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From Voice to Value: Listening, Believing, Empowering, and Partnering with Patients in Rheumatology

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Introduction

Rheumatology stands at the forefront of cultural change in healthcare, where partnership between patients and professionals has evolved from principle to practice [1]. The management of chronic rheumatic and musculoskeletal diseases (RMDs) increasingly emphasises collaboration between patients, their families, and healthcare professionals (HCPs) from the multi-disciplinary team [2]. Health systems globally, including the National Health Service (NHS) in the United Kingdom, are transitioning towards individualised care frameworks that prioritise co-production, shared decision-making (SDM), and supported self-management [3]. Although co-production and shared decision-making have been embedded in some health systems for decades, recent pressures on healthcare delivery have risked deprioritising these principles in routine care. In the UK, workforce shortages, increasing outpatient demand, and service redesign initiatives such as patient-initiated follow-up (PIFU) have altered traditional clinician–patient interactions, making it timely to revisit how patient partnership can be preserved and strengthened rather than unintentionally eroded. British Society for Rheumatology (BSR) recently organised the inaugural 'Patient Voices in Rheumatology' course in 2025 in order to highlight this issue. Rheumatology has seen collaborative initiatives such as the Outcome Measures in Rheumatology (OMERACT), which formalised patient involvement in research agenda setting [4]. However, despite progress, many patients continue to report feeling unheard or their concerns ignored, particularly with subjective and complex symptoms. The introduction of PIFU can potentially make this disconnect worse [5]. This has several consequences: 1) many patients will have less interaction with their team over potentially longer periods of time 2) the pressure on workforce and a system which is struggling to cope tends not to prioritise SDM and co-design when faced with a backlog of people waiting to be seen and these are often the first things to disappear 3) Patient organisations working collaboratively with health professional bodies such as the BSR can help to keep such priorities in the public eye and on the NHS' agenda. The NHS 10-year plan talks about patient centred care which is well meaning but there is concern about unintended consequences. Hence, we propose a practical, multi-level engagement framework spanning patient, clinician, and organisational domains, designed to translate patient voice into sustained value in routine rheumatology care.

Trust, Communication, and Validation

Trust forms the foundation of the HCP–patient relationship and is the cornerstone for building self-management skills. A breakdown of trust can have lasting effects on health behaviours and care outcomes [6]. When symptoms are difficult to measure—such as fatigue, pain, or cognitive fog—patients often perceive that their experiences are undervalued or dismissed. Studies in chronic illness show that perceived disbelief contributes to disengagement from care and consequently, lower adherence to treatment and worse health practices [7]. Patients with prior experiences of invalidation or misdiagnosis may exhibit defensive or avoidant behaviours in subsequent encounters [8]. HCPs who explicitly acknowledge uncertainty and validate patient experiences ("I believe you") can rebuild psychological safety and foster mutual trust.

Communication that integrates empathy, curiosity, and shared reflection enhances both diagnostic accuracy and therapeutic alliance [9]. It is also important to recognise that psychological distress, including anxiety and depression, can reduce patients' capacity or motivation to engage with their healthcare team and to sustain self-management behaviours. Addressing these symptoms through open dialogue, screening, and timely referral to psychosocial and other sources of support (e.g. relevant patient organisations) is essential to restoring confidence and participation in care. Conversely, rigid biomedical consultations risk reinforcing power imbalances and perpetuating the notion that invisible symptoms are less legitimate. In rheumatology, where biomarkers often poorly reflect lived disease burden, validation becomes a prerequisite for accurate assessment, sustained engagement, and effective long-term management. Validation transforms the consultation from information exchange into partnership, strengthening trust, adherence to treatment, and self-efficacy, ultimately improving overall health outcomes.

