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From patient to partner: Crowdsourcing and digital innovations reshaping scar research and scar care management

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Summary Traditional scar research has historically prioritized clinician-driven outcomes, often neglecting patient-identified needs and real-world experiences. This narrative review synthesizes developments in patient-powered innovation across scar research, drawing from the last decade of literature on patient-reported outcome measures (PROMs), real-world data, digital health tools, and participatory models. Increased adoption of PROMs (e.g., Patient and Observer Scar Assessment Scale 3.0 and SCAR-Q), crowdsourced initiatives, and digital tools (e.g., ScarPath, smartphone apps, and AI-based assessments) are transforming scar research and management by centering patient priorities. Patient-powered approaches—through digital tools, crowdsourcing, and participatory research—are reshaping scar care by promoting real-world engagement and more meaningful, personalized outcomes.

In the past decade, innovative research methods and technologies have transformed scar management worldwide. Burn-related and non-burn scars have benefited from a shift toward more patient-centric research and care paradigms. Scars pose a substantial long-term burden on patients and their families, with several uncertainties in treatment and outcomes.[1]

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Given the historical gap between clinical research priorities and patient needs, researchers and clinicians have increasingly embraced patient partnerships to realign research with real-world concerns. Key themes in recent literature include greater patient and public involvement in research, the rise of patient-reported outcome measures and real-world data to guide care, participatory "crowdsourced" research models, and use of digital health technologies (telemedicine, digital care pathways, and artificial intelligence) for personalized scar management.

Here, we present a perspective view of major findings and trends from the past 10 years, based on a narrative review to identify relevant papers, highlighting the novel, patient-centered approaches transforming scar care, aligned with the following research question: "How can patient-powered innovation, including crowdsourcing, patient-reported outcomes, real-world data, and digital "patient-oriented" health technologies, transform scar research and therapy development to better align with patient priorities and improve outcomes?".

Patient and public involvement in scar research

Nowadays, contemporary scar research emphasizes patient and public involvement (PPI) to ensure that studies and innovations address outcomes that matter the most to patients. Traditional clinician-led research often overlooked patient priorities—for example, patients tend to focus on symptoms and daily function whereas clinicians historically focus on clinical disease parameters, such as blood pressure or range of movement.[1] To bridge this gap, funding bodies such as the US Patient-Centered Outcomes Research Institute and UK National Institute for Health Research now support co-production of research with patients and clinicians working together.[1] In practical terms, this has led to priority-setting initiatives and study designs that directly incorporate patient input. An important example is the Global Burn Research Priority Setting Partnership, which brings burn survivors, carers, and professionals together to jointly identify the most urgent research questions in burn management.[1,2] Early findings from such efforts show that including patient voices can reorient research toward areas such as scar pain, itching, psychological impact, and functional recovery, which patients rank highly.

Patients are increasingly participating as active collaborators in scar research, rather than being passive study objects. For instance, a recent qualitative study in the UK exploring burn patients' perspectives on scar assessment involved burn survivors at every stage.[3] In that study, a burn patient advisory panel helped design the interview guide to ensure that the questions were relevant and patient-centered, and a follow-up PPI meeting was held so patients could help interpret and validate the results.[3] This level of involvement—from design through dissemination—marks a significant cultural shift in scar research. It helps ensure that interventions (such as new therapies or assessment tools) align with patient needs and values. Overall, the last decade has witnessed scar research become more collaborative and inclusive, with PPI leading to more meaningful outcomes and higher relevance to the scar-affected community.

Patient-reported outcomes and real-world data

In modern scar research, measuring patient perspectives has become as important as clinical assessments, leading to the adoption of standardized patient-reported outcome measures (PROMs) and real-world data (RWD) collection for treatment education. Historically, scar severity was assessed mainly by clinician-rated scales (e.g., Vancouver Scar Scale) or objective measures, with little input from patients. Recent research recognizes that patient perception of a scar's impact is crucial, and that subjective outcomes (such as pain, itch, appearance satisfaction, and psychosocial impact) must be measured alongside objective findings.[4] In response, new scar-specific PROM instruments have been developed through rigorous international efforts. Major breakthroughs were the creation of the Patient and Observer Scar Assessment Scale (POSAS) 3.0 and SCAR-Q, two PROMs designed for surgical, traumatic, and burn scars.[5-8] The POSAS 3.0 patient scale, assessing scar quality, was co-developed with information from patients during focus groups and pilot tests.[6,7] SCAR-Q was field-tested in more than 700 patients across four countries and covered three domains important to patients—appearance, symptoms, and psychosocial effects.[8] Both scales demonstrated high reliability and validity, and importantly, they were developed with extensive patient input to ensure content relevance.

