

Youth and Family Experiences of the CHEO Gender Diversity Clinic

January 2019

**Presented to the Children's Hospital of Eastern
Ontario (CHEO) by Support and Education for Trans
Youth Ottawa (SAEFTY Ottawa)**

Written and prepared by Kaeden Seburn, Jason Burns,
Emily Clarke, Sam Faulkner, Rowan Garcia, O.G Thorne,
and Donnie Warren

Table of Contents

Table of Contents	2
Content Warning	3
Executive Summary	4
Background	5
Methodology	5
Demographics	6
Summary of Results	7
Impact of the Clinic	7
Gender Affirming Care Model and its Application to Practice	8
Overall Experiences at CHEO	8
Nonbinary Identities	9
Preferred Name and Pronoun Use	10
Gender Affirming Care	11
Desistance	13
Timelines and the Assessment Process	13
Intake	13
Hormone Blockers	13
Hormone Replacement Therapy	14
The Assessment Process	15
Gatekeeping	17
Best Practices for Client-Centered Care	18
Autonomy in Decision Making	18
Client Centered Care	20
Supporting Letters, Referrals and Aging Out	21
Best Practices for Trauma Informed Care and Research Ethics	22
Trauma Informed Care	22
Physical Exams	22
Research	23
Discussion and Potential Solutions	24
Gender Affirming Care Model and its Application to Practice	24
Nonbinary Identities	24
Preferred Name and Pronoun Use	24
Gender Affirming Care	25
Desistance	26

Timelines and the Assessment Process	27
Hormone Blockers	28
Hormone Replacement Therapy	29
The Assessment Process	29
Gatekeeping	31
Best Practices for Client-Centered Care	32
Autonomy in Decision Making	32
Client Centered Care	33
Supporting Letters, Referrals and Aging Out	34
Best Practices for Trauma Informed Care and Research Ethics	34
Trauma Informed Care	34
Physical Exams	35
Research	36
Suggestions for the Future	37
References	38

Content Warning

This survey includes quotes directly from respondents that detail experiences of transphobia, cissexism, physical exams, and questions about sexuality and sexual assault which may be difficult to read. Please reach out for support or contact @saeflyottawa on social media or by email at saeflyottawa@gmail.com.

Executive Summary

A total of 53 youth and parents responded to a survey by SAEFTY, describing their experiences accessing transition-related care at CHEO's gender identity clinic. Respondents described a wide range of experiences, giving the clinic an overall average rating of 3.1 on a scale of 1 to 5. Some clear trends indicated which clients who were most likely to have positive or negative experiences with generally higher ratings from parents compared to youth. Nonbinary identified youth also tended to report having more difficulties accessing the services they needed and feeling less affirmed in the clinic. As a result, many nonbinary youth were not open about their identity with all of their providers.

Most clients reported good experiences with staff in the clinic using the correct name and pronouns when referring to them, although some people had concerns with the wrong name being used when referring to the electronic system. Overall, approximately one half of respondents reported feeling that their gender was affirmed consistently when accessing services at CHEO, while 40% described having the autonomy to make their own decisions about the care that they wanted. Other youth indicated a range of concerns and recommendations which are briefly outlined below.

Respondents who described having positive experiences accessing care at the clinic often reported that the staff were kind and attentive, that they felt listened to and that their gender was believed and affirmed. Some respondents also described feeling a sense of community in the clinic, which they appreciated.

There were many different concerns that respondents raised when describing negative experiences in the clinic. Some key concerns included:

1. Long wait times to access services, which significantly impacted many youth's mental health and wellbeing. This was particularly noted for access to Lupron, since many youth experienced significant distress from the unwanted puberty changes that occurred when their access to Lupron was delayed.
2. Clients were required to attend too many appointments in order to access the care that they needed. The average number of appointments required before starting hormones was 11, which indicates both a significant wait time and an extensive assessment process.
3. Youth felt that their gender was not believed or affirmed by providers or that they were required to prove their identity in order to access services.
4. Youth experienced gatekeeping from providers who required youth to meet specific requirements in order to access services.
5. Youth were asked uncomfortable or invasive questions by providers, which many respondents did not feel were relevant to their readiness to access transition-related services. Often these questions were viewed as an attempt to force youth to prove that they were "trans enough."

