programme Team Public Health	Health Needs Assessment	GM Strategic Health Needs Assessment 2015	Request for Public Health Trainee. but no take up. Gap Analysis report covered elements of this.	Macmillan Programme Manager Public Health Trainee	01 March 2020
Enhanced engagement with people affected by or at risk of lymphoedema for co-produced solutions	People affected by and people at risk of lymphoedema	User Involvement Facilitator Lymphoedema Services People affected by or at risk of lymphoedema	Understanding of patients lived experience Patients voice in developing ideas to address the gaps. Patient voice to ensure changes are made to achieve the drivers	Beginning of Programme 0 patients	Case Studies Focus Groups Steering Group members Planning events Yammer Surveys Core Group meeting	User Involvement Facilitator Programme Manager Service users	December 2019 March 2020 Throughout 2020
Improved Healthcare professionals' knowledge through training opportunities and engagement.	Healthcare professionals e.g. CNS, Practice Nurses, GPs and clinicians linked to risk factors People affected by lymphoedema	Macmillan Clinical Lead Services	Evidence of need Training provided Evaluations to show how improved knowledge is making a benefit to patients	Lymphoedema provision in GM Strategic Health Needs Assessment 2015	Evidence from questionnaires showing need for education Lymphoedema Practitioners reviewing training and commenced engagement to sustain learning	Macmillan Programme Manager Lymphoedema practitioners network.	31 July 2019 Throughout late 2019 - all 2020 September 2020
Increased referrals into services	Services Primary Care Cancer services People affected by lymphoedema	Services Programme team	People with lymphoedema accessing appropriate services for the treatment and management of their condition	data received from services including MDS	Increased referrals of Head & Neck Patients. Documents that will be shared with referral details Requires further evaluation once top tips documents are launched	Macmillan Programme Team Lymphoedema services	01 December 2020
Proactive measures to reduce risk of lymphoedema	People affected by and people at risk of lymphoedema Professional that work with people who are at risk	Macmillan Programme Team Lymphoedema services Commissioners	Education for wider workforce Tools to support wider workforce to be proactive	Gap Analysis report	Set of Standards provides clear guidelines on where outcomes are required for wider workforce to embed proactive measures. Some measures are being developed with a group of lymphoedema practitioners	Programme and Lymphoedema Services	Ongoing – business as usual

