

# POSITION PAPER

## **Bridging the Gaps: *Optimizing the Transition from Pediatric to Adult Rheumatology Care***



---

## Executive Summary

While most Canadians hold the perception that arthritis only affects adults and the elderly, a range of rheumatic and musculoskeletal diseases (RMD) affect youth.



*“I was diagnosed with Juvenile Idiopathic Arthritis at 2 years of age and for the past 21 years, my life has consisted of all the specialist appointments, bloodwork, and many medication trials and errors to control the disease. Today, I struggle mostly with using my hands, my wrists, and my knees along with some chronic fatigue that impedes my day-to-day life.”*

Despite advances in treatment, majority of Canadians who are diagnosed with RMDs in childhood are living with these life-long conditions into adulthood<sup>1, 2</sup>. Unfortunately, youth transitioning from pediatric to adult care shift from a highly resourced system with multiple services and supports that is coordinated between a variety of health care professionals to an adult system that is less connected and under-resourced to meet the unique needs of youth living with RMDs<sup>3</sup>.

Differences between pediatric and adult rheumatology care have caused too many young people to experience gaps in their care, which has translated to poorer health outcomes. These negative impacts include not only physical, mental, and emotional challenges for individual patients, but also major health system challenges, from increased hospital admission rates due to poor adherence to treatment increasing risk of disability and morbidity<sup>4, 5</sup>.

With these challenges in mind, transition programs across Canada have been created with two specific goals: (1) improving the independence and skills of youth to meaningfully engage in their own care; and (2) smoothly moving patients from pediatric to adult care<sup>6</sup>. Despite focused efforts on improving access and continuity of high-quality care, youth transitioning still experience inconsistent care and services.

More work needs to be done to further optimize, spread and scale models of care for transitions across Canada. Knowing this, the Canadian Rheumatology Association’s (CRA) **Youth to Adult Transition Working Group** is advocating for new policies, programs, and funding to ensure that Canadian youth living with RMDs can access high-quality transition services that meet their needs.

This report highlights the key challenges impacting rheumatology patient transition and identifies potential solutions to best address these challenges to ensure current and future generations receive the care they deserve.

## DEFINITIONS

**Childhood-onset Rheumatic and Musculoskeletal Diseases (RMDs)** includes several autoimmune and autoinflammatory conditions affecting mostly the joints, tendons, ligaments, bones, and muscles and can also affect the entire body (multi-system disease). Examples include but are not limited to Juvenile Idiopathic Arthritis (JIA), Systemic Lupus Erythematosus (SLE), Juvenile Dermatomyositis (JDM), vasculitis, localized and systemic scleroderma.

**Transition of Care** is defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems”<sup>7</sup>. Transition of care is a complex process that occurs over time, significantly different than a simple administrative transfer that occurs after referral to a physician focused on adult care.<sup>6</sup>

### Transitions occur in three phases

- (1) Preparing to transfer
- (2) The time of transfer
- (3) Post transfer

**Transfer of Care** is a one-time event that occurs when a youth is transferred out of the child health system and into the adult care system.<sup>2</sup>



*To illustrate key points of the position paper, quotations of anonymized patient experiences have been included throughout. We want to thank Cassie + Friends, a Canadian charity dedicated to supporting the pediatric rheumatology community, for contributing these patient experiences.*

---

## Introduction

Rheumatic and musculoskeletal diseases (RMDs) are debilitating conditions affecting millions of Canadians<sup>1</sup>. Many RMD patients are diagnosed in childhood or adolescence, and where this arises, their care is commonly delivered by multidisciplinary teams that not only focus on disease management but also provide age-appropriate development and informational supports.

The transition from pediatric to adult healthcare systems is not standardized or well resourced. As a result, more than half of young people that are transferred to adult rheumatology services experience inadequate follow-up<sup>8</sup>. For many young people, these care gaps occur in adolescence – a formative time physically, emotionally, and neurodevelopmentally<sup>6</sup>. They have not fully developed the important skills for planning, emotional regulation, judgement, and self-awareness required to navigate health systems, making the transition to adult care especially challenging<sup>9, 10, 6</sup>.

Individuals with childhood-onset RMDs require extra support for a range of other physical, mental, and emotional conditions that have stemmed from living with a chronic condition – support which is often not provided in adult rheumatology care. This leads to inconsistent follow-up and poor medication adherence which increases the risk of disease flares. Without sufficient access to rheumatology care, many youth with RMDs end up in emergency departments<sup>3</sup>. This ultimately results in lifelong impact on health and wellness.



