TRAnsitional STructured pain care for adolescents and young adults: *TRAST* model.

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LIST OF ABBREVIATIONS.

AEPMU	Alan Edwards Pain Management Unit
AYA	Adolescents and young adults
CAPHC	Canadian Association of Pediatric Health Centres
CFPC	College of Family Physicians of Canada
CPS	Canadian Pediatric Society
CP	Chronic pain
FMG	Family medicine groups
HFPC	Herzl Family Medicine Unit
ICD-11	International Classification of Diseases, version 11
IKT	Integrated knowledge translation
MUHC	McGill University Health Center
PCP	Primary care practitioners
RUIS	Réseau Universitaire Intégré de Santé (integrated university healthcare network)
WHO	World Health Organisation
HCTRC	Health Care Transition Research Consortium

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ABSTRACT

Introduction. Chronic pain (CP) affects one in 3-5 adolescent and young adults (AYA). In Canada, when AYAs turn 16-18, pain care is transferred to adult providers. The post-transfer transitional period (16 to 25 years of age) is almost a decade long and marked by multiple simultaneous bio-psycho-social transitions requiring complex multi-disciplinary care approach. There exists no pain-specific transitional care guideline, putting this vulnerable group of patients at risk of poor outcomes. Existing transitional models are still in development, with many important elements, like the role of primary care physicians (PCP), remaining poorly defined. The **objectives** of this thessis work are i) to understand the most important gaps that exist in transitional post-transfer pain care provision; ii) to identify the potential role that PCPs should play in this collaborative process; and iii) to formulate a set of actionable recommendations to optimize existing transitional strategies. **Settings**. McGill healthcare network, primary and tertiary outpatient settings, Quebec, Canada. **Methods.** Sequential-consensual qualitative design with a longitudinal participatory component. An exploratory stage informed further steps of this research. This followed by twelve semi-structured interviews with academic and non-academic PCPs. Next, three deliberative stakeholder consultations groups that involved clinicians, allied healthcare professionals, and patients with their supporters we conducted. Deductive-inductive thematic analysis was used. An adopted three-level Health Care Transition Research Consortium's theoretical framework was applied. **Results** were tabulated, summarized narratively, and stakeholders' recommendations were presented graphically. The study resulted in fifteen actionable recommendations, six of which were supported by all stakeholder groups (ex., developing a pivot nurse position); six more were supported by two of three groups (ex., training in adolescent medicine), and the rest were chosen by one of the groups only. A vision of the TRAST post-transfer transitional pain care model was discussed. **Conclusion**. Post-transfer transitional pain care for AYAs remains unstructured and fragmented. A representative group of stakeholders from the primary and tertiary care settings made fifteen actionable recommendations pertaining optimization of transitional pain care for AYA population. A transitional pain care model was formulated. The TRAST model could be adopted to all settings where transitional pain care is being optimized.

RÉSUMÉ

Introduction. La douleur chronique (DC) touche 20-30% des adolescents et jeunes adultes (AJA). Au Canada, lorsque les AJA atteignent l'âge de 16-18 ans, les soins de la douleur sont transférés aux services pour les adultes. La période de transition post-transfert (16-25 ans) dure près d'une décennie. Cette période est marquée par des transitions bio-psycho-sociales simultanées nécessitant une approche de soins multidisciplinaires. Il n'existe aucune ligne directrice visant les soins transitionnels pour la DC. Cette lacune expose le groupe vulnérable de AJA à un risque de résultats suboptimaux. Les modèles de transition existants sont encore en développement avec des nombreuses composantes essentielles restant mal définies, comme le rôle des médecins omnipraticiens (MO). Cette recherche vise à comprendre i) les lacunes les plus importantes qui existent dans la prestation de soins transitionnels post-transfert; ii) le rôle que les MOs devraient jouer dans ce processus de collaboration ; et iii) ainsi qu'à formuler des recommandations faisables pour optimiser les stratégies de transition existantes. **Environnement**. Le réseau de santé intégré de McGill, milieux ambulatoires primaires et tertiaires, Québec, Canada. **Méthodes**. Étude qualitative séquentielle-consensuelle avec une composante participative longitudinale. Une étape exploratoire a éclairé les prochaines étapes. Cela a été suivi par douze interviews semi-structurés avec des MOs académiques et non-académiques. Ensuite, trois groupes de consultations délibératives (impliquant des cliniciens, des professionnels paramédicaux et des patients) ont étaient menées. Nous avons utilisé une analyse thématique déductive-inductive et nous avons appliqué un modèle théorique développé par le Consortium de Recherche sur la Transition des Soins de Santé, qui comporte trois niveaux. Les résultats ont été tabulés par niveau et résumés de manière narrative. Les recommandations faisables proposées par les parties prenantes ont été présentées sous forme graphique. L'étude a conclue avec quinze recommandations dont six ont été retenues par <u>tous</u> les groupes (ex., infirmière pivot); six autres ont été retenues par <u>deux des trois</u> groupes (ex., une formation en médecine de l'adolescence); et les autres ont été retenues par <u>l'un des groupes</u> seulement. **Conclusion**. Les soins transitionnels post-transfert pour les AJA restent non structurés et fragmentés. Un groupe représentatif d'intervenants des milieux de soins primaires et tertiaires a formulé quinze recommandations faisables concernant l'optimisation des soins transitionnels pour la population AJA qui vivent avec DC. Ces recommandations ont été utilisées pour formuler un modèle de soins transitionnels en DC, le modèle TRAST, qui pourrait être adopté pour tous les milieux où les soins transitionnels doivent être optimisés.

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CONTRIBUTION OF AUTHORS.

The student is a practicing family physician working as a pain consultant, who initiated several informal inquiries during regular clinical consultations and brought up their results to the attention of the AEPMU team members. The student then received much support and encouragement from the AEPMU clinic Director and the Herzl pain service Director (primary care) to write a grant application for a primary care innovation project competition announced by the *Réseau-1 Québec/ Fonds de la Recherche en Santé du Québec*. The project received its funding in 2017, received its ethics approval and was launched the next year.

The student was the author of the original idea, 1st author of all documents and protocols in both languages, posters and presentations, PI on the project, and the 1st author on the manuscript. All team members and future co-authors were involved starting with the preparatory stage of the project and further supported by three research assistants (JG, SL, JG) and patient-partners. As a Principal Investigator, the student led a clinical research team from both centers that discussed adolescent and young adult (AYAs) patients' feedback received during clinical encounters, reviewed existing documentation and data bases, identified main themes, and composed an interview guide for the second part of the project. The second part (interviews with primary care practitioners) lasted from February 2018 to November 2018 and was assisted by two research assistants and PhD students (JMB and SL) at different times. The final, third part of the project, finished by the end of January 2019, was helped by all three research assistants. There were three to five partners at different stages. All co-authors participated in all stages of the project and contributed to the data review, conceptualization, and interpretation. They attended meetings, reviewed and gave feedback on all documents, and took part in the formulation of the final set of interdisciplinary recommendations to improve transitional care. Final version of the manuscript was circulated, proofread, and approved by whole team.

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1. BACKGROUND

Chronic pain and transition of young adults to adult services

Chronic pain (CP) affects about 20% of the Canadian population[2],[3] of all ages resulting in a set of unique challenges for pain specialists and primary care practitioners (PCP) alike. Pain represents one of the most common reason for a doctor visit,[4, 5] affecting person's quality of life[6] and resulting in low physical, mental, social and family functional capacity with significant direct and indirect costs to the society.[7] In 2017, the World Health Organisation voted into action a new classification of CP recognising it as a common chronic condition and declaring its treatment a basic human right. A revision of the 11th version of the International Classification of Diseases (ICD-11) defined CP as "persistent or recurrent pain lasting longer than 3 months".[8] Further, the CP was operationalized into the seven main categories: primary, cancer, post-surgical and post -traumatic, neuropathic, headache and orofacial, visceral, and musculoskeletal chronic pain,[8] thus attesting to its complexity and variability of bio-medical presentations. This complexity is accentuated when prolonged and poorly treated pain[9] results in co-morbid depression, poor would healing, immunosuppression,[10] polypharmacy and more.

CP is more prevalent among vulnerable populations already dealing with social inequities, mental health co-morbidities, discriminated minorities, elderly and women.[2] In 2020, the Canadian Pain Task Force report identified Canadian youths as one of the vulnerable populations disproportionately affected by pain, systemic inequities and lack of equitable access to pain services.[11] In general, CP in youths and young adults is less well researched yet, based on the Canadian Community Health Survey,[12] it was estimated that 9-12% of the Canadian population aged 12 to 44 lived with at least one CP condition the year the survey was conducted. Post-traumatic and post-surgical pains as well as visceral pain persisting into adulthood were the most common conditions in this population. [13-15] King et al. [16] reported comparable estimates of the medium prevalence rates of CP in children and adolescents varying by age and sex and ranging from 8% to 83% for headaches; 4% to 53% for abdominal pain; and up to 40% for musculoskeletal pain. Poorly treated pain in this age group is also not without consequences, including poor psycho-social and physical development and an increased risk of mood and substance use disorders.[17] The importance of recognising and treating CP in AYAs comes with the understanding of a complex bio-psycho-social context these persons live though the adolescent and young adulthood years.

AYAs affected by chronic illnesses reach their developmental milestones at different ages and with differing degrees of maturity, frequently as a function of their overall poorer health and decreased functional capacity.[18]

In Canada, children and adolescents could be followed by the specialized pediatric pain services and then transferred to the adult pain specialists as they reach 16-18 years of age. The period of preparation for healthcare transition and further adaptation to the realities of a new world appear one of the most challenging periods in the vulnerable AYAs life. During this time, three main transition stages could be identified: i) preparation for transitions, ii) transfer of the patient's file and temporary overlap in services, and iii) integration into the adult pain services post-transfer.

The preparation phase is well described in the pediatric literature and frequently involves an elaborate multi-faceted process focusing on young patients' independent decision-skill acquisition, preparedness, and gradual relinquishing of their dependence on the family members and their treating team.[19] The Six Core Elements of Health Care Transition (3.0)[20] became the foundation of a structured transitional policy implemented as a part of the American Medicare plan, allowing for the customization of structured transitional services for adolescents. The six transitional core elements encompass all generic procedures required to assist young patients in connecting with adult specialists, community-based resources and ensure a complete and timely transfer of the relevant medical information. This policy, however, does not represent a medical field-specific transitional model but rather a set of generic policy rules, customisable and adoptable to a variety of situations.

The existing literature thus, is not pain-specific, mainly focusing on the preparation for transitions and the transfer of the patient's medical file to an adult care provider. The last two stages of the transition process, when a AYAs with complex needs start integrating into the adult services, appear the least researched and therefore poorly described. Insufficient data about what happens after the file transfer are compounded by discordant advice from the existing guidelines on the role of primary care, thus contributing to the inconsistencies in the health care transition process, fragmented service coordination, further exacerbated by the limited or absent resources and gaps in professional training.[21]

Due to a multitude of pain diagnoses, involvement of various specialties and therefore several types of frequently simultaneous transitions, AYAs suffering from CP appear to represent a unique yet heterogenous and challenging population for the family and pain physicians. As a significant number of young adults living with CP face transitions to adult pain services, the role of primary care providers in assisting with or orchestrating transitional pain care needs a better understanding. To ensure the most optimal transitional outcomes, multi-disciplinary adult-pediatric services, mixed clinics or focused youth clinics[22] working in close collaboration with the primary care teams would appear as intuitive models to provide continuity of care and help AYAs with CP conditions to adopt to adult care.

Transition to adult care

According to the Canadian Institute in Health Research (CIHR) Transitions in Care initiative, "*when gaps occur in care transitions, individuals are susceptible to fragmentation in care, poor quality of care, unfavorable experiences, compromised patient safety, and adverse medical events*."[23] The literature usually refers to a long well-planned and coordinated process spanning years well into the adulthood. Therefore, a true transition duration depends on the patient's individual circumstances, specific diagnosis, and available support from the medical and community services. Not surprisingly, this time is considered one of the most challenging periods in medical care as transitions happen at several levels: individual, service and system.

Patient level

First, young patients and their supporters must sever their ties with the general and specialised pediatric services they have worked with. A classical pediatric care provision model is family-centered and includes parents (or guardians) as substitute decision-makers for the young patients. Pediatric services thus, tend to follow their young patients closely and employ very different (from adult services) protocols, allowing for close communications between the families, patients, and their care providers. On the other hand, upon the transfer to adult services, AYAs are expected to adapt to the new reality of the adult patient-oriented care and start functioning at a very different level. Patient-oriented care of adult services emphasizes patient's autonomy, self-management, and confidentiality of patient's data, which changes guardians' and/or parents' roles, and transfers the power of decision and responsibility to the patient. Somewhat more important for the States than for Canadian provinces, this also means getting insured independently of their parents, facing out-of-pocket expenses, and dealing with the employment and vocational training. Patient individual circumstances like the availability of family support, social life, extend of a handicap, vocational training and educational needs, would inevitably affect AYAs' capacity to adopt to yet another challenge.

Service level

Transitions at the service level represent a transfer of the care provision to a different facility, including outside of the known institution, or even to a different geographic region. This might also mean registering with a new primary care team and/or losing connections to the old one. For AYAs living in Quebec and especially on the territory of the Greater Montreal region, another challenge is a significant shortage of PCPs available to accept new patients.[24-26] Undoubtedly, resources shortages result in various communication and information transfer breakages, and in the postponement or lack of some treatments, investigations and connection to important resources that should have happened with a new provider.

System level

At the healthcare system level, depending on the location of the adult services, existing institutional and provincial regulations, AYAs might need to connect to a different network of community resources, psycho-social and financial support organisations in place. This also means choosing among different medical insurance providers, and the networks of educational institutions and employers depending on the degree of disability, accommodations, and available support. Access to care, inter-institutional communications, referral practices and logistics, might represent unsurmountable barriers or significant facilitators for the transitioning AYAs. Ideally, a functional inter-connected well-resourced system with clear and intuitive policies for transitions would enable a highly orchestrated multi-disciplinary transitional continuous care.

To illustrate the inherent complexity of the transition in care period, below, we provide three clinical vignettes based on the real cases seen at the AEPMU. To preserve confidentiality, several details have been changed.

Clinical vignettes

The study took place in Montreal, Quebec on the territory of the McGill academic healthcare network (McGill RUIS) comprising of the family medicine groups (FMG) and McGill Center of expertise in pain, the Alan Edwards Pain Management Unit (AEPMU). AEPMU is an adult pain service that receives referrals from the community-based clinics, McGill university-based pediatric and adult specialists, including pediatric pain and orthopedic centers. The youngest patients that could be seen by the AEPMU pain clinicians are 16 to 18 years of age. As opposed to the pediatric counterparts, after a course of treatment, AEPMU discharges AYAs under the care of their family physician and/or a specialist, if possible. Therefore, the involvement of the primary care services in the transitional care for these complex patients appears rather punctual. The three vignettes below describe examples of real patient cases that inspired this inquiry. I will revisit these three cases in the thesis Discussion section while putting study findings in the context of my work as a pain consultant and a primary care physician.

Patient 1

A 21-year-old man was referred to the AEPMU by his family physician because of recurrent severe abdominal pain episodes. Extensive medical investigations were conducted, but no specific reason for his pain was established. The team understood that this young man grew up in a mono-parental family (with his mother), had no close relatives, was an “A+” college student and worked part-time at a restaurant to provide for his family. Since past year, he was struggling with his classes and lost his job few months prior to his evaluation at the AEPMU. Because of these unexplained pain episodes, the patient was seeing his pediatrician and was treated with small doses of opioid analgesics, which appeared to be helpful.

During his first clinical assessment led conjointly with an AEPMU psychologist, the patient appeared anxious and depressed; thus, individual psychotherapeutic sessions were initiated as a part of the multi-disciplinary treatment. After several sessions, patient reported to the team that his mother was diagnosed with ovarian cancer and treated with narcotic analgesics prescribed to control her abdominal pain. The patient declared that he became the main caregiver for his mother, who was not working any more. An AEPMU social worker got involved to explore if any additional help might be available for the family, but the patient stopped coming to his appointments. When his family physician was contacted, he reported that the patient was “fired” from his practice as he admitted to selling opioids to his friends. The family physician was not aware of the mother’s diagnosis as she was not a part of his patient. All further attempts to reach the patient were unsuccessful.

Patient 2

A 19-year-old woman, accompanied by her boyfriend, presented to her first evaluation at the AEPMU being referred by her family physician with the diagnosis of Crohn’s disease and sacro-iliac joints inflammation. The patient’s boyfriend insisted on coming with the patient as he and patient’s family members were concerned about patient’s situation. Patient was described as “not being there”, looking drowsy and unable to follow a usual conversation.

On a team evaluation, it became clear that the patient suffered from poorly controlled pain, which she was self-managing by mixing prescription opioids, illicit cannabis, and occasional alcohol, thus rationing her pain medications while waiting for an adult gastro-intestinal (GI) specialist appointment. After the initial assessment, diagnoses of opioid and cannabis use disorders were established. The patient agreed to a detoxification therapy, from which she was successfully discharged few weeks later. Her pain medications were adjusted, she started working closely with an AEPMU physiotherapist and a psychology intern, and was admitted to the adult GI services, all resulting in good pain control. The patient was then discharged from the pain center back to her family physician practice and continued with community-based long-term psychotherapy.

Patient 3

An 18-year-old woman was transferred from the pediatric pain services to the AEPMU with a presumptive diagnosis of a psychosomatic pain syndrome. She reported poorly controlled episodic pain in her legs and arms and multiple falls. All investigations by different pediatric specialists were negative. The patient was using a walker “just in case” and had no difficulty mobilizing. For the initial evaluation at the AEPMU, the patient was accompanied by her mother, who reported to the team that both parents were in their late 50-s and had CP diagnoses: the father suffered from a cancer-related pain, and the mother was diagnosed with diabetic neuropathy and fibromyalgia.

Patient’s younger brother was diagnosed with autism and required specialized home-schooling services. The patient dropped out of high school as the school did not offer any accommodation for her non-specific pain diagnosis. She later graduated from an adult education center but remained unemployed, fully relying on her parents’ pension and provincial Social Aid program. Psychiatric assessment conducted at the AEPMU resulted in the diagnosis of schizoaffective disorder. Even after patient’s medications were adjusted and pain control improved, the team struggled for several months trying to discharge the patient back to the community as her family did not have a primary care provider and was relying on the emergency and specialists care only.

These three cases are based on the real patient encounters. Several details were changed to preserve confidentiality. Such cases frequently present a plethora of various clinical and administrative challenges and become a focus of multi-disciplinary team assessments and weekly pain team discussions. A well-organized multidisciplinary transitional pain service is imperative to improve medical and psycho-social outcomes for this vulnerable clientele.

Thesis general objective

The general thesis objective is, therefore, to formulate a vision for multi-disciplinary transitional pain care for the population of young adults (16-25 years of age) living with chronic pain and integrating into the adult services.

2. THESIS LITERATURE REVIEW

Complexity of transitions

Traditionally, health care transfers to adult services happen when adolescents turn 18 and pediatric care ceases. "… Our Canadian health systems are organized in a way that requires individuals to receive health services from a number of care providers, in a number of locations, leading to multiple transitions in care over time. This is especially true for individuals experiencing changes to their health status, as they grow older, experience a change in care need and/or have a change in their location of care". [23] Complexity of transitions, therefore, is due to a multitude of factors ranging from a lack of hospital or community-based transitional services to a variety of individual circumstances and resources in place.

With the advances in modern medicine, more patients with childhood-onset conditions live to the adulthood and move to the adult services [27, 28] making transitional care of the outmost importance to many clinical fields. A recent systematic review indicated that "…in North America… over 98% of these AYAs are expected to reach age 20, thereby requiring transition from paediatric to adult healthcare".[29] Improved chances of survival into adulthood after diagnoses of childhood cancers, cystic fibrosis, cardiac defects, organ transplants, and other previously fatal childhood conditions heralded a new era of chronic care transitions, presenting a unique array of previously rarely encountered childhood diagnoses for adult specialists and PCP alike [27, 28].

Sanabria et al. (2015),[30] citing results of the 2009-2010 National Survey of Children with Special Health Care Needs, reported another transitional challenge, this time, experienced by the pediatricians who may struggle finding appropriate care transfer opportunities or analogous adult services as many adult specialists do not have adequate training in the management of childhood-onset conditions. Findings from another survey report similar concerns.[31] Consequently, patients might also perceive the available support as inadequate, care coordination and resources as insufficient,[29] resulting in suboptimal outcomes,[32, 33] extensive use of emergency services[34] and the overall worsening of various transitional social and health indicators.[35]

Role of primary care

As it stands, family medicine is the only specialty that has the capacity to follow patients "from cradle to grave" and to be closely involved in the transitional care of the young patients.[36] Canadian primary care services have recently adopted a model of the "patient medical home",[37-39] which emphasises an equitable accessibility to the necessary socio-medical services that would be found in the proximity of patients' neighbourhoods and available to all segments of Canadian population. Following, a fairly recent development in philosophy of primary care provision has led to the expansion of the role of family medicine in including adult patients with multiple co-morbidities like the elderly;[36] yet, to date, pediatric specialists continue to provide the bulk of specialty care to the pediatric population as primary care involvement with young patients can be limited.[40]

A joined position statement by the Canadian Paediatric Society (2007), supported by the College of Family Physicians of Canada (CPS/CFPC guideline) [41] states that family physicians should be "an integral part of the [transition] treatment team" as a part of specialized medical teams. The Canadian Association of Pediatric Health Centres (CAPHC) guideline[42] on the other hand, recognizes a unique position of family physicians "…to address a AYAs' primary health care needs and act as a referral agent and 'gate keeper' to secondary and tertiary care providers". The CAPHC guideline recommends that all young patients with chronic conditions should be registered with a community-based PCP, ideally the one with an interest in young adults, working in collaboration with specialist clinicians to provide "continuity and access to adult care".[42] However, the CAPHC does not specify if these young adults will have to find yet another PCP when they become mature adults.

Interestingly, none of these guidelines provides any guidance regarding the extend of training needed for the PCPs to work competently with different speciality teams, neither describes the PCP's role in the last post-transfer transition stage. Additionally, care transfers to PCPs or family medicine groups with no or limited support from the specialty teams, which is probably the most common scenario in today fragmented system, are not addressed by any of these guidelines. Research on the role of primary care in the multi-disciplinary transition processes and medical and patient-centered outcomes relevant to CP in AYAs also appears unexplored.

Existing transition models

The need for the well-orchestrated transitions exists primarily due to the strict divide of the Canadian healthcare systems into the pediatric and adult sectors, the two worlds working in silos and providing different types of care: family-oriented vs. adult patient-centered. It should also be noted that not all pediatric services have their adult analogues or corridors of transfers to the adult world. Most of the literature thus focuses on the existing transition models for "classical" childhood conditions like diabetes,[43, 44] respiratory conditions[45] or complex care transfers for AYAs with neurological conditions and developmental disorders.[46, 47] Except for the general guidelines on transition of Canadian AYAs with chronic conditions,[41, 42] we identified no literature on the optimisation of transition pathways for AYAs with CP.

The development of a generic transition pathway for AYAs with CP, however, might be challenging. A pain patient population is far less homogenous than the populations followed by individual specialties or disease-based services (diabetes or kidney transplant clinics, for example). This heterogeneity adds to the complexity of the transition planning and coordination. Ideally, pain services should have a high degree of integration with primary and specialty services within their respective networks to address various patients' needs at various stages of a CP condition. Thus, coordination of transfers from the pediatric to adult sites would also need some degree of service overlap and interconnectedness, implementation of standardized inter-service practices yet, accounting for the uniqueness of each clinical case, availability of primary care accompaniment and specifics of each pain team and resources in place. This multi-directional multi-disciplinary ideal however, is far from the Canadian reality.

Several transition models that exist across Canada are mostly based in the pediatric specialties with a minimal to no participation from the adult services, and thus mainly focus on preparing patients and their supporters for transitions during early pre-transfer stages. These programs, therefore, remain unipolar and end when pediatric services' support ends. Some of them also rely on community services, including family medicine, but overall, outcomes of various transitional services have not been systematically evaluated and knowledge on the optimal models is lacking. Two main components appear entirely absent from the existing transition literature: the role of the recipient adult service in the post-transfer stage and involvement of primary care (patient medical home) team during the process.

As transitional research on the post-transfer period has been limited to date, several sporadic initiatives across Canada, like those in British Columbia, Ontario, Alberta and Nova Scotia [48] led to the development of the community-based programs. This type of data is difficult to publish and they are frequently retrieved from the grey literature and administrative on-line resources, thus creating a significant void in today knowledge. Nonetheless, some literature on transitional models exists. Thus, reviewing five existing Canadian transition models for AYAs with chronic illnesses, Grant and Pan [49] came to the conclusion that only two of the five models discussed in their study would reflect all transition principles delineated by the CPS/CFPC guidelines. These principles include i. developmentally appropriate care; ii. enhancement of patient autonomy; iii. collaboration between healthcare providers; iv. teaching negotiation skills required to navigate adult care; v. gradual delegation of responsibilities to adolescents; vi. provision of community resources; vii. designated professional with responsibility for the entire transition process; viii. portable summary of healthcare needs; and ix. documented transition plan. None of the discussed services was based at the level of primary care, although two programmes (*Maestro System Navigator* in Manitoba, *Be Your Own Boss Program* in Alberta) were based in the community and the other three were hospital- and specialty-based programmes (*ON TRAC* in British Columbia, *Good2Go* in Ontario, and *Young Adult with Rheumatic Disease* in Alberta).

A brief summary of existing Canadian community- and specialty-based transition models [48] that assist young patients with specific diagnoses is presented in the **Table 8** (Existing transitional models). As seen from the presented data, except for the rheumatology, neurology, and mental health programs, also described above, we identified no relevant literature on CP transition models adopted in Canada. Furthermore, the involvement of the PCPs and community-based services appears inconsistent across the transitional models. The systematic use of on-line based and patient-focused material, transitional protocols or type of medical summaries could not be determined, same as specific outcomes measures or criteria for evaluation, if any.

Young adults and emerging adulthood

The ease of navigating adult-oriented services depends on the patient maturity and autonomy gradually acquired during the second and third decades of life [50] thus, making care transitions far from being linear in the trajectory. During these two decades of life, AYAs face multiple simultaneous life transitions, including those in education and employment, social and family responsibilities, and in their financial and personal independence. If planning and support of all transitional facets are insufficient, and patients fall through the cracks due to the system imperfections, this makes families, friends and emergency services the ultimate providers of an indispensable, but suboptimal care, resulting in an increased risk of variety of complications.[49] The influx of young adults with pre-existing medical needs, including CP, might be significant. So, what are the specific challenges that healthcare providers are presented with while caring for this population?

In 2019, about 4.6 million (12%) Canadians aged 15 to 25 [51] and would fall into a category of young adults, astutely named "emerging adults".[52-54] *Emerging adulthood* is a term coined by J. Arnett (2000) that describes a process of developing of a young adult identity[52, 53]. Greig and Tellier[55, 56] further characterised *emerging adults* as those "…who are still in the process of acquiring autonomy, have marked similarities with adolescents and differ from older individuals who have attained full independence." Emerging adulthood is thus a period marked by a higher risk of a new psychiatric diagnosis and increased likelihood of suicidality,[57-59] high-risk behaviours, [60] including substance use, [61-63] unplanned pregnancies, inter-partner violence and sexually transmitted infections, [64-66] This might also be compounded by poor eating habits [67] and sedentary lifestyles [68].

