

# Experiences of UK-based adult transition services for interstitial lung disease in childhood: “There's a lot less cushioning”

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## Funding information

None

## Abstract

Interstitial lung disease in childhood (chILD) is rare and no longer purely a childhood issue as many survive into adulthood, and so have to transition from pediatric to adult healthcare services. Transition is a significant life event that has the potential to impact on physical and mental health outcomes. The European Respiratory Society (ERS) statement on chILD transition highlighted the lack of standardised transition services for chILD transition resulting in a haphazard process. This qualitative study explores how young people and parents in the United Kingdom experienced transition from paediatric to adult healthcare services for chILD. Participants ( $n = 7$ ) were recruited from chILD patient organisations and online communities. We focused on the experience of transition exploring if there were any information packs or support provided for the transition. Such support may be generic, such as “Ready Steady Go” which provides a systematic approach to transition and disease-specific literature. These latter have not been developed for ILD. Data were analysed by constructivist grounded theory. We present a lived experience of transition with themes of lack of transition preparation and planning, challenges of adapting to adult services, and a changing healthcare scene. Due to the complexity of chILD, parents discussed their need to remain, in part, as an advocate for the young person. Respondents provided recommendations for how transition could be improved along with tips for young people who are new to the transition process, which include educating oneself about the condition, learning medical terminology, and reaching out for support.

## KEYWORDS

childhood interstitial lung disease, parents, qualitative, transition, young people

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## 1 | INTRODUCTION

Interstitial lung disease in childhood (chILD) is a relatively newly described diverse group of more than 200 rare conditions.<sup>1,2</sup> Although chILD begins in childhood, patients frequently need to transition to adult services.<sup>3</sup> Transition can be described as “the purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-orientated healthcare systems.”<sup>4</sup> Paediatric medicine differs greatly from adult medicine. For those with a chronic respiratory condition, pediatric care is often multidisciplinary, individualized, and heavily focuses on issues of development, growth, and family inclusion. Successful transition is a process where the young adults learn self-advocacy and to communicate their care needs; this is part of the young person taking responsibility for the management of their own healthcare.<sup>5,6</sup> Poor transition has been shown to have detrimental impact on long-term health and wellbeing, and is also a time when patients may be lost to follow up.<sup>7,8</sup> Therefore, it is of critical importance that those with chILD are able to transition smoothly to adult services.

Rare respiratory diseases who do have access to specialist centres and funded co-ordinated care, cystic fibrosis (CF) and primary ciliary dyskinesia (PCD) use the “Ready Steady Go” transition programme.<sup>9,10</sup> “Ready Steady Go” is disease agnostic and recommended by National Institute for Health and Care Excellence<sup>11</sup>; however, not all hospitals adopt this as it requires a co-ordination of communication between pediatric and adult teams.<sup>12</sup> The European Cooperation in Science and Technology (COST) Action dedicated to European Network for Translational Research (EnTER) in Children's and Adult interstitial lung disease (COST action 16125) found chILD transition is highly variable and inconsistent across the EU.<sup>2</sup> Despite the great strides in clinical research and genetics, one aspect lacking is chILD surveillance in adulthood. There are many benefits of long-term health surveillance with respiratory conditions. These include knowledge of disease development and relapse,<sup>3</sup> treatment adherence and comorbidity management<sup>13,14</sup>; learning of continued disease risk factors into adulthood<sup>15</sup>; understanding of long-term treatment effects<sup>16</sup>; along with potential missed opportunities for genetic diagnostics with idiopathic cases; these are all important aspects of longitudinal health care.

We investigated the current UK provision of transition services through interviews with young adults and parents of young people affected with chILD. Before the study, an informal UK-based pre-recruitment survey indicated that only approximately 50% of young adults with chILD transitioned to adult services. With chILD services being uncoordinated and the conditions being rare- to ultra-rare, coupled with the far smaller numbers of chILD transitioning compared to CF or PCD across the United Kingdom, understanding current chILD transition is important as we aim to highlight gaps and improve services for these patients. To our knowledge, this is the first qualitative study to focus on the lived experience of transition and chILD.