*“It all happened really fast. I went to an appointment, and I was given a referral and that was pretty much the last time that I heard from my pediatric care team...and all communication pretty much stopped from the Children’s Hospital. There was a four-month period that I didn’t have any doctor because I hadn’t had a chance to talk with the new adult rheumatologist.”*

Loss to follow-up from pediatric to adult rheumatology care is driven by multiple interdependent challenges, from a lack of multidisciplinary teams in adult rheumatology and inadequate access to rheumatology care outside major urban centres, to lack of health record integration in pediatric and adult rheumatology care systems and insufficient health care provider training and support for transition care.

These challenges are further described over the coming pages, followed by proposed solutions, designed to help Canadian provinces and territories better respond to the complex needs of youth with RMDs.

## The Challenges Impacting Pediatric to Adult Transition of Care

Around 25% to 75% of youth with rheumatic diseases experience a gap in care or are lost to follow-up after transfer to adult rheumatology care<sup>8, 11, 12, 13</sup>. This is especially concerning since most of these patients will require ongoing treatment and monitoring throughout their lives. Living with a RMD puts individuals at an overall higher risk of disability, early morbidity, and limitations in social participation<sup>14</sup>. Even though treatment and rehabilitation have improved over the last decades, without effective transition processes, Canadians living with RMDs will continue to experience poorer health outcomes<sup>15</sup>.

Multiple challenges prevent young people living with childhood-onset RMDs from receiving the necessary support when transitioning from pediatric to adult rheumatology care, which are highlighted below and further explored in the following pages.

### Challenges Impacting the Transition of Youth from Pediatric to Adult Care

1. Inadequate Access to Rheumatology Care
2. Insufficient Health Care Provider Training and Support for Transition Care
3. Lack of Multidisciplinary Teams in Adult Rheumatology Care
4. Lack of Health Data Integration

#### 1. Inadequate Access to Rheumatology Care

*An unbalanced distribution of rheumatologists across Canada causes major access gaps in care, especially in rural and remote regions.*

Too few rheumatologists are spread across Canada's vast geography. There is no province or territory achieving the recommended ratio of 1 rheumatologist per 75,000 population served. Therefore, approximately 20% of patients travel 2 or more hours for rheumatology care<sup>10, 16</sup>.

Rheumatologists are often clustered in urban centres. Young people who begin transferring from pediatric to adult care may find challenges in securing an adult rheumatologist that is accepting new patients, is close by and has the necessary knowledge and experience to provide appropriate transition care. These challenges are further compounded in many rural, remote communities across Canada due to a dearth of rheumatologists, especially in parts of Northern Canada<sup>10</sup>.



*“Living in a smaller town means my resources are limited. I know it would take a lot of work to find a rheumatologist that I liked, but also one that had the time to see me and can comprehend my intensive medical history because I come with a massive paper trail that is often hard to navigate. I opted to stay with my rheumatologist [in home city], so I will schedule my appointments when I know I’m coming home to visit my family.”*

---

## 2. Insufficient Health Care Provider Training and Support for Transition Care

*Limited opportunities for educational programs to provide the necessary knowledge and training for youth in transition, especially among adult rheumatologists.*

Rheumatology training programs have limited opportunities to provide transition care education and skill development. Significant knowledge gaps in caring for these patients at a unique and formative time are further compounded, particularly among adult rheumatologists, by the fact that their needs are quite unique compared to others who are diagnosed later in life<sup>17</sup>. At a minimum, both adult and pediatric rheumatologists should know what constitutes best practices for transition care and have mechanisms to access transition-related resources. Adult rheumatologists specifically need to enhance their skills in childhood-onset RMDs and emerging adult development<sup>18, 17</sup>.

The impact of knowledge, training and experience gaps is further exacerbated by the fact that overburdened rheumatology providers often have limited time to support patients through the transition process<sup>18, 17</sup>. Too many sites with established transition programs and expertise lack the appropriate resources, supports, and educational opportunities to meet optimal standards to transitioning<sup>18</sup>.