Beyond individual instruments, the integration of PROMs into routine scar care has paved the way for gathering RWD on a large scale. In clinical practice, patients now regularly complete questionnaires about their scar symptoms and quality of life, generating data that can guide personalized treatment decisions and broader research. However, collecting such data can be time-consuming and inconsistent if carried out on paper or ad hoc.[4,9] To address this, researchers turned to digital solutions. The ScarPath project, developed by Oscare, is an example of an electronic platform to standardize scar assessment and follow-up across patients.[4] ScarPath combines objective measurements with patient-reported questionnaires in a user-friendly application, empowering patients to input data about their scars and track their progress over time.[4] This streamlines data collection and opens the door to pragmatic real-world studies; with a large pool of standardized data, clinicians can evaluate how different treatments perform outside of trials and identify trends. ScarPath explicitly aims to enable large, pragmatic trials of new scar therapies by providing a simple, patient-oriented evaluation tool, and even foresees using machine learning on the collected dataset to predict scar outcomes and tailor therapies.[4] Early reports highlight that such platforms improve patient participation and provide individuals a sense of ownership in their care. In short, the past decade has witnessed scar outcome measurement move into the real world by leveraging PROMs and digital data capture to ensure that treatment success is defined by patients and research priorities reflect real-life needs.[10,11]

Crowdsourcing and participatory research models

Inspired by rare diseases, scar researchers are exploring crowdsourcing and participatory models to accelerate innovation. Rare diseases have shown that engaging the entire community of stakeholders—patients, families, clinicians, and scientists—can generate high-impact research questions and drive progress even when expert resources are limited. A striking example is the Castleman Disease Collaborative Network, which in 2021 crowdsourced research questions by inviting ideas from patients, loved ones, physicians, and researchers, then prioritized them to create a patient-centered research agenda.[9] This process ensured that studies addressed what patients cared about the most and resulted in a coordinated research strategy rather than fragmented projects.[12] The success of this model, and similar approaches in rare illnesses research, offers a framework for scar research, which also encompasses diverse patient populations and often lacks a cohesive research agenda.

In the last decade, we observed early signs of such participatory approaches evolve in the scar field. International scar and burn survivor networks increasingly use surveys, social media, and patient advocacy forums to gather input on unmet needs. For instance, the Scar Free Foundation in the UK (a charity focused on scar prevention and treatment) has involved patient focus groups to help shape its research funding priorities, ensuring they align with survivors' lived experiences. On a broader scale, digital technology enables crowdsourcing of data from patients on an unprecedented scale. A recent project in dermatology, introduced by Google, demonstrated this potential by leveraging the internet to crowdsource an open-access dataset of skin condition images from the public. Over eight months, more than 5000 individuals contributed a total of 10,408 images of various skin conditions along with demographic and symptom information.[13] The result, known as the Skin Condition Image Network dataset, greatly expanded the diversity of images available for research and was highlighted as evidence that online outreach can effectively engage patients to contribute to science.[13] Similar crowd-driven data initiatives for scars—for example, asking patients worldwide to submit photos of their scars or share healing experiences—could vastly enrich scar research. By pooling real-world observations from many contributors, researchers can study patterns (such as the kind of therapies that individuals find most helpful for itch or which scar types cause the most distress) in ways not possible through traditional trials alone.

Although true crowdsourced scar research is still emerging, the trend is clearly toward more participatory science. Patients are increasingly seen as partners who can help to determine the research agenda and even contribute data and funding (through advocacy or crowdfunding campaigns). This democratization of research is a novel development in scar care. It brings in fresh ideas (potentially identifying novel treatments or coping strategies that professionals might overlook) and keeps research priorities aligned with patient-important outcomes. Going forward, one can expect scar research consortia to adopt more of these open, crowd-inclusive methods to ensure that innovation in scar therapy is accelerated by the collective wisdom and needs of the community.

