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Early View

Original Research Article

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French consensus statement on transition of adolescent and young adults with rare pulmonary disease from paediatric to adult care: a Delphi method study

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Author Contributions: E Peulier-Maitre and G Thouvenin developed the concept and designed the study with help from M Goutaki, N Nathan, M Patout, S Hascoet and N Remus. E Peulier-Maitre managed the study, designed the eDelphi surveys, analysed the data, and drafted the manuscript. All authors contributed to the surveys, interpreted results, and revised critically the manuscript. E Peulier-Maitre and G Thouvenin take final responsibility for all content.

Key words: Transition ; rare pulmonary disease ; adolescent ; young adults ; Delphi study

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Abstract

Title: French consensus statement on transition of adolescents with rare pulmonary disease from paediatric to adult healthcare

Background: Transition of adolescents with chronic diseases to adult care is at risk of health complications and loss of medical follow-up. There is currently no official general consensus specific to rare pulmonary diseases. We aimed at setting up a consensus of experts to establish consensus statement for the transition of patients with rare pulmonary diseases in France.

Methods: We sought consensus using a three-round Delphi method, involving the French rare lung disease network. Statements were submitted to a panel of 38 experts (including nurses, patients, physiotherapists, specialized and general physicians, social workers, psychologists). A statement was validated if 80% of the respondents rated it with 7 or more on a Likert scale.

Results: We received completed all 3 surveys from 37 respondents. We identified 77 key elements that reached consensus, to be included in future guidelines. The main topics discussed correspond to the future guidelines' structure, as follows: Transition overview and main objectives; Subjects to discuss with the patient during transition; Practical aspects of consultations during transition and transfer; and early follow up in adult care. The main remaining ideas were: 1) to coordinate global care for each patient, 2) to formalize transfer, and 3) to integrate patients' will and needs into their care in order to support their empowerment.

Conclusion: This study has established key elements to a successful transition for patients with rare pulmonary disease, by a multidisciplinary panel of experts. We achieved consensus on a formalized transition pathway to guarantee a successful transition for patients and their families, but also for healthcare professionals.

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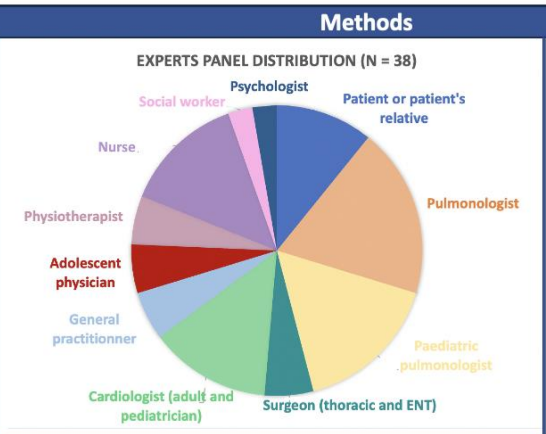
Graphical Abstract

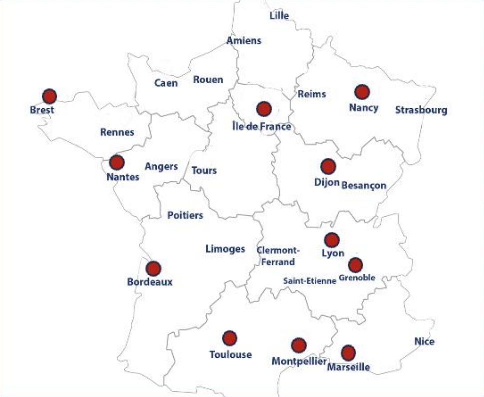
Methods

Key elements for successful transition of adolescent with rare pulmonary disease

Delphi method

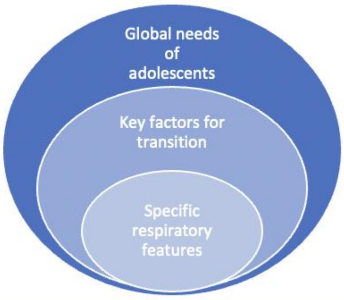
RespiFIL
Filière Maladies Respiratoires Rares





Results

- Transition overview and main objectives
- Topics to discuss during transition
- Practical aspects of paediatric consultations during transition
- Practical aspects of transfer
- Practical aspects of early follow-up in the adult medical system



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Introduction

Adolescence brings deep cognitive, emotional and physical changes. These changes can have an impact on the stable condition of a chronic illness, as well as a chronic condition may affect developmental steps of adolescence [1, 2].

Transition of adolescents and young adults concerns the whole medical process and period of time that aim to meet the needs of chronically ill patients as they move from a paediatric to an adult care system. The main goal of this process is to support patients and families as they move towards autonomy, and as they build their personal and professional future integrating their disease constraints [3]. While transition is long, transfer refers to the precise moment in time when responsibility for the patient's care is transferred from paediatric to adult medical care [4, 5].

