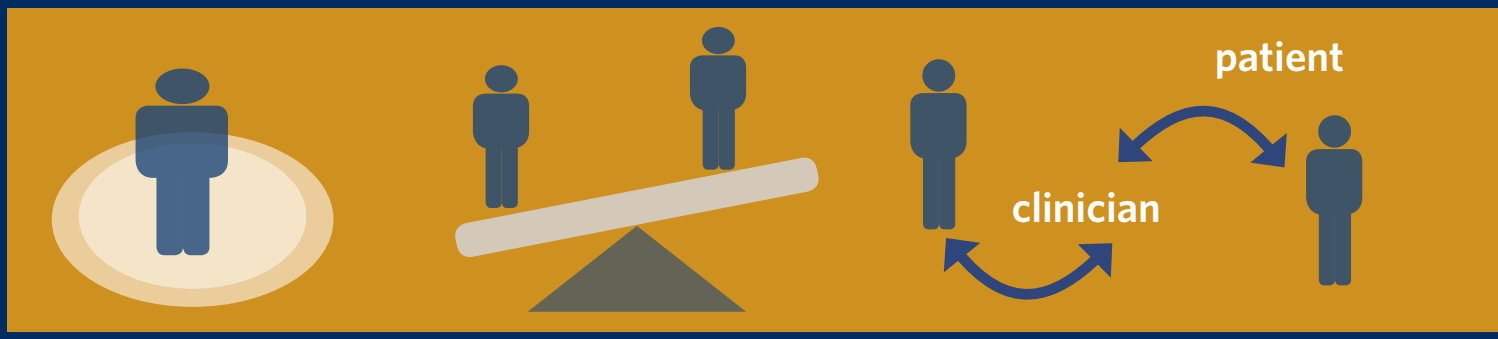
INTERNATIONAL BEST PRACTICE

BEST PRACTICE STATEMENT:

OPTIMISING PATIENT INVOLVEMENT IN WOUND MANAGEMENT



Wounds International

FOREWORD

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Living with a wound can lead to loss of independence or control; all individuals should have the chance to understand their condition, be involved in decisions about treatment and take responsibility for managing their wound where they are able to do so[1]. For this reason, an international group of wound care experts met in May 2015 to discuss the potential ways to empower, engage and support patients living with a wound.

The group acknowledged that to achieve a shift in thinking around patient involvement in wound management, a common, agreed understanding of its impact and its added value with a defined meaning is needed. Discussions centred on the current drivers for policy changes that encourage patient involvement in general and evaluated whether there are different levels of patient involvement, and how these can be best achieved for patients living with a wound. Initiatives that encourage patient self-management and the types of support that people might expect were also discussed alongside the potential impact patient involvement may have on the delivery of future healthcare services.

The conclusions reached form the basis of this document, which aims to provide best practice statements that offer practical guidance to clinicians to deliver services in a manner that encourages patients to be more involved in their wound care according to their ability, and encourages a meaningful shift in perception to build a deeper understanding of the concept.

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What is patient involvement?

Involving patients in their own care is a complex concept, but it is now widely recognised as a key component of a 21st century healthcare system

Encouraging a more active role for patients is referred to as **patient empowerment**, **patient engagement** or **patient involvement**. Despite extensive research, studies such as the 2012 Eurobarometer Qualitative Study[2] have shown that the concept of patient empowerment is not clearly understood by either patients or clinicians and often means different things to different people (*see* Box 1 for Key findings). It is often perceived as meaning 'following doctors' orders' and is more often than not seen as unidirectional, with patients providing clinicians with factual information about their symptoms, and less widely perceived to include a more interactive two-way dialogue or an opportunity for patient feedback[2].

The term **patient involvement** is the preferred term selected by the expert group and was defined as follows:

- For patients, it means being active in the management of their own health and health care, and in any decisions made about available treatment options
- For clinicians, it means knowing who their patients are and developing a partnership that facilitates a transparency of information for both parties.

As such, patient involvement is considered to be wider than the concept of 'shared decision-making', and to encompass approaches and interventions that enable patients to participate in care planning over time and influence how services are delivered, rather than just being a passive recipient of the services provided.

The degree of patient involvement is highly dependent on a number of factors, including patient beliefs about their illness and a willingness to enter into this way of thinking about their care.

Patient involvement aims to improve a person's capabilities to self-manage their condition effectively, but should not be considered synonymous with the concept of self-management. Many patients are able to understand their condition and be involved in decisions about their treatment, but are not able to take full responsibility for monitoring and managing their condition. Encouraging patients to be involved in their own care is said to encompass three main overlapping aspects: patient autonomy, patient rights and health literacy (Figure 1).

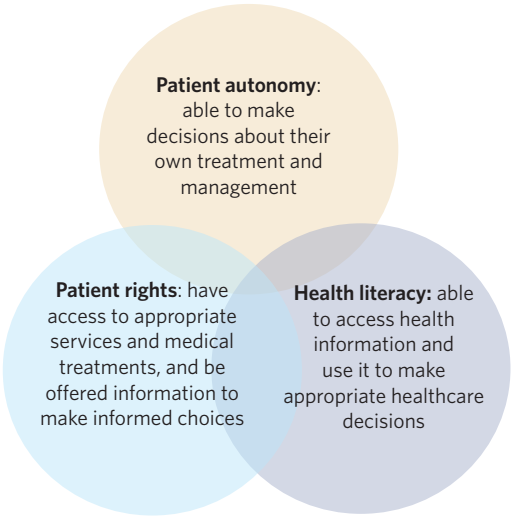


Figure 1: The three overlapping aspects of patient empowerment (adapted from[3])

Success is based on the ability of the patient or caregiver to understand basic health information and to use it to make informed decisions about their healthcare[4] (Box 2). This requires patients to have access to appropriate advice and for clinicians to be able to offer information or direct patients to appropriate sources that are patient-friendly and can support decision-making (see Supporting patient involvement through education, page 10).

Studies have shown that patients with a higher level of education, those with a greater healthcare experience (e.g. previous treatment) and patients with chronic disease are more likely to see themselves as having responsibility for their care and so will be more actively involved[2].

Ultimately, patient involvement aims to encourage patients to make decisions about their health and manage aspects of their care, where appropriate, with the rationale that it will help maximise their health and wellness, and contribute to greater satisfaction with their care[5].

BOX 1: KEY FINDINGS OF THE EUROBAROMETER QUALITATIVE STUDY FOR PATIENT EMPOWERMENT[2]

- Patient empowerment should be a fundamental part of effective healthcare reform
- Patient empowerment means different things to different people
- Communication is central to patient empowerment, however, the main barrier to effective communication is the limited available time a clinician has to spend with the patient
- Patients need time to ask questions and understand how the decisions about their care are being made
- Currently, patient empowerment remains a 'feel good' initiative rather than one that is widely accepted

BOX 2: A HEALTH LITERATE PERSON IS ONE WHO[4]:

- Can think things through and make health choices to solve his/her own problems, as well as those of family members
- Is responsible and makes health choices that benefit him/herself and family members
- Is in charge of his/her own health learning and teaches family members to do the same
- Can use communication skills to express needs, questions and concerns to healthcare providers and staff

Why is patient involvement a priority?

Strategies that engage, support and empower patients are vital to the sustainability of healthcare systems worldwide

There are increasing numbers of people living with a wound, due in part to an aging population and a rising prevalence of obesity, diabetes and other long-term conditions[6].

Traditional healthcare systems have been unsuccessful in stemming the growth of chronic disease; at the same time, health and social care budgets are under increasing pressure, creating tension between resource availability and demand[7]. Providing high-quality care in austerity means that difficult choices have to be made about how money is spent. Indeed, if we are to reconcile supply with demand, fundamental changes will need to be made in the way healthcare services are delivered in the future[8] (Box 3).

There is an increasingly popular notion that patients will not be able to continue accessing unending health care for all their problems[9]. More and more, patients will be expected to self-manage, with a greater emphasis on individuals taking responsibility for their own health and adopting healthier lifestyles, with direct healthcare only provided to those in greatest need[9].

This expectation has been driven by a broad agreement that strategies and solutions that engage, support and empower patients are vital to the sustainability of health systems around the world and that these will lead to an improved patient experience, patient-centred service delivery, improved patient concordance with treatment and the potential for better outcomes[11].

The goal is to change the clinical paradigm from 'what's the matter?' to 'what matters to you?' The challenge, however, is agreeing how to put this into practice.

In practice, patient involvement is dependent on a number of key factors:

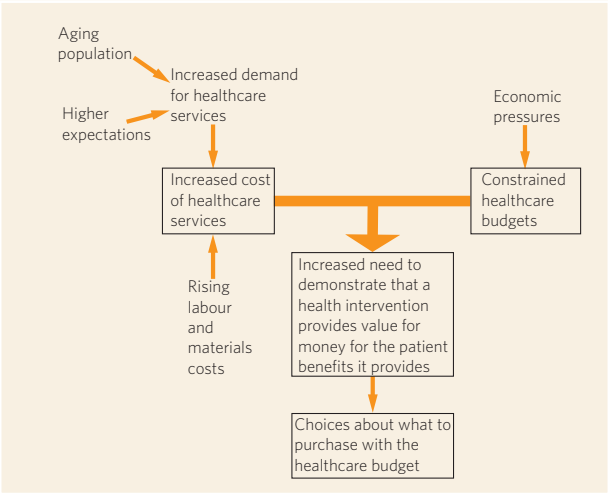
- Clinician attitudes towards patients in their care
- Patient expectations, which are often variable
- Availability of systems and resources to facilitate the move to greater patient involvement
- Need for outcome measures that encompass patient involvement.

