

RESEARCH ARTICLE

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# Consensus on transition care for juvenile idiopathic arthritis: a Delphi study with youth, caregivers, and health professionals

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## Abstract

**Background** The field of transitional care for chronic conditions in adolescents, notably juvenile idiopathic arthritis (JIA), is rapidly growing. Transitioning these patients to adult healthcare systems presents significant challenges in practical implementation. Consequently, it would be appropriate for each country to develop a transition program tailored to its specific infrastructure. To pursue this goal, a Delphi study was conducted to identify the key components of transitional care in JIA.

**Methods** Three panels and two rounds were held consisting of adolescents and young adults, parents, and clinicians (pediatric or adult rheumatologists). As a result, feedback on acceptance of the key statements of transitional care was obtained using the Delphi method.

**Results** Out of 102 contacted, 88 (86.3%) participants responded to the Round 1 survey, which included 48 clinicians, 20 youths, and 20 parents. In Round 2, the number of clinicians dropped to 29, while the number of youths and parents remained constant. Based on expert opinions, 29 statements were selected for the first round. Statements that received  $\geq 70\%$  approval in the first round advanced to the next round. Sixteen statements did not achieve  $\geq 70\%$  approval. Of the remaining, 12 were reviewed in the second round, while four were excluded.

**Conclusion** Although consensus has been reached on the basic transitional care issues for JIA patients, several issues still need to be agreed upon. Acceptance and applicability of the final 20-item checklist in clinical practice are critical for advancing JIA transition care in Turkey.

**Keywords** Adolescent, Arthritis, Chronic disease, Delphi-study, Juvenile, Transition to adult care

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## Background

The field of transitional care for adolescents with chronic conditions is rapidly expanding. Research emphasizes that maintaining continuity of care during adolescence enhances patients' integration into the healthcare system and reduces the likelihood of long-term adverse health outcomes [1, 2].

Juvenile idiopathic arthritis (JIA) is the most common chronic arthritis in childhood, affecting approximately one in every 10,000 children [3]. After periodic fever syndromes, JIA emerges as the primary concern within our region's pediatric rheumatology domain [4]. Since a substantial proportion regrettably of these patients persist with active disease into adulthood [5–8], it is quite important to provide a proper transition from pediatric to adult healthcare systems [2]. In pursuit of this goal, a panel of experts convened to develop guidelines for the transitional care of adolescents and young adults (AYAs) with juvenile-onset rheumatic diseases [9]. These experts put forth a set of 12 specific recommendations aimed at facilitating a seamless transition [9]. These recommendations focus primarily on establishing a well-coordinated and timely network between child and adult health organizations. While the theoretical approach is straightforward for the transition process according to these recommendations, substantial challenges arise in practical implementation. For instance, a recent survey conducted among European pediatric rheumatologists revealed that less than one-third of respondents had a documented transition policy [10]. Data for developing countries is even more bleak. A sole survey conducted in Brazil, a developing nation, revealed that merely 13% of pediatric rheumatology centers had implemented a robust transition program [11]. Hence, every nation needs to develop a tailored transition program that aligns with its unique infrastructure and meets patients' expectations. The primary objective of this study was to formulate a comprehensive set of recommendations for the transitional process that effectively meets the expectations of both patients and clinicians.

## Methods

### Study participants

Participants eligible for inclusion in one of the three-panel categories were recruited as follows: (1) Panel 1 consisted of JIA patients, specifically young individuals aged 18–21 who had previously transitioned to an adult rheumatology unit, (2) Panel 2 comprised of family members or caregivers of young individuals who had undergone the transition, (3) Panel 3 included clinicians (pediatric or adult rheumatologists) having experience in pediatric rheumatic disease for at least 5 years.

For Panels 1 (youth) and 2 (caregivers), our research project engaged patients and their parents who had previously transitioned to an adult rheumatology unit. Individuals who expressed interest in participating were informed via electronic mail by the research team. For the constitution of Panel 3, a systematic approach consisting of two distinct strategies was adopted. To participate in the study, an invitation email was first sent to all members of the National Association of Pediatric Rheumatology ( $n=49$ ) who are pediatric rheumatologists working in tertiary health centers in Turkey. Secondly, we extended invitations to adult rheumatologists ( $n=13$ ) through email who participated in transition care.