## 2 | METHODS

### 2.1 | Participants

Participants were recruited from chILD-related patient organisations and online community support groups via adverts placed on forums. Potential participants were asked to contact the research team directly to receive study information and to screen for UK-based participants. We recruited three young adults and five parents of young people affected with ILD. Table 1 presents participant details. One participant who was interviewed was found not to meet diagnostic eligibility criteria after review.

Data saturation was monitored but not expected to be achieved within this small study.<sup>17,18</sup> Ethical approval was granted from The University of Liverpool Institute of Population Health Research Ethics Committee (ref: 10014).

### 2.2 | The interviews

Interviews were conducted between mid-July and mid-September 2021. Seven were conducted remotely using teleconferencing software and one by telephone. Interviews lasted between 20 and 45 min. Before consenting to the interview, respondents were sent a participant information sheet via email and were asked to sign an online consent form, assuring their responses would be treated confidentially and anonymised in any study output. The interview was semi-structured; however, a chronological approach from pediatric to adult transition service changes was used, coupled with an understanding of the impact of the participants condition along with two main questions of interest “what is your experience of transition?” and “were any information packs or support provided for transition?” Parents were asked how their child's experience of transition from their perspective. Finally, participants were asked what advice they would give to others in the same situation, or any recommendation of services change that may improve future transition experiences.

### 2.3 | Analysis

The Zoom interviews were audio-recorded and transcribed verbatim. All identifying features within the interviews such as names, locations and hospitals were removed from the transcripts; however, the chILD diagnosis was retained. The telephone interview was not recorded but notes and quotes were checked by the participant to confirm accuracy of information. Transcripts were analysed using the constructivist grounded theory method.<sup>19</sup> Line-by-line coding was primary method of the analysis as this allowed for exploration of emerging themes in the data. Quotes were selected to allow for participant “voice” and experience to come through the data, without

TABLE 1 Respondents information.

Participant	Age of young person	Gender of young person	Diagnosis	Age transition commenced	Age transition completed	Information pack received?	Transition stage
Young person (YP1)	22	Female	Surfactant Protein deficiency ABCA3	15	16	No	Completed
Young person (YP2)	23	Female	Bronchiolitis Obliterans (OB)	18	18	No	Completed
Young person (YP3)	18	Male	Undefined ILD	18	18	Yes	Completed
Parent 2 (P1)	18	Female	Bronchiolitis Obliterans (OB)	18	18	Yes	Completed
Parent (P2)	16	Male	Bronchiolitis Obliterans (OB)	15	-	No	Early transition
Parent (P3)	20	Male	Surfactant Protein C deficiency (SP-C)	18	18	No	Completed
Parent (P4)	15	Female	Surfactant Protein C deficiency (SP-C)	15	-	Yes	Early transition

Note: Excluded participant interviewed information: parent participant; non-CF bronchiectasis; transition completed.

researcher personal inference or assumptions. This was a reflexive process as the codes generated from the interview data developed into categories and each transcript was then compared to identify commonalities and broader themes. The coding, category building, and text analysis was an iterative process where central themes were developed.

### 3 | RESULTS

We present our findings in three themes of transition preparation and process; adaption and accessing adult services; the changing of healthcare relationships, and lastly, for parent respondents, the parent as a continued advocate for the young person.

#### 3.1 | Transition preparation and process

Transition occurred predominately around the age of 18 (Table 1). The speed varied depending on the young person's circumstances. YP1 required lung transplantation evaluation and so completed transition earlier than expected to access the new adult services hospital with lung transplant facilities. YP1 described a feeling that paediatric services did not wish to deal with the complexity of her condition as she was "at an awkward age where they didn't want to deal with me" (YP1). Whereas P2 positively described "a really slow transition" due to the young person requiring multidisciplinary care along with additional support for mental health and neurodevelopmental needs.