While the idea of patient involvement is not new, more needs to be done to engage patients and their carers in the planning and delivery of care so they can be more informed and prepared to be involved in decision-making[4].

While patient involvement may be seen as reducing healthcare costs, this benefit may be short term only. The primary driver should be getting the treatment right for the individual, as this will support improved outcomes with the potential for more effective and efficient use of resources in the longer term.

BOX 3: RISING COSTS OF HEALTHCARE

- Challenges facing healthcare (see opposite) mean that choices have to be made about how money is spent[8]
- In 2013, global healthcare spend was estimated to have grown by 2.8% and it has been predicted to rise by an average of 5.3% per year between 2014–2018
- The US has the highest health spend in the world (17.6% of gross domestic product)
- Across Europe, healthcare is barely managing to cover its costs. According to World Bank figures, public expenditure on healthcare in the European Union could jump from 8% of GDP in 2000 to 14% in 2030 and continue to grow beyond that date[10] (Available from: http://bit.)ly/1KVvvCy)



WHY DOES PATIENT INVOLVEMENT IN WOUND CARE MATTER?

Worldwide, non-healing wounds are a substantial problem, with 1–1.5% of the population estimated to have a wound during their lifetime. This translates to 2–4% of the total healthcare expenditure in Europe being used in wound management, with an average of 6,000–10,000 euros spent on each patient per year[12]. In the US, it is estimated that the cost of managing wounds exceeds $50 billion per year[13–15]. In Australia, chronic wounds are estimated to cost the healthcare system AU$2.85 billion per annum[16].

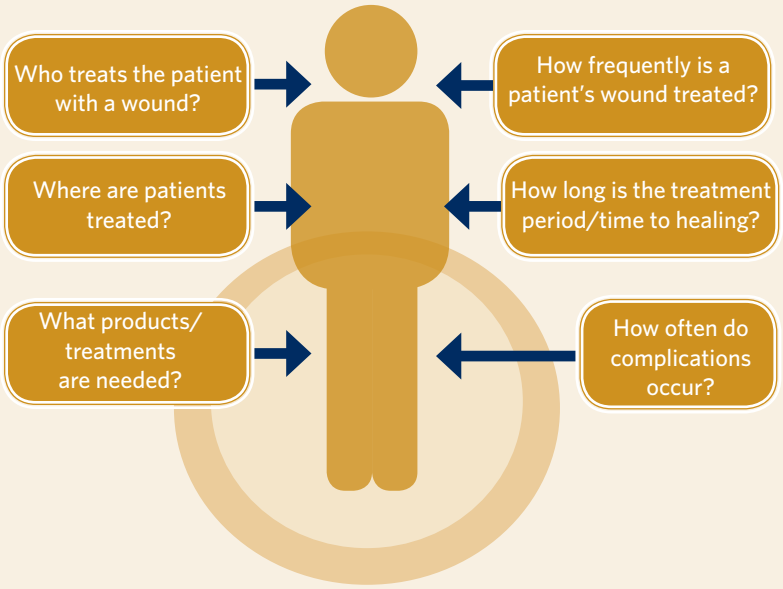
To balance the future cost of care, clinicians will need to be more proactive in their approach to wound care, adopting new strategies that empower and involve patients in their care, and have economic value[17].

The majority of costs arise in hospital, with 27–50% of acute hospital beds likely to be occupied by a patient with a wound[12]. As a result, means to help reduce healthcare costs are being considered with a shift occurring in the management of chronic wounds from the hospital towards community and home care settings[18] (Box 4).

Many patients with wounds living at home may feel isolated; they may have symptoms that affect daily living and be anxious about their own ability to care for their wound[18]. It is vital that good relationships, reinforced by effective communication, are built between the patient and/or caregiver and those who are delivering the care, particularly as patients may be supported by a number of clinicians rather than a single care provider[19].

Chronic wounds are a long-term condition that have a significant impact on people living with them. Compliance or concordance with treatment is often highlighted as a challenge to healing. Involving patients in their own care can help to self-motivate and give a feeling of control (see Best Practice Tip ☑).

BOX 4: KEY COST DRIVERS IN WOUND CARE (ADAPTED FROM [20])



☑ **INVOLVING PATIENTS IN THEIR OWN CARE**

This example is of a private wound care clinic (based in Canada), which provides short-term wound care support and long-term prevention/education for the management of lower-limb problems. When a patient presents with a wound, goals are established, costs and a care plan are discussed and a mutual agreement made. There is education and hands-on training for the care of the wound; a follow-up visit is made to see how the patient and/or family is progressing and if the wound is responding to treatment. Suggestions may be made to support the patient when appropriate. If the patient requires ongoing wound care and is not able to be involved/self-manage (alone or with the help of a family member/caregiver), the patient is often referred to a home care agency to prevent escalating costs and allow continuity of care.

Patient involvement in wound management requires the right patient having access to the right services and the right information, which will give them the knowledge and confidence to make informed decisions about their own care.

The degree to which patients are involved in their care has been shown to have a great impact on the quality of treatment, patient satisfaction[21], and can make a major difference to costs[11].

Key barriers to patient involvement

To make patient involvement a reality, healthcare services need to adopt strategies that enable patients to make choices and influence decisions that affect them

Many factors can act as drivers or barriers to ensuring patients are involved in their healthcare. Often this requires changes to how services are delivered and to roles — not only the roles of clinicians, but of patients too — and the relationships between patients and clinicians[11].

The historic, traditional relationship between clinician and patient was more of a paternalistic model, with all decisions based solely on the knowledge of the medical staff. In the patient-centred model, the focus is on two-way communication to support patient involvement. However, pressures on time often limit opportunities for effective communication; clinicians may not be able to adequately explain the different treatment options and patients may not be able to provide feedback[2].

Some patients may continue to perceive their relationship with a clinician as a traditional one where he or she should not be questioned — this may be particularly true where services are publically funded, or be due to cultural differences (see Best Practice Tip ☑).

Sometimes a patient's ideal might be to act with responsibility and make the decision about their healthcare themselves, but in practice they may prefer to leave the decision to the clinician, as they do not have the courage or confidence to decide themselves[22].

Alternatively, some clinicians may not want to relinquish their paternalist role and may feel threatened by an involved or engaged patient. Disputes may arise when a patient questions or disagrees with the approach advocated by the clinician[2]. This may make it difficult for a clinician to partner with a patient.

While not all patients will want to be responsible for decision-making; it is important for the clinician to keep an open mind about whether they are willing to be involved.

Being able to ask questions and understand how decisions are made is important, and for many, choice is a key aspect of patient involvement. Choice encompasses a range of issues including being informed about the risks and benefits of different treatments and what this may mean in terms of expected outcomes. Being unaware of which choices are available and how these can be delivered will impact on an individual's ability to make decisions about their care. When discussing these options, it is important to manage unrealistic or unachievable expectations and to explain why certain treatments may not be available or appropriate, which may be a difficult conversation to have.

For clinicians, a commonly cited barrier is that many believe they already empower their patients. However, the evidence shows that this is often not the case. It is important to equip clinicians with skills and knowledge to close the gap between what they believe patients experience and what patients say they actually experience[23].

Ultimately, individuals at all levels of the healthcare system, including both clinicians and patients, have a role to play in promoting patient involvement.

☑ **OVERCOMING CULTURAL DIFFERENCES**

Cultural differences may challenge a clinician's efforts to involve patients. Some patients feel it is disrespectful to say 'no' to a particular treatment plan, but discontinue it as soon as they leave clinic, despite having been given all the information they require at the consultation.

Hints and tips to achieve a therapeutic relationship

1. Establish the patient's level of insight into their specific wound problem
2. Establish the patient's expectations of the healthcare practitioner
3. Establish the level of social support the patient has
4. Outline the model of care employed, emphasising the central role of patient involvement
5. Establish the patient's willingness/ability to be involved in their care
6. Set realistic, achievable goals and establish good follow-up communication and support. Patients who are committed are more likely to follow the care plan

Tools for patient involvement in wound management

The most important tools to promote patient involvement in wound management are knowledge, skills and understanding

In wound management there are specific challenges associated with involving patients. There may be a tendency for patients to 'normalise' the 'abnormal' over time or to simply view their wound as part of the aging process. Others may not see their wound as a problem because they cannot see it or feel it, while others may be profoundly affected and feel socially isolated. Patients may also experience a loss of control, or have learnt 'helplessness' and like their care to be directed[24].

A recent international quantitative evaluation of 200 wound care patients and healthcare professionals, however, found the majority of patients and relatives in the study to be actively engaged in their wound treatment. Sixty-four percent of patients perceived themselves or 'their relative' to be the most important helper in taking care of their wound, while more than 90% of patients or relatives had a desire to know more, seeking information from one or more source to learn about their wound and wound treatment[25].

CAN ALL PATIENTS BE ACTIVELY INVOLVED?

Effective engagement of patients is not achievable unless they gain the necessary knowledge and skills and are educated about their condition[26]. Appetite for greater involvement may vary across different groups, and as a patient's condition progresses[27]. It is important to reassess beliefs about and capacity to self-manage over time to identify when health goals and care planning needs re-adjustment[28].

The ability of patients to be active participants may be dependent on their:

- Age
- Duration of disease
- Level of education and literacy

These factors have been found to affect a patient's readiness to make changes to their lifestyle[26]. Other factors may include the patient's mental capacity, cultural beliefs and attitudes and the type of decisions they need to make. However, it should not be assumed that just because someone is elderly, has a chronic wound and comes from a low socio-economic background, he/she is not able to be empowered[27].

DEVELOPING TOOLS FOR PRACTICE

The expert group agreed that patient involvement can be viewed as a series of simple steps:

1. Appreciate there is a problem
2. Know there is a choice
3. Accept the choice and know there is a benefit.

Identifying the problem and establishing the patient's ability to participate in decisions is fundamental to developing a therapeutic partnership. Doing so will facilitate discussion about management options and allow patient expectations to be managed[1].

