



MAKING LEGS MATTER

A CASE FOR SYSTEM CHANGE AND TRANSFORMATION IN LOWER-LIMB MANAGEMENT

This consensus document is endorsed by The Queen's Nursing Institute (QNI) and The Queen's Nursing Institute Scotland (QNIS).





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INTRODUCTION

here is agreement on what constitutes an acceptable standard of care for people with ulcers on the lower limb (leg ulcers, foot ulcers and ulcers associated with oedema). Despite this consensus, many people still do not receive the required standard. They often endure months, even years, of unnecessary suffering. The personal cost to individuals and the economic burden to UK's NHS is significant. Unfortunately, the reality is that such harm, as it may be described, is avoidable.

In September 2020,* a group of representatives of the Legs Matter coalition attended a virtual consensus meeting hosted by the Journal of Wound Care (JWC). The objective of the meeting was to identify the extent of the problem around lower-limb management in the UK, highlight its potential devastating impact on patients and families, and issue a call-to-action for a change in mindset and culture, to ensure that best practice is implemented as standard and that patients no longer must endure avoidable and unnecessary harm.

There is good news, as there is now a visible collaboration to drive change nationally through the National Wound Care Strategy (NWCS), NHS England, and NHS Improvement. The Queen's Nursing Institute (QNI) and Queen's Nursing Institute Scotland (QNIS) are supporting this change. Legs Matter and JWC are putting the extent of the problem into perspective, and via this consensus document, outlining the potential for transformation.

This document is not a best practice document. It is hard-hitting in parts, but has been designed with care and concern in mind. It contains referenced evidence, as well as anecdotal comments and experience from the group of Legs Matter representatives (ie, the consensus panel).

Without a doubt, the ability of the NHS to respond to the need for change has been realised with the covid pandemic. Barriers have been broken down and people put at the centre. This call-to-action for lower-limb conditions requires commissioners, healthcare providers, and industry leaders to adopt a similar mentality to bring change and work together for the common cause.

There is an opportunity to create transformation in lower-limb management that has been needed for some time, but first, there is a need to debunk common beliefs and misconceptions among commissioners, healthcare providers, and industry leaders, and spell out the potential for change.

The first section describes Legs Matter's commitment to challenge and transform the current system, which has created unacceptable human and financial costs. It establishes the need for this consensus document, spells out its objectives, and highlights the urgency for transformation.

Section 2 focuses on the management of chronic oedema/lymphoedema, leg ulcers, peripheral arterial disease, and diabetic foot ulcers (DFUs). It identifies the issues in current practice and the consequences of leaving these unaddressed—a devastating impact on patients, their families, and the health and social care system.

The third section sees the glass half full, in that most of the tools needed to solve the lower-limb management challenge are already there. Several national strategies, local guidelines, and measuring instruments can help achieve this—there is no need to reinvent the wheel. Yet the problem remains unsolved.

Section 4 states that commissioners, healthcare providers, and industry leaders should collectively embrace the need for change and not allow any existing beliefs to get in the way of this action occurring. Before the system can change, some common misconceptions should be debunked.

The last section summarises the things which can be done immediately to begin the process of change. The first step is for commissioners, healthcare providers, and industry leaders to recognise there is a problem. Acknowledging poor-quality care can drive the case for change.

The consensus panel trusts this document will help you improve and transform the status quo.

*Since this consensus meeting took place, there has been a significant change in the structure of the commissioning landscape in England. While this has not yet been constituted in law, Integrated Care Systems (ICS) are currently in situ and under construct. The consensus panel recognises that this new infrastructure will impact the commissioning process and the areas of focus for population, health management and delivery. With the correct approach, this could benefit lower-limb care. However, this area is not identified as a priority for action in the ICS remit.

SECTION 1: A STORY OF COMPLICIT FAILURE

THE CALL FOR VISUAL TRANSFORMATION

Every day, the quality of life for thousands of people is compromised by the lack of support and advice on the prevention and management of lower-leg and foot conditions. This can be compounded by a failure to provide the correct diagnosis and treatment. For patients, this can mean months, and possibly years, of potentially unnecessary pain and suffering. For healthcare practitioners, this continuing trend of failed management results in hours of activity with no tangible end in sight either for them or the patient in terms of resolution. The Legs Matter coalition was founded in 2017 to raise the profile of this challenge and to begin to work with systems to address this.

What is Legs Matter?

Legs Matter¹ is an independent coalition of eight healthcare charities and not-for-profit organisations. We are a collaborative force; a single voice that exists to challenge the system and drive the delivery of improved experience and outcomes for patients. The collaborative embraces the principles of self-care and, in this context, works to empower individuals to better understand both their condition and the quality of service that they should receive.

A large part of this approach involves raising awareness of some common conditions which can affect the lower limb and/or the foot. Legs Matter's campaigns focus on lower-limb conditions that are the result of long-standing (chronic), often undermanaged and interlinked diseases. Lymphoedema (lymphatic failure) may also be an intrinsic part of a lower-limb condition which is a swelling of the lower limbs that is often, but not exclusively, a consequence of chronic oedema due to venous disease. Lower-limb oedema is often a precursor to leg ulceration and delays healing where an ulcer is already established. Peripheral arterial disease (PAD), a well-known marker for cardiovascular diseases such as heart attacks and strokes, is another chronic condition which may lead to lower-limb ulceration. Foot ulcers may develop in people with a range of diseases, including diabetes and PAD, or conditions which may cause nerve damage. All these lower-limb conditions have the potential to have a major impact on an individual's quality of life; they are often painful and at worst may severely limit a person's mobility.

In the UK, too many of these foot and leg conditions are not being managed either efficiently or effectively; too many ulcers are not healing. This, in turn, means that resources may be used ineffectively, bringing productivity challenges to teams of nurses and often leaving individuals to live a life with unnecessary pain and

distress, sometimes over many years. This creates both unacceptable human cost as well as an ongoing waste of limited NHS resources.

The Legs Matter coalition believes that:

- Non-healing wounds of the lower limb and foot are one
 of the biggest health challenges of our time, but it is a
 challenge that can be solved
- Under the principles upon which the NHS was founded, everyone has a right to good-quality lower-leg and foot care that promotes healing and reduces the risk of harm
- Creating improved awareness and understanding of management, treatment, prevention, and early intervention will drive change across current working practices
- It is essential that healthcare practitioners are involved at the very early stages of each patient's journey and that they are knowledgeable about lower-limb conditions
- We can achieve more by working together than we can by working alone.

Establishing the need for this document

After decades of research into lower-limb conditions, there is now an improved understanding of how they are caused and how best to manage them. Many published documents explain how best to treat these conditions. But despite this wealth of information, the healthcare system is still failing people with lower-limb conditions. Research demonstrates how few patients are treated in the most appropriate way, or, indeed, achieve good outcomes.² Although vast amounts of money is spent trying to tackle the problem,³ it is clear that NHS financial resources are not being spent efficiently, for maximum gain, in this specific area.

Realistically, not enough is done to tackle the root causes of lower-limb conditions. Not enough is done to adopt

the best-practice techniques that research has shown work well.^{2,4} And not enough is done to support patients in their journey back towards health and a good quality of life.

At best, this amounts to poor quality care; at worst, this can represent neglect and patient harm.

NHS bodies across all four countries of the UK have identified the need to improve quality in healthcare.⁵⁻⁸ The question remains: is the care available today for lower-limb conditions of a good enough standard, and therefore of good enough quality? Looking objectively at the facts, the answer to that question is often 'no.'

What can be done to improve the situation? The first step is for all involved to recognise there is a problem. Acknowledging poor-quality care can push the system to act. Many areas of medicine have seen vigorous action

FACTS YOU NEED TO KNOW

Over half (57%) of patients who access community nursing services in the UK are estimated to have lymphoedema,⁹ many of whom are not able to access specialist services to manage their condition because such services are not commissioned and, therefore, do not exist.

It is estimated that 30% of wounds lack a proper diagnosis. This means that the identification of a suitable treatment and a supportive management plan² becomes impossible to achieve.

Every year, more than 57% of all chronic wounds do not heal.² This a problem for the patient and the system.

