

Consensus of the Spanish society of pediatric rheumatology for transition management from pediatric to adult care in rheumatic patients with childhood onset

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Abstract To develop recommendations on the transition from pediatric care to adult care in patients with chronic inflammatory rheumatic diseases with childhood onset based. Recommendations were generated following nominal group methodology and Delphi technique. A panel of 16 experts was established. A systematic literature review (on transitional care) and a narrative review were performed and presented to the panel in the first panel meeting to be discussed. A first draft of recommendations was generated and circulated. Focal groups with adolescents, young adults and parents were organized. In a second meeting, the focus group results along with the input from invited psychologist were used to establish definitive recommendations. Then, a Delphi process (two rounds) was carried

out. A group of 72 pediatric and adult rheumatologists took part. Recommendations were voted from 1 (total disagreement) to 10 (total agreement). We defined agreement if at least 70 % voted ≥ 7 . The level of evidence and grade of recommendation was assessed using the Oxford center for evidence-based medicine levels of evidence. Transition care was defined as a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic inflammatory rheumatic diseases with childhood onset as they move from child-centered to adult-oriented healthcare systems. The consensus covers: transition needs, barriers and facilitators, transitional issues (objectives, participants, content, phases, timing, plans, documentation and responsibilities), physicians' and other health professionals' knowledge and skill requirements, models/programs, and strategies and guideline for implementation. Preliminary recommendations and agreement grade are shown in the Table (first Delphi

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round). These recommendations are intended to provide health professionals, patients, families and other stakeholders with a consensus on the transition process from pediatric to adult care.

Keywords Pediatric rheumatology · Transitional care · Adolescent

Introduction

During the last decades, the management of patients with pediatric rheumatic diseases has substantially evolved improving survival and quality of life [1, 2]. However, there are some areas that currently require further research and development.

One of these challenges is transitional care from pediatric to adult care. Transitional care is a holistic, multidimensional, multidisciplinary and active process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults as they move from child- to adult-centered care [3]. Nowadays, although there have only been limited evaluations of transitional care programmes that support beneficial outcomes in rheumatic and other chronic diseases [3–9], the need for transitional care in rheumatology is well established.

However, it has been published that up to 45 % of pediatric rheumatologists are reluctant to attend patients over 18 years and 50 % of adult rheumatologists to treat patients under 17 years [10]. There also seems to be a lack of coordination between professionals and healthcare levels [11], and unmet education and training needs as well [12–14].

Another aspect to consider is that adolescence is a very important period. Mental health professionals call attention to this age, as it is the time when individual identity develops [15]. This is extremely important, since 50 % of patients with juvenile idiopathic arthritis and depression must suffer their first episode between 15 and 25 years [16].

Despite increasing calls for the development of transitional care in rheumatology [17, 18], changes have been slow to occur [19–22]. In fact, it has been reported that only 14 % of 5400 adolescents with special healthcare needs among respondents received appropriate guidance and support for the transition process to adult age [23].

Based on the exposed above, the Spanish society of pediatric rheumatology (SERPE) launched the NextStep project. A part of this project is the generation of a consensus statement on transitional care in pediatric rheumatology. We have covered general aspects of transitional care as well as transition models and strategies for implementation (taking into account the applicability of the consensus according to the specificity of the Spanish rheumatology

system). We are confident that this will be very useful not only for pediatric and adult rheumatologists, but also for other specialists, health professionals and health policy makers that care for persons with pediatric rheumatic diseases.

Methods

Setting

The SERPE issued these recommendations (but have no other role in the development of the recommendations). This consensus was approved by the Ethic Committee of Hospital La Fe. For the development of these recommendations, we applied: nominal and discussion groups, systematic and narrative reviews and Delphi surveys. A panel of 16 experts (8 pediatricians, 8 rheumatologists) based on their clinical and academic expertise in transitional care was selected. Geographical representativeness was also taken into account.