Through discussion, the clinician needs to develop an understanding of patients as individuals (including dependence on others and access to support systems) and establish who is the first point of contact, and whether and how they would like their partner, family members and/or caregivers to be involved and to review this regularly[28].

The complexity of wound management differs between patients. Discussion needs to take into account the underlying cause, comorbidities and medications the patient takes, how long the patient has had a wound, its size and location, as well as any symptoms (e.g. pain, problems with exudate leakage or odour) that may impact on their wellbeing[30]. Symptom management, including pain control, may be an important contributing factor in patient involvment[1].

Identifying levels of involvement

Active involvement in wound management may not mean making clinical decisions, but instead having the ability to make the decision to use a particular dressing and be involved in decisions about when to change it. This may include deciding when to move from the chair to a bed at night or knowing when to seek help.

Recognition of what a patient or carer is able to take on physically is essential to the process. For example, if the wound is in an anatomical location that cannot be seen or reached by the patient, activities of self-

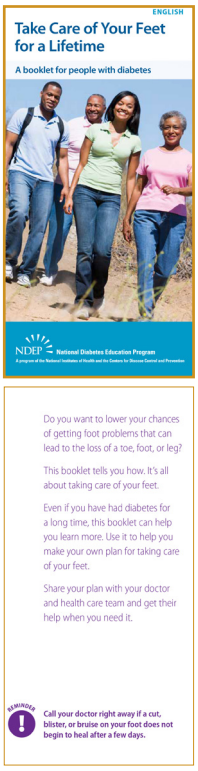


Figure 3: Patient information can support discussion about what the patient can do to help themselves

management may not be possible. Further, a patient who cannot see or feel their wound needs to be made aware of its presence to engage with decisions about treatment[31]. The clinician also needs to recognise that a patient will not adhere to a treatment plan if they do not perceive the wound as a problem[31]. Often being shown the wound (e.g. using a mirror or taking a photograph) and explaining how the wound arose in the first place can help in this process, aiding the patient's understanding of the importance of good wound care and prevention of further trauma[31].

Connecting care planning with patient priorities is central to ensuring their involvement.

A patient's priorities need to be established once a full assessment and diagnosis has been made. It is important that discussions are held in a manner that encourages patients to express their preferences and personal needs, as well as their fears and concerns[32], and to allow adequate time for this. The environment created should be conducive to discussion[1] and communication processes should also involve the use of open-ended questions. The Question Builder (Figure 2) can be used alone or with established health-related quality of life assessment tools to assess the impact of living with a wound and what patients can do to support their care.

When talking to patients, they should feel listened to. It is important to pay attention to how they are responding (e.g. actively listening or disengaged) to establish their readiness to engage and how much information to provide. Positive messaging should be used to motivate the patient[1].

Clinical expertise is important to allow patients to move past any fears and concerns, and to help patients understand what is involved in their care and what support they might expect to receive. For example, explaining to the patient how their care may change over time will help to avoid misunderstandings and a loss of confidence in their treatment[1].

Supporting verbal information using patient information leaflets or online education where available will help to reinforce key messages (Figure 3).

Figure 2: Question Builder: a discussion tool for identifying levels of patient involvement

Seek patient views and understanding of their condition	Identify any fears or concerns	Establish what is important to the patient	Assess patient willingness to be involved in their care
Do you understand why you have a wound?	What worries you most about your wound?	What do you want to achieve in the short-term?	What do you need to know about your wound and how to manage it?
What are you interested in learning about your wound?	How does your wound affect your daily living activities?	What do you want to achieve in the long-term?	What can you do to help heal your wound?
How do you feel about your wound (e.g. angry, anxious)?	How does your wound affect your personal relationships?	Is wound healing the main priority?	What are your living circumstances?
			Who else needs to be involved to help you manage?

Patient information should be based on what the patient already knows and focused on what they are willing to learn[33]. If they have already sought information (e.g. online), the sources used should be discussed, and for those who have been given poor information, any misconceptions should be dispelled.

Focusing on what is important to patients (e.g. controlling infection, reducing pain, getting back to work/engaging in social activities) can help to integrate clinical knowledge with patient preferences. It is also important to know what products are available (this may be cost driven where patients are purchasing dressings) and to be aware of what can be done within the clinician's scope of practice and current service provision. If something is beyond the clinician's own expertise, patients should be referred to a suitable specialist.

Developing a care plan in partnership with the patient will be influenced by whether:

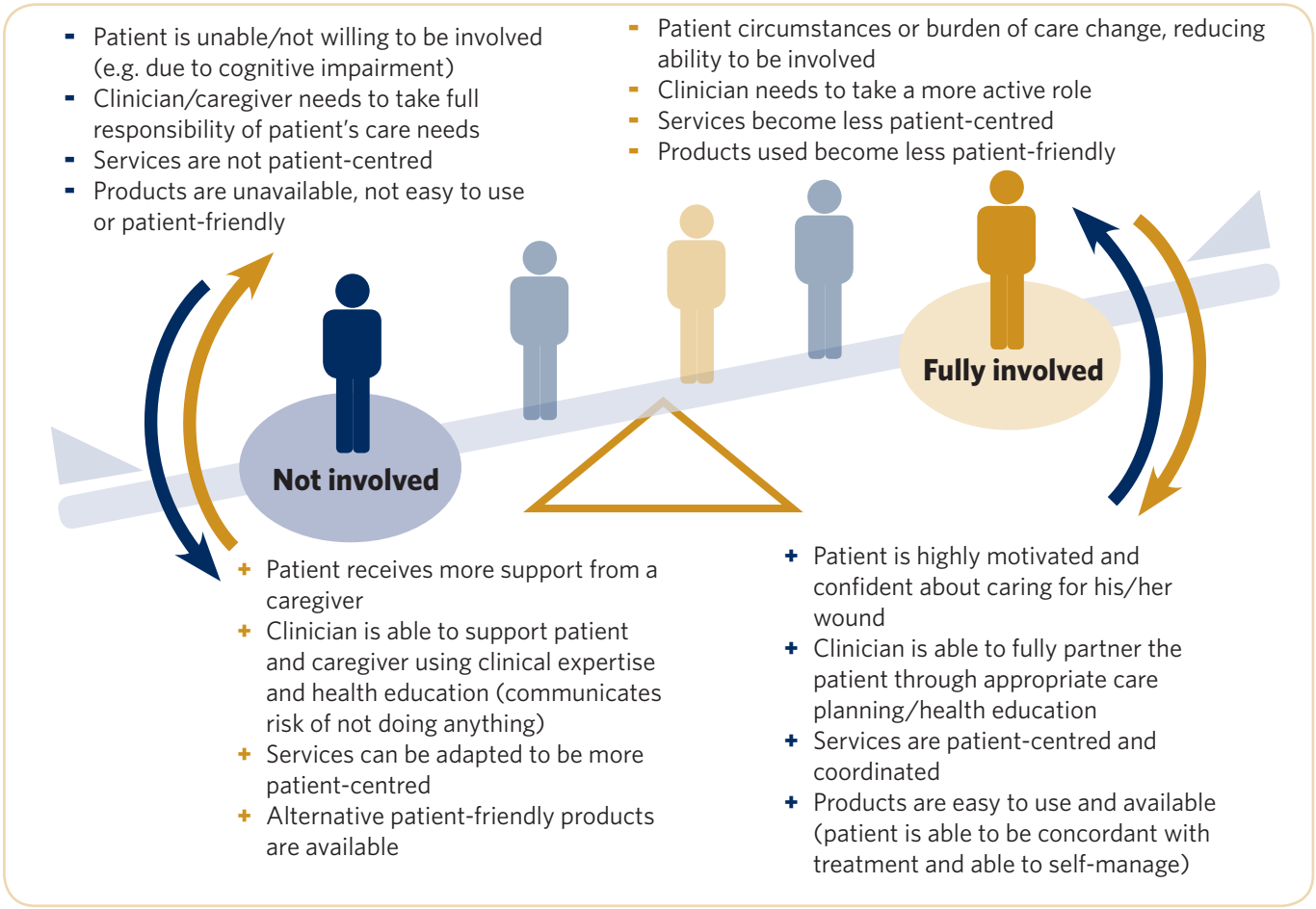
- The patient is interested in being involved
- The patient is interested but not able to self-manage
- The patient is not interested in being involved/not able to be involved.

Patient involvement in wound management is not a linear process; patients should be assessed at each review to ensure they are able to cope with care planning and delivery[34]. Further education or support can be provided, with opportunities for the patient to renegotiate their level of involvement (Box 5). Figure 4 shows how the levels of patient involvement may change over time, with the role of the clinician becoming less important as the patient takes on more responsibility, or increasing as the patient becomes less involved (e.g. due to advancing age or a decline in mental wellbeing).

BOX 5: LEVELS OF PATIENT INVOLVEMENT

1. **Fully involved**: the patient feels confident and is capable of monitoring and managing the wound on a daily basis, supported by regular visits to a clinician, and is able to make decisions about their care
2. **Shared involvement:** where the patient and the clinician have equal responsibility for the monitoring and management of the wound
3. **Not involved**: where the patient is passive or unable to take on responsibility of a wound and relies on others to make decisions about his/her care. This may be caregivers in collaboration with the clinician or the clinician alone

Figure 4: Positive and negative factors affecting ability of patients to be involved in their wound management



Where the burden of care affects patient or carer participation or where patients have been non-concordant with treatment, it is important to encourage them to get back on track and understand why they were not able to follow the agreed care plan. The key is to stay focused on the common goal to minimise the risk of patient failure[35].