What did we learn about general health of AYAs in Canada? According to Statistics Canada, in the last 20 years, the rates of Canadian youth living with mental health disorders, obesity, poor eating habits and sedentary lifestyles have been increasing.[69] Although tobacco smoking rates have been steadily decreasing,[69] cannabis use has increased in this same population.[70] It is noteworthy that there has been a trend to substitute many pharmacological agents used in pain (opioid medication, antidepressants, sleep and ADHD medications) for the authorized or recreational cannabis.[71, 72] Thus, in the fourth quarter of 2020, more than a third (35.6%) of Canadians aged 15 and older self-reported as active cannabis users in the past three months, with the prevalence in

Quebec population of 10.6% (95% CI 8.3-13.4%) vs. overall Canadian total use of 20% (95% CI 18.3-21.8%), with the highest proportion of daily or almost daily use in persons aged 18 to 44.[70]

Transition to adult care CAPHC guideline

In 2016, Canadian Association of Pediatric Health Centers (CAPHC) published a guideline for transition from pediatric to adult health care for AYAs with special health care needs [73]. This guideline does not target AYAs with chronic pain (CP), Quebec province population or the third stage of transition (post-transfer) specifically. Most of the steering committee members on the CAPHC guideline are pediatric specialists and allied professionals working in pediatric settings. No family physician or nurse were identified among the steering committee members. At least one committee member (KS) was listed as working at an adult center, another member (AM) was a part of a provincial primary care management structure, and at least one other member (SM) worked in the pain field.

Our search for a Canadian or Quebec guideline that would be applicable to young patients in the final transition stage, suffering from a CP condition, and involving primary care or where primary care's role would be clearly delineated, did not yield any result. Thus, the team focused on the CAPHC's work as it outlined several general principles that should be applicable to the transition in care within any specialty.

The original CAPHC guideline was published in 2012, then reviewed and reaffirmed in 2016. It states that today literature remains limited to a body of qualitative studies identifying barriers to successful transitions and some quantitative data pertained to poor clinical outcomes as a result. CAPHC adopted a definition of AYAs as persons aged 12 to 25. Building this guideline, the CAPHC formulated 39 recommendations and voted in as the most important, albeit to a different degree, 19 of them. All recommendations were based on a rigorous literature review, consultations with multiple stakeholders and application of a consensus building survey. In the Consensus Survey phase that rated all 39 recommendations, Quebec was represented by 3.4% of all respondents (N 9).

Of the three primary goals identified by the CAPHC guideline, two main goals included the provision of a framework to support such transitions, and the identification of the processes, tools, and resources to support the implementation of the CAPHC transition guideline. The third one aimed to assist transitions at the personal, clinical and system levels. Therefore, its final recommendations are formulated based on the three-level approach (**Table 3**).

The highlighted recommendations were found to be the most pertinent to the final (adult) stage of transitions in care and were reflected in our further data collection strategy. The recommendation 18 guided our second stage data collection, and recommendation 19 – the concluding stage of the project.

In conclusion, transitions in care happen in many contexts, including situations when there is a change in care providers, institutions, geographical regions, and age-related care transfers. Vulnerable populations, like those with multiple co-morbidities, significant burden of disease, and at the extremes of age (children and elderly) are at risk of falling through the cracks while transitioning between providers in our fragmented healthcare system. Transitions of young patients with evolving needs, including those suffering from chronic pain conditions, represent a significant challenge due to the lack of adopted universal practices, limited research on transition processes and patient-oriented outcomes, and minimal experience with the post-transfer transition stage in the pain field. The absence of guidelines pertinent to the Canadian and Quebec AYAs suffering from chronic pain to guide primary care and pain physicians results in several gaps. One of them is the need for the additional competency training for primary care providers as well as the development of optimal ways of collaborating with specialized services like pain centers. Another inter-related question is whether an adult pain practitioner is sufficiently prepared to deal with the AYAs population and how primary care teams might complement this expertise. The existing guidelines mostly target pediatric services and focus on the pre-transfer and transfer periods of the transition process, thus offering little guidance for the post-transfer time representing almost a decade of AYA's live. Several existing Canadian transition models are pediatric specialty-based and frequently disease-specific, and do not include primary care services in the planning of care provision, thus rarely focusing on the assistance to vulnerable AYAs post-transfer. Transitions of AYAs with chronic pain appears a new and poorly explored area in pain and family medicine, although many vulnerable AYAs with various painful chronic conditions transfer to adult services every year.

The specific objectives of this work thus, were:

i) To understand the most important gaps that exist in transitional post-transfer pain care provision.
ii) To identify the potential role that PCPs should play in this collaborative process.
iii) To formulate a set of actionable recommendations to optimize existing transitional pain care provision strategies.

3. EXPLORATORY STAGE and METHODS

How this project was developed

The initial suggestion to evaluate existing practices in transitional pain care for AYAs was brought up by our young patients and their supporters (ex., family members or friends) seen during clinical encounters at the AEPMU. Young patients and their supporters would frequently compare a variety of experiences at the pediatric pain services with those at the adult pain center, expressing some unease about the differences in the care organisation and communication practices, feeling disoriented, unsupported, and even misunderstood. Concerns about discordant messages from some adult healthcare providers and lack of complementarity with the primary care services were also commonly mentioned (**Table 9**).

Therefore, this project was developed as a collaborative inter-disciplinary effort to evaluate the existing support for AYAs who live with CP and have transitioned to adult pain services. As this idea was taking shape, the future investigators involved tertiary and primary care teams, including clinicians, allied professionals, medical trainees, decision-makers, and patient-partners.

Exploratory stage of the TRAST project

The exploratory stage of the project lasted about a year (2016-17) and involved multiple team members and three to four patient-partners at different times (see team composition in **Table 1**). The team evaluated the feedback received from the young patients living with CP that concerned the support available from the adult services during the final transition stage. These data informed further steps of the project.

Participatory component

The participatory component is described in more detail in the thesis manuscript. Our *patient-partners* did not participate in the decisions related to the choice of research methodology however, they were involved in the ideas exchange, study findings discussion, validation, interpretation and helped us understand the significance of the identified gaps and to plan future steps. Thus, the team attempted to apply the integrated knowledge translation principles by employing collaborative strategies, integrating new knowledge creation and translating it into action.[74] The patient-partners shared their unique expertise related to the environment; their ability to see whether this new knowledge could be easily applied to the present context of translation pain care for AYAs (taking into account the barriers and facilitators they experienced); and their vision for the outcomes of the outmost importance to the young patients with CP.

Those *patient-partners* who participated in the study were acknowledged in the manuscript either by their name or their chosen alias.

Settings

The study took place on the territory of the McGill integrated healthcare network (*Réseau Universitaire Intégré de Santé,* RUIS McGill),[75] Quebec, Canada (2017-2019). This university-based network is comprised of the McGill university academic facilities (community and hospital-based) and non-academic healthcare services, including community family medicine groups (FMG).[25] The McGill university center of expertise in pain (AEPMU)[75] serves patient population from a large territory of the Quebec province. The AEPMU works with the academic and non-academic FMGs, whose many physicians commonly refer their patients to the AEPMU. It should be noted that the Greater Montreal territory, which includes suburbs, has about 16 hospital- and rehabilitation centers-based pain management facilities[76] as well as private clinics and stand-alone practices focused on pain and addiction treatments these physicians could also choose to work with.

In two fiscal years preceding the project (April 1, 2015, to March 31, 2017), the AEPMU received 1,242 new patient visits (in addition to those patients already followed at the AEPMU). Of these, 132 persons aged 16 to 25 years constituted about 11% of all new patient visits. Reviewing 2015-2017 data, the team noted that on average, young patients would miss every fifth of their scheduled appointments, which was 27% higher than an average AEPMU patient, including the most disabled ones. About two thirds of the newly coming young patients were referred by the McGill specialists, and about one third was referred by the PCPs. More than half of all young patients were followed by specialty clinics only and had no information on file about their registration with a PCP.

In McGill, some AYAs would meet an adult pain care provider for the first time at the age of 16-17 while preparing to transition to the AEPMU from the Montreal Children's Hospital or from the

Shriners orthopedic hospital. Some AYAs, however, would be referred to the center by their specialists (rheumatology, for example) and/or family physicians. Traditionally, all incoming patients receive an AEPMU introductory package and attend an orientation session, introducing the AEPMU multi-disciplinary team and its services.

Preliminary findings

At the clinical rounds, the team reviewed about ten clinical cases, discussed the input from the young patients and their supporters, and later presented a summary (**Table 9**) to a larger group that included patient-partners. Next, a group of interested clinicians and researchers reviewed existing literature and documentation on existing transitional practices (current guidelines, orientation session information, relevant studies etc.), conceptualized the findings, and composed an interview guide. The interview guide (see thesis Appendix) was later used in the second part of the project during the semi-structured interviews with the PCPs. During this stage, the team exchanged emails, documents and held several in-person meetings. The process was assisted by a PhD family medicine student (JG), who acted as a liaison member between the team and *Reseau-1* support group.

The findings were categorized into common themes, emerging sub-themes and summarized in **Table 9**. For each subtheme that transpired from these informal discussions, the most typical examples were chosen. Five main themes have been identified at this stage: 1) age-appropriate care, 2) PCPs' practice profile, 3) PCPs' experience working with pain services, 4) Possible mitigation strategies, 5) Overlapping concerns (team members, young patients, and their supporters).

The existing transition process and perceptions of young patients with CP about the support available from adult services during the final transition stage is presented in the **Figure 3** below:

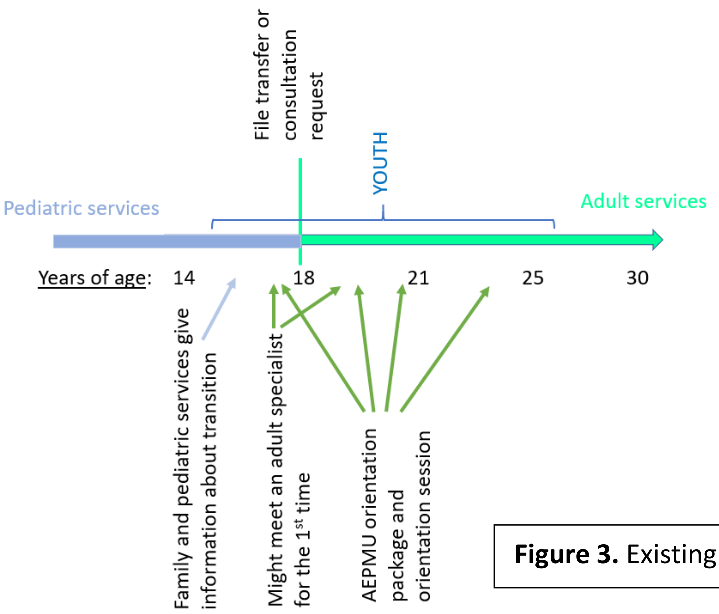

Figure 3. Existing transition process as perceived by youth.

**Adult and pediatric services: any adult or pediatric specialty, including family and pain medicine.*

Some AYAs and their supporters described seeing an adult pain care provider at the age of 16-18, and others were not familiar with the adult services until coming to the AEPMU. Information about transitions came either from the pediatric pain team or patient's family and friends. Some AYAs were not registered with a PCP however, even those who were, did not report that PCPs or primary care team members were giving them information about adult care or transition processes. Patients who were transferred via corridors of care from the Montreal Children's Hospital or Shriner's hospital (orthopedic facility) might have already seen an adult pain specialist or have received an orientation package before coming to the AEPMU. These reports, however, were inconsistent, and comments on the helpfulness of this information varied from patient to patient. Altogether, the AYAs did not identify any clear transition strategy supported by the specialty or primary care services, did not report using any specific tools or resources related to transition preparedness, or being followed by a transition team member.

The AEPMU always documents the presence (or absence) of a treating PCP to communicate with. No matter if the AYAs were registered with a PCP or not, primary care involvement in the transition process was expected and desired by the patients and their supporters, but rarely acknowledged as being available (**Figure 4**).

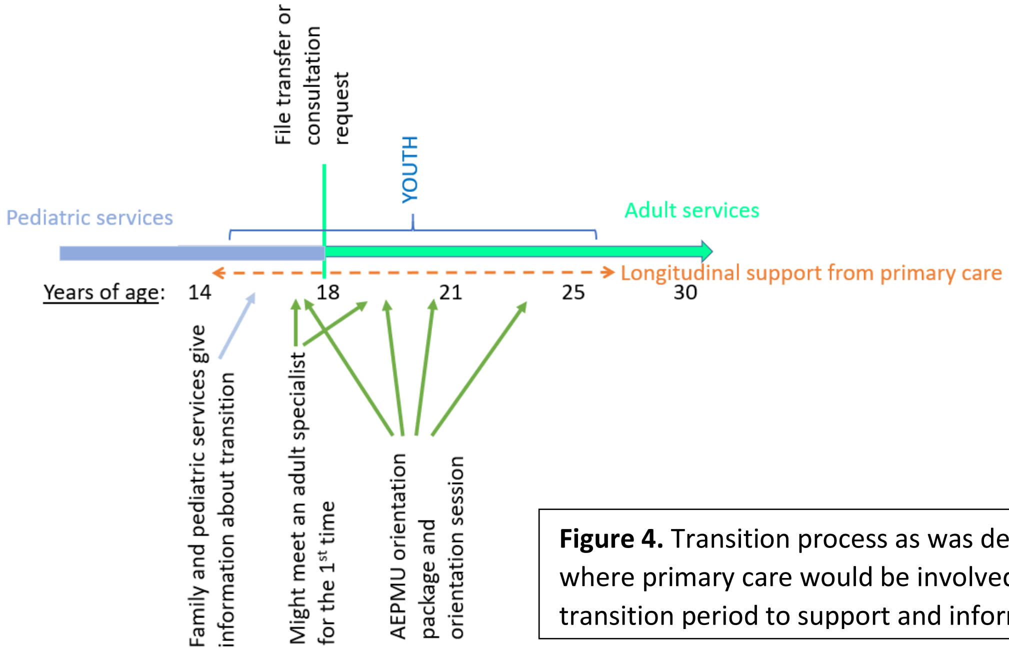

Figure 4. Transition process as was desired by youths, where primary care would be involved in the entirety of the transition period to support and inform the patient.

**Adult and pediatric services: any adult or pediatric specialty, including family and pain medicine.*

Based on the reviewed literature and CAPHC guideline, as well as patients' and their supporters' feedback, it became clear that existing transition processes are not smooth, need to be better planned and coordinated to allow for the best clinical and personal outcomes.

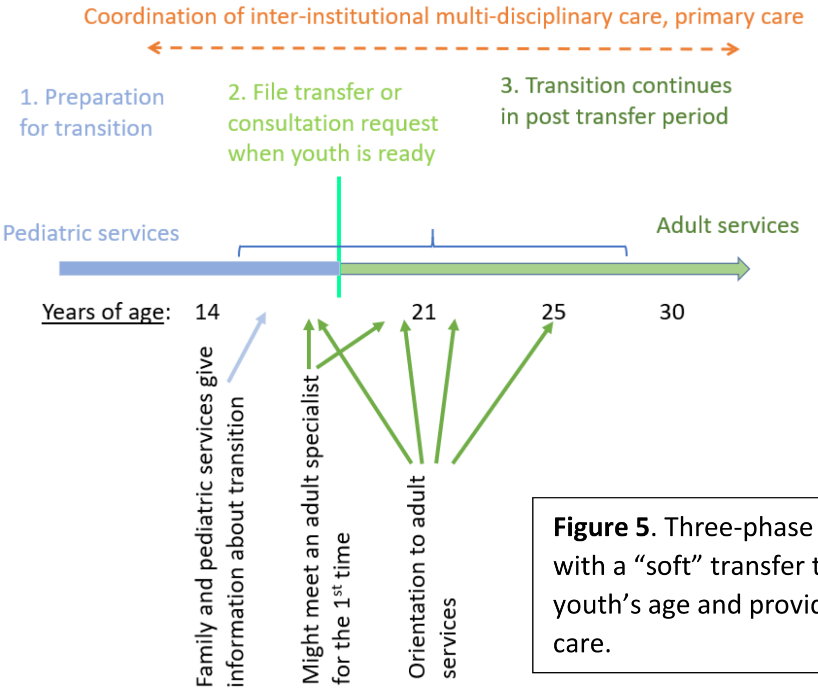

Figure 5. Three-phase coordinated transition process with a "soft" transfer time point not based on the youth's age and providing developmentally appropriate care.

Semi-structured interview guide development

The findings summarized above informed the development of our semi-structured interview guide aimed to explore how PCPs structure their practices to include transitions in care, their comfort providing transitional and pain care for vulnerable AYAs with CP, and their views on the role of primary care in this process. Additional team's questions were included in the interview guide in a close-ended format. The interview guide comprised of closed-ended and open-ended questions, concluding with one reflective question to offer additional ideas not mentioned during the interview (see thesis Appendix).

To be inclusive of both dominant languages in Quebec, the interview guide was professionally translated from English to French. The content of both versions was verified, corrected, and approved by all team members, including *patient-partners*. The team piloted this interview guide with three PCPs in both languages, in one in-person and two online video-call interviews. The interview guide was then finalized with minor corrections related to punctuation, order of closed-ended questions, and the clarity of several statements.

McGill Joint Adult-Pediatric Task Force on Pediatric Transition to Adult Care.

To get informed of the existing McGill University Health Center's policies and resources, the team made several attempts to contact three different members of the McGill Joint Adult-Pediatric Task Force on Pediatric Transition to Adult Care[77] (a specialist, a family medicine unit Director, and a family medicine researcher), but was unable to obtain any information or documentation from the Task Force. Therefore, our discussion is based solely on the published literature findings.

In conclusion, the exploratory stage lasted about a year (2016-17) and involved a multidisciplinary team composed of primary and tertiary research and clinical healthcare professionals, supported by the three to four *patient-partners* (**Table 1**). The review of the literature and available documentation, case discussions and team meetings, and the input from the patient-partners brought the team to a conclusion that transitional pain care represents one of the most important periods in AYAs' medical care as it must be designed to manage multiple inherent risks related to the fragmented organisation of health care services, inter-disciplinary and inter-service information transfer, and the age-appropriate guidance to assist YAYs' adaptation to adult care.

The AYAs seen at the AEPMU perceived this adaptation period as challenging and insufficiently supported by the adult healthcare teams from both levels of services. The consensus (among the patients, their supporters and team members) was that the PCPs, being ones of the main stakeholders, were minimally involved in the last stage of the transition process. PCP's involvement "from cradle to grave" was cited as desirable and even necessary as this would represent a *safety net* for the vulnerable AYA population. The primary care teams were expected to ensure continuity of care, psycho-social and general medical care support, and multidirectional information flow and coordination of transitional pain care.

PREFACE to the MANUSCRIPT

The format of the present thesis is by manuscript. The thesis describes a three-stage qualitative research with a participatory component. The preparatory stages are discussed in the thesis Background, and the rest constitutes one manuscript. The research evaluates the need for the improvement of multi-disciplinary transitional pain care experiences of adolescents and young adults diagnosed with chronic pain and integrating into the adult-focused pain services. A representative sample of stakeholder participants from the specialty and primary care levels, including patients themselves, identified gaps in the present transitional pain care provision model. A theoretical framework was applied. This work resulted in a set of actionable recommendations based on the existing Canadian transitional care guidelines (CAPHC). The results were further discussed in the context the pain field and published transitional and pain literature. The implications of findings, a vision for a transitional pain care model, and a discussion on future directions concluded this thesis work. The thesis manuscript will be submitted for publication to a peer-reviewed journal.

4. THESIS MANUSCRIPT

Transitional pain care and youth: Primary care perspective and multidisciplinary recommendations. *The TRAST project.*

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Abstract

Introduction. Chronic pain (CP) affects one in 3-5 adolescents. In Canada, when adolescents with CP turn 16-18, their care is transferred to adult pain care providers. Well orchestrated multi-disciplinary transitions prevent the breach in continuity of care and increase adolescents and young adults' (AYAs) ability to navigate adult services with confidence and maturity. A variety of transitional chronic disease guidelines have been published but none exists to address pain-specific needs of the AYA population. The respective roles of the transitional care team members are not well-defined, including those of the primary care providers (PCP). Care fragmentation affects AYAs' physical and mental health, cognitive and social functioning leading to overall poor outcomes. The objective of this study was to formulate a set of actionable recommendations inclusive of primary care services, to optimize transition strategies for AYAs. **Settings.** McGill University Healthcare Network (primary and tertiary care settings), Quebec, Canada. **Methods.** Sequential-consensual qualitative design with a participatory component. The data from twelve semi-structured interviews with PCPs informed deliberative stakeholder consultations groups. Three groups took place: i) primary and tertiary care clinicians, ii) allied healthcare professionals, and iii) patients with their supporters. Inductive-deductive thematic analysis was used. A three-level (*Individual, Service, and Healthcare system*) theoretical transitional framework adopted from the Health Care Transition Research Consortium model was applied. **Results.** The study resulted in fifteen actionable recommendations, of which six were supported by all three stakeholder groups, seven recommendations were endorsed by two of three stakeholder groups, and the rest of the recommendations came from one of the groups only. **Conclusion.** Post-transfer transitional pain care for AYAs remains unstructured and fragmented. A representative group of stakeholders, including patients, their supporters and healthcare professionals from primary and tertiary care services made several actionable recommendations pertaining optimization of transitional pain care for AYAs. The assumed approach and resulting recommendations could be adopted in all settings, where transitional pain care for AYA requires further improvement.

Introduction.

Chronic pain (CP) is one of the most frequent conditions affecting children and adolescents with the medium prevalence rates ranging from 11% to 38%.[1] The uniqueness of CP is rooted in its complex biopsychosocial nature, influenced by complex individual experiences in physiological, psychosocial and cognitive domains.[2] The recent understanding of the multi-faceted character of CP has resulted in the recognition of pain management and education approaches as likely superior to the pain cure seeking philosophy.[3, 4] In the modern world where biologic conceptualization of pain treatments and disability still prevails among medical professionals, this resulted in a poor access to non-pharmacological therapies[5, 6] and significant burden for patients and society.[7, 8] The data suggest that there is a significant segment of adolescents and young adults (AYAs) whose childhood onset pain continues into adult years, and therefore successful pain management would be the paramount to preserve these persons functionality. In a longitudinal sample of 48 youths diagnosed with primary juvenile fibromyalgia, more than half reported continuous physical and psychological symptoms and pain-related disabilities after 2-6 years of follow-up.[9] Concordant with this observation, in a tertiary pain center sample (n=1045), every 6th adult patient reported having suffered from a childhood onset pain condition; a majority were women describing associated psychological symptoms and decreased functional status.[10] Likewise, more than 60% of children continued experiencing pain after several years of follow-up at a pain center.[11] Such youths transitioning to adult services and making their first steps as independent adults, a well-orchestrated transitional pain care models are instrumental in assuring best possible outcomes.[12-14]

Conventionally, transitions are thought of as dynamic longitudinal and multidimensional processes depended on several factors including patients' individual characteristics, healthcare system resources, organization and logistic. Transitions could be conceptualized as including three distinct phases: pre-transfer preparation, transfer of care, and post-transfer adaptation and integration periods. One of the most important factors determining transition success is the young person's capacity to navigate adult-oriented services with maturity and independence. The acquisition of independence however, is a long process that could be marked by various setbacks from the underlying illness and age-specific challenges,[15, 16] resulting in life milestones being reached at different ages and degrees of maturity.[17, 18] Transitional age is also known for a higher risk of new mental health diagnoses, risky behaviors and experimentation with substances.[19-23] Furthermore, AYAs with CP[24] are reported to have an almost double risk of suicidality, making pain care anything but simple. Additionally, the development of cognitive capacity and executive skills such as planning, selective attention, and self-regulation, which are the cornerstones of one's self-management abilities, are rarely fully attained until mid-20s.[25-27] As all these factors exhibit reciprocal influences, transitional pain care for AYAs must address multiple dimensions of the emerging adult formation and its associated complexities.[28]

Factors outside of the AYAs' personal characteristics that also have significant impact on a variety of relevant outcomes might include multiple simultaneous social, cultural, and financial transitions. This makes AYAs population vulnerable to poor outcomes,[29-32] especially if left without a developmentally appropriate[25] psycho-social guidance and healthcare accompaniment.[14, 33] In other words, AYAs' emerging individuality and quickly changing life circumstances along their continuously transforming psychosocial needs will evolve during the post-transfer period, influencing transitional pain care in many ways. The importance of the well organised and efficient transitions in care is unquestionable[5, 34, 35] and has been advocated for by the American Academy of Pediatrics (AAP) since the mid-90s,[36] resulting in a vast literature published by pediatric specialties. Yet, these efforts remained mostly unparalleled in the adult clinical and research worlds.

The Canadian Association of Paediatric Health Centres (CAPHC)[37] and the National Institute in Care Excellence (NICE) consensus recommendations[38] stress the importance of implementing a stepwise approach to connect transitioning AYAs to the appropriate multidisciplinary teams, community resources, and primary care providers (PCPs). As the age range of AYAs falls under the two types of services, pediatric and adult, the NICE[38] provides its guidance for the population of 25 years of age and younger. On the other side of the transition spectrum, the AAP, the American Academy of Family Physicians, and the American College of Physicians[39-41] recommend introducing transitions to patients as young as 12-15 years of age to allow for the ample time to prepare for the change in care. The post-transfer phase, therefore, is the longest transition period ranging from approximately 16 to 25 years of age, and thus resulting in almost a decade of transitional care that must be provided by the adult or mixed types of services.

Nevertheless, there is a significant gap in the transition literature concerning the post-transfer multi-disciplinary care provision and transitional pain management. Today research is mostly disease or pediatric specialty-specific (neurology, cardiology, rheumatology, diabetes, transplant) with very little data on the role of primary care in it.[42] Our knowledge of patients' perspectives on transitional pain services is also scant. A group of researchers[15] conducted focused groups with the youths suffering from CP and their pain care providers. This research revealed several concerns regarding pain impact on AYAs' lives, gaps in care organisation, and fragmented information flow between the care providers. In the same study, patients reported that PCPs were not sufficiently helpful with their ongoing pain care, and that the primary care's role was poorly understood. In sum, the organization of transitional pain services and the identification of relevant transitional outcomes have been an uncharted territory, making primary care and patient-informed research imperative to guide the nascent field of transitional pain research and affect positive change in today clinical practices. [15]

Admittedly, the available general data on pediatric transitions for chronic conditions like diabetes, for example, is of limited use to the post-transfer pain care modeling. There is a unique set of challenges, such as pain-associated stigma, lack of training in pain management and adolescent medicine for healthcare providers, and limited population access to the specialised pain services[41] that require bold solutions and innovative approaches to the delivery and implementation of transitional pain services for AYAs. The literature shows that none of the existing transitional care models has relied on a theoretical framework like the healthcare transition model,[14, 43] or been systematically examined beyond a set of specific criteria.[14] A systematic review[43] examining the models of care transfers to various specialists and PCPs using Effective Public Health Practice Project criteria gave only a weak rating to all 17 transitional studies included in the paper, citing multiple limitations in designs and methodology. The authors concluded that systematic evidence remains insufficient to guide transitional models' implementation in clinical practices. The NICE guideline[38] echoed this impression, stating that there exist many models, yet little evidence to their clinical and cost effectiveness. These models remain largely exploratory, which represents another significant gap in knowledge regarding the optimization of transitional care practices.