*“Transitioning is uncomfortable on its own and it’s even harder when we’re gearing up to leave high school and go to University, maybe move away from home. There’s a lot of changes in that little amount of time. Mentally, of course, it can be extremely stressful, since now, there’s another burden of making sure your health is in order.”*

## 3. Lack of Multidisciplinary Teams in Adult Rheumatology Care

*Adult Rheumatology resources do not include education and funding for multidisciplinary teams.*

The lack of funding to support dedicated and highly skilled multidisciplinary teams in adult rheumatology is a significant barrier to successful transition of youth with RMDs. A multidisciplinary care approach, which is common in pediatric rheumatology care, is the gold standard for the management of RMDs<sup>10</sup>. Such teams comprise physicians, specialized nursing care and allied health professionals. They effectively deliver a range of pharmacological and nonpharmacological interventions required by people living with RMDs<sup>19</sup>.

Adult rheumatologists typically work independently in their practice. Youth experience a shift from a strong team-based model of care to one where they lack access to a multidisciplinary team to provide a range of life management needs. With the range of impacts that youth experience living with RMDs (e.g., physical, psychosocial, and vocational), it is clear why multidisciplinary teams are an optimal model of care.



*For the first time, I really had to advocate for myself and utilize the little time I had with the new adult rheumatologist to make sure I had all my questions answered and my requisition and prescription slip signed and in my hands before leaving because once I left, I’d have to go through a few people by phone in order to get in touch with a doctor which wasn’t a quick process like it had been [with my pediatric rheumatologist].”*

---

#### 4. Lack of Health Data Integration

*Health records are not integrated between pediatric and adult care systems, which limit patient care and health system improvement.*

Lack of data integration across medical centres is another major challenge. In some provinces, pediatric and adult rheumatology care records are not linked, which makes transferring young people even more difficult as well as collecting longitudinal data, which impacts ongoing care management, robust long-term patient follow-up data, and general knowledge about outcomes<sup>17</sup>. These siloed data repositories that are not always accessible also impede evaluation and quality improvement work that would support the optimization of health care transitions. Quality improvement markers and agreed upon standards are essential to evaluate the effectiveness of different transition models to inform clinicians and administrators of the best and most cost-efficient care model for this population<sup>20</sup>.



*“[When I transitioned] they only had half of my file, which was a little confusing because I didn’t have a file. With no communication from the Children’s Hospital, it was really hard to get the half file that was missing. They ended up having to run further tests so they could complete my file.”*

---

## Solutions to Optimize Pediatric to Adult Transition of Care

There is a strong interest from both pediatric and adult rheumatology providers across Canada to improve transition care services. Continuity of care is a key indicator for successful transitions and will not only support young people living with childhood-onset RMDs to independently manage their long-term chronic condition, but also likely improve their health outcomes<sup>18</sup>. To move towards successful models of transition care, four solutions and their corresponding recommendations are outlined below.

### Solutions to Optimize Transition of Youth from Pediatric to Adult Care

1. Increasing Integration Between Pediatric and Adult Rheumatology Care
2. Building Health Care Professional Knowledge and Networks
3. Leveraging Digital Health Technologies
4. Embedding Flexibility in All Pediatric to Adult Rheumatology Care Transition Models

#### 1. Increasing Integration Between Pediatric and Adult Rheumatology Care

*Leveraging multidisciplinary teams to serve as a bridge between pediatric and adult rheumatology care systems.*

Multidisciplinary teams are essential to successful transitions<sup>18</sup>. Rheumatologists see such teams as vital to the success of transitions as they would strengthen collaboration and communication between pediatric and adult rheumatology care systems. Increased collaboration and communication will allow for optimal patient support throughout the transition process, and interdisciplinary sharing of knowledge and learning between health care professionals<sup>18</sup>. Such practices are commonplace in pediatric sites; therefore, additional resourcing would be required within adult rheumatology. Many adult rheumatologists have expressed a desire to increase the level of multidisciplinary support, but noted finances being a barrier in doing so<sup>16</sup>.

Integration between pediatric and adult rheumatology care could also be done through Advanced Clinician Practitioners in Arthritis Care (ACPAC) program or through ACPAC Extended Role Practitioners (ERPs), a Canadian program that was established in 2005. Graduates from this program gain additional training in rheumatic disease assessment and management allowing them to facilitate communication and implementation of the transition care plan and serve as navigators for youth with RMDs<sup>21</sup>. Utilization of ACPAC trained health professionals has demonstrated efficiencies in triage and co-management of patients in transition<sup>21</sup>. Unfortunately, funding and support (e.g., medical directives) for ACPAC-trained health professionals is inconsistent and hard to secure, despite the evidence showcasing their value<sup>23, 21</sup>. British Columbia has introduced remuneration for non-physician health care professionals to support outpatient rheumatology care and such a policy worth emulating<sup>22</sup>.





