

From paediatric to adult care in Still's disease: addressing barriers and proposing a transition model for Italy

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Still's disease is a rare, idiopathic, systemic autoinflammatory disorder characterised by spiking fevers, evanescent rash, arthritis and elevated ferritin levels (1). Historically, it was considered as two distinct diseases, namely systemic juvenile idiopathic arthritis (sJIA) and adult-onset Still's disease (AOSD) (2, 3). However, these conditions now represent a continuum of Still's disease, distinguished by age at onset (2, 3).

Previously, sJIA was classified as a subtype of juvenile idiopathic arthritis (JIA), the most common rheumatic disease in childhood (4). JIA encompasses a group of several chronic arthritides, which are the leading cause of acquired physical disability in paediatric patients (3-5). This historical classification means that much of the evidence in JIA is relevant for patients across the Still's disease spectrum. Because sJIA and AOSD are now recognised as the paediatric- and adult-onset manifestations of a single disease continuum that shares overlapping clinical features, pathogenesis, and treatment responses, the transition models and evidence developed for JIA can be reasonably extended to the entire Still's disease spectrum.

Nearly half of patients with JIA require a structured transition from paediatric to adult healthcare to ensure continuity of care, prevent dropout, and reduce disease activity (6-9); yet its implementation is challenging (10). Several factors contribute to this issue, affecting up to 50% of patients who experience care discontinuation, including (10):

- Poor treatment adherence, limited self-advocacy and reluctance to leave trusted paediatric providers.

- Few centres have tertiary expertise in this rare condition, leaving patients without access to the specialist knowledge.
- Difficulty among parents and paediatric providers in 'releasing' the young person.
- Incomplete transfer of medical records.
- Inadequate education of patients and caregivers.
- Limited adolescent-specific expertise among adult healthcare providers.

To address these challenges and create a clear and structured framework for the transitional program in rheumatological care, the EULAR/PReS 2017 guidelines were developed (11).

In Italy, however, their implementation remains limited by heterogeneous practices across centres, unclear division of responsibilities, and insufficient organisational and funding support (5). These challenges are not unique to Italy; they reflect the international absence of formalised transition frameworks and adequately resourced implementation strategies (10, 12).

This editorial discusses the main barriers to effective transition of care for Still's disease within the Italian healthcare system and proposes a tailored transition model for local clinical practice. Drawing on existing literature and a structured discussion among Italian Key Opinion Leaders (KOL) in rheumatology, it outlines practical, standardised criteria for implementing a structured transition pathway for Still's disease. Supported by appropriate governance, workforce capacity, and resources, the proposed pathway aims to reduce loss to follow-up and improve patient-centred outcomes.

The Italian landscape: barriers to transitional care

Several barriers hinder effective transitional care in rheumatology, spanning system-level organisation, clinical harmonisation, education and funding.

System-level and organisational gaps

Key system-level barriers to effective transitional care in Italy are: (5)

- Heterogeneous implementation of transition pathways across centres.
- Poorly defined responsibilities between paediatric and adult rheumatologists.
- Limited availability of centres offering both paediatric and adult rheumatology services.
- Lack of a formal definition and structured organisation of the transition process.
- Absence of dedicated funding.

The structured discussion between KOL also highlighted several organisational gaps, most notably the absence of dedicated case managers, as their inclusion has been shown to improve transition outcomes (13). This reflects both the heterogeneous organisational structures across Italian centres and the high personnel turnover.

Another organisational gap is represented by the lack of standardised processes for shared documentation and the limited interoperability of information systems. Successful transition requires strong coordination between paediatric and adult teams and the timely transfer of complete clinical information (10). Evidence suggests that incorporating standardised transition documentation into the records transferred to the adult rheumatologist improves outcomes (14, 15).

