

Giving voice to the patient with wounds. An internationally shared need? The Italian experience.



Author: Giuseppe Mancullo

Giuseppe Mancullo has more than 28 years business experience in the Medical Device arena. He developed his career with Smith and Nephew Italy managing various departments. For the past 18 years he focused on the wound care industry leading project launches, project development, supporting the development of new therapeutic concepts (TIMECare) and participating on the Board of Clinical Associates.

Much has been written about the centrality of the patient's own experience to the delivery of the care of their chronic wound. Their importance as stakeholder and actor in their own treatment is recognised but in many countries they remain without their own lobbying and self-help organisation. In the main, their interests are defended by clinicians' societies and generalist patients' associations, for example the report "Fears for wound care patients after COVID-19 pandemic" published in the UK in May 2022 by The Patient Association: <https://www.patients-association.org.uk/blog/fears-for-wound-care-patients-after-covid-19-pandemic>).

Italy however, has SIMITU, the association for patients living with complex wounds (www.simitu.it) founded in 2010 by patients and clinicians who, realising that there was a lot of talk about skin ulcers and little about the patient, decided to found an association that would give voice to the unmet and often misunderstood needs of people with wounds. SIMITU now has a regional network of more than 1,500 patients and through the internet and social media it delivers wound care education, counselling and practical advice to patients and caregivers. In the words of the SIMITU MD Giuseppe Nebbioso *'Too often we focus on the disease, forgetting the patient who is affected, his anxieties, his fears, his hopes for recovery'*.

SIMITU's close cooperation with the clinicians' wound care societies resulted in the first Italian study on the quality of life of patients with chronic skin ulcers ([Quality life study in wound care](#)) in cooperation with AIUC (the Italian Association on Skin Ulcers) and with whom it is carrying out a Communication and Clinical Literacy programme on chronic wounds "PAUC". In addition, SIMITU has been in constant dialogue with industry and its representative trade bodies (e.g., Confindustria Dispositivi Medici).

When the Emilia-Romagna Region issued its new guide to choice of dressings, SIMITU pointed out that despite the good intentions, the guide threatened the principles of equal access by restricting treatments available to patients in the region. The objective of the guide was to ensure good quality but in SIMITU's opinion it could have proved to be detrimental to the principle of equity, efficiency, appropriateness and transparency of the health service.

It would be interesting, at a European level, to investigate the state of the art of the representation of patients with skin ulcers.

Lastly, it is worth pointing out that all this activity represents a great success for an association that does not require membership fees from patients and where everything is done by those who believe in what they are doing. SIMITU's president and founder firmly believes *'Involving patient associations in a process of sharing and dialogue, which aims to improve care and the quality of life of patients and their families will certainly improve the quality of our NHS (National Health System)'*.

SIMITU has been most involved in raising public awareness and lobbying policy makers. Some of its achievements have been:

- ▶ the adoption of regional PDTAs (Diagnostic-Therapeutic Care Pathways); the inclusion of the treatment of skin ulcers in the "LEA" (the basic standard of care to which every citizen has a right)
- ▶ lobbying for the use of the most advanced technologies;
- ▶ reporting on the implications of government policies and actions detrimental to patients
- ▶ participation in technical roundtables on the procurement of Medical Devices