Patients with lower-limb ulcerations suffer a marked reduction in their quality of life, 10-12 resulting in increased costs to the NHS and ongoing day-to-day challenges in daily living.

Two-thirds of clinical commissioning policies were found to be non-compliant with National Institute for Health and Care Excellence (NICE) guidance in providing access to venous services.⁴ A simple change in commissioning processes could rectify this.

The number of amputations in patients who do not have diabetes but do have a foot ulcer is rising,¹³

WHAT IS COMMISSIONING IN THE NHS?

The continual process of planning, agreeing, and monitoring services. Commissioning is not one action but many, ranging from the healthneeds assessment for a population, through the clinically-based design of patient pathways, to service specification and contract negotiation or procurement, with continuous quality assessment. This happens differently in Northern Ireland, Scotland and Wales.

over the last decade, leading to great improvements in outcomes: for example, improved detection of pre-diabetes can reduce the number of people progressing to type 2 diabetes, 15 and early intervention for patients experiencing stroke have improved longer-term outcomes. 16 The fact is, when it comes to lower-limb conditions, there is a lack of drive towards coordinated action, therefore the outcomes this consensus panel sees today are not of an acceptable standard.

The Legs Matter coalition believes this is the right time to shine a spotlight on poor-quality care. We trust that in doing so, we will push the system to act and get the patients the care they deserve. Legs Matter want to achieve a fundamental shift in attitudes, treatment and prevention of lower-limb conditions to reduce the prevalence, severity and impact of lower-limb problems.

Objectives

The objectives of this document are to:

- Create political awareness. We aim to emulate the kind of success in the care of the lower limb that has been achieved with pressure ulcers over the last decade
- Encourage those who commission, provide and deliver healthcare services to recognise their accountability for what health systems are failing to achieve
- Bring everyone together in a shared desire to improve the delivery of care in lower-limb management
- Make patients aware about the care they have a right to expect, and to encourage and empower them to raise relevant questions
- Reach those with the power to transform poor care and demonstrate to them why the current system is not acceptable
- Promote transformation of lower-limb care, not only as the best solution for the patient but also for healthcare systems striving toward population management.

SECTION 2: A CASE FOR CHANGE AND TRANSFORMATION

THE STATUS QUO IS NO LONGER ACCEPTABLE: WE MUST CHANGE IT

This section explores some of the reasons why the current system, despite massive effort on the part of healthcare professionals, fails to deliver the quality level of care needed. The NHS strategic frameworks advocate that healthcare services are designed around the needs and preferences of individuals, leading to variation across the UK. Failure to manage lower-limb conditions appropriately can lead to the development of more wounds. As things stand, dependency on the system is an inevitable, unmanageable consequence. Have we, inadvertently, created a toxic culture?

Chronic oedema/lymphoedema: the problem

Chronic oedema, regardless of the cause, is a build-up of fluid in the tissues of the body that has been present for more than 3 months. This causes swelling of the affected body part. The lymphatic drainage system would usually work to remove this fluid and, along with it, various toxins that the body needs to excrete via the kidneys. If the oedema does not completely resolve overnight or with elevation, this indicates lymphatic failure, or lymphoedema.¹⁷ Lymphoedema can lead to changes in the skin and deeper tissues. It can also lead to localised and systemic infection (cellulitis). Lymphoedema in the lower limbs is commonly related to chronic venous insufficiency, when an abnormality in the veins, resulting in blood not being able to flow back properly to the heart, causing it to pool in the feet and legs, overburdening the lymphatic svstem.

Who is affected by lymphoedema?

Older people and those who are overweight have a greater risk of developing oedema. This problem is often seen in primary care and affects over 420,000 people in the UK.¹⁸ The age of the UK population and the proportion of people who are obese is increasing, which means that the number of people with chronic oedema is likely to rise.¹⁸ People who have survived cancer treatment are also at particular risk of developing lymphoedema.¹⁸

How is lymphoedema treated?

Too often, those with lymphoedema, which may be classed as a life-long condition, are being told that nothing can be done, and they must learn to live with it. This is not the case. Compression is an essential part of effective treatment for most patients, but may not be available to patients in many areas, as such services are not generally commissioned except for those who have experienced cancer: In some

patients, venous insufficiency can be treated surgically. Otherwise, treatment is often only given once the oedema has led to a more serious medical consequence.¹⁸

What are the consequences?

Around 80% of people with lymphoedema must take time off work, with around 8% of people having to give up work completely.¹² Half of sufferers describe their condition as painful.¹² The costs of treating lymphoedema in England alone is almost £200 million per year.¹⁸ Left untreated, lymphoedema can lead to cellulitis, a serious bacterial infection underneath the skin surface. Half of sufferers will experience more than one episode of cellulitis with over a quarter needing to be treated in hospital.¹⁹ Cellulitis is responsible for over 400,000 bed days per year, resulting in annual costs to the NHS England in excess of £96 million.²⁰

A serious consequence of chronic oedema and lymphoedema is the development of chronic, non-healing wounds (ulcers) on the lower limb. These are discussed below.

Leg ulcers: the problem

A leg ulcer may be described as an open wound between the knee and the ankle that remains unhealed for at least two weeks. Around 70% of leg ulcers are linked to venous insufficiency—these leg ulcers are called venous leg ulcers (VLU). VLUs are thought of as the most advanced stage of venous insufficiency.²¹ Other types of lower-limb ulcers are associated with reduced blood flow in the leg (arterial ulcers). Some patients have problems with both the veins and the arteries in their legs; ulcers in these patients are called mixed ulcers. Many other medical conditions, including dermatological problems and some types of arthritis, can cause leg ulcers.

Who is affected?

Around 730,000 people in the UK develop a leg ulcer every year. This equates to 1.5% of the adult population.³ Older people are more likely to suffer with a leg ulcer, with approximately 3% of people aged over 80 diagnosed with a VLU.²²

How should leg ulcers be treated?

Different types of leg ulcers should be treated accordingly, and a correct diagnosis is vitally important. In the UK, around 30% of leg ulcers do not have a confirmed diagnosis. This means that the most effective course of action cannot be identified and administered.

Compression bandaging is considered the cornerstone treatment for VLU and can be extremely effective. Compression reduces oedema and venous hypertension, and is proven to help the ulcer to heal.²³ As the application of compression requires a level of education and experience, variation in service provision across the country is not consistent because this required degree of capability and competency is not always available. There is currently a growing trend of sub-optimal use of compression through the use of reduced compression regimes. Improved education is required to minimise the unwarranted variation and access to this vital therapy. In addition, many healthcare providers are reluctant to apply any level of compression without having investigated the patient's ankle-brachial pressure index (ABPI), a simple bed-side test to measure the flow of blood to the lower limb. The focus within all guidelines on ABPI prior to the application of even mild compression has created a risk-averse culture. This is now being addressed through guidelines from the National Wound Care Strategy Programme (NWCSP). This new strategy document encourages the first-line use of mild compression for the vast majority of patients in the absence of red flags (see box on page 14. 'Red flags in the lower limb').²⁴ If mild compression is not effective, this strategy describes escalation to a full holistic assessment within 2 weeks. Following this, the patient should be treated with the appropriate level of compression, often of at least 40mmHg.²⁴

Other than compression, there is a wide range of treatments and dressings designed to support the management of leg ulcers,²⁵ but treatment is often provided on a 'trial and error' basis. Surgical intervention can also be very effective—surgery can both address the underlying problem⁴ and prevent recurrence.²⁶ Despite this, surgical intervention is seldom offered, with such provision varied across the UK.

What are the consequences?

Leg ulcers not only result in high human cost but also financial cost with significant implications for an already stretched healthcare economy. Leg ulcers cost UK's NHS around £2 billion every year.² However, leg ulcers take a heavy toll on those who have to live with them—they can be very painful, smelly, and can leak fluid, which profoundly affects people's ability to sleep, move about, work, and socialise.²7 There is also loss of independence and increased dependency on family/carers. In fact, almost every facet of their lives can be very severely affected.²7-²9 The pain often needs to be managed with pain-relieving medication, which in many cases is not effective and can cause side-effects.