Should a situation occur where the demands placed on the individual exceed his or her ability to meet them, additional clinical support may be needed to restore the balance[36]. This balance needs to be found when establishing how much support the patient needs and what actions need to be implemented.

Patients who are actively involved in their wound management tend to:

- Feel greater control over their wound management (decreased sense of helplessness)
- Have improved lifestyle/quality of life (better control of symptoms)
- Have a more realistic view of outcomes
- Have a better understanding of their treatment
- Feel listened to more effectively
- Feel a safe shift in responsibility from clinician to themselves[27].

In comparison, patients who are not actively involved in their wound management tend to:

- Feel overwhelmed with the task of managing their health
- Have little confidence in their ability to have a positive impact on their health
- Have previous experience of failing to manage their health
- Have reduced health-related quality of life
- Have become passive in managing their health and dependent on their clinician and others for care[37].

Although it may not be possible to involve all patients in their wound management, it remains important to:

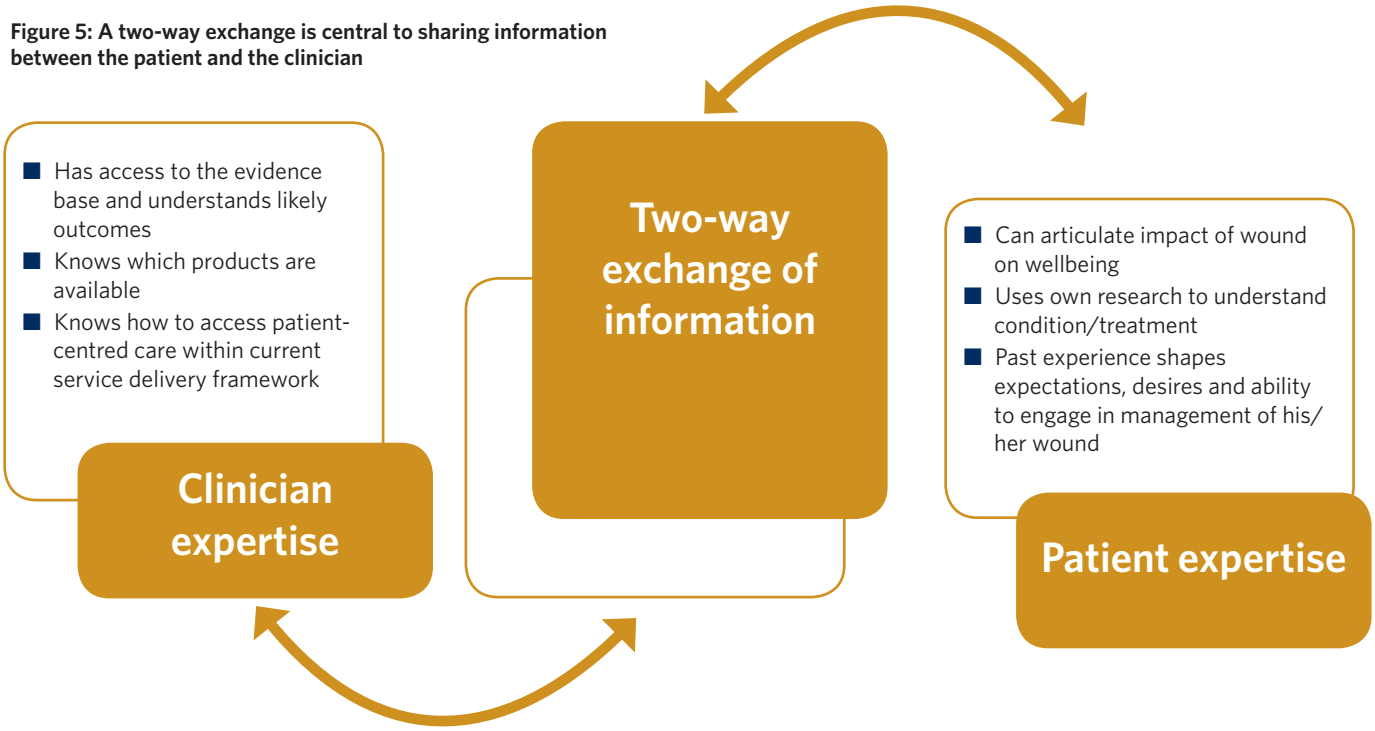
- Set realistic goals and document these goals for continuity of care
- Continue to motivate the patient through positive feedback and achievements
- Track and adjust care planning as the patient moves through the wound healing continuum — the level of involvement may increase over time (Figure 4, page 7).

COORDINATING CARE FOR PATIENT INVOLVEMENT

Living with a chronic wound often requires patients to have ongoing interactions with different parts of the healthcare system due to the presence of multiple comorbidities[12]. As a result, many patients with complex wound healing issues may have a high level of dependency and require a network of support systems that are coordinated[38].

It is important that all participants are knowledgeable about their roles and have access to systems that facilitate good information exchange[18]. This requires individual team members to take responsibility, without overloading the patient with too many decisions.

Figure 5: A two-way exchange is central to sharing information between the patient and the clinician



SHARED DECISION-MAKING

Shared decision-making is at the core of patient involvement in wound management and focuses on effective communication between the patient and clinician to prioritise treatments that best suit the patient's needs and expectations. Often this is an incremental process[1].

However, collaboration may be threatened by knowledge and power differences, and may lead to treatment failure and patients not adhering to recommendations[1]. Patients may feel overwhelmed by the changes they need to make to their lifestyle, and the clinicians involved in their care need to be prepared to listen and provide information that allows a decision to be made in partnership, although this decision might not always be one the clinician necessarily agrees with[27]. This requires a shift from a paternalistic approach to care towards a model that recognises the expertise of the patient as well as the clinician (Figure 5).

Shared decision-making can help to identify the best course of action[39]. As a part of this process, it is important that clinicians share information about alternative treatments, including any benefits and/or risks, while the patient shares information about their prior experience(s), goals, expectations and values.

The ability of the clinician to move the patient along the continuum of wound healing is essential and should include regular feedback and praise in recognition of what they have achieved, and review of healing outcomes to date.

Patients who are resistant to best care advice, for example, wearing lifelong compression therapy or taking measures to prevent ulcer recurrence, need to be made aware of what will happen if they do not wear the compression or take certain preventative measures. Patients who are still resistant to best care advice, despite knowing the consequences of doing nothing, should receive a structured education programme with frequent interventions using evaluated communication techiques[40].

Communicating healthcare risks effectively is challenging and can never be a one-size-fits-all approach. Consciously building a sense of partnership is the best way to overcome the patient's emotional resistance to considering difficult-to-receive information that the clinician is anxious to get across[41].

Supporting patient involvement through education

Patient education is key to enhancing patient competence

USING DECISION AIDS

Information that helps patients assess the potential advantages and disadvantages of different treatment choices, including any risks involved and how common they are, along with the likely success rate, can be enhanced by the use of decision aids. For example, this may be a simple pictorial representation to show the percentage risk reduction for amputation and 5-year mortality in patients with diabetic foot ulcers of those who wear offloading devices versus those who do not comply with treatment.

Decision aids can give patients confidence in decisions made and create opportunities to discuss different aspects of care, and why certain interventions are being considered[42].

Decision aids should be evidence-based, have specific aims and learning objectives, and meet the educational needs of the patient[43]. These can take the form of:

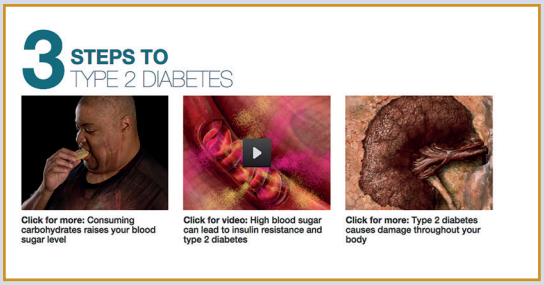
- Booklets
- Audio booklets
- Videos
- Computer or web-based interactive information.

Decision aids can be used by the patient alone, alongside their carergiver, or with members of the multidisciplinary team to help them make informed choices and determine what they want. Consideration should be given to optimising when and how the patient accesses decision aids or health information (see Best Practice examples ☑).

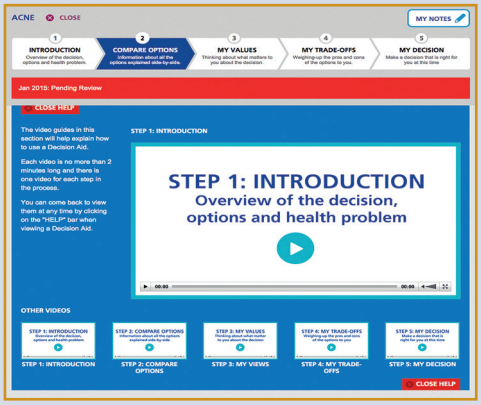
Selection of a decision aid should be based on the language they are available in and the user's ability to engage, and should take into account cultural, linguistic and literacy considerations. In addition, the patient's age and/or computer skills should be assessed as this may impact the decision to use printed, electronic or web-based information. Follow-up should involve discussion about the various options and agreement on how care should be delivered according to the final decision made (Figure 6).

