

Wounds UK debate: Lost in the system: Why we still don't know the true burden of leg ulcers in the NHS

Despite significant advances in lower-limb wound management, the true burden of leg ulceration within the NHS remains unknown. This paper explores the systemic invisibility of leg ulcers through findings from a Freedom of Information exercise undertaken by the Legs Matter coalition across NHS trusts in England and health boards in Wales. The results reveal a profound lack of accessible, reliable epidemiological data, with most organisations unable to report basic information on prevalence, duration of care, or healing outcomes. This absence of data reflects deeper structural issues, including fragmented digital systems, inconsistent coding, and the dispersal of care across multiple providers, which collectively obscure accountability and hinder service planning. The paper argues that this data vacuum perpetuates inequity, limits investment, and prevents meaningful quality improvement, leaving patients trapped in cycles of delayed care and poor outcomes. Drawing on debate contributions from clinical and strategic leaders, the discussion highlights how organisations with robust data systems are able to quantify demand, monitor healing trajectories, evaluate interventions, and deliver more efficient, patient-centred care. The paper concludes by calling for urgent national action to prioritise leg ulcer data as a system-wide requirement, including the adoption of a standardised minimum dataset aligned with existing national programmes. Without consistent, embedded data collection, leg ulceration will remain hidden in plain sight, undermining efforts to improve outcomes and deliver equitable lower-limb care across the NHS.

Despite decades of clinical progress in lower-limb and wound management, one of the most fundamental questions in leg ulcer care remains unanswered: how many people are affected?

In an attempt to begin to answer this question, the Legs Matter coalition undertook a targeted data-gathering exercise between July and September 2025. Freedom of Information (FOI) requests were submitted to thirty NHS trusts across England, alongside requests to all seven health boards in Wales, seeking basic epidemiological data on leg ulcers. The FOI also included questions relating to foot ulcers (excluding diabetic foot ulcers) and lymphoedema.

A concerning lack of usable data

Of the 30 trusts contacted in England, only 15 responded to the FOI request, and of those, just eight were able to provide patient numbers. In Wales, four of the seven health boards responded, with only two able to supply any

numerical data. This exercise exposed an uncomfortable truth – much of the NHS cannot accurately tell us how many people currently have a leg ulcer, how long they have been receiving care, or what outcomes have been achieved.

This absence of data is not just a technical gap; it is a systemic failure. In the absence of robust information, leg ulceration remains hidden in plain sight, dispersed across primary care, community nursing, and specialist services without consistent coding, monitoring, or accountability. The result is a silent epidemic that continues to consume NHS resources while remaining invisible to policymakers and commissioners.

Why this must become an urgent national challenge

In an era where health systems strive for precision, transparency, and population health management, the lack of basic epidemiological data for leg ulcers should alarm us all. These

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wounds are chronic, costly, and life-limiting. They affect quality of life, contribute to social isolation, and increase hospital admissions. Yet because data are fragmented or non-existent, services struggle to justify investment or demonstrate improvement.

The NHS has the digital tools and ambition to manage long-term conditions effectively, but leg ulcer care remains excluded from this progress. Where data are captured, it is often done through local audits or short-term projects, which are quickly lost once funding ends. This lack of visibility enables continued inequity in care: some areas lead the way in integrated lower-limb pathways and electronic wound records, while others have no idea of the scale of their problem.

Until leg ulcer data are treated as a system-wide priority, the NHS cannot plan the workforce, commission effective services, or measure healing and recurrence rates. As a result, patients remain trapped in a cycle of delayed care, poor outcomes, and avoidable suffering.

This debate aims to bring together varying views to discuss how we move from invisibility to accountability. Because "If we can't see the problem, we can't fix it."

Questions for debate

1. Why did so few NHS organisations respond to the FOI request?

What does this say about the visibility and prioritisation of leg ulcer care across the system?

UA: The most likely explanation is that most of the NHS organisations were unable to answer the relatively simple questions because they do not hold the answers in a system from which they can easily retrieve the information. So, they are probably unaware of the impact of leg ulcer care on the workloads of their staff and, despite the recommendations of the 2024-25 NHS England Priorities and Operational Planning Guidance, are not prioritising evidence-based wound care.

This is worrying at a time when other surveys show that lower limb wound care forms a large proportion of community nursing time. NHS organisations cannot afford to remain blind to the leg ulcer issue, ignoring the opportunity to improve wound care, which would allow scarce NHS resources to be released for other health care needs.

AH: Organisations simply do not collect these data in any systematic fashion. In my experience, understanding the wound population need and the activity associated with this has only been achievable using surveys or audits. In addition to this, across an

integrated care board, what is collected by providers again varies, and there is a paucity of data on referrals even to specialist services. Thus, responding to this FOI request was simply impossible to provide.