6. Youth experienced pressure or expectations to follow a typical cookie-cutter transition path when this did not best meet their transition goals or needs.
7. Youth experienced inappropriate physical exams and were not informed of the reasons for their physical exams. On many occasions, providers did not ask about or respect their boundaries during exams.
8. Some youth or families were told that 80% of prepubescent trans youth do not go on to identify as trans as adults, despite this being untrue and widely considered to be harmful.
9. Clients are concerned that research is occurring that includes trans youth in the clinic without their knowledge or informed consent, and that aspects of their assessment processes are used for research purposes rather than for their individual care.

Background

It is estimated that 0.6% of the population identifies as transgender. In Canada, the transgender population is estimated to be over two hundred thousand. A person who is transgender is a person whose gender assigned at birth differs from their gender identity. Transgender can be used as an umbrella term for both binary (male, female) and non-binary identities.

In Ottawa, many General Practitioners are uncomfortable treating transgender youth or may not have the resources to do so. If trans youth need medical intervention, the most common practice is to refer them to the Children's Hospital of Eastern Ontario (CHEO). Before accessing gender affirming medicine, the youth must go through the Adolescent Health Clinic, Clinic C5, which provides the client a formal diagnosis of gender dysphoria, sends letters of confirmation for name changes and gender marker changes, and refers clients to other clinics inside and outside of CHEO. There is no public data on how many people access clinic C5 because of gender dysphoria.

Many facilitators and attendees of SAEFTY Ottawa have accessed services at the CHEO gender identity clinic. We have been sharing and hearing experiences of youth and families accessing the clinic for several years and these interactions have included many positive and negative experiences. The youth are grateful for the clinic; however, there are areas of concern and needed improvement that many have brought to light, indicating that the clinic does not adequately meet the needs of all trans and gender diverse youth who access it.

Methodology

Based on information gathered from informal conversations among trans and gender diverse youth and families in Ottawa, SAEFTY Ottawa administered a survey in the summer of 2018 to better understand the experiences of trans and gender diverse youth who have gone through Clinic C5. The survey included both quantitative and qualitative questions in order to identify an average experience, as well as highlight personal experiences of note. Forty-five questions were asked about many aspects of client experience at the CHEO Gender Identity clinic. The

questionnaire was open to youth and parents or guardians of youth who accessed or attempted to access care at the clinic. Parents or guardians who filled out the survey were instructed to respond to questions on behalf of the child that they were representing, including demographic questions (i.e. the age of respondents reflects the age of the youth accessing the clinic, not the parents or guardians who responded to the survey). The survey was electronically promoted and accessed through SAEFTY’s social media including Facebook and Instagram. The survey was also promoted at events throughout the summer of 2018 and an in person consultation was hosted in August 2018.