The effectiveness of decision aids should be measured to ensure they present the information in a balanced manner, use up-to-date evidence, are easy to understand, and are effective for the patient. O'Connor[44] suggests that a decision aid should: help a patient realise that a decision needs to be

☑ DECISION AIDS TO SUPPORT PATIENT INVOLVEMENT

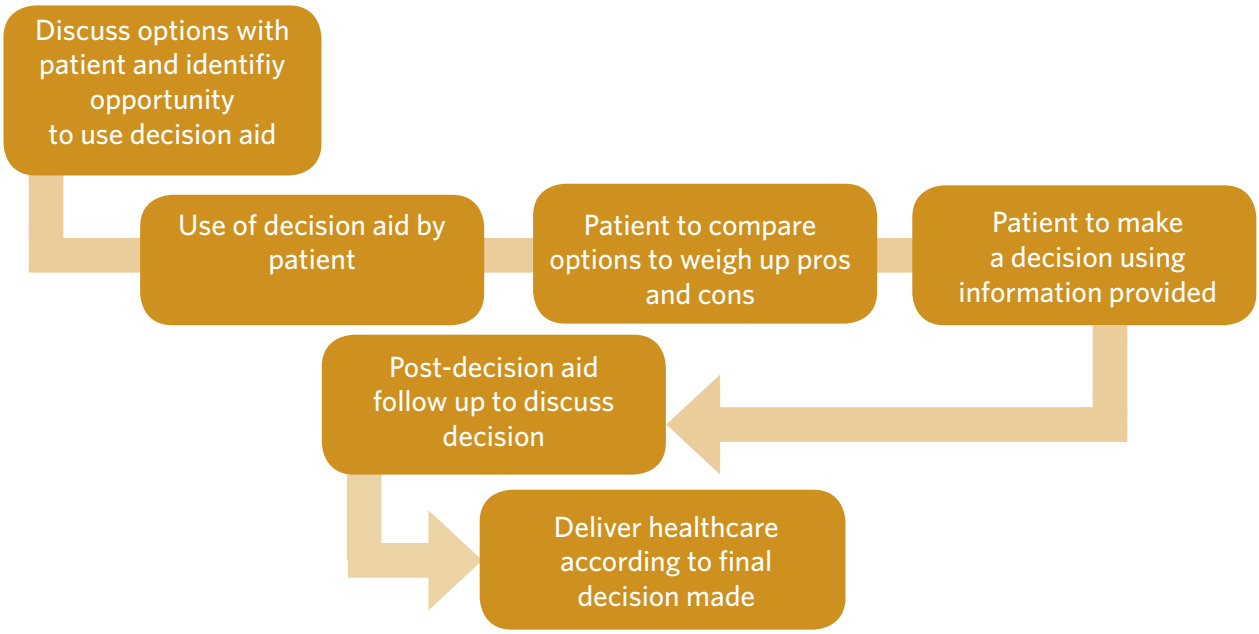


ADvaMedDX Type 2 Diabetes:
http://www.thevisualmd.com/advameddx/



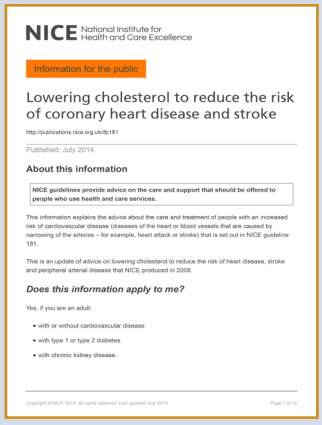
NHS English decision aids:
https://www.england.nhs.uk/our-work/pe/sdm/tools-sdm/pda/

Figure 6: An algorithm for using decision aids

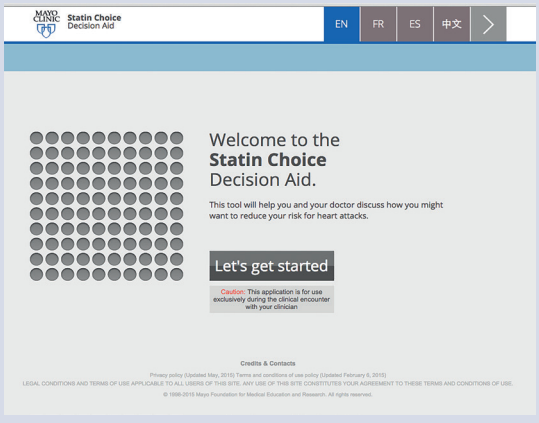


made; let them to know their options; allow them to understand that values affect the decisions made; be clear about the options featured that matter the most; and empower them to discuss these values with their clinician[44].

Evidence suggests that patients often overestimate the benefits of medical care[45]. This problem may be overcome by using clear, unbiased, evidence-based information at the point of decision-making. This can help to set realistic goals and manage expectations. Stacey et al[42] showed that the use of patient decision aids improved the decision quality with 13% higher knowledge, 82% more accurate risk perception and improved patient-healthcare professional communications[42].



NICE Decision Aids: https://www.nice.org.uk/guidance/cg181/resources/cg181-lipid-modification-update-patient-decision-aid2



Mayo Clinic statin choice decision aid: http://statindecisionaid.mayoclinic.org/

ADAPTING EDUCATION TO PATIENT NEEDS

Patient education needs to be delivered at a time of day when the patient learns best. In this example, the patient was given e-learning materials that required staff to sit with him; however, he would often fall asleep during the education sessions. A simple step of assessing the patient and changing the time of day for reviewing the e-learning materials led to conducting the session at a time when the patient was not sleepy or medication causing problems, and this made a huge difference in his ability to be involved and receive education.

☑ USING EDUCATION TO SIMPLIFY WOUND MANAGEMENT

A wound management programme was introduced using a dressing that included a visual indicator for dressing change and a masking layer for exudate. Training and education for clinicians was provided, as well as the introduction of tools and use of videos by patients. Evaluation of the programme demonstrated a much less complex approach to the use of dressing products: the mean number of dressing changes decreased by 50% with a concomitant reduction in nursing time. Materials expenditure was reduced, with a 79.6% reduction in the number of dressings per patient per week[16].

SELF-MANAGEMENT PROGRAMMES

Healthcare systems that have been successful in involving patients have relied on putting skills and tools in the hands of patients, as well as supporting professionals to gain the required skills to play a more enabling role in their care[17]. Programmes that teach patients self-management have been shown to be more effective than information-only patient education at improving clinical outcomes[47]. Self-management programmes need to enable patients to manage their wound medically when appropriate, carry out activities of daily living and manage the emotional effects of their condition[48].

Patient education using an e-learning approach has been found to be successful among people with venous leg ulcers[49], with significant changes reported in their understanding of venous disease, leg ulcer treatment, skin care and exercise. Key components of successful patient education for this group included the provision of simple, evidence-based information that could be moderated by the clinician to meet the patient's individual needs.

Training for patients and caregivers

Opportunities for engaging patients in self-management can be initiated in hospital and continued at home. For example, a therapist or nurse could train patients and caregivers and plan three or four learning sessions while still in hospital, and before discharge the patient and caregiver could be observed changing a dressing or applying a compression device. A follow-up appointment could be made for a week later to ensure the process is working well. Where necessary, adjustments can be made to the care plan to help match patient needs. This approach allows patients to develop confidence quickly, especially when they know they can access help if they need it or that a clinician will be checking on them at a specific time.

☑ USE OF REAL-TIME VIDEO CONFERENCING IN RURAL AUSTRALIA

Real-time video conferencing was used with a person who lived in rural Australia and who was self-treating a venous leg ulcer. The client received an initial assessment and advice at an interdisciplinary wound clinic in the city. This provided an opportunity to show his partner how to apply multilayer compression bandaging. Between clinic reviews, the client treated his wound and his partner applied the compression bandaging. Real-time video conferencing was conducted periodically with a clinical nurse consultant to discuss the progress of the wound and to provide education and support. This approach was found to be acceptable to the patient and beneficial in that it allowed him to remain connected to the healthcare team and receive professional support without leaving the home. The ulcer subsequently healed and has not recurred.

Supporting patients with technology

Patients who self-manage may also be supported by the use of telecommunication technologies, such as text messaging and video conferencing (see Best Practice Tip below ☑). These technologies are low cost and widely available, many relying on regular telephone systems. Using 'teleheath' can facilitate remote consultations and be a cost-effective and convenient way of monitoring patients and their wounds, reviewing a patient's ability to self-manage and adjust treatment targets when required[18]. The main barriers to this approach are often age (and associated visual or auditory limitations) and a lack of familarity with technology[50].

Using products that support self-management

Increasing financial pressures on healthcare services means that more complex wounds are being treated in the community18. This places greater demands on non-specialist clinical staff to become familiar with advanced wound care products. Simple strategies such as the use of a dressing that incorporates a visual indicator to show when it needs changing can give patients and clinicians a greater sense of control[46]. Approaches such as this have been shown to improve dressing change frequency and nursing practice efficiency[46] (see Best Practice Tip left ☑).

Helping practitioners to support patients

Just as patients require ongoing support, clinical teams need to learn skills and techniques and feel confident in supporting patients to self-manage. To meet this need, workshops or 1-2-1 training can help staff to know how to listen to patients effectively, to use products appropriately, and educate patients to recognise when they need to seek help and who to contact.

Patients supporting patients

Patient self-help and support groups play an active role in self-management. These may be run by patients or be organised by healthcare charities, with opportunities for chat rooms, social clubs (e.g. Leg Clubs®) or organised summer camps for patients. These organisations often allow patients to share their stories, and motivate patients to take ownership of their care, alleviate their suffering and reduce the stigma attached to their condition[51].

Measuring outcomes for patient involvement

While good evidence exists for patient involvement, there is a lack of research to inform which interventions should be adopted as part of a standard protocol

Evidence suggests that patients' involvement in their healthcare is associated with improved treatment outcomes in chronic illnesses[52,53]; however, there is no agreement about the best way to demonstrate that patients have been empowered[54] and there is a lack of hard evidence to inform which strategies to adopt to allow for effective change in this area[55].