Adolescence has been shown to be associated with a higher risk of acute complications and hospitalizations, especially in intensive care unit, and of loss of follow-up in people with increased care needs [6]. Adverse outcomes seem to occur in cases of abrupt transfer. Many factors can explain these difficulties, such as insufficient coordination of care or changes in social security coverage. During transition, major modifications in the responsibility distribution between patient and parents occur whereas differences between paediatric, typically family-centered, and adult care appear [7, 8].

Several transition programs have already been studied [9]. They highlighted that good collaboration between paediatric and adult care teams is needed, as the early introduction and ongoing discussion to prepare transfer [10–12]. Structured and coordinated processes, such as the Ready Steady Go program, support a smoother transfer for patients, according to large review evaluations [13, 14].

Advancements in medicine have improved survival in children with a chronic respiratory condition, especially rare diseases such as cystic fibrosis or neuromuscular disease [15–17]. Several rare diseases networks have developed transition programs in France, in order to improve care and follow-up of these patients. Within a rare cardiac disease network, the TRANSITION-CHD randomized controlled trial recently demonstrated the positive impact of a structured transition program on health-related quality of life and disease knowledge in transitioning adolescents with congenital heart disease [18]. RespiFIL, the French rare

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pulmonary diseases' network, coordinates adult (Orphalung, Pulmotension) and paediatric (RespiRare) healthcare, including transition, throughout French territory.

In certain rare respiratory diseases, such as childhood interstitial lung diseases (chILD), long-term follow-up into adulthood remains essential, even when remission or low disease activity is often observed during adolescence. In other conditions, including cystic fibrosis and primary ciliary dyskinesia, disease progression is more gradual, and may require the initiation of advanced therapies in adulthood, such as long-term oxygen therapy, non-invasive ventilation, or lung transplantation. The existing literature on transition in rare respiratory diseases emphasizes the need to address adolescents' medical, psychosocial, and educational needs, which are broadly similar across different diagnosis [15, 19, 20]. However, the respiratory involvement and the rarity of these conditions present specific challenges, including limitations in physical activity, restrictions on certain career paths due to exposure to inhaled substances, or again the requirement for coordinated multidisciplinary care. There are currently no general guidelines for rare respiratory diseases.

This manuscript reports on the development of French transition consensus statement following RespiFIL's identification of an unmet need for transition guidelines in rare pulmonary diseases. We sought to identify key elements to a successful transition for patients with rare pulmonary diseases, using a three-round Delphi method to synthesize opinions and to obtain consensus of experts [21].

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Methods

Setting

This study was conducted between February and December 2023, using a Delphi method. This consensus study was approved by our institutional review board (Paris University Hospital Data Protection Department, registration number: 20231206142118).

In this study, a modified Delphi method was used to develop consensus statement on transition from paediatric to adult care for patients with rare pulmonary disease. Key elements to a successful transition for patients with rare pulmonary diseases were named "statements". As a foundation for the initial statements, we conducted a systematic review of relevant literature and analyzed documents from European Scientific Societies related to transition. The search was conducted using the PubMed bibliographic database and covered publications from 2010 to the present. It was not restricted to rare pulmonary diseases, in order to capture a comprehensive understanding of the transition needs of adolescents with chronic illnesses, beyond the respiratory spectrum.

The following keywords were used: "transition," "adolescents," "young adults," "from paediatric to adult healthcare system," "to adult care," "adolescents with chronic conditions," "chronic respiratory diseases," "cystic fibrosis," "asthma," "interstitial lung disease," "primary ciliary dyskinesia," "pulmonary arterial hypertension," "sleep breathing disorder," "ventilated patients," "bronchopulmonary dysplasia," "transitional care," "transfer of adolescents," "recommendations to improve transition," and "transition Delphi study." A total of 59 articles were identified through this process. Studies were selected based on their relevance to the objectives of the Delphi study, which aimed to develop consensus statements on the transition of care for adolescents and young adults with chronic respiratory diseases. The review included both qualitative and quantitative studies, exploring the experiences and perceptions of patients, caregivers and healthcare professionals. The analyzed literature included rare and common respiratory conditions, as well as insights from other chronic diseases (e.g., diabetes, sickle cell disease, paediatric liver diseases) to fully address adolescent transition needs.

First and last authors coordinated the study and were responsible for writing the statements that were initially included in the Delphi process. Five expert physicians, members of RespiFIL,

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formed the “core group”. Their role was to read and correct initial drafts of the statements, and select the members of the experts’ panel.

Experts panel, or rating group

Experts were identified based on the professional network of the RespiFIL pilot group and on their expertise in rare respiratory diseases. The panel also included patients or patient relatives with various rare respiratory diseases, who were identified and contacted via existing patient organizations.