Systematic and narrative reviews

A systematic literature review (on transitional care) following the Cochrane Collaboration guideline and a narrative review (websites, clinical guidelines and other relevant documentation) were performed. In the systematic review, studies were identified by sensitive search strategies in the main bibliographic databases (MEDLINE, EMBASE and Cochrane Library). Mesh terms and text word were used. Two reviewers (EL and MGY) screened the titles and abstracts of the retrieved articles independently. EL reviewed the selected articles in detail and collected data. A hand search was completed. An ad hoc risk of bias scale was used.

Focus groups and survey

A total of five focal groups of 10–15 participants each (from the same hospital) with adolescents, young adults and parents were organized separately. We developed a typological box to identify the profiles of participants to ensure the diversity of views and the number of groups that would be necessary. At the same time, a survey addressing adult rheumatologist's knowledge, barriers and facilitators on transitional care was sent to almost 300 rheumatologists (response rate ~40 %).

Recommendations generation

The results of the reviews were presented and discussed in the first panel meeting. In this meeting, the panel decided

on the framework (a particular set of rules, ideas and structure) in order to deal with transition-related problems or decisions, aims, scope, and users of the document. The panel also took into account the characteristics of the Spanish health system and defined the document structure and topics. The panelists were grouped and assigned to the document parts. Then, though several teleconferences with the methodologist, each part was discussed in detail taking into account the evidence and their experience, and main points and recommendations agreed. A first draft of recommendations was generated and circulated for comments and wording refinements to all panelists.

In a second panel meeting, the focus group and survey results along with the input from an expert psychologist were used to establish definitive recommendations. Then, a Delphi process (two rounds) was carried out. A large group of 72 of pediatric and adult rheumatologists took part. Recommendations were voted and graded from 1 (total disagreement) to 10 (total agreement). Agreement was defined if at least of 70 % of participants voted ≥ 7 . After the first round (presential, tele-voting), those statements showing an agreement lower than 70 %, or a high variability (e.g., when some of the panelist voted very low or the marks were distributed from 1 to 10), were reedited and approved by the initial panel of experts and voted in a second round (online). New recommendations were allowed at this point. Recommendations with <70 % agreement in the second round were deleted from the final document.

The level of evidence and strength of recommendations were graded according to the Oxford center for evidence-based medicine guidelines [24]. Afterward, recommendations and the other materials were consolidated into a document forwarded to the panel for comments and corrections.

Results

Definitions and considerations

We defined transitional care as an active, dynamic and continuous process in which a young patient with a rheumatic disease develops the skills for an independent adult care. Transition starts within pediatrics but continues on into adult services, and is not necessarily related to biological age, but to maturity.

On the other hand, we define transfer as an event that happens on one occasion when information or people move from one place to another. In the context of moving from pediatric to adult care, the moment of transfer can be considered to have happened when the pediatrician discharges a young person from their care and sends a referral to an adult physician or when the adult healthcare team sees a patient for the first time.

Transitional care is a multidisciplinary process in which different health professionals along with parents and others take part to address the psychosocial and educational/vocational aspects of care in addition to the traditional medical areas. It is also flexible in terms of time and objectives, appropriate to patient's characteristics and needs as well as the professionals and health systems involved. Finally, the panel also considers that patient care during transition should always be individualized.

Consensus recommendations are depicted in Table 1.

Barriers and facilitators

Several barriers have been reported in the literature, suggesting that different approaches and strategies should be developed (supplement 1). Commonly expressed barriers to developing transition programming are funding, staff (including training) and resources [4, 8, 11–14, 25–27].

Although barriers vary depending on country or even within the same country, the panel considers the most significant the lack of specific and appropriate training and the lack of recognition of pediatric rheumatology at different levels including professionals, health policy makers and regulatory training organizations.

Following, we describe transition through different age stages.