Digital health technologies in scar management

Technological advancements in digital health have been essential in making scar care more accessible, personalized, and patient-centered. Several digital modalities have come to the forefront:

Telemedicine and Remote Care: The expansion of telemedicine has greatly improved access to scar expertise, especially for patients who live far from specialist centers or during pandemics. In burn care, for example, telehealth services are now widely used for remote assessment of scars and follow-up consultations. Studies show that even a basic smartphone video call can enable reliable evaluation of burn scars from a distance.[14] In one study, clinicians in the United States assessed burn scars on patients in Nepal via live video conferencing and obtained scar ratings (using the POSAS scale) that were consistent with in-person assessments.[11] The video-based remote evaluation was deemed an acceptable and low-cost solution for settings with limited access to burn specialists.[15] Thus, telemedicine helps overcome geographical barriers, allowing more frequent monitoring of scar maturation, therapy adjustments (e.g., compression, splinting, or laser treatments), and timely interventions for complications—all without requiring patients to travel. Patient satisfaction with tele-scar management has generally been high, and outcomes (in terms of scar appearance and function) have been comparable to traditional in-person care in reported cases. Although telemedicine in scar care currently ranges from simple "store-and-forward" wound images to real-time video clinics, emerging tools such as augmented reality are on the horizon to further enhance remote assessment and even guide therapy.[16]

Integrated Digital Care Pathways: Beyond one-off teleconsultations, comprehensive digital care pathways are being developed to coordinate scar management across time and providers. ScarPath (moveUP, Gent, Belgium) is a leading example of a personalized digital care pathway for scar patients.[4] It provides a platform where patients can input data about their scar (photos and symptom scores) and clinicians can log objective measures, all feeding into a shared record. This standardizes follow-up and ensures continuity as patients transition through various specialists (including surgeons, dermatologists and physiotherapists). Importantly, ScarPath was designed with patients as active users—they become "active players in assessing their scars," tracking their progress and treatments over time.[4] Early reports suggest that using ScarPath leads to more consistent scar evaluations and empowers patients by giving them feedback on their improvement. The system has also facilitated research: data collected via the pathway have been used in pragmatic studies and to develop predictive models for scar outcomes.[4] Notably, developers report that patients are key partners and the main focus of ScarPath, which aligns the technology with patient-centric care goals.[4] As more clinics adopt such digital pathways, we expect improved coordination of scar care (for instance, automatic reminders for therapy or alerts when a scar is

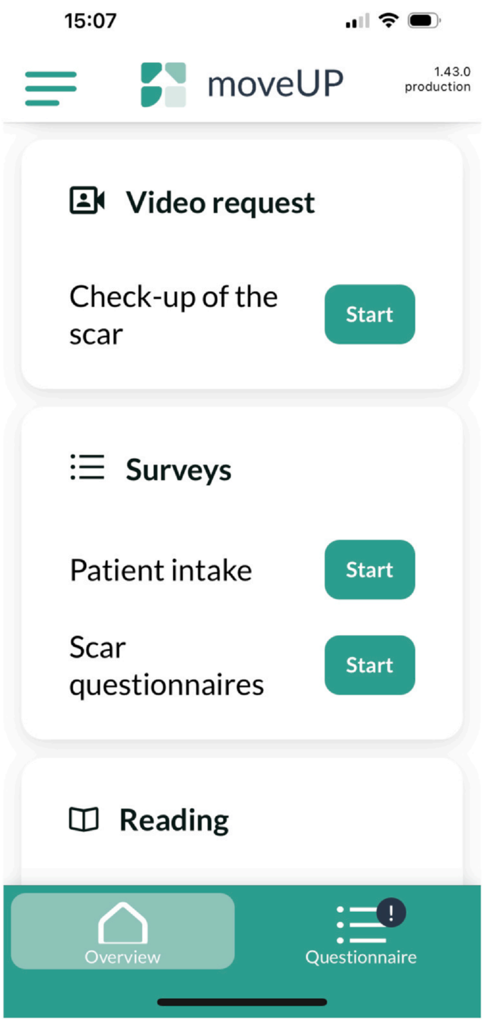

Figure 1 Screenshot of moveUP frontend ScarPath.

worsening) and more robust real-world evidence to refine treatment guidelines (Figures 1 and 2).