Each member of the expert panel was contacted prior to the start of the study and agreed to take part. The panel met one time online between the second and the third Delphi round, with the members of the core group, in order to optimize the statements of the last survey. All the statements were submitted to the panel of experts in French and translated into English after validation for the purposes of this manuscript.

Delphi process

We did not predetermine a number of Delphi rounds for the project. We defined our wished consensus level a priori and proceeded to several Delphi rounds until consensus was reached. For each round, experts received an email with instructions and a Google Form® link giving access to the survey. For each round, participants could respond within three weeks, with a first personal reminder email one week before the due date, and a second reminder two days before the survey closed.

Experts iteratively rated statements individually and anonymously, based on the existing literature and their personal experience. Statements were rated on a Likert scale from 1 (fully disagreed with the statement) to 9 (fully agreed with the statement). A free-text comment field was available on each statement, to enable expert panel members to explain their rate attribution, if necessary.

Our predetermined criteria for deciding when consensus was reached for each statement was that at least 80% of the panel positively (7 or more) or negatively (3 or less) rated a statement. The statement was considered as “key element” to be included in the final consensus statement if 80% of the rating was 7 or above.

The study required three rating rounds, revising statements without consensus and using qualitative analysis of free-text comments to develop or refine statements as necessary.

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Results

Expert panel

The panel was composed of 38 experts, including physicians and other healthcare professionals selected on the basis of clinical and academic expertise in the management of transition from paediatric to adult care or rare respiratory diseases. We selected the members of the experts' panel to ensure multidisciplinary and national geographical representativeness. The distribution of expert panel members is shown in Figure 1. The participants represented a broad spectrum of rare pulmonary diseases and included both paediatric and adult care providers. Among the medical specialists were pulmonologists managing children or adults with conditions such as suppurative chronic lung diseases, interstitial lung diseases, chronic respiratory failure requiring ventilation, bronchopulmonary dysplasia, as well as cardiologists involved in the management of pulmonary arterial hypertension. Thoracic and otolaryngologist surgeons, nurses specialized in cystic fibrosis care were also included. Physiotherapists had experience with patients affected by suppurative chronic lung diseases or neuromuscular diseases. From the patient and caregiver side, the group included individuals with primary ciliary dyskinesia, cystic fibrosis, and parents of patients with congenital central hypoventilation syndrome. The participants also included healthcare professionals specialized in adolescence and transitional care, such as adolescent medicine physicians, a social worker and a psychologist with expertise in transitional care, and general practitioners. The gender composition of the expert panel consisted of 15 men and 23 women.

Delphi process

The response rate was of 97% as 37 experts completed all 3 surveys. One expert did not go through the entire study because of professional reasons. A total of seventy-seven key elements (statements) were identified, for which consensus was reached, to be included in the future consensus statement. These 77 statements were validated with more than 80% of experts rating them with 7 or higher rates. No statements were rated with more than 80% of rates under 3, so no statement was consensually eliminated. Fourteen statements were validated in the first round, 48 in the second round and the last 15 statements in the third round. Six additional statements did not get validation even after the third round, but received a 73-78% of ratings of 7 or higher. Between the first and the second round, several statements were revised following expert suggestions from free comments even if they obtained more

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than 80% of rates over 7. These modified statements were submitted to experts for new ratings.

Consensus statement

Consensus statement was structured as follows: 1) Transition overview and main objectives; 2) Topics to discuss during transition; 3) Practical aspects of paediatric consultations during transition; 4) Practical aspects of transfer; 5) Practical aspects of early follow-up in adult care. Statements, level of consensus, and Delphi round were validated as presented in Tables 1-5.

1. The first part addressed “**Transition overview and main objectives**” (Table 1). It was mainly composed of definitions and general statements, and aimed to clarify the terms and issues of transition for the different stakeholders. It was the section with the highest number of validated statements already in the first round.
2. The section “**Topics to discuss during transition**” was designed to approach topics specific to adolescence, in order to give indications and tools to specialist medical teams to discuss them with patients. Five sub-groups were identified: education and professional projects, socialization and personal projects, nutrition, exercise and sleep, risky substance use (tobacco, alcohol, drugs), and sexual health. The statements in this section have generated the most comments from the experts. All statements were re-written with the help of experts’ comments to improve them after first round. They were resubmitted for a second round (Table 2).
3. The part “**Practical aspects of paediatric consultations during transition**” involved practical aspects of care and suggested a timeline for transition. Consideration was given to the heterogeneity of local resources. The practical details of transition are reached as soon as the patient's maturity allows it. Transition should be anticipated, even though no specific age reached a consensus for starting the transition process (Table 3).
4. The part “**Practical aspects of transfer**” addressed the practical aspects of transfer that depended a lot on the potential medical relocation of the patients, their maturity, and their clinical stability (Table 4). For example, a specific medical transfer form has been elaborated.
5. The part “**Practical aspects of early follow-up in the adult medical system**” dealt with the specific recognition of the young adults’ needs, the adaptation to the new healthcare system, and the continuation of comprehensive care (educational support) (Table 5). Young adults require special attention after transfer (gradual and consistent patient involvement,

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continuation of therapeutic education, longer consultations, etc.). The three statements that did not reach consensus in this part were reported by some experts as being not feasible in practice.