Patients under 14 years

The panel considers that transition starts approximately when patients are aged 10–14 years, but this might change depending on patient's development.

Since the diagnosis, it is vital to properly explain the disease (impact, prognosis, adherence to medical recommendations, etc.) to parents and patients (see Table 2). Clear and constructive messages including the right to confidentiality should be provided. Even in early stages, as a part of this continuous process, information on final transfer to adult healthcare providers will probably be useful to decrease parents' and/or patients' anxiety and uncertainty. We strongly believe that confidence and sincerity between patients, parents and health professionals along with continuity of care increase the success of managing these patients.

Although patients are not independent at this point yet, and most of decisions are made with parents' consent, in general, they are receptive, and therefore, physicians should actively listen to and take into account their opinions. This could be a good start point to promote their autonomy and implication in the disease decision making.

We will also have to deal with overprotective parents, particularly at the beginning. In these cases, patience and fluid communication are very effective. Moreover, there are

Table 1 Delphi results and level of evidence and grade of recommendation

#	Recommendations	n	% ≥7	Median (DS)	Median (p 25–75)	Min–Max	LE; GR*
<i>General aspects of transitional care</i>							
1	Transition in pediatric rheumatology should be considered as a continuous, natural and flexible process (start, transition models, etc.)	65	92	9.09 (1.51)	10 (9–10)	4–10	5D
2	To standardize, to plan ahead, and to define specific protocols related to transitional care (including transfer)	66	94	8.56 (1.94)	9 (8–10)	1–10	5D
3	To facilitate (evidence-based) useful information (electronic, printed) about disease, management and related relevant issues for patients and parents	69	91	8.89 (1.61)	10 (8–10)	4–10	5D
4	To promote effective communication, collaboration and coordination, among all health professionals involved in the transitional care	65	98	9.46 (1.16)	10 (9–10)	2–10	5D
5	To facilitate academic/work adaptations when necessary	64	90	8.58 (1.57)	9 (8–10)	1–10	5D
6	To facilitate multidisciplinary care implementing a transitional care model adapted to the characteristics and resources of each center	68	97	8.79 (1.65)	9 (8–10)	1–10	5D
7	To carefully plan and to develop strategies for the implementation of a transitional care model	65	94	8.61 (1.72)	9 (8–10)	4–10	5D
8	To promote clinical excellence during transition	65	92	8.93 (1.67)	10 (9–10)	1–10	5D
<i>Transition models and strategies for implementation</i>							
9	To promote specialized nursing care during transition	68	88	8.16 (2.32)	9 (7–10)	1–10	5D
10	During transitional care, health professionals should communicate to patients and parents normally, with optimism, sincerity, and should actively listen to and talk to them efficiently	69	97	9.39 (1.26)	10 (9–10)	5–10	5D
11	To support and reinforce patients' autonomy and participation adapted to the age/maturity of them during transition	69	99	9.71 (0.81)	10 (10–10)	5–10	5D
12	To actively involve patients and parents in all processes of the transitional care	69	94	9.10 (1.47)	10 (9–10)	4–10	5D
13	To inform patients and parents about the disease and transitional processes including adult care	68	99	9.26 (1.08)	10 (9–10)	5–10	5D
14	To actively monitor adherence (to treatments, visits, etc.)	68	90	8.70 (1.91)	10 (8–10)	1–10	5D
15	To organize clinical sessions between pediatric rheumatologists and adult rheumatologists and with other specialists or health professionals involved in the transitional care	68	90	8.63 (2.21)	10 (8–10)	1–10	5D
16	When transferring a patient to the adult care, to deliver a full report on the disease course, impact, treatments and other relevant aspects	65	100	9.93 (0.24)	10 (10–10)	9–10	5D
17	Training in pediatric rheumatology should ideally include an specific training in transitional care and models	65	81	7.88 (2.09)	8 (7–10)	1–10	5D
18	To guarantee an appropriate and specific training for all healthcare professionals involved in transitional care	64	92	9.12 (1.56)	10 (9–10)	1–10	5D

SD standard deviation; p percentile; min minimum; max maximum; LE level of evidence; GR grade of recommendation

* Level of evidence and grade of recommendation were established using the Oxford center for evidence-based medicine guidelines

national and international websites where relevant, empowering and unnerving health information and disease-related resources are available such as PRINTO [28–30]. Other useful activities include telephone consultation, groups/programs for self-management, and opportunities to meet similar others.

