

## Macmillan Greater Manchester Lymphoedema Programme Information and Analysis Framework

### Version Control

*The purpose of this strategy is to define the programme approach to information and analysis.*

**Programme:** Macmillan Greater Manchester Lymphoedema Programme

**Version:** V.1

**Date:** 15 May 2019

**Author:** Alison Reddicken and Debra Allcock

Each revision of this document must be approved by:

	Macmillan Lymphoedema Steering Group

### Revision History

Revision Date:	Version:	Changes:
April 2019	Draft	First draft of document
15/05/2019	v1	Amendments of draft for sign off
21/5/2019	V1	Steering Group Approved

## Information and Analysis Strategy

### Objective:

The Programme will research and engage with key stakeholders including patients and healthcare professionals to gain an understanding of the current lymphoedema provision in Greater Manchester and ascertain the education requirements of the lymphoedema workforce, wider healthcare professionals and patients for prevention, signs and symptoms, referral pathways and management and monitoring of self-care.

This document will provide the framework to how the information will be collated and analysed to support the specific outcomes of the Programme.

To achieve these outcomes we will address the five following areas:

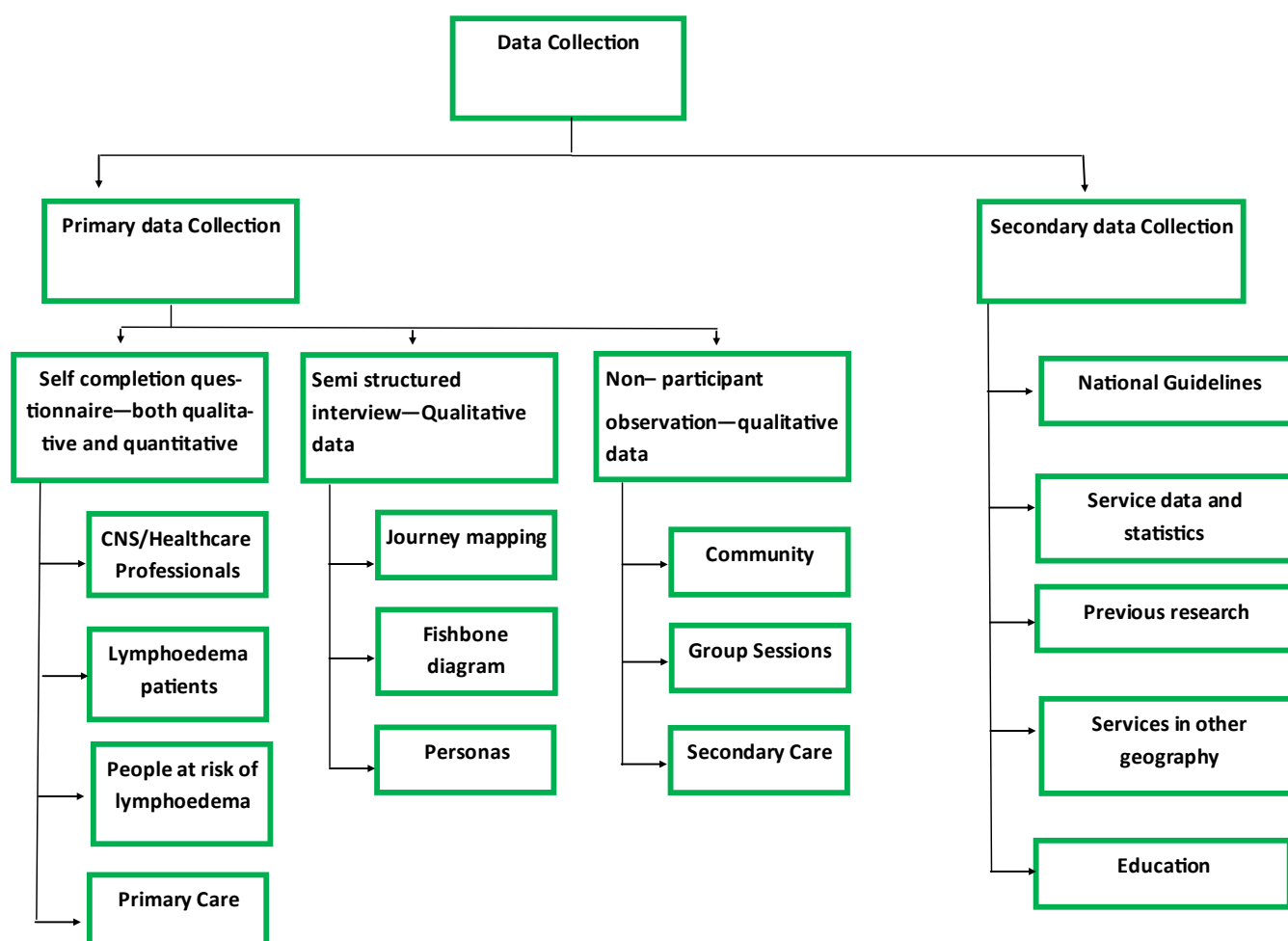
1. **Prevention & Early diagnosis** - Propose an effective prevention structure across the system within each risk factor (primary, secondary; cancer and non-cancer), to reduce incidences and increase earlier diagnosis (stage 1).
2. **Service Provision** - Propose (through theory and identified gaps in current provision) a set of standards for an equitable model of care across Greater Manchester including referral, treatment (for stage 2, 3, & 4), and self-management with a sustainable, multi-tiered and multi-skilled workforce.
3. **Education** - propose what education needs are required for:
  - a. Patients to identify signs & symptoms and self-management
  - b. Lymphoedema workforce to enable an equitable offer:
    - i. What is the required workforce for an equitable service
    - ii. Workforce that has career progression for sustainable upskilling to support workforce succession planning and reduce risk of workforce crisis
  - c. Wider Healthcare Professional to support:
    - i. the prevention from risk to stage 2
    - ii. signs and symptoms
    - iii. referral pathways to a lymphoedema specialist for early diagnosis
  - d. Embed lymphoedema in education for the future Healthcare professionals (modules within degrees or other training qualification routes)
  - e. Protocols for accurate prescribing of compression garments and other treatment materials
4. **Investment** - Propose the above three areas that specific stakeholders may be able to progress either directly or through a GM network approach.
5. **Implementation** - produce a strategic plan of how the agreed recommendations will be implemented, in addition to demonstrating the cost benefits.