Before transition, young people were encouraged to attend a portion of their medical appointment alone. This was part of the process to build confidence and autonomy by encouraging the young person to learn to take responsibility for their own health and gaining independence from their parent/caregiver.<sup>5,6</sup> YP2 and YP3 reported this approach as having a positive impact on their transition experience as this process allowed them to be "very open" (YP3) about communicating their needs. YP2 reported her parent actively encouraged this too:

*"It was very important from my Mum's perspective that I ... knew what to do and how to deal with, and what questions to ask. So, it made it a lot easier for me transitioning to being into adult services."* (YP2, Bronchiolitis Obliterans)

Parental encouragement is highlighted from the parental responses. P2 discussed her son's slow transition preparation to "get him more independent with his own medical needs" (P2) yet adds that her input is still required since her son has also been diagnosed with autism and mental health issues. However, already even though they are in early phases of transition discussion, P2 is seeing signs of acceptance developing in her son about a change to adult services.

"I think he is ready to leave because of the screaming babies and toddlers running around and hallways. But we are going to miss his consultant." (P2, Bronchiolitis Obliterans)

However, parental encouragement does not always go as expected. P3 describes their son as currently healthy, and his focus is more on engaging with physical exercise and nutrition to support his health condition. Due to poor experience with pediatric care, the son does not wish to engage with an adult medical team. Despite P3's encouragement and concern, this highlights that it is the young person's choice on how to manage their own condition.

"Don't want him to not attend his appointments, but I do want him to get balance. Got to let him get this [responsibility to own health] himself." (P3, Surfactant Protein C deficiency)

Three respondents reported that they were provided with transition information packs. YP3 was provided with a general information pack and had access to an administrative team liaison who acted as communicator between the pediatric and adult hospital. This liaison was able to deal with any issues answer questions throughout the process (the patient was not sure of their professional background). P1 and P4 reported they received the NICE-approved "Ready-Steady-Go" program pack for transition.<sup>11</sup>

Four respondents reported delays to their transition due to COVID pandemic (YP1, YP3, P3) and due to staff changes within adult care (YP3). None of these respondents experienced transition aspects such as the new hospital visit or face-to-face first introductions with the adult consultant.

### 3.2 | Adapting—Accessing adult services

ChILD patients require multidisciplinary care and have varying needs.<sup>1,2</sup> However, disappointingly, respondents who have transitioned reported that there was no longer the same access to services within adult care. This left over half of the respondents with a feeling of uncertainty such as what to do if the young person becomes unwell or managing travel if based at a new adult center. One example of this was open access so that the young person could directly access their local children's ward if they become ill, allowing by-passing the General Practitioner (GP) or Accident and Emergency department (A & E) to a service where the young person and their condition is known. Respondents who have experienced poor health are aware this open access service was no longer in place:

"As soon as "M" became ill she'd be seen straight away. But when they go to the adult clinic, well, it is just like anybody else when you become ill." (P1, Bronchiolitis Obliterans).

"I actually was admitted to hospital with a bad infection, and I was absolutely terrified. Seeing these older people dying all around me on the ward. I was 18 and didn't know what to expect, but certainly not this." (YP1, Surfactant Protein deficiency ABCA3)

This could mean expectations need to be better managed. YP2 explains her perspective of the changes between pediatric and adult care:

"I think you have to be prepared for that they [adult services] will be a lot more removed and I think this leaves a feeling that there's a lot less cushioning. So being in paediatric care, they will naturally kind of soften everything. That's how it is. It's just going to be a lot more different than paediatric care." (YP2, Bronchiolitis Obliterans)

Professional and personal experience can also shape those expectations. P4 described being nurse-trained and has experience in adult respiratory ward care. Due to this, managing at-home treatments are a consideration to avoid accessing adult hospital services:

"You can do a parental course to do IVs at home... I'm willing to do that while she's still in the paediatrics so that I could carry that over if it's easier to get that done quickly ... at home rather than maybe having to wait [for adult care]." (P4, Surfactant Protein C deficiency)

Two respondents reported being hopeful for the future with adult services. YP3 is looking forward to exploring potential treatment and management options such as reducing oxygen supplementation.