On the other hand, current treatments and strategies require specific monitoring. Along with this, it is also important to closely monitor growth and psychological, cognitive development (Table 2). When necessary, assistance/guidance with issues of education or relationships inside and outside the family should be offered.

Finally, due to the characteristics of inflammatory rheumatic disease, coordination with other specialists, health professionals and teachers is essential.

Patients aged 14–16 years

In this stage, adolescence-related problems arise in many patients. In some of them, they will be mild, but serious in others such as oppositional defiant behaviors. Patients with chronic rheumatic diseases throughout childhood might become weary of the medications and doctors' appointments, and have a feeling of being different from peers.

Table 2 Evaluation of patient during transition and main objectives

	<14 yr	14–16 yr	16–18 yr	18–24 yr
<i>General</i>				
Generic recommendations for healthy people (growth and development, vaccines, common diseases)	√√	√√	√	√
Socioeconomic and/or cultural factors (beliefs, practices, etc.)	√	√	√	√
Disease knowledge and understanding (characteristics, impact, flares, prognosis, etc.)	√√	√√	√√	√√
Treatment knowledge and understanding (names, doses, AE, adherence, etc.)	√	√√	√√	√√
Laboratories, imaging and others' knowledge and understanding (indication, objectives, etc.)	√	√√	√	√
Roles of healthcare providers	√	√√	√√	√
Autonomy and independence (self-care, compliance/adherence to treatments, visits, decision making, etc.)	√	√√	√√	√
Body image	√	√√	√√	√√
Daily life activities (housework, physical activity, hobbies, spare time, etc.)	√√	√√	√√	√√
Diet and exercise	√	√√	√√	√√
Education, vocation and employment	√	√√	√√	√√
Social issues (family, peers, teachers, dating, etc.)	√	√√	√√	√√
Risk-taking behaviors (drugs, alcohol, etc.)	√	√√	√√	√√
Psychological need and support	√√	√√	√√	√
Sexual health information and counseling (sexuality, fertility, pregnancy, contraception, etc.)	√	√√	√√	√
Parental education and support	√√	√√	√	√
<i>Objectives</i>				
Promote autonomy and self-management	√	√√	√√	–
Engage patient in the decision-making process	√	√√	√√	√√
Improve communication skills	√	√√	√√	√√
To inform and plan the transfer to the adult care	√	√√	√√	–

Yr year; AE adverse events

√ important

√√ very important

They may become severely noncompliant with medications and appointments and also may engage in risk-taking behaviors (alcohol, drugs, etc.).

This might negatively influence transition key goals including the consolidation of the identity of the individual, the establishment of relationships inside and outside the family, and the achievement of an independent adult life. On the other hand, overprotection in many parents will be present. This protection may frustrate or limit this pursuit of independence and ultimately self-advocacy. Therefore, it is essential to find a balance between patient care in order to guarantee adolescent independence and autonomy process and parent support and education. Achieving a consensus on the appropriate level of protectiveness during the continuum of child and adolescent development is a key skill for all parents. In some selected cases, assistance with separation from parents with respect to medical issues might be required.

As shown in Table 2 along with disease/treatment monitoring and the recommendations in the previous stage, there are other important aspects to address in this stage such as the impact of the disease (sometimes negative) on body image and self-esteem that might cause depression, anxiety

and problems with peer relationships: sexual health information and counseling (sexuality, fertility, pregnancy, contraception, etc.), risk behaviors (alcohol, drugs, etc.) or diet and exercise as well.