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Discussion

This study allows to propose recommendations for the transition of patients with rare respiratory diseases within the RespiFIL French national network, a significant achievement as no guidelines existed until now.

This national consensus will enable the standardization of the transition process to be formalized. Some healthcare centers have implemented programs or initiatives aimed at improving the transition of their patients from the paediatric to the adult system. Similarly, local or national programs have been developed only for specific respiratory diseases, these initiatives however remaining limited to one disease or to one center that have implemented them [22, 23]. This new consensus aims to reduce inequities in care, especially healthcare and socio-economic disparities. A formalized protocol is crucial to prevent morbidity and loss to follow-up after patient transfer, to be beneficial for patients [24, 25].

The strength of this study was to include healthcare professionals from specialties other than those commonly represented by RespiFIL (such as adolescent medicine and general medicine), and to incorporate perspectives from both paediatric and adult care providers. The involvement of patients and their families in the transition process was already well known as essential [26]. The use of the Delphi method ensures that this work represents the opinions of involved stakeholders as accurately as possible. Participants' ability to comment on each statement has significantly added value to rewriting the statements between each round. We were able to submit a large number of proposed statements to the expert panel, covering various themes related to chronic illness and adolescence, beyond the specificity of rare respiratory diseases. Physicians managing rare respiratory diseases are often responsible for patients with a range of different conditions, reinforcing the need for individualized yet structured transition process and making general guidelines for all rare respiratory diseases more relevant. Although we did not include a dedicated subsection on the specific needs of adolescents with rare respiratory diseases, we integrated disease-specific elements, such as respiratory rehabilitation and the necessity for hospital-based follow-up, throughout each section. At the same time, practical guide with clinical forms was developed to be adapted to the specificities of each rare respiratory disease, enabling personalized care while ensuring a cohesive approach to the overall transition process.

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A key achievement of this work is its broad approach to adolescent issues during the transition process. Compared to other transition programs for rare respiratory diseases, this consensus places greater emphasis on the psychological, educational, and social needs of patients. Young adults who have experienced the transition often report unmet considerations during adolescence [27–29]. Despite recognizing these challenges, specialists expressed limited confidence in managing adolescent-specific issues, making it difficult to reach consensus on two points: the involvement of adolescent medicine specialists in complex transition pathways (Table 2, unnumbered statement), and the need for specific training sessions on transition management for healthcare professionals (Table 5, unnumbered statement), even though such practices have been successfully implemented in other countries [6, 30]. To support practitioners and patients, we provided reference to relevant French resources and documents in the practical guide on the RespiFIL website.

Another aspect of our work is the focus on the practical organization of paediatric consultations, the transfer process, and the initial consultations in adult medicine. Although no specific age reached consensus to initiate the transition process, anticipation is essential to ensure patients are adequately prepared for transfer, as highlighted by patients themselves [31, 32]. This early focus empowers the young person to become comfortable as an adult actively engaged in managing their health. The experts reached a consensus that young adults require special attention during and after the transfer (statement #4). It is often noted that patients and caregivers feel apprehensive when entering an adult care service [33]. Practical measures such as longer consultations, alternating visits between peadiatric and adult care, organizing a “welcome day”, and facilitating appointment rescheduling aim to ease the transition process (statements #65, #67, #68 and #75). Continuing therapeutic education sessions is crucial to maintain gradual and consistent patient involvement (statement #71).

This consensus statement defines the roles and responsibilities of the various stakeholders involved in the care of patients with rare respiratory diseases. Although the role of general practitioners in transition process was not fully adopted by consensus, the importance of their involvement in providing continuity of care and preventive health is underlined (statements #41, #46, #56 and #58) [34]. Interestingly, while the need for a designated transition coordinator and the use of peer support groups are advocated in the literature, these elements did not reach consensus in our group [35, 36].