A total of 20 patients and 20 parents participated in the study by responding to emails. Forty-eight clinicians were accepted to be a participant while the remaining 14 refused to attend due to their busy working schedules. Finally, a Delphi panel was constituted, with 39 pediatric rheumatologists and 9 adult rheumatologists from 33 centers.

### Delphi method

The Delphi method is a technique employed to facilitate group communication when addressing intricate problems [12]. This method involves a multi-step process that includes the use of questionnaires, ensuring the anonymity of participants, and the provision of feedback information at various stages. The Delphi method has found extensive application across a diverse range of fields, including but not limited to rheumatology, for the purpose of achieving consensus on specific topics. Moreover, it is also utilized to explore a broad spectrum of opinions, even in cases where a consensus is not attainable. An intrinsic advantage of the Delphi technique is its capacity to facilitate group communication among individuals located in disparate geographic regions, as it does not necessitate face-to-face meetings [12, 13].

In the first stage of the Delphi study, an exhaustive literature search was conducted, and a shortlist of 29 core statements, grouped into six core elements, was created, all through the collaboration of NS, HES, NAA, and BS [14]. During the initial description of the core statements, the panelists were tasked with responding to open-ended ideas. In round 1, the key insights gathered from the initial description of the core statements were transformed into statements (Table 1), each rated on a 9-point Likert scale (ranging from 1, denoting “strongly disagree,” to 9, signifying “strongly agree”). Round 2 revisited statements that had not achieved consensus in the previous round (Table 1). Before each round, an overview of the collective responses from the entire panel was furnished, and the panelists were requested to reassess their responses accordingly.

**Table 1** The list of core statements grouped into six core elements in the first stage of the Delphi study and core statements carried over from Round 1 to round 2

Core Statements	Round 1	Round 2
<b>1. Transition policy</b>		
<b>1.1 Transition Guide</b>	A guide should explain all stages of the transition process to the patient.	A guide should explain all stages of the transition process to the patient.
<b>1.2 Nationwide Program</b>	A joint transition program should be established based on societal characteristics nationwide.	The Pediatric and Adult Rheumatology Departments should collaboratively develop a transition program or protocol.
<b>1.3 Clinic-Based Program</b>	A transition program should be established in the facilities based on the specific characteristics of each clinic.	The developed program should be adaptable to accommodate each patient's individual needs.
<b>1.4 Individualized Care</b>	Transition care should be tailored to each patient's needs.	
<b>1.5 Interdisciplinary Team</b>	The transitional care team should include a pediatric rheumatologist, an adult rheumatologist, healthcare personnel such as nurses, physiotherapists, psychologists, and a medical secretary.	
<b>1.6 Training Requirement</b>	Persons involved in the transition program must have knowledge and training on transition.	Persons involved in the transition program must have knowledge and training on transition.
<b>1.7 Defined Responsibilities</b>	The responsibilities of the transition program personnel and the person managing this process should be clearly defined.	The responsibilities of the transition program personnel and the person managing this process should be clearly defined.
<b>2. Transition Tracking and Monitoring</b>		
<b>2.1 Patient Selection Criteria</b>	Criteria should be established to determine which patients will go through the transition process.	Criteria should be established to determine which patients will go through the transition process.
<b>2.2 Transition Tracking Logbook</b>	A logbook should be maintained to track the transition process.	A logbook should be maintained to track the transition process.
<b>3. Transition readiness</b>		
<b>3.1 Preparation Age Range</b>	The preparation phase for transitional care should commence between the ages of 12 and 14 and continue until the age of 16.	Preparations for the transition should be started between the ages of 16 and 18.
<b>3.2 Family Role Discussion</b>	During the transition process, the changes in responsibilities and roles between the family and the patient should be discussed with the family.	During the transition process, the changes in responsibilities and roles between the family and the patient should be discussed with the family.
<b>3.3 Readiness Assessment Tool</b>	The TRAQ is sufficient to assess transition readiness.	A validated questionnaire, such as TRAQ or TransitionQ, should be utilized to evaluate the transfer readiness of the patients and their parents.
<b>3.4 Illness Knowledge Requirement</b>	Patients ready to transition should be able to describe their illness, treatment medications, and how and why they use them.	Patients ready to transition should be able to describe their illness, treatment medications, and how and why they use them.
<b>4. Transition planning</b>		
<b>4.1 Adult Clinic Selection</b>	It should be collaborated with the patients and parents to determine the suitable adult rheumatology clinic for the transfer.	The adult rheumatology clinic for the transfer should be determined as much as possible with the patients, their parents, and their physicians.
<b>4.2 Differences Briefing</b>	The patient should be briefed on the different approaches of the future adult rheumatology center to which they are scheduled for referral and their current pediatric rheumatology center.	The differences between the adult rheumatology clinic and the pediatric rheumatology clinic to which the transfer will occur should be explained.
<b>4.3 Pre-Transfer Meeting</b>	The patient, parents, pediatric team, and adult rheumatology team should convene at least six months before the transfer to organize the transfer phase jointly.	The patient, parents, pediatric team, and adult rheumatology team should convene at least six months before the transfer to organize the transfer phase jointly.
<b>4.4 Appointment Training</b>	Before the transfer, the patient should learn to make an appointment.	Before the transfer, the patient should learn to make an appointment.
<b>4.5 Transfer Date Agreement</b>	The ideal transfer date should be determined through patient and parent collaboration.	The ideal transfer date should be determined through patient and parent collaboration.