Finally, as transfer will be close in many cases, full information about adult healthcare providers and an individualized transfer plan should be discussed with patients and parents.

Patients aged 16–18 years

Most of adolescence-related problems will probably continue in this stage, they may even worsen. The panel recommends following the recommendations exposed before and those from Table 2. Moreover, it is vital to provide opportunities for adolescents to express opinions and make informed decisions. These opportunities promote independence and the development of advocacy skills especially if they are given in an environment that feels confident, safe and comfortable for the adolescent and the parents. As in the previous stage, some patients might require assistance with separation from parents.

During or at the end of this stage, most patients will be transferred to the adult care. Thus, the development of an individualized, effective (and inclusive) planning and coordination with the adult rheumatologist is mandatory.

Patients aged 18–24 years

Almost 100 % of patients are in the adults care. But, although in this stage most are young adults who can be, in many aspects (not all), managed as adults, there are still some patients with developmental delays, the same way, parents that have not properly accepted patient's independence. In these cases, we should follow the recommendations depicted in previous stages.

During this period, the young adult is also engaged in making vocational and employment decisions, establishing more relationships, and, for some young adults, leaving home and establishing independent living. Counseling when necessary should be provided for this and other relevant issues (Table 2).

See transference section (next) for more information about recently transferred young adults.

Transference

We have defined transfer as an event that happens on one occasion when information or people move from one place to another, irrespective of the model of transition care (see next section) and patient's age. The timing of the patient's final transfer to an adult rheumatologist is individualized.

The panel recommends assessing readiness for transfer following the criteria shown in Table 3. First of all, ideally, this should be with a stable disease and appropriate development and independence from parents. The same way, it is highly recommended a close monitoring of these patients in order to increase confidence and to an early detection of non-adherence or other problems.

The panel also strongly recommends establishing effective collaboration between pediatric and adult rheumatologists and between rheumatologists and other healthcare providers to define, according to the center characteristics and available resources.

Another important point is the information to transfer, printed or electronically. Table 3 also summarizes the most relevant information to transfer including disease onset and course-, treatment- and patient-related issues.

Training

A key component of transitional care is the availability of appropriately trained staff and in-service training to maintain staff members' skills and knowledge in this area. In

fact, it has been reported that among the determinants of adolescent satisfaction with transitional care in rheumatology, provider characteristics were significantly more important than the physical environment and process issues (42). Unfortunately, availability of professionals who were knowledgeable in transitional care is not feasible in many places [14].

Although formal training requirements and needs of health professionals involved in the transition care have yet to be defined and implemented, the panel, in order to assure the best quality to patients during transition, has developed a minimum set of training requirements that are detailed in supplement 2. Along with this statement, the panel also considers that other activities such as the inclusion of transitional care in training programs, shared clinical sessions between health professionals will improve this situation.

Transition models in rheumatology

Few transition models of pediatric rheumatology patients into adult care have been described in the literature, and there is still a paucity of data regarding the impact of these models, though they have shown benefits [3, 4, 7, 8, 31]. Most of them are based on multidisciplinary, generic, adolescent health services, with specific structures and individualized transition plans for patients and parents.

However, these kinds of well-developed adolescent services are not universally feasible. Therefore, the most common, simple and practical model for transitional healthcare services for youth with rheumatic disease is a disease-focused transition (Fig. 1b). Traditionally, in this model, pediatric and adult services work independently and transfer the patient based on chronological age, in some cases with a medical report. It is now clear that this does not meet the multifaceted needs of the young people requiring ongoing medical care in adult services [11]. Therefore, the panel does not consider it an appropriate transition model.