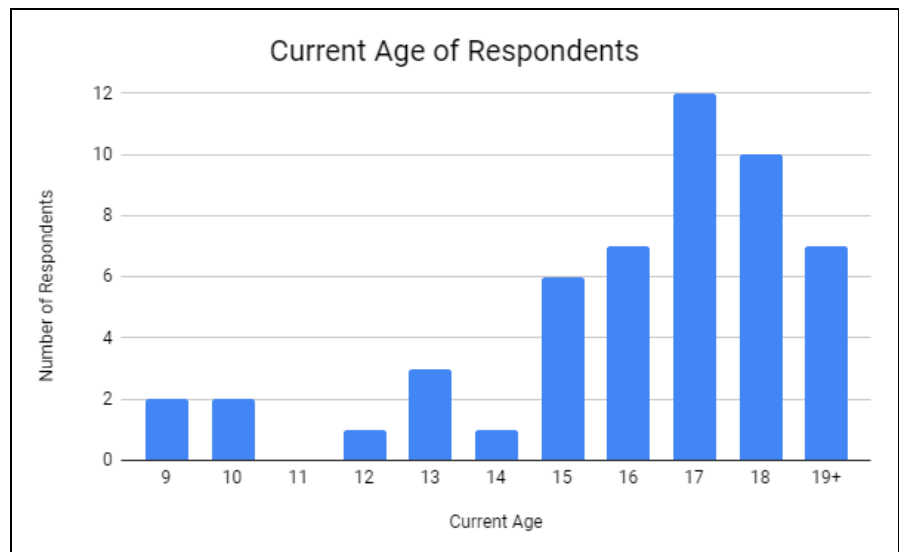
The survey received 53 responses from August 12, 2018, until the time it closed on October 13, 2018. While, there is no public data to indicate the total number of clients who have accessed the clinic since its inception, it is estimated that this represents between 5% and 15% of the population. It is worth noting that youth who have had a negative experience or those more politically involved may have been more likely to respond. As well, people who are active online within the trans community are more likely to have accessed the survey due to how it was promoted.

The survey data were analyzed by members of SAEFTY to identify common themes in youth and family experiences and recommendations were identified based on these themes. This report consists of statistical analysis of quantitative data, informal data coding and analysis of qualitative answers. Some information was also included from informal follow-up interviews and other conversations that members of the SAEFTY team have had with trans and gender diverse youth and families in Ottawa.

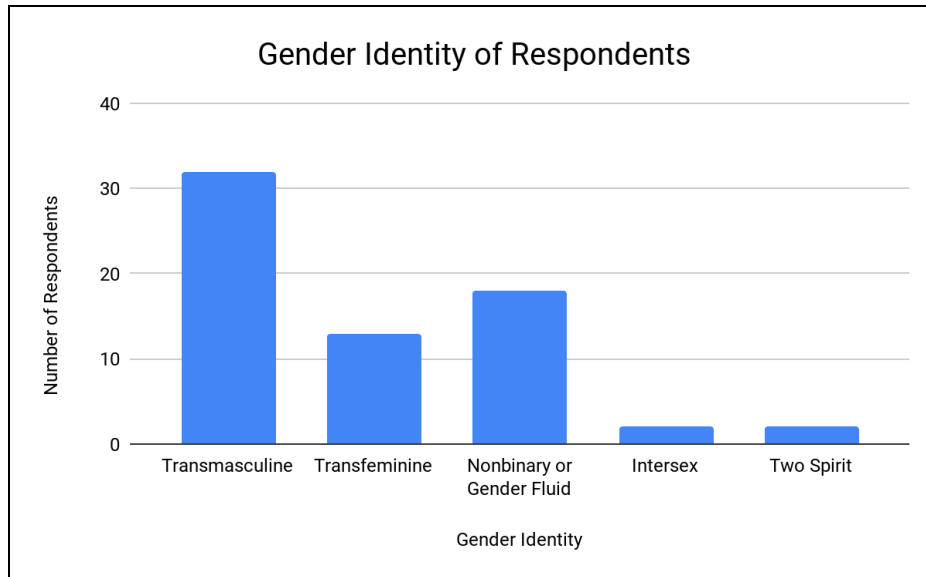
Demographics

The survey received 53 responses, 73% of which were youth and 27% of which were parents or guardians. Respondents began accessing the clinic between the ages of 7 and 16 with the majority of the youth between 13 and 16 when they first accessed the clinic. The respondents ranged in age from 9 to over 19 at the time of response, with most youth

being 15 or older. All respondents began accessing the clinic between 2011 and 2017, with the majority beginning to access it between 2015 and 2017.