**Table 1** (continued)

Core Statements	Round 1	Round 2
<b>5. Transfer care</b>		
<b>5.1 Recommended Transfer Age</b>	The transfer should occur when the patient is between 18 and 20 years old.	When the patient reaches the age of 18, the transfer should be made.
<b>5.2 Stable Disease Requirement</b>	The disease activity should be inactive at the time of transfer.	Care should be taken to ensure the disease is stable (in inactive disease) at the time of transfer.
<b>5.3 Transfer Documentation</b>	The transfer letter, transition process registry, and discharge summary should be forwarded to the adult rheumatology team with the patient's consent.	The transfer letter, transition process registry, and discharge summary should be forwarded to the adult rheumatology team with the patient's consent.
<b>5.4. Youth-Friendly Environment</b>	The transfer meeting should be in a setting tailored to adolescents and young adults.	The transfer meeting should be held whenever possible in a setting tailored to adolescents and young adults.
<b>5.5. Collaborative Clinic Visit</b>	Whenever possible, the pediatric and adult rheumatology departments should arrange at least one outpatient clinic visit jointly.	Whenever possible, the pediatric and adult rheumatology departments should arrange at least one outpatient clinic visit jointly.
<b>5.6. Annual Follow-Up</b>	To ensure ongoing follow-up and appointment adherence, it is recommended that the patients and their parents continue visiting the pediatric rheumatology department annually until the age of 24.	
<b>5.7. Feedback Collection</b>	Following the first and second visits to the adult rheumatology department, the patient should provide feedback to the pediatric rheumatology department about their experience.	After the first visit to the adult rheumatology department, the patient should give feedback about the visit to the pediatric rheumatology department.
<b>5.8 Appointment Compliance</b>	It should be ensured that appointments for control visits are made	It should be ensured that appointments for control visits are made.
<b>5.9. Independent Visit Attendance</b>	After transfer to the adult rheumatology department, the patient should attend examinations independently (without a parent).	
<b>6. Transfer completion</b>		
<b>6.1. Transition Completion Age</b>	The transition process should be completed between the ages of 20–24.	The transition process should be completed between the ages of 18–20.
<b>6.2. Life Plan Development</b>	At adult rheumatology visits, patients should have a plan regarding their education, work life, and disease to complete the transition.	At adult rheumatology visits, patients should have a plan regarding their education, work life, and disease to complete the transition.