The Information and Analysis workstream will provide the evidence and themes to enable the programme to develop the ideas for points one to three above. It will then provide vital information to demonstrate the need for change and how this change can be achieved within the above points four and five.

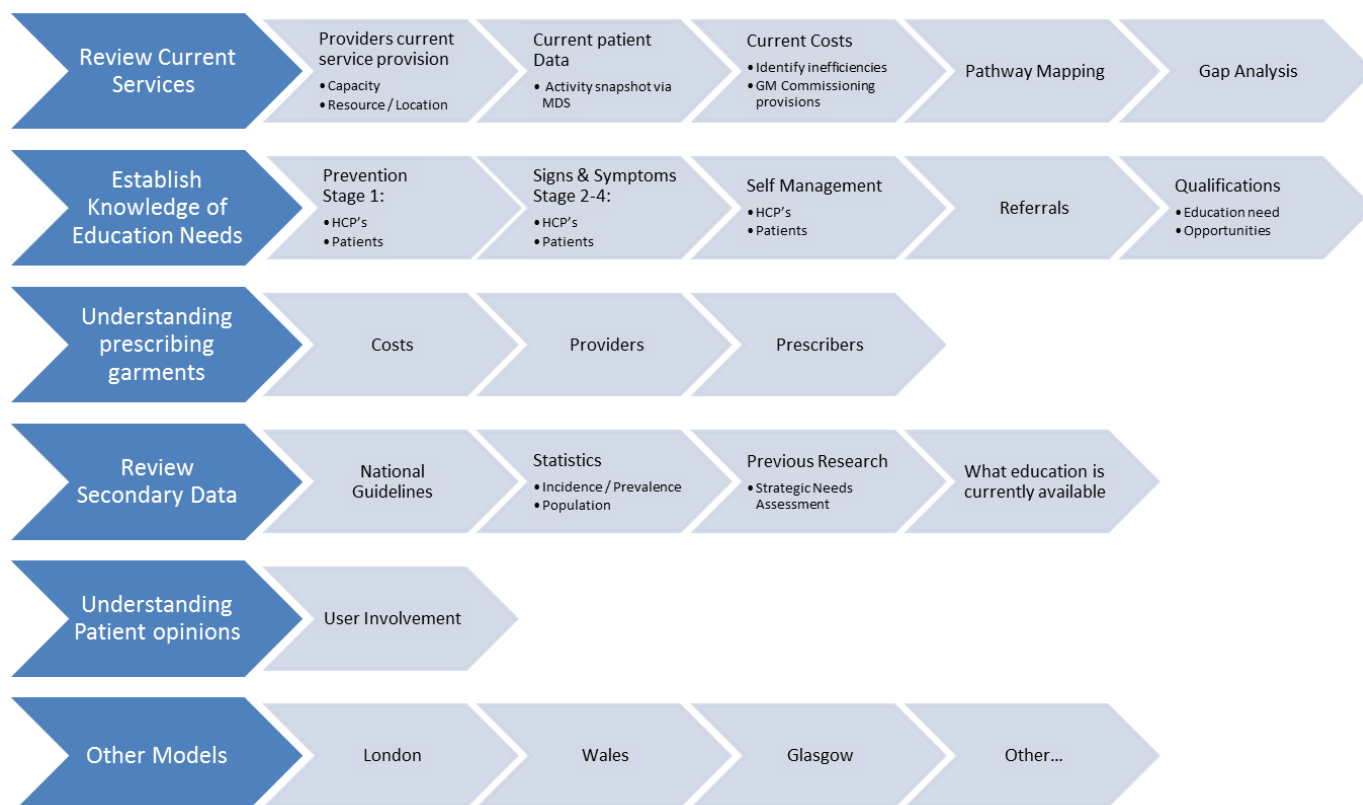
### Data Collection

Illustrated below are the various types of data we plan to utilise to enable appropriate data collection from stakeholders and resources, in addition to our approach on how we will collate the information.

The information obtained will enable subsequent analysis and the production of infographics for each locality and service.



### The framework



### Outcome Mapping

#### Key:

L&D – Learning and Development

BC – Business Case

IP – Implementation Plan

Activity	Data Required	Method / Source	Who	Output	To benefit what project/programme objective		
					Model of care	L & D	BC/ IP
Review Secondary Data	Incidence – No. of People diagnosed with lymphoedema (2016-2018)	GMHSCP/CCG BI	AR	To evidence the growth of need to such services	Yes		Yes
	Prevalence – No. of people living with lymphoedema	GMHSCP BI BLS calculator	AR	To demonstrate the potential demand for lymphoedema services	Yes		Yes

Activity	Data Required	Method / Source	Who	Output	To benefit what project/programme objective		
					Model of care	L & D	BC/ IP
	How many diagnosed lymphoedema by each locality are: Stage 1 - 4	GMHSCP BI /individual CCGs	AR	Understanding the level of complexity in each area. Are there more people at a higher stage when the locality has a lesser service?	Yes		Yes
	What are the average annual cost for: Prevention / Stage 1 - 4	Commissioning Guidance for Adult Lymphoedema 2019 BLS calculator	AR	Evidence that if signs and symptoms are recognised and referred in a timely manner that it will be cost effective	Yes	Yes	Yes
	Number of people at risk of lymphoedema: 1. Data on each cancer that is a consequence 2. Determine if possible to find out risk of non-cancer (Obesity, Vascular & Diabetic)	Commissioning Guidance Document March 2019	MS / KL / AR	Understand the cohort of people that need to be informed in how to prevent	Yes	Yes	Yes
	New national community data set code 41 Lymphoedema	GMHSCP BI	AR/ MS	Understand what this data set is and if it is being used			
Review Current Services	Snapshot of the current activity for the current services	Minimum data set to be completed by GM providers	AR/ KL	To understand the current provision, workload	Yes	Yes	Yes
	Current Service demand 1. How many people on services books	Minimum Data Set 1:1 Interviews with current providers	KL / AR	1. Understand if current demand is higher than the workforce capacity and evidence variation, help to set	Yes		Yes