Youth reported a range of gender identities, with a significant overrepresentation of transmasculine people. Of the respondents, 62% identified as transmasculine, 32% as nonbinary, 24% as transfeminine, 4% as intersex, and 4% as Two Spirit. Respondents selected any of the identities that apply to them, thus many selected more than one option and the percentages add to greater than 100%. SAEFTY notes that due to an underrepresentation of



transfeminine respondents, the results might not accurately reflect their experiences.

Nearly all respondents identified as white. As a result, we are not able to make recommendations regarding the needs of racialized and Indigenous clients, and we strongly recommend that

CHEO conduct further consultation with BIPOC (Black, Indigenous, People of Colour) clients and communities to identify both barriers to BIPOC youth and families accessing the clinic, as well as barriers that they are experiencing within the clinic.

Of the respondents, 81% indicated that they had received or that they desired puberty suppressants. The majority of the respondents also indicated a desire for or had already received hormone replacement therapy (HRT). Some respondents indicated a desire for HRT without puberty suppressants, or that they desired puberty suppression but did not want or were uncertain about HRT. Those who did not indicate a desire for either puberty suppression or HRT were most frequently interested only in counselling or top surgery, possibly with the potential for requesting other medical services in the future.

Summary of Results

Impact of the Clinic

Respondent feedback indicates that the CHEO gender diversity clinic is doing important work. Clients described that being able to access hormone blockers¹ and hormones when needed led to improved mental health, wellbeing, and reduced dysphoria. Respondents indicated that this

¹ Each instance of “hormone blockers” or “blockers” is referring specifically to the commonly used hormone blocker Lupron

change gave them hope, made them feel able to be their authentic selves, and in certain cases, saved their lives.

In instances where youth felt as though they were not able to access the services needed as a result of delays, the youth expressed a negative impact on their mental health including feelings of shame about their identity or experiences. Many respondents described feeling excluded from their gender diverse peers when they were unable to access care. Youth also described feeling hopeless or like they could never transition because the process would take too long.

“CHEO has allowed me to express my authentic self. If I had not been able to transition with the aid of blockers and hormones...but blockers especially... I feel like I may not be here today.”²

“Starting lupron [and] when estrogen started causing physical changes greatly improved my overall mood and reduced dysphoria a lot. I no longer feel as if I have to hide my body and I feel a lot more confident meeting new people.”

“Without affirming care when I needed it most, I am not sure if I would be alive.”

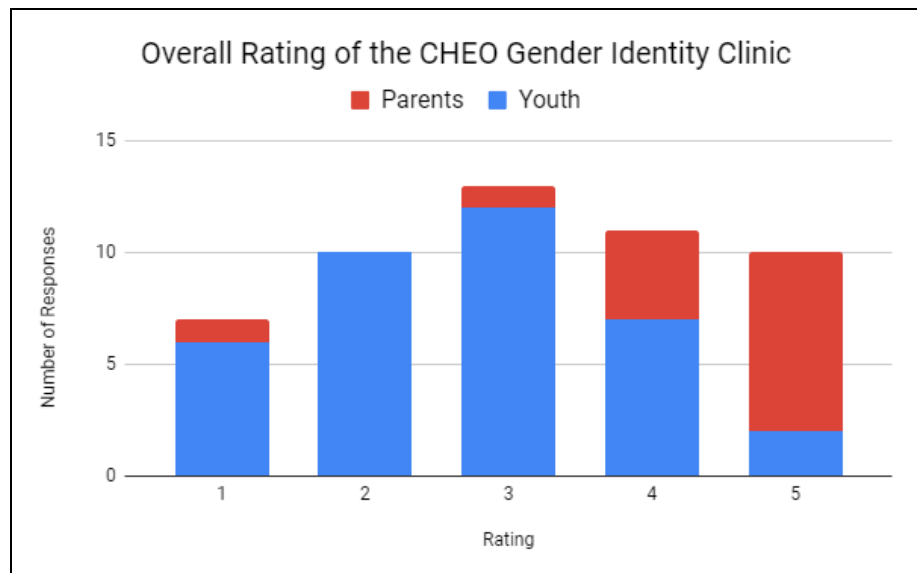
“[CHEO] was a big source of depression and dysphoria to me until they referred me to a different clinic. That referral has had an incredibly positive impact on my life however, and if they had believed me and helped me sooner I would have been in a much better place much earlier, and maybe avoided homelessness and a suicide attempt.”