Health Literacy, Risk Communication, and Adherence

Adherence to conventional synthetic, biologic and targeted synthetic disease-modifying antirheumatic drugs (DMARDs) remains variable, with rates of 50–80% reported in the research literature [10,11]. Effective adherence begins with shared understanding – a product of communication as much as cognition. One of the most overlooked determinants of adherence is health literacy: the ability to obtain, process, and act upon health information. Rowlands et al. highlighted a systemic mismatch between public health literacy levels and the complexity of medical communication [12]. Patients frequently struggle to interpret risk–benefit information about therapies when explained in health jargon rather than within a lay context leading to anxiety and inconsistent use. The 'teach-back' approach, where HCPs ask patients to repeat information in their own words, can significantly improve understanding and recall [13]. Motivational interviewing (MI), particularly using open questions, affirmations, reflections, and summaries (OARS), can help HCPs explore ambivalence and align treatment choices with patient priorities [14]. Applying MI principles within rheumatology consultations has been shown to improve methotrexate adherence, supporting sustained treatment engagement and better long-term disease control with cost savings – in this study from Manchester, non-adherence reduced from 24.7% to 7.4% with improvements in remission rates from 13% at baseline to 37% post intervention resulting in estimated cost savings of £30 000 per year [15]. This degree of improvement highlights motivational interviewing not merely as a communication technique, but as a high-value clinical intervention with tangible effects on adherence, remission, and healthcare costs. Addressing cultural and linguistic barriers to health literacy through tailored communication and co-produced materials further enhances engagement. It is important to remember that for patients where English is not the first language, accredited interpreters and translators should be considered as relying only on native-speaking patients/family members may compromise accuracy, confidentiality, and shared decision-making.

SDM and Collaboration

SDM lies at the core of collaborative care, particularly when treatment options involve uncertainty and trade-offs. Elwyn et al. conceptualised SDM through three phases: team talk, option talk, and decision talk [16]. In rheumatology, SDM supports nuanced discussions around long-term immunosuppression, pregnancy planning, and lifestyle modification, amongst many other important topics. Decision aids, such as risk communication graphics and interactive tools, can reduce decisional conflict and enhance patient satisfaction [17]. However, implementation remains inconsistent, hindered by time pressures and variable HCP familiarity and confidence. Training programmes in SDM and empathic communication can bridge gaps, and integrated patient-reported outcome measures (PROMs) can guide dialogue. Patients who perceive genuine involvement in decisions report higher trust, adherence, and sense of control [18].

Supported Self-Management and Empowerment

Empowerment is not an adjunct to care provisions – it is a mechanism through which care succeeds over time by upskilling patients. The 2021 European Alliance of Associations for Rheumatology (EULAR) recommendations for implementation of self-management strategies emphasised embedding self-management strategies throughout the patient journey, supported by multidisciplinary input and co-design [19]. Effective self-management includes adherence, symptom monitoring, lifestyle modification, and psychological adaptation [20] and requires the right support from different sources, e.g. rheumatology team, patient organisations, family/friends at the right time. The Self-Management Individualised Learning Environment (SMILE) in RA e-learning programme from the National Rheumatoid Arthritis Society (NRAS), for example, evaluated in 134 participants using pre-/post-module survey comparison, has demonstrated significant improvements in patient knowledge (50% vs 90%, $p<0.01$) and confidence to manage flares (44% vs 90%, $p<0.01$) [21]. These findings illustrate how structured, co-produced educational interventions can measurably improve confidence and self-management skills at scale, beyond what can realistically be achieved within time-limited outpatient consultations. HCPs enabling supported self-management can transform the outpatient model—from reactive review to proactive partnership—reducing unnecessary consultations, thus reducing clinical burden while improving outcomes.

Advocacy, Co-Production, and Cultural Responsiveness

Cultural change becomes tangible when patient interactions move from consultation to co-creation. There is a diverse range of rheumatology patient organisations in the UK (Supplementary Table S1). These organisations, in addition to the Arthritis and

Musculoskeletal Alliance, have co-produced educational materials, established peer support networks, and influenced policy development, placing lived experience at the centre of rheumatology education, service design, and advocacy. Co-design ensures that communication reflects diverse needs, literacy levels, and cultural contexts. Cultural competence has evolved towards cultural responsiveness—actively adapting practice to patient context, language, and values [22]. This includes recognising socioeconomic barriers, digital exclusion, and intersectional identities that influence access to care. Adopting inclusive language ("people with RA" rather than "RA patients") promotes dignity and shared humanity. We consider cultural humility to be of paramount importance, and not just cultural sensitivity and cultural competence. When co-production becomes culture, equity and quality are no longer parallel ambitions—they become the same outcome.

