The feasibility of collecting a minimum dataset within lymphoedema services

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Key words

Lymphoedema services, minimum dataset

Abstract

Data collected by a lymphoedema service can be valuable to demonstrate the type of patients referred to a service and the complexity of its workload. Similar data collected across a range of services can paint a broader picture and be used to illustrate staffing and resource requirements. The feasibility of using a standardised tool for the collection of a minimum set of data by lymphoedema services was tested by the London Lymphoedema Community of Practice over a 1-month period. The project highlighted that a minimum data set tool was feasible and suggested areas for further consideration in the data collected.

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Across the UK and Ireland, lymphoedema services share similarities in their approach to the assessment of patients and individualised strategies of management. Accurate record keeping is a legal requirement for all healthcare professionals, facilitated by electronic or paper records. The style and content of these records is agreed locally. This means that, although services commonly record the assessment and care of individuals they see, there can be variation in the type of data and the way it is saved by services, and it is not known whether data can be easily compared across services or if at all.

In addition, data saved by lymphoedema services most frequently focuses on the assessment and care of individuals within the lymphoedema service with a lack of more general information about the specific type of patients being referred to the service and the resources required to care for them.

A lymphoedema service that collates the data of its individual patients can demonstrate their complexity, workload requirements and required resources. The gathering of similar data between services enables a picture to be created of those receiving care at a local and national level. Ultimately, this can support the strategic development of services by painting a national picture to indicate the needs of patients with lymphoedema and the resources required to provide appropriate care.

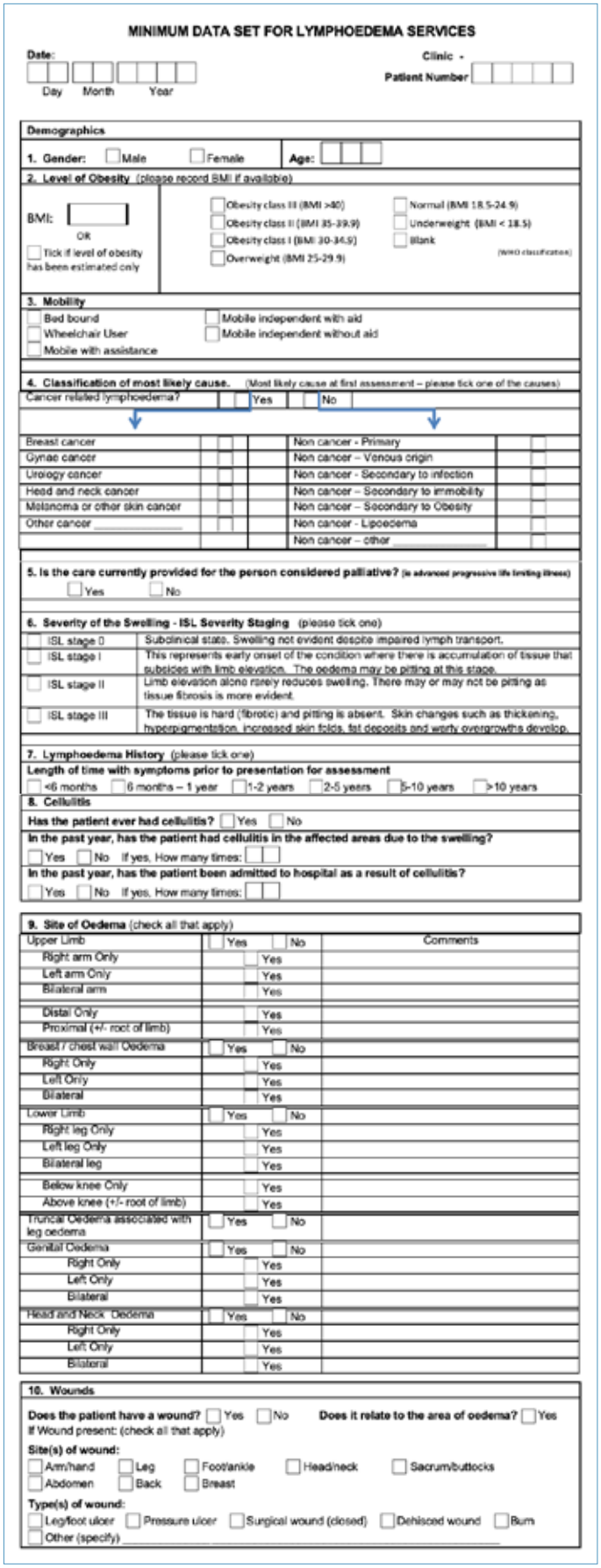
This paper describes a project completed by the pan London Lymphoedema Community of Practice (COP) to explore the feasibility of lymphoedema services using a minimum data set (MDS) tool to collect and share comparable data among London lymphoedema services. The tool was designed by the National Lymphoedema Partnership (NLP).