*I began my transition to adult care when I was 17. Two years into my treatment. This was facilitated by my pediatric rheumatologist within our regular appointment. There was about a couple of months overlap after I was referred to adult rheumatology where I was seeing both my adult rheumatologist and my pediatric rheumatologist. I got to meet my new doctor, while kind of wrapping up my time in [pediatric care]...so my transition experience overall, I got to say was pretty successful.”*

### **RECOMMENDATION: EXPAND THE SUPPORT OFFERED BY MULTIDISCIPLINARY TEAMS**

Incorporate multidisciplinary teams into transition care models by (1) securing consistent funding support for multidisciplinary teams; and by (2) establishing provincial medical directives that can be utilized by ACPAC graduates to build out their roles within multidisciplinary teams<sup>1</sup>.

## **2. Building Health Care Professional Knowledge and Networks**

*Increasing access to training, transition care information and best practices we well as networks to better support health care professionals caring for youth living with RMDs.*

Given that many young people transitioning with a life-long chronic condition have complex medical, psychosocial, educational, and vocational issues, it is essential to promote access to training, and improve skills and knowledge among all adult rheumatology teams related to these complex problems<sup>14,18</sup>. Therefore, training programs should focus on content reflecting pediatric to adult rheumatology care transition, childhood RMD-specific knowledge, and how to employ effective teaching strategies. Providing these skills and training will increase understanding of the importance of transitions among a broader pool of trainees and increase their interest in providing optimal pediatric to adult rheumatology transition care<sup>18</sup>.

Programs like Extension for Community Healthcare Outcomes (ECHO), for which a Rheumatology Hub is already established in Ontario, is a model meant to build workforce capacity in a system for the purpose of better care delivery. Within rheumatology, it would involve a community of practice with primary care champions around transition care<sup>24</sup>. This would further support integration, knowledge development and network connections by having primary care providers become an important part of the care delivery team when youth transition into adult care. This is important as youth evolve from working closely with their pediatrician to, in many instances, having a primary care provider as their closer point of contact with close collaboration with an adult rheumatologist.



*“Providing high quality care that supports youth living with RMDs in their transition to adult rheumatology requires all of us to learn and practice as a collective. It is not just about what medication should be used next; we need to think about the whole patient and where they are at in their development, what their needs are, and ensure we have the right knowledge and skills to take on our roles.”*

Adult Rheumatologist

### **RECOMMENDATION: DELIVER TARGETED EDUCATION TO ALL RHEUMATOLOGY PROVIDERS**

All health care providers (e.g., pediatric rheumatologists, adult rheumatologists, occupational therapists, ACPAC therapists, primary care providers, physiotherapists, social workers, nurses, etc.) should have

---

focused training or through continuous professional development on topics related to pediatric to adult rheumatology care transition.

### 3. Leveraging Digital Health Technologies

*Increasing access to digital health technologies is essential to better utilize and link patient data as well as improve access to enhanced services in pediatric and adult rheumatology care systems.*

Digital health technologies, ranging from virtual care, healthcare applications, and patient portals can better connect patients to the support they need, and ultimately improve patient outcomes<sup>25</sup>. Better leveraging digital health tools would be especially welcomed by young Canadians, who are eager to engage with their health providers over the phone, through email and other social engagement platforms<sup>26</sup>.

#### **RECOMMENDATION: EXPAND AND SUPPORT THE USE OF DIGITAL TECHNOLOGIES**

Optimize the use of a range of technologies for both pediatric and adult rheumatologists. Digital technologies can be used for self-management and behavioural interventions which are more readily used by youth<sup>27</sup>. Digital health technologies can also better support best practices by making it easier for youth to connect with an adult rheumatologist prior to their transfer or even have a joint virtual meeting with their pediatric team and their new adult team<sup>28</sup>.

### 4. Embedding Flexibility in All Pediatric to Adult Rheumatology Care Transition Models

*When developing, scaling, and spreading models supporting youth transitioning from pediatric to adult rheumatology across Canada it is important to keep in mind that one size doesn't fit all and therefore, flexibility must be embedded within all models of pediatric to adult rheumatology care transitions being pursued.*

As with all areas of healthcare delivery, the fundamental principle of person-centred care applies to transition care. Increased engagement and empowerment of patients and families will identify where gaps exist and how to shift the culture of care to be more equitable in terms of experience and quality of care provided<sup>10</sup>. With this in mind, optimal health care transitions will require flexibility to be accessible across various geographies, to consider a range of socioeconomic factors, and cultures.