Mobile Apps for Self-Care: Another important trend is the development of smartphone applications aimed at helping patients manage their scars independently. These apps act as digital companions, offering educational resources, monitoring features, and also aiming to improve (sometimes direct) communication channels with care teams.[17] For instance, a 2018–2020 project in Iran resulted in a burn self-care smartphone app designed specifically to improve post-burn rehabilitation and education on scar outcomes.[18] This application featured interactive modules covering wound care, scar massage techniques, compression therapy methods, mobility-enhancing exercises, nutritional guidance for optimal healing, strategies for managing pain, and psychological support.[18] Burn patients who pilot-tested the app over one week reported it to be highly usable and found that it significantly enhanced their understanding of scar care and methods to prevent hypertrophic scarring.[18]

Complementing such digital applications, informative websites such as myscarspecialist.com have emerged as valuable resources for patients seeking evidence-based guidance on scar management.[19] MyScarSpecialist.com provides comprehensive educational materials, expert recommendations, and practical advice on various aspects of scar care, including therapeutic options, self-management strategies, and latest research updates.[19]

Within the mobile self-care ecosystems, MyScarSpecialist.com functions as a web-first companion that behaves similar to an app: users can enter via scar type, symptoms (Figure 3), or treatments (Figure 4) and receive concise "why/benefits/risks/next steps" guidance with a link to a verified database of specialized health care providers. Compared with society portals (e.g., AAD.org or nhs.uk/health-a-to-z/), which are authoritative but text-heavy, and industry-sponsored hubs (e.g., product-led

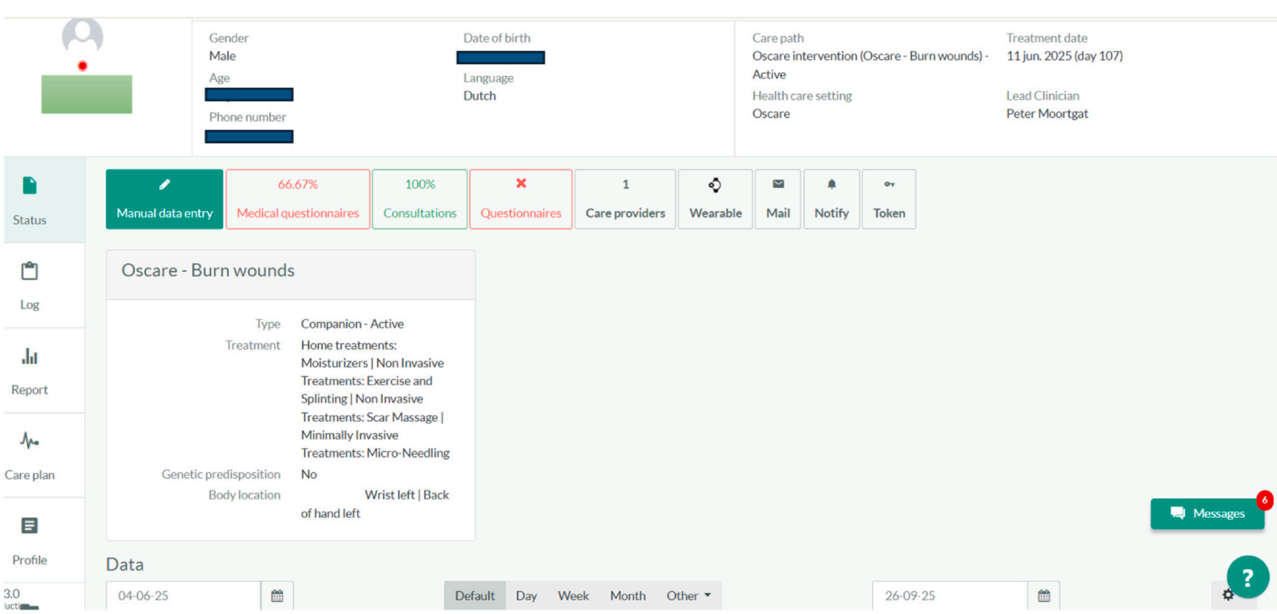

Figure 2 Screenshot of moveUP backend ScarPath.