The panel strongly supports, on the other hand, transition models based on an active communication, coordination and collaborative working between services (Fig. 1b). The panel is also aware that regional and local health service characteristics as well as staff training and resources are very likely to influence the way this collaboration is implemented. The different formats potentially include (1) pediatric clinics which continue at the same location, and the adult physician who will be taking over the patient's care takes part at defined times (moves to that clinic, often in the same center); (2) a period when a patient has overlapping appointments at adult and pediatric clinics before they are transferred; (3) a pediatric and adult working physically independently (including

Table 3 Criteria to be considered for determining patient's readiness to and information to transfer

Criteria	Description
Age/development	~16–24 years Appropriate mental development in order to achieve an effective adaptation to adult care and assume adults' responsibilities (booking own appointments, contacting medical team for advice, informed decision making, treatment and visit adherence, effective adult care communication, etc.)
Independence and assertiveness	Ability to follow an independent adult care (appointments, laboratories, transportation to clinic, etc.) Self-advocacy
Knowledge	Disease and treatments Characteristics of adults care
Clinical	Stable disease
<i>Information to transfer</i>	
Family history	
Obstetric history	
Pediatric history	
Vaccines	
Oral health	
<i>Related to the disease</i>	
Diagnosis, symptoms at the onset, flares, etc.	
Initial physical examination	
Disease course: relevant decisions and events	
Physical examination at transfer	
Laboratories: main findings	
Imaging: main findings	
Treatments: type, doses, adverse events, etc.	
<i>Related to patients</i>	
Family and social relationships	
Education/vocation/expectations	
Employment	
Exercise	
Hobbies	
Risk-taking behaviors	
Driving license	
Diet/body mass index	
Sleep	
Sexual health and contraception	
Independence: living alone, etc.	
Adherence to treatments and visits	
Other relevant information	

different centers) but with active communication sharing patient care; and (4) the panel also considers valid well-developed adolescent units as described in the literature that could be a reference for complex patients [8, 32, 33]. All these models also include the possibility of interaction and collaboration between services once the transfer is effective. Finally, we could also find a model in which the same person cares in the pediatric and adult period (Fig. 1c).

Irrespective of the model, the panel encourages all professionals involved in the transitional care to follow all the exposed recommendations during this document.

Strategies for the implementation of transition models

Depending on each center feature, different strategies to implement the most feasible transition model can be developed (Table 4).

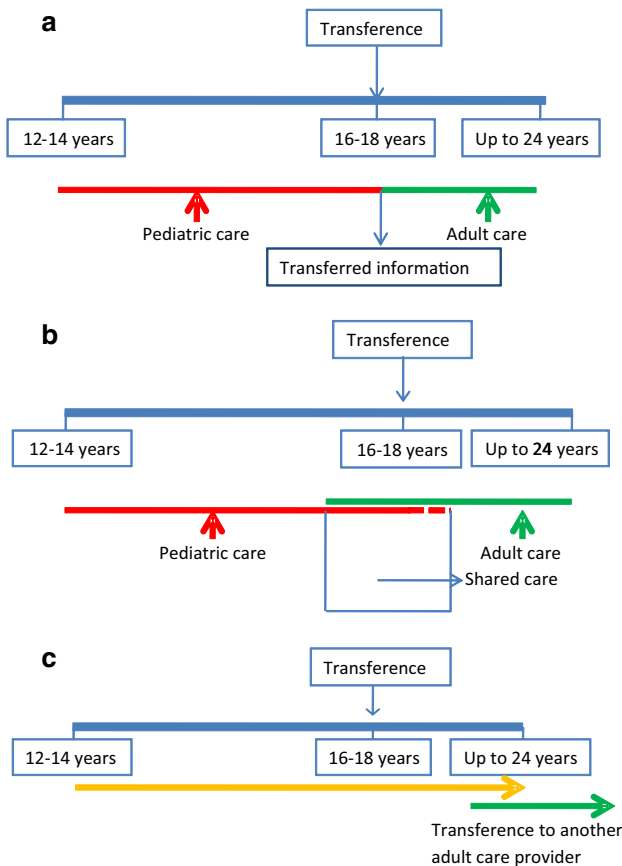


Fig. 1 Transition models

But first of all, we would like to highlight that the implementation of one of the exposed transition models is a long process that requires, apart from human, material and economic resources, an enormous effort, coordination, generosity, agreement and implication of all health professionals that are going to lead this project, particularly pediatric and adult services. Moreover, it is vital to bear in mind that the aim of transition care is to support and provide the best care to patients and families.