Reacting to the dearth of data, the NICE postulates that the future *“research could usefully focus … on transition interventions in adult services and on young adults receiving a combination of different services”* as well as the role of primary care for AYA populations whose transition pathways are more indirect or changed with time.[38] This acknowledgement is important for the persons who live with CP as their care pathways are frequently complex and indirect. CP could result in various physiological and psycho-social dysfunctions, leading to complex treatment regimens by a plethora of specialists and community-based services. Unsurprisingly, a crucial role of PCPs in orchestrating complex care for such patients is widely acknowledged yet, there exists no structural model whereby PCPs can closely communicate with the transitional care providers or participate in the transitional pain care directly. It should be noted that AYAs frequently transition with the knowledge and expectations based on their past experiences from the relatively resource-rich pediatric services. The complexity associated with the management of multiple issues by the adult services with fewer resources then, undoubtedly, puts less prepared AYAs at risk of sub-optimal care.[13, 44, 45]

The idea of the longitudinal integration of primary care in complex care models is reflected in the recent development of so-called “patient’s medical homes”[46] that strive to provide the needed continuity of care in the proximity of the patient. To date, there are more than 400 Quebec multi-disciplinary family medicine groups rostering patients of all ages.[47] The vision of the patient medical home is still relatively new and the respective roles of each service in this partnership have not taken a clear shape yet. A positive impact that community-based services might play in such collaborative models[48] suggests an urgent need to explore PCPs’ perceptions of their role in transitional pain care, and to formulate multi-disciplinary actionable recommendations to optimize its provision for the AYA patients in our network and, as applicable, elsewhere.

The **two study objectives therefore were** 1) to explore PCPs’ perceptions on primary care services as part of transitional pain care, and 2) based on these perspectives and patient-partners’ guidance, to engage a representative group of stakeholders and formulate a set of actional recommendations regarding the optimization of post-transfer transitional pain care for AYAs.

Methods

Context

The study took place in McGill University integrated healthcare network (Réseau universitaire isntégré de santé, RUIS),49 Quebec, Canada. Our multidisciplinary clinical research team was comprised of healthcare professionals from the Alan Edwards Pain Management Unit (AEPMU), a multidisciplinary university centre of expertise in chronic pain, and the members of Department of Family Medicine of McGill University (**Table 1**). A multi-site approval was granted by the Saint Mary's Hospital Ethics Review Board (Protocol# SMHC-17-28).

Health Care Transition Research Consortium framework and its adaptation

The study was guided by the Health Care Transition Research Consortium (HCTRC) theoretical framework[14] and the CAPHC guideline.[50] The HCTRC framework is a conceptual model proposing a comprehensive description of variables known to influence transitions in care for the AYAs with complex care needs. This model conceptualizes transitions as happening simultaneously at several levels: Individual, Family and Social support, Environmental and Healthcare system domains. A simplified version of the HCTRC domains is presented in **Table 2**. Similarly, the CAPHC guideline presents its transitional care recommendations at the three (Person-centered, Clinical, and System) levels. For the purposes of this research, the categorization in several hierarchical levels and multiple non-categorical variables was adopted to match CAPHC guideline. We thus, conceptualized all results into the three domains: Individual, Service, and Healthcare System levels.

To adopt the HCTRC, the emerging variables were categorized based on several assumptions. First, the clinical services and community-based resources were categorized as *Service* level variables (instead of the *Healthcare System* level of the HCTRC) as it was felt that they play an equally important and complementary roles in transitions and would be comparable only regionally, in the proximity to the patient medical home, and likely different at the System level. Secondly, the patterns of service use by AYAs, individual co-morbid conditions, independent living, self-efficacy, and self-advocacy variables were categorized at the *Individual* level (rather than *Healthcare System* level of the HCTRC), as they were seen to be person dependent. We also postulated that *Individual* variables are highly inter-dependent with those related to the immediate environment like Family and Social support, which might be limited or even non-existent in some specific cases (migrants, for ex.). Therefore, these two domains were considered at the *Individual* level. Another assumption pertained to the degree of readiness for transitions as in our context, it has a limited application: the transfer to adult services is based on the age, not readiness. Thus, to favor actionable recommendations over the theoretical concept of readiness, we proposed that the *Service* and *Healthcare System* level variables were evaluated based on their propensity to maximize AYAs' capacity during transitions. In other words, in the post-transfer period, the *Service* and *Healthcare System* variables were considered as the main facilitators of the integration and adaptation of AYAs to adult services, regardless their degree of readiness or maturity. Third, a communication variable was pre-categorised based on the level of attribution by the participants (ex., inter-professional communication was treated as a *Service* level variable).

Study design

To inform and influence change at the institutional level (McGill RUIS), we chose a sequential-consensual qualitative design[51] with a participatory component (discussed below).[52]

Participatory component

Our study was designed to capture rich insights from the key informants and triangulate data collected at various stages. Our team partnered with young patients suffering from CP and their supporters (further *patient-partners*) in the entirety of the research process. When patients become co-researchers,[53] generated research' pertinence increases. Thus, three *patient-partners* participated in the project questions development, validated study findings, and helped us understand the significance of identified gaps. This approach meant to strengthen external validity of findings at all stages.

Sequential-consensual design

The sequential-consensual qualitative design can be used in the institutional context as it allows for enhanced external validity of qualitative data to affect policy change. Groleau et al.[51] highlighted that the impact on decision-makers stems from the fostered insights into specific problems and credibility such data have in the public eye. For the initially collected data to be further discussed in the group settings, it should be sufficiently simplified, come from a representative sample, and resonate with the participants' experiences and meaning they assign to the problem. Thus, the sequential-consensual design can yield qualitative data with strong internal and adequate external validity appropriate for healthcare environments.[53]

This study was framed following an exploratory brainstorming period, when our team collected informal AYA patients' feedback, reviewed transitional literature, pertinent guidelines, and the theoretical frameworks. The transitional pain care gaps and main stakeholders were identified. The qualitative data collected during the next phase of semi-structured interviews was then deliberated on by three stakeholder focus groups, being put in context of our specific clinical reality, and validated by the patient-partners, which further strengthened internal and external validity of our findings. The schematic of the sequential steps is presented in the **Figure 1** below.

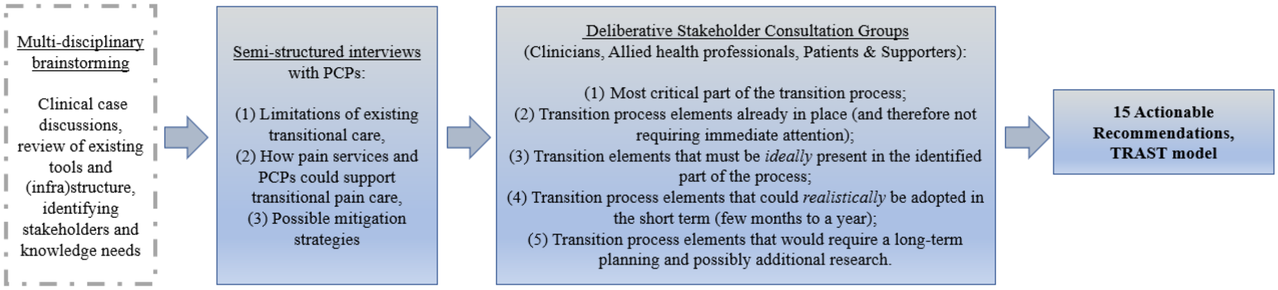

Figure 1. Sequential-consensual design.

- ***Qualitative semi-structured interviews with PCPs***

A qualitative descriptive approach using semi-structured interviews was chosen to capture PCPs' perspectives on the primary care role in complex pain transitions. Qualitative interviews allowed PCPs to offer as many details to their narratives as they felt comfortable. An interview guide was carefully constructed in a way that initial probing questions helped to establish a link between the interviewer and the interviewee. This approach also encouraged PCPs to talk about themselves and their practices first, thus making connections between PCPs' daily experiences and allowing to reflect on the meaning of transitional pain care for AYAs. This helped PCPs to clarify important ideas and put positive and negative reflections in the context of transitional pain care experiences they and their patients had within the McGill University Healthcare Network. Researchers were interested in more “typical” experiences as this allowed for the highest internal validity. To assure data transferability, we also relied on careful planning, meticulous choice of informants, and data validation by the patient-partners. The clinical research team guided by the patient-partners conceptualized three main themes to be explored during the interviews with PCPs: (1) limitations of the present transitional pain care process, (2) how pain services could involve PCPs to support transitional pain care, and (3) possible mitigation strategies. A semi-structured interview guide was constructed in English and then translated into French by a professional translator, and then validated and approved by the team.

Sampling for semi-structured interviews with PCPs

To assure applicability of findings to our specific (institutional) context, the researchers employed random purposeful sampling strategy[54, 55] i.e., randomly choosing from a pool of purposefully selected potential participants. The data collected from a sufficiently large sample of PCP participants and focused on predetermined themes thus represented a strong argument to support a call for specific developments in transitional pain care. The sample adequacy[56] is the term preferred in qualitative research and refers to the composition and size of the sample, important in the appraisal of validity and transferability, while evaluating the overall data adequacy. In this study, we approximated that 10-12 interviews would be needed to obtain sufficient data from PCPs of both sexes, working in academic and non-academic settings, and presenting at least 2-3 different referral pathways for the first line practitioners (from the family medicine groups or polyclinics, private offices, emergency rooms). Academic and non-academic PCPs working at the primary care level within the McGill University Healthcare Network and who had referred at least one patient aged 16 to 25 years to the AEPMU were invited to participate. To identify participants, we queried our hospital administrative database (MediVisit) and collected data on referred patients’ age. Among those identified, only records for patients aged 16 to 25 and their referring care providers were retained. Approximately half of all identified consultation requests came from 22 academic or non-academic primary care clinics, and more than 30 PCPs.

PCPs recruitment.

From February to October 2018, research assistants (JMB or SL) contacted clinical sites and/or PCPs offices via email, telephone, and/or fax, listed in the provincial physician roster database.

Invitation letters accompanied by a recruitment flyer were sent to all potential participants up to three times. In addition, a snowballing strategy was implemented, we contacted colleagues of PCPs we had already interviewed. (**Table 4**)

Semi-structured interviews.

To protect confidentiality, each participant chose an alias. All participants signed an informed consent indicating that participation is voluntary. A professional transcriptionist transcribed the interview data verbatim. Important findings were limited to several predetermined domains to inform focus groups that followed.

Twelve PCPs were interviewed in-person or via video-call (*Zoom* video communications). Participants chose the language in which they were interviewed (English or French). Each interview lasted between 60 and 90 minutes and was conducted by one of four trained team members (JC, VP, MS, SL). Each interviewer was accompanied by one or two additional team members taking notes during the interviews. The interview recordings were anonymized and transcribed verbatim by a professional bilingual transcriptionist.

- ***Deliberative stakeholder consultations groups***

Data from qualitative semi-structured interviews with PCPs informed deliberative stakeholder consultations groups (DSCGs).[58, 59] The DSCG participants were put in the role of subject experts to formulate a set of relevant actionable recommendations regarding the optimization of transitional pain care for AYAs. This method is growingly popular with various policy and decision-makers, governmental and research institutions as it fosters key stakeholder participation in the shared decision-making process, counteracting existing power differentials.[58, 60] Such deliberations *"involve the careful and serious weighing of reasons for and against some proposition or to an interior process by which an individual weighs reasons for and against courses of actions."*[61] There were three separate DSCGs held at convenient time (late afternoon) and place (two different downtown university campuses).

Group sampling for DSCG.

For DSCGs, we employed a purposive homogenous sampling technique [54] used to select focus groups' participants based on a specific characteristic, such as a being a part of a group or a professional team. Seven participants were recruited to each of the three DSCGs (21 in total): (1) Clinicians (medical doctors, residents, nurses, and clinical service director) and (2) Allied health professionals, AHP (psychology, physiotherapy, social work, administration, and public health physician-researcher) (**Table 5**). These two groups were working at the tertiary (AEPMU) and primary care levels, and well-positioned to deliberate on the collected data. The compositions of these two DSCGs were relatively balanced, representing both sexes, various career stages (including those in training), different degree of administrative seniority, and a spectrum of experiences, including decision-making. (3) Patients with supporters, P&S (friends and/or significant others) was a separate DSCG. Eligible young patients had a diagnosis of a CP condition, were carried for at the AEPMU in the past, and had lived experiences in transition to adult care. Some of them were accompanied by a supporter.

Deliberation steps and processes.

A week before DSCGs took place, a preparatory package of documents was emailed to all stakeholder-participants. The day of deliberations, all participants attended a 20-minute power-point presentation describing identified gaps, transition literature, existing guidelines, and results of collected data. Each participant received a folder with printed information that was previously circulated by email. Participants also received several clean paper sheets, a pencil, a pen, and a hand-toy (to help sustain attention during deliberations). A light supper was served. This followed by a period of clarifying questions. To protect confidentiality, each group participant chose an alias, different from the ones used for the semi-structured interviews. All participants signed an informed consent indicating that their participation in DSCGs was voluntary.

All three DSCGs were tasked with identifying the most important information based on the above material. First two groups lasted closer to 120 mins, and the P&S group finished in about 90 mins. Two participants were absent (AHP and P&S). One clinician submitted his notes and left after ~90 mins. Discussions were conducted in separate, distinct locations for each of three groups to further mitigate power differentials and allow for a free unrestricted expression. Two first groups (Clinicians and AHP) took place at the pain center, a familiar environment for all participants. The P&S group was organised on a university campus at a non-clinical setting. All participants' aliases were categorized by group: Clinicians were given city names to choose from, AHPs were denoted as planets, and P&Ss chose a month of the year. Each participant was given an equal number of opportunities and minutes to participate in deliberations and spoke after naming his/her alias. All deliberations were audio-recorded.

The discussion guide contained five open-ended questions. Participants had to use results of the interviews with PCPs and CAPHC guideline on transitions to make their recommendations.

Each group was led by two moderators: a general moderator who guided the discussion, and a content-expert moderator who fielded questions about the study and the literature.[58] Both moderators took notes and encouraged participants to elaborate on specific arguments. To mitigate a possible power differential, the participants-decision makers spoke after all other participants in the group. The participants took notes of their ideas and recommendations. At the end of deliberations, each group chose three to five final recommendations. As with PCP's interviews, the data from the group discussions were transcribed verbatim by a bilingual professional transcriber. The participants' notes were analysed along the group transcripts.

Analysis

We performed an iterative deductive-inductive thematic analysis of the transcribed bilingual interview data using QRS International's NVivo 11 software (2015, London).[57] For semi-structured interviews, we adopted a three-level transitional framework (*Individual*, *Service*, and *Healthcare System*). This hierarchical categorization of healthcare processes is common in the literature[37, 14] Based on the pre-determined themes (1) limitations of the present pain care transition process, (2) ideal pain services to support transitions and role of primary care, and (3) PCP-proposed mitigation strategies, the reviewers deductively categorized the codes into the corresponding framework domains. The data were then analyzed inductively to allow for the emergence of new codes. The reviewers iteratively identified and discussed emerging themes and drew conclusions about the meaning and relation of the themes. The transcripts were independently coded by a bilingual research assistant (SL). To triangulate coding, 20% of the interview transcripts (two longest transcripts) were also independently coded by two other bilingual researchers (IK, JMB) and compared with the initial codes.

The DSCGs' were tasked to review the literature, supporting transitional guidelines, study findings and extracts of interviews (circulated to the group via email and discussed during the DSCGs introduction session), mitigations strategies proposed by the PCPs. The objective was to transfer the produced knowledge, deliberate on the most relevant strategies, and agree on their final choices for each group. A similar approach was used by Groleau and colleagues[51] for the discussion of breast-feeding promotion programs during a multi-stakeholder symposium in Montreal. A three-level transitional framework (*Individual*, *Service*, and *Healthcare System*) was applied with results matching the CAPHC guidelines per-level recommendations.

Results

Semi-structured interviews with PCPs

Participants were diverse in age (29-70 years) and number of years in practice (3-40). They were predominantly male, representing all three types of practices (family medicine groups, emergency medicine, and solo practice private office) and pain management experiences (**Table 4**). Most interviews were conducted in English. Except for one participant practicing within the Greater Montreal area, all PCPs were practicing in Montreal. Most also commented on other Montreal-based pain services like geriatrics, private clinics, and another academic pain center. Our results are categorized as shown in a "3 by 3" table (**Table 6**), which presents participants' quotes as follows: the three vertical columns correspond to the predetermined Themes 1, 2, and 3 identified above; and the three rows represent data categorisation into the *Healthcare System, Service,* and *Individual* levels. The quotes (**Q**) are numbered sequentially within each theme and subtheme.

Theme 1. Limitations of the present healthcare system as perceived by PCPs

Synthesis of the PCP interview data unveiled several perceived limitations at the *System* level (sub-themes included Hospital-centred care provision, Fragmented information flow, and Care logistics). At the *Service* level, there were two sub-themes (Lack of training in pain medicine and AYAs healthcare needs, and Poorly defined role of primary care). Finally, at the *Individual* level, PCPs discussed two other issues (Stigma, and Young patients' experiences with adult system).

Healthcare System level

(1) *Hospital-centred care provision.* PCPs reported limited access to publicly covered pain services outside of the hospital system. For AYAs in transition, PCPs felt it was nearly impossible to gain access to necessary pain therapies without referring for a consultation to a hospital-based pain specialist. Obtaining services was reported as exceedingly difficult. In addition, PCPs were

unaware of transitional pain options for AYAs from the community. (**Q 1.A.1-1** to **Q 1.A.1-4**). One of the PCPs hoped that with a referral to a hospital-based service, *"… maybe they can get physiotherapy more easily, maybe they can get psychological interventions that are specific for chronic pain…" - (P-9)*

(2) *Fragmented information flow*. PCPs reported major issues with information flow and communication between primary care and pain consultation services, including the AEPMU. They discussed limited and inconsistent information flow after their patients had been seen and cited a desire to be kept in the loop regarding their patient's progress at the pain center (**Q 1.A.2-1** to **Q 1.A.2-5**). As one of the participants described, "*…that we don't get follow-up reports, so you just get the initial consultation and it's hard to kind of get the follow-ups of the multiple visits that the patient has.*" *- (P-10)*

(3) *Care logistics*. PCPs admitted they had poor knowledge of pain services, how to identify them, and reported finding information about pain care organization as challenging (**Q 1.A.3-1** to **Q 1.A.3-3**): *"[one] can only become aware through personal connections, you know…nobody advertises pain clinics." - (P-11)*

Service **level**

(1) *Lack of training in pain medicine and AYAs healthcare needs*. PCPs felt uncomfortable managing young patients with CP, citing a lack of knowledge and awareness. Lack of awareness about CP in young people was perceived as common to the public in general, to medical trainees and practicing physicians (**Q 1.B.1-1** to **Q 1.B.1-3**). One PCPs who was already in practice for some time described his reaction to learning about CP prevalence in AYAs as being "very surprised", *"I've been told that chronic pain is just as common in children and young people as it is in adults. I was very surprised by that information…" - (P-9)*

(2) *Poorly defined role of primary care*. In general, PCPs were unclear on their potential role in transitional pain care and reported a mix of passive and active attitudes, perceiving themselves as external to the pain management process or desiring a direct involvement (**Q 1.B.2-1** to **Q 1.B.2-5**). Two juxtaposition views on the need for PCP involvement are exemplified in the next two quotes: *"I think the GP should stay involved, and then they keep a distance based on how involved they need to be" (P-11),* and that it is *"…good to let the pain service manage the pain, if they're applying their expertise and they're working with the patient actively, I would let them handle the case until they decide that situation has been stabilized and they send the patient back to me, and then I'll continue the management."* - *(P-6)*

Individual level

(1) *Stigma*. PCPs felt strongly about the stigma surrounding AYAs with CP. Many agreed that perception of such patients as difficult to follow, which may fuel unpredictable experiences during transitions to adult care. Additionally, PCPs acknowledged that the complexity of care was confounded by the vulnerability of young age, perceived lack of maturity and age-related impulsivity (**Q 1.C.1-1** to **Q 1.C.1-6**). One PCP eloquently described this as *"…nothing is settled. It's shifting sands in every way, within their personal life, their professional life, their studies, their love life, their whatever, their family relations, …So, I think they're much more vulnerable to screwing up."* - *(P-6)*

(2) *Young patients' experiences with adult system*. PCPs perceived the threshold of 18 years as an arbitrary cut-off point for transitioning to adult care. Despite acknowledging AYAs' special needs, PCPs considered waiting times for the young patients to be seen by pain services as being unacceptable and the overall pathway as poorly identified. PCPs reported trying to mitigate these issues by "*spinning*" reported experiences "*in a more positive light*" (P-11) (**Q 1.C.2-1** to **Q 1.C.2-7**) or letting AYAs to help themselves: *"I give them a referral and… they have to try multiple different centres…they're going to leave their request in every single hospital, and whichever one calls them back first is the one that they're going to take…" (P-11)*

Theme 2. How ideal pain services could involve PCPs to support transitional pain care

While discussing an *ideal* pain service to support transitions and a potential role of primary care in this process, PCPs described a service that would be smooth, well organized, and inclusive of primary care services. The sub-themes identified for the *Healthcare system* level and describing *ideal* pain transition services were: Accessible and available; Interdisciplinary or multidisciplinary; and Inclusive of primary care. At the local *Service* level, PCPs felt that an ideal service should be Convenient, and offer Training and educational opportunities. At the *Individual* (AYAs') level, PCPs recognized Patient's active and passive roles, suggesting for the pain services to adopt a Patient- and family-centered approach.

Healthcare System **level**

(1) *Accessible and available*. PCPs did not discuss any specific transition trajectory for young patients with CP but rather a perceived lack of such an option in general. They felt that ideally, their young patients should be seen quickly and would even benefit from the PCPs' visits to the pain clinics (**Q 2.A.1-1** to **Q 2.A.1-2**). PCPs did not discuss if AYAs' access to pain services should be prioritized relative to adults yet, PCPs referred to their overall experiences.

(2) *Interdisciplinary or multidisciplinary*. PCPs envisioned a supportive pain service as an interdisciplinary/multidisciplinary orchestrated collaborative effort of health care professionals from different disciplines working together to achieve a common patient-centred treatment goal. Additionally, such team would succinctly document their compiled assessment and share it with the involved PCP (**Q 2.A.2-1**). *"[S]o ideally you would have an MD…specialize[d] in pain, a psychologist related to pain, a physiotherapist available for the patients… maybe social workers, because there's probably a lot of psychology involved in pain… [as] multidisciplinary as possible"* stated one of the participants (P-10).

(3) *Inclusive of primary care*. PCPs expressed a strong desire to be included in the transition process and overall pain care of their young patients. They emphasized a need for a joint (specialist-PCP) assessment, continuous well-established communication, and comprehensive and concise documentation (**Q 2.A.3-3** to **Q 2.A.3-3**).

Service level

(1) *Convenient*. PCPs cited the ability to seek advice in proximity during opportune times as an important and desirable characteristic of ideal pain services which could support their work with patients **(Q 2.B.1-1).** One PCP gave an example of a real-life situation: *"Well, I don't know, I had a crazy man in my office, and I called [Dr. X] who agreed to talk with me right away… it was very, very accessible, she had lots of practical information about where or who might be able to help, and yeah, it was very good in that way." - (P-9)*

(2) *Training and educational opportunities*. PCPs emphasized the importance of training in CP management, especially in musculoskeletal disorders and narcotic prescribing, to be offered at all career stages. **(Q 2.B.2-1 to Q 2.B.2-4).** *"[Need] to have training in [pain] medicine for the students and for the primary care physicians that they become more informed about pain and musculoskeletal problems." (P-5)*

Individual level

(1) *Patient's active role*. When discussing a patient's role, PCPs agreed that young patients should become active partners in their care, working closely with their care providers, and being open and honest about any issue. AYAs with CP were regarded as experts in their conditions who could *"help do the job" (P-8)* searching for resources and information on-line. PCPs also felt a need to ensure patients' understanding and involvement in developing their treatment plans (**Q 2.C.1-1** to **Q 2.C.1-7**). One PCP felt that pain management starts with the AYA's engagement: *"The younger population also tends to come in having done some research, and they try to be the drivers of their pain management..." (P-8)*

(2) *Patient's passive role*. To avoid unneeded disruptions to the flow of the clinic or the ongoing treatment, reliability and adherence to the plan and service rules were also deemed necessary by PCPs (**Q 2.C.2-1**).

(3) *Patient- and family-centered approach*. In consideration of the specific AYA's needs, an ideal service would provide a comprehensive multidisciplinary needs assessment, keep patient's family involved (if desired) and help the patient to feel more in control of the situation, engaging him/her in the process (**Q 2.C.3-3** to **Q 2.C.3-3**)**,** *"I mean, it's much-much easier, you negotiate with the kid, and keep the parents and the kid as a unit if you can." (P-1)*

Theme 3. *PCP-proposed mitigation strategies*

To mitigate perceived issues with the transitional pain care provision, at the *Healthcare System* level, PCPs proposed several strategies. The sub-themes included the improvement of Inter-service coordination; Sharing of information; and suggested Adult services adopting some characteristics of paediatric care. At the *Environment* (service) level, PCPs felt that Primary care support; Pain specialists visits to primary care; Tour of the pain clinic(s), and designated Office hours with pain specialists for PCPs would facilitate transitional pain care. At the *Individual* level, PCPs suggested several strategies to make overall care more patient-centered.

Healthcare System level

(1) *Inter-service coordination*. PCPs felt most strongly about developing a pivot nurse position to help coordinate inter-service care for AYAs with CP, to be the first point of contact during emergencies, to direct to the relevant community-based resources, and facilitate communication between the patients and clinical teams (**Q 3.A.1-2** to **Q 3.A.1-2**): *"There has to be a pivot nurse managing these pain cases. I would like to see a pivot nurse for the communication with these patients." (P-5)*

(2) *Sharing of information*. PCPs felt that to ease referrals, inter-service communication, provision, and coordination of care between PCP and pain services, a common information/electronic platform is needed. Such resource would mitigate PCPs' difficulties in finding information on relevant pain services and resources. This could resemble the already existing platforms and have some characteristics of a shared electronic medical record system (**Q 3.A.2-4** to **Q 3.A.2-4**).

(3) *Adult services adopting characteristics of paediatric care*. To address AYAs' transition needs, PCPs suggested that adult care adopted some characteristics of paediatric care and implemented a standardized referral and transition processes across all related services (**Q 3.A.3-2** to **Q 3.A.3-2**). One of the participants compared characteristics of pediatric and adult services, suggesting that transitional pain services might need to have both: *"I've seen adolescence services and certainly paediatric services, and…they hold their hands more. I think it would be better… if the adult services were kinder and more nurturing to the adults… I think … that we're too harsh on some of the adults." - (P-9)*

Service level

(1) *Primary care support*. PCPs would feel more supported in providing care for AYAs with CP if they had easy and timely access to pain specialists via electronic consultations or designated office hours, over the phone or in-person. (**Q 3.B.1-1 to Q 3.B.1-2**): *"…[Dr. X]… she has…[office] hours where…physicians can just call in and discuss certain things or certain aspects… I have actually been able to send less patients … because I already have the answer to the question… or I'm given a few more things that I can try before I have to officially consult." (P-11)*

(2) *Pain specialist visits to primary care*. The current health care provision is highly hospital-centric, and PCPs discussed the advantage of having an "in-house" consultation service citing examples of other specialists (**Q 3.B.2-1** to **Q 3.B.2-2**) coming to meet the patient at his/her medical home: *"…so patients are familiar with our service, or familiar with our building, it's less of a shock when they come see a doctor in the same environment that they're in, and to have…a specialist in pain in our clinic, I find [it reflects]…positively for our patients, I feel like it helps them to navigate our system easier…"* - *(P-10)*

(3) *Tour of the pain clinic(s)*. On the other hand, PCPs also felt that they would be more informed to guide their patients after receiving a tour of the pain center that would explain how the clinic functions (**Q 3.B.3-1** to **Q 3.B.3-1**)

***Individual* level**

Patient-centered transitional pain care. To minimize treatment and care interruptions and avoid unnecessary emergency room visits, PCPs proposed to offer on-demand appointment slots, a direct "crisis line" with the pivot nurse, work on increasing awareness in the medical community of CP in AYAs and adopt some existing models of care (condition and self-management-focused) targeting young patients (**Q 3.C.1-1** to **Q 3.C.1-5**). Thus, one PCP said:*" The same thing, this should be a telephone line that one could call during the day, and really talk with his pivot nurse."* - *(P-3)*

Deliberative stakeholder consultations groups

Participant's demographics, age, gender, and level of clinical experience (**Table 5**) varied to achieve a roughly balanced representation of opinions. Recommendations by the DSCG participants according to the CAPHC guideline are presented in **Table 7.** Recommendations are discussed below denoted as (R-#) while applying the three-level transition framework.