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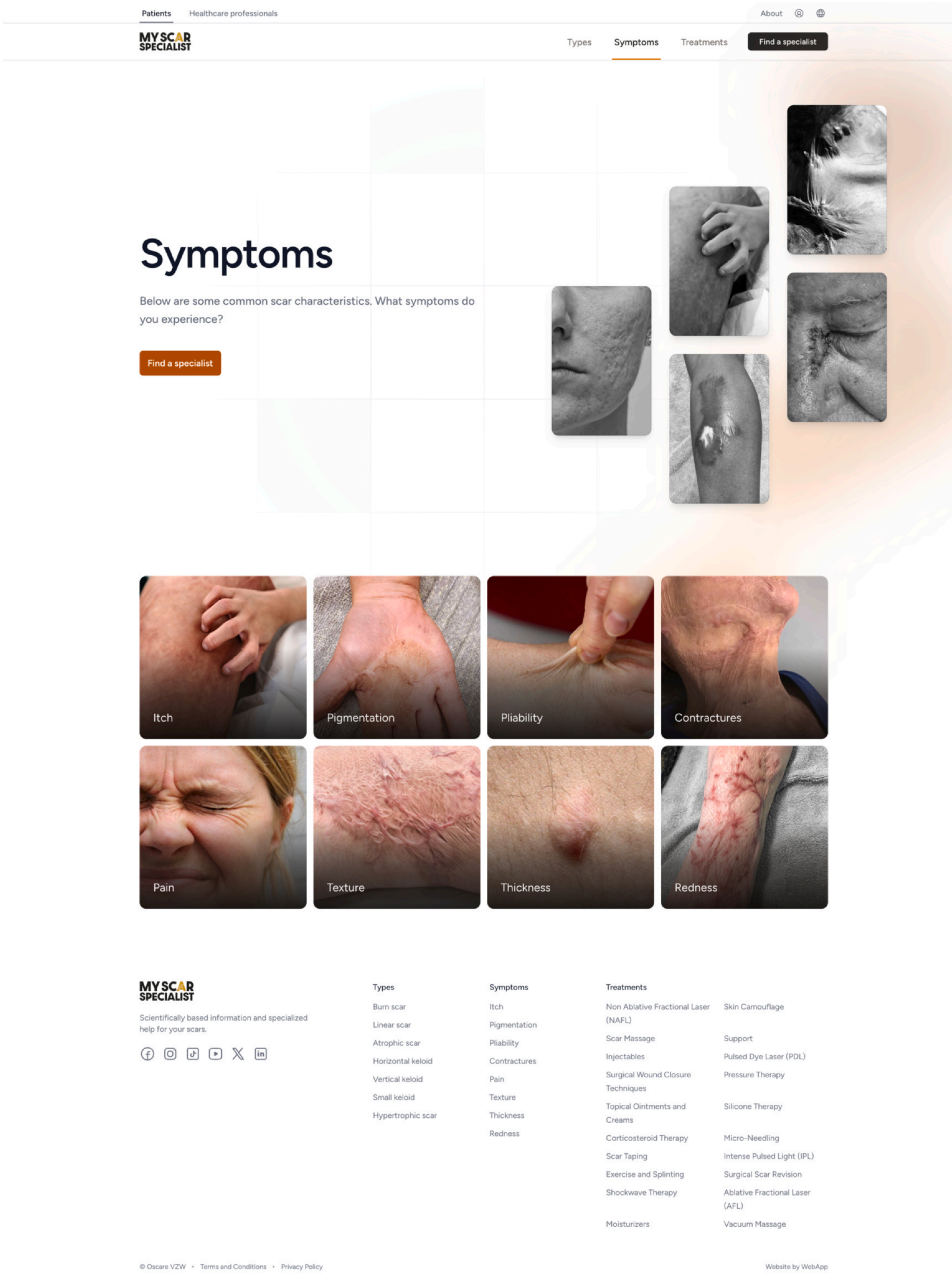

Figure 3 Overview scar symptoms from MSS.