AC: Essentially, there is no meaningful way that these data are collected and stored in individual departments rather than one specific place. Responding to the FOI request involves a lot of detective work to first find where the data could be stored, or if indeed they are even collected. Unlike the data collected for cancers or other conditions, the data for wounds are not easily accessible. This is a huge concern, and the NHS and, indeed the government, cannot ignore this, considering the enormous financial implications of wound management and the suffering of patients with wounds. The lack of data screams to me that this simply is not a high priority, and that has to change.

2. Why is it so difficult to extract meaningful data about leg ulcers from NHS systems? How do coding, service design, and digital fragmentation contribute to the invisibility of these patients?

UA: The typical leg ulcer 'journey' involves a series of different care providers. People with leg ulcers may first seek care from a high street pharmacy or a home carer. When there is no improvement, they probably then see their GP or practice nurse. If the wound deteriorates, they might be referred to a community nursing team, who might seek the advice of a specialist nurse, who might then refer to a vascular service or lymphoedema service. These providers are likely to have different data systems and use different coding, so the information is difficult to retrieve, and thus, the leg ulcer population becomes invisible.

When leg ulcer services are centralised to a unified lower limb assessment and treatment service to which patients can be referred early in their leg ulcer journey, then it becomes easier to gather good quality data to inform patient care and service provision.

AH: Historically, leg ulcer or lower limb care has been a part of community nursing wound care provision. The contract is a block contract, and thus, activity related to wound care of any kind is not separated off. The number of pressure ulcers is known because of the system of review required; the nursing activity for this cohort, however, would not be known. For primary care, wound type may be in the notes, but often not coded efficiently for extraction.

There is now photographic software that can produce the data required. However, this is used in pockets and not always fully integrated

into the patient record system. Extraction is an additional task and may not include all patients.

AC: There is a multitude of factors in answering this question. Data for wounds, such as pressure ulcers, are collected as an indicator of quality and patient safety. The same should be said for lower limb wounds. Unfortunately, the data are spread across multiple systems, GP, Community nurses and specialist nursing services. Much of the clinically relevant data, such as size, duration and time to healing, will be stored within the clinical notes, and this can make the extraction of data difficult.

3. How does the lack of data allow the scale of the problem to remain hidden?

Does the absence of information prevent investment and accountability?

UA: As the adage goes, 'It is impossible to improve what cannot be measured'. In other words, without data, it is difficult to make informed decisions to make something better and prove that any change has led to improvement. So, leg ulcer care will only improve when efforts are made to improve the quality of the data to provide a basis for investment and accountability.

The tissue viability community cannot do this alone. They need the committed support of commissioners, managers and IT teams.

AH: Questions around wound care provision have historically been seen in the 'hard box', allowing community nursing and medical leadership to sidestep the concerns raised about poor outcomes. There are many specialist nurses around the country who continue to collect their own local data on patients and their outcomes, often for their own service development and assurance, but these data often remain unpublished. Thus, we also have no comparative data to reference or a national benchmark to aspire to; in fact, we do not truly know what 'good looks like' for a population or where the variance needs to be accounted for.

It is clear that for healthcare systems to own their failings, they need their own data and are reluctant to utilise published data and the conclusions these hold, even those developed by the National Wound Care Strategy. The lack of baseline data also means that a system-wide quality improvement project is not possible.

Non-healing wounds use more resources in personnel, dressings and unplanned admissions. Each of these areas is not brought together to understand where savings can be made for reinvestment. Wound dressing data hold a great deal of information about system

management and clinical delivery. This is rarely used to understand where quality improvement could be fostered in order to release savings.

AC: Data are king, and to prove any need for change, we need to show the problem; without this, it will remain a hidden problem. Leg ulcers consume significant funding, and poor data mean these costs are underestimated, leading to deprioritisation in comparison to conditions with a stronger evidence base. As we have said already, because data are often collected in isolation, this helps contribute to service development, but needs to be used on a national basis to raise the agenda and bring lower leg incidence out from under the rug, shining a light on the wider issues of leg ulcer management and the issues this can have on patients.

4. What can we learn from NHS organisations that do have robust leg ulcer data?

How data can drive quality improvement, what exactly are the data or what questions need to be asked to drive these changes.

UA: The independent evaluations of the National Wound Care Strategy Programme and the Transforming Wound Care programme's implementation work proposed the following 6 metrics (full details can be found in the reports) (Health Innovation Wessex, 2024; NHS England National Wound Care Strategy Programme, 2024).

1. Number of patients with a lower limb wound currently on the case-load.
2. Number of new referrals for foot wounds and lower leg wounds each month.
3. Number of new referrals for foot wounds and lower leg wounds receiving full assessment in line with national recommendations
4. Number of new referrals for foot wounds and lower leg wounds receiving full care in line with national recommendations each month.
5. Number of adult patients with a lower leg wound and adequate arterial supply, where no aetiology other than venous insufficiency is suspected, being treated in strong compression (40 mmHg) each month.
6. Proportion of patients recorded as healed within 12 weeks, between 12 and 24 weeks, between 24 and 52 weeks, and after 52 weeks each month.