Identifying adult rheumatologists for complex cases also remains difficult. This reflects the limited training adult rheumatologists receive in managing paediatric-onset diseases and the insufficient clinical support they often report (16). Referral to adult rheumatology is further governed by pragmatic organisational criteria, such as catchment area boundaries and patient proximity, constraints that have also been reported in UK clinical networks (17). Moreover, the sparse and uneven distribution of

tertiary referral centres leaves large areas of the country without local coverage, forcing patients to travel outside their region for specialist care.

These gaps result in a transition process based on individual clinical initiatives and informal inter-institutional agreements rather than on standardised protocols. This situation mirrors the European landscape, where only 27% of centres have a formal written transition policy, and most clinicians report the absence of structured procedures (12).

Clinical harmonisation and therapeutic alignment

The absence of harmonised clinical parameters is a critical gap in Still's disease management. Notably, no validated disease-activity score exists for adult patients (18), which hinders cross-study comparison and limits the ability to draw robust conclusions from the literature (19). Second, no standardised outcome measures are available to evaluate the effectiveness of transition interventions, making it difficult to assess whether structured transition pathways translate into meaningful clinical benefit (6, 19, 20). Moreover, no single assessment tool includes both age groups, so disease-activity measurement remains inconsistent across the transition, exacerbating the difficulty of evaluating the transition pathway in its entirety.

While disease activity assessment is relatively well characterised in children, significant gaps remain in adults and across the transition period. The sJADAS-10 (ESR) is a validated tool that discriminates between inactive, moderately active, active, and highly active disease states in children (21, 22). No equivalent tool has been established for adult patients (18), leaving clinicians without a reliable benchmark for longitudinal assessment beyond childhood.

Although standardised disease activity assessment is a prerequisite for consistent monitoring, it remains insufficient to determine whether the transition process itself has succeeded. Outcome measures for transition interventions remain poorly defined (6, 19, 20), mainly because the definition of 'successful transition' varies across clinicians,

health services, patients, and families (20, 23). As a result, interventions are evaluated inconsistently, with few studies measuring the same outcome.

Together, these gaps undermine disease monitoring across paediatric and adult settings and are a priority area for future research.

Education and training gaps

KOL identified three interrelated barriers to effective transition in the domain of education and training. First, disease awareness remains limited among both general practitioners and specialist clinicians outside dedicated rheumatology centres (24). Second, practice patterns across paediatric and adult rheumatology centres are heterogeneous, with limited alignment of care strategies across age groups (25, 26). Third, structured patient education programs remain inconsistently implemented, leaving many young adults insufficiently prepared to self-manage their condition (2, 27).

These gaps are compounded by structural deficiencies. The absence of dedicated transition staff, inadequate funding, and the lack of a specific reimbursement code within national or insurance billing systems all undermine the sustainability of structured transition models. Despite their potential to improve transition outcomes in patients with chronic conditions, these initiatives are frequently constrained by limited resources (25). A European survey found that while many centres offer some form of transition service, only a minority have designated transition staff, reflecting broader gaps in funding and staffing models (12).

The Italian landscape of transitional care: where do we stand?

In Italy, transition typically occurs through direct clinical handover between paediatric and adult rheumatologists, based on personal communication and the transfer of clinical and therapeutic summaries, often without formal procedures (5). As a result, the process lacks standardisation and varies across centres, depending on the clinicians involved and on the available resources. In some Italian settings, however, tran-

sition is achieved effectively and concretely. Some centres have established dedicated transition clinics and multidisciplinary teams, including a psychologist and a reference nurse or case manager, as recommended by EULAR/PRES guidelines (11). Where resources allow, paediatric and adult rheumatologists conduct joint consultations, either in person or remotely, with regular time slots or virtual boards dedicated to case review and asynchronous documentation. Shared care is maintained whenever possible until the patient's transfer to the adult rheumatologist.

This model reflects current service constraints and limited funding (5) rather than an optimal, needs-based model approach. It should be systematically refined to better account for diagnosis, disease severity, and patient preferences, as outlined in the practical criteria that follow.