***Individual* level**

Recommendation-1 (R-1): *Transition planning.* Transition planning was discussed by the Clinicians and AHP groups as it would be applicable to the post-transfer transitional pain care. The participants agreed that transition planning should include an orientation for the AYAs to the adult pain services prior to coming in, because pediatric and adult care models differ in their focus. Participants felt that the patient experiences could be improved through the implementation of a patient peer network. Thus, in pre-transfer phase, patients would undergo *"an orientation session [with] their parents where the whole process can be explained, and we're (pain service team) up front setting expectations about what this service is about, and then they have time to be thinking about it before their first appointment, and their roles can be clarified in that meeting…kind of concrete protocols or concrete steps that could be implemented at the system level to facilitate that transition"* (Earth, AHP**).** This orientation would also describe "*who are we (pain services team), what ... we do here, what type of treatments are here, and what kind of engagement we expect and anticipate in working with them*" (Rio, clinician). At or following the orientation, new patients could be paired with peer mentors who are "*patients [who] have had experience with the system*" (Earth, AHP) because "*they're in the service already, they know how it is*" (Paris, clinician).

R-2-3: *Integration facilitators.* The needs of AYAs during post-transfer integration period were discussed by Clinicians and P&S groups. Clinicians felt that there is a need for accommodation of the AYAs' vocational and working schedules, they also recommended establishing a telephone helpline that might deflect some urgent visits and answer simple questions without bringing a patient in and community services capacity building. In the same vein, the P&S group recommended to implement "drop-in hours" similar to walk-in clinics at the primary care service level, and develop a common information resource site, where AYAs and their families could educate themselves about non-pharmacological approaches to pain management. Clinicians and

P&S agreed that most patients were full-time university students who are "*...not necessarily willing, as much as [they] need[ed] to see the doctor, to skip a class or 2 or 3...*" (February, P&S). This resulted in some bitter dissension as reported by one of the supporters: *"...he's been told "well if you cancel this one, I don't know if and when I can make you another one". That's a horrible thing to say to someone who has chronic pain, because the doctor is their lifeline. It's not like he can just go see another doctor"* (February, P&S). Clinicians sympathized with the difficulties experienced by the youth suffering from CP, emphasizing that *"... it's even more important sometimes in this group of people who do have chronic pain, who miss a lot of school, who miss a lot of working opportunities, to give them the flexibility to have later evenings, or early mornings, that we promote that they don't miss school or don't miss work"* (Paris, clinician). Clinicians recognized the impact and the lack of alternative arrangements and the "*...inflexibility with clinic settings of this 8-4...We really do have to think of maintaining these young adults in their academic settings, having different flexible hours perhaps out of the conventional 8-4, 8-5, 9-5 setting*" (Rio, clinician), "*... accommodate[ing] kids either before school or preferably after school ... could be much better."* (Miami, clinician). In addition, AYAs alleged that obtaining a supporting documentation to have disability-related accommodations at school could also be difficult: *"I have to have accommodations at school so that I can keep up with the other students and sometimes just to get those kinds of letters and stuff can take months... if I have midterms, if I have finals in university, I need them right now. So ah, again because, well I'm not necessarily going to blame the secretaries but just because of that gap in communication, getting documents, simple documents and such becomes really, really tough."* (July, P&S)

AHP suggested that care should be inclusive of patients' views: "*I find that we're not including much of the patients in the discussions, it's about them right, and all the solutions, all the problems we're raising are at the system level. And I'm not bringing solutions, but I think there must be ways to get them more involved so that they're more engaged and they're missing less appointments, I don't know. I guess it comes back to the expectations comment I was making earlier*." (Earth, AHP)

Healthcare System level

R-4: *Teaching patients.* Clinicians and P&S groups discussed the need for education and support of AYA's engagement in pain management during the last stage of transitions. Participants emphasized strategies like patient activation and development of dedicated age-based tools and programs.

R-5: *Multidirectional communications.* The need for multidirectional communication strategies was one of the most contentious points of deliberative consultations. All participants agreed that the quality and flow of information need to be improved at all levels to ensure "safe, caring and effective transition".[50] The AHP group felt that communication strategies with PCPs could be improved by providing regular detailed clinical updates on the patient's progress to primary care. P&S group, on the other hand, found that the information flow from the pain clinicians to the PCPs was a crucial component of transitions, and recommended implementing web-based communication channels. All stakeholders agreed on the need for multimodal strategies such as the development of a common e-platform accessible to all stakeholders such as *"…an electronic sort of communications network that would house information that would be available to adult and pediatric. So I'm sitting in the office and [a] pain specialist is starting to say "Look, we've tried a couple of things, and you're going to be coming a few more times to see me and maybe my other nurse in the clinic or the psychologist, and I'm going to send a message on this platform" it may be a bit more patient friendly, as well. There might be a visual component that might be more interactive and say "These are my colleagues up in the Montreal General Hospital, I'm going to open up the screen here, and we're going to make an appointment with them to come and join us at your next visit. And you're going to meet one of them, it may be the nurse, it may be the doctor, it may be the psychologist from up there. They're going to start hearing a little bit about who you are."* (Rio, clinician) An e-platform would allow for clinical and non-clinical information exchange, would serve as an administrative tool to coordinate transitions, and would help PCPs in reaching pain team members via e-consultation modality while managing AYAs at the community level. This platform would also have specific functionalities for youth patients such as a virtual orientation and ability to contact their physician. Thus, the proposed e-platform could standardize the referral process by providing "*…a uniform referral protocol that may include a web-based referral form that obtains the essential information needed by the pain treatment clinic*" (Titan, AHP) and stores some general AYA's information that *"… you can have your medications, you can have your accommodations and also it can be accessible for your doctors so that again you can see the symptoms and you can see the issues… at that point then word of mouth wouldn't be as necessary as it is now."* (July, P&S) It was essential to our expert groups that the same e-platform was available for case discussions and expertise sharing across healthcare providers: *"…there's the hub experts of the pain clinic and then physicians, it's not limited to physicians, but allied healthcare professionals in the community as well logged through a web platform and they present cases every week and their recommendations that are being made, about your case if you're the one presenting it, but then you're learning about recommendations made to others."* (Earth, AHP)

R-6: *Primary care involvement.* There was a unanimous agreement with the same recommendation of involving PCPs to support transitional care coordination for AYAs with CP from all stakeholders. AHP expressed their desire for ongoing assistance from the PCPs. Clinician group felt that primary care services represent a "safety net" for AYAs in transition; and P&S recommended involvement of PCPs more as patients' allies and supporters who's trusted and understanding presence is a prerequisite for successful adaptation to adult services. PCPs, due to their scope of training and practice, might be helpful in handling clinical encounters with AYAs and their supporters: "*…they're different from older adults which requires different interviewing and management techniques. So, that's why I do what I do, I teach family medicine physicians how to deal with teenagers, because they're different. I can imagine someone like myself, someone like you, you're here already, coming in already and training the staff, this is how teens are different, you've got to manage them in such and such a manner."* (Titan, AHP)

R-9-10: *PCP's presence at the first appointment.* P&S were the only group recommending that PCPs attend AYAs' first encounter with an adult pain specialist to help understand their chronic condition, participate in the development of a treatment plan, and discuss strategies for pain self-management. Both groups, Clinicians and P&S, agreed that one of the strategies to educate AYAs about the imminent transition and prepare for the care transfer would be an early overlap in pain care with PCPs (clinicians) and with pediatric services (P&S).

R-13: *Pivot nurse position.* To monitor AYAs' attachment to primary care services, attendance at adult appointments, and ongoing communication between the patients and involved healthcare providers, all stakeholders recommended the development of a pivot nurse position. In fact, this was one of the most supported recommendations. Thus, clinicians felt that there should be a common point of contact for patients and PCPs requiring immediate assistance or advice, *"…I would prioritize at least getting like a resource person that people can call at all times, and even after hours, like one person per week with like a pager for example if it's like an emergency, and that person could sort of switch every week, like an on-call system. That's what I think I would prioritize in terms of a contact person."* (Montreal, clinician) P&S believed that the pivot nurse would help optimize care logistics by absorbing some of the physician's responsibilities, *"So, if ever there is a problem and you are suffering, you call the pivot nurse, the pivot nurse tells you "You know what? Come into the hospital, I'm going to squeeze you in right away", or "You need a referral for something, I'll write the referral", or "You need more medication, I'll give you more medication". All these sorts of things… [are] the root of the problem, is the fact that there is no person in the middle. We are the people in the middle, and it has to be someone else in the middle, not the patient."* (June, P&S) In addition, the pivot nurse could be *"…be devoted to communications between schools, between primary care…"* (February, P&S), *"communicate between primary care providers and… pain specialists"* (June, P&S) and *"be the go between"* professional. (Jupiter, AHP). The concept of advocacy on behalf of the patient was deemed as the *"… paramount because … unless you have that advocate or unless you can really advocate for yourself, not everyone has that makeup to really put themselves out there… A lot of people have emotional things that are attached to their physical things and cannot put themselves out there."* (February, P&S) Thus, one of the important roles of the pivot nurse would be responding to the patient's needs by facilitating communication with a care provider becoming *"… the liaison to the doctor. So, often patients will call us, they're not feeling well, they're not reacting well to this medication, you transmit the information to the doctor… So, the patient doesn't have to displace himself, come to the clinic, and it's all managed that way so, any concerns go through the nurse, right… [This] could be any liaison person, but is always there to do the intake, basically.*" (Toronto, clinician)

Resources.

Another sub-theme that emerged from the DSCG was scarcity of local resources. Thus, AHPs were concerned about staffing needed to provide additional specialist office hours for PCPs and increase in psychology services for AYAs. Clinicians mentioned that ideally, clinic's design should be more age friendly, but this would not be possible in the short-term. A similar feeling followed from the P&S group calling for more clinic hours to accommodate AYA's school and working schedules but wondering if this could be done.

Inter-/multi-disciplinarity.

It was felt that there might be a fundamental difference in how primary and specialty care are set up, thus affecting their collaboration and relation with the AYAs: "*I agree, at least I'll speak for my clinic, it's more multidisciplinary than interdisciplinary. I think it speaks perhaps with the philosophy of family physicians versus other physicians, where they're kind of cats versus dogs. Where I think it's hard to herd cats. It's not a hierarchical structure as it would be in a hospital setting. They're more like independent practitioners. So, the mentality continues within the group. And that's one of the reasons I love working where I work because I'm truly treated as an equal… And as a result, I find that we work very well because people are very well respected for their expertise. I think interdisciplinary care only works when there is a lot of respect for everybody. But it can be terrible for even the patient at the core of it, when there is true disrespect for the hierarchy and people are told what to do rather than respect them for what they can do. So that you have to be careful with.*" (Titan, AHP)

***Healthcare System* level.**

R-14-15: *Standardized transitional pain care.* Although no written policy for the provision of transitional pain care was discussed in relation to the post-transfer period, all stakeholders agreed that such transitional care should be standardized across the whole province. All group experts believed that the lack of such a system has led to significant disturbances in care transitions. This, the pain team reported receiving inconsistent and incomplete referral information, *"…when we get a primary care doctor who may be referring a young adult, and they have to use the standard Quebec chronic pain form. And the details there are grosso modo, they are just sort of ticked off, and so you don't have that sense of how solid they have been in terms of investigating"*, for example (Rio, clinician)

In addition to the development of an e-platform functionality helping multi-directional communications among the involved healthcare professionals and the patients at a clinical site, all stakeholders agreed that such functionality should be available across the provincial healthcare system to support collaborative communication among sectors. AHP felt that the difficulties experienced with the transition process could be curtailed with the implementation of a province-wide standardized transition and referral approach that would ensure *"that you always get a uniform base of knowledge in your referral"* (Titan, AHP). Similarly, patients recommended *"…a standardized transition system...Maybe a task force of different… doctors … who lay out their… 10 steps that need to happen when a patient aged 17 goes through for the next 12 months until they are kicked out and they start at the [adult] hospital… at age 18, there isn't then another 6 months of transition while you are waiting for this orientation and waiting to be connected with a doctor that is in charge of your case. … [this] standardized system … can be adopted no matter what hospital you are part of, no matter what your health issue is… To transition, you have to go through steps 1 through 10."* (February, P&S) Therefore, the standardized transition process would be supported by *"a common system of clinical information that transitions smoothly from primary to secondary to tertiary… a kind of communications pipeline where they will collect information from various GMF's, various tertiary centres, secondary centres, and they will provide an environment in which you can make a request for data, and as long as you've built your request correctly and the right people have signed off on it, you'll get your data."* (Venus, AHP)

R-17: *Training for medical and clerical staff.* Training was discussed by two stakeholder groups, AHP and P&S. The experts called for more training in adolescent medicine, for example, *"I think the medical practitioners in the adult hospitals need to be trained in terms of dealing with this age group because I went to a medical appointment with July, ah, and let me tell you something… I saw the medical practitioner talking to July, the medical practitioner thought he had a 50-year-old, or a 40-year-old in front of him. The moment I tried to intervene and advocate for July, I was shut down because the fact that she's obviously over 14."* (May, P&S) AHP give examples on how PCPs learn about AYAs' needs during their residency training: "*So, I was saying, so they're different from older adults who require different interviewing and management techniques. So, that's why I do what I do, I teach family medicine physicians how to deal with teenagers, because they're different. I can imagine someone like myself, someone like you, you're here already, coming in already and training the staff, this is how teens are different, you've got to manage them in such and such a manner."* (Titan, AHP) P&S echoed this feeling by describing their experiences with a health professional possibly needing training in adolescent medicine: "*the doctor that is* *attending to July had maybe the demeanor or lack of training in terms of interacting with patients this age so it's the experience, which speaks to my earlier point that maybe they require a little bit more training."* (May, P&S) This also led to the realization that pain care might be affected by the existing gaps in knowledge and pain-associated stigma: "*… doctors should be more trained in pain management… I feel like all the doctors I saw never treated me for pain, they kind of just treated me for maybe symptoms and things like that, and I feel like if maybe a course was offered or mandatory in university where doctors had to learn… so if doctors were taught that in school, maybe you wouldn't have to be thrown around all over the place … I just noticed that a lot of the older doctors seem to be more kind of against like, "Oh there's nothing wrong with you" or… and the younger doctors they try but maybe they don't have the knowledge that they need..."* (March, P&S) Another participant added that "*…there's going to be training in terms of dealing with this age group and … maybe some form of sub medical system that's involved to support them… February talks about advocating and having the available resources and time to do this…"* (May, P&S) The concerns about the lack of training were also pertaining to the non-physician staff of the pain center: **"***So, … they present a big part of the problem as well, the people up front, the secretaries, the people who are booking the appointments, handing off the referrals. Well it starts with the doctors, it ends with them and they do, if I can be brutally honest, a terrible job… So it presents a problem because the doctor never finds out and then you go to the doctor and you say to the doctor "I was begging for repeats and they only managed to squeeze me in a month after I needed the medication, what am I to do?" They have no idea. They have no idea.*" (June, P&S)

Summary of actionable recommendations

The DSCG resulted in deliberations of the literature, CAPHC guideline recommendations and PCP-proposed mitigation strategies. In total, 15 recommendations were made. The summary of actionable recommendation results is presented in the Venn diagram (**Figure 2**). The results converged to demonstrate that all three expert groups agreed on six recommendations: *Individual* level: i) Building of the youth capacity and orientation to the adult pain services; *Service* level*:* ii) Development of a pivot nurse position; iii) PCPs involvement; iv) Multidirectional communication strategies between all stakeholders; *Healthcare System* level v) Standardized transition process across the province, vi) Common e-platform to support all transitions. Recommendations supported by two of three stakeholder groups include *Individual* level: vii) Patient peer network; *Service* level*:* viii) Training in adolescent medicine for healthcare professionals; ix) Strategies on accommodation of individual AYA's needs; x) Overlap in care pre-transfer between specialists and PCPs / pediatric and adult providers; xi) Age-friendly clinic design; xii) Training in communication strategies for the clerical staff.

In addition, the AHP group recommended xiii) an increase in resources to provide specialist office hours for PCPs and psychology support for AYAs. Clinicians put more emphasis on xiv) the need for direct contact with PCPs via e-consults, telephone help line and receiving preliminary information on incoming AYA patients. P&S felt that xv) PCPs should directly participate in transitional care by attending AYAs' first adult appointment.

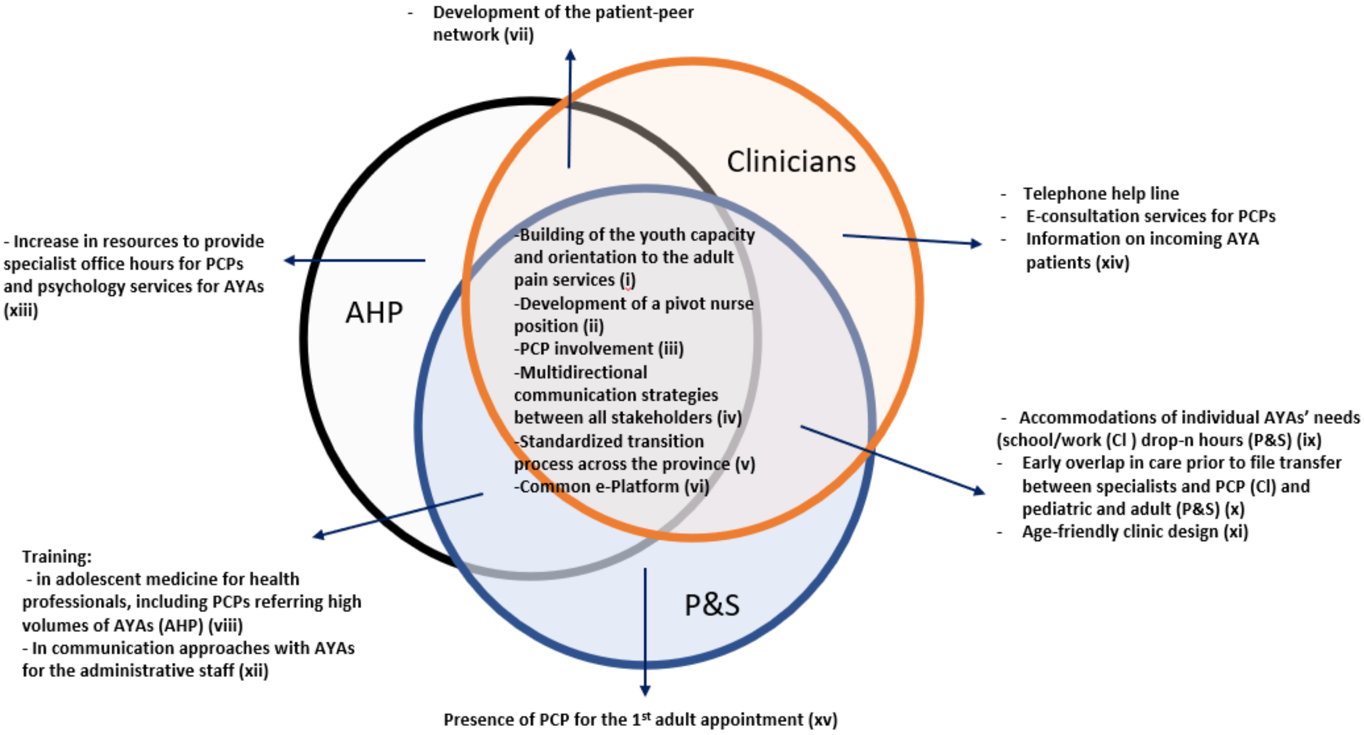

Figure 2. Venn diagram. Actionable recommendations.

(AHP – allied health professionals; P&S – patients and their supporters).

Discussion

We conducted a multi-site qualitative study and deliberative dialogue on transitional pain services for AYAs at the McGill University Healthcare Network in Quebec, Canada. The participants of DSCGs reviewed the literature, existing practices, collected patients' feedback and PCPs' semi-structured interviews data. The clinical research team chose to address several CAPHC recommendations (R-1-3,4-6,9,10,13-15,17) as pertinent to the post-transfer period. Transitions in pain care were acknowledged as complex longitudinal processes involving a significant number of stakeholders and therefore requiring a significant degree of coordination at different levels. The study resulted in 15 recommendations, of which many were concerned with the *Service* level variables.

Vision of a transitional pain care model

Our study resulted in a vision of a three-level post-transfer transitional pain care model as possessing several characteristics. At the *Healthcare System* level, all participants agreed that transitions in pain care must be part of a pan-provincial strategy relying on a set of criteria, like provincial guidelines. The harmonization of these complex multi-faceted processes must be streamlined by the addition of a common electronic tool such as a provincial e-platform. In fact, these were two of the five most discussed propositions reinforced by all stakeholders. Such process-harmonizing platform was envisioned as a multi-functional instrument allowing for the on-line data collection, storage and exchange, supporting and multi-directional communications for all transition stages. This modality should be accessible to all involved healthcare providers and patients across the province, thus eliminating communication gaps, a variety of errors, allowing for the analysis of empirical data and transitions quality improvement. In turn, such infrastructure would smoothen collaborative multi-disciplinary practices, decrease task redundancy, and medical waste.[62, 63] As an example, an already existing provincial on-line tool (Dossier santé Québec, DSQ)[64] securely stores laboratory and imaging results, and individual pharmacological histories; it is accessible to patients and care providers, and improves quality and efficiency of care provision.

At the *Service* level, transitional pain care model is envisioned as developmentally appropriate multi-/inter-disciplinary with an overlap of pediatric and adult services. It is inclusive of primary care in a way that PCPs become an integral part of transitions by directly participating in specialised care provision and providing continuity of care at the community level. Community-based pain care providers' immediate and long-term needs are supported via different strategies, ranging from training in adolescent and pain medicine, to common resources sharing and a spectrum of synchronous and asynchronous communication modalities. Communications are thought of as being of three types: concerning transitional care and treatments plans, information sharing and guidance for AYA patients, and inter-provider exchanges. Thus, transitional services must employ multi-directional communication strategies locally, regionally, and liaise closely with the AYAs and community. The most important role, therefore, was assigned to a transitional pivot nurse, who would be tasked working directly with all stakeholders. A pivot nurse position was by far the most discussed recommendation, advocated for by all participants. In addition, transitional pain services should possess sufficient flexibility to accommodate multiple emerging needs of their clientele, related to AYAs' personal, educational, and vocational transitions. An integral part of this model appears to be an appropriate training for the clinical and clerical staff as well as the development of suitable transition clinic designs.

At the *Individual* level, transitional pain services must facilitate post-transfer period by enhancing AYAs' capacity to navigate adult care. They must prepare AYAs for a change in care model and offer patient-oriented tools, supply ample information related to services and specific medical diagnosis, and orient to adult and community services. Orientation to adult services and capacity building was the most discussed *Individual* level strategy supported by all stakeholders. Development of a peer network was also envisioned as a part of the transitional pain care services model.

Weighing on concordant and differing views

Although suggestions to standardize transition processes are not new, a scaling up of transitional pain model to the provincial level, practices harmonization and support by a dedicated provincial e-platform, indeed, represents a very progressive vision for the future that were delivered by the stakeholders and not sufficiently discussed in the literature. This could be facilitated by the introduction of innovative approaches such as e-consults,[65] e-platforms, and tele-medicine thus, bringing care closer to patient medical home.

There was a partial overlap of recommendations on a type of service that could be termed as "transition clinics". Clinicians recommended an early overlap in care that should happen prior to the transfer and involve specialists and PCPs. P&S on the other hand, recommended a mix of pediatric and adult specialties with PCPs attending the 1st AYA appointment with an adult care provider. Together, the stakeholders described multi-/inter-disciplinary services that would follow patients of 16 to 25 years of age. The evidence on the effectiveness and composition of multi- and inter-disciplinary transition clinics remains insufficient[66] as there is no established set of outcomes or funding policies. Nonetheless, Canadian rheumatology transition clinics might serve as an interesting example for the future model in pain care. They operate using a written transition policy, shared pre- and post-transfer responsibility for care, and are supported by a transition coordinator and the use of different transition tools.[67]

All stakeholders discussed a potential role of PCPs in transitional pain care. The interviewed PCPs had the outmost difficulty defining the extend of their potential involvement that was described as ranging from passively receiving information from the pain services to actively collaborating in the AYA care, accessing patients' charts, and visiting pain center facilities. P&S group participants expressed their desire to see PCPs being involved in their first appointments with adult practitioners, and AHP group felt that all care providers would benefit from direct contact and closer collaboration with PCPs. Clinicians described that PCPs should be involved longitudinally, representing a "safety net" for AYAs patients should they need other psycho-social and medical needs to be addressed. Different views on potential roles for PCPs discussed during the study are not surprizing as existing transitional models[68] rarely include family medicine and community services as part of the process. There remains a significant gap in transitional knowledge and research [42, 69] on the primary care involvement in transitions. The CPS/CFPC guidelines[70] however, suggest that PCPs should "be integrated into existing specialty clinical settings" becoming an essential part of these teams. CAPHC[50] and NICE[71] guidelines also emphasize the inclusion of family physicians at all stages of transition process to ensure continuity of transitional care. However, involving a PCP in all specialty transition teams may be unfeasible, particularly without a clearly defined role and additional training. Furthermore, in Montreal, access to primary care remains very limited,[72] with 30-40% of population having no registration with a family physician. Thus, a type of multi-disciplinary intermediate level transitional care clinic, where trained PCPs work alongside several specialists from complementary services might be a potential solution. In Quebec, there is a network of local community service centres (*centre local de services* *communautaires*) already providing chronic disease programs and following populations of all ages, collaborating with family medicine groups as part of the patient medical home model.

Healthcare providers shared patients' concerns on the cost of drugs and services such as physiotherapy. It was felt that gaining access to hospital-based insured services was essential for the young patients. This finding is not surprising, given that the insurance coverage under conventional plans is more challenging for young Canadians and the "working poor" (annual income $30 000 or less).[73] In addition, the odds of borrowing are higher among AYAs without prescription drug insurance and people suffering from several chronic conditions[74] – all the known risk factors for this population. Health Canada describes present situation as "… a confusing patchwork of over 100 public prescription drug plans and over 100,000 private plans... [When] approximately 20 per cent of Canadians have inadequate drug coverage or no coverage at all".[75] Today hospital-centric resource distribution resulted in hospital-based care provision models when medications, procedures, and some services could be accessed via pain centres or emergency rooms only. This results in a negative downstream consequence of inability of the primary care groups to provide sufficient support to their patients in the community. A recently published Canadian Pain Task Force report discusses similar issues across all Canadian provinces, urging "federal, provincial, and territorial governments to discuss how best to develop and implement innovative person-centred care pathways (such as … transitional pain services) to improve early access to pain assessment, treatment, and management… enable[ing] models that cross provincial boundaries…".[6]

The sub-theme of hospital-centric resource distribution is well-supported by the literature on the "siloed" budget allocation practices allowing for little development and flexibility in delivering enhanced outpatient care.[76] This is compounded by the fragmented structure of the Canadian health care system that is "composed largely of community hospitals and self-employed physicians"[77] frequently remunerated via a fee-for-service (FFS) model, which in turn disincentivizes patient-centred care and increases task redundancy.[62, 63] Indeed, the task redundancy was a significant irritant for the PCPs discussed during interviews. Unsurprisingly, all three stakeholder groups' recommendations converged on prioritizing a standardized transitional care approach across the province to streamline transitions. Considering the above, PCPs' desire to be better supported by the hospital-based and comparatively resource-rich pain services becomes more understandable.