The implementation sites proved that it is possible to collect these data and use them to drive quality improvement. There is an urgent need for other organisations to adopt this good practice.

AH: If the health system were truly bothered about patient outcomes, healing rates must

surely be a question all services should be looking at. However, healing rates are rarely considered a key performance indicator in community nursing contracts. This key performance indicator is more likely to be asked of specialist providers, and hence why these data and much more are available from non-NHS providers.

Another critical issue is how healing rates are calculated; the methodology for how we calculate healing rates at 12 weeks needs to be explicit. There is inconsistency regarding who is being measured, who is being excluded, how to manage bilateral leg ulceration and also the relationship to the demographics of the population or site of care. There is no national agreement for either the methodology or the aspiration for what is a 'good' healing rate benchmark.

AC: NHS organisations that have invested in systematic data collection for lower-limb wounds demonstrate the transformative value of good intelligence. These services are able to quantify the true burden of leg ulcers in their population, track healing trajectories, and understand variation in outcomes across teams, neighbourhoods, and clinical pathways. Having accurate prevalence and healing-rate data provide far more than operational insight; they enable strategic planning, resource allocation and targeted quality improvement.

Where robust datasets exist, organisations can identify unwarranted delays to assessment, recognise which cohorts are at risk of non-healing, and evaluate the effectiveness of interventions such as compression therapy or early venous procedures. This level of visibility allows services to move from reactive care to proactive population health management. Crucially, it also creates the foundations for economic modelling, demonstrating the cost of poorly healed wounds and the savings achievable through evidence-based practice.

Learning from these organisations shows that robust leg-ulcer data are not a luxury; they are a prerequisite for safe, equitable and efficient care. They reveal what is currently hidden in many NHS systems, the scale of the problem, the outcomes patients experience, and where investment can make the greatest impact.

5. What needs to happen next?

Should there be a national minimum dataset or wound registry? How can we embed routine data collection into clinical pathways without adding unnecessary burden?

UA: National registries are a useful means of attracting attention to an issue, but they are

only as good as the data they hold. So, the initial focus needs to be on improving the quality of leg ulcer data and information at the local level.

The National Wound Care Strategy Programme and the Transforming Wound Care programmes have already proposed and tested a 'minimum dataset' for quality improvement (see above), and this, combined with the Professional Record Standards Body Wound Care Information Standard (Professional Record Standards Body, 2026), provides a good basis for improving the quality of wound care data across the UK. The challenge now is to implement these recommendations into the routine data collection of clinical care, using the existing electronic data systems.

If we all record data in the same way (regardless of which electronic data system is used by our organisation), then information can easily be retrieved to inform organisational audits, answer future FOI requests and populate any future national registry.

AH: Lower leg wounds are the largest group of the wound management cohort and the most costly in nursing time, thus energy needs to be focussed here. Unfortunately, embedding any change requires extra work; it is critical that the clinicians know why this is required and that they are absolutely assured that these data will be used to transform outcomes for the people they care for and improve the system.

In addition to collecting referral data and use of compression therapy, clinicians should also know how effective they are. This is primarily established by healing rates at 12 and 24 weeks, and crucially, understanding the dosage of compression therapy provided. All surveys have demonstrated a lower-than-expected use of strong compression therapy; we all think we are doing better than we are. Data exposes the system of care more than anything else, and until then, it is hidden in plain sight. It is incumbent on us all to change this and challenge the system of complacency. The burden of proving your worth as a specialist service should be inherent in any service management, and it is critical to have a national agreement on methodology for the collection of healing rates for lower leg wounds.

AC: Robust leg ulcer data are not just a reporting exercise; they are the foundation for quality improvement, cost efficiency, and patient-centred care. Without it, the true scale of the problem remains hidden, investment is limited, and accountability is weakened. NHS organisations that embrace structured data collection can transform outcomes, reduce costs, and improve patient experience. The recording of data in the same way nationally

will ensure lower limb care is visible and measurable. In the future, the information will then be available to answer FOIs. We must challenge the system and make this a priority.

Summary

Leg ulceration remains a substantial but largely invisible burden within the NHS, obscured by fragmented data systems, inconsistent coding, and the absence of routine wound surveillance. The Legs Matter FOI exercise revealed that most organisations cannot report even basic epidemiological information, making it impossible to understand prevalence, monitor healing, or demonstrate outcomes. This invisibility perpetuates variation in care, prevents meaningful investment, and allows poor healing rates to remain unchallenged.

Where robust datasets do exist, organisations can quantify demand, track healing trajectories, identify delays, and evaluate interventions such as compression therapy, driving measurable improvements

in both quality and efficiency. Legs Matter is calling for urgent national action, including a standardised minimum dataset and alignment with the Transforming Wound Care programme outcome measures. Only through consistent, embedded data collection can the NHS accurately see the scale of the problem, plan services effectively, and improve outcomes for the many patients currently hidden in plain sight. ●

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