Background

The (NLP) comprises key stakeholders across the UK and Ireland who came together to share their understanding of lymphoedema service provision, address issues of common concern and champion improved care and better outcomes for people with lymphoedema (Rankin, 2016).

An early objective of the NLP was to develop an MDS to stimulate the gathering of consistent data about people accessing lymphoedema services. A consensus approach was used to identify data that members considered key to describing their lymphoedema population. From this, a tool was developed and piloted within one lymphoedema clinic in the north of England over a 3-month period from May to July 2016.

The findings indicated that it was possible to collect information at the initial patient assessment, which would form an MDS. The tool was simplified with improvements to the format and then shared with the membership of the British Lymphology Society (BLS) with the aim of wider use among a range of lymphoedema services to provide further information to strengthen the picture of required resources for lymphoedema service provision. To date,



MINIMUM DATA SET FOR LYMPHOEDEMA SERVICES

Date: Day Month Year

Clinic -

Patient Number

Demographics

1. Gender: Male Female Age:

2. Level of Obesity (please record BMI if available)

BMI: OR Tick if level of obesity has been estimated only

Obesity class III (BMI >40)
Obesity class II (BMI 35-39.9)
Obesity class I (BMI 30-34.9)
Overweight (BMI 25-29.9)
Normal (BMI 18.5-24.9)
Underweight (BMI < 18.5)
Blank
(WHO classification)

3. Mobility

Bed bound
Wheelchair User
Mobile with assistance
Mobile independent with aid
Mobile independent without aid

4. Classification of most likely cause. (Most likely cause at first assessment – please tick one of the causes)

Cancer related lymphoedema? Yes No

Breast cancer		Non cancer - Primary	
Gynae cancer		Non cancer – Venous origin	
Urology cancer		Non cancer - Secondary to infection	
Head and neck cancer		Non cancer – Secondary to immobility	
Melanoma or other skin cancer		Non cancer – Secondary to Obesity	
Other cancer		Non cancer - Lipoedema	
		Non cancer – other	

5. Is the care currently provided for the person considered palliative? (in advanced progressive life limiting illness) Yes No

6. Severity of the Swelling - ISL Severity Staging (please tick one)

ISL stage 0	Subclinical state. Swelling not evident despite impaired lymph transport.
ISL stage I	This represents early onset of the condition where there is accumulation of tissue that subsides with limb elevation. The oedema may be pitting at this stage.
ISL stage II	Limb elevation alone rarely reduces swelling. There may or may not be pitting as tissue fibrosis is more evident.
ISL stage III	The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths develop.

7. Lymphoedema History (please tick one)

Length of time with symptoms prior to presentation for assessment

<6 months 6 months – 1 year 1-2 years 2-5 years 5-10 years >10 years

8. Cellulitis

Has the patient ever had cellulitis? Yes No

In the past year, has the patient had cellulitis in the affected areas due to the swelling?

Yes No If yes, How many times:

In the past year, has the patient been admitted to hospital as a result of cellulitis?