In wound care, outcome measures have traditionally focused on wound healing, time to healing and recurrence[56]. However, healing may not always be possible and small, incremental steps towards success should be seen as beneficial. When measuring outcomes, it is important to predict which patients will or will not respond to different treatment modalities and to set realistic goals for individual patients. This may be problematic in that high-quality evidence is often lacking for many of the interventions commonly used in wound care[37].

There is a growing body of evidence that suggests outcomes should also capture how the patient feels through diaries, evaluations of symptoms (e.g. pain, odour, leakage), reports of satisfaction with treatment, and general and health-related quality of life[23]. Patient preferences, for example, about wound dressings, may focus on pain reduction, exudate absorption, the ability to lead a normal life and faster healing, rather than dressing change frequency and cost reduction[37].

MacAllister et al[5] argue that patient empowerment should be considered as a directly measureable patient-reported outcome to assess whether being more involved has changed the patient's knowledge, attitudes and behaviours and concordance with treatment protocols in any way.

Patient questionnaires can be used to assess the success of the decision aid and shared decision-making process. Patient questionnaires can also be used to evaluate the client-centredness of home care. Responses can give clues for improving care, highlighting expectations, client needs, capabilities and wishes in decision-making[57].

Another scale that can be used to measure shared decision outcomes is the 'observing patient involvement in decision-making' (OPTION) tool that accepts that it is difficult, if not impossible, to judge where and when patients will want to make decisions[58].

Clinicians are required to involve patients in the process of understanding their condition, and the different options available to them, and that, if they wish, they can be involved in the decision process for their care. The 12-point OPTION scale regards these steps as constituting the process of involving the patient in decision-making and the extent to which they 'strongly agree' to 'strongly disagree'[58] (Box 6). Patient behaviour and patient knowledge will indirectly change expectation of care.

Part of the measure of success is to provide a system to better manage resources and ensure that this is part of optimising care and not seen as shifting care to patients as this can have negative connotations.

BOX 6: OPTION 12-POINT SCALE[58]

1. The clinician identifies a problem(s) needing a decision-making process
2. The clinician states that there is more than one way to deal with an identified problem ('equipoise')
3. The clinician lists "options" including the choice of "no action" if feasible
4. The clinician explains the pros and cons of options to the patient (taking 'no action' is an option)
5. The clinician checks the patient's preferred information format (words/numbers/visual display)
6. The clinician explores the patient's expectations (or ideas) about how the problem(s) are to be managed
7. The clinician explores the patient's concerns (fears) about how problem(s) are to be managed
8. The clinician checks that the patient has understood the information
9. The clinician provides opportunities for the patient to ask questions
10. The clinician asks for the patient's preferred level of involvement in decision
11. An opportunity for deferring a decision is provided
12. Arrangements are made to review the decision (or the deferment)

Developing an empowering health service

Gathering and acting on patient and carer feedback will help to develop services that are patient-centred, accessible and cost-effective

Future healthcare services need to embed patient involvement within their mission statement and consider the use of validated empowerment assessment tools[11,27].

Improving people's experience of healthcare involves gathering experiences of patients and staff and bringing them together to develop service improvements. Patients' sense of satisfaction has been shown to increase when they are able to exercise choice in care interventions[48]. This may be demonstrated through patient feedback, which can be used to reframe what health services do and to work with patients to identify — often small — changes that could make a big difference to their experience of care (see Best Practice Tip ☑).

Any healthcare system needs to make sure its resources are targeted in a way that will produce positive outcomes[59]. This is especially the case when budgets are under pressure. By encouraging patient involvement — taking into consideration a patient's preferences and priorities — clinicians can ensure they are not prescribing treatments that patients will not use or referring them for services or further interventions that they would prefer not to have[59]. For some, it may be deemed effective to spend more money up front to avoid spending more later on. This decision should be made on an individual patient basis[23].

Work undertaken by the King's Fund in the UK demonstrates cost savings and reductions in service use related to activities that are patient-centred. For example, when people are better informed, there is a tendency for less invasive and less expensive treatments to be chosen, while people who are supported to manage their own care more effectively are less likely to use emergency hospital services[39,61]. In addition, people who take part in shared decision-making are more likely to stick to their treatment plan and take their medicines correctly[62,63]. This helps to ensure that what money is spent, goes toward those things that patients value the most.

This finding is further supported by the World Health Organization, who argue that if patient literacy is enhanced it may mean that patients may not necessarily choose the most expensive therapies[4]. In the US, many patients have to pay for their own dressings and their priority is for the product to do what it says it does.

As patients become customers in health care, there is a need to identify concerns directly related to them, such as costs and quality of life. Having an influence allows patients to 'buy' into their care, and being given access to electronic healthcare records may create fewer boundaries between the patient and the healthcare system — with a focus on what the patient views as success[64].

THE ROLE OF INDUSTRY

The development of wound care products comprising newer technologies that are easy to use, affordable and encourage self-management can empower and engage patients and their carers in their wound management[17].

Involving patients and clinicians in product design supports the development of devices and dressings that not only meet the needs of patients, but are fit for purpose and therefore are more likely to be adopted[65].

☑ DEVELOPING PATIENT-CENTRED COORDINATED CARE

Patients with lymphoedema were engaged in the design ideas and prototypes for a service specification. This led to a service that offered care closer to home, reducing transport costs, and the introduction of personalised patient care plans.

Patients had access to education and public health programmes to support wellbeing. This led to greater satisfaction with the service, with feedback used to ensure the best possible services were provided. All patients reported improvements in mobility, general wellbeing, improved pain levels and decrease in discomfort.

This unique collaborative design ensures sustainability while providing high quality care that meets the needs of patients[60].

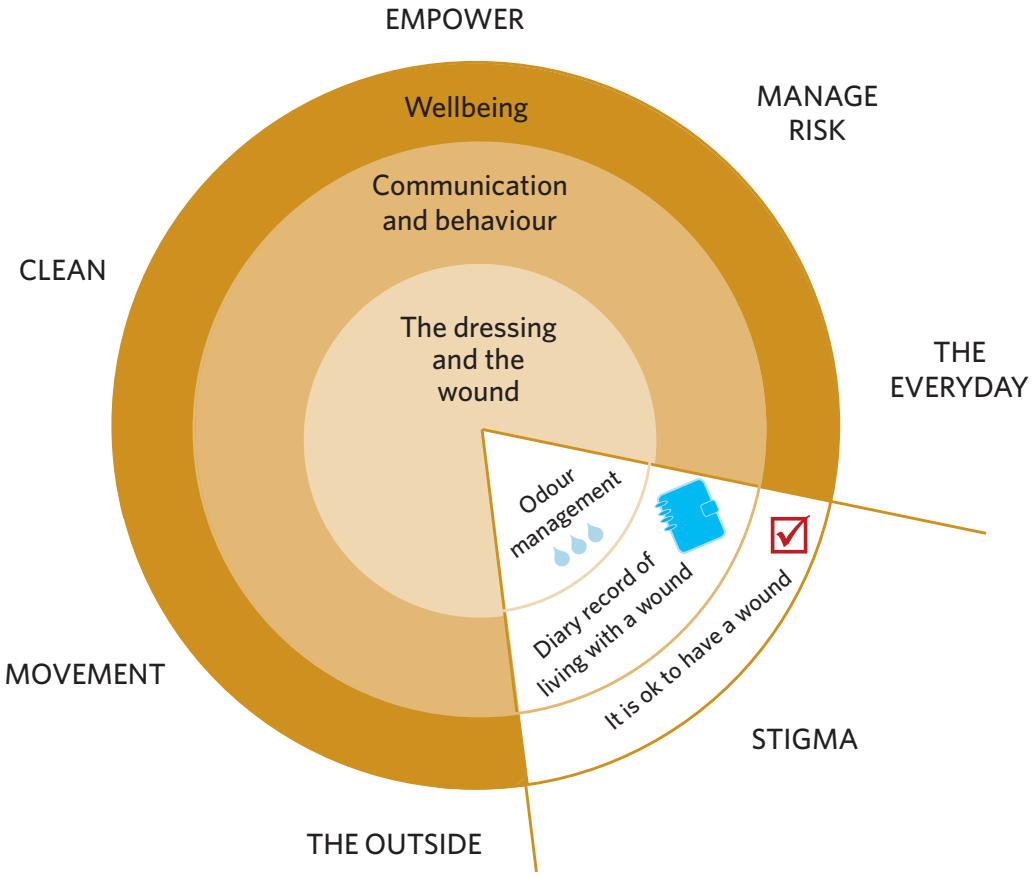


Figure 7: The eight key principles of wellbeing identified using an ethnographic approach (adapted from Wounds International, 2012. Acknowledgement: Anatomy HCD Ltd)

The importance of a partnership approach for wound product design was recently recognised. An ethnographic study involving industry, researchers and patients was conducted to help understand the impact of living with a wound. The research team conducted over 850 interviews with patients and clinicians; topics included everyday wound management routines and focused on factors that influence quality of life, such as hobbies or social engagements, the impact of chronic wound care, clinical practices, family life, the local community and support networks. The research team identified eight key principles (Figure 7), which influenced the design of a new multi-layer foam dressing that aimed to improve patient wellbeing by improving dressing performance[1,66].

Industry could also support collaborations with clinicians and involve patients by supporting Meet the Expert sessions at healthcare meetings. When these have been used in other disease areas, patients not only felt involved and part of the decision-making process on treatments and research, but they also provided a chance for manufacturers to meet patients and learn about their needs.

In addition, there is a role for industry to provide information for patients based on social listening research that increases understanding of their condition and allows peer-to-peer exchanges with opportunities for patient feedback. Demand for such information is increasing (see Best Practice Examples of industry involvement ☑, page 17).