Concerns about the inadequate access to pain services and long waiting times for appointments are well supported in the literature. In fact, persons with rheumatic conditions on average, wait six months to be seen in a multidisciplinary pain facility in Quebec.[78] Thus, most stakeholders' vision was the optimization of transitional care delivery close to patient medical home[46, 47] by enhancing interprofessional collaborations and optimizing resource allocation and sharing. In our study, one of the mitigation strategies proposed by the PCPs was having specialists to visit primary care units. Furthermore, all stakeholders agreed with the guidelines[50] on the crucial role of a pivot nurse as a case coordinator to liaise with various services and support multidisciplinary care provision. It remained unclear however, if the pivot nurse position should be located at the primary or tertiary care level, but the need for this position appeared indisputable.

To optimize the care for AYAs at the community level, an ongoing training in pain and adolescent medicine made another strong recommendation supported by P&S and AHP. Interestingly, Clinician group did not deliberate on the clinical training despite this being one of the mitigation strategies advised by the PCPs. As complexity and specifics of AYA care "do not really fit" pediatric or adult medical services concepts, the stigma of unreliability and unpredictability surrounding this population was extensively discussed by many stakeholders. The recommendation on such training is in line with the literature showing that post-graduate education in chronic pain, narcotic analgesic prescribing, and adolescent medicine could be insufficient or even absent.[79, 80] The extension of this recommendation however, also pertained to the clinic clerical staff communication style, thus pointing at the important role all team members play in the perception of quality of provided care. Importantly, it should be realized that the pain-related stigma in AYAs could be afflicted not only by the peers and healthcare professionals but by the family members of the affected youths.[81]

PCPs had several suggestions on how AYAs needs should be met by the translational care providers. Thus, mitigation strategies encompassed several additions to already existing services and included crisis management options (on-demand appointment slots, telephone crisis line with a nurse) and educational therapeutic approaches (condition-specific programs, psycho-social coping skills groups). The transitional pain services would be expected to adopt some characteristics of pediatric services to respond in a more age and development-appropriate manner. Both, Clinicians and P&S groups, agreed that drop-in hours to accommodate AYAs' school and work schedules are needed. Both groups' recommendations also converged on the need to make clinic's design more age friendly. AHP recommended an increase in specialist office hours and increase in psychology services for AYAs. These strategies are well-supported by the guidelines and other literature aiming to arm AYAs with more tools to navigate multiple simultaneous life and health transitions and enhancing self-management skills.

One of the most important factors making any transition successful is, of course, is the AYAs' capacity to navigate adult care. An almost a decade-long period, from 16-18 to 25 years of age, is a long time that falls in the post-transfer transition stage. Young patients continue developing their executive decision-making skills while being already exposed to adult healthcare and other life complexities.[27] The challenges of this age were well-recognized by all stakeholders, including patients themselves. Gradually emerging adult identity[28, 82, 83] and autonomy acquisition[84] occur in a period associated with an increased likelihood of suicidality and new psychiatric diagnoses,[17, 19] high-risk behaviours, substance use,[20-22]unplanned pregnancies, inter-partner violence and sexually transmitted infections.[23, 85] This vulnerability might be compounded by poor eating habits[86] and sedentary lifestyles.[87] In chronic pain, many of these factors become important predictors of disability and poor functional status.[88-92] Acknowledging these characteristics of the AYA population, all stakeholders recommended that a transitional pain service must help orienting the incoming AYA patients to its structure and function, and, most importantly, contribute to the youth capacity building and growth.

Two other recommendations that received the most attention pertained to the training and peer mentoring programs. Peer mentoring recommendation is well supported by the literature in chronic pain[93-95] and existing guidelines. This modality is advised for most health care transitions.

Strengths and limitations

To our knowledge, this study was the first one to explore and formulate a vision for a post-transfer out-patient transitional care model for AYAs living with chronic pain. This study has several strengths, namely, its sequential consensual design that allowed our team to reach to a very heterogeneous group of stakeholders, encompassing various experiences. It contributed to the scarce literature on transition in pain and especially to its last stage of AYAs' integration to adult services. We contributed to the use of contextual pain specific variables pertaining to the three domains on the adopted HCTRC model. This design along its participatory component strengthened study findings generalizability and utility to influence existing service policies at the institutional level. The sample size[56] of 12 semi-structured interviews with PCPs was considered sufficient as data adequacy (information to answer research questions) and lack of the emergence of new data (saturation) were achieved at this point. Using random purposive sample technique,[54] we attempted to balance participant samples for the PCP interviews and deliberative stakeholder groups in terms of years in practice for professionals, language spoken, participants' sex and age, and thus considered our sample adequate. Another strength of this study is the multidisciplinary team diversity representing three provincial academic institutions, and PCP from a variety of practices and backgrounds, including one working outside of the Montreal metropolitan area.

Our findings were limited by the inclusion of care providers from the McGill University Healthcare Network. However, due to increased external validity, our approach and results could be relevant to other settings with fragmented transitional pain care for AYAs. We employed a single interview and a single deliberative group approach, which likely led to some loss of secondary information or ideas. Nonetheless, we consider such loss minimal as our approach was reiterative between the phases, and all participants were given an opportunity to send more feedback and contact us any time later. Given our findings were supported by the literature and validated by patient-partners, this approach was considered sufficient to identify the areas where action is the most needed.

Impact on clinical practices and Conclusion

Transitions for young patients with chronic pain remains a logistically challenging and poorly structured process, mostly guided by the pediatric and adult specialty services from the academic centers. There is a fragmented involvement of primary care, albeit a significant desire to have the involvement of PCPs in transitional care models to be better defined and formalized. We explored PCPs' perceptions about their potential role in multi-disciplinary transitional pain care services for AYAs within the McGill University Healthcare Network. A representative group of stakeholders formulated a set of 15 actional recommendations regarding the optimization of transitional pain care provision. A vision for a transitional pain care model was presented based on these recommendations. The need for a multi- or inter-disciplinary transitional pain service seemed important to all stakeholders. Study findings were communicated to all study participants, their clinical sites, involved institutions and presented at the regional, provincial, and Canadian conferences. Several pan-provincial changes are presently being implemented, including tele-medicine, e-consult, discussion on provincial e-Platform. Locally, changes in the triage and discharge systems for AYAs with CP have been made.

Future directions

Future directions include more research in Canadian context on transitions, chronic pain and role of primary care, and specifically on post-transfer transitional service provision development. We also found almost no literature on the transition outcome measures, which therefore were not included in this study. The development and implementation of standardized evidence-based transitional pain pathways will benefit all AYAs with CP entering adult care. There is a need for the further development of the proposed conceptual model encompassing multidimensional longitudinal nature of transitions in pain care that would assume a non-categorical approach and focus on adopted HCTRC theoretical domains. We believe that researchers and decision-makers should explore this subject by testing context-mediating variables in the larger scale studies and their associations with successful outcomes to develop funding models and optimally structured transitional services in chronic pain care.

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APPENDIX 1

MANUSCRIPT TABLES and FIGURES.

Table 1. Multidisciplinary clinical / research team and patient-partners.

Level of care	Position	Number of persons
Primary care	Clinical Director	1
	Medical residents	3
	Researcher-methodologist	1
	Clinician	1
Tertiary care	Clinical Director	1
	Clinical psychologist	1
	Social worker	1
	Administrative Director	1
	Physiotherapist	1
	Nurse	1
Patient-partners	Patient-partners	2(-3)
	Supporter	1

Table 2. Simplified HCTRC healthcare transition model.

Individual domain
Demographic characteristics and socio-economic status Impairment: Disease complexity and course Developmental competencies/functional capabilities Personality processes Participation Self-Management: Disease/condition related Self-Management Health-related Self-advocacy
Family/social support domain
Level of family support Social support
Environment domain
Secondary and postsecondary education system Community services and support Health policy and legal system
Health care system domain
Pediatric system of care Adult-focused health care system characteristics Access to adult health insurance plan Patient-provider relationship Health care payment/reimbursement structures/models

Table 3. CAPHC guideline summary of recommendations.

(*Individual*) **Person-centered level**	
1.	Transition **planning** is youth-focused and family-centred, inclusive of personal choice and is adaptable to the abilities and complexities of the youth's needs.
2.	Transition of youth and their families address the youth's physical, developmental, psychosocial, mental health, educational, lifestyle, cultural and financial **needs**
(Service) **Environmental level**	
3.	Transition for youth is supported by individualized planning in the paediatric and community settings, a **coordinated transfer of care** and secure attachment to adult services.
4.	**Healthcare providers engage**, educate and build capacity of youth and their families regarding transition.
5.	Collaborative respectful **communication** between stakeholders (youth, families, their natural networks, community, paediatric, primary and adult care provider(s)) supports the flow of information and ensures safe, caring and effective transition.
6.	All youth have a **primary care provider** support care coordination.
7.	A developmentally appropriate **individualized transition plan** is prepared and documented in collaboration with the youth and family.
8.	Paediatric and primary providers assess the **youth's readiness** for adult care, identifying **gaps in skills** and knowledge requiring intervention.
9.	**Healthcare providers and family members support** youth at their appropriate developmental level to understand their chronic condition, treatment plan, and level of self-management
10.	Care providers **educate the youth and family about transfer of care, at least one year prior to transfer**, encouraging them to share in the responsibility of accessing community and adult services, and if needed, provide additional navigational support
11.	Priority for care coordination is given to **youth with complex needs** and their families
12.	Each transferring program is responsible to provide a **comprehensive health summary** at the time of referral, **to the adult health care provider(s), primary care provider(s), youth** and family.

13.	Transfer of care to adult services includes **monitoring of youth's attachment to adult services, attendance at adult appointments** in an expected timeframe, ongoing **communication** between paediatric, primary and adult providers, and shared responsibility for management of youth with lapses in care.
	(Health care) **System level**
14.	All services have a **written policy** for the provision of transition.
15.	Develop efficient and accredited **health information systems to support transfer of information and collaborative communication** among sectors.
16.	**Organizations** designate **transition champions** within their paediatric and adult settings to facilitate and evaluate transition.
17.	**Organizations** provide ongoing **transition education, training, and knowledge translation** for all Stakeholders.
18.	Researchers and clinicians develop a method for **consistent data collection** at an individual and systems level, including qualitative narratives of lived experiences and quantitative data, to be used by clinical teams, decision makers and researchers for quality improvement and evidence-based practices.
19.	Involve youth, young adults and families, policy and decision makers, administrators, researchers, and government agencies, to jointly identify system barriers, system enablers and future development opportunities for the responsible transitioning of youth.

Table 4. Demographic and practice profiles of interviewed PCPs.

Participant	Alias	Interview type	Language of interview	Sex*	Age (years)*	Years in practice*	Practice	Academic- or community-based
P-1	Dr. Lily	In-person	ENG	F	61	35	Obstetrics / maternal health	Academic community / hospital-based
P-2	Dr. Ezekiel	Online	ENG	M	44	18	Emergency / general practice	Academic, community-based
P-3	Dr. Vin	Online	FR	M	45	19	Emergency room	Academic hospital
P-4	Dr. B	Online	ENG	M	40	15	General practice	Community-based
P-5	Dr. Kefas	In-person	FR	M	55	25	General practice / pain practice	Community-based
P-6	Dr. Office	In-person	ENG	F	36	35	General practice / pain practice	Hospital / community-based
P-7	Dr. One	Online	ENG	M	57	32	General practice	Academic, community-based
P-8	Dr. MDZERO	Online	ENG	M	42	10	General practice	Community-based
P-9	Dr. Diego	Online	ENG	F	70	45	General practice	Academic, community-based
P-10	Dr. Alessandra	Online	ENG	F	29	3	General practice	Academic, community-based
P-11	Dr. Water Bottle	In-person	ENG	M	42	16	General practice /Sports Medicine	Community-based
P-12	Dr. T	Online	FR/ENG	F	-	3	General practice	Academic, community-based

Note: **Reported, not verified.* Language of the interview was either English (ENG) or French (FR). Sex was either male (M) or female (F)

Table 5: Deliberative stakeholder consultation groups composition.

Group	**Care level**	**Stakeholders**	**Number of participants**
Clinicians	Primary care	Nurses	2
		Medical Residents	3
	Tertiary care	Nurses	1
		Physician, clinical service director	1
Allied health professionals (AHP) **One AHP was unable to participate*	Primary care	Clinical psychologist	1
		Clinician-researcher (public health)	1
	Tertiary care	Social worker	1
		Physiotherapist	1
		Clinical psychologist	1
		Administrative director	1
Youths & supporters **One patient was unable to participate*	--	Supporters	2
		Youths	4

Table 6. Themes and selected citations. Semi-structured interviews with PCPs

Theme 1: **Limitations of the healthcare system as reported by PCPs**	**Theme 2:** **Ideal pain service to support transitions and role of primary care**	**Theme 3:** **PCP-proposed mitigation strategies**
A. HEALTHCARE SYSTEM		

1.A.1 Hospital-centred care provision: Access to publicly covered services outside of the hospital system is significantly limited. • Consulting to obtain publicly-covered services. **Q 1.A.1-1** "… *maybe they can get physiotherapy more easily, maybe they can get psychological interventions that are specific for chronic pain*…" - Dr. Diego **Q 1.A.1-2** "*[A]lmost all of my pain patients… they… have lost their jobs, or they're not working, so almost none of them have insurance to pay for outside physical therapies, be it physio, osteo, or any of the physiatry procedures*." – Dr. Lily • Limited access to pain services. **Q 1.A.1-3** "*When you get here, the demand is so great at the MUHC*, it takes ages to get anybody in*." – Dr. Lily *McGill University Health Centre **Q 1.A.1-4** "*[I]t takes so long to get people into a pain clinic*." – Dr. B **1.A.2 Fragmented information flow:** PCPs expect concise and regular updates. • Insufficient information received from the pain services.	**2.A.1 Accessible and available**: "the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use healthcare services and to actually have a need for services fulfilled" [78] **Q 2.A.1-1** *"… the ideal service [is] one that [a PCP] could communicate with easily and maybe even visit at the time my patient is there. So, if they were close to where I'm practicing."* - Dr. One • Young patients should be seen quickly. **Q 2.A.1-2** *"…within two months, they would be assessed by the pain specialists, by the social workers, by the psychologist."* – Dr. Ezekiel **2.A.2 Interdisciplinary or multidisciplinary:** An orchestrated collaborative effort by healthcare professionals from different disciplines aimed to achieve a common patient-centred treatment outcome. • Multidisciplinary or interdisciplinary. **Q 2.A.2-1** *"[S]o ideally you would have an MD…specialize[d] in pain, a psychologist related to pain, a physiotherapist available for the*	**3.A.1 Inter-service coordination:** There is a need to inter-connect pain service(s), primary care and the patient. • Pivot nurse: A nurse with knowledge of patients to coordinate care. **Q 3.A.1-1** « *Une infirmière pivot en gestion de la douleur pourrait aider dans la gestion de ces cas. (J'aimerais) une infirmière pivot pour la communication avec ces patients.* » - Dr. Kefas <u>ENG</u>: "There has to be a pivot nurse managing these pain cases. I would like to see a pivot nurse for the communication with these patients." **Q 3.A.1-2** « *…ça devrait être une ligne téléphonique qui peut appeler durant la journée, être capable de parler vraiment à leur infirmière pivot.* » - Dr. Vin <u>ENG</u>: "There should be a telephone line that one could call during the day to talk to their pivot nurse."

Q 1.A.2-1 « (Je) ne reçois pas des communications, ou rarement des communications. » - Dr. Kefas **Q 1.A.2-2** “*…the other thing that is disappointing is that we don't get follow-up reports, so you just get the initial consultation and it's hard to kind or get the follow-ups of the multiple visits that the patient has.*” - Dr. Alessandra **Q 1.A.2-3** “*… I just need to know the patient was seen, we're in the process trying to figure out what he's got, our differential diagnosis is 1-2-3, we are going to see them again and we will write to you once we have a better idea of what's going on.*” – Dr. One • Insufficient information received from the patient. **Q 1.A.2-4** « *...j'aimerais ça que mon patient me revienne et il me dise "écoutez j'ai vu un médecin en douleur, voici les traitements, voire ce qu'on m'offre*. » - Dr. Vin ENG: “I would like that my patient would come and tell me ‘look, I saw a pain doctor, here is the list of treatments, this is what he offers to me’.” • Incongruency of information between the patient and the pain service.	*patients… maybe social workers, because there's probably a lot of psychology involved in pain… [as] multidisciplinary as possible.”*- Dr. Alessandra **2.A.3 Inclusive of primary care**: In assessments and ongoing communication • Common inclusive plan. **Q 2.A.3-1** *“But I think we could make a more cohesive plan and manage the situation better with the patient, if we all did our assessment together.”* – Dr. Office Established ongoing communication loop that includes PCPs. **Q 2.A.3-2** *“I sometimes wish communication was a little bit better with the pain clinic. Just to get updates, and not just an initial assessment, but to get ongoing communication as to how patients are doing.”* – Dr. B • Comprehensive and concise documentation. **Q 2.A.3-3** *“I mean, [the pain service is] multidisciplinary but it's a single service, so I would still like to get one report. It starts to get*	**3.A.2 Sharing of information:** Between PCP and pain services to ease referrals, provision and coordination of care. • A shared electronic medical record (EMR) system. **Q 3.A.2-1** *“I mean ideally if we all had the exact same EMR* service and we were all linked in the exact same dossier, or have a way to go from one dossier to another seamlessly, that would really open up the communication… from physician to physician.”* – Dr. Diego • Resource with information on relevant services. **Q 3.A.2-2** *“...a website with resources for family doctors to give [to] patients”* - Dr. Lily **Q 3.A.2-3** *“There should be a site or something that gives us the adequate [information on the services]- because sending stuff, it doesn’t go through the CRDS*, so you have to know where you’re sending them.”* – Dr. Lily

Q 1.A.2-5 “*He says [the consultant] never commented. He says to me all the time “She’s not like you. She doesn’t bug me about my eating habits and my exercise habit”. I said “Really!” “She never mentions them”. Do I believe him? No. So, people hear what they want to hear*.” – Dr. Office **1.A.3 Care logistics**: Commonly encountered issues. - Lack of knowledge on existing resources. **Q 1.A.3-1** “*I mean like, it's not clear to me how I should go and look for what [pain service] might have been established…*”- Dr. Diego **Q 1.A.3-2** *“[one] can only become aware through personal connections, you know…nobody advertises pain clinics.”* - Dr. Water Bottle - Task redundancy. **Q 1.A.3-3** “*If I’m referring a patient, and I do this all the time, … in a timely fashion provide all of the documentation, the tests that have been done, [if documents are lost] I shouldn’t have to do it twice.*” – Dr. Lily	*heavy when you have to remember…the names of these people, and who’s doing … but if you get that all in a report, you know that your patient was seen by our physiotherapist, this was done, progress is going well, the patient was seen by a psychologist, this is what needs to be worked on, the pain, you know, specialist anesthesiologist has seen your patient, they think that they would benefit from injections, et cetera, just a summary of what's happening.”* - Dr. MDZERO	**Q 3.A.2-4** *“…If they had a CRDS* system for… the 10 chronic pain centres that are on the island of Montreal… it would be so much simpler, you know?”* – Dr. Water Bottle * FR: Centre de répartition des demandes de service (ENG: A regional distribution center of consultation requests from PCPs to specialists) **3.A.3.** Adult services adopting characteristics of paediatric care. **Q 3.A.3-1** *“I've seen adolescence services and certainly paediatric services, and…they hold their hands more. I think it would be better… if the adult services were kinder and more nurturing to the adults. I think that some of the things that go on in pediatrics would be a good thing to do in adults. It doesn't mean we should mother them and not let them decide anything, but I think that some of the things that are done, that we're too harsh on some of the adults.”* - Dr. Diego

		- Standardized referral and transfer process across related services. **Q 3.A.3-2** *"…one referral could be used with all the centres…"* – Dr. Water Bottle
B. **ENVIRONMENT.**		

Theme 1: **Limitations of the healthcare system as reported by PCPs**	**Theme 2:** **Ideal pain service to support transition and primary care**	**Theme 3:** **PCP-proposed mitigation strategies**
1.B.1 Lack of training in pain medicine and AYAs healthcare needs: • Lack of training affects PCPs’ understanding of the significance of chronic pain in young patients. **Q 1.B.1-1** *“I think a lot of physicians or people in general need more education that… young people can suffer from chronic pain, and …it should be taken more seriously, and that the signs and symptoms should be, by the medical community … appreciated more… I think people need better education and awareness that this problem can also exist in this population, and to not just be, oh, you're young, you'll get over it.”* - Dr. Water Bottle **Q 1.B.1-2** *“I've been told that chronic pain is just as common in children and young people as it is in adults. I was very surprised by that information…”* - Dr. Diego **Q 1.B.1-3** *« Pour (moi), mon sentiment est que comme étudiant de médecine on n’est pas bien formé dans la*	**2.B.1 Convenience:** Ability to seek advice in proximity. **Q 2.B.1-1** *“Well, I don't know, I had a crazy man in my office and I called [Dr. X] who agreed to talk with me right away… it was very, very accessible, she had lots of practical information about where or who might be able to help, and yeah, it was very good in that way.”* – Dr Diego • **2.B.2 Training and educational opportunities:** Perceived as important at all career stages. **Q 2.B.2-1** *« …avoir de l’enseignement en médecine [de douleur] pour les étudiants, que les médecins de famille soient la première ligne, qu’ils soient plus informés dans la douleur et dans les problèmes musculosquelettiques »* - Dr. Kefas ENG : “[Need] to have training in [pain] medicine for the students and for the primary care physicians that they become more informed about pain and musculoskeletal problems.”	**3.B.1 Primary care support:** Easy and timely. **Q 3.B.1-1** *“I would like to see something like, they have in Ontario, where you could send an e-consult and get back some preliminary advice even before they see the patient”* - Dr. One • Office hours with pain specialist for PCPs. **Q 3.B.1-2** *“I know for example [Dr. X] at the CHUM, she has…[office] hours where…physicians can just call in and discuss certain things or certain aspects, whether it's their patient or not, um, which is, sometimes you just need a little bit of advice, um, that's really, that's a very helpful thing, and I have actually, in some of those cases, I have actually been able to send less patients to their centre because I already have the answer to the question*

douleur chronique et les problèmes musculosquelettique. » - Dr. Kefas ENG: « For me, my feeling is that as medical students, we were not well trained in chronic pain and musculoskeletal issues.” **1.B.2 Poorly defined role of primary care**: There is a mix of passive and active attitudes from PCPs. • Staying involved but keeping a distance. **Q 1.B.2-1** *“I think the GP should stay involved, and then they keep a distance based on how involved they need to be.”* - Dr. Water Bottle **Q 1.B.2-2** “*...I just feel like adding more information [for the pain team] sometimes is a bit of information overload, and… as a physician we have plans in our head if one thing doesn't work we already have a plan of what we're going to do next, so instead of…messing with someone else's plan… I do take a step back…unless I feel like they're not adequately being followed by the pain clinic…*” – Dr. Alessandra • External to the process. **Q 1.B.2-3** *“...good to let the pain service manage the pain, if they’re applying their expertise and they’re working with the patient actively, I would let them*	**Q 2.B.2-2** *« Ça serait très important d’informer, d’enseigner aux médecins de famille qui ne sont pas formés pour les douleurs musculosquelettiques très tôt dans leur enseignement.* » - Dr. Kefas ENG: “It would be very important to inform, to teach family physicians who are not trained in musculoskeletal pain, very early in their education” **Q 2.B.2-3** *“...sometimes I just need a little bit of direction from them, you know, … either to clarify the diagnosis, or to give an algorithm of treatment that could be attempted, and…if it's not some sort of unusual type of procedure or injection that they're going to do…I can order those things outside… I can follow a lot of those things before I would send [the patient] back.”* - Dr. Water Bottle **Q 2.B.2-4** *“I'm glad that I have help from my chronic pain colleagues, because in the past I was using too much narcotics and they showed me how to avoid that trap.”* – Dr. One	*that I need, or I'm given a few more things that I can try before I have to officially consult.”* – Dr. Water Bottle **3.B.2 Pain specialist visits to primary care:** Care provision in proximity to the patient (patient medical home [18, 37]). **Q 3.B.2-1** *“…it's always nice to have someone in our clinic…so patients are familiar with our service, or familiar with our building, it's less of a shock when they come see a doctor in the same environment that they're in, and to have…a specialist in pain in our clinic, I find [it reflects]…positively for our patient, I feel like it helps them to navigate our system easier if there's someone available… next door to our office, which is, you know, better for them, it's harder to kind of find doctors in the hospital and know where to go.”* - Dr. Alessandra **Q 3.B.2-2** *“… why couldn't the pain specialist come to my office? I know it's crazy but, I like the idea that I like what we are doing with psychiatry, I like the idea of having this guy who spent a year with us.*

handle the case until they decide that situation has been stabilized and they send the patient back to me, and then I’ll continue the management.” - Dr. Office • Difficulty getting involved or to become a part of the process. **Q 1.B.2-4** *“I send notes with the patient, you say “I understand that you’re doing this and this and this with this patient, would you just give me a quick update on the current situation?” And I’ve had specialists say to the patient “Tell Dr. B I don’t have time for this”. Or they’ll scribble one word on the back of my note and send it back to me. It’s quite outrageous how bad communication is between some specialists and [family] doctors.”* - Dr. B **Q 1.B.2-5** *“I usually will go out of my way to go look up on Oasis and see what’s been going on and try and review the notes and see if there’s a prescription on the file…so I try to sort of review everything and go through things myself.”* – Dr. B • **1.B.3 PCPs adopting to existing limitations:** Compensating by moderating their expectations. **Q 1.B.3-1** *“…what I do is I try to look for things on the internet and stuff like that…”* – Dr. Lily		*He would come into my room and would show me things about my patient that I hadn't appreciated. If we live in an ideal world, sometimes it's better for the pain specialist to come to my office.”* – Dr. One **3.B.3 Tour of the pain clinic (s):** To understand everyone’s roles. **Q 3.B.3-1** *“[A] meeting ahead of time so that you actually get a tour of the pain centre and you see what they’re doing, so meeting everybody face to face. You know, and they could have a little tea party or a 5 à 7 at the place and show you, “Okay this is our physio…this is where our patients have their physical therapy or where we do the injections or whatever”* – Dr. Lily

Q 1.B.3-2 *"I tend to only refer when I don't really know what the next step is, and sometimes there is no next step…"* – Dr. Alessandra		
C. INDIVIDUAL.		