Yes No If yes, How many times:

9. Site of Oedema (check all that apply)

Upper Limb	Yes	No	Comments
Right arm Only	Yes		
Left arm Only	Yes		
Bilateral arm	Yes		
Distal Only	Yes		
Proximal (+/- root of limb)	Yes		
Breast / chest wall Oedema	Yes	No	
Right Only	Yes		
Left Only	Yes		
Bilateral	Yes		
Lower Limb	Yes	No	
Right leg Only	Yes		
Left leg Only	Yes		
Bilateral leg	Yes		
Below knee Only	Yes		
Above knee (+/- root of limb)	Yes		
Truncal Oedema associated with leg oedema	Yes	No	
Genital Oedema	Yes	No	
Right Only	Yes		
Left Only	Yes		
Bilateral	Yes		
Head and Neck Oedema	Yes	No	
Right Only	Yes		
Left Only	Yes		
Bilateral	Yes		

10. Wounds

Does the patient have a wound? Yes No Does it relate to the area of oedema? Yes

If Wound present: (check all that apply)

Site(s) of wound:

Arm/hand Leg Foot/ankle Head/neck Sacrum/buttocks
Abdomen Back Breast

Type(s) of wound:

Leg/foot ulcer Pressure ulcer Surgical wound (closed) Dehisced wound Burn
Other (specify)

Figure 1. Original version of the minimum data set (BLS, 2017).

Box 1. Minimum data set items.

1. **Gender**
2. **Age**
3. **BMI or level of obesity**
4. **Mobility**
5. **Classification of most likely cause of lymphoedema**
6. **Palliative care**
7. **Severity of symptoms — ISL staging**
8. **Lymphoedema history, i.e. duration of symptoms**
9. **Cellulitis: frequency and hospitalisation**
10. **Site of swelling, proximal/distal, mid-line involvement**
11. **Wounds: site, type and whether associated with oedema.**

there have been no published reports of the MDS tool being used to collate data from multiple services.

The pan London Lymphoedema Community of Practice (CoP) was developed in 2018. It comprises active lymphoedema practitioners from different professional backgrounds and types of service provider who contribute collective knowledge to discuss and influence specific problems relating to the provision of lymphoedema services. The CoP members undertake active networking, in order to share best practice, engage in benchmarking and peer review, raise standards and support the development of new services. The overall aim of the group is to improve the outcome of patients with lymphoedema. As members of the group are from across the London region, the group were able to support the further development of the MDS tool with a project designed to test its use within a wider group of lymphoedema services in another part of England.

The minimum data set

The aim of the MDS tool is to:

- Provide information on the types of patients seen
- Demonstrate workload and capacity
- Provide a baseline to benchmark against other services

Data collection is divided into three areas:

- Data relating to the person to include age, gender, body mass index and mobility
- Data relating to the underlying cause of the oedema
- Data relating to markers of oedema complexity to include staging, the site of the oedema, cellulitis history and the presence of wounds.

Project aim

To explore the feasibility of using a MDS tool within a wide group of lymphoedema services in the London area which had not previously used the MDS tool and who operated with different service models.

Methods

Participants

All COP members were invited to participate in this project over a 1-month period.

MDS tool

The original MDS tool was formatted from the original version (*Figure 1*) into an excel spreadsheet (*Figure 2*) with drop down menus and text boxes. The tool comprised 11 questions with supplementary

Table 1. Proportion of valid minimum data set (MDS) data provided by each lymphoedema service, highlighting feasible data[1].

	Lymphoedema services							
MDS questions	**1**	**2**	**3**	**4**	**5**	**6**	7	**Services with ≥67% data**
Patients, *n*	33	25	31	23	14	21	109	
1. Gender	100%	100%	100%	100%	100%	100%	100%	7 (100%)
2. Age	0	100%	100%	100%	100%	100%	100%	6 (86%)
3. Obesity level	100%	100%	100%	100%	100%	100%	0	6 (86%)
• BMI value	70%	64%	0	0	0	95%	0	2 (29%)
4. Mobility	100%	100%	100%	96%	100%	100%	82%	7 (100%)
5. Classification	100%	100%	100%	100%	100%	100%	72%	7 (100%)
6. Palliative care	100%	100%	100%	0	0	100%	0	4 (57%)
7. Staging	100%	100%	100%	100%	100%	100%	77%	7 (100%)
8. History	100%	100%	100%	100%	100%	100%	98%	7 (100%)
9. Oedema site	97%	96%	94%	100%	100%	100%	95%	7 (100%)
• Prox/dist	29%	40%	6%	0	0	48%	0	0
• Trunk & leg	18%	100%	0	0	0	100%	0	2 (29%)
10. Cellutis history	100%	100%	100%	100%	100%	100%	97%	7 (100%)
• Past year	100%	100%	100%	100%	100%	100%	86%	7 (100%)
• # in past year	80%	100%	100%	0	100%	100%	84%	6 (86%)
• Hospitalised	100%	100%	100%	100%	100%	100%	76%	7 (100%)
• # hospitalised	100%	100%	100%	100%	100%	100%	76%	7 (100%)
11. Wounds	100%	100%	100%	13%	100%	100%	0	5 (71%)
• Oedema site?	97%	100%	98%	0	86%	n/a[3]	0	5 (71%)
• Wound site	100%	100%	98%	0	100%	n/a[3]	0	5 (71%)
• Type	100%	100%	98%	0	100%	n/a[3]	0	5 (71%)
Feasibility of service-level MDS	No	Yes	Yes	No	No	Yes	No	-