Peripheral arterial disease (PAD): the problem

Peripheral arterial disease (PAD) is a common condition, in which a build-up of fatty deposits (atheroma) in the arteries restricts blood supply to the muscles and tissues in the leg. It is strongly linked with cardiovascular (heart) disease and can lead to lower-limb amputation.³⁰

Who is affected?

PAD affects around 20% of people over the age of 60 in the UK;³⁰ this equates to over 3 million people in the UK alone. People who are at risk of PAD have an increased risk of lower-limb amputation and are also at risk of cardiovascular events, such as stroke and heart attack.

How is it treated?

The treatment of PAD varies in each patient according to its severity. Patients with milder cases of PAD should be encouraged to make lifestyle changes and take medication to reduce the potential for further atheroma development. Key lifestyle changes include smoking cessation and exercise. For more severe cases, treatment involves medical intervention, which ranges from angioplasty (unblocking of blood vessel) to arterial bypass grafts (where a piece of plastic or vein is used to reroute the blood around a blocked vessel).³⁰

What are the consequences?

About 80% of patients with PAD experience no symptoms but continue to be at an increased risk of cardiovascular events; it is therefore important that patients are screened for asymptomatic PAD at every opportunity. The most common first symptom of PAD is pain in the muscles of the lower limb while walking (known as intermittent claudication). For some patients, the disease can progress to 'rest pain' and tissue loss (ulceration)—this is called critical limb ischaemia (CLI). If revascularisation is not performed quickly at this stage, the patient is at risk of major limb amputation. PAD is the largest single cause of non-traumatic lower-limb amputation in the UK.³⁰

Diabetic foot ulcers (DFU): the problem

Foot ulcers are areas of broken skin on the foot that can affect people with a diagnosis of diabetes, nerve damage (neuropathy) and/or reduced arterial blood flow (see the section above on PAD). Although a variety of people with

different conditions are affected by foot ulcers, most of the available information describes diabetic foot ulcers (DFU).

Who is affected?

Around 169,000 DFUs are diagnosed every year. This is equal to 5% of adult patients with a diagnosis of diabetes having a foot ulcer per year.³

How is it treated?

DFUs are managed primarily by 'off-loading'. This entails the patient wearing a device on the affected foot designed to redistribute the pressure on the foot caused by day-to-day weightbearing activities. If the patient's foot also has poor blood flow, this should be addressed where possible. Finally, the wound should be managed by removing any dead tissue (a process called debridement) and treated with an appropriate dressing or device. Any infection should also be treated.³⁰

What are the consequences?

The cost of caring for patients with DFUs in England alone is estimated at £837 million per year.³¹ This is equal to £1 in every £125 spent by NHS England. Around 6,000 people with a diagnosis of diabetes have leg, foot or toe amputations each year.³² The prognosis for people with diabetes who have an amputation are poor; up to 55% of people can be expected to die within 5 years of the operation,³³ a similar or worse survival rate than many common types of cancer.^{34,35} Having a DFU can also affect a patient's mental health and quality of life.

These conditions all have a devastating impact on patients, their families, and the health and social care system.

Sue's story

In her late 40s, Sue was diagnosed with renal cancer. Although the cancer treatment was successful, it left Sue with some serious side effects, including lymphoedema that caused her legs to swell. Unfortunately, there was no lymphoedema service in her area. Prior to her surgery, Sue had Type 2 diabetes for a number of years, which was initially well managed by diet and prescribed medication. However, since her surgery, the control of her diabetes has required daily insulin injections.

Fourteen years later, Sue was living with her condition, the management of which has been complicated by recurrent wound infections further to the onset of a leg ulcer.

'I was back at work, and I noticed that my leg was dripping. I had a tiny scratch on my leg that just kept on dripping. I wrapped kitchen roll around my leg to soak up the fluid. Within two hours I'd used up the entire roll. I was sent to the lymphoedema clinic and they gave me some [compression]

stockings that were really thick and tight. The scratch on my leg had turned into an ulcer by this point, so they sewed some silk into the stockings to stop it rubbing. But the silk kept on slipping and the bandages would rub the ulcer until essentially I had a hole in my leg.'

The lymphoedema clinic that Sue was initially referred to was newly established within South Lincolnshire and had been set up primarily to manage patients with the condition as a consequence of cancer. The service was led by a former district nurse with an interest in lymphoedema but no specific training. This service was stopped at a later date.

Sue's chronic wound proved exceptionally hard to treat, leaving her in significant pain and often house-bound. The nearest alternative lymphoedema service at the time was a considerable distance away, and Sue felt unable to travel due to the symptoms associated with her leg ulcer and associated lymphoedema.

'My legs and feet kept on getting infected. In one year alone, I had 14 infections. Last year, I got an infection in my leg that caused fluid to build up around my heart. It's left me with heart problems, which makes compression difficult. At one stage, the wound was green. My legs and feet were so swollen from the lymphoedema that I couldn't even wear shoes. I just didn't leave the house. I wouldn't see anyone all day. Being house-bound also affected my weight. When you can't leave the house for years, you're going to put on weight. Being overweight makes the lymphoedema worse but I can't exercise because I can't walk easily. It's a vicious circle.'

Following referral to a new local specialist complex wound clinic where a comprehensive assessment was undertaken, Sue's clinical situation started to improve and an ongoing management plan was agreed between Sue, the complex clinic lead and the case manager of her current district nursing service. A successful collaborative approach as to the most appropriate wound management and compression for both her leg ulcer and lymphoedema was maintained.

Sue eventually found further success with compression wraps rather than bandages, but her problems with her legs and feet continued due to her care being moved to a different health centre.

'I tell people that I went to bed at 50 and I woke up in my 60s. It's like I've lost 13 years of my life. I can't go round to friends anymore because I worry about leaking. My grandson is 10 now and he has never seen me without a bandage on my leg. People don't realise how serious leg and foot problems are. You think it's just a scratch and then you end up with no life.'

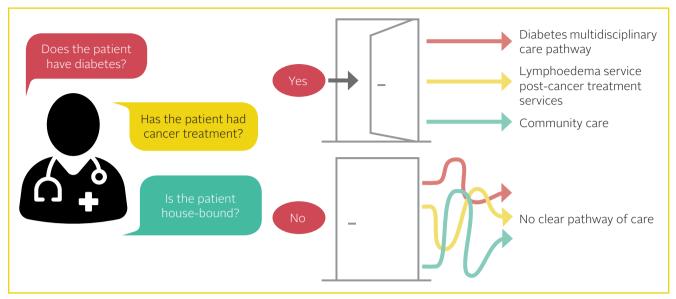


Diagram 1. Unequal and siloed healthcare services do not provide all patients with an acceptable pathway of care.

In the last couple of years Sue's condition has improved due to a stabilised district nursing input, supported by the former lead of the complex wound clinic (at both a clinical and an educational level). Unfortunately, the local acute healthcare trust decided to close the complex wound clinic in 2019 in order to save money and to redeploy specialist staff (all disciplines) into other clinical inpatient areas to reduce the agency spend the trust was incurring on a regular basis.

Finally, in Sue's own words:

'I am pleased to say that my leg ulcers have healed now and in the next few weeks I will be able to have new shoes and be out of bandages and wraps after 17 years, so I'm looking forward to the future with new hope'. (July, 2020)

Take-home message: Failure to manage Sue's lymphoedema at an early stage, and then lack of continuity in service provision for complex wounds, undoubtedly contributed to her developing leg ulcers and suffering recurrent infection, generally requiring admission to hospital for intravenous antibiotics. As a consequence, she suffered severe pain and had to give up work that she enjoyed as her life became more restricted due to pain, infections, large quantities of exudate from her wounds, subsequent cardiac problems and weight gain. It has been a needlessly long and tortuous journey for Sue. At long last she is getting her life back and is taking pleasure in making positive plans for the future.

What blocks current systems from working more effectively?

This section explores some of the reasons why the current system, despite massive effort on the part of healthcare

professionals, fails to deliver the quality level of care needed for patients.