German portals such as narbeninfo.de) that are engaging yet potentially biased, MyScarSpecialist balances breadth and neutrality (Table 1). Compared to community or advocacy sites, it offers deeper therapeutic coverage and clearer action cues, though it lacks inline primary citations and a native app. For self-care, this design supports the same behaviors targeted by mobile apps—daily massage, silicone use, sun protection, progress tracking—by turning educational content into structured, navigable tasks. In short, it bridges classic websites and self-care apps, complementing both and lowering the barrier for novices to act. Such online platforms empower patients by helping them make informed decisions regarding their scar treatments, in conjunction with the advice received through clinical care.

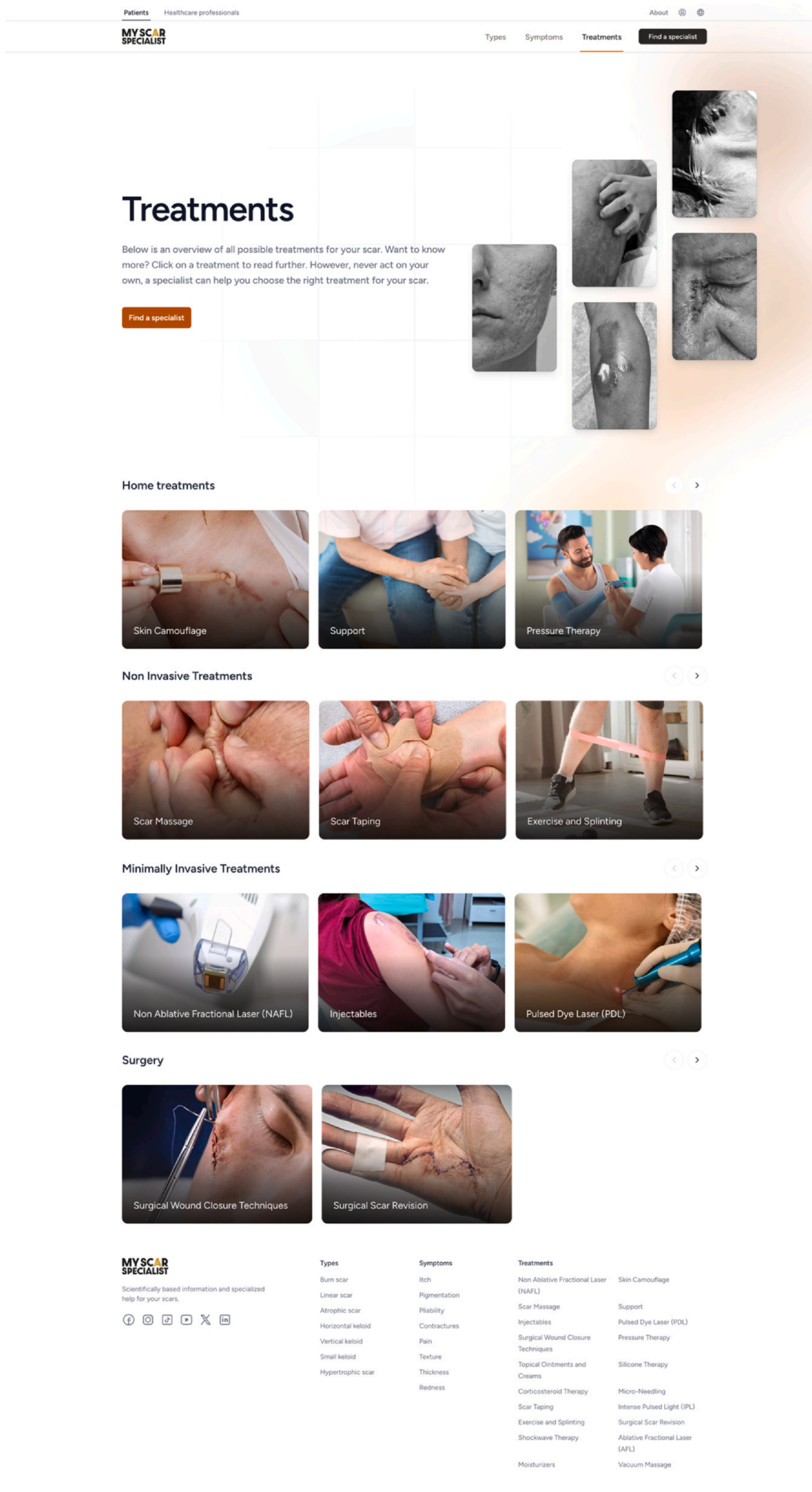

Figure 4 Overview scar treatments from MSS.