[1] Feasibility defined as ≥67% of data; feasible data in bold text
[2] Feasibility of each MDS question when considering number of services reporting ≥67% valid data
[3] n/a, no wounds reported so no data required
[4] Feasibility of service-level data, i.e. ≥67% of data provided by service for all MDS questions

questions for three items (*Box 1*). Three services in the CoP piloted the MDS tool in April 2019, with further minor amendments made to the format.

Data collection procedure

All services were asked to collect a MDS for each new referral seen in their lymphoedema service over a 1-month period during May 2019. Ethical approval for the project was not required as the data collected was anonymised and not patient sensitive, but each service was asked to obtain permission from their organisation to share their anonymised data. Following the 1-month period of data collection, the data were forwarded to the project co-ordinator using the excel spreadsheet.

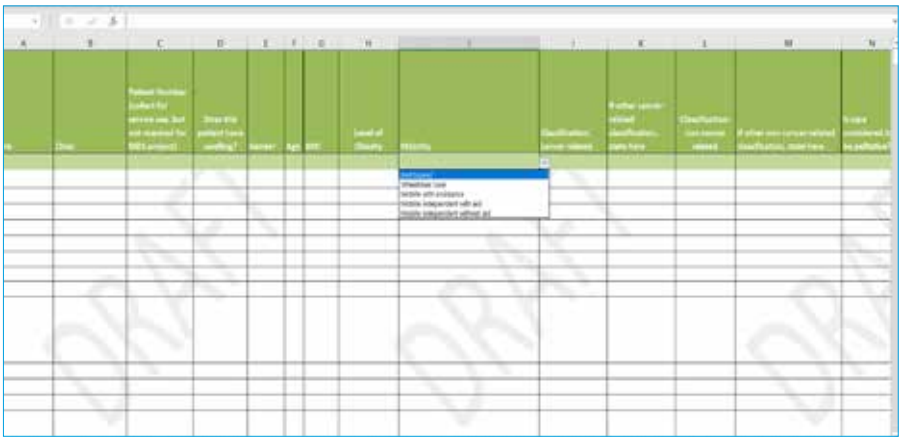


Figure 2. Formated Excel spreadsheet.

Participating lymphoedema practitioners were sent a short questionnaire 1 month later to establish their experience of the project, the MDS collection process, the time involved and whether the data were routinely collected. Practitioners who