Activity	Data Required	Method / Source	Who	Output	To benefit what project/programme objective		
					Model of care	L & D	BC/ IP
	2. Waiting time for referrals			standards 2. Demonstrate consequences to longer waiting times			
Review Current Services	Process Mapping : GP referral to treatment	Questionnaire 1:1 Interviews with current providers		Understand the process to identify gaps, good practice, issues. Evidence the variation across GM	Yes	Yes	Yes
Review Current Services (Finance)	Costs allocated to each service	GMHSCP BI /individual CCGs	DA	Does the commissioned costs cover the services currently being delivered			Yes
	Secondary Care Costs that are avoidable	GMHSCP BI /individual CCGs	DA	Prove that if we get prevention and management of mild/moderate then reduction costs within secondary care			Yes
Review Current Services	Pathway Mapping Cancer Pathway:	Attend Pathway Boards	AR/ DA/ KL	Understand Cancer pathways. Is it a consequence of treatment on treatment summaries? Are patients educated on signs and symptoms	Yes change s to transfo rm preven tion	Yes (pre vent ion)	
	Non- cancer pathways: Primary Vascular Tissue Viability Palliative District Nurses Podiatrist Dermatologist Lipodema	Minimum Data Set 1:1 Interviews with current providers Questionnaire	AR/ DA/ KL	How would wider workforce recognise signs and symptoms? How would they refer Do DN, Physios other staff manage lymphoedema?	Yes change s to transfo rm preven tion	Yes (pre vent ion)	Yes
Understand Patient Opinions	UI Case Studies/ Personas	1:1 Interviews Focus groups	LT	Gain good and bad experiences from a user's perspective	Yes	Yes	Yes

Activity	Data Required	Method / Source	Who	Output	To benefit what project/programme objective		
					Model of care	L & D	BC/ IP
(SUI)	Self -management and garment compliance	Focus group 1:1 interviews Questionnaire	LT	Can we risk stratify patients so less on services books?	Yes	Yes	Yes
	Observations		KL	Idea of observing vascular clinic in how vascular manage identification of lymphoedema patients			
	Focus Groups		LT	Gain themes	Yes	Yes	Yes
	Journey Mapping		LT	Understand the process to identify gaps, good practice, issues. Evidence the variation across GM			
Understanding Prescribing Garments	Garments prescriptions: - Costs - Prescribing process - Wasted garments	Hosiery providers Meds Management data	KL/A R	Annual costs to localities on garments Gaps/Challenges/issues	Yes	?	Yes
Knowledge of Education Needs	Birmingham University	1:1 Interviews Questionnaire ?	KL	Understand the benefit and issues of providing dedicated education.		Yes	
	Hosiery companies offering Tissue Viability services	1:1 Interviews Questionnaire	KL/A R			Yes	
	Gateway C	1:1 Interviews	KL/A R	Provide training opportunities for Primary Care		Yes	Yes
Other Models	London	1:1 Interviews	KL	Their learnings and successes	Yes	Yes	Yes
	Wiltshire	1:1 Interviews	KL	Their learnings and successes	Yes	Yes	Yes
	Wales	1:1 Interviews	KL	Their learnings and successes	Yes	Yes	Yes
	Northern Ireland	1:1 Interviews	KL	Their learnings and successes	Yes	Yes	Yes
	Scotland	1:1 Interviews	KL	Their learnings and successes	Yes	Yes	Yes



### Analysis

By May 2019 the programme team will provide an initial analysis of the data that has been collated on the provision of services, incidence and prevalence of lymphoedema across the geographical area. The initial finding will be presented to the Programme Steering Group to direct the team to ensure all data and evidence is collated in a timely manner and to maximise the information collated in preparation for a full gap analysis.

### Gap Analysis

#### Layering the research

During June 2019 through to September 2019, the programme team will collate all the information that has been gathered. The programme team will offer the opportunity for a working group to analyse all the data and develop themes. These themes are likely to confirm the variation and need for changed for the Model of Care and Learning and Development.

**Gap Analysis report** – From the themes a report will be produced with recommendations of what the programme should prioritise. This report is required to be signed off and agreed with the Steering Group members to ensure the programme team does not start developing ideas that are not sustainable within the system.

### Double Diamond methodology

The first diamond of the diamond methodology will be completed. However the programme recognises that this workstream will maintain open as further evidence is likely to be obtained as ideas are developed and a focus on what information is required in the Business Case will evolve.