Globally, apps have also been introduced in the scar and skin world, allowing patients to take standardized photographs of their scars, receive immediate feedback, or systematically track scar progression over time. Some integrate standardized clinical assessment tools, such as the Vancouver Scar Scale or POSAS. Although several of these apps remain in early phases or are currently undergoing validation studies, they collectively signify an important transition toward continuous, patient-led scar management. Equipped with practical care tips, tracking

Table 1 Comparison of scar-education platforms.

Initiative (language)	Scientific quality	Design and visual appeal	Navigation and interactivity	Understandability	Content completeness	Unique value-add
MyScarSpecialist.com (EN)	**Good** – written by Oscare vzw burn-scar research center; gives quantitative details (e.g. 15-25 mm Hg for pressure garments) but provides *few in-text citations*	Modern, image-rich, mobile-responsive; "Less Scarring, More Confidence" hero banner and photographic scar gallery draw users in (My Scar Specialist)	Multi-layer menus by **scar type, symptom, or treatment** plus a geolocated **"Find a Specialist"** directory (My Scar Specialist, My Scar Specialist)	7-9th-grade wording, bulleted; pros/cons: readable but some clinical terms remain	Broadest of all reviewed sites > 30 treatments from moisturizers to lasers; covers symptoms, psychosocial support, and provider search (My Scar Specialist)	Combines encyclopedic content with a directory of vetted clinicians (Oscare network)—something lacking on most other sites
AAD.org (EN)	Excellent; dermatologist-peer-reviewed, updated regularly	Clean but text-heavy	Tabs and side index	Moderate (8th-grade)	Exhaustive	Authoritative brand trust
NHS.uk (EN)	High	Plain, high-contrast	Simple A-Z	Very easy (≈6th-grade)	Moderate	UK-specific care pathway links
Narbeninfo.de (DE)	Good, cites German guideline but product-sponsored	Bright, engaging	Quiz and video blocks	Lay German, friendly	Extensive	Emphasizes Contractubex® gel
Dermato-Info.fr (FR)	Very high (society authors)	Spartan	Encyclopedia index	Dense, technical	Extensive	Pathophysiology detail
LiveScarFree.org (EN)	Good (expert board; still growing)	Sleek, community-focused	Short cards and CTAs	Very easy	Moderate	Youth-oriented advocacy

functionalities, and reliable sources of information readily available on their mobile devices or through specialized websites, patients become better positioned to consistently follow recommended treatments (e.g., daily massage and silicone gel application) and proactively communicate concerns to clinicians when necessary.

The specialized multidisciplinary ambulatory Oscare approach,[20] making use of these digital tools, among others, appears to lead toward a better health-related quality of life (HRQoL). Preliminary results of a prospective observational study comparing burn aftercare approaches in Belgium over 12 months indicated that specialized aftercare patients showed the highest HRQoL, with EQ-5D-5L utility scores increasing from 0.73 to 0.87 and visual analog scale from 68.25 to 81.90. These HRQoL outcomes suggest that intensive aftercare in a specialized center may aid recovery, but several influencing factors must be considered, including differences in care structure, accessibility, and provider specialization.[21]

Artificial intelligence (AI) and Automation: Cutting-edge AI technologies are beginning to augment scar assessment and treatment planning.[22,23] Machine learning algorithms can analyze medical images and patient data to detect patterns that might be imperceptible to the human eye.[24] In the realm of scars, researchers have trained AI models on clinical photographs of scars to evaluate severity and predict future scar development. A recent 2023 study developed a deep neural network to predict post-surgical (thyroidectomy) scar severity from patient photos and clinical parameters.[25] Remarkably, the AI's performance in classifying scar severity was on par, achieving an accuracy comparable to that of experienced dermatologists.[25] Such an AI tool could be used in practice to identify high-risk scars early (e.g., predicting which surgical incisions are likely to become hypertrophic), allowing proactive treatment such as steroid injections or laser therapy at the optimal time.[25] Beyond classification, AI is also being explored for scar measurement (e.g., automatically calculating scar length, area, or color uniformity from images) and for personalized therapy recommendations (by learning which interventions worked best for similar patients).[26] Although still emerging, these AI applications hold promise for a future where scar management can be data-driven and tailored to the individual. Importantly, the integration of AI into scar care will rely on the robust datasets mentioned above—including real-world images and outcomes contributed by patients—underscoring how technology and patient involvement go hand in hand.