It all starts with an absence of person-centred care. The NHS strategic frameworks in all four countries of the UK advocate that healthcare services be designed and delivered around the needs and preferences of individuals, 5-8 creating a silo effect to care. In the worstcase scenario, if a patient doesn't have a particular diagnosis, they can be excluded from entering a service. regardless of their need for care. The end result is health inequality. Several examples of this are described and shown in Diagram 1. Siloed services operate as separate entities with little communication between them. For patients with complicated medical histories, who may have access to more than one type of service, patients often experience frustration at the lack of coordinated thinking, communication and management, with the absence of a single point of contact.

Examples of inequality in lower-limb services

Diabetes vs no diabetesThere are many excellent care structures in place for people with diabetes, including access to a mu

for people with diabetes, including access to a multidisciplinary foot service and regular check-ups which is recommended by the National Institute for Health and Care Excellence (NICE). The purpose is the prevention and optimal treatment of DFUs. But there are other groups of people who are also at high risk of developing foot ulcers, for example people with neuropathy in their lower limb. If an individual does not have a diagnosis of diabetes, they may be systematically excluded from accessing the full service regardless of their clinical need.⁷ For these patients, all that is typically offered is access to a practice or community nurse who often don't have the necessary level of specialist training in this area.

Lymphoedema with or without cancer

Services across the UK are patchy. Some services are only offered to people who develop lymphoedema following cancer treatment. Some areas have no service at all.¹⁸

Chronic oedema with or without an ulcer

Chronic oedema is a significant risk factor in the development of a VLU. Despite this, some lymphoedema services do not accept patients with wounds. Equally, many patients demonstrating a high body mass index (BMI), regardless of their need for a service to help manage their swollen limb, may also find themselves excluded. Across the country, wound care services vary in quality dependent upon setting, therefore the root cause of the ulcer (the swelling) may not be adequately managed in such non-specialist settings. This leads to a vicious cycle of failing care.

Mobile vs immobile patients

While in many areas house-bound/immobile patients may access care via community nursing services, this is not available for the mobile person who develops a lower-limb wound. In reality, the practice nurse may be unable to see them because the GP contract may not include care of those with wounds, and, being mobile, they are by the very nature of their mobility not eligible for care in the home. The only option is a leg ulcer clinic, but this depends on availability. Some mobile patients simply deteriorate unnecessarily while they wait for their problem to be addressed.³⁶

Postcode lottery

As with many healthcare conditions, a patient's address may dictate the care they receive. Different services are offered across and between all areas of the UK. One example is that some, but not all CCGs, offer patients with VLU a referral for a vascular consultation, with the potential for surgical intervention. Patients whose local

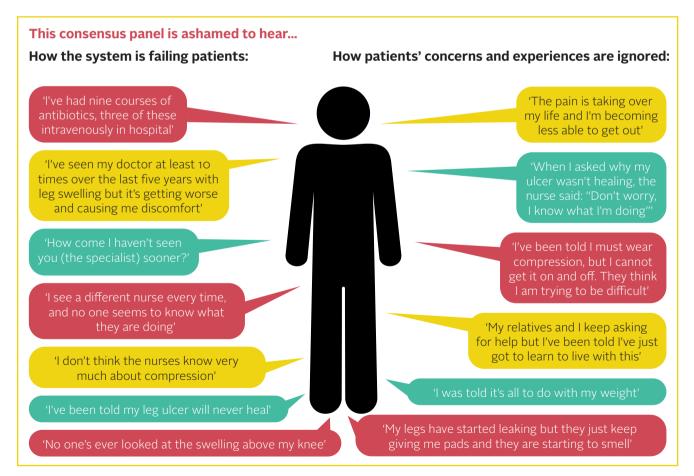


Diagram 2. These comments are examples of what that the authors of this document have heard in clinical practice over the last few years in the UK. The panel believes there is an absence of patient-centred care, which leads to the system failing patients.

CCGs do not offer these services often struggle to access specialist intervention. Another example is with diabetes services; some areas have excellent provision but there are still many areas where services for patients with diabetes do not comply with NICE guidelines.

Where there is no clear pathway, the provision of care can often feel chaotic for the patient and may not address their needs as a result (Diagram 1). While wound care may not be detailed as a fundamental deliverable in the GP contract, leg ulcer care may be offered via a local enhanced service. This means GPs would be paid for providing what may be considered an extra service. But GPs in many areas do not have access to such an enhanced service. Those working in general practices would often acknowledge they have little specific knowledge relating to the lower limb with care for such patients often being delegated to the practice nurse, who may also be relatively unskilled in this area. With no specific service to refer patients on to, GPs and practice nurses may not be able to provide treatment that best addresses their patient's needs.

This consensus panel believes that anyone with lower-limb conditions should be able to access high-quality, appropriate care, to address their needs. Silos are certainly irrelevant to patients and, in reality, may be described as a by-product of the way services are organised. They don't exist for the benefit of the patients and are not patient-centred. While some patients benefit from the best available care, many find the door to high-quality service closed to them. This is not an acceptable state of affairs and is one which can be addressed by commissioners. The knock-on effect to the healthcare system of this approach to care is the creation of significant and unnecessary cost pressures, generating a double negative impact.

Patient's needs and preferences are not at the heart of treatment

Even when a patient is given access to care, it does not always meet their needs or preferences (Diagram 2). Currently, much of the wound care delivered may be described as transactional in that it is driven by a tick box, or rote, approach with little attention paid to and understanding the patient before carrying out an action which addresses their particular needs and preferences.

Patients may feel frustrated when they experience what may be considered a lack of continuity of care. As clinicians, this consensus panel will often hear patients describe how they are unable to develop a relationship with the practitioner managing their care, as each time they are seen it is by a different person.

More importantly is the tendency to blame poor outcomes on the patient. If a patient has been given a treatment that they do not want, understand or agree with, or do not/are not able to comply with their care instructions, they are often labelled as 'non-compliant.' This consensus panel believes this label is more reflective of a lack of responsibility, accountability and understanding on the side of the healthcare provider than a reflection of the patient.

Non-compliance is genuine evidence of a serious disconnect between the patient and the healthcare provider. In our experience, patients believe that their actions are reasonable ('My treatment was so painful I couldn't sleep, so I removed it'), but the healthcare provider sees the same behaviour as an obstruction ('The patient won't keep their dressing on, so it is their fault that the treatment is not working'). Compromise is not often explored. There is a visible need for healthcare providers to understand the patient's perspective and the value of patient engagement and activation,³⁷ if they are to help them tolerate the vital treatment of optimal compression therapy.

If a patient's needs are not being listened to and acted upon, this can lead to neglect and can result in patient harm.³⁸

This unsolved and misunderstood area of 'compliance,' where blame is apportioned inappropriately, will inevitably lead to patient harm: the patient continues to deteriorate because a shared understood position cannot be reached. At this juncture, the problem becomes one of a quality-of-care issue.

As things stand, dependency on the system is an inevitable, unmanageable consequence

People with lower-limb conditions can experience devastating consequences.²⁸ If lower-limb conditions are not managed effectively early on, the patient's overall health can deteriorate. This may inevitably lead to a deepening dependency on the health and social care system. Some examples are shown in Diagram 3.

Pain is a major problem common to many patients with lower-limb conditions. This pain may be experienced throughout the day and night, and can have a profound effect on mood and sleep. ^{26,32} Pain can be brought on by weight-bearing, affecting a person's ability to move around and their independence. Indeed, one of the biggest impacts of lower-limb conditions is the effect they have on mobility and independence. Lack of physical activity is one of the most significant public health challenges of our time, and is often linked to other major public health problems, including obesity, diabetes, cardiovascular disease and depression.³⁹ As people become less able to mobilise, some are unable to work. This has an enormous impact on their financial position as well as their feelings of self-worth. Being unable to get out and about leads to

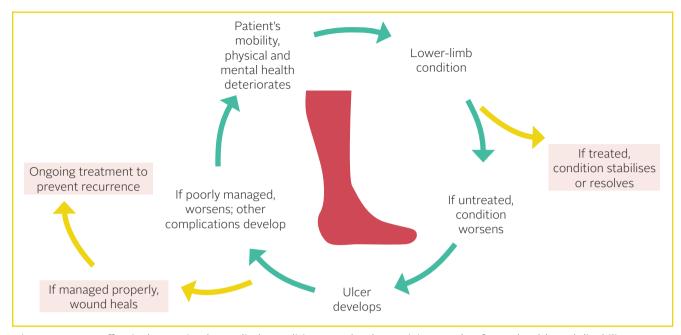


Diagram 3. Not effectively treating lower-limb conditions can lead to a vicious cycle of poor health and disability.

feelings of isolation and depression,²⁷ leading to a poorer quality of life.³ Failure to exercise and developing obesity results in the patient becoming less healthy which, in turn, risks causing the lower-limb condition to further deteriorate.