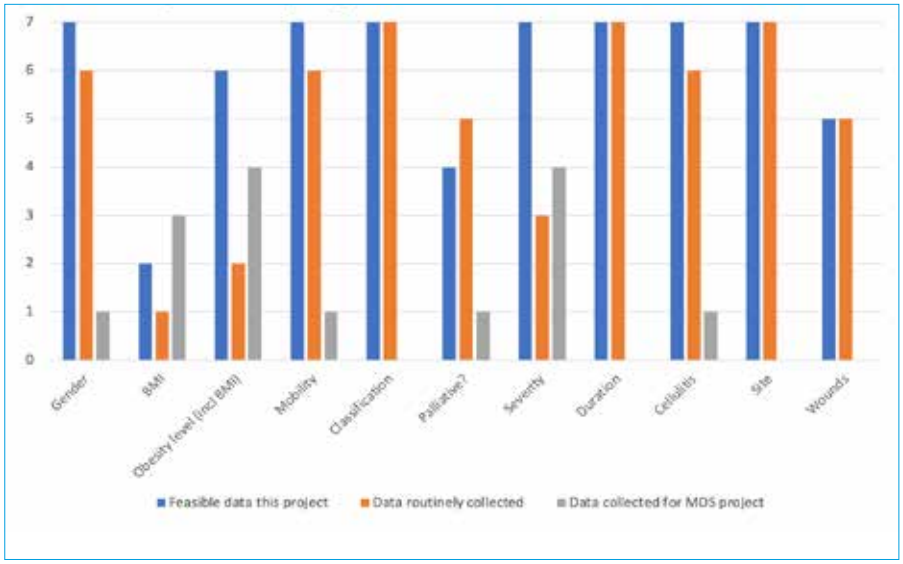


Figure 3. Comparing feasible minimum data sets with routine data collection.

had not contributed data were asked to identify their reasons for not participating and the likelihood of contributing to a future MDS project.

Analysis

Individual-level data were cleaned to identify missing or incomplete data and services were offered one opportunity to supply missing data within 1 week. Each service was allocated an identification number to protect their identity. Data were analysed to identify:

- The proportion of valid data reported by each service
- The feasibility of services to report a MDS
- The experience and opinions of practitioners who participated in the project and those who did not.

Findings are reported descriptively, using counts, frequencies and percentages. Feasibility was set at 67% meaning that ≥67% of participating services must provide ≥67% valid data for each MDS item for the overall findings to be considered representative of the group.

Results

Seven out of a possible 15 lymphoedema services (47%) participated in the project reporting a total of 256 patients newly referred to a lymphoedema service over the 1-month period. *Table 1* displays the proportion of data provided by each lymphoedema service for each 11 MDS questions. Three services (43%) provided sufficient data (i.e. ≥67%) for all questions; of the other four services, two did not supply data for one item (age, palliative care), one service omitted three items (obesity, palliative care, wounds) and another omitted one item (palliative care) and supplied incomplete data for another (wounds). Five services (71%) supplied sufficient data for each question except palliative care, which was answered by only four services (57%).

Data relating to the person

All seven services provided information on gender and six (86%) supplied the age of the patient. Although only two services (29%) supplied any BMI values, body mass index (BMI) categories were provided by six services (86%) demonstrating it is feasible to report level of obesity. All services (100%) provided sufficient valid mobility data; one service reported some patients (12%) as either "housebound" or "housebound with aids" so these data were invalid as it could not be aligned with the MDS descriptors.

Data regarding the underlying cause of the oedema

All services provided sufficient data regarding the most likely cause of oedema, demonstrating that it was feasible to collect this data. All data regarding cancer-related causes were viable for analysis. However, one service reported multiple non-cancer-related causes of oedema and these data (28%) could not be analysed: for example, it was unclear whether the service intended to report venous oedema as a complicating factor for bilateral primary lymphoedema or the most likely cause for swelling in one leg.

Four (57%) of the seven services provided data regarding palliative care status, three of which reported >90% patients with cancer-related oedema and the other one reported <50% with cancer-related cause. Of the three services that did not report any palliative status, one saw only cancer-related oedema and the other two services reported less than one third of patients with cancer-related oedema.

All services reported the site of oedema, whether unilateral, bilateral limb or midline swelling. Swelling in more than one site could be reported, but not any absence of swelling.

No service provided sufficient detail in their data to indicate the extent of the swelling and whether, for example, leg oedema had extended onto the trunk or whether the oedema was limited to the proximal or distal portion of the limb only.

Data relating to markers of oedema complexity

Severity and duration of oedema

Six services supplied the International Society of Lymphology (ISL) severity stage for all patients (ISL, 2016). As the form provided only one opportunity to indicate oedema severity, it was unclear which oedema site was reported when a patient had multiple oedema sites.

All seven services supplied data relating to the duration of oedema. However, one service reported patients with less than 12 months duration of symptoms and did not identify those with less than 6 months symptom duration. This data could be analysed by combining patients with <6 months and 6<12 months symptom duration, although this sacrificed details regarding early presentation for treatment; for example, the other six services reported 126 patients with less than 12 months symptom duration of whom 98 (78%) had symptoms for less than 6 months.