Gender Affirming Care Model and its Application to Practice

Overall Experiences at CHEO

When asked to rate their overall experience at the clinic on a scale of 1 (bad) to 5 (good), the average rating was 3.1. There was a distinct difference between parent and youth ratings with the average rating from parents being 4.3 and the average from youth being 2.7.

Transfeminine youth rated the clinic lowest



² All quotes that appear in italics are direct quotes from the respondents of this survey.

at 1.8, while nonbinary or genderfluid youth also rated the clinic lower than average at 2.4.

Given the low response rate of transfeminine youth, this rating could have a sample bias. Additionally, there is a potential for skewed ratings given that many people accessed the survey through their involvement with support groups, which are often attended by youth who have had more difficulty in accessing services or support.

The most cited reasons for youth rating the clinic lower were feeling like they were not affirmed or taken seriously and long wait times. The youth also mention feeling as though they had experienced gatekeeping from providers which prevented or delayed them from accessing services. Gatekeeping, in this situation, refers to when an individual has to “prove” to a medical professional that they are “trans enough” or that they meet other imposed criteria to undergo HRT or the medical services the client wants and needs. While it may not be the intention of providers to act as gatekeepers, clients may feel as though they are experiencing this.

“My first initial appointment I was told I would be on hormones in 6 months only to be told 3 months later that I would likely not be put on hormones while still at CHEO at all.”

“I was very clear and confident about what I wanted and I was not taken seriously, leading to two years of appointments with huge wait times before receiving a referral to an endocrinologist outside of [CHEO]. Also, my doctor forgot to actually refer after he said he would, leading to an additional 6 months of waiting.”

This survey’s intention is to measure the experience of youth and families accessing the clinic and to identify factors that lead to positive or negative experiences and outcomes. By identifying, from a client perspective, how clients and providers can work together for the best outcomes, practices can improve to best meet clients’ needs. Gatekeeping is discussed in more detail below.

Some additional specific concerns mentioned by respondents included: having issues with appointments or referrals not being made or scheduled correctly; having difficulty contacting the clinic between appointments; being given inaccurate timelines regarding when they would be able to start Lupron, start HRT, or be referred for surgery; and the lack of trans staff at the clinic. These concerns are discussed in more detail below.

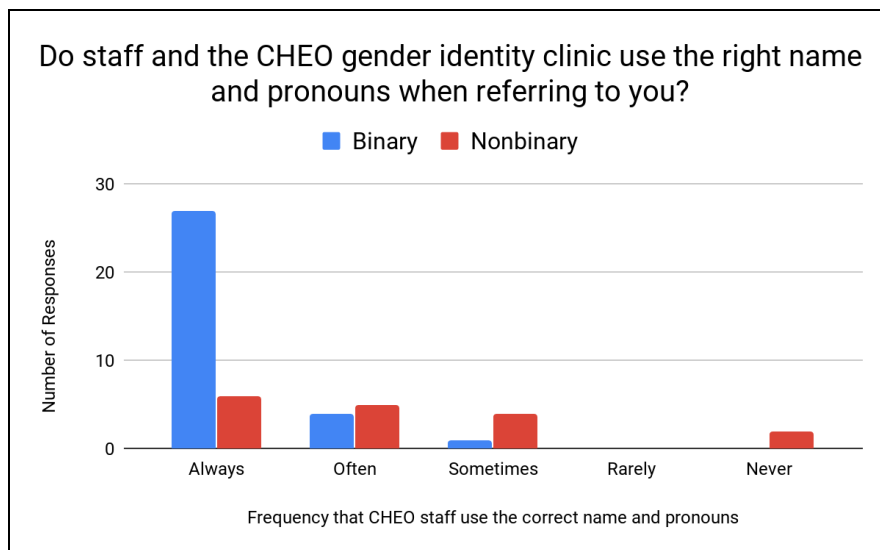
Common reasons for respondents to give the clinic high ratings included positive interactions with staff and receiving the information and care that they needed.