### Statistical analysis and determining consensus

Data for each statement was gathered using Microsoft Excel (Microsoft Corporation, Redmond, WA) and SPSS 22.0 (IBM, Armonk, NY) to perform survey analysis. Descriptive statistics, such as mean, mode, median, percentage, and minimum-maximum, were computed for each statement. If 70% or more of the participants rated any of the statements with an 8 or 9 on the Likert scale, it was considered to have consensus in agreement. Such statements were then carried over to the next round [15].

## Results

### Participant characteristics

Eighty-eight (86.3%) participants out of 102 contacted responded to the Round 1 survey. Round 1 included 48 clinicians, 20 youths, and 20 parents. In Round 2, the number of clinicians declined to 29, while the number of others who participated remained constant.

Thirteen (65%) of the youths were female, 7 (35%) were male. 17 (85%) of parents were mothers. The median disease duration of youths was 46 (14–180) months. The median age of the youths was 19.6 (18–21) years. The region they lived in was a city center in 5 (25%), a district in 10 (50%), and a villagetown in 5 (25%).

A total of 48 clinicians took part in this study. Among them, 39 were pediatric rheumatologists, and 9 were adult rheumatologists. Half of the participants ( $n=24$ ) were working in a public hospital, while 22 were in a university hospital, and 2 were in a private hospital. The median duration of working in the field of rheumatology was 6 years, with a range of 5 to 36 years.

### Round 1

The results of the Round 1 survey are presented in Supplementary File 1. Among the clinicians who participated, the highest level of agreement was observed for the core statement 'Appointment Training,' which received strong endorsement from 95.8% of the panel. Additionally, two other core statements, 'Illness Knowledge Requirement' and 'Transfer Documentation,' received high endorsement from at least 90% of the participants. However, it was noted that 16 core statements did not reach at least 70% agreement, including statements 'Nationwide Program,' 'Clinic-Based Program,' 'Individualized Care,' 'Interdisciplinary Team,' 'Preparation Age Range,' 'Readiness Assessment Tool,' 'Adult Clinic Selection,' 'Differences Briefing,' 'Pre-Transfer Meeting,' 'Recommended Transfer Age,' 'Stable Disease Requirement,' 'Youth-Friendly Environment,' 'Annual Follow-Up,' 'Feedback Collection,' 'Independent Visit Attendance,' and 'Transition Completion Age.'

The level of agreement among the parents who participated was highest for core statements 'Training Requirement,' 'Defined Responsibilities,' 'Adult Clinic Selection,' 'Differences Briefing,' 'Pre-Transfer Meeting,' 'Collaborative Clinic Visit,' and 'Appointment Compliance,' with all receiving strong endorsement from 100% of the participants. Additionally, two other core statements, 'Stable Disease Requirement' and 'Transfer Documentation,' received high endorsement from at least 90% of the panel. Seven core statements did not reach at least 70% agreement, including statements 'Nationwide Program,' 'Individualized Care,' 'Preparation Age Range,' 'Readiness Assessment Tool,' 'Independent Visit Attendance,' 'Transition Completion Age,' and 'Life Plan Development.'

The level of agreement among young people who participated was 100%, the core statement was 'Training Requirement,' and five statements (Defined Responsibilities, Illness Knowledge Requirement, Differences Briefing, Appointment Training, and Collaborative Clinic Visit) were highly agreed upon by at least 90% of the youth. However, ten core statements, including 'Nationwide Program,' 'Individualized Care,' 'Transition Tracking Logbook,' 'Preparation Age Range,' 'Readiness Assessment Tool,' 'Recommended Transfer Age,' 'Youth-Friendly Environment,' 'Annual Follow-Up,' 'Appointment Compliance,' and 'Transition Completion Age,' did not reach at least 70% agreement.

### Changes from round 1 to round 2

Core statements that did not receive at least 70% agreement were removed without any replacement or were revised. Four core statements (Clinic-Based Program, Interdisciplinary Team, Annual Follow-Up, and Independent Visit Attendance) were removed, and no new ones were added. Twelve core statements (Nationwide Program, Individualized Care, Preparation Age Range, Readiness Assessment Tool, Adult Clinic Selection, Differences Briefing, Recommended Transfer Age, Stable Disease Requirement, Youth-Friendly Environment, Feedback Collection, Transition Completion Age, and Life Plan Development) were revised (Table 1).