Theme 1: **Limitations of the healthcare system as reported by PCPs**	**Theme 2:** **Ideal pain service to support transition and primary care**	**Theme 3:** **PCP-proposed mitigation strategies**
1.C.1 Stigma: Chronic pain in young patient is “*almost like they have leprosy*”. • Unease dealing with young patients affected by chronic pain. **Q 1.C.1-1** *“…[E]verybody will open the door for an old person with a cane or a walker, right, but a young person, everybody looks at them, and it’s almost like they have leprosy. It’s like there’s something wrong with them, what did they do, you know.”* - Dr. Lily **Q 1.C.1-2** *“I think it’s more difficult because you want them to retain a good level of functioning, or at least resume what they were able to get before, whereas if you have somebody who is 70, and having chronic pain, a little bit more acceptable I guess from a society point of view, but somebody who is 18-25, it’s not something that you often hear about.”* - Dr. B **Q 1.C.1-3** *“Well I think because it’s not expected to have somebody who is so young dealing with a chronic*	**2.C.1 Patient’s active role**: Patients need to be engaged and at the centre of their care. • Patient as an active partner in the process. **Q 2.C.1-1** *“Well ideally, we want our patients to be partners in managing very chronic pain condition [they have]… It needs to be a contract between the physician and the patient, so we have to work together as a team. Otherwise, it doesn’t work.” –* Dr. Office • Chronic pain as a contract to work closely. **Q 2.C.1-2** *« …je vais en parler au début avec le patient, s'ils sont intéressés à voir un spécialiste à la clinique de la douleur puis si oui, à ce moment-là je vais entrer en contact, soit par fax ou appel l'infirmière spécialisée et c'est elle qui va essayer d'arranger le suivi. »* - Dr. Vin ENG : ”…to begin, I would talk about it with the patient, if they are interested to see a pain specialist at the pain clinic, and if yes, only then, I would	**3.C.1 Patient-centered transitional pain care:** Strategies could be adopted to address individual needs. • On-demand appointment slots **Q 3.C.1-1** *« Le rôle du service idéal c'est qu'il prenne en charge le patient et qui puisse aussi avoir une ligne téléphonique ou avoir des "slots" durant la journée pour si le patient a des douleurs aiguës sur une douleur chronique qui peuvent avoir accès [à éviter la visite à l’urgence]. »* - Dr. Vin ENG: ”The role of the ideal service is to take a patient “in charge” and that it could have a telephone line or have slots during the day in case if the patient has acute on chronic pain that s/he has access [to avoid an ER visit]” • Direct “crisis line” to discuss situation with a pivot nurse first.

medical condition, period. [...] it might not always be visible on the outside as to what's going on." Dr. B • Multiple simultaneous transitions of emerging adulthood. **Q 1.C.1-4** *"…nothing is settled. It's shifting sands in every way, within their personal life, their professional life, their studies, their love life, their whatever, their family relations, ...So, I think they're much more vulnerable to screwing up."* - Dr. Office • Patient's impulsivity vs. prioritization **Q 1.C.1-5** *"I think it has to do with how their brain's work, and they're more impulsive, and they're more in their present. So, if it's not in the front of their awareness, they, other things are more important, and that's what they focus on."* – Dr. Diego • Young patients perceived as unreliable. **Q 1.C.1-6** *"…patients in this 18-25 age group are generally very unreliable in terms of dealing with their medical health and, you know, unless they have a chronic condition … that they manage on their own. Um, most of them are not very reliable."* – Dr. Water Bottle	contact, be it by fax or by calling a specialized nurse, and this is the nurse who will try to arrange a follow-up visit. **Q 2.C.1-3** *"… [patient is] honest about things, working closely… having regular contact with [their] primary care physician, that's something that often doesn't happen in chronic pain, people show up when they have an exacerbation, whereas this should be something that's managed on a regular basis with regular intervals to have a global treatment plan as opposed to a reactive type of plan."* - Dr. MDZERO • Understanding chronic pain: Patient-expert. **Q 2.C.1-4** *"Je pense que un, le patient doit connaître très bien son état. [...] Il faut bien lui expliquer le pourquoi, la physiologie, la mécanique de la douleur. Si le patient comprend bien la douleur, je crois qu'il sera plus facile à gérer à ce moment-là."*- Dr. Vin ENG: "I think, first, a patient should now his condition well; it needs to be explained, why, the physiology, the mechanism. If the patient understands pain well, I believe, starting this moment, it will make it easier to manage it."	**Q 3.C.1-2** *« La même chose, ça devrait être une ligne téléphonique qui peut appeler durant la journée, être capable de parler vraiment à leur infirmière pivot. »* - Dr. Vin ENG: "The same thing, this should be a telephone line that one could call during the day, and really talk with his pivot nurse." • Education about pain in young adults. **Q 3.C.1-3** *"I think a lot of physicians or people in general need more education that…young people can suffer from chronic pain, and … it should be taken more seriously, and that the signs and symptoms should be, by the medical community it should be appreciated more…I think people need better education and awareness that this problem can also exist in this population, and to not just be, oh, you're young, you'll get over it."* – Dr. Water Bottle

1.C.2 Young patients' experiences with adult system: Uncharted waters. • Inappropriate age of transition **Q 1.C.2-1** *"We expect them to turn 18 and sort of take on all their responsibility, which I don't think is very reasonable, they need a little bit more care and…support….Just because you turn 18, doesn't mean that you're all of a sudden emotionally mature enough to deal with everything."* - Dr. B • Consideration of patient's outside commitments **Q 1.C.2-2** *"One of the big things is that … [s]he's a young girl, she's trying to think of the future and what she wants to do eventually, so it's discouraging. It's very frustrating."*- Dr. B • Waiting times **Q 1.C.2-3** *« Le temps d'attente est de 6 à 8 mois et c'est absolument trop long pour (moi). »* - Dr. Kefas <u>ENG</u>: « The waiting time is 6 to 8 months and this absolutely too long for [me]" Exacerbation of pain problems • No clear pathway – The onus is on the patient.	**Q 2.C.1-5** *"The younger population also tends to come in having done some research, and they try to the be drivers of their pain management..."* – Dr. MDZERO **Q 2.C.1-6** *"…they [young patients] tend to seek out specialized treatments, and they help me do my job, because they become aware of things that I wasn't even aware of in Montreal, and they helped with that referral process, so it's actually fun to work with them."* – Dr. MDZERO • Patient in charge of transferring information to PCP. **Q 2.C.1-7** *"I actually have my patients come in and kind of go over everything"* – Dr. B **2.C.2 Patient's passive role**: There are elements of the patient-PCP relationship that should also be passive. • Compliance with the treatment plan. **Q 2.C.2-1** *« …le patient doit être "compliant" avec ses traitements. Donc avec les médicaments. Faut qu'il soit "compliant" avec ses rendez-vous et s'il manque un rendez-vous, faut pas juste qu'il ne se*	• Addressing personal needs by adopting existing models (condition or skills-focused) **Q 2.C.1-4** *"…they had a specific program for fibromyalgia that my patient participated in...it was very, very useful to her…and that's the kind of thing that I think we need more of."* – Dr. MDZERO **Q 2.C.1-5** *"[T]he [patients] who've benefited most [from pain referrals] definitely are the ones who did the pain management group and learned through skills how to manage their pain and how to live with their pain."* – Dr. Office

Q 1.C.2-4 *"I give them a referral and… they have to try multiple different centres based on where they live, or even having nothing to do with where they live…they're going to leave their request in every single hospital, and whichever one calls them back first is the one that they're going to take. I had a patient who…had seen an orthopedist or some specialist years before…who had recommended a referral to the pain clinic, and by the time the call came in for her appointment it wasn't even an active issue any more."* – Dr. Water Bottle • Managing patient's expectations. **Q 1.C.2-5** *"I mean if they have a negative experience [with a pain service] it just exacerbates their problem, and they come back to me…"* – Dr. MDZERO **Q 1.C.2-6** *"I had to manage that patient's expectation and try to put, try to spin that visit that she had in a more positive light."* – Dr. Water Bottle • Need for consistent support from pain services. **Q 1.C.2-7** *"They're happy for a bit, and then they're very unhappy – the pain comes back, and they can't get [a follow-up] appointment, and so on."* – Dr. Office	*présente pas, mais doit appeler avec une raison. » -* Dr. Vin ENG: "… the patient should be "compliant" with his treatment. Including medications. There is supposed to be "compliance" with the scheduled visits, and if he misses one, it is not supposed to be that he [simply] does not come, but he calls and explains the reason." **2.C.3 Patient- and family-centered:** Consideration of emerging adult's needs**.** Comprehensive assessment of young patient with chronic pain. **Q 2.C.3-1** *"I think that service ideally would probably have a nurse to do an intake for the patient. The patient will have, should take time and fill out a questionnaire, be seen by a nurse with a questionnaire to, sort of, go over and specify certain things. Um, then they should probably see a physician, and then that could also include evaluation by a physiotherapist or an occupational therapist."* – Dr. Water Bottle • Keeping family involved.	

	Q 2.C.3-2 *"I mean, it's much much easier, you negotiate with the kid, and keep the parents and the kid as a unit if you can."* – Dr. Lily • Patient feeling in control / informed. **Q 2.C.3-3** *"… it's important that they feel they have some control over what's going on."* – Dr. Diego	

Table 7. Deliberative Stakeholders Consultation Groups recommendations in the context of CAPHC guideline.

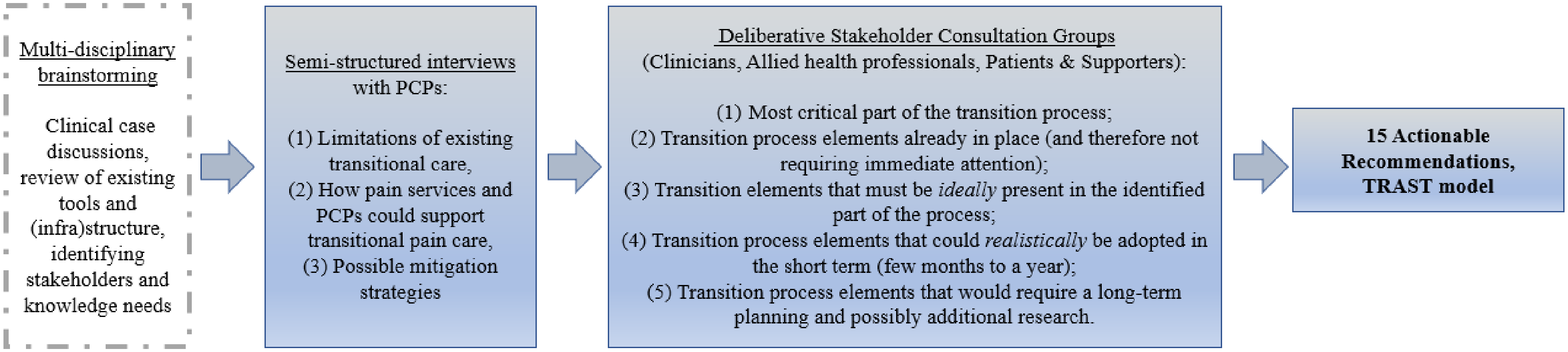
CAPHC guideline recommendation summary		Allied health professions (AHP)	Clinicians	Patients and Support
(*Individual*) Person-centered level				
1.	Transition **planning** is youth-focused and family-centred, inclusive of personal choice and is adaptable to the abilities and complexities of the youth's needs.	Need for patient orientation to the adult services. Development of the patient-peer network	Need for patient orientation to the adult services. Development of the patient-peer network	
2.	Transition of youth and their families address the youth's physical, developmental, psychosocial, mental health, educational, lifestyle, cultural and financial **needs**		Accommodation of individual needs (school, work) Telephone helpline.	Accommodation of individual needs (drop-in hours) Information on recommended alternative resources (physio, psychology, alternative medicine, etc.)
(Service) **Environmental level**				
3.	Transition for youth is supported by individualized planning in the paediatric and community settings, a **coordinated transfer of care** and secure attachment to adult services.		Community capacity building	
4.	**Healthcare providers engage**, educate and build capacity of youth and their families regarding transition.	Strategies on patient activation and patient engagement.	Early introduction for AYA to adult pain team	Dedicated age-based programs
5.	Collaborative respectful **communication** between stakeholders (youth, families, their natural networks, community, paediatric, primary and adult care provider(s)) supports the flow of information and ensures safe, caring and effective transition.	Development of communication by AHP to PCPs (detailed reports and regular updates)	Common e-Platform (virtual orientations, bidirectional e-communication, "patient feedback") e-Consultations for PCPs Inform pain team about incoming AYAs.	Strategies to improve communication between Clinicians and PCPs
6.	All youth have a **primary care provider** support care coordination.	Pain team needs a PCP's contact for ongoing assistance.	PCPs as "safety net" for patients during transitions	PCP as trusted and understanding presence

7.	A developmentally appropriate **individualized transition plan** is prepared and documented in collaboration with the youth and family.			
8.	Paediatric and primary providers assess the **youth's readiness** for adult care, identifying **gaps in skills** and knowledge requiring intervention.			
9.	**Healthcare providers and family members support** youth at their appropriate developmental level to understand their chronic condition, treatment plan, and level of self-management			PCP is present for the first adult appointment
10.	Care providers **educate the youth and family about transfer of care, at least one year prior to transfer**, encouraging them to share in the responsibility of accessing community and adult services, and if needed, provide additional navigational support		Early "overlap" in care between specialist and PCP prior to transfer	Early "overlap" in care between pediatric and adult prior to transfer
11.	Priority for care coordination is given to **youth with complex needs** and their families			
12.	Each transferring program is responsible to provide a **comprehensive health summary** at the time of referral, **to the adult health care provider(s), primary care provider(s), youth** and family.			
13.	Transfer of care to adult services includes **monitoring of youth's attachment to adult services, attendance at adult appointments** in an expected timeframe, ongoing **communication** between paediatric, primary and adult providers, and shared responsibility for management of youth with lapses in care.	Pivot nurse	Pivot nurse	Pivot nurse
(Health care) **System level**				
14.	All services have a **written policy** for the provision of transition.	Standardized transition process across the province	Standardized transition process across the province	Standardized referral process across the province
15.	Develop efficient and accredited **health information systems to support transfer of information and collaborative communication** among sectors.	Common e-Platform (standardized referral process across sites, shared general patient information)	Common e-Platform (general patient information; multi-directional communication for PCP, pain specialist as pain care coordinator, and patient)	Common e-Platform (shared general patient information)
16.	**Organizations** designate **transition champions** within their paediatric and adult settings to facilitate and evaluate transition.			

17.	**Organizations** provide ongoing **transition education, training, and knowledge translation** for all Stakeholders.	Training (adolescent medicine, for practitioners referring high volume of patients)		Training (for administrative staff in communications with patients and their caregivers)
18.	Researchers and clinicians develop a method for **consistent data collection** at an individual and systems level, including qualitative narratives of lived experiences and quantitative data, to be used by clinical teams, decision makers and researchers for quality improvement and evidence-based practices.			
19.	Involve youth, young adults and families, policy and decision makers, administrators, researchers, and government agencies, to jointly identify system barriers, system enablers and future development opportunities for the responsible transitioning of youth.			
		Need in additional resources for specialist office hours for PCPs, and increase in psychology services for AYAs.	Age-friendly clinic design	Age-friendly clinic hours

MANUSCRIPT FIGURES

Figure 1. Sequential-consensual design. Semi-structured interviews with PCPs.



Multi-disciplinary brainstorming

Clinical case discussions, review of existing tools and (infra)structure, identifying stakeholders and knowledge needs

Semi-structured interviews with PCPs:

(1) Limitations of existing transitional care,
(2) How pain services and PCPs could support transitional pain care,
(3) Possible mitigation strategies

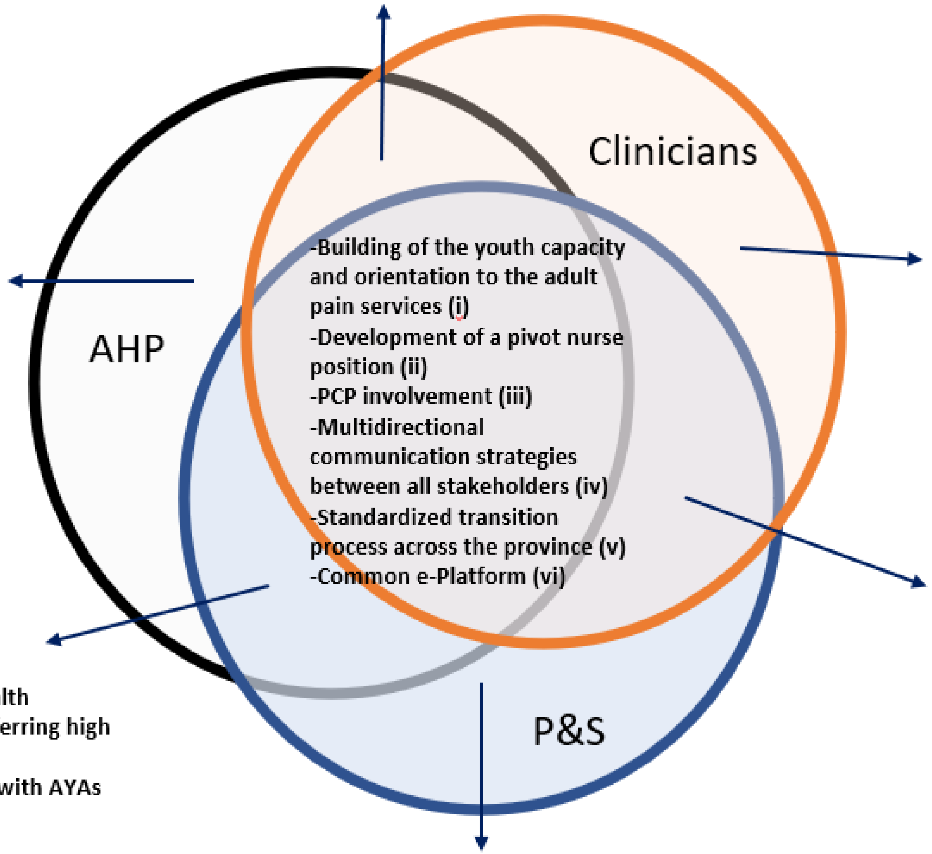
Deliberative Stakeholder Consultation Groups (Clinicians, Allied health professionals, Patients & Supporters):

(1) Most critical part of the transition process;
(2) Transition process elements already in place (and therefore not requiring immediate attention);
(3) Transition elements that must be *ideally* present in the identified part of the process;
(4) Transition process elements that could *realistically* be adopted in the short term (few months to a year);
(5) Transition process elements that would require a long-term planning and possibly additional research.

15 Actionable Recommendations, TRAST model

Figure 2. Venn diagram. Summary of actionable recommendations.

(AHP – allied health professionals; P&S – patients and supporters).



- Development of the patient-peer network (vii)

- Telephone help line
- E-consultation services for PCPs
- Information on incoming AYA patients (xiv)

- Increase in resources to provide specialist office hours for PCPs and psychology services for AYAs (xiii)

-Building of the youth capacity and orientation to the adult pain services (i)
-Development of a pivot nurse position (ii)
-PCP involvement (iii)
-Multidirectional communication strategies between all stakeholders (iv)
-Standardized transition process across the province (v)
-Common e-Platform (vi)

- Accommodations of individual AYAs' needs (school/work (Cl) drop-n hours (P&S) (ix)
- Early overlap in care prior to file transfer between specialists and PCP (Cl) and pediatric and adult (P&S) (x)
- Age-friendly clinic design (xi)

Training:
- in adolescent medicine for health professionals, including PCPs referring high volumes of AYAs (AHP) (viii)
- In communication approaches with AYAs for the administrative staff (xii)

Presence of PCP for the 1st adult appointment (xv)

5. DISCUSSION

This thesis' general objective was to formulate a vision for multi-disciplinary transitional pain care for the population of young adults (16-25 years of age) living with chronic pain and integrating into adult services. The student conducted a three-stage qualitative research project that had a participatory component. The research took place in the McGill integrated healthcare network that consists of academic and non-academic primary and tertiary health care units. Our study involved a multi-disciplinary clinical research team and young patients who live with pain with their supporters.

In its first (exploratory) stage, the research evaluated existing practices and identified several gaps that were further explored in the next two stages. The second stage aimed to develop a better understanding of the potential role of primary care in the post-transfer transition period in our specific clinical context. Twelve PCPs participated in semi-structured interviews. These data were analysed and conceptualised using the HCTRC theoretical framework and CAPHC guideline, leading to a better understanding of the primary care role in transitions and the formulation of mitigation strategies. To discuss findings from and propose actionable strategies to improve transitional pain care provision, 19 stakeholders took part in three deliberative consultation groups (Clinicians, Allied Health Professionals, Patients and Supporters) in the last stage of this study. The research concluded by formulating a set of multi-disciplinary recommendations concerned with all levels of transitions (Individual, Service, and Healthcare system) and describing our team's vision for a transitional pain care model that is potentially relevant to other Canadian pain healthcare settings.

The three patients' stories presented above as clinical vignettes are prototypical examples of complex clinical cases regularly encountered by our team at the AEPMU. In all three cases, psycho-social comorbidities and substance use disorder were not identified until these patients presented to the pain center and different complications, or side effects of medications, were identified. In all three cases, a longitudinal primary care-based assessments initiated prior to the transfer would likely provide a *safety net* by engaging AYAs' families, community resources and appropriate services these cases required. A continuous transitional care provided by the pediatric and/or adult specialists would likely result in the prevention or earlier identification of the psychiatric diagnoses, including a possible substance use disorder and their appropriate treatments.

Thus, from the conception of this project, the team and the patients with their supporters agreed that the management of psychiatric co-morbidities in AYAs living with pain and a structured multi-/inter-disciplinary transitional pain care would be of a paramount importance for this population.

The results of exploratory stage were highly concordant with the findings at the later stages, confirming and expanding the initial young patients' feedback. Yet, the most intriguing difference between the themes across the study was the issue of risky behaviors and substance use among the AYAs. The authorization of medicinal cannabis and the use of opioid analgesics were mentioned by two PCPs as one of the present clinical challenges requiring additional guidance and assistance; however, neither the PCPs nor the deliberative consultation group participants explored these themes any further. This is especially surprising as the Canada's opioid overdose crisis has been worsening for years [79] and both, pain physicians and primary care practitioners, have been called to contribute to its curbing.

As was noted in the manuscript, the literature shows that PCPs do not get sufficient training on the management of chronic pain or narcotic analgesics prescribing [80] and were likely uncomfortable to discuss this theme in more detail. The challenges related to a limited or absent pain training are common across the country[11, 81] and have resulted in increased rates of opioid use disorder and the worsening of opioid-associated mortality and morbidity,[82, 83] The skyrocketing cannabis use for all age groups, including AYAs, is albeit a separate yet a connected issue[72] as the patients have been choosing licit and illicit cannabinoids to substitute for a variety of pain medications, including analgesics. Thus, although initially anticipated by the team, the last two stages did not result in any formal discussion of how substance use by the AYAs and age-associated risky behaviors should be handled during the transitions.

As noted, risky behaviors and narcotic analgesics use were mentioned in the exploratory as well as in the second part of the project. The lack of continuity of the discussion on this very important topic by the group participants, who were tasked with identifying actionable strategies, is alarming. This might be attesting to the fact that despite a very detailed discussion on pain-associated stigma[84] and the acknowledgement of age-associated risk of mental health diagnoses,[59, 61-63, 65, 84, 85] the stakeholders (healthcare professionals and the patients with their supporters) did not consider problematic cannabis and opioid use as a part of the transitional care mandate. Yet, the limited access to pain services[86] could be compounded by even more limited access to psychiatric and addiction specialists, [87] thus rendering transitions very challenging. A tool kit to address some of these concerns has been recently proposed by the Canadian Centre on Substance Use and Addiction in collaboration with the Health Canada.[88]

Otherwise, the results of the second and third stages were discussed in detail in the thesis manuscript. The resulting set of actionable recommendations is presented in the **Table 7** of the thesis appendix. Based on the results of this study, in addition to the CAPHC guideline recommendations, the most important elements of transitional pain care model (**Figure 6**) would involve all three levels of transitions as presented below.

Individual level

- Programs and approaches to build AYAs' capacity post-transfer to adult pain services. For example, the development of a patient peer pain network to guide and support AYAs as they adapt to the adult services and acquire self-management and decision-making skills.
- Increase in resources to provide support for AYAs in crisis. For example, additional psychology hours, crisis line, direct phone line with the pivot nurse.
- AYAs-focused education therapeutic approaches. For example, group sessions on the coping skills and management of fibromyalgia.

Service level*:*

- Development of a pivot nurse position/s to liaise with the community services, patients and involved adult and pediatric specialists.
- Longitudinal PCPs / primary care involvement to orchestrate the overall bio-psycho-social care plan, improve multi-directional information flow, and provide complementary care.
- Multidirectional communication strategies between all stakeholders, including patients, primary and specialty teams.
- Ongoing training in adolescent and pain medicine for all healthcare professionals.

- Strategies on accommodation of individual AYA's needs (drop-in hours, evening consultations, forms and certificate filling etc.)
- Continuous dynamic overlap in transitional care between pain specialists and PCPs, pediatric and adult providers.
- Age-friendly pain clinic designs, allowing AYAs to meet their peers and mentors.
- Training in communication strategies with AYAs for the clerical staff in healthcare institutions.
- Increase in resources to provide pain specialist office hours for PCPs, direct contact with PCPs via e-consults, telephone help line, and communication about preliminary information on incoming AYA patients.
- Direct longitudinal PCPs' involvement in transitional pain care, including AYAs' first adult appointment. Provision of complementary (general medical) care as art of the transitional care for AYAs.

Healthcare System level

- There is an urgent need for a standardized transition and referral process across the province to clearly identify patients' trajectories and follow with the focused distribution of resources.
- A common e-platform to support all transitions, facilitate information sharing, care coordination and communication between all stakeholders.

The suggested characteristics of such "transitional pain care" model were:

- Universal longitudinal post-transfer pain care for patients 16-25 years of age living with a CP diagnosis.
- Inter-/multi-disciplinary set up with an overlap between pediatric, adult, and primary care services, which might include vising clinicians-consultants from the relevant specialties.
- Located in a relatively resource-rich environment that is connected to the local community, such as out-patient community hospital services or local community service centres (*centre local de services communautaires*).
- Using standardized validated clinical tools and patient-focused material.

- Functioning based on a defined set of relevant clinical and patient-focused outcomes, employing a written transition policy emphasizing a shared pre- and post-transfer responsibility for care.
- “Soft” developmentally - appropriate transition deadline to exclude care fragmentation.
- *(Psychiatric, psycho-social and addiction care mandate)*

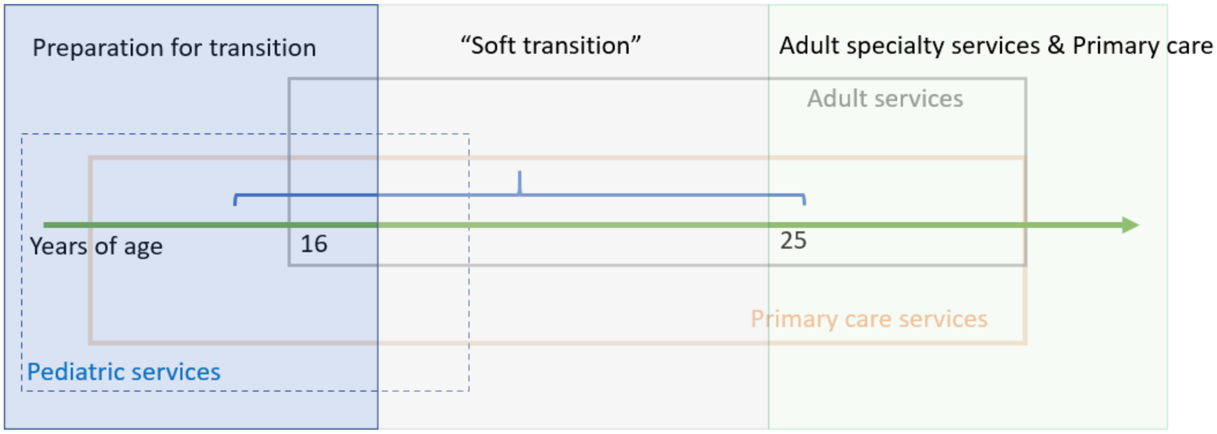


Figure 6. Transitional pain care model with a “soft” developmentally - appropriate transition deadline.

CONTRIBUTION TO ORIGINAL KNOWLEDGE

Transition in care guidelines from the United States, Europe and Canada emphasize the need to assist young patients in better understanding and optimal use of existing resources while transitioning to adult services. The existing guidance is mostly generic and applicable to different chronic disease diagnoses, and thus not specific to the pain field. Such guidance on complex transitions is important to decrease the inherent risk associated with poorer care outcomes and high personal and societal cost when the continuity of care is affected. Present study makes several contributions to the original knowledge. First, to our understanding, this is the first research on post-transfer transitional pain care in Quebec and most likely in Canada. Secondly, the study contributes significant original data on the gaps of pain care provision for Canadian youths and discusses potential mitigation strategies. These data add to transitional pain research field, which is still in its infancy. The study includes a multi-disciplinary and patient perspective, thus also contributing to the patient-oriented and primary care research fields.