This becomes a vicious cycle where a patient's decreasing mobility causes their general health to deteriorate, worsening their lower-limb condition (Diagram 3).⁴⁰ In this context, the patient becomes more reliant on social care and, in turn, develops additional healthcare needs. It could be regarded that maintaining the status quo is promoting the development of long-term debilitating conditions and encouraging dependency on an already challenged healthcare system.

Failure to manage lower-limb conditions can lead to the development of further issues

More antibiotics and other prescriptions

Prescription charges for lower-limb wounds alone cost UK's NHS over £50 million per year.² Cellulitis is often incorrectly diagnosed and over-treated, leading to overuse of antibiotics.⁴¹ Failing to get lower-limb ulcers to heal can prolong the need for prescriptions and increase the risk of developing infection, as well as the need for antibiotics.

A waste of nursing resources

Failure to use compression therapy in patients with lowerlimb wounds increases nursing visits by 45% compared with patients who are managed with compression.³⁸ Patients with unhealed wounds need 20% more practice nurse visits and 104% more community nurse visits compared with patients with healed wounds.2

More pain medication

People with lower-limb conditions often experience chronic pain²⁹ and are prescribed analgesics to address the pain.⁴² Failure to achieve healing of lower-limb ulcers exacerbates the need for pain control.

Increased hospital admissions

There are around 290,000 hospital admissions related to lower-limb wounds in the UK every year.² Cellulitis developed as a consequence of lymphoedema causes an additional 105,000 hospital admissions each year.¹⁸

Increasing numbers of amputations

In England, someone over the age of 50 has a minor foot amputation every hour, with someone having a major amputation (above the ankle) every two hours.¹³ The lower-limb amputation rate for people with diabetes in England varies widely between CCGs. It is believed that at least half of all these major amputations are avoidable through effective lower-limb care.³⁵

The focus in the UK is on amputations in people with diabetes, but 55% of all non-traumatic amputations are in people without a diagnosis of diabetes.⁴³

Restricted ability

Over 80% of patients living with a VLU say it affects their mobility.⁴⁰ Failing to tackle lower-limb conditions leaves

a patient with increasing disability that can worsen over time,⁴⁰ reducing independence and leading to reliance on caregivers and the social care system.

Poor quality of life

Lower-limb conditions can deeply affect patients' quality of life¹⁰⁻¹² and can lead to feelings of isolation and mental health problems. Around 30% of patients with a chronic wound show signs of depression.⁴⁴

Prevention: a key to the way forward

The key to successfully managing lower-limb conditions is identifying problems early and treating them properly in order to stop them from becoming more serious.⁴⁰

In the current system, there is no pathway for formally detecting venous disease at an early stage. If these conditions are not identified, they are not able to be appropriately managed and treated. If untreated, they are likely to worsen; for example, mild venous congestion can lead to oedema, which could progress to a leg ulcer before the patient is provided with any form of management or treatment.⁴⁵

Early signs of a lower-limb problem can be obvious to the patient. As well as swelling and pain, symptoms can include itching or redness of the skin.⁴⁵ Skin changes caused by venous insufficiency are associated with an increased risk of developing an ulcer. Addressing the underlying condition at this early stage can help to prevent progression. Where there is no specific service for venous conditions, nor multidisciplinary teams available for the treatment of venous disease, these early signs are often not addressed.⁴ Vascular and dermatology departments can have long waiting lists, during which time the leg may have deteriorated.³⁶

As well as preventing venous leg ulceration from developing, it is also essential to prevent these wounds from recurring. This consensus panel agrees with other experts, who believe that ulceration of the leg and foot should never be considered 'healed', but be considered to be 'in remission'.46-48 This is an acknowledgement that the problems which have led to the development of an ulcer are a life-long condition for the patient, needing life-long care. The aim of care should be to maximise the number of ulcerfree days (increasing the number of days in remission).47

The reality today is that over three-quarters of people who have had a VLU will go on to develop another ulcer within 3 years.⁴⁹ In practice, this consensus panel observes that patients who progress to a 'healed' VLU are often discharged from care.

Recurrence is an ongoing problem for patients who have experienced a DFU, with over a third of patients having a recurring ulcer within 1 year.⁵⁰ Evidence shows that

RED FLAGS IN THE LOWER LIMB

Patients with the following red flags should NOT be given compression but SHOULD be urgently referred to the relevant specialist:

- Acute infection of the leg or foot (eg, increasing redness, swelling, pus, pain, heat)
- Acute or chronic limb threatening ischaemia
- Suspected deep vein thrombosis (DVT)
- Suspected skin cancer

All other patients should be eligible for at least mild compression (intended to apply around 20mmHg or less at the ankle).²⁴

making treatments and services available can effectively prevent these ulcers from recurring. Examples include ongoing compression²³ or off-loading.²⁵ Participation of 'healed' patients in care pathways aimed at prevention or early warning of recurrence are likely to be beneficial in reducing recurrence.⁵¹

Have we, inadvertently, created a toxic culture?

This consensus panel observes that patients with lower-limb conditions are often met with apathy among general healthcare providers. We believe that some of this stems from a perception among healthcare providers that problems associated with the early stages of lower-limb conditions (eg, ankle swelling or skin tears) are minor nuisances and are therefore left untreated. This lack of early treatment can progress to conditions which fail to heal in many patients. This apathy is also partially due to system neglect. The profile of chronic conditions of the lower limb is much lower compared with other problems such as pressure ulcers, diabetes or obesity, with no major incentive to improve the system. Where there is no ready pathway for a patient to follow, it becomes difficult for a healthcare provider to help the patient access the care they need.

At a managerial level, there is often a general lack of responsibility and accountability in this area. We notice that delays, whether for accessing assessment, diagnosis or the correct treatment, are part of the 'normal' practice and are not seen as important enough to raise concern. We also see a lack of specialist knowledge; complex conditions are all too often being improperly managed by generalists. The approach to leg ulcer management is often variable, with best practice not being sustained. Where there are local leg ulcer specialists, they may not have the autonomy required to address or improve the system. This is exacerbated by poor clinical leadership, a culture of task-working, and outdated local policies that do not deliver results. The attitude being,

as long as a local policy is followed, then all must be well.

The Francis report, set up to explore the reasons for failures at an NHS trust, identified "a culture focused on doing the system's business—not that of the patients" and that there was "too great a degree of tolerance of poor standards and of risk to patients." This still seems to be the case with lower-limb care in many places around the UK. Blind adherence to systems and protocols that are not fit-for-purpose can potentially lead to patient harm and neglect.

Caring nurses who follow inadequate local protocols may unwittingly harm their patients by failing to achieve good outcomes.

Adherence to protocols is seldom monitored, so there are rarely any record or consequences for poor delivery of care.

Although many individuals in the healthcare system recognise these problems, there is little appetite to do anything about it—we want to challenge these levels of apathy. Changing the behaviours and attitudes of the healthcare providers, and the way services are designed to meet the needs of the patients, is essential to create quality healthcare services in relation to lower-limb conditions.⁵

A lack of measurement and diagnosis

A key obstacle to good outcomes in lower-limb conditions is the lack of measurement. One major problem with lower-limb conditions is that baseline information is not collected in a formal and system-wide way. Two exceptions are PAD and diabetes-related neuropathy (but not ulceration), which are both included in the NHS Quality and Outcomes Framework, meaning that medical practices in some parts of the NHS are rewarded for formally capturing basic information about these conditions.⁵³ For PAD, all that is currently required is a register of affected patients, their smoking status and whether support to stop smoking has been offered. This consensus panel believes this information is only the beginning with much more data needed.