Combating Misinformation and Digital Health Literacy

Digital platforms now shape clinical conversations before they begin. Online communities can foster peer support and advocacy but also propagate misinformation, particularly around pharmacotherapy and complementary treatments. HCPs play a vital role in fostering digital health literacy by guiding patients toward evidence-based sources of information and encouraging critical appraisal of such information [23]. Co-produced educational resources, such as video explainers and patient-authored content, offer credible, accessible counterpoints to unverified claims. Severe time pressures and implicit biases and assumptions can impact consultations, and these can be mitigated by training, reflection and better planning. Artificial intelligence (AI) is further transforming the healthcare landscape and is becoming used widely by HCPs and patients—amplifying both opportunity and risk. Whilst these tools can enhance access to understandable health information, they also have the potential to perpetuate inaccuracies or biases in existing literature and HCPs therefore need to carefully incorporate trusted, transparent, and co-developed digital tools [24,25,26]. HCPs should continue to approach misinformation with empathy, exploring the emotions underlying belief in non-evidence based or wrong information rather than confrontation or dismissal. By believing in patients' capacity to learn and lead, and by collaborating on digital and AI-enabled education, HCPs can

transform misinformation into shared digital empowerment. Some practical steps to support optimal patient partnerships are outlined in Table 1.
{Insert Table 1 here}

Integrating the Patient Voice in Research and Service Design

Patient involvement in research has evolved from consultation to genuine partnership in recent years. The OMERACT initiative pioneered patient involvement in research, leading to inclusion of fatigue and participation as core rheumatoid arthritis outcomes [27]. Similarly, the National Institute for Health and Care Research (NIHR) in the UK and EULAR People with Arthritis/Rheumatism in Europe (PARE) have formalised frameworks for patient involvement in research governance. Several other co-designed interventions already exist such as EULAR self-management course, development of Rheumatoid Arthritis Impact of Disease (RAID) score, translated and culturally adapted educational resources for patients from ethnic minority groups (such as 'Apni Jung' (NRAS) and 'Yeh Hai Lupus' (Lupus UK)), and co-designed online symptom trackers.

Patient partners contribute experiential knowledge that supports the identification of relevant unmet needs and appropriate research questions, while enhancing study design, recruitment, evaluation, and dissemination. In service design, patients can help tailor clinical environments and communication practices to better meet real-world needs. Embedding patient voices in governance structures ensures that services remain responsive, accountable and equitable. However, systemic barriers—HCP time, fragmented care pathways, digital inequity, lack of accessible resources in clinics and organisational inertia—limit widespread adoption. Improving this culture requires institutional commitment and resourcing, training, and the integration of patient-centred metrics into performance frameworks. This partnership can also reveal barriers and priorities that are frequently missed in clinician- or system-led design alone, improving acceptability, feasibility, and real-world uptake of interventions and services. Building on the engagement framework outlined earlier, we propose a preliminary conceptual model of empowerment relevant to rheumatology, comprising seven proposed domains: (1) understanding the condition; (2) recognising and responding to flares; (3) confidence in treatment decisions; (4) feeling believed and validated; (5) partnership and shared decision-making; (6) self-management skills and confidence; and (7) navigation of services and support.

Conclusion

Patient voices are not peripheral—they are fundamental and must be at the heart of rheumatology practice. Believing, empowering, and partnering with patients re-humanises care and aligns medical success with personal wellbeing. Embedding co-production, cultural responsiveness, cultural humility, motivational interviewing and SDM into clinical routines strengthens trust and equity, and ultimately, improves outcomes. A whole-system approach that integrates patient voices at individual, clinician, and organisational levels can strengthen therapeutic relationships, support self-management, and improve the quality and value of rheumatology care as well as improving patient outcomes.

Statements and Declarations

Competing Interests

Shirish Dubey: No conflicts relating to this article.

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Spencer Ellis: Trustee British Society for Rheumatology

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