STRENGTHS AND LIMITATIONS

First, to our knowledge, this study might be the first Canadian research that looked at the last stage of transition to adult pain services in relation to the primary care's role and that also includes patients' perspective. The resulted recommendations are meant to be a practical actionable set of suggestions relevant to multi-disciplinary care transfers for transitioning young adult patients and might be adopted across Quebec, and possibly Canada, as these account for today context of scars healthcare resources. Secondly, an important strength of this study is its sequential-consensual qualitative design, which enhances external validity of qualitative data and ensures that the study's findings are applicable to the institutional context.[89] This design was initially described by Groleau and colleagues in their study regarding breast-feeding practices among Quebec women. Initially, the authors attempted to understand "*the experience and meaning that economically disadvantaged French-Canadian mothers attribute to their infant feeding choices (bottle vs. breast)". B*ased on this information and with the input from the mothers, researchers *"formulate[d] … recommendations for public health policy, programming, and guidelines for the promotion of breast-feeding."* The authors highlighted that the impact on decision-makers stemmed from the fostered insights into the specific problem and credibility such data had in the public eye. Our team ensured that the data came from multiple sources (patients and their supporters, literature, guidelines and a representative sample of PCPs), were sufficiently simplified, and resonated with the deliberative group participants' experiences and the meaning they assigned to the problem.[89] Finally, the study involved patients and their supporters as well as patient-partners who guided the team and validated all study findings longitudinally.

The main limitation of this research includes single interviews with the PCPs, which likely limited the depth of the data collected during this stage of research. The deliberative consultation groups were also limited to only one session, although all participants were asked to email any additional ideas to our team. The findings were more specific to the McGill healthcare network however, the study used the HCTRC theoretical transitional framework developed by the Canadian researchers as well as the Canadian transitional guidelines. The number of transitional models could have changed since the last review of the grey literature in 2020. Our transitional pain care model remains theoretical and would benefit from the development of relevant outcome measures. Yet, this study and the HCTRC identified several important variables that could serve as the foundation for the future research.

THESIS CONCLUSION and FURTHER DIRECTIONS

This thesis work was based on the three-phase qualitative study that resulted in the pain filed specific theoretical transitional model for AYAs living with a CP condition. The presented model is based on 15 multi-disciplinary recommendations, has several advisable pain and local resource specific characteristics, and relied on the Canadian HCTRC theoretical transitional framework and country's transitional guideline. Due to the rich inputs from multiple stakeholders, consensual-sequential study design and its participatory component, the TRAST model could be adopted in all settings, where transitional pain care for AYA requires further improvement.

This research revealed several significant gaps in the pain and primary care literature. More research is required to understand how healthcare resources could be redistributed to decrease task redundancy, reallocate required resources to the community and optimize pain care pathways. The most significant concerns discovered during the study were related to all types of communication difficulties that further complicated already complex transitional pain care. Adult pain and primary care literature demonstrated almost a complete lack of transitional studies for youths living with pain, the dearth of original data on the sequela of pain care continuity, and no studies on the involvement of the primary care or family medicine groups in transitions. Furthermore, we identify no studies or guidance on the inclusion of the psychiatric and addiction services in the mandate of transitional pain care clinics. Additionally, there is a poor understanding of the optimal structure, composition, location, funding, and relevant measurable outcomes to systematically evaluate transitional pain models.

Thus, our study offers one of the first transitional pain model visions that should be further explored in the larger scale studies to develop optimally structured and efficient transitional care pathways for Canadian youths who live with chronic pain.

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APPENDIX 2.

Table 8. Existing transitional models.

Program /Tool	**Province**	**Main elements of transition program**	**Professionals**	**Post-transfer component**	**Primary care involvement**
1.**Good2Go**	United States Canada, Ontario	Adolescence until discharge from pediatric services Developmental, leadership, shifting responsibilities domains Health summary “My health Passport” tool	Specialty-based Adult care providers meet AYAs before transfer	?	?
2.**ON TRAC** [90]	Canada, British Columbia	Early, middle and late adolescence Task and skill-based Indicators and outcomes for each step Developmental milestones tailored teaching “Your Plan-It” tool	Subspecialty teams-based, Nurse-coordinator	?	?
3.**The Maestro Project**	Canada, Manitoba	Administrative model “Coordinator” and peer “Mentor” Support and assistance with adult appointments Community-based resources On-line resources Drop-in services Educational events	Community-based, specialty service (diabetes resources)	**Yes**	?
4.**Be Your Own Boss (BYOB)**	Canada, Alberta	Based on Stanford Chronic Disease Self-Management model	Community-based	**Yes**	No

		Self-management participative	Non-health professionals, peer program. Nursing, psychology		
5.**Young Adults with Rheumatic Disease (YARD)**	Canada, Alberta	Continuity in transition clinic Medical, psycho-social, career counselling, educational Connections to complementary / alternative therapies Nurse as a care coordinator Liaises with rheumatology services across Canada Multidisciplinary (physiotherapy, psychology, education, nursing)	Pediatric and adult rheumatologist together	**Yes**	No
6.Well on Your Way [91]	Canada, Alberta	Alberta Children's Hospital	Pediatric services	?	?
7.Adolescent Transition-In Program	Canada, Alberta	Medically complex patients Medical knowledge transfer, emergency needs Engagement of caregivers, anxiety around adult care Spiritual / psychological support	Emergency Department tour visits, in-patient/ICU specialty-based	?	NO
8.ON My Way: Transition to Adult Care	Canada, Ontario	Transitioning to adult neurology Dedicated adolescent clinic On-line resources	Specialty-based	?	? Yes
9.You're in Charge!	Canada, Nova Scotia	3-hour workshop + on-line resource Readiness check list Bilingual services	Multi-disciplinary	? No	Yes

		Guidelines for all stages Evaluation of all stages PCPs Specialists			
10.Cystic Fibrosis Clinic	Canada, Ontario	Age-based, 3-18 y.o. 6 stages Nurse case-manager, dietician, physiotherapy, social worker, respirology	Specialty-based	No	No
11.**Transitioning to adult care: Starting Early and Finishing Strong**	Canada, Quebec, MUHC	Age based, three stages 11-13, 14-16, 17-18 y.o. Categories: Complex patient care, Transplant recipients, Cognitive impairment Transition Preparation Tools, a Medical Passport and Transfer Readiness Checklists Recommends registering with a PCP	Specialty-based	No	No
12.**The Launch Program**	Canada, Alberta	Autism spectrum disorders Individualized transition Plans Resource guides Workshops, on-line, skill-based Multidisciplinary	Community-based	?	No
13.**Teen Transition Planning**	Canada, British Columbia	Autism spectrum disorders Paid services. Age-based, 13-18 y.o. 5-hour workshop	Community-based	No	No

		Team-based transition coordination program			
14.**Adolescent Transition**	Canada, Nova Scotia	Diabetes care Age-based, multi-step, 13-19 y.o. Knowledge, skills, educational Health Record and other tools Transition consultant Pediatric and Adult designate (team member responsible for coordination and completion of the process, case manager)	Community-based	**Yes**	?
15.**The Stay Connected Mental Health Project**	Canada, Nova Scotia, British Columbia	Mental Health and Addiction services Peer support program Skills training. Electronic application. Literacy and education. Book. Family mentorship, peer support Resource mapping	Community-based	**Yes**	No
16.iCanCope[92, 93]	Canada, Norway	Self-management mobile application	Mobile	**-**	-
17.iPeer2Peer program [94]	Canada, Ontario	Chronic pain self-management Tailored mentorship program 18-25 y.o. 10 Skype video-calls over 8 weeks	Skype video-calls	**-**	-
18. Got Transition tool [95]	United States	Transition tool, 6 Core Elements Guidance on 6 sequential steps (policy and guidance; tracking and monitoring; readiness assessment;	All	**Yes**	Yes

		transfer planning; transfer to adult care; transition completion and integration to adult care)			

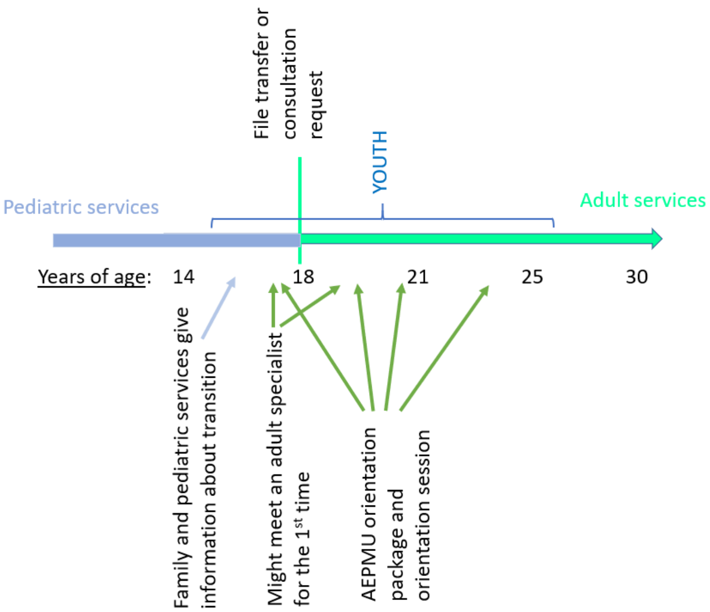
Table 9. Summary of exploratory stage.

Theme	Sub-theme	Examples from clinical interviews with patients and their accompaniers
1. Age-appropriate care	Collaboration between primary and specialty services, developmental needs, AYAs' role in their own care.	- AYAs expected holistic coordinated pain management based on collaborative effort of PCP and pain specialists. - AYAs reported that their age-related needs were not addressed by adult health providers, including PCPs. - AYAs were advocating for more guidance yet more independence in making health-related decisions. - AYAs wanted guidance on the tools for pain self-management. - Added responsibilities (evening work or school, for ex.) resulted in lack of accommodations and differences in expectations between patients and care providers.
2. PCPs' practice profile	Lack of comfort working with AYAs living with CP, unstructured pain referring practices, poorly defined role of PCPs in supporting transitions.	- Difficulty finding a PCP, who followed pediatric population; and therefore, many AYAs were not registered with a PCP. - PCPs appeared unprepared managing chronic pain and/or young patients. - For pain care, AYAs would be referred to several pain adult specialists, with some overlap (different clinics, but one physician or vice versa). - AYAs registered with a PCP and followed at the pain clinic reported that their PCPs were not involved in transitional care.

3. PCPs experience working with pain services	Knowledge about pain services, sideways involvement, limited communication, transitional care logistics.	- AYAs commented that their PCPs appeared to have limited knowledge about or experiences with the pain services. - PCPs would follow AYAs for other health concerns not related to pain. - PCPs appeared to receive inconsistent documentation on transitional pain care if they referred for pain care. - AYAs reported that their PCPs did not have evaluation documentation or discharge summaries if they were not the referring physicians.
4. Possible mitigation strategies	Care orchestration, communication, longitudinal support of AYAs by primary care team/s, access to local resources.	- Patients and their supporters felt that primary care team/s should be pivotal during transition process to i) orchestrate transitional care, ii) improve multi-directional communication, iii) follow on pain-related medical and psycho-social issues, and iv) support AYAs orienting them to various community services, tools, and resources.
5. Overlapping concerns (team, patients, and supporters)	Suboptimal use of available services by AYAs, inter-provider communication, inter-professional complex care coordination, co-management of comorbidities.	- AYAs' overreliance on emergency services and caregivers despite being introduced to adult services. - AYAs missing scheduled clinic appointments, frequently lost to follow-up with adult care providers. - Poor communication between patients and PCPs (AYAs would miss PCP's appointments). - Lack of primary care and tertiary service complementarity or planning. Bidirectional fragmented communication flow. - PCPs lacking familiarity with specialized services within their institution. - Lack of an individualized interdisciplinary plan for structured transitions. - Psycho-social comorbidities, substance use disorders (cannabis and opioids), various handicaps that the pain team must address without / with limited involvement of PCPs. - Lack of longitudinal primary care involvement.

FIGURES

Figure 3. Existing transition process as perceived by youth.



**Adult and pediatric services: any adult or pediatric specialty, including family and pain medicine.*

Figure 4. Transition process as was desired by youths.
Primary care would be involved in the entirety of the transition period to support and inform the patient.

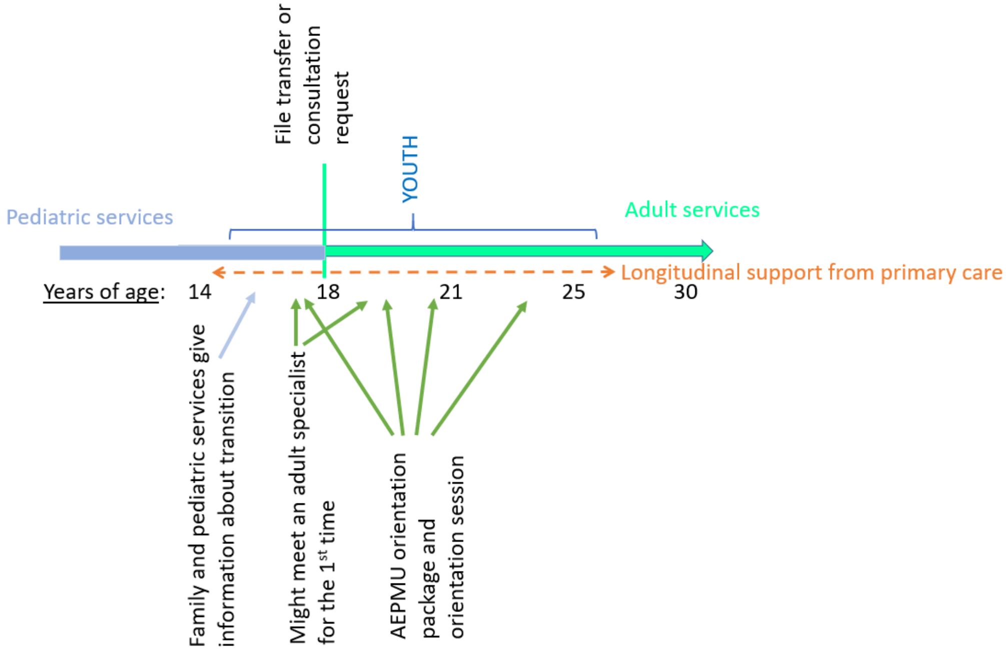


Figure 5. Three-phase coordinated transition process with a "soft" transfer time point not based on the youth's age and providing developmentally appropriate care.

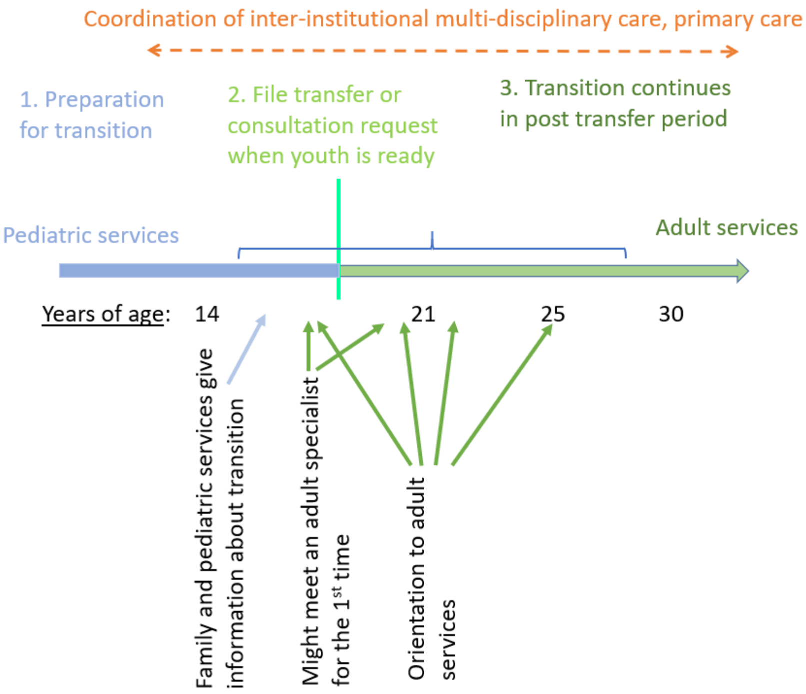
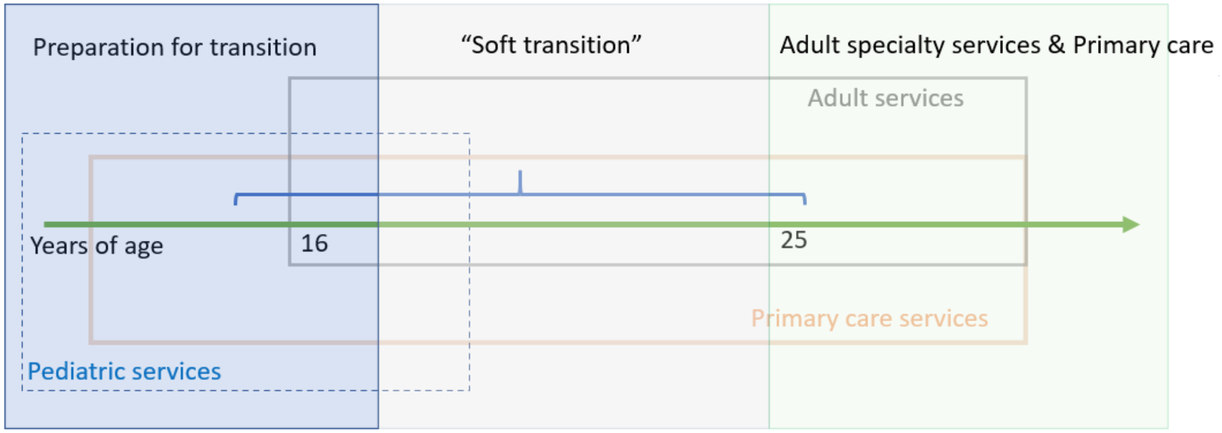


Figure 6. Transitional pain care model with a “soft” developmentally - appropriate transition deadline.



INTERVIEW GUIDE

(semi-structured interviews with primary care practitioners). English version.

Chosen alius: ____

Date (dd/mm/yyyy): ____/_____/_______ **Time (24-hour)**: __________:_________
City:____

Setting (clinical, academic setting, home / personal device, room / office outside of the clinical setting, other):

____

Interview format: (A) Face-to-face (B) online video interview / Skype

Gender / Sex: M / F **Age**: ________ **Years in practice including training such as residency / fellowships**: -______________________

Medical specialty (staff family physician / resident family physician, nurse-clinician, nurse practitioner, physician assistant, other):____

INTRODUCTION.

The TRAST project aims to **evaluate pain services** provided for the adolescent and young patient population suffering from chronic non-cancerous pain conditions such as post-traumatic or post-surgical pain, sickle cell–related pain, Crohn's colitis, etc. The process of referral and consulting with adult services without the **proper transition** from children's services or the familiarity with Quebec's **adult system** might be confusing. As a result, and young adults might fall victim to the imperfections of the health system. We have identified your name from our database of primary care referring practitioners. Through this **semi-structured interview**, we hope to receive your most honest feedback about your experience working with patients suffering from chronic pain, including, young adults **aged 18 to 25 years**. All of your answers will be **anonymous**. We will analyze all received data and present a summary of the results to the TRAST team members to discuss and propose realistic recommendations (such as patient- and physician-oriented material, tools, protocols, etc.) The **summary of results and recommendations will be available** to the primary and tertiary care teams. This project includes evaluation and feedback, but does not include tool development or implementation phases.

.

Part A: Yes / No / Uncertain questions

1	Is chronic pain management part of your **practice profile**?	Yes No Uncertain
2	Do **you have young adults** suffering from a chronic pain condition in your practice?	Yes No Uncertain
3	Is it important for you to **confirm** that your **young patients attended** their pain specialist appointments?	Yes No Uncertain
4	Do you feel that you receive **adequate summaries of your young patients' ER visits** related to chronic pain?	Yes No Uncertain

Part B: Open-ended questions

B.1. Practice profile /
Profile de pratique.

B.1.1.

- **Which chronic pain condition would you feel comfortable managing in your practice without referring to a pain specialist?**

- Which chronic pain condition would you feel comfortable managing **in a young patient aged 18 to 25?** (3 min)

(example and the reason)

*Memory aids:*Neck pain, radiculopathy, neuropathy etc.

B.1.2.

- **In general, under what circumstances or for what reasons would you request a pain management consultation?**

- Under what circumstances or for what reasons would you request a pain management consultation **for a young patient aged 18 to 25?** (3-7 min)

(an example)

Memory aids:
- Specific diagnoses / diagnostic difficulties
- Specific knowledge about pain management / medications
- Specific interventional procedures
- Second opinion / difficulty managing / non-compliance (ask for an example)
- Multidisciplinary treatment (why and how do you decide when it is needed?)
- Other services available (physiotherapy, psychology, social work, psychiatry etc)

B.1.3.

- **How is the decision to refer to a pain consultation service made in you practice?**

- **Why would you (or would you not) negotiate this with your patients?**

- Would your negotiation strategy be different if your patient is a **young adult aged 18 to 25?** (4-5 min)

Memory aids:
- Suggested by a nurse
- It is the patient who initiates/asks questions/makes request
- It is you who recommends a specific experience and recommend a pain service.
- You prefer sending multiple consults to related specialties simultaneously to optimize pain management / sequentially (ask for an example and reason)
- You make a unilateral (your) decision to refer because your practice profile does not include pain management.

B.1.4.

- **Which other services (including other pain services) would you consult simultaneously to manage your patients' pain condition and why?**

- **How do you or your team follow these consultation requests?** (0-3 min)

(example and the reason)

Memory aids: For example, pain service and orthopedics for osteoarthritis, or several pain centers.

B.2. Global pain management (**Holistic care**)

B.2.1.

- **Describe an *ideal* consultation service providing global pain management you would like to work with.**

- What would be the difference if your patient were **a young adult aged 18 to 25?** (3-5 min)

Memory aids:
- Composition (which specialty should provide the service)
- Location (in-house, community, hospital, private office etc)
- Role of the service provider (diagnosing, treating, stabilizing, advising, developing common treatment plan / back-up plan, reviewing the case without seeing the patient / answering questions, one-time consulting, longitudinal follow-up etc)

B.2.2.

- ***Ideally*, what would be the patient's role in his or her global pain management?**

- What would be the difference if your patient were a **young adult aged 18 to 25?** (3 min)

Memory aids:
- To ask questions / learn about his/her condition
- To receive treatment and return to the referring practitioner
- To inform referring practitioner about medications and interventions
- To engage referring practitioner into the management plan
- To validate pain management plan with the referring practitioner
- Engage into active self-management

B.2.3.

- ***Ideally*, when a pain service is actively involved, what should be the referring physician's role in the global pain management?**

- **What would be the difference if your patient were a young adult aged 18 to 25?** (3 min)

Memory aids:
- Collect summaries of what was done,
- Participate in the development of the pain management plan along the pain service,
- Involve other resources, initiate treatment, change treatment post-consultation

B.3. The gaps in service

B.3.1. **Which pain services have you worked with?** (1 min)

- Alan Edwards Pain Management Unit, Montreal General Hospital
- Montreal Institute of Geriatrics pain clinic
- Verdun pain clinic
- Jewish General Hospital pain service
- In-house pain consultant (Herzl, Queen Elizabeth FMG)
- Other (which ones?)

CLARIFY ALL FURTHER ANSWERS IF ONE WORKED WITH 2 OR MORE SERVICES

B.3.2.

- **What was positive about your experience with these pain services?**
- **How did this experience affect your young patients?** (3-5 min)

Memory aids:
- Time involved
- Availability of information about the service
- Documentation
- Quality of information learned about patient's condition and its management
- Your satisfaction with the relevance of the response
- Patient's satisfaction with service received

- <u>Family / caregiver satisfaction</u>

<u>B.3.3.</u>

- **What was <u>negative</u> about your experience with these pain services?**

- **How did this experience affect your patients?** (15 min)

Memory aids:

- <u>Time</u> involved
- Availability of <u>information</u> about the service
- D<u>ocumentation</u>
- Q<u>uality</u> of information <u>learned</u> about patient's condition and its management
- Your satisfaction with the <u>relevance</u> of the response
- <u>Patient's satisfaction</u> with service received
- <u>Family / caregiver satisfaction</u>

B.4. <u>Mitigation strategy (possible solutions)</u>

<u>B.4.1.</u>

- **After a consultation request to a pain management service was sent, what would be an <u>*ideal* pain service response</u>?**

- **Ideally, how could you or your team be involved while waiting?**(3-7 min)

Memory aids:
- Time frame / triage urgency (which cases are considered more urgent, ask for an example and reason)
- Communication with the referring practitioner (written, oral, electronic etc)
- Type of communication (phone call, letter, form, standardized, non-standardized)
- Specific expectations from the pain service (knowing triage status, waiting time, available interim treatment options, etc)
- Longitudinal follow-up in the form of multiple communications based on standardized report forms
- Guidance in managing pain in the interim.
- Additional patient and physician resources.

B.4.2.

- ***Ideally*, what would facilitate communication between the pain service, the patient and the referring practitioner?**

- **How would this help your young patients aged 18 to 25?** (7-10 min)

Memory aids:
- Patient's verbal recount of the treatment
- Written or other types of communication from the pain service (what would be an ideal way to do that?)
- Structured interim / summary note (what should be included in it?)
- General information about pain service structure, mission, consult structure
- Information video (what kind of information?)
- Communication tools (letters, notes, patient booklet with dates, names, medications)

B.4.3.

- **In your opinion, what are the main issues that should we address first to serve young adults with chronic pain?**

- **How could primary care teams help young patients during their transition to adult services?** (5-10 min)

Memory aids:
- Communication strategies
- Access to services
- Consultation summary
- Treatment plan
- Post-active treatment support
- Time frame
- Development of local / in-house services
- Access to additional pain specialties (addiction, physiotherapy, social work, psychiatry, rehabilitation)

5	**Do you use a structured form of documentation, such as templates or fillable forms, for chronic pain assessment and follow-up?**	**Yes**	**No**	**Uncertain**
6	Do you use an **opioid contract** or any other similar tools to follow narcotic therapy in your practice?	Yes	No	Uncertain
7	Do any of your **patients use tools** to monitor their pain and medication such as pain diary, smart phone applications, appointment calendar, or electronic medication reminders?	Yes	No	Uncertain
8	In chronic pain, **should the primary care teams be responsible** for a **structured transition** of adolescents and young adults to adult care?	Yes	No	Uncertain
9	Are you **satisfied with your skills and knowledge** of chronic pain management as a primary care provider?	Yes	No	Uncertain

B.4.4. **COMMENTS**

What are <u>other approaches</u> that could help contribute to ensuring a smoother transition to adult services? (5 min)

We highly appreciate your collaboration in the study! With full acknowledgment of your heavy schedule and other responsibilities, Thank you! from the TRAST team.

INTERVIEW GUIDE.

Semi-structured interviews with primary care practitioners. French version.

Chosen alius: ____

Date (dd/mm/yyyy): ____/_____/_______ **Time (24-hour)**: __________:_________ **City**: _____________________________________

Setting (clinical, academic setting, home / personal device, room / office outside of the clinical setting, other):

____

Interview format: **(A)** Face-to-face **(B)** online video interview / Skype

Gender / Sex: M / F **Age**: _________ **Years in practice including training such as residency / fellowships**: _________________________

Medical specialty (staff family physician / resident family physician, nurse-clinician, nurse practitioner, physician assistant, other):____

INTRODUCTION.