### 3.3 | Changing of healthcare relationships

Many respondents reported having a good relationship with the young person's pediatric team who have supported them with any healthcare issues:

"They have known him since he was 3. They have also dealt with all the school stuff or dealt with everything, and they've always been on the phone for us so it will be very different when the time comes [to transition]." (P2, Bronchiolitis Obliterans)

The pediatric respiratory consultant provided an invaluable role in facilitating this multidisciplinary approach along with supporting other services such as education and mental health. This is a relationship that has developed over time, not just with the young person but also with the parent:

"A's' consultant has known her since she was a little baby. And she knows her really well. She knows what works for her and knows what works for me. She also knows my level of anxiety and what gets me wound up... we've got a good rapport now, so I want to transfer that." (P4, Surfactant Protein C deficiency).

Transferring the positive pediatric relationship across to adult services is seen as "important" (P4) for adult transition. However, some responses indicate low confidence in the adult consultant who are unfamiliar with chILD:

"I don't really know very much about your illness and I don't really know your story', which is not what you want to hear your doctor say." (P1, Bronchiolitis Obliterans)

"I'm never a hundred percent of if the doctor understands my diagnosis. It is kind of vague, and he seems to be reliant on his computer more" (YP2, Bronchiolitis Obliterans)

"Because I had this rare condition no-one knows about, nobody knew what to say to me. No one wanted to see me. And if they did see me, it was a five-minute chat of "we don't know what to do for you, how to help you" ... and I was only 18, they sent me into this doctor, and I went in and asked if I had been given a consultant... and he said, "she's not here" ... "we all know how lung fibrosis works." (YP1, Surfactant Protein deficiency ABCA3)

Yet, conversely, one respondent described their hopes for having an adult consultant who understands the distinction between chILD and adult ILD:

"We'll probably get a really good consultant who knows we're not dealing with an adult who is developing interstitial lung disease; we're dealing with a child who's had interstitial lung disease and it's very different. And the treatment, the prognosis and the outcome is very different" (P4, Surfactant Protein C deficiency)

### 3.4 | The parent as continued advocate

Pediatric healthcare services are focused on growth and development, along with a strong family-centered approach to enable the young adult to build confidence, autonomy, and self-care skills.<sup>5</sup> However, for complex chronic conditions, parents may retain an intimate involvement in their child's health care. During the interviews, there was conflicting information between the theme of the young adult taking responsibility for their own care

and balancing this with what the parent knows is being shared with the adult healthcare team. All parents described issues with either how their child communicated current health to their adult healthcare team, or lack of knowledge about their condition which impacted on the information relayed back to the adult consultant:

"Because she's in an adult clinic, they don't expect to have anybody talk for her. She meant to talk for herself, which she's not very good at ... If anybody asked her how she is, 'she's fine.' But, you know, even when they were trying to pump morphine into her, 'she was fine.' So, she doesn't explain herself very well". (P1, Bronchiolitis Obliterans)

This highlights that parents may still have a role to play for young adults, particularly for those young people who require ongoing support due to additional communication or developmental needs:

"... what is going to happen if he needs to be admitted to hospital because he still needs me? With his PTSD [posttraumatic stress disorder], it is really scary for him." (P2, Bronchiolitis Obliterans)

However, there is a consideration about the nature of the ILD itself. Many of the chILD conditions that need to transition to adult care are ones that require ongoing treatment or have the potential for progressive disease.<sup>3</sup> The emotional burden of this as a parent is something that is very much at the forefront of future planning:

"you never know what the what is going to happen with your children in the future ... I made a life decision recently... that I've got to stay in this house, and that was through talking to the consultant about lung transplants and things. Now, I do not live in thinking, 'oh she's going have to have a lung transplant'... I really don't want that to happen. But I have decided that I need to keep this house because it is adaptable if we needed the space if anything happens ... And it's sad we have to think like that. I would much rather to have thought and planned than not." (P4, Surfactant Protein C deficiency)

Due to potential miscommunication of information and ongoing burden of planning and care, there may be a benefit for the parent to remain as a healthcare advocate for the young person. This may require specialized support during transition processes to understand and plan what this advocate role may look like, without it infringing on the young person's rights and desire to develop their own identity.<sup>20</sup> Yet, the most successful transitions are those where the young person and their family is prepared,<sup>5,6</sup> so therefore, identification and, if necessary, parental integration is recommended to prepare all for transition.