ROLE OF HEALTHCARE ORGANISATIONS

To deliver empowered health services, there is a need for more research and funding in wound care to allow for:

- Better risk stratification of patients for improved outcome reporting[67]
- Better understanding by payers of the needs of wound care[1]
- Effective training of staff to improve competency levels of wound care[1].

However, to achieve such a change in service design and function, organisations need to move away from a paternalist model to one that involves patients in their care delivery, supported by the use of care pathways. This can help to empower patients

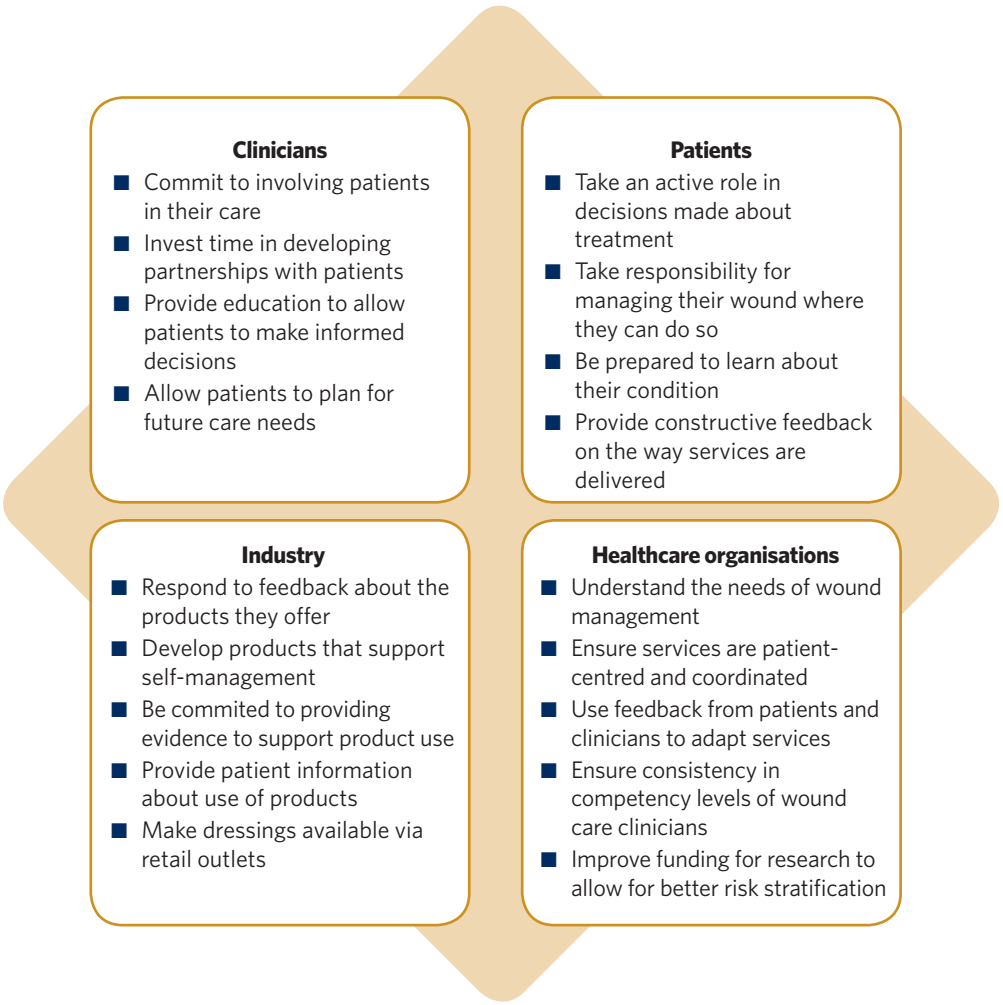


Figure 8: The role of clinicians, patients, industry and organisations in developing an empowered health service

SELF-TREATMENT OF WOUNDS STUDY

A study investigating the perspectives and experience of people with a chronic wounds who self-manage is being conducted in Australia. The study requires all participants to complete a survey (online, paper or over the phone), with some people invited to participate in in-depth interviews to assess the impact of their wounds and self-treatment on quality of life.

The research has been conducted by Suzanne Kapp, and Professor Nick Santamaria at the University of Melbourne. Data collection has been completed and analysis is due to be reported late 2015 (http://www.selftreatmentofwounds.net).

as the expected standard of care is well documented and eliminates the *ad hoc* nature of care delivery.

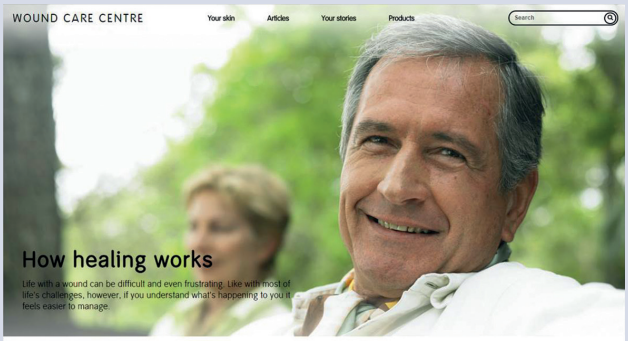
There is also an onus on wound management providers to know the type of care pathways that are most appropriate. These should be founded on evidence and acceptable to patients[68].

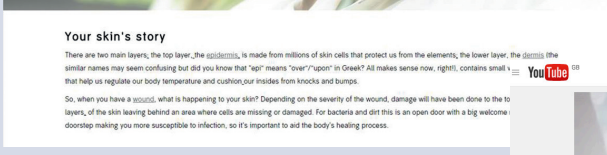
Moving towards a more standardised approach to wound care will allow for collection of good-quality routine data on the performance of wound management services, outcomes and resource use[8].

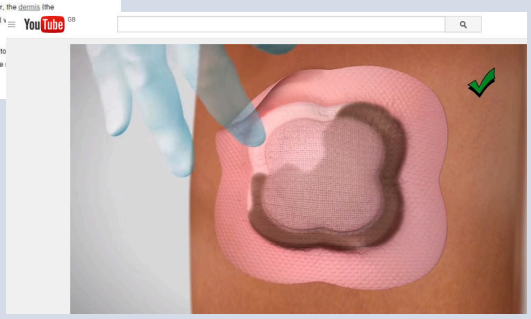
Further research is needed to assess patients living with a chronic wound, the impact of their wounds and how they self-treat. This has the potential to inform the development of healthcare services and educational resources to support patients who self treat. This in turn has the potential to improve wound healing, prevent pain and reduce the financial burden of wound management (see Best Practice Tip left ☑)

Implementation of patient involvement in wound management requires a whole-system approach with a need for clinicians, patients, industry and healthcare organisations to agree on clear goals and a coherent strategy (Figure 8).

INDUSTRY-SUPPORTED ONLINE WOUND CARE INFORMATION FOR PATIENTS







Industry can help to increase patient knowledge about their condition through online education, using patient stories, resources, hints and tips and instructional videos

FUTURE GOALS FOR PATIENT INVOLVEMENT IN WOUND MANAGEMENT

For patient involvement to become central to wound management, there is a need to reshape traditional healthcare professional attitudes to patients and for services to be restructured to meet patient needs[11]. In aspiring to meet this goal, is it important that:

- Patient involvement is not seen as an add-on to care, rather it is seen as the most appropriate healthcare delivery method
- Healthcare is organised to provide structures and support for clinicians to adapt their practice
- Feedback is used from patients to drive patient-centred care (e.g. patient satisfaction is a primary goal)
- Wound management is compared with other disease areas to establish overlap and share strategies that involve patients in their own care
- Clinicians are given the necessary training and supportive environment to foster the changes needed for patient involvement (e.g. to determine key competencies)
- Governments strive for improved health literacy to educate individuals about long-term conditions such as diabetes, lymphoedema and cardiovascular disease, with a focus on prevention
- Clinicians and researchers measure outcomes from patient involvement to grow the evidence base pertaining to the efficiency and effectiveness of this approach to care delivery.