Proposed transition model for Still's disease

System-level and organisational structure

To address the structural and organisational gaps described above, we propose a formalised transition model for Still's disease in Italy, designed to standardise practice and ensure continuity of care from paediatric to adult settings. Structured transition programs in rheumatology improve adherence to adult follow-up, patient and parent satisfaction, and reduce dropout rates (28, 29); while standardisation clarifies roles and responsibilities and improves resource allocation (30).

The model should also include shared paediatric and adult outpatient clinics, which have been associated with higher patient satisfaction, improved follow-up, and lower dropout rates (31, 32). Telemedicine should be incorporated in the transition process to facilitate collaboration between paediatric and adult teams and support continuity of care (33). Its capacity to connect patients in underserved regions with expert centres reduces travel burden and expands access where specialist services are limited or absent (33). The transition-timeline we proposed is depicted in Figure 1. We also propose stratifying referral

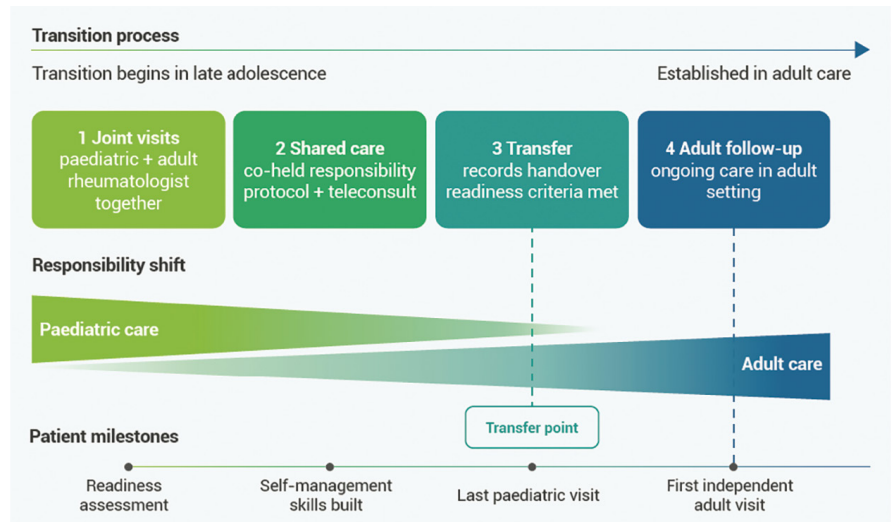


Fig. 1. Proposed pathway for rheumatological transition from paediatric to adult care.

pathways according to the availability of paediatric and adult referral centres in the same Institution and disease severity (Fig. 1). In an ideal situation, the transition process is carried out between the paediatric facility and the adult facility located within the same Institution or the same city, in accordance with the procedures outlined in Figure 2 and the EULAR recommendations (11). In the absence of territorial continuity between the paediatric and adult reference centres, the transition procedure may involve a series of joint telemedicine visits, with the patient physically present at the paediatric centre during the first visits and subsequently at the adult centre. Complex cases would be directed to specialised Still's disease centres, while stable or low-complexity cases would be managed at a local level through shared-care protocols, with rapid access to reference centres when needed through a hub and spoke model (Fig. 2). In this context, the regionalisation of the Italian healthcare system, which mandates the establishment of second-level centres across all regions, may further support implementation of this stratified referral framework. To put this into practice, the Italian Society for Rheumatology (SIR) and the Italian Society for Paediatric Rheumatology (Reumaped) should map and formally designate specialised Still's disease centres across the national territory. With their national reach across adult

and paediatric care, they can lead this effort by defining transparent accreditation criteria, identifying the centres that meet them, and maintaining an up-to-date register of accredited Still's disease reference centres.

The transition process should be coordinated by a dedicated case manager: the paediatric rheumatologist when the receiving centre is a local adult second-level facility, or the adult rheumatologist at third-level centres. In these scenarios, having a pool of 2–3 experts can facilitate communication with peripheral centres.