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The effectiveness and feasibility of these recommendations remain to be proven. Future research should focus on assessing transition success indicators and ensuring greater patient representation to better address the diversity of needs. Patients involved in our network likely have different needs due to the diversity of their conditions, which can differ significantly in terms of severity, progression, and therapeutic burden [37]. While promoting patient autonomy is crucial, it should not overshadow the role of caregivers, who often play an essential role in ensuring consistent follow-up and supporting the transition to adult care [38–41]. Another limitation of this study is the development of statements based on a literature review not specifically focused on rare respiratory diseases. It allowed to have a wide spectrum of adolescence related topics, but the general scope of the bibliographic search may not fully address the unique aspects of rare respiratory diseases, even though the experts possess the necessary knowledge and expertise.

In conclusion, this French consensus statement was developed by identifying essential elements for a successful transition for adolescents with rare pulmonary diseases. Future discussions should focus on the roles of adolescent specialists and general practitioners, the contribution of caregivers, and the training required for all stakeholders involved in the transition process.

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Tables

Table 1 ***Transition overview and main objectives***

Each numbered statement has reached consensus. The unnumbered statements did not reach consensus.

Statements	Validation time	Level of consensus reached (%)
Transition overview		
#1 Transition is the care process that supports our patients with a chronic disease from the paediatric to the adult healthcare system.	1st round	90
#2 This is different from "transfer", which refers to the exact moment in time when responsibility for the patient's care is transferred from paediatric to adult medical system.	1st round	90
#3 A successful transition is anticipated, with preparation starting several years ahead.	1st round	90
#4 Particular attention should be given to patients during this time, especially young adults immediately following their transfer.	3rd round	95
#5 It is a flexible, natural and continuous process. - Flexible because transition is adapted to each patient: their perspectives and preferences should be considered as much as possible. - Natural because transition occurs alongside the patient's psychological, social and physical maturation - not just their medical journey. It takes place as adolescents and young adults gain autonomy in all areas of their lives, not only in managing their health. - Continuous, because a successful transition requires extensive preparation and special support that continues into adulthood, enabling patients to gradually achieve independence.	2nd round	95
#6 When asked, patients express the need for a trusted individual to discuss this topic with. It is most often the child's specialist paediatrician, but it can also be a transition coordinator nurse, as it exists in certain care centers.	3rd round	81

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#7 A high-quality transition relies on effective communication and mutual trust between the paediatric and adult healthcare teams.	1st round	82
Main objectives		
#8 Transition should facilitate the patient’s autonomy in decisions regarding their health.	1st round	92
#9 It allows the patient to enhance their understanding of the disease, if they wish so, and to explore new themes relevant to adolescence or adulthood.	1st round	92
#10 Healthcare providers should be able to support the patient’s medical, psychological and social goals, helping them make the best possible choices considering the constraints related to their illness.	1st round	92
#11 Promoting shared decision-making strengthens the patient's confidence in their ability to make informed health-related choices. To facilitate this, adolescents and young adults need guidance and the opportunity to develop essential notions about their illness.	1st round	92
A non-exhaustive list of these notions is mentioned below:		
#12 Describe their illness and its consequences, in order to communicate about their illness and health needs.	1st round	90
#13 Understand therapeutics used.	1st round	87
#14 Understand why the main additional examinations are carried out.	1st round	84
#15 Recognize the signs of worsening or complication of the disease.	1st round	87
#16 Knowing what action(s) to take and whom to contact in case of worsening.	1st round	97
#17 Knowing the key members of the healthcare team, their roles and how to contact them (identifying the resource persons).	1st round	87

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Table 2. ***Topics to discuss during transition***

Each numbered statement has reached consensus. The unnumbered statements did not reach consensus.

Statements	Validation time	Level of consensus reached (%)
Topics to discuss during transition		
#18 During the transition process, whether in consultation or in a formalized therapeutic education session, it is crucial to address the detailed topics outlined below with patients. These notions should be revisited over time, adapting the approach according to the patient's maturity and needs.	2nd round	92
#19 The goal is to help the patient to make their own choices while taking into account the real constraints related to their illness.	2nd round	89
#20 Caregivers must be able to support reflection on these projects without defining them on behalf of the patient.	2nd round	92
#21 Asking about the patient's knowledge of the topic can be a starting point for discussion.	3rd round	89
#22 Although the specialist is not the primary actor on these topics, they play a key role in guiding, supporting and screening.	3rd round	89
#23 Clinics dedicated to adolescents or transition are valuable resources to rely on when available locally.	2nd round	81
The general practitioner, when present and in partnership with the specialist, is a key resource person for all these subjects, especially within the French territorial organization of care pathways.	Not validated	78
Similarly, peer support groups are often appreciated by patients.	Not validated	76
The physician specialized in adolescence serves as a recourse for managing complex situations or pathways, providing a different perspective from the specialist physician.	Not validated	78
<u>Education and professional projects</u>		
#24 The patient should know where they can find advice on educational and vocational guidance. Patients must have access to this information.	2nd round	92
#25 Factors that the patient should consider when choosing an education or profession need to be discuss:	2nd round	87