**TABLE 2** Suggestions for transition care provision.

If hospitalizations needed, admit to young adult ward
Adult ILD support groups to include newly transitioned young people with ILD
Assign an ILD consultant with chILD experience (may require adult ILD team education)
Continued open access if young person is unwell
Defined communication paths for parents/caregivers

Abbreviation: chILD, interstitial lung disease in childhood.

**TABLE 3** Transition tips for young people.

Be open and speak up about your care
Arm yourself with some knowledge about your condition
Learn some medical terminology to help communicate any physical symptoms
If you are struggling, ask for help

### 3.5 | Suggestions for improved transition for chILD

The interviews have presented a picture that adult transition has been a challenging experience for some respondents. As a part of capturing their experience, respondents were asked if there were any suggestions for service changes. Due to the uncoordinated care and lack of specialist funding of chILD across the United Kingdom, these suggestions may not be achievable; however, we present these experiences for what the respondents believe will be improved transition care. Table 2 provides an overview of these suggestions.

The main suggestions were learning to communicate about their health, educating oneself about the condition, and learning medical terminology, along with being open if there are issues and reaching out for support (Table 3).

## 4 | DISCUSSION

This study presents seven heterogeneous lived experiences of ChILD transition. The common experiences included lack of transition preparation and planning, the need for learning how to adapt to adult services and a changing healthcare scene, and the subject of how to include the parent as a continued advocate for the young person. For many respondents, transition to adult services has been challenging, with some respondents' hopeful for the future and for access to new treatments that may not be available under pediatric care.

The small sample means data saturation may not have been achieved. The implication for nondata saturation is lack of content validity. However, since a lot of the experiences and themes are representative and in agreement with current literature, it can be

assumed that the interview data is a valid presentation of lived experience which can be compared with the transition process for other chronic conditions.<sup>21-23</sup> In addition, the recruitment was online and in a nonclinical setting. Our approach to recruit from patient organization groups and online communities will have excluded those who are not linked to these online groups thus potentially introducing a selection bias.

Respondents' recommendations for how transition could be improved include that patient organizations appreciate that chILD is "similar but different" to adult ILD, along with improved access to adult services and consultants with experience of chILD, perhaps using joint adult-pediatric clinics to build up expertise. There is also a need for better inclusion of the parent (if required), if this does not impinge on the young person's rights and autonomy. Young people recommend those who are new to the transition process to practice and learn how to self-advocate for their care. This can be achieved by learning medical terminology to help support them communicate their healthcare needs and ask for help if it is needed.

Among the weaknesses in the current transition process the often the lack of a specific transition coordinator, the generally haphazard timing of first discussion about transition and for the most part the lack of involvement of professionals such as psychologists and social workers. Realistically, these professionals will have to be shared with other disease groups, because chILD is so rare, but this is surely feasible. Furthermore, there is no disease-specific transition literature, and generic literature such as "Ready, Steady, Go" was used inconsistently. The European Respiratory Society (ERS) Task Force on chILD Transition will hopefully address these and other points, including providing patient-accessible resources. We also strongly advocate for patient-led studies to further explore patient perspectives in transition care, and the involvement of the patients in the ERS Task Force is welcome. For nearly half of chILD patients to drop out of medical services without transitioning to adult care is unacceptable and needs to change.

### AUTHOR CONTRIBUTIONS

**Carlee Gilbert:** Conceptualization; investigation; formal analysis; writing—original draft; writing—review and editing; methodology. **Kate M. Bennett:** Methodology; formal analysis; supervision; writing—original draft; writing—review and editing. **Christopher Brown:** Supervision; writing—original draft; writing—review and editing; project administration; formal analysis. **Andrew Bush:** Writing—original draft; writing—review and editing; formal analysis.