*"I was diagnosed with rheumatoid arthritis...when I was 15 years old...I could not have been more fortunate with the team that I had. My treatment team was amazing, and they really empowered me to take ownership over my treatment and have an active role in my treatment."*

#### **RECOMMENDATION: CONTINUOUS ENGAGEMENT AND EMPOWERMENT WITH YOUTH AND FAMILIES TO SUPPORT FLEXIBILITY IN SERVICES AND PROGRAMS FOR TRANSITION CARE**

Given the wide range of geographic and clinical diversity across Canada, governments should ensure that increased funding for transition programs is accompanied by sufficient flexibility. This will allow clinics better tailor transition services to their specific needs. With such a shift, it will be critical to focus on clinical need rather than patient age to allow for optimal integration and flexibility between pediatric and rheumatology care<sup>14</sup>.

---

## Summary and Next Steps

Existing gaps in transition care are causing a high rate of young Canadians to be lost to follow-up, a distressing reality that leaves already vulnerable patients at even higher risk of morbidities and premature mortality. There is an urgent need to address existing care gaps by raising awareness of the importance of continuity of care for youth transitions, implementing various health care transition service models, developing transition care policies that can support pediatric and adult rheumatologists and highlighting best practices in transition care<sup>17</sup>.

The Canadian Rheumatology Association and its Youth to Adult Transition Working Group are eager to work with federal, provincial, and territorial governments to address the challenges and implement the solutions required to significantly improve the lives of the young Canadians living with RMDs.

---

## References

1. Widdifield J, Barber CEH, Bernatsky S, Eder L, Ahluwalia V, Pope JE, et al. Evaluation of rheumatology workforce supply changes in Ontario, Canada, from 2000 to 2030. *Healthcare Policy*. 2021;16(3).
2. Canadian Association of Pediatric Health Centres (CAPHC), National Transitions Community of Practice (2016). A Guideline for Transition from Paediatric to Adult Health Care for Youth with Special Health Care Needs: A National Approach  
<https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/Transitioning+from+Paediatric+to+Adult+Care/A+Guideline+for+Transition+from+Paediatric+to+Adult+Care>
3. White PH, Cooley WC. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5).
4. Hersh AO, Pang S, Curran ML, Milojevic DS, von Scheven E. The challenges of transferring chronic illness patients to adult care: Reflections from pediatric and adult rheumatology at a US academic center. *Pediatric Rheumatology*. 2009;7.
5. Sabbagh S, Ronis T, White PH. Pediatric rheumatology: Addressing the transition to adult-orientated health care. Vol. 10, *Open Access Rheumatology: Research and Reviews*. 2018.
6. McColl J, Semalulu T, Beattie KA, Alam A, Thomas S, Herrington J, et al. Transition Readiness in Adolescents with Juvenile Idiopathic Arthritis and Childhood-Onset Systemic Lupus Erythematosus. *ACR Open Rheumatology*. 2021;3(4).
7. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*. 1993;14(7).
8. Hazel E, Zhang X, Duffy CM, Campillo S. High rates of unsuccessful transfer to adult care among young adults with juvenile idiopathic arthritis. *Pediatric Rheumatology*. 2010;8.
9. Tucker LB, Cabral DA. Transition of the Adolescent Patient with Rheumatic Disease: Issues to Consider. Vol. 33, *Rheumatic Disease Clinics of North America*. 2007.
10. Lee JY, Laxer RM, Feldman BM, Barber CEH, Batthish M, Berard R, et al. Variations in Pediatric Rheumatology Workforce and Care Processes Across Canada. *The Journal of Rheumatology*. 2021;48(11).
11. Jensen PT, Karnes J, Jones K, Lehman A, Rennebohm R, Higgins GC, et al. Quantitative evaluation of a pediatric rheumatology transition program. *Pediatric Rheumatology*. 2015;13(1).
12. PA van P, RJEM D, AA K, JJW A, JW H, JWJ B, et al. Disease activity and dropout in young persons with juvenile idiopathic arthritis in transition of care: a longitudinal observational study. *Clinical and Experimental Rheumatology*. 2018;36(1).