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- Potential adaptations during studies or professional life: such as limiting exposure to certain factors or organizing work schedules that accommodate medical care. It is also important to consider the challenges associated with different professions.		
- #26 If possible, reach out to the school or occupational physician for optimized and personalized care.	3rd round	92
#27 There are a number of resources available to facilitate the discussion, the list of French resources is available in the appendix	2nd round	87
Socialization and personal projects		
#28 Assess the patient’s family and social support, and the patient's ability to talk to others about their illness, if they wish to do so.	2nd round	89
#29 Promote the development of life projects by integrating health-related choices and providing support adapted to the patient’s needs.	2nd round	97
#30 At the patient's request, existential dimensions can be approached, such as the potential impact of the illness on self-image, the ability to envision the future, and one's sense of place in society...	3rd round	81
Nutrition, exercise and sleep		
#31 It is recommended to promote physical activity. To this end, it is necessary to discuss the various physical activities available, to help the patient find the one(s) that are right for them, and to discuss any special arrangements or precautions that need to be taken.	3rd round	100
#32 An assessment of current activities and their future prospects can be carried out, if possible with an adapted physical activity teacher and/or physiotherapist.	2nd round	84
#33 It is also recommended to discuss diet specificities adapted to the disease and treatments, and sleep hygiene and its implications, thus enabling the patient to gradually develop a constructive analysis of their lifestyle habits.	2nd round	87
Risky substance use (tobacco, alcohol, drugs)		
#34 To identify and screen for risky behavior, it is recommended to assess consumption using a non-judgmental method. Specific documents on addictions are tools to help with screening and support, some can be provided to the patient and discussed with them.	2nd round	92
#35 This allows the patient to have comprehensive knowledge about the risks associated with substance consumption.	2nd round	97

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#36 This provides an opportunity to discuss the specific risks associated with the disease and substance use, as well as the preferred adaptations in the event of consumption.	2nd round	84
#37 “Consultations for Young Consumers" (CJC) can be offered if substance use is identified, following an assessment of the patient’s motivation to reduce or stop consumption. Other existing resources include: Adolescent Centers, Youth Reception and Listening Points, Medical-Psychological Centers and hospital addictology departments.	2nd round	92
Sexual Health		
#38 Sexuality is an integral aspect of overall health and should be addressed from a positive, open perspective, rather than through the potential risks.	3rd round	87
#39 Inquiring about the patient's perceptions of sexual health allows to better target the information to provide. Offering the opportunity to discuss sexual health during consultations helps to answer questions and resolve difficulties related to sexuality.	3rd round	87
#40 The transition period is a suitable time to inform the patient about the potential impact of the disease on sexuality, including quality of sexual relationships, consequences on fertility, preferred contraception methods considering the illness, necessary information for those wishing to have children or become pregnancy, and general risks such as sexually transmitted infections.	2nd round	95
#41 If the patient wishes, they are encouraged to discuss emotional and sexual issues, and if needed, are referred to a qualified professional, such as a general practitioner with expertise in this area or a gynecologist.	2nd round	90
#42 The available support structures and possible next steps should be clearly explained to the patient, if necessary, including Sexual Health Center, Assisted Conception Center, and Gamete Storage and Research Center.	2nd round	87
#43 If the condition warrants it, genetic counseling is offered, particularly if there are concerns about the possible risk of transmitting the disease to future generations.	2nd round	89
#44 Websites or information booklets on sexual health should be presented to the patient if they feel the need for it.	2nd round	84

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Table 3. ***Practical aspects of paediatric consultations during transition***

Each numbered statement has reached consensus. The unnumbered statements did not reach consensus.

Statements	**Validation time**	**Level of consensus reached (%)**
Practical aspects of paediatric consultations during transition The practical details of transition are reached as soon as the patient's maturity allows, but the following timeline and recommendations can be applied:		
#45 During early adolescence, the physician systematically offers to see the patient alone, with their consent, for at least part of the consultation.	2nd round	89
#46 Re-announcing the diagnosis to the adolescent during discussion about the disease in the transition period provides dedicated time for any general questions the teenager may have. Depending on their preferences, the conversation can be held alone or with someone close to the teenager.	2nd round	100
#47 The right to confidentiality is clearly explained to the patient and their parents. Medical confidentiality will be upheld for the young person as long as there is no significant risk to their well-being.	2nd round	97
#48 Starting in middle school, the paediatrician informs the patient that their specificity is to treat children only, and that a transition to a trusted adult physician will occur at the appropriate time.	2nd round	81
#49 New specific topics related to adolescence (refer to part 2) are introduced to the teenager starting in middle school, and continue throughout the transition process.	2nd round	89
#50 Existing clinics dedicated to adolescents or transition in some healthcare centers can be recommended to patients.	2nd round	89
#51 Useful tools to support transition include the “Ready Steady Go" program, the Good2Go questionnaire and therapeutic education programs	2nd round	84
#52 Identifying specialist physicians across regions of France who are willing to dedicate part of their practice to the care of adolescents or young adults with a rare respiratory disease helps ensure continuity of care between the paediatric and adult sectors, especially if the patient relocates for personal or educational reasons.	2nd round	92
#53 The choice of the adult specialist referring physician should be anticipated.	2nd round	89

