



## **Estimating the Prevalence of Lymphedema in the United States**

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The exact prevalence of lymphedema in the United States is not known. Estimates have ranged widely from 2-10 million. The Lymphedema Advocacy Group has a keen interest in understanding the need for, and the potential impact of, the Lymphedema Treatment Act. As such, we have undertaken a literature review to better assess what is known about the prevalence of lymphedema, and to assess which estimate is most likely to align with the actual burden of the disease in the United States. Of note, while the Lymphedema Treatment Act applies specifically to Medicare patients, it is anticipated that the law would benefit all insured patients as Medicare benefits generally set the minimum standard coverage for all types of insurance.

Subsequent to literature review, the Lymphedema Advocacy Group estimates that **3 to 5 million Americans** suffer from lymphedema in the United States. Our basic method of estimation is summarized here.

### **Estimate of the Number Currently Diagnosed with Lymphedema in the United States:**

2012 Total US population = 315,073,604<sup>1</sup>

2012 Non-Medicare = 265,037,325<sup>2</sup>

2012 Medicare = 50,739,561<sup>3</sup>

2012 Known Medicare Patients Diagnosed with Lymphedema = 291,900 (0.57%)<sup>4</sup>

2012 Estimated Non-Medicare Patients Diagnosed with Lymphedema = 821,615 (0.31%)<sup>5</sup>

2012 Total Estimated Diagnosed Patients with Lymphedema in the United States: 1,228,787.

2015 Total Estimated Diagnosed Patients with Lymphedema in the United States<sup>6</sup>: 1,248,287.

The above data are just for *diagnosed* patients with lymphedema. Lymphedema is, unfortunately, chronically under-recognized owing in large part to low levels of physician and patient education. For this reason, we also undertook an estimate of likely *actual*, rather than just diagnosed, number of lymphedema patients in the United States (see below).

### **Estimate of the Total (Diagnosed and Undiagnosed) with Lymphedema in the United States:**

There are two broad categories of lymphedema: primary and secondary. Primary lymphedema represents a number of genetic conditions which cause the lymphatic system to fail. It may manifest in childhood or later in life. Secondary lymphedema, on the other hand, is the result of injury to the lymphatic system such as may occur from accidents, infection, or most commonly, related to cancer treatment. Like primary lymphedema, secondary lymphedema may not manifest immediately after the damage occurs.

The prevalence of most common types of cancer in the United States is known<sup>7</sup>. Using published rates of *monitored for* lymphedema<sup>8,9</sup> within several types of cancer commonly associated with lymphedema, we can estimate the numbers of patients with cancer related lymphedema. Here, the percentages represent the *average* of published rates of lymphedema, thus, the reality may be higher.

- Breast: 2,899,726 x ~ 25% = 724,931
- Cervical: 249,632 x ~ 30% = 74,886
- Bladder: 571, 518 x ~ 15% = 85,728
- Vulvar 4850 x ~ 27% = 1,455
- Melanoma: 960,231 x ~ 23% = 220,853
- Prostate: 2,707, 821 x ~18% = 487, 407
- Testicular: 277,406 x ~10% = 27,740
- Sarcoma: 267,942 x ~ 27%<sup>10</sup> = 72,344
- Penile: 5000 x ~ 25% = 1,250

The total amounts to 1,696,594 with cancer related lymphedema in the United States. If, however, we utilized the upper limits of published lymphedema rates, we would arrive at as many as 1,992,937 patients with cancer related lymphedema within *just these* particular types of cancer.

Moving on to a calculation of the total of all types of lymphedema in the United States, we note that cancer related lymphedema is believed to represent between 50 and 75% of the whole<sup>11,12,13</sup>. The remaining 25-50% have non-cancer related lymphedema which includes primary lymphedema patients and other forms of secondary lymphedema apart from cancer. If 1,498,449 - 1,992,937 patients have cancer related lymphedema, then we can extrapolate a total range of approximately 2,650,606 - 3,985,874 individuals are living with all forms of lymphedema in the United States.

There exists an emerging understanding, however, that the full scope of lymphatic dysfunction should include an as yet unknown, but not insignificant fraction of some rather large populations of patients including those with lymphatic overload or malfunction due to extreme obesity, lipedema, or venous insufficiency<sup>13</sup>. The component of swelling related to secondary lymphedema in these patients is likely significantly under-recognized (and under treated) so that the estimated fraction of the whole which is represented by non-cancer related lymphedema, i.e. 25-50%, may under-represent total burden of lymphedema in the United States.

Furthermore, the number of calculated cancer patients expected to have lymphedema (see list above) represents only the calculated rate of lymphedema in about 60% of all cancer patients. Most of the remaining 40% are cancer patients bearing little to no risk of lymphedema (such as lung or brain cancer) however, the rate of lymphedema in this population will not be zero. Thus the estimated cancer related numbers above may also constitute an under-representation of reality.

For these reasons, although our base calculation is 2.65 - 3.98 million, we are confident estimating approximately **3-5 million individuals in the United States are suffering from some degree of lymphedema.**

1. <http://www.census.gov/popclock/>

2. This value represents the total minus Medicare.

3. <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/MedicareEnrpts/index.html?redirect=/medicareenrpts/>

4. [http://lymphedematreatmentact.org/wp-content/uploads/2015/05/Lymphedema\\_Treatment\\_Act\\_HR1608.pdf](http://lymphedematreatmentact.org/wp-content/uploads/2015/05/Lymphedema_Treatment_Act_HR1608.pdf)

5. LAG obtained proprietary insurance data indicating that the prevalence of diagnosed lymphedema in the Non-Medicare population is ~ 53% that in the Medicare population. We know the prevalence for lymphedema in the Medicare population is 0.57% from the Avalere study, thus, 53% of that is 0.31% of the Non-Medicare group is likely to be currently diagnosed with lymphedema.

6. Based on population growth estimates from US Census. (see reference #1).

7. <http://seer.cancer.gov/statfacts/>

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