Lack of formal and systematic measurement has the potential to create a blind spot, with caring healthcare professionals potentially wasting their time providing ineffective care. With no means of measuring progress or deterioration, there is no way of telling the difference between effective and ineffective treatments. There should not be any reason to prevent regular and objective monitoring of the wound being conducted. If a patient's rate of healing falls below the expected standard, a referral to a specialist service should be triggered immediately. Outcome data should be measured both at the patient level and also on a system level in order to test how well the system is working.

We can't over-emphasise the importance of compression in the management of the lower limb. There are cases where compression has been removed because of a widespread misconception relating to the measurement of ABPI.

There is a belief that patients need to have had their ABPI measured, with repeat ABPI assessments every 3–6 months, for compression to be applied. There is no substance or evidence for this reasoning. Compression should not be removed merely because a recent ABPI measurement isn't available. At best, this can waste nursing time and resources: at its worst, it may deprive a patient of gold-standard treatment. There is a growing understanding that the benefits of mild compression outweigh the risks, even in people with no obvious signs of venous insufficiency.^{24,54} Recent guidelines published by the National Wound Care Strategy (NWCS)²⁴ support the widespread use of mild compression, provided the following red flags (see box on page 14, 'Red flags in the lower limb') are absent. In this instance, mild compression is defined as a compression system intended to apply around 20mmHg or less at the ankle. When an ABPI assessment is not available or possible (eg. in a swollen limb), a clinical assessment should be undertaken. Guidance and assessment tools are available from the British Lymphology Society (BLS) to support safe decision-making.54

A lack of wound measurement can also mean a lack of an accurate diagnosis. In the UK, up to 30% of patients lack a confirmed diagnosis for their wound.² This means the correct treatment option is unknown. Cellulitis is also often misdiagnosed and gets confused with acute lipodermatosclerosis due to venous hypertension; around a third of patients admitted to hospital for the treatment of cellulitis are incorrectly diagnosed and did not require to be admitted.²⁰ Many hospital admissions and associated costs may therefore be avoided through improved attention to differential diagnosis.

Without measurement, knowledge of a patient's condition is vague at best, with diagnosis and treatment compromised. Above all, the system's ability to monitor the success or failure of services is compromised. We think there needs to be nation-wide awakening to these problems.

While reviewing the management of lower-limb conditions in the UK, this consensus panel has identified many areas where we believe the status quo is not acceptable. Things need to change not only to enable patients to access the care they deserve but also to support healthcare professionals in improving their skills in the management of lower-limb conditions.

SECTION 3: SEEING THE GLASS HALF FULL

WE CAN SOLVE THE LOWER-LIMB CHALLENGE

Although much work needs to be done, the good news is that effective instruments are already available to use (national strategies, local data, measuring tools). Listening to patients and treating them as partners in their care would help us save time, money, and unnecessary pain, as would a national policy directing care for lower-limb management. This section summarises a few actions that can help solve the culture challenge across the NHS.

How you can solve the measurement challenge Chronic oedema/lymphoedema and PAD

There are simple solutions that can be developed to tackle a lack of measurement in this area within a matter of weeks. By recording and collating episodes related to these conditions (for example, cellulitis, patient disability, quality of life, hospital admissions, ulceration or repeat ulceration, and duration of ulcer remission), patterns will emerge over time, suggesting success or failure of your service. Local data relevant to your service can then be used to drive real change.

When treating patients, encourage awareness that their condition is not normal. Discourage a "wait and see" approach. Listen to what your patient is telling you and take this seriously—they know when their legs and/or feet are painful, swollen, heavy, and affecting their function and mobility. Patients also know how pain affects their ability to exercise and conduct activities of daily living. Encourage people to read possible side effects of medications in case these are implicated. Use patient-reported outcome measures to monitor how quality of life and the ability to function and mobilise are affected. Many patients can become confident in simple measurement and monitoring of their condition, and feel empowered by being involved.

Some other solutions may rely on new services being developed that provide continuity of care for these patients. Only when patients are kept 'in the system' will outcomes be gathered in the longer-term.

Leg and foot ulcers

In the NHS, there are hundreds of policies directing care for VLU alone. Instead of relying on so many different policies, this consensus panel recommends that a single national policy, such as the NWCS, be implemented. This could drive consistency across the country, regardless of the team providing treatment, and improve standards of care.

Integral to the NWCS is the capture of metrics to

IMPROVING MEASUREMENT: THINGS TO CONSIDER

- Can you implement a national strategy (eg, NWCS) instead of relying on local policy?
- Are you waiting for IT systems to start talking to each other? Don't wait—devise your own way to collect the data!
- Local data should be the minimum standard to aim for. You don't need to reinvent the wheel your commissioner support unit should have a lot of basic data which they can share on request
- Make sure your data includes ALL relevant patients. Don't let any fall through the gaps.

measure quality improvement.²⁴ The key metric in wound management is the change in wound size over time,24 with others including changes in the quality of the wound bed, limb swelling, pain, and the condition of the skin.²⁴ In practical terms, these metrics need to be measured and recorded regularly for every patient—the NWCS suggests every 4 weeks. The data collected need to be regularly collated and scrutinised to spot trends, problems and successes. For an individual patient, the benefits of regular measurement may be significant: in some parts of the UK, many services automatically refer a patient for specialist tissue viability services if the rate of wound healing does not meet a pre-defined minimum standard. The NWCS suggests patients who have not shown 'significant progress' within 12 weeks should be escalated to a specialist service, where they can receive the highest quality of care and the best chance of an excellent outcome. Regular and detailed measurements are required to enable these kinds of services.

There are other measuring tools available specific to VLU, but many have serious limitations. For example, Commissioning for Quality and Innovation (CQUIN) is optional, only applies to England, is limited to community

CAN WE HARNESS PATIENT EMPOWERMENT?

In the future, patients may be able to log their own outcomes independently from their healthcare providers via a dedicated smartphone app. The benefit of this would be to be able to have patients keep track of their outcomes even if they have been discharged from a service. This consensus panel envisages an app for wound care, like the COVID-19 app, that could measure ulcer-free days, pain-free days, and other wellness indicators that can be logged in by the patient themselves.

services, has a time duration, and only covers leg ulceration. Use of this system would allow the care of lots of patients to fall through the gaps (including those treated by GPs, in nursing homes or in outpatient clinics).

The National Diabetes Footcare Audit (NDFA, England and Wales) is an excellent tool that can be used to audit outcomes in patients with diabetes.⁵⁵ This audit enables all diabetic foot care services to measure their performance against NICE clinical guidelines and peer units, and can be used to monitor adverse outcomes for people living with a diagnosis of diabetes who develop foot disease. Currently, 27,700 patients in 221 specialist foot care services are being tracked through this audit.

Services in Scotland can be monitored using the Scottish Care Information – Diabetic Collaboration (SCI-DC) tool, which provides data for national and local audit programmes.⁵⁶

Solving the culture challenge

The need for a change in culture and the link with improved care has been identified before in the NHS. In 2013, the Francis report called for the "NHS and all who work for it [to] adopt and demonstrate a shared culture in which the patient is the priority in everything done".⁵⁷ This consensus panel believes that some of the recommendations from the Francis report are directly applicable to the care of lower-limb conditions and still need to be applied in this area.

Commissioners (England only)

The Francis report stated: "Commissioners should be the drivers for improvement in services" and "should aim to set standards over and above the minimum and should tackle non-compliance with these contracted standards".⁵⁷ Some of the challenges in lower-limb care can only be addressed by commissioners acknowledging problems which exist with current patient pathways and taking

action to address this.

The Francis report set out the important role that GPs should have in monitoring outcomes on behalf of their patients who go on to receive care and treatment in an acute hospital and other specialist services. This consensus panel considers this is particularly true in lower-limb conditions where treatment pathways are not always clear, and a patient's main point of access is often their GP. Robust internal systems are therefore needed to enable the monitoring of clinical outcomes.

Service providers and healthcare providers

Listen to your patients and address their needs and preferences. Patients respond better if they feel they are partners in their care.⁵⁸ Healthcare providers need to communicate properly with the patient in order to understand reasons for non-compliance to address any issues or concerns.