- 
13. Son MB, Sergeyenko Y, Guan H, Costenbader KH. Disease activity and transition outcomes in a childhood-onset systemic lupus erythematosus cohort. *Lupus*. 2016;25(13).
  14. Foster HE, Minden K, Clemente D, Leon L, McDonagh JE, Kamphuis S, et al. EULAR/PreS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Annals of the Rheumatic Diseases*. 2017;76(4).
  15. Selvaag AM, Aulie HA, Lilleby V, Flatø B. Disease progression into adulthood and predictors of long-term active disease in juvenile idiopathic arthritis. *Annals of the Rheumatic Diseases*. 2016;75(1).
  16. Kulhawy-Wibe SC, Widdifield J, Lee JJY, Thorne JC, Yacyshyn EA, Batthish M, Jerome D, Shupak R, Jilkine K, Purvis J, Shamis J, Roberts J, Kur J, Burt JE, Johnson NA, Barnabe C, Hartfeld NMS, Harrison M, Pope J, Barber CEH. Results From the 2020 Canadian Rheumatology Association's Workforce and Wellness Survey. *J Rheumatol*. 2022 Feb 1;jrheum.210990. doi: 10.3899/jrheum.210990. Epub ahead of print. PMID: 35105708.
  17. Voorheis P, Wilson MG, Scallan E. Rapid synthesis: Identifying features of novel approaches to supporting transitions from child to adult care for young people with special healthcare needs in Canada. Hamilton: McMaster Health Forum, 27 March 2020.
  18. Barnabe C, Chomistek K, Luca N, Hazlewood G, Barber CEH, Steiman A, et al. National priorities for high-quality rheumatology transition care for youth in Canada. *Journal of Rheumatology*. 2021;48(3).
  19. Conti F, Pontikaki I, D'Andrea M, Ravelli A, de Benedetti F. Patients with juvenile idiopathic arthritis become adults: the role of transitional care. Vol. 36, *Clinical and experimental rheumatology*. 2018.
  20. Stringer E, Scott R, Mosher D, MacNeill I, Huber AM, Ramsey S, et al. Evaluation of a rheumatology transition clinic. *Pediatric Rheumatology*. 2015;13(1).
  21. Landon K, Inrig T, Paton M, Shupak R, Kennedy C, McGlynn M, et al. Measuring Advanced/Extended Practice Roles in Arthritis and Musculoskeletal Care in Canada. *ACR Open Rheumatology*. 2020;2(4).
  22. Connell J, Kur J, Gurmin JH. Assessing the impact of a nursing model of care on rheumatology practice patterns and patient satisfaction in british columbia. *British Columbia Medical Journal*. 2020;62(3).
  23. Ahluwalia V, Larsen TLH, Kennedy CA, Inrig T, Landon K. An advanced clinician practitioner in arthritis care can improve access to rheumatology care in community-based practice. *Journal of Multidisciplinary Healthcare*. 2019;12.
  24. ECHO Ontario. A revolution in medical education and care delivery. [Internet]. Project ECHO - What Is Echo. [cited 2022 Jan 28]. Available from: <https://www.echoontario.ca/What-is-ECHO>

- 
25. Goh YI, Bullock DR, Taylor J, Pooni R, Lee TC, Vora SS, et al. Exploring Pediatric Tele-Rheumatology Practices During COVID-19: A Survey of the PROIN Network. *Frontiers in Pediatrics*. 2021;9.
  26. Herrington J, Batthish M, Beattie K, & Matsos M. Transition navigator reflections on adaptations to providing support to young adults with rheumatic diseases during the COVID-19 pandemic [Internet]. Children's Healthcare Canada; 2021 [cited 2022 Jan 28]. Available from: <https://www.childrenshealthcarecanada.ca/transitions-poster-hall/2021/1/11/transition-navigator-reflections-on-adaptations-to-providing-support-to-young-adults-with-rheumatic-diseases-during-the-covid-19-pandemic>
  27. Huang, J., Gottschalk, M., Pian, M., Dillon, L., Barajas, D. & Bartholomew, K. Transition to adult care: systematic assessment of adolescents with chronic illnesses and their medical teams. *Journal of Pediatrics*, 2011;159(994-8).
  28. McDonagh JE, Tattersall R, Clinch J, Swan J, Foster HE, McCann L. Developmentally appropriate transitional care during the Covid-19 pandemic for young people with juvenile-onset rheumatic and musculoskeletal diseases: the rationale for a position statement. Vol. 19, *Pediatric Rheumatology*. 2021.