“Overall experience has been very good. As a parent, it was wonderful to have this clinic in my community. It would have been difficult, otherwise, to find the support my son needed to transition.”

Nonbinary Identities

Approximately one third of survey respondents indicated that they identify as nonbinary, however, less than 50% of them reported disclosing their nonbinary identity to all of their providers at CHEO. Rather, many nonbinary youth told their providers that they identify as binary trans female or male when this is not the case. The majority of those who had not disclosed their identity to all providers indicated that this choice was because they did not feel comfortable telling their providers about their identity since they were concerned that being nonbinary would delay their access to services. This fear was often cited based on experiences that they had heard from others in the community or their own experiences of previously coming out to providers in the clinic and having their access to services delayed. Some respondents also indicated feeling as though being open about their nonbinary identity had made providers hesitant to refer them to endocrinology.

“I was told due to my nonbinary identity that I was ‘too fluid’ to transition and receive the services I wanted.”



Preferred Name and Pronoun Use

Approximately two thirds of all respondents said that care providers in the clinic always used their preferred name and pronouns. An additional 18% indicated that this was often the case. Many people described being asked about their preferred name and pronouns immediately upon intake and indicated

that all of the staff used them with no issues.

Despite this, only 35% of all nonbinary or genderfluid respondents said that their name and pronouns were always respected, while an additional 29% said that this was often the case. This outcome may be influenced by the fact that not all nonbinary and genderfluid youth were out to their providers, and some people were not comfortable asking to have gender neutral pronouns used. Among nonbinary respondents who were out to all providers 56% reported that providers always used the correct name and pronouns, a number which is significantly lower than the overall rate of 67%.

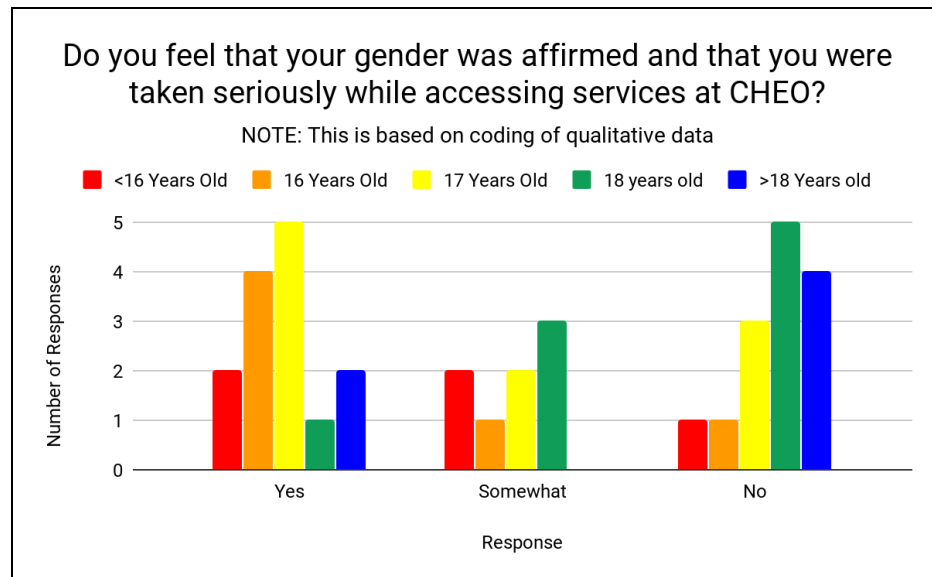