Le projet TRAST vise à **évaluer les services** de traitements de douleur chronique fournis aux adolescents et jeunes adultes souffrants de douleur chronique non-cancéreuse comme les douleurs post-traumatique, post-chirurgicale, anémie falciforme, la colite du Crohn et les autres. Le processus de référence et de consultation avec les services pour les adultes au Québec pourrait être déroutant et menant à des complications additionnelles de santé physique et/ou mentale sans un **programme structuré de transition et d'adaptation des jeunes adultes** vers les services pour les adultes. Nous avons identifié votre nom dans notre base de données des cliniciens référents. Grâce à cette **entrevue semi-structurée**, nous espérons recevoir vos commentaires les plus honnêtes sur votre expérience de travail avec les patients souffrant de douleur chronique, y compris les jeunes adultes **âgés de 18 à 25 ans**. Toutes vos réponses seront anonymes. Nous allons analyser, résumer toutes les données reçues et présenter un résumé aux membres de l'équipe TRAST afin de discuter et proposer des solutions réalistes (de l'information additionnelle, des outils pour les patients et spécialistes de soins primaires et spécialisés, des protocoles, etc.) Nous espérons que cette stratégie améliorera votre expérience professionnelle et les soins de vos patients de manière significative dans un avenir proche. Le **résumé et les recommandations** seront disponibles pour les équipes de soins primaires et spécialisés. Le projet TRAST inclut l'évaluation et le transfert des connaissances, et n'inclut pas le développement des outils ou la phase d'implémentation.

PARTIE A : Oui / No / Pas certain.

1	Est-ce que la gestion de la douleur chronique fait partie de votre **profile de pratique?**	Oui	No	Pas certain
2	Avez-vous parmi vos patients des **jeunes adultes souffrant** de douleur chronique ?	Oui	No	Pas certain
3	Est-il important pour vous de **confirmer** si vos **jeunes patients se pressentaient à leur rendez-vous** avec les spécialistes de la douleur chronique ?	Oui	No	Pas certain
4	Est-il important pour vous d'avoir le **résumé de chaque visite** liée à la douleur chronique de votre patient **à l'urgence** ?	Oui	No	Pas certain

Part B: OPEN-ENDED QUESTIONS **B.1**. Practice profile / Profile de pratique.

B.1.1. (3 min)

- **Quelle condition de douleur chronique vous sentiriez-vous à l'aise de gérer dans votre pratique sans référer votre patient à un spécialiste dans le domaine de gestion de la douleur?**

- Quelle condition de douleur chronique vous sentiriez-vous à l'aise de gérer **chez les jeunes adultes âgés de 18 à 25 ans ?**

(exemple et la raison)

Aide-mémoires : Douleur au cou, radiculopathie, neuropathie etc.

B.1.2. (3-7 min)

- **En général, dans quelle circonstance ou pour quelle raison demanderiez-vous une consultation en gestion de la douleur ?**

- Dans quelle circonstance ou pour quelle raison demanderiez-vous une consultation en gestion de la douleur pour **un jeune adulte âgé de 18 à 25 ans ?**

(exemple)

Aide-mémoires :

- <u>Diagnostics</u> spécifiques ou difficultés de poser un diagnostic
- <u>Connaissances</u> spécifiques sur la gestion de la douleur / médicaments
- <u>Procédures</u> d'interventions spécifiques
- <u>Deuxième opinion</u> / difficulté de gestion / non-respect du plan de traitement
- Traitement <u>multidisciplinaire</u> (pourquoi et comment décidez-vous quand cela est nécessaire?)
- Autres <u>services disponibles</u> (physiothérapie, psychologie, service de travailleur social, psychiatrie, etc.)

B.1.3. (4-5 min)

- **Comment la décision de demander la consultation au service de gestion de la douleur est-elle prise ?**

- **Pourquoi voudriez-vous (ou non) la négocier avec le patient ?**

- Votre stratégie de négociation serait-elle différente si votre patient est **un jeune adulte de 18 à 25 ans ?**

Aide-mémoires :
- Suggéré par une infirmière
- C’est le patient qui initie / pose des questions / fait la demande
- C'est vous qui indiquez que vous avez une expérience spécifique et que vous recommandez un service de douleur
- Vous préfériez envoyer des demandes de consultation simultanément/ séquentiellement à plusieurs spécialistes associés afin d’optimiser la gestion de la douleur (demandez un exemple et une raison)
- Vous prenez une décision unilatérale de faire la demande de consultation car votre profil de pratique ne comprend pas la gestion de la douleur.

B.1.4. (0-3 min)

- **Quels autres services (y compris un autre service de la douleur) consulteriez-vous simultanément pour gérer l'état de souffrance du patient et pourquoi** ?

- **Comment vous ou votre équipe suivez-vous ces demandes de consultation ?**

(un exemple et la raison)

Aide-mémoires : Par exemple, un service de la douleur et d'orthopédie pour l'arthrose, ou plusieurs centres de la douleur.

B.2.1. (3-5 min)

- **Décrivez un service *idéal* de gestion globale de la douleur chronique avec lequel vous aimeriez travailler.**

- Quelle serait la différence si votre patient était **un jeune adulte de 18 à 25 ans ?**

Aide-mémoires :
- Composition (quelle spécialité devrait fournir le service)
- Emplacement de service (interne, communautaire, hôpital, privé etc.)
- Rôle du fournisseur de service (diagnostique, traitement, stabilisation d'état physique et mental, conseil, élaboration d'un plan de traitement commun et plan de sauvegarde, revue du dossier médical sans visite de patient, réponse aux questions d'équipe médicale, consultation unique, suivi longitudinal etc.)

B.2.2. (3 min)

- ***Idéalement*, quel serait le rôle du patient dans sa gestion globale de la douleur ?**

- Quelle serait la différence si votre patient était un **jeune adulte de 18 à 25 ans ?**

Aide-mémoires :
- Poser autant des questions / connaître son état
- Recevoir un traitement et retourner au praticien référent
- Informer le praticien sur les médicaments et les interventions
- Engager le praticien référent dans le plan de gestion
- Valider le plan de gestion de la douleur avec le praticien référent

- <u>Engager en autogestion</u> active

B.2.3. (3 min)

- Alors qu'un service de la douleur est activement impliqué***, idéalement*****, quel devrait être le <u>rôle du praticien référent</u> dans la gestion globale de la douleur ?**

- Quelle serait **la différence si votre patient était un jeune adulte de 18 à 25 ans ?**

Aide-mémoires :
- <u>Rester au courant</u> du traitement offert,
- Participer au développement du <u>plan de gestion</u> de la douleur avec le service de la douleur,
- Impliquer d'autres <u>ressources</u>, <u>initier</u> le traitement, <u>modifier</u> le traitement après consultation

<u>B.3</u><u>. The gaps in service</u>

B.3.1. (1 min)

- **Avec quels services de douleur avez-vous travaillé ?**

- Unité de gestion de la douleur Alan-Edwards, l'Hôpital *général* de *Montréal*
- L’Institute de gériatrie, Clinique de gestion de la douleur
- Clinique de gestion de la douleur Verdun
- Service de gestion de la douleur de l’Hôpital Général Juif
- Consultation de gestion de la douleur interne (Herzl, Queen Elizabeth GMF)

- Autres (lesquels ?)

CLARIFY ALL FURTHER ANSWERS IF ONE WORKED WITH 2 OR MORE SERVICES

B.3.2. (3-5 min)

- Quels étaient **les éléments positifs de votre expérience** avec ces services de traitement de la douleur ?

- Cette expérience, comment a-t-elle **affecté vos jeunes patients ?**

Aide-mémoires :
- Temps impliqué
- Disponibilité d'informations sur le service
- Documentation
- Qualité de l'information apprise sur l'état du patient et sa gestion
- Votre satisfaction quant à la pertinence de la réponse
- Satisfaction du patient avec le service reçu
- Satisfaction de la famille / des soignants

B.3.3. (15 min)

- Quels étaient les **éléments négatifs de votre expérience** avec ces services de traitement de la douleur ?

- Cette expérience, comment a-t-**elle affecté vos jeunes patients ?**

Aide-mémoires :
- Temps impliqué

- Disponibilité d'information sur le service
- Documentation
- Qualité de l'information apprise sur l'état du patient et sa gestion
- Votre satisfaction quant à la pertinence de la réponse
- Satisfaction du patient avec le service reçu
- Satisfaction de la famille / des soignants

B.4. Mitigation strategy (possible solutions)

B.4.1. (3-7 min)

- Après qu'une demande de consultation ait été envoyée, quelle **serait une réponse *idéale* d'un service de gestion de la douleur ?**

- ***Idéalement*, comment vous ou votre équipe pourriez-vous être impliqué en attendant ?**

Aide-mémoires :

- Le délai / urgence de triage (Quels cas sont considérés plus urgents, demandez un exemple et une raison)
- Communication avec le praticien référent (écrite, orale, électronique, etc.)
- Type de communication (appel téléphonique, lettre, formulaire, standardisé, non standardisé)
- Les attentes spécifiques du service de la douleur (connaissant le statut du triage, le temps d'attente, les options de traitement intérimaires disponibles, etc.)
- Suivi longitudinal sous la forme de communications multiples basées sur des formulaires de rapport standardisés
- Aide à la gestion de la douleur entre-temps.
- Ressources supplémentaires pour les patients et les médecins.

B.4.2. (7-10 min)

- ***Idéalement*,** qu'est ce qui **faciliterait la communication** entre le **service** de la douleur**, le patient** et **le praticien référent ?**

- **Comment aiderait-il vos jeunes patients âgés de 18 à 25 ans ?**

Aide-mémoires :
- Le traitement tel que rapporté verbalement par le patient
- Communication écrite ou autre type de communication envoyées par le service de gestion de la douleur (quel serait le moyen idéal pour le faire?)
- Intérimaire structuré/ note récapitulative / (qu'est-ce qu'il faut y inclure?)
- Information générale sur la structure du service de la douleur, la mission, la structure de consultation
- Vidéo (quel type d'information?)
- Outils de communication (lettres, notes, carnet de patients avec dates, noms, médicaments)

B.4.3. (5-10 min)

- Quels sont les **problèmes principaux** qui devraient être **améliorés** d'abord pour **mieux servir les jeunes adultes** souffrant de douleur chronique ?

- Comment les **équipes de soins primaires** pourraient-elles **aider les jeunes patients pendant leur transition** vers les services pour adultes ?

Aide-mémoires :
- Stratégies de communication
- Accès aux services
- Résumé de la consultation
- Plan de traitement
- Support post-traitement actif
- Plage de temps
- Développement de services locaux / internes
- Accès à d'autres spécialités de la douleur (dépendance, physiothérapie, travail social, psychiatrie, rééducation)

5	**Utilisez-vous des formulaires préétablis / gabarits / formulaires électroniques pour l'évaluation et le suivi de la douleur chronique ?**	**Oui**	**No**	**Pas certain**
6	Dans votre pratique, utilisez-vous un **contrat pour les opiacées** ou un autre outil similaire pour assurer le suivi de la prescription des narcotiques ?	Oui	No	Pas certain
7	Vos **patients utilisent-ils** au moins un **outil** préétabli pour gérer leur douleur et médicaments ex., un journal de la douleur, une application pour téléphone, un calendrier de rendez-vous, ou une notification électronique pour leurs médicaments ?	Oui	No	Pas certain
8	Est-il important pour vous de **confirmer** si vos **jeunes patients se pressentaient à leur rendez-vous** avec les spécialistes de la douleur chronique ?	Oui	No	Pas certain
9	Est-il important pour vous d'avoir le **résumé de chaque visite** liée à la douleur chronique de votre patient **à l'urgence** ?	Oui	No	Pas certain
10	Selon vous, dans le domaine de la douleur chronique, **les équipes de soins primaires** devraient-elles être **responsables** d'une **transition structurée** des adolescents et des jeunes adultes vers les services pour les adultes ?	Oui	No	Pas certain
11	Êtes-vous **satisfait de vos connaissances et savoir-faire** dans le domaine de la douleur chronique en soins primaires ?	Oui	No	Pas certain

COMMENTAIRES (5 min)

Quelles sont **les autres approches** qui pourraient contribuer à la fluidité de la transition vers les services adultes ?

Vos collaboration et participation à l'étude seront grandement appréciées, d'autant plus que nous nous rendons compte de votre horaire surchargé. Merci d'avance de la part de l'équipe de TRAST !

OTHER STUDY MATERIAL

1. EXAMPLE OF THE CONSENT FORM in French (PARTNER)

Titre du project.
Programme TRAnsitionnel STructuré contre la douleur chronique pour adolescents et jeunes adultes : **projet TRAST**.

Présentation des chercheurs.
Cette recherche est dirigée par Dre Irina Kudrina (groupe de médecins de famille Reine Elizabeth) et Dr. Michael Dworkind (centre de médecine familiale Herzl). Cette étude est supportée par l'Unité de gestion de la douleur Alan-Edwards et Le Réseau-1. Universités participantes : l'Université McGill et l'Université de Montréal.

Avant d'accepter de participer à ce projet de recherche, s'il vous plaît prenez le temps de lire ce formulaire et de comprendre les informations qu'il contient. Posez autant de questions que vous voulez pour bien comprendre ce qu'on vous demandera de faire. Vous n'êtes pas obligés de participer si vous ne le voulez pas.

Nature de l'étude.
Vous êtes invités à participer à cette étude en tant que partenaire de l'équipe TRAST ayant une expérience de travail avec les services de gestion de la douleur chronique. Votre point de vue nous aidera dans l'évaluation des écarts de soins et de services pour les jeunes adules lors de la période de transition et d'adaptation aux services pour les patients adultes souffrant de douleur chronique. À la fin de cette étude d'une durée approximative de 12 mois, nous espérons identifier des écarts de services et formuler des recommandations pour la collaboration et la communication entre les services de soins primaires et spécialisés.

Cette étude a été financée par le Reseau-1(réseau de connaissances en services et soins de santé intégrés de première ligne, Québec).

Déroulement de votre participation.
Si vous acceptez de participer, nous vous demanderons de rejoindre plusieurs réunions d'équipe, qui durerons entre 60 et 90 minutes et / ou d'envoyer-nous vos commentaires par courriel. Vous aurez la chance de partager vos expériences et de parler des soins que vous avez reçus. Plus précisément, nous sommes intéressés d'avoir l'information sur les problèmes administratifs, bureaucratiques et autres difficultés que vous jugez comme affectant votre santé physique, sociale et familiale. Votre avis et vos conseils seront pris en compte pour la planification du projet. À la fin du projet, vous discuterez des résultats de l'étude et participerez à la formulation des recommandations finales.

Risques associés à votre participation.
Au cours de l'étude, il est possible que l'équipe vous pose des questions sur les soins que vous avez reçus, votre diagnostic, la façon dont il vous a été annoncé et votre expérience en général. Certaines des questions peuvent vous rappeler de mauvais souvenirs ou des moments stressants et déclencher des émotions négatives. Vous n'êtes pas obligés de divulguer l'information personnelle, sensible ou confidentielle. Si vous décidez d'utiliser votre exemple personnel, vous acceptez le risque de le divulguer à un nombre limité de professionnels de la santé ainsi qu'aux autres partenaires et membres de l'équipe TRAST.

Avantages et remboursement associés à votre participation.
En participant à ce projet, vous pouvez partager votre expérience et vos commentaires avec les équipes aspirant à améliorer la collaboration et la communication entre nos services. *L'objectif principal de cette étude est de partager les expériences, les idées et améliorer le système.* Il n'y aura pas de compensation pour la participation à ce projet, toutefois, nous rembourserons vos frais de stationnement / taxi au besoin (maximum de 20 $ par jour). Un repas léger sera commandé pour chaque réunion. Votre participation sera reconnue dans la publication qui en résulte (s'il y en a une).

Participation volontaire et droit de retrait.
Vous n'êtes pas obligés de participer. Si vous refusez, il n'y aura pas de conséquence sur vos soins et votre refus sera gardé confidentiel. Même si vous acceptez de participer, vous pouvez décider de quitter n'importe quand sans aucune conséquence et sans jugement. Vous n'avez pas besoin de nous dire les raisons pour lesquelles vous ne voulez plus participer. Vous pouvez aussi choisir de ne pas répondre à certaines questions pendant les rencontres.

Confidentialité et gestion des données.
Vous pouvez choisir d'être reconnu dans la publication résultante sous votre nom réel ou sous un alius (nom faux). Si vous décidez d'utiliser un alius, vous pouvez l'écrire sur la page 3. Aucune information personnelle ou médicale ne sera incluse sans votre permission. Vous recevrez les copies de tous les documents utilisés pour vérifier si l'information est exacte. En tant que membre de l'équipe, vous participerez à l'approbation des recommandations finales. D'autres mesures mises en place pour assurer la sécurité des données incluent :

- Les résultats seront présentés sous la forme d'un résumé ou de citations anonymes. Il n'y aura pas de noms réels d'individus spécifiques sauf les alias ;
- Le matériel que nous utiliserons pour notre projet (enregistrements, retranscriptions, notes des chercheurs…) sera gardé sur le réseau du Département de médecine familiale et l'Unité de gestion de la douleur Alan-Edwards de l'Université McGill où travaillent Dr Kudrina et les membres de l'équipe de TRAST. Pour y accéder, il faut passer par un ordinateur branché sur le réseau. Tous les ordinateurs sont protégés par un mot de passe ;
- Tous les documents papier avec votre nom (formulaire de consentement…) seront gardés dans une filière verrouillée, dans une suite barrée du Département de médecine familiale de l'Université McGill. Seuls les chercheurs principaux et leurs assistants auront accès à ces documents ;
- Nous allons présenter les résultats de notre projet dans les revues scientifiques ou dans des congrès. Les résultats seront présentés de manière générale sans être liés à votre identité. Par contre, il pourrait arriver que nous utilisions quelques citations de votre récit. Dans ce cas-là, nous pouvons utiliser votre alius ;
- Toutes les données seront détruites de façon permanente et sécuritaire au plus tard en janvier 2024 : nous déchiquetterons les données papier et nous demanderons à notre service IT de supprimer de façon permanente les données sur nos ordinateurs et nos serveurs. Il ne restera aucune de vos données personnelles ;

Pour des raisons de contrôle et de surveillance, votre dossier de recherche pourra être consulté par une personne mandatée par le comité d'éthique de la recherche, par l'établissement ou par une personne mandatée par des organismes publics autorisés. Toutes ces personnes et ces organismes sont formés pour assurer votre confidentialité.

Renseignements supplémentaires
Si vous avez des questions sur la recherche ou sur votre participation, vous pouvez communiquer avec la chercheure principale Dre Irina Kudrina à l'adresse courriel : irina.kudrina@mcgill.ca
Vous pouvez également contacter les membres de l'équipe TRAST à l'adresse de notre équipe
project.trast@gmail.com

Si vous désirez parler avec une personne qui n'est pas membre de l'équipe de recherche au sujet de vos droits en tant que participant, ou si vous avez des plaintes à propos du projet, veuillez communiquer avec :
Commissariat aux plaintes et à la qualité des services
Point d'accès : Institut Douglas
Numéro sans frais : 1 844 630-5125
commissariat.plaintes.comtl@ssss.gouv.qc.ca

Remerciements
Votre avis et votre expérience sont précieux pour nous permettre de réaliser cette étude avec succès. Nous apprécions votre collaboration et vous remercions d'y participer !

Signatures

Je soussigné(e) ________________________________consens librement à participer à la recherche intitulée : « Programme TRAnsitionnel STructuré contre la douleur chronique pour adolescents et jeunes adultes : projet TRAST».
J'ai lu le formulaire et j'ai compris le but, la nature, les avantages, les risques et les inconvénients du projet de recherche. Je suis satisfait(e) des explications, précisions et réponses que le chercheur m'a données sur ma participation à ce projet. J'ai reçu une copie de ce formulaire de consentement. Je comprends que je suis le partenaire de l'équipe TRAST et non le sujet de cette étude.

____ ________________________
Signature du/de la participant/e Date

Si vous préférez utiliser un alius, écrivez-le ci-dessous :

____

J’ai expliqué le but, la nature, les avantages, les risques et les inconvénients du projet de recherche au partenaire de l'équipe TRAST. J’ai répondu au meilleur de ma connaissance aux questions posées et j’ai vérifié la compréhension du partenaire de l'équipe TRAST.

____	_______________________
Signature du chercheur	Date

2. EXAMPLE OF THE CONSENT FORM in French (PARTICIPANT)

Titre du projet.
Programme TRAnsitionnel STructuré contre la douleur chronique pour adolescents et jeunes adultes : **projet TRAST**.

Présentation des chercheurs.
Cette recherche est dirigée par Dre Irina Kudrina (groupe de médecins de famille Reine Elizabeth) et Dr. Michael Dworkind (centre de médecine familiale Herzl). Cette étude est supportée par le l'Unité de gestion de la douleur Alan-Edwards et Le Réseau-1. Universités participants : Université McGill et Université de Montréal.

Avant d'accepter de participer à ce projet de recherche, s'il vous plaît prenez le temps de lire ce formulaire et de comprendre l'information qu'il contient. Posez autant de questions que vous voulez pour bien comprendre ce qu'on vous demandera de faire. Vous n'êtes pas obligés de participer.

Nature de l'étude.
Vous êtes invités à participer à cette étude en tant que professionnel ayant une expérience de travail avec les jeunes adultes souffrants de douleur chronique, ainsi qu'avec leurs soignants, leurs amis et leurs membres de famille. Votre point de vue nous aidera dans l'évaluation des écarts de soin et de services pour les jeunes adultes pendant leur période de transition et d'adaptation aux services pour les patients adultes. À la fin de cette étude d'une durée approximative de 12 mois, nous espérons identifier les écarts de soins et de formuler les recommandations pour améliorer la collaboration et communication entre les services de soins primaires et spécialisés.

Cette étude a été financée par le Reseau-1(réseau de connaissances en services et soins de santé intégrés de première ligne, Québec).

Déroulement de votre participation.
Si vous acceptez de participer, nous vous demanderons de participer à une entrevue semi-structurée qui prendra environ 60-80 minutes. Plus précisément, nous sommes intéressés à obtenir votre avis sur les problèmes administratifs, bureaucratiques et autres difficultés qui affectent la santé, la vie sociale et familiale de vos patients ainsi que vos pratiques de médecine

Risques associés à votre participation
Vous aurez la possibilité de partager votre expérience et votre opinion sur les soins donnés à vos patients. Toutes les données reçues seront anonymes et sauvegardées dans un endroit sécurisé. Certaines des questions peuvent vous rappeler de mauvais souvenirs ou des moments stressants et déclencher des émotions négatives. Vous n'êtes pas obligés de divulguer des informations personnelles, sensibles ou confidentielles.

Avantages et remboursement associés à votre participation.
En participant à ce projet, vous pourrez parler de votre expérience avec quelqu'un de neutre. Vous pourrez discuter des bons et mauvais aspects du service reçu par vos jeunes patients souffrants de douleur chronique. *L'objectif principal de cette étude est de partager les expériences, les idées et d'améliorer le système,* donc les groupes de discussion formés lors des étapes prochaines pourraient proposer des recommandations réalistes et des idées de développement basées sur un résumé anonyme de vos commentaires. Nous espérons que cette stratégie améliorera votre expérience professionnelle et les soins de vos patients de manière significative dans un avenir proche.

Il n'y aura pas de compensation pour la participation à ce projet, toutefois, nous rembourserons vos frais de stationnement / taxi au besoin (maximum de 20 $ par jour).

Participation volontaire et droit de retrait.

Vous n'êtes pas obligés de participer. Aucune conséquence ne découlera d'un refus de participer. Même si vous acceptez de participer, vous pouvez décider de quitter cette étude à n'importe quel moment sans aucune conséquence et sans jugement. Vous n'avez pas besoin de nous dire les raisons pour lesquelles vous ne voulez plus participer. Vous pouvez aussi choisir de ne pas répondre à certaines questions pendant l'entrevue.

Confidentialité et gestion des données

Pour nous assurer que votre identité ne soit connue que par les membres de notre équipe, nous avons mis en place ces mesures :

- Dès que vous serez inclus dans l'étude, vous choisirez un alius (faux nom). Comme ça, votre vrai nom n'apparaitra jamais dans nos rapports ;
- Nous utiliserons votre alius pour tous nos documents. Le chercheur est la seule personne qui aura accès à la liste qui relie votre nom et votre alius ;
- Un membre de notre équipe retranscrira votre entrevue ;
- Nous présenterons toujours des résultats en utilisant des alias ;
- Le matériel que nous utiliserons pour notre projet (enregistrements, retranscriptions, notes de chercheurs…) sera gardé sur le réseau du Département de médecine familiale et l'Unité de gestion de la douleur Alan-Edwards de l'Université McGill où travaillent Dre Kudrina et les membres de l'équipe de TRAST. Pour y accéder, il faut passer par un ordinateur branché sur le réseau. Tous les ordinateurs sont protégés par un mot de passe ;
- Tous les documents papier avec votre nom (formulaire de consentement…) seront gardés dans une filière verrouillée, dans une suite barrée du Département de médecine familiale de l'Université McGill. Seuls les chercheurs principaux et leurs assistants auront accès à ces documents ;
- Nous allons présenter les résultats de notre projet dans des revues scientifiques ou dans des congrès mais il ne sera pas possible de vous identifier personnellement ou de vous reconnaitre. Les résultats seront présentés de manière générale sans être liés à votre GMF (groupe de médecins de famille) ou à votre identité. Par contre, il pourrait arriver que nous utilisions quelques citations de votre entrevue. Dans ce cas-là, nous utiliserons les alias ;
- Nous distribuerons un court résumé de nos résultats aux participants qui sont intéressés. Si vous êtes intéressés, écrivez votre adresse courriel (voir page 3) ;

- Toutes les données seront détruites de façon permanente et sécuritaire au plus tard en janvier 2024 : nous déchiquetterons les données papier et nous demanderons à notre service IT de supprimer de façon permanente les données sur nos ordinateurs et nos serveurs. Il ne restera aucune de vos données personnelles ;

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Pour des raisons de protection, si nous avons besoin de communiquer avec vous rapidement, vos coordonnées et la date de début et de fin de votre participation au projet seront conservés pendant un an après la fin du projet dans un répertoire à part maintenu par le chercheur responsable de ce projet de recherche.

Renseignements supplémentaires
Si vous avez des questions sur la recherche ou sur votre participation, vous pouvez communiquer avec la chercheure principale Dre Irina Kudrina à l'adresse courriel : irina.kudrina@mcgill.ca
Vous pouvez également contacter les membres de l'équipe TRAST à l'adresse de notre équipe
project.trast@gmail.com

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Numéro sans frais : 1 844 630-5125
commissariat.plaintes.comtl@ssss.gouv.qc.ca

Remerciements
Votre collaboration est précieuse pour nous permettre de réaliser cette étude, et nous vous remercions d'y participer malgré votre horaire chargé !

Signatures

Je soussigné(e) _________________________________consens librement à participer à la recherche intitulée : « Programme TRAnsitionnel STructuré contre la douleur chronique pour adolescents et jeunes adultes : projet TRAST».

J'ai lu le formulaire et j'ai compris le but, la nature, les avantages, les risques et les inconvénients du projet de recherche. Je suis satisfait(e) des explications, précisions et réponses que le chercheur m'a données sur ma participation à ce projet.

______________________________________ _______________________

Signature du/de la participant/e Date

Veuillez choisir votre **alius :**

____

Un court résumé des résultats de la recherche sera expédié aux participants qui sont intéressés. Pour le recevoir, écrivez votre adresse courriel sur la ligne. **Les résultats ne seront pas disponibles avant 2019. Si cette adresse change d'ici cette date, vous êtes invités(-ées) à donner votre nouvelle adresse à la chercheure principale.**

Votre adresse électronique :

____

J'ai expliqué le but, la nature, les avantages, les risques et les inconvénients du projet de recherche au participant. J'ai répondu au meilleur de ma connaissance aux questions posées et j'ai vérifié la compréhension du participant.

_____________________________________ _______________________

Signature du chercheur Date