Desired benefit	Stakeholders impacted	Enablers required to realise benefit	Outcomes	Current baseline measure	Current positions	Who is responsible	Target date
Increased demand on services	Services People affected by lymphoedema	Services People affected by lymphoedema	increased referrals waiting times risk to workforce	Services referral waiting times	For services to evaluate and share with commissioners post December 2020.	Lymphoedema services	throughout programme
Reduction in the variation of services	People affected by lymphoedema	Macmillan Programme Team	To be agreed	Gap Analysis report	The development of handover documents to each Locality of what is required in order to reach the agreed GM Lymphoedema Standards.	Stakeholders aligned to the handover document	December 2020
Improve consistency & equitability of lymphoedema provision with GM standards	Lymphoedema Clinicians	Providers of lymphoedema services					
	Wider healthcare professionals	Commissioners					
Improved cost efficiencies and prescribing of lymphoedema prescriptions	People affected by lymphoedema Lymphoedema Clinicians CCG's Medicine Optimisation Hosiery companies	CCG's Medicine Optimisation teams Lymphoedema Clinicians Hosiery Companies	Local GM formulary Improved ways to prescribe garments Reduction of Cellulitis	Gap Analysis report Medicine Optimisation	Submitted a scoping document to GM Medicine Management Group. Recommendation to look at delivering a proof of concept in order to obtain the cost efficiencies and patient outcomes.	Programme Manager	Ongoing
Increase consistency of reporting within services & Primary Care to understand local incidence and prevalence	Lymphoedema services	BI teams	Robust data to enable future auditing and evidence of need	Minimum dataset	Handover document to services to aligned to the approved set of standards to embed this GP standardised template with appropriate coding CCGs to request reports to understand prevalence	Programme Team	September 2020
	Primary Care People with and at risk of lymphoedema	Data systems Lymphoedema services					Ongoing
Sustainable training solutions for wider healthcare professionals	Wider Healthcare professionals Lymphoedema practitioners People at risk of lymphoedema and people with lymphoedema	Lymphoedema practitioners National guidance	Healthcare professionals can provide guidance of self-care to reduce risk Support the self-management of care for those that have lymphoedema	Questionnaire results/analyses	Programme Team developed list of known training. Meetings held with End of Life and Palliative Care, GM Active, University of Manager and Compression garment companies	Programme Team and lymphoedema practitioners	Moving into business as usual
Increased level of self-management or supported self-management	People affected by lymphoedema	People with lymphoedema	To be agreed	User Involvement Focus Groups and Case Studies	Care Plan guidelines that have been signed off and shared with all services to embed personalised care.	User Involvement Facilitator	December 2020
	Lymphoedema practitioners Wider NHS	Lymphoedema practitioners					
Reduction in incidences of complex and severe lymphoedema due to increased patient awareness.	People affected by lymphoedema	People affected by lymphoedema	Agreed referral pathways.	Minimum dataset of Moderate and Severe Cases Wales's audit May 2019 report of their % caseload of complex and severe	Services to embed reporting to obtain this information to support their capacity and demand. Recommendations to services is to review case load and look at how they support mild lymphoedema in a more effective way	Lymphoedema services	Ongoing moving into business as usual
	Lymphoedema practitioners	Lymphoedema practitioners	Self-care and signs and symptoms for prompt referrals Accurate reporting of levels of severity				
	Wider healthcare professionals	Wider healthcare professionals					
Reduction of non-elective admissions for cellulitis and lymphoedema	People affected by lymphoedema	CCG-Medicine Optimisation teams	Improved outcomes for patients	ICD codes and costs	Reviewing as part of hosiery formulary. Pilot on proof of concept	To be agreed	
	Lymphoedema practitioners A&E Ward staff	People affected Lymphoedema A&E/Acute staff	Reduction of demand on wider services				

APPENDIX 7 - ANDREW'S STORY



I was seen by the district nurses three times a week. Initially my wounds were just being cleaned, until I had a doppler. Once the doppler had been done I was ok to have compression bandages on my lower limbs. I continued to have compression bandages applied for around 3 months. Once the wounds had healed I had compression stockings up to my knee. I carried on using compression stockings until late 2019, at which point the tops of my legs (knee upwards) started to swell. There was a small amount of fluid leakage but not much. As the fluid was not coming out, my legs began to swell (at the biggest point they were between 48" and 51", so they were very big).

I went to see my GP, his actual words were "I have never seen anything like this". He then wrote me a prescription for Hydrocortisone Cream. It was only when I questioned him that he referred me to the district nurses and I asked about a referral to a Lymphoedema clinic, which he agreed to do. I went to see the district nurses, they measured me for new compression stockings for my lower legs and advised that there was nothing they could do for my upper legs so they advised I had been removed from their books.

I received a call from someone asking for my height and weight. Only people with a certain BMI could be treated. Once I had the information I contacted my GP and advised them of my height and weight and after that I heard nothing for months. At the same time, the whole Covid situation was kicking in so I just assumed it was down to that.

My family were becoming more and more concerned as time went on as my legs were getting bigger and by this time it was affecting my mental health too. We started to do our own research and I was given a phone number by my Doctors for a lymphoedema centre. When I called they advised that they deal with women who have had breast cancer and wouldn't be able to help me. They gave me the details of the Lymphoedema Support Network. My mum contacted them and she was given the details of Fiona Sanderson at St Anne's Hospice (initially I was concerned when I heard hospice, but my fears were quickly allayed).

As a stroke of luck, Fiona happened to live in the same town as me and she agreed to come and see me at home. This was 26th August 2020 and was the first time I actually knew I had lymphoedema. That initial meeting with Fiona taught us more in 45 minutes than we had learned in the previous 12 months.

From there I have been having appointments to have compression bandages on my legs and have now progressed to having compression garments. The difference is already vast and has made a huge difference