Case managers should be supported by a psychologist and a reference nurse. Nurses may serve as transition coordinators, facilitating communication between paediatric and adult teams (10, 12), supporting patient education, parent guidance, and peer support initiatives (10). Transition programs that include a nurse and a dedicated case manager have been shown to reduce dropout from adult clinics among adolescents with chronic inflammatory diseases (13, 34). The integration of a psychologist is essential, as adolescents with chronic diseases face an increased risk of depression and anxiety (35). Beyond these professional roles, effective implementation of this model also requires a standardised coordination and communication infrastructure (36). Studies support the adoption of centralised interoperable systems that enable information sharing across

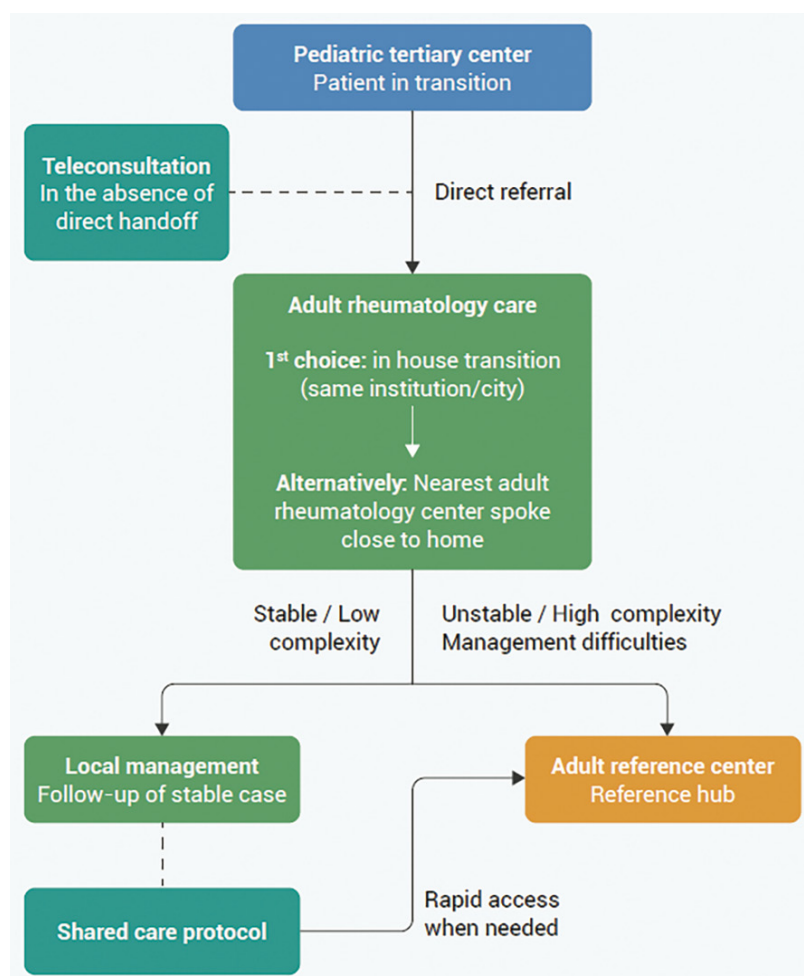


Fig. 2. Proposed referral pathways stratified by diagnosis and disease severity.

providers and care settings (23, 37). To address this need, we propose implementing a shared electronic medical record that facilitates information exchange among paediatric services, adult services, and general practitioners or primary care paediatricians. The system should provide real-time access to clinical documentation across institutions, supporting coordinated care throughout the transition process.

The model should also include formal inter-institutional agreements that authorise paediatric rheumatologists to practice in adult hospitals and adult rheumatologists in paediatric settings. Such arrangements support joint consultations and shared clinical protocols, which have been associated with high patient satisfaction, improved retention, and better disease outcomes (20). While developed in the context of Still's disease, this transition model is not disease-specific in its architecture.

Its core components may be transferable to other rare and autoinflammatory conditions, where the challenges of paediatric-to-adult transition remain largely unaddressed (38, 39).