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#54 Organizing a joint meeting between the paediatric team and the adult team facilitates the exchange of information on the management and specific issues of each patient prior to transfer. The primary care physician should be invited. These meetings ideally take place in person, but can also be held by videoconference if necessary.	2nd round	95
#55 Continuity of care can be ensured by gradually enabling the patient to manage their own appointments, request prescription renewals, etc.	2nd round	89
#56 The role of the general practitioner in the healthcare pathway is essential. In accordance with regulations, patients must choose a primary care physician from the age of 16.	2nd round	95
#57 The specialist must promote the involvement of the general practitioner, right from the start of paediatric care.	3rd round	92
#58 The general practitioner can be the patient's first contact in case of acute events, if it is compatible with the patient’s condition and the resources available in the care facility. The general practitionner receive updates from each consultation and hospitalization.	2nd round	95

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Table 4. ***Practical aspects of transfer***

Each numbered statement has reached consensus. The unnumbered statements did not reach consensus.

Statements	Validation time	Level of consensus reached (%)
Practical aspects of transfer		
#59 The timing chosen for the transfer from paediatric to adult care is primarily based on the adolescent's maturity rather than their civil age, though it typically occurs around 18 years old.	2nd round	84
#60 The "Medical Transfer Form" allows for the transmission of key medical and social information to the referring adult physician prior to transfer. The "Medical Transfer Form" should be reviewed and completed by the young patient, and their parents' involvement if desired. This "Medical Transfer Form" can be shared with the primary care physician.	2nd round	87
#61 Whenever it is possible, transfer should take place at a time when the patient is medically, psychologically and socially stable.	2nd round	92
#62 Therapeutic modifications should be avoided immediately before or after transfer. Any modifications should ideally be discussed by both teams as part of a long-term care plan.	2nd round	92
#63 The frequency of consultations before and after the transfer should be adapted to the patient's feelings, and not just medical reasons. Particular vigilance is required to ensure regular follow-up.	3rd round	95
#64 Transfer often relates to the educational project, which should be respected: for example, a change of city for studies. In some situations, a change of team can be beneficial if it occurs at a time of personal empowerment for the patient (for example: a new place of residence, a new school structure…).	2nd round	95
#65 Depending on local constraints and the individual needs of each patient, it is advaisable to offer one to two joint or alternating consultations with the paediatric specialist and the adult specialist. If necessary, these consultations can be conducted via videoconference.	2nd round	87
#66 It is essential to ensure that the patient's administrative status is current. An appointment with the social worker can be easily arranged. By understanding the medical and social benefits to which they are entitled, the patient will be in a better position to apply for them on their own in adulthood.	2nd round	92

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Table 5. ***Practical aspects of early follow-up in the adult medical system***

Each numbered statement has reached consensus. The unnumbered statements did not reach consensus.

Statements	Validation time	Level of consensus reached (%)
Practical aspects of early follow-up in adult medical system		
#67 It is advisable to introduce the adult care team, the ward, and the hospital prior to the transfer, or to schedule dedicated time on the day of the first consultation in the adult department. If this is not feasible, a video with a map can serve as an alternative.	2nd round	81
#68 During the first consultation, a time alone with the patient and a time with the patient and their parents should be scheduled, if the patient agrees. The consultation generally lasts 45 minutes.	2nd round	89
#69 The patient's caregivers will gradually take on a less active role in the care process, but will remain an essential source of support. In order to foster the patient's desire for autonomy, it is important to instill confidence in both the patient and their parents.	3rd round	100
#70 At the beginning of care in adult medical system, teams should emphasize the involvement of young adult patients so that they feel considered in their decisions.	3rd round	100
#71 Therapeutic education sessions should continue into adulthood.	2nd round	95
#72 The structuring of the arrival of young adults in adult sector could be formalized with: - The presence of a transition coordination nurse, who would be the teenager's referent and could accompany them into the adult sector. - An introductory consultation - A systematic discussion on social rights - Educational and vocational support	2nd round	92
#73 A letter to the general practitioner with the contact details of the adult department and the National Diagnostic and Care Protocol (PNDS) for the pathology can be systematically sent by the secretariat at the first appointment after transfer.	2nd round	92
#74 The handover to the adult specialist is confirmed to both the paediatrician and primary care physician following the first consultation.	2nd round	95

