Freedom of Information Request: Our Reference CTMUHB_623_24

You asked:

Can you please provide the following information under the Freedom of Information Act 2000. This query relates to a piece I am working on for BBC Wales.

The piece is on women with lipoedema/lipalgia in Wales and my understanding is that patients with the condition will be seen in your lymphedema clinic(s).

1. How many women were diagnosed with lymphoedema, lipoedema/lipalgia and both conditions during the following periods:
    - 2019/20
    - 2020/21
    - 2021/22
    - 2022/23
    - 2023/24-present

2. What is the treatment pathway for patients with lymphedema, lipoedema/lipalgia and for those that have both conditions?

Our response:

Women's health is vitally important to NHS Wales and thank you for raising this issue. Within Lymphoedema Wales Clinical Network we wanted to gather important information in understanding more about the differential diagnosis between Lymphoedema and Lipalgia Syndrome (Lipoedema) and the evidenced based treatment outcomes. Lymphoedema Wales Clinical Network comprises of a national team (researchers, educationists, clinical programmes, data analysts, psychology, Childrens service and a dietitian) plus the seven Lymphoedema Health Board Services.

All patients with Lymphoedema, Lipalgia Syndrome(Lipoedema) or both can be referred to any of the Lymphoedema Services in Wales depending where they reside. Each Health Board in NHS Wales accepts referrals for all patients. A New Patient Model is embedded so all patients are assessed virtually (if appropriate) and then offered a face to face appointment based on their needs. Treatment pathways are based on the assessment findings. Treatment pathways may include skin care, activity/ movement/ exercises, dietary advice / referral to national Lymphoedema Dietitian, referral to Psychology Lymphoedema Service, Compression garments, self-massage or intensive treatment including multi-layer lymphoedema bandaging and manual lymphatic drainage. Super micro surgery for lymphoedema patients is also available and we have monthly access to a surgery MDT.

All patient data for Lymphoedema Wales Clinical Network (LWCN) was sent from the Health Boards at an aggregate level for analysis- this means that we are unable to accurately indicate numbers of women with Lymphoedema, women with

Lipalgia (lipoedema) or both. Patient clinical notes are available but that level of detail has not been digitally recorded within the patient level systems.

Table 1 below shows the individual patient level data for Cwm Taf Morgannwg UHB.

Table 1

2024-25	CTMUHB
Numbers of women with Lymphoedema	1,126
Numbers of women with Lipalgia Syndrome	87
Numbers of women with Lymphoedema and Lipalgia Syndrome	76

Lipalgia Syndrome (Lipoedema) is very different to Lymphoedema. In 2023 a new Lipalgia Syndrome Programme has been developed to gain more detailed and accurate information to support patient care and outcomes. The Lipalgia Syndrome Programme is run nationally from LWCN but has representation from each of the Health Board Lymphoedema Services. Research, clinical outcomes, detailed assessments and education are all included within the programme.

Since mid-2024, LWCN have created new Lipalgia syndrome patient assessment documentation so much more accurate information is now being collected. Currently 160 patients have been assessed by the national/ local health board team using this dedicated assessment paperwork including patient reported outcome measures and quality of life questionnaires which will provide the basis for future service delivery. Interestingly only 89/160 – 56% of the patients assessed have been diagnosed with Lipalgia Syndrome. Thus, we are aware that many women who think they have this condition do not actually have it. There is a general lack of understanding and knowledge which is why LWCN have committed to research and education. Moving forward we anticipate all patients suspected as being diagnosed with Lipalgia Syndrome will be assessed using this documentation.

In February 2024, all Lymphoedema clinical staff attended a Lipalgia Syndrome Education day raising awareness of this condition. A patient advisory support group also includes those patients with lymphoedema and Lipalgia syndrome.