Cellulitis and wounds

All seven services supplied sufficient data regarding a history of cellulitis, with a high level of completeness for all supplementary cellulitis-related questions. Five services (71%) provided sufficient data regarding the presence of a wound and, where appropriate, the site and type of wound. However, the number of patients with wounds (6%) was too small to test the feasibility of collecting supplementary wound data.

Practitioner evaluation of MDS project

All seven services who participated in this project completed an evaluation of the MDS project. They all considered it feasible to

both collect and collate data using the MDS tool and reported that the time required to collect the data was acceptable. *Figure 3* shows that none of the services reported the routine collection of all 11 items on the MDS form; five services (71%) did not routinely record either obesity level or BMI and four services (57%) did not routinely record ISL severity stage. Two services reported routinely collecting BMI and palliative care data although they each supplied <67% of these data.

Five services (71%) suggested it would be useful to record presence of lymphorrhoea in the next MDS project and three (43%) suggested recording whether patients were local or out-of-area referrals.

Only one (13%) of the eight non-participating services completed a survey. This service routinely collected all MDS data except ISL severity stage and was willing to participate in a future MDS project, but had been unaware of the current project until it was too late to participate.

Discussion

Much data are routinely recorded by lymphoedema services, but this is the first project to report the feasibility of collecting data within an MDS. However, for this to be widely used within a range of lymphoedema services, precise reporting is required. There were areas where the data recorded was confusing. An example of this is the reporting of cellulitis where three services reported a frequency of cellulitis or hospitalisation in the previous year in patients they had reported as not ever having had cellulitis.

Similarly, when looking at the data recorded concerning mobility, it is clear that there was some ambiguity in interpretation, particularly when mobility aids were required. One service reported some patients as housebound, which was not a descriptor included on the MDS form. As the level of mobility was, therefore, unknown, these patients were recoded as mobile with a mobility aid. Further clarity with the descriptors would make it easier for analysis in future projects of this nature and also for local analysis within individual services.

In order to determine how much data were missing from each service for this project, raw data, rather than aggregated data were requested from each service. The analysis of this was time consuming and required a level of skill with Microsoft Excel spreadsheets and formulae which needs to be taken into consideration in future projects.

Limitations

A limitation of this project was the small number of participating lymphoedema services. The CoP comprised of 15 lymphoedema services at the time the project was designed, but only seven services participated. The reason for none-participation was unclear.

The project could be strengthened with data acquired from a larger group of lymphoedema services.

Strengths

Although the number of participating lymphoedema services was small, the data acquired came from a range of lymphoedema services based in different settings. This added richness to the picture of the services within the pan-London area and the lymphoedema population within them.

The MDS tool was quick and easy to use requiring tick box answers only. Once standardisation of the form is achieved and clarity of the descriptors has been addressed, the results of this project suggest that is feasible that the collection of a MDS can be incorporated into routine data collection.

Weaknesses

A clear weakness in this project was the variability in understanding of some of the descriptors and the incomplete data provided by some services. The final tool needs to reflect accurate, complete data recorded by cancer and non-cancer services to ensure it is representative of the services being studied.

Conclusion and recommendations

The power of data cannot be underestimated and this project has shown that it is feasible to develop an MDS tool for lymphoedema services. Information about the differences between services has not been published before, so data from an MDS tool can add to knowledge about the lymphoedema population in the UK.

An MDS tool cannot describe the treatment provided or outcomes of treatment for patients, but it can demonstrate caseload and capacity and be used to support applications to fund additional services. It can also be used to provide background evidence for collaborative projects and future research.

At a local level, an MDS tool could assist in the planning of treatment pathways based on the complexity of patients, provide a baseline to benchmark against other services and be used to demonstrate the cost of providing an effective lymphoedema service.

It is essential that the same tool and descriptors within an MDS tool are used by all lymphoedema services if meaningful data are to be collected and analysed. Future projects will, therefore, be planned once this has been achieved.

The outcome of the project has shown the potential for future collaboration on benchmarking projects within the CoP to meet the aims of the group.

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