This consensus panel believes motivation through fear is common practice in nursing. This culture is not healthy and should be tackled. Those with line management and mentoring responsibilities should consider their approach to managing their staff. Are people afraid to make a treatment decision based solely on the patient's needs? Do you allow them to make such judgement calls?

One special plea to healthcare providers is not to be afraid to apply at least mild compression. Make mild compression, not crepe bandages, your first choice. Avoid

IMPROVING THE CULTURE: THINGS TO CONSIDER

- Listen to your patients. Treat them as partners in their care
- Identify the barriers preventing delivery of effective care
- Many specialists and generalists are involved in lower-limb care. Invite your colleagues (physical therapists/physiotherapists, podiatrists, tissue viability nurses and orthotists) to collaborate, share skills and pool resources
- Don't allow stagnant hierarchies to get in the way of change. Challenge the blockers
- Remember: the first principle in healthcare is to cause no harm, not to protect yourself. Never be afraid to do the right thing by your patient. A good way to start is to revisit your compression policy
- Recognise and apply the values of transparency, honesty and candour.

the red flags (see box on page 14, 'Red flags in the lower limb') but for all other lower-limb patients, the benefits will outweigh the risks.²⁴

Outcomes from motivated and empowered patients can be hugely significant. Patient activation measures (PAM) can play an important role in identifying a patient's capacity to self-manage, allowing programmes to be tailored to a patient's capability. Treatment can then be seen as a joint initiative between patient and caregiver.³⁷ Another way to motivate patients is to develop community leg clubs, which are non-medical, social, self-help environments. A good example is shown in the experience of the Lindsay Leg Club.58 Initiatives like these can empower members to take a sense of ownership and involvement in their own treatment, act as an informal support network as well as providing continuity of care and a coordinated approach of delivery,36 These clubs can also be an ideal opportunity to encourage and monitor patients who are between episodes of ulceration, without them needing to be fully enrolled in an active management program,36 as well as acting as quick and easy referral points for GPs when presented with chronic lower-limb problems.

Solving the challenge of implementing best practice

First, look at what the evidence tells you. Some of the burden of lower-limb conditions can be avoidable or reduced if appropriate care is started early on. Lower-limb problems end up being more expensive to treat if they are not managed properly in the first place.

Best practice in chronic oedema/lymphoedema and venous leg ulcers

Managing lymphoedema before complications (such as cellulitis) arise is a massive potential opportunity. Treatment can be effective; nearly 80% of patients actively treated for lymphoedema had it under control, compared with only 29% of those who were not offered treatment.¹⁹

Studies have also shown how £1 spent on lymphoedema can save £100 through the prevention of hospital admissions. There needs to be a push for improved treatment of lymphoedema in anyone with this condition.

Where chronic oedema is caused by venous insufficiency, there are various different treatments that can correct or treat this condition. These range from compression, to drug treatments (vasoactive therapies) as well as surgical options, including keyhole varicose vein treatments and the placement of deep vein stents.⁴ The key to these effective treatments is getting patients access to

specialist vascular services. If these services were to be commissioned, the risk of venous leg ulcerations could be massively reduced and the benefits for patients could be enormous.⁴

Where a VLU has developed, the cornerstone treatment is compression;⁵⁹ with this treatment, over 90% of leg ulcers can be healed within 24 weeks.⁶⁰ A realistic and achievable goal is to make sure that compression is provided to every patient who would benefit from it. High rates of patients being treated with compression is expected to reduce the overall number of people with ulcers in the area.⁶¹ If they have trouble with their compression, patients and healthcare providers need to work together to find a way to make it tolerable and effective.

More can be achieved by taking a multi-faceted approach. The surgical and medical treatments described above can improve healing rates by addressing the underlying problem. This approach is proven to be cost-effective.⁴ Clinical studies have shown that patients with VLUs who have surgery to correct the problem with their veins and are also given compression treatment have fewer recurring ulcers than those treated with compression alone.²⁶ Experts throughout Europe largely agree that these combination strategies are likely to be more effective than relying on compression alone.⁵⁹

Peripheral arterial disease (PAD)

Patients with PAD should receive the best medical management in line with NICE guidelines, focussing on blood pressure and blood glucose management, and including statin treatment and antiplatelet therapy. This reduces their overall risk of cardiovascular events such as heart attacks and stroke. Patients should be supported to make some lifestyle changes, including, smoking cessation, improving their diet and increasing physical activity. To support these changes, several different services may need to be integrated. As well as clinicians involved in the medical management of their disease, patients will also need access to podiatrists, dieticians, supervised exercise programmes and smoking cessation programmes. One pilot-integrated pathway designed to coordinate these services in patients with PAD saw several short-term benefits, including the severity of their claudication and in their quality of life. 62 Exercise is particularly important in managing patients with PAD, including intermittent claudication, and is a first line treatment recommended by NICE. This includes 2 hours of supervised exercise a week for a 3-month period.30

Despite this recommendation, the provision of supervised exercise programmes is poor in the UK with only 42% of vascular services able to refer patients into these services.⁶³ These supervised exercise services may already exist for other groups of patients (eg, cardiac rehabilitation

services) and it may be relatively easy to expand provision to include patients with PAD by using the skills, staff and facilities already in place.⁶⁴ Patients given access to supervised exercise programmes have shown improved daily physical activity compared with other option,⁶⁵ with a noted reduction in symptoms.⁶⁴

Diabetic foot ulcers

Many people living with a diagnosis of diabetes in the UK are fortunate, by comparison, as there is greater access to multidisciplinary services, routine check-ups and preventative care.

The Royal College of Podiatry has advice for commissioners on how to improve existing services,³⁵ with part of these services being an integrated foot care pathway. Many examples of integrated care being delivered in ways that suit their patients have been published in the UK.^{62,66,68} Early intervention has been shown to be cost effective.⁷⁰ It is up to all to ensure these services are being accessed by every patient who is eligible. Any barriers that stop patients from accessing this service needs to be identified and siloed services

overcome. This extends to patients with non-diabetes-related foot ulcers who may currently be denied access to the multidisciplinary service that a patient with a diagnosis of diabetes can access. It may be a quick win to expand this service to include other groups of patients.

Guidelines on the prevention and management of diabetic foot problems have been set out by NICE.²⁵ A cornerstone in the management of DFUs is off-loading. Although this area is notorious for "non-compliance" in that patients don't typically like wearing their off-loading device, giving patients more control over the choice of off-loading device is a way of putting their preferences at the heart of treatment decisions and potentially improving outcomes.

This consensus panel believes commissioners, healthcare providers and industry leaders all need to embrace the need to make changes, but that existing beliefs or institutional setups are getting in the way of action. Before the system can change, some common misconceptions must be debunked. The next section spells these out, as well as the potential for change.

SECTION 4: TEST YOUR THINKING

Commissioners, service leaders, and industry all need to collectively embrace the need to make changes. But before the system can change, some common misconceptions must be debunked.

COMMISSIONERS

This consensus panel has listed a number of potential common beliefs, which may exist among commissioners. We invite you to consider how they reflect the services that you commission. A series of questions appear underneath each belief to challenge them. Find out what your service actually looks like, and what the potential for change is. Does this resonate with you?

☐ Is your evidence truly reliable? ☐ Do you commission a lower-limb service for ☐ Does your service measure and report chronic oedema/lymphoedema? patient-outcome data and healing rates? ☐ Does this service accept non-cancer patients ☐ Are you aware of the savings your service is and patients with a BMI over 35? ☐ Do you commission a lower-limb service for making? diabetic foot ulcers? ☐ Do you believe that all patients with lower-limb wounds are managed by nurses ☐ Is this multidisciplinary led? or podiatrists using evidence-based guidelines? ☐ And is it able to see patients within 48 hours? ☐ Do you commission a lower-limb service for neuropathic foot ulcers? ☐ Do you commission a service for people with non-diabetic foot ulceration? ☐ Do you commission a specialist leg ulcer ☐ Do you understand the true cost on lower-limb management service? in your area? Both direct and indirect? ☐ Does your service see new referrals within ☐ Do you understand how poor care in this area impacts on two weeks? every single measurable outcome you have within your ☐ Has the service got the right skills to make a commissioning services (eg, obesity, mobility, mental health)? differential diagnosis? ☐ Do you truly understand the cost of doing nothing—the cost ☐ Does your service assess for correctable of the status quo? venous disease? ☐ Do you fully understand the level of transformation that can ☐ Do you know that patients are entitled to be achieved with focus on lower-limb management? compression stockings for life? ☐ Are you aware of the potential savings (both human and ☐ Is prevention of ulceration in the remit of economic) your service could make? your service?