Clinical harmonisation and therapeutic alignment

The need to harmonise clinical parameters across settings is a prerequisite for consistent disease monitoring and reliable comparison of patient outcomes following transition (19, 40). They must be valid, reliable, and transferable across clinical settings, and should incorporate precise definitions of the clinical features that characterise the patient's condition (18). Because Still's disease is a single disease across age groups (2, 3), these parameters should remain consistent throughout the transition process. However, clinical parameters that fulfil these criteria are currently lacking, contributing to

a reliance on heterogeneous endpoints across studies, which limits their comparability (6, 19, 41).

This absence is evident across two key areas: (i) the lack of standardised disease activity assessment tools and (ii) the absence of harmonised outcome measures for evaluating transition interventions.

To address the first, we propose the development of a validated disease-activity score applicable across age groups as a cornerstone of effective transition. Rather than adapting instruments originally designed for either paediatric or adult populations alone, such a tool should incorporate age-adjusted weights and thresholds, ensuring continuity of measurement across the transition period. In the meantime, validation of instruments in the counterpart age could help to fill the gap.

In parallel, we advocate for the establishment of standardised, consensus-driven outcome measures for transition interventions. These should be built around an explicit, agreed-upon definition of successful transition, one that captures clinical stability, healthcare self-management, and patient-reported outcomes, enabling consistent evaluation across studies and settings.

The model should also incorporate a unified therapeutic strategy. A joint EULAR/PRoS task force has proposed a shared two-step treatment algorithm for Still's disease, recommending early IL-1 or IL-6 blockade, defined glucocorticoid tapering targets, treatment escalation or switching in non-responders, and referral to expert centres (2). Shared outcome measures can reinforce treat-to-target goals at all ages (2). Transition planning should be personalised to each patient's phenotype, disease severity, and individual needs. Still's disease-specific documentation, for both paediatric and adult settings, should clearly define roles, responsibilities, and key professionals along the care pathway.

Education and training for sustainable implementation

The barriers identified previously (limited disease awareness, heterogeneous specialist practices, and insufficient patient education) require coordinated

interventions at multiple levels of the healthcare system.

Limited disease awareness beyond dedicated rheumatology settings remains a challenge. We propose integrating primary care clinicians, including general practitioners and paediatric primary care physicians, not only during the transition, as suggested by EULAR/PReS recommendations (11), but also into the post-transition continuum of care. This would support ongoing monitoring and comorbidity management in patients who may have limited access to specialist follow-up.

At the specialist level, we propose joint training programmes for paediatric and adult rheumatologists, focused on the specific features of paediatric-onset Still's disease, the management of comorbidities emerging in adulthood, and the alignment of care strategies across age groups. Shared case discussions and cross-centre collaborations could serve as practical vehicles for this exchange.

In parallel, structured patient education programs should be systematically integrated into transition pathways, equipping patients with the knowledge of disease and self-monitoring skills to manage their condition independently in adult care settings (42).

Finally, implementing an effective transition model demands adequate funding, dedicated personnel and physical spaces, and the introduction of a specific transition reimbursement code within national or insurance billing frameworks, ensuring that transition services are formally recognised, billable and staffed appropriately.

Conclusions

Transitional care in Still's disease remains inadequate in practice. Dropout rates are high, continuity of care is fragile, and the EULAR/PReS guidelines, while well-conceived, are difficult to implement without adaptation to local contexts (12, 24, 43).

We propose a structured transition model for Still's disease tailored to the Italian healthcare system. Drawing on EULAR/PReS recommendations as a foundation, the model goes beyond their translation into clinical practice by introducing a novel organisational

framework that addresses system-level barriers through clear roles, referral pathways, and shared clinical standards. Its success, however, depends on political will and sustained investment. Without dedicated personnel, adequate infrastructure, and a specific reimbursement code, implementation will remain fragmented and unsustainable, and this model risks joining a long list of well-intentioned guidelines that never reached the clinic.

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