Challenges and considerations in digital health technologies

Although digital health innovations are transforming scar management, their rapid adoption introduces several critical challenges that must be addressed to ensure safe, equitable, and effective use.

Data privacy and security

Platforms such as ScarPath, smartphone apps, and telemedicine portals routinely collect sensitive patient data, including clinical details and scar photographs. Without robust encryption, secure storage, and transparent consent procedures, these systems are vulnerable to data breaches and misuse, risking patient trust. The ethical complexity increases when private, public, or commercial entities manage such data, necessitating stringent safeguards and regulatory compliance such as the General Data Protection Regulation (GDPR) or HIPAA.[27,28]

Algorithmic bias in AI

AI systems used for scar image assessment or outcome prediction can inadvertently perpetuate bias if trained on non-diverse datasets. For example, dermatology AI models may perform substantially worse on darker skin tones or uncommon conditions, as demonstrated by significantly lower accuracy in diverse datasets.[29,30] Unaddressed bias can lead to inequitable diagnostic accuracy, reinforcing disparities within already underserved communities.[31-35]

Equity in digital access

Although telemedicine has expanded access—such as enabling remote scar assessments via video consultations—it is contingent on patients having reliable internet access, appropriate devices, and sufficient digital literacy. This digital gap can deepen health inequities, particularly in rural and low-resource settings.[34,36] Addressing this calls for inclusive, multilingual interfaces, hybrid care models, and interventions tailored to reach underserved populations.

Black-Box AI and transparency

Several AI tools operate as "black boxes," producing outputs without explainable reasoning. This lack of transparency, specifically in the reasoning behind a certain outcome, undermines clinician and patient trust and complicates validation and accountability in clinical contexts.[37] Transparent, interpretable AI models and continuous human oversight are essential.

Clinical validation and regulatory oversight

Numerous digital tools are deployed before they have undergone thorough clinical validation or obtained regulatory approval. Ensuring tools are subject to rigorous testing, interoperability reviews, and compliance with healthcare standards is essential for safe integration into clinical practice.[29,38,39]

Addressing these challenges—by ensuring strong privacy protections, building diverse datasets, promoting equitable access, enforcing transparency, and pursuing proper validation—will be crucial to ensure that digital innovations enhance rather than fragment patient-centered scar care.

Conclusion and future directions

Over the past 10 years, scar care has undergone a clear evolution toward more innovative and patient-centered practices. Patients are no longer passive recipients of care; they help determine the research agenda, define meaningful outcomes, and even contribute data through digital means. The major advancements—from PPI in research design to increased use of PROMs, from crowdsourced insights to telehealth and AI—converge on a paradigm shift that scar management is becoming more holistic, personalized, and grounded in real patient experience. This shift is generating practical benefits, such as treatments that target patient-prioritized issues (such as itch, pain, and appearance), and care delivery models that improve access and engagement (via virtual clinics and apps). Notably, the focus on patient-reported outcomes ensures that "success" is measured by improvements in the perceived quality of life and not just clinical scar parameters.[8]

The coming years will likely build on these foundations. We need larger international collaborations with strong patient representation to tackle the remaining challenges of scarring (e.g., regenerative therapies that truly minimize scarring). Digital health tools will continue to mature—we may see AI embedded in smartphone apps that can instantly evaluate a scar's progress or suggest care adjustments. Similarly, ongoing collection of RWD through integrated pathways will feed continuous learning and improvement of treatment protocols. This narrative review is not systematic but reflects our unit's viewpoint, among several others, shaped by a multidisciplinary framework and active patient involvement.

In summary, the transformation in scar care is well underway, driven by innovative methods and technologies and characterized by an unprecedented levels of patient involvement. This patient-centric approach, supported by modern digital innovation, promises better outcomes and a future in which scar management is as responsive and adaptive as the patients it serves.

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Declaration of Competing Interest

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Declaration of Generative AI and AI-assisted technologies in the writing process

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