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#75 In case of a missed appointment in the years following the transfer: - Ideally, the patient is called by their referring physician to schedule a new appointment. - In all cases, a letter of non-attendance with the department's contact information (for appointments scheduling, in particular) must be sent to the patient. - The general practitioner must be informed of the young adult's not attending the appointment.	2nd round	92
#76 The general practitioner and private practitioners (physiotherapist, independent registered nurses, pharmacists) ensure good continuity of care before and after transfer.	3rd round	97
#77 Psychosocial follow-up should be proposed at least once a year.	3rd round	81
Welcoming young adult patients transitioning from paediatric care is a skill not typically covered in initial healthcare training and could benefit from specialized instruction.	Not validated	73
The differences between paediatric departments and adult departments, such as encountering patients at a more advanced stage of the disease, can be discussed during the visit.	Not validated	78
A member of the adult department team can meet with the patient in the paediatric department prior to their transfer.	Not validated	78

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Figures

Patient or patient's relative	4
Pneumologist	7
Paediatric pulmonologist	6
Cardiologist (adult and paediatrician)	5
Surgeon (thoracic and ENT)	2
General practitionner	2
Adolescent physician	2
Physiotherapist	2
Nurse	5
Social worker	1
Psychologist	1

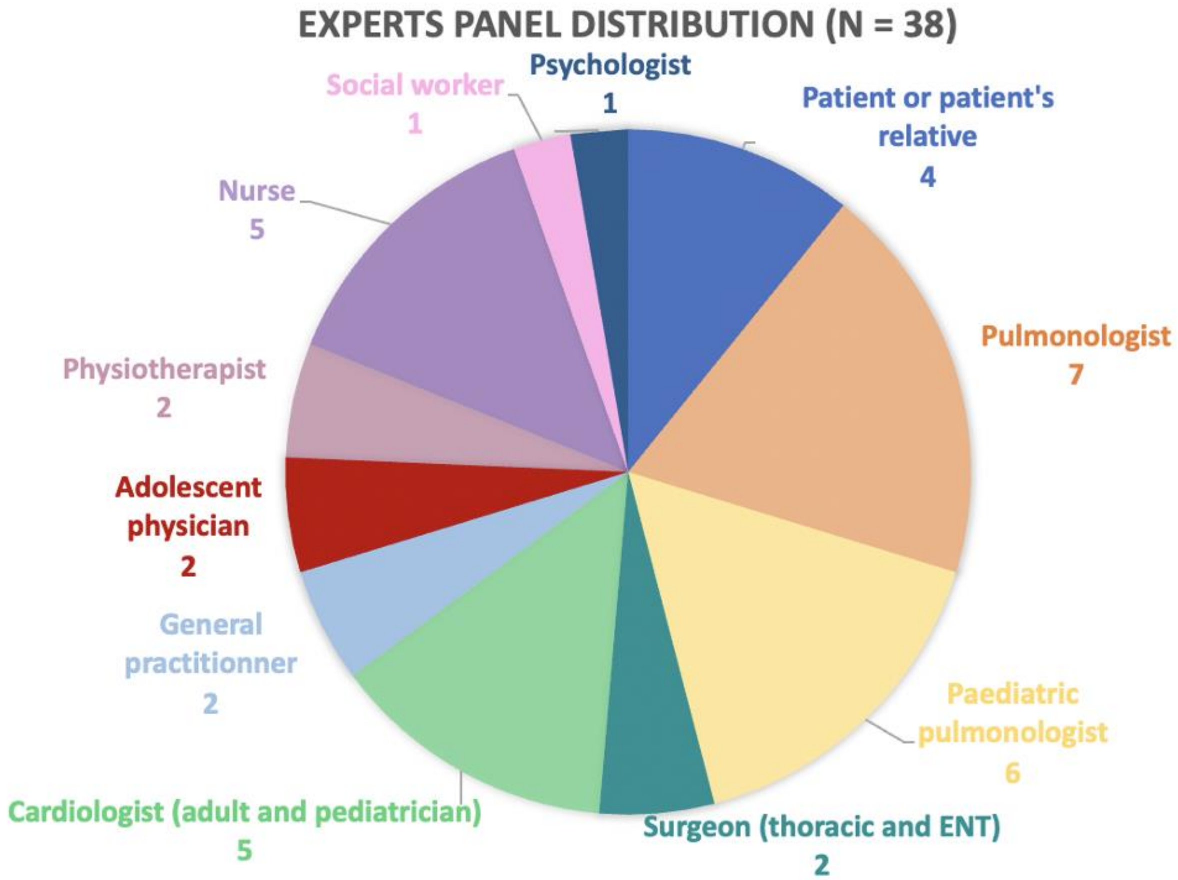

Figure 1. Experts panel distribution

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