Discussion

Transition is an age and developmentally appropriate process, addressing the psychosocial and educational/vocational aspects of care in addition to the traditional medical areas. Transition starts within pediatrics but continues on into adult services. The benefits of transition care plans and models in rheumatology have been reported, but their implementation is scarce [7, 12, 20–22].

Besides, the level of transition programming is variable and depends on many factors that often are related to the local healthcare systems. Therefore, these

Table 4 Strategies and key points to consider for an effective implementation of a transition model

Stakeholders

Analysis of health needs related to transition in the community and of transitional care in rheumatology at host center including barriers and facilitators to the implementation of the model

Justification (opportunity, clinical excellence, required resources, economic efficiency), plan to solve potential problems in the development and implementation of the transition model

Pediatric and adult services leadership: shared responsibilities and capable of providing transitional care

Demonstrate health professionals' implication in the integrated and patient- and family-centered care, decision making, resources allocation, etc.

Access and coordination with health professionals involved in transitional care

Guarantee continuity of care

Services description (team members, staff member as the transitional care program coordinator, facilities, techniques, etc.) and schedule

Audit (regular review of policy, plans, processes, outcomes, participation of young people and their parents in evaluation and future development of the service)

Health professionals

Engage health professionals truly motivated and interested in transition care with skills for team work and leadership

Target services and health professionals of interest including primary care (ophthalmology, orthopedic, psychologists, etc.)

Training in transition care and pediatric rheumatology

Shared and informed decision making

Transition program elements (plans, protocols, educational and informational resources, transfer, involvement of primary care, etc.)

Quality indicator development (including patients' and families' satisfaction)

Clinical sessions

Incentives such as personal recognition, career promotion, skill development opportunities and research.

Administrative support

Unique appointment system implementation

Integrated in routine care

Recognition of transitional care

Others

Parents, patients' associations, scientific societies, health decision makers' implication

Active promotion of the transition model and outcomes

recommendations should be carefully interpreted in order to assess their applicability out of the Spanish health system. From a practical point of view, it is also essential to carefully plan and prepare the implementation of the selected transition model and to engage parent, patients' associations and relevant stakeholders in this project.

We have developed these recommendations in order to provide a guide for professionals who care these patients. Improving transition requires collaboration between

pediatric and adult rheumatologists and between rheumatologists and other healthcare providers. Providers of transition care must recognize that these patients present complex medical and psychological needs. Therefore, trained professionals are required to deal with these patients.

Strengths of this paper are the broad participation of experts and patients, the use of research data however limited, and the use of an evidence-based format. Therefore, experimentation and formal evaluation will be needed to evaluate health and economic outcomes and to compare different models of transitional care.

The NextStep members are currently working at national level with the authorities in order to define strategies to implement these recommendations.

Conflicts of interest Jaime de Inocencio has received honorarium for being a speaker for BMS, Abbvie y Pfizer end research grant from Gebro; Inmaculada Calvo research grants from Pfizer, Abbie, Roche, BMS y Novartis; Jordi Antón research grants from Pfizer, abbvie, honorarium from advisory boards (Novartis, GEBRO, Pfizer), as a speaker (Abbvie, Pfizer, Roche, Novartis, SOBI, GEBRO); Carmen Vargas for being a speaker (Roche, Pfizer, Abbvie); Estíbaliz Loza research grants from MSD, Roche, Abbvie, Pfizer, UCB, BMS.

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