REFERENCES

1. Wounds International. *Optimising wellbeing in people living with a wound. An international consensus*. Wounds International, 2012
2. Eurobarometer Qualitative Study. Patient involvement. Aggregate report, May 2012. Available from: http://ec.europa.eu/health/systems_performance_assessment/docs/eurobaro_patient_involvement_2012_en.pdf
3. Berger B. Patient empowerment. The Standing Committee of European Doctors (CPME), date. http://www.activecitizenship.net/files/patients_rights/8th_european_patients_rights_day_conference_materials/06-beger.pdf
4. WHO. Health education: theoretical concepts, effective strategies and core competencies. A foundation document to guide capacity development of health educators , 2012. Available from http://applications.emro.who.int/dsaf/EMRPUB_2012_EN_1362.pdf
5. McAllister M, Dunn G, Payne K et al. Patient empowerment: The need to consider it as a measurable patient-reported outcome for chronic conditions. *BMC Health Services Res* 2012;12:157
6. Sen CK, Gordill GM, Roy S, et al. Human Skin Wounds: A Major and Snowballing Threat to Public Health and the Economy. *Wound Repair Regen* 2009; 17(6): 763–71. doi:10.1111/j.1524-475X.2009.00543.x
7. McDonald C. Patients in control. Why people with long-term conditions must be empowered. Institute for Public Policy Research, 2014. Available from http://www.ippr.org/files/publications/pdf/patients-in-control_Sept2014.pdf
8. Wounds International. *Making the case for cost-effective wound management. An international consensus*. Wounds International, 2013.
9. Economist Intelligence Unit. The future of healthcare in Europe. A report from the Economist Intelligence Unit 2011. Available from: http://www.janssen-emea.com/sites/default/files/The-Future-Of-Healthcare-In-Europe.pdf
10. Economist Intelligence Unit. Global outlook. Healthcare. May, 2014. Available from: http://pages.eiu.com/rs/eiu2/images/GlobalOutlook_Healthcare.pdf
11. All Party Parliamentary Group on Global Health. Patient Empowerment: *For Better Quality, More Sustainable Health Services Globally*, 2014. Available from: http://www.appg-globalhealth.org.uk/reports/4556656050
12. Posnett, J, Gottrup F, Lundgren H, Saal G. The resource impact of wounds on healthcare providers in Europe. *J Wound Care* 2009; 18(4): 514-161
13. Kuhn BA, Coulter SJ. Balancing ulcer cost and quality equation. *Nurs Econ* 1992;10(5):353–359
14. Driver VR, Fabbi M, Lavery LA, Gibbons G. The costs of diabetic foot: the economic case for the limb salvage team. *J Am Podiatr Med Assoc* 2010;100(5): 335–41
15. Gordon MD, Gottschlich MM, Helvig EI et al. Review of evidence-based practice for the prevention of pressure sores in burn patients. *J Burn Care Rehabil* 2004; 25(5): 388–410
16. Graves N, Zheng H. Modelling the direct healthcare costs of chronic wounds in Australia. *Wound Pract Res* 2014; 22: 20-33
17. Dowsett C. Breaking the cycle of hard-to-heal wounds: balancing cost and care. *Wounds International* 2015 6(2): 17-21
18. Probst S, Seppänen S, Gethin G et al. EWMA Document: Home Care-Wound Care. *J Wound Care* 2014;23 (5 Suppl.): S1–S44
19. Kapp S, Annells M. Home based nursing care of older people with a pressure ulcer. *Br J Community Nursing* 2010; 15(12): S6-13
20. Franks P, Gottrup F. Outcomes and structures of care: the European perspective. *WOUNDS* 2004; 16(5): 173-83.
21. Kapp S, Simpson K,Santamaria N. Perspectives on living with and self-treating venous leg ulcers: a person's story and a health care perspective. *Wound Practice and Research* 2014; 22 (2): 98-101.
22. Stiggelbout AM, Molewijk AC, Otten W, Timmermans DRM et al. Ideals of patient autonomy in clinical decision making: a study on the development of a scale to assess patients' and physicians' views *J Med Ethics* 2004;30:268-274 doi:10.1136/jme.2003.003095
23. American College Of Wound Healing And Tissue Repair Chicago, Illinois and The Angiogenesis Foundation. *Patient-Centered Outcomes in Wound Care. A White Paper*, 2013. Available from: https://www.angio.org/wp-content/uploads/2013/10/Wound_Care_White_Paper.pdf
24. Pereira MT de Jesus, Salome G, Openheimer DG, et al. Feelings of powerlessness in patients with diabetic foot ulcers. *WOUNDS* 2014;26(6):172-177
25. Dowsett C, Martin Nyløkke Gronemann, Hardking K. Taking wound assessment beyond the edge. *Wounds International* 2015; 6(1): 19-23
26. Tol A, Baghbanian A, Mohebbi B et al. Empowerment assessment and influential factors among patients with type 2 diabetes. *J Diabet Metabol Dis* 2013, 12:6 http://www.jdmdonline.com/content/12/1/6
27. Hibbard J, Gilburt H. Supporting people to manage their health. An introduction to patient activation. The Kings Fund, May 2014
28. Kapp S, Miller C. The experience of self-management following venous leg ulcer healing. *J Clin Nurs* 2015 24(9-10): 1300-9
29. National Institute for Health and Care Excellence. Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. Clinical Guidance 138. 2012. Available from: https://www.nice.org.uk/guidance/cg138
30. European Wound Management Association (EWMA) Position Document: *A holistic approach to hard to heal wounds.* MEP: London 2008. Available from www.woundsinternational.com
31. Wang SC, Anderson JAE, Jones D, Evans R. Patient perception of wound photography. *Int Wound J* 2014; doi 10.11111/iwj.12293
32. Mudge E, Spanou C, Price P. A focus group study in patients' perception of chronic wound pain. *Wounds UK* 2008; 4(2): 21-28
33. Euromed Info. Assessing learning needs. Available from: www.euromedinfo.au/assessing-learning-needs.html
34. Bethell E, Cadogan J, Hildegard C, et al. Issues in wound care: empowering patients - developing a framework for practitioners. *J Wound*

Care 15(1): doi http://dx.doi.org/10.12968/jowc.2006.15.2.26889
35. Royal College of General Practitioners. Care Planning: improving the lives of people with long term conditions. Clinical Innovation and Research Centre, 2011
36. Orem DE. *Nursing Concepts of Practice*. St Louis, MO: Mosby, 1991
37. Corbett LQ, Ennis WJ. What do patients want? Patient preference in wound care. Adv Wound Care 2014; 3(8): 537-43
38. Moore Z, Butcher G, Corbett LQ, et al. AAWC, AWMA, EWMA Position Paper. Managing wounds as a team. *J Wound Care* 2014; 23(5 Suppl): S1-S38
39. Coulter A, Collins *A. Making shared decision-making a reality. No decision about me, without me.* Kings Fund, 2011. Available from: http://www.kingsfund.org.uk/sites/files/kf/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf
40. Bakker K, Apelqvist J, Schaper NC, International Working Group on Diabetic Foot Editorial Board. Practical guidelines on the management and prevention of the diabetic foot 2011. *Diabetes Metab Res Rev* 2012 Feb;28 Suppl 1: 225-31
41. Ahmed H. Communicating risk. *BMJ* 2012; 344 doi: http://dx.doi.org/10.1136/bmj.e3996
42. Stacey D, Leagare F, Col NF, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2014; 28(1): CD001431
43. O'Connor A. Using patient decision aids to promote evidence-based decision making. *Evidence-Based Medicine* 2001; 6: 100-2
44. O'Connor AM, Bennett CL, Stacey D et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2009; 8(3): CD001431
45. Hoffmann TC, Del Mar C. Patients' expectations of the benefits and harms of treatments, screening and tests: a systematic review. *JAMA Intern Med* 2015; 175(2): 274-86
46. Joy H, Bielby A, Searle R. A collaborative project to enhance efficiency through dressing change practice. *J Wound Care* 2015; 24(7): 312, 314-7
47. Adams RJ. Improving health outcomes with better patient understanding and education. *Risk Manag Healthcare Policy* 2010; 3: 61-72
48. Coulter A, Parsons S, Askham J. Where are the patients in decision-making about their own care. *Health Systems and Policy Analysis*. WHO Europe 2008. ISSN 1997-8073. Available from: http://www.who.int/management/general/decisionmaking/WhereArePatientsinDecisionMaking.pdf
49. Kapp S, Miller C, Sayers V, Donohue L. The Leg Ulcer Prevention Program. Client outcomes of a multimedia education package for people with venous leg ulcers. *Wound Practice and Research* 2010; 18(2) 80-90
50. Moore Z, Angel D, Kröger K et al. E-health in wound care: from conception to implementation. J Wound Care 2015; 24(5): S1-44
51. Lindsay E. Lindsay Leg Clubs: clinically effective, cost effective. *J Comm Nurs* 2013; 27(1)
52. Greenfield S, Kaplan SH, Ware JE et al. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med* 1988; 3(5): 448-57
53. Arnetz JE, Bergstrom AL, Franzen Y, Nilsson H. Active patient involvement in the establishment of physical therapy goals. Effects on treatment outcome and quality of care. *Adv Physiotherapy* 2004; 6(2): 50-69
54. Barr PJ, Scholl I, Bravo P et al. Assessment of patient empowerment: a systematic review of measures. *PLOS One* May, 2015
55. Coulter A. *Leadership for patient engagement.* The Kings Fund, 2012. Available from: http://www.kingsfund.org.uk/sites/files/kf/leadership-patient-engagement-angela-coulter-leadership-review2012-paper.pdf
56. European Wound Management Association. Outcomes in controlled and comparative studies on non-healing wounds. Recommendations to improve the quality of evidence in wound management. EWMA Patient Outcome Group Document, 2010. Available from: http://ewma.org/fileadmin/user_upload/EWMA/Wound_Guidelines/POG_PrintFile_FINAL.pdf
57. De Witte L, , Schoot T, Proot I. Development of the Client-Centred Care Questionnaire. *J Adv Nursing* 2006; 56: 62-68
58. Elwyn G, Hutchings H, Edwards A et al. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. *Health Expectations* 2005; 8: 34-42
59. Health Foundation. Person-centred care made simple. Quick Guide, 2014. Available from: http://personcentredcare.health.org.uk/sites/default/files/resources/person-centred_care_made_simple_1.pdf
60. Joy H, Allanson D, Scott Z. A collaborative approach to service creation — the non-cancer lymphoedema service experience. Poster presentation, Wounds UK, Harrogate, 2014
61. Mulley A, Trimble C, Elwyn G. Patients' preferences matter. Stop the silent misdiagnosis. The Kings Fund, 2012
62. De Silva D. Evidence: Helping people help themselves. The Health Foundation, 2011.
63. De Silva D. Helping people share decision making. The Health Foundation, 2012.
64. Ventres WB, Frankel RM. Patient-centered care and electronic health records: it's still about the relationship. *Fam Med* 2010 May;42(5):364-6
65. McNichol E, McKay A, Milligan C et al. A patient-led approach to product innovation in patient education and wound management. *EWMA Journal* 2015; 15(1): 47-51
66. Stephen-Haynes J, Bielby A, Searle R. The clinical performance of a silicone foam in an NHS community trust. *JCN* 2013; 27(5): 50-59
67. Horn SD, Fife E, Smout RJ et al. *Wound Rep Rengen* 2013; 21: 823-2
68. Five Year Forward View (2014) Available at: https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

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