### Round 2

Of those in Round 1, 38 (79.2%) clinicians and 20 (100%) youth and 20 (100%) parents participated in Round 2. Round 2 survey results are displayed in Supplementary File 2, showing the number of participants and their agreement rates. In Round 2, 6 of the 12 core statements that changed from Round 1 achieved at least 70% agreement among clinicians. The core statements with the highest agreement among clinicians were 'Nationwide Program,' 'Transition Guide,' and 'Appointment Training' with agreement rates of 97.4%, 92.1%, and 92.1%,

respectively. However, clinicians could not agree on core statements ‘Differences Briefing’, ‘Pre-Transfer Meeting’, ‘Recommended Transfer Age’, ‘Feedback Collection’, and ‘Transition Completion Age’ in Round 2. While the youths agreed that all the core statements were altered between Round 1 and Round 2, the parents disagreed with only one of these core statements (Life Plan Development). Among youth, core statements ‘Training Requirement’ and ‘Stable Disease Requirement’ had the highest agreement with 100%, and core statements ‘Transition Guide’, ‘Defined Responsibilities’, ‘Illness Knowledge Requirement’, ‘Differences Briefing’, ‘Appointment Training’ and ‘Collaborative Clinic Visit’ had  $\geq 90\%$  agreement. Among the parents, ‘Training Requirement’, ‘Defined Responsibilities’, ‘Adult Clinic Selection’, ‘Differences Briefing’, ‘Pre-Transfer Meeting’, ‘Stable Disease Requirement’, ‘Collaborative Clinic Visit’, and ‘Appointment Compliance’ were the core statements that provided the highest agreement with 100%, and core statements ‘Appointment Training’ and ‘Youth-Friendly Environment’ had  $\geq 90\%$  agreement. The top 3 core statements with the highest agreement of clinicians, youths, and parents were different (Table 2).

**The final list of core statements**

In the final round of Round 2, core statements that did not reach at least 70% agreement were removed, and as a result, 20 core statements were listed (Table 3).

**Discussion**

We presented the findings of a Delphi study involving patients, parents, and experts on implementing transition care for AYAs with JIA in Turkey. This Delphi study produced 29 statements rated on a 9-point Likert scale based on an extensive literature review and open-ended

feedback. The statements were finalized in repeated rounds based on the panelists’ agreement.

Before this study, our group presented a comprehensive systemic review investigating the need for transition care in JIA [13] and a survey examining the status of transition care in JIA in Turkey [16]. Finally, we conducted the Delphi study to develop a checklist for transition care in JIA that is usable nationwide in Turkey.

In this Delphi study, we used a multi-panel approach to gather input from doctors, youth, and caregivers. Unlike previous Delphi studies on pediatric to adult healthcare transitions, which often relied heavily or exclusively on healthcare professionals, this study included significant input from patients and caregiver groups [17–19]. Although many statements in the top 3 among youths and parents had the same agreement rate, only three were in the top 3 among clinicians. “The Pediatric and Adult Rheumatology Departments should create a collaborative transition program.” While clinicians showed the highest agreement with this statement, it did not rank in the top three for youths but was third among parents. Parents highly agreed with statements about the collaboration of youths, parents, and clinicians in transition planning, the importance of holding the transfer meeting in a youth-friendly environment, and the arrangement of the control visit appointment. However, these statements did not rank in the top three for youths and clinicians. In conclusion, our results revealed different views on transitional care among clinicians, youth, and parents.