### ACKNOWLEDGMENTS

The authors wish to acknowledge the young people and parents who participated in this study. Open access funding was facilitated by The University of Liverpool, as part of the UK JISC agreement.

### CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.



## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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## REFERENCES

- Bush A, Cunningham S, De Blic J, et al. European protocols for the diagnosis and initial treatment of interstitial lung disease in children. *Thorax*. 2015;70(11):1078-1084.
- Griese M. Chronic interstitial lung disease in children. *Eur Respir Rev*. 2018;27(147):170100.
- Koucký V, Pohunek P, Vašáková M, Bush A. Transition of patients with interstitial lung disease from paediatric to adult care. *ERJ Open Res*. 2021;7(2):00964-2020.
- Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. *J Adolesc Health*. 1993;14(7):570-576.
- Rosen D. Between two worlds: bridging the cultures of child health and adult medicine. *J Adolesc Health*. 1995;17(1):10-16.
- Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child*. 1999;81(3):271-275.
- Sloper P, Beecham J, Clarke S, Franklin A, Moran N, Cusworth L. Models of multi-agency services for transition to adult services for disabled young people and those with complex health needs: impact and costs. Report to the Department of Health.
- Schmidt A, Ilango SM, McManus MA, Rogers KK, White PH. Outcomes of pediatric to adult health care transition interventions: an updated systematic review. *J Pediatr Nurs*. 2020;51:92-107.
- Connett GJ, Nagra A. Ready, steady, go—achieving successful transition in cystic fibrosis. *Paediatr Respir Rev*. 2018;27:13-15.
- Harris A. Diagnosis and management of children with primary ciliary dyskinesia. *Nurs Child Young People*. 2017;29(7):38-47.
- Transition from children's to adults' services for young people using health or social care services. NICE; 2016. Accessed November 2, 2022. <https://www.nice.org.uk/guidance/ng43/ifp/chapter/About-this-information>
- Thwaites R, McErlane F, Lim E, Dauncey L. 1413 Healthcare transition for young people across the North-East and North Cumbria: scoping exercise against national standards. *Arch Dis Child*. 2022;107:A523.
- Margaritopoulos GA, Antoniou KM, Wells AU. Comorbidities in interstitial lung diseases. *Eur Respir Rev*. 2017;26(143):160027.
- Yohannes AM. Depression and anxiety in patients with interstitial lung disease. *Expert Rev Respir Med*. 2020;14(9):859-862.
- van Moorsel CHM, van der Vis JJ, Grutters JC. Genetic disorders of the surfactant system: focus on adult disease. *Eur Respir Rev*. 2021;30(159):200085.
- Kovar J, Willet KE, Hislop A, Sly PD. Impact of postnatal glucocorticoids on early lung development. *J Appl Physiol*. 2005;98(3):881-888.
- Guest G, Namey E, Chen M. A simple method to assess and report thematic saturation in qualitative research. *PLoS One*. 2020;15(5):e0232076.
- Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol*. 2018;18:148.
- Charmaz K. *Constructing Grounded Theory*. Sage; 2014.
- Care Quality Commission. From the Pond into the Sea Children's Transition to Adult Health Services UK [Internet]; 2014. [https://www.cqc.org.uk/sites/default/files/CQC\\_Transition%20Report.pdf](https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf)
- Nanzer AM, Lawton A, D'Ancona G, Gupta A. Transitioning asthma care from adolescents to adults. *Chest*. 2021;160(4):1192-1199.
- Brumfield K, Lansbury G. Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. *Disabil Rehabil*. 2004;26(4):223-234.
- Dale CM, Carbone S, Amin R, et al. A transition program to adult health services for teenagers receiving long-term home mechanical ventilation: a longitudinal qualitative study. *Pediatr Pulmonol*. 2020;55(3):771-779.

**How to cite this article:** Gilbert C, Bennett KM, Brown C, Bush A. Experiences of UK-based adult transition services for interstitial lung disease in childhood: "There's a lot less cushioning". *Pediatr Pulmonol*. 2023;1-7. doi:10.1002/ppul.26423