THE CASE FOR CHANGE

Some simple and attainable steps could transform your service into one that truly works for patients with lower-limb conditions:

- Question how you commission your lower-limb service.
 Is it hidden in a block contract? Are you able to measure the benefits it brings to patients or to the system?
- Undertake a local lower-limb audit to fully understand
- the real opportunity for change
- Commission lower-limb services differently and in that, define and measure outcomes
- Invest in education as an enabler of change—the impact of this investment can then be measured in terms of the impact on patients' lives
- Create shared ownership by commissioning for collaboration across primary and community care.

SECTION 4: TEST YOUR THINKING

SERVICE LEADERS AND HEALTHCARE PROVIDERS:

The unfortunate reality is that evidence regarding lower-limb conditions is not good. The burden is enormous. Before change can be made, some uncomfortable truths need to be faced and a few common myths must be addressed. Your series of questions appear underneath each potential common belief for you to reflect on. Are your beliefs getting in the way of a quality service for your lower-limb patients?

I believe lower-limb care is not my job:

- My priority is pressure ulcers
- Lower-limb swelling is not my business
- Lower-limb amputation is only in the remit of diabetic foot ulceration
- ☐ Do you prioritise some conditions over others? How can this be done differently?
- ☐ Are you and your department delivering care for lower-limb conditions in detrimental silos?
- ☐ Do you pay any attention to prevention?
- ☐ Are departmental targets (eg, pressure ulcer targets) more important than each individual patient?

I believe my patients are often non-concordant

- ☐ Do you make too many assumptions when planning your patient's care?
- ☐ Are you listening to your patients—really listening?
- ☐ Are you acting on your patients' wishes?
- ☐ Are patients truly considered partners in their care?
- ☐ Do you hear an emphasis on blaming patients for the treatment regime not working?
- ☐ Where patients have been labelled as nonconcordant, is this ever discussed directly with them, so that they are aware of the implications?
- ☐ Do you believe that you may contribute to patient 'non-concordance'?

- I believe everything that could be done is being done:
- I don't have time to do any more
- Lam good at this
- The local guidelines are enough to ensure best practice
- We have always done it this way, so nothing's wrong
- ☐ Is your team only delivering 'transactional' wound care?☐ Are the guidelines working for your patients? Does your
- ☐ Are the guidelines working for your patients? Does your team believe they are enough?
- ☐ Are you following best practice correctly?
- ☐ By doing what you've always done, are you and your team actively blocking NHS transformation?
- ☐ Is your team really using time and products available effectively? How would you do this differently?
- ☐ Are you reluctant to challenge your managers and ask why the burden has to be this big?

I believe many leg ulcers won't heal, no matter what I do

- Harm-free care doesn't apply to legs and feet
- ☐ Could the provision of consistent compression therapy optimise your patient's treatment?
- ☐ Are you failing your patients by not making appropriate, timely referrals?

THE CASE FOR CHANGE

Some simple and attainable steps could transform your service into one that truly works for patients with lower-limb conditions.

- The foundation and evidence for change are already available within the guidelines of the national bodies
- Listen to your patients and make sure you understand their perspective; embrace patient activation
- Embrace a desire to change, provide clear leadership and invest time in creating structured change
- Don't be afraid of doing the right thing by the patient
- Undertake regular local audits.

SECTION 4: TEST YOUR THINKING

INDUSTRY

Industry leaders are recognised as a key partner when providing training, offering data and information, delivering bursaries for clinical staff, and funding research and development. Legs Matter would not exist without its industry partners, neither would many of the societies involved in lower-limb conditions. We are all united in agreeing that change is needed and believe that industry can be part of the solution. Below are a number of potential beliefs considered common among industry—you are invited to think whether these reflect your corporate beliefs. Ask yourself, is there anything your company can do differently to help your customers provide improved care for their patients? Does this resonate with you?

We believe all that matters is the bottom line

- ☐ Does your corporate vision include the patient perspective, and is this lived out in your sales and marketing strategies?
- ☐ Do you have an equal perspective towards shareholders, customers and patients?
- ☐ Do you recognise that good-quality, clinically effective and cost-effective products are easier to sell than ones that are not, and that a 'me too' is not an exciting alternative?
- ☐ Do you give true consideration to patient outcome measures and the individual patient?
- ☐ Do you have a balanced perspective with regard to the overall effectiveness of the product you are selling and the unit price of accessing that product?
- ☐ Are you working to be seen as a true partner rather than a partner with a hidden agenda?



We believe education is a waste of our time unless it is education specifically on our products

- ☐ Have you considered the 'value added' from providing a useful resource like impartial education? Your customers will thank you for your impartiality
- ☐ Are your educational programmes up-to-date and accurate?
- ☐ Are you aware that many of your customers lack the skills to persuade their colleagues of the healtheconomic benefit of your products? Should you consider how you could teach them these skills?
- ☐ Do you help customers understand the cost of bringing a product to market and the timeline open to recoup investment?
- ☐ How aware are you of the gap in patient education? How could you, as a company, plug this gap?

THE CASE FOR CHANGE

Some simple and attainable steps could transform your company into one that truly benefits patients with lower-limb conditions:

- Be a reliable and impartial source of education for healthcare providers and patients who cannot access this anywhere else
- Teach healthcare providers business skills; provide them with tools that demonstrate the cost-effectiveness of your products, services and

- interventions
- Produce high-quality research that honestly reflects the capability of your product
- Truly care for the patients, the lives of whom your products most affect
- Help to give patients a voice
- Develop innovative products that address patients' and healthcare providers' unmet clinical needs, not just a 'me too' or an 'add on' to extend a product range lifecycle.

SECTION 5: WHAT'S NEXT?

THE CALL TO ACTION

The personal cost to individuals and the economic burden to the NHS is significant. This consensus panel believes there are some simple things that can be done immediately to begin the process of change. These are listed below.

Call to action for commissioners:

- Take advantage of the current national change to talk about the limb in its totality
- Understand what data and information you need to identify the gaps and to implement new services
- Understand the clear opportunity that will bring benefits to the system and to patients
- Recognise the opportunity for transformation commission lower-limb services differently and correctly
- Think laterally—you may need to take an alternative approach to commissioning in order to achieve a different result.

Call to action for healthcare professionals:

- Put lower-limb management on your agenda and commit to making a change
- Be brave. Don't be afraid to challenge the status quo. Realise your potential
- Recognise the constraints you experience, including those you impose on yourself
- Acknowledge there is an issue and work to recognise the problem by gathering evidence
- Break down the silos: work together with a common cause.

Call to action for industry

- Tell customers more about your company and the investment you make in supporting this specific area of care
- Work in conjunction with providers to influence commissioner decision-making in relation to service change
- Offer skills development in relation to change management to your customers
- Move away from overselling and focus on benefits realisation for systems, patients, the customer and you as the company... embrace the 'which means that' philosophy
- Work with healthcare professionals and patients/public to improve your products and the information provided.

THE BURDEN CAN'T BE IGNORED

- The costs of treating lymphoedema in England alone is almost £200 million per year¹⁸
- Prescription charges for lower-limb wounds alone cost the UK's NHS over £50 million per year²
- The cost of caring for patients with DFU in England alone is estimated at
 £837 million per year. This is equal to
 £1 in every £125 spent by NHS England³¹
- Leg ulcers cost UK's NHS around
 £2 billion every year²
- Cellulitis is responsible for over 400,000 bed days per year, resulting in annual costs to the NHS England in excess of £96 million²⁰
- PAD affects around 20% of people over the age of 60 in the UK; this equates to over 3 million people in the UK alone³⁰

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