In round 1, due to the varying conditions and facilities of each center, it was questioned whether each clinic should develop a transition program tailored to its own characteristics. However, we found that this statement was not accepted. Many publications show pediatric and adult rheumatologists attempting to develop a national transition program [11, 19, 20]. Therefore, in Round 1, we

**Table 2** Top 3 statements having high agreement in round 2

Clinicians	Parents	Youths
1.2 Nationwide Program	1.6 Training Requirement, 1.7 Defined Responsibilities, 4.1 Adult Clinic Selection, 4.2 Differences Briefing, 4.3 Pre-Transfer Meeting, 5.2 Stable Disease Requirement, 5.5 Collaborative Clinic Visit, and 5.8 Appointment Compliance <sup>a</sup>	1.6 Training Requirement and 5.2 Stable Disease Requirement <sup>a</sup>
1.1 Transition Guide	4.4 Appointment Training and 5.4 Youth-Friendly Environment <sup>c</sup>	4.2 Differences Briefing and 4.4 Appointment Training <sup>b</sup>
4.4 Appointment Training	1.1 Transition Guide, 1.2 Nationwide Program, 2.2 Transition Tracking Logbook, and 3.4 Illness Knowledge Requirement <sup>d</sup>	1.1 Transition Guide, 1.7 Defined Responsibilities, 3.4 Illness Knowledge Requirement, and 5.5 Collaborative Clinic Visit <sup>c</sup>

<sup>a</sup> Having 100% agreement

<sup>b</sup> Having 95% agreement

<sup>c</sup> Having 90% agreement

<sup>d</sup> Having 85% agreement



**Table 3** Core statements accepted with at least 70% agreement in the final round**The final core statements****1. Transition policy**

A guide should explain all stages of the transition to the patient process.

The Pediatric and Adult Rheumatology Departments should collaboratively develop a transition program or protocol.

The developed program should be adaptable to accommodate each patient's individual needs.

Persons involved in the transition program must have knowledge and training on transition.

The responsibilities of the transition program personnel and the person managing this process should be clearly defined.

**2. Transition Tracking and Monitoring**

Criteria should be established to determine which patients will go through the transition process.

A logbook should be maintained to track the transition process.

**3. Transition readiness**

During the transition process, the changes in responsibilities and roles between the family and the patient should be discussed with the family.

A validated questionnaire, such as TRAQ or TransitionQ, should be utilized to evaluate the transfer readiness of the patients and their parents.

Patients ready to transition should be able to describe their illness, treatment medications, and how and why they use them.

During the transition process, the changes in responsibilities and roles between the family and the patient should be discussed with the family.

**4. Transition planning**

The adult rheumatology clinic for the transfer should be determined as much as possible with the patients, their parents, and their physicians.

Before the transfer, the patient should learn to make an appointment.

The ideal transfer date should be determined through patient and parent collaboration.

**5. Transfer care**

The transfer letter, transition process registry, and discharge summary should be forwarded to the adult rheumatology team with the patient's consent.

The transfer meeting should be held whenever possible in a setting tailored to adolescents and young adults.

Whenever possible, the pediatric and adult rheumatology departments should arrange at least one outpatient clinic visit jointly.

It should be ensured that appointments for control visits are made.

**6. Transfer completion**

The transition process should be completed between the ages of 18–20.

At adult rheumatology visits, patients should have a plan regarding their education, work life, and disease to complete the transition.

questioned the statement that a national transition program should be established. However, this statement was not accepted either. In Round 2, instead of the two previously mentioned statements, the statement that a transition program should be developed jointly by the pediatric and adult rheumatology departments was questioned and agreed upon. As a result, it became clear that developing a center-based transition program would be more suitable for our country than a nationwide program. The statement, "A transition program should be created in the facilities according to the unique characteristics of each clinic," was likely difficult to understand and was not accepted initially. However, it was received when expressed more comprehensively.

Ideally, it is recommended that transitional care be provided by a multidisciplinary team comprising doctors, nurses, physiotherapists, psychologists, occupational therapists, and other health professionals, such as youth workers or social workers [9, 21, 22]. Various members can perform some responsibilities of other team

members, and the team composition can vary. However, the EULAR/PReS recommendations specify that there should be a designated transition coordinator [9]. In our country, the number of health professionals other than clinicians is unequal in every center. For this reason, there was no agreement on the statement that other health professionals and clinicians should be included in the transitional care team. However, in our Delphi study, having knowledge and training about the transition of personnel involved in the transition program and defining the responsibilities of the transition program staff and the person managing the process reached an agreement.

The most debated aspect of transition is the timing of the transition stages and the appropriate age range for each stage. EULAR/PReS states that the transition process should start as early as possible or, in cases of adolescent-onset, immediately after diagnosis [9]. Based on these suggestions, we questioned the statement that the transition preparation phase in round 1 should start at 12–14 and continue until 16. But no agreement was

reached. There are differences between Eastern and Western cultures, particularly in living arrangements, parenting styles, and child-rearing practices. For example, in our country, most young adults live with their families until they get married. Considering these differences in Round 2, we changed it to “transition preparation phase should start between the ages of 16–18,” and an agreement was reached on this statement. The timing of the completion of the transfer and transition is as critical as the start of transition preparations. In structured transition programs, AYAs are jointly followed up by adult and pediatric rheumatologists at the transition clinic until the age of 23–24 and are transferred after this age [19, 23]. Our participants agreed to transfer at age 18 and complete the transition care by age 18–20. Based on these statements, we believe that problems with hospital records and health insurance were decisive for the individuals participating in our study.

The statements accepted in the first round and included in the final statement pertained to the general outlines of transition care. These included establishing a transition program, determining a program manager, informing the family and patient about the transition, maintaining transition records, providing an epicrisis at the time of transfer, and scheduling a post-transfer follow-up appointment. Although statements regarding issues requiring resources such as personnel, time, and economy could not be agreed upon in round 1, the participants reached an agreement in round 2 when the expression, whenever possible, was added to these statements. The primary consideration in distributing limited resources in health services is efficiency, incorporating ethical and economic dimensions [24]. The study reflects our participants’ acknowledgment of limited financial resources in transition care.

The primary limitation of this Delphi study was that the average professional experience in rheumatology among participants was limited to only five years. It is due to pediatric rheumatology being recognized as a subspecialty in our country only in 2010, with independent pediatric rheumatology clinics established in 2013. Moreover, since not all rheumatologists in our country participated in the study, the findings may not comprehensively reflect the perspectives of the entire rheumatology community. This limitation stems from the heavy patient load and demanding workload rheumatologists face here.) Also, Delphi studies face challenges, such as defining expertise, determining panel size, achieving consensus, and selecting statistical methods. Respondents might avoid negative responses, and an excess of survey items may compromise the accuracy of their reactions.

Even with consensus, findings should not be seen as definitive proof [15]. Qualitative approaches like the Patient and Community Engaged Research (PaCER) offer an alternative for transition care research in JIA patients [25–27]. PaCER involves patients in setting research questions and data collection through three phases: Set, Collect, and Reflect. This approach increases participant engagement and strengthens contextual validity by centering the patient experience. In a study using the PaCER methodology, nine individuals who participated in focus groups revealed three main themes with subthemes for transition care in JIA: preparation for transition (including preparation for transfer of care and self-advocacy), continuity and breadth of care (including changing relationships and new responsibilities), and need for support (including social and mental health support, notably with peer support) [27].

## Conclusions

While this Delphi study agrees on the key issues in transitional care for JIA patients, many issues still need to be agreed upon. The future acceptability and applicability of the ultimately agreed 20-item checklist in clinical practice will help to develop and improve transitional care in JIA in Turkey.

## Abbreviations

AYAs Adolescents and young adults  
JIA Juvenile idiopathic arthritis

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12969-024-01047-2>.

Supplementary Material 1. Clinicians’, patients, and parents response and agreement rates in Round 1.

Supplementary Material 2. Clinicians’, patients, and parents response and agreement rates in Round 2.

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## Authors’ contributions

Study conception and design: NŞ, BS, NAA, HES. Data acquisition: All authors. Statistical analysis: NŞ, BS, HES. Data interpretation: All authors. All authors read, critically revised, and approved the final manuscript.

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## Data availability

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.



## Declarations

### Ethics approval and consent to participate

Kocaeli University Ethics Committee approved the study protocol and adhered to the principles of the Declaration of Helsinki (2023/297).

### Consent for publication

Not applicable.

### Competing interests

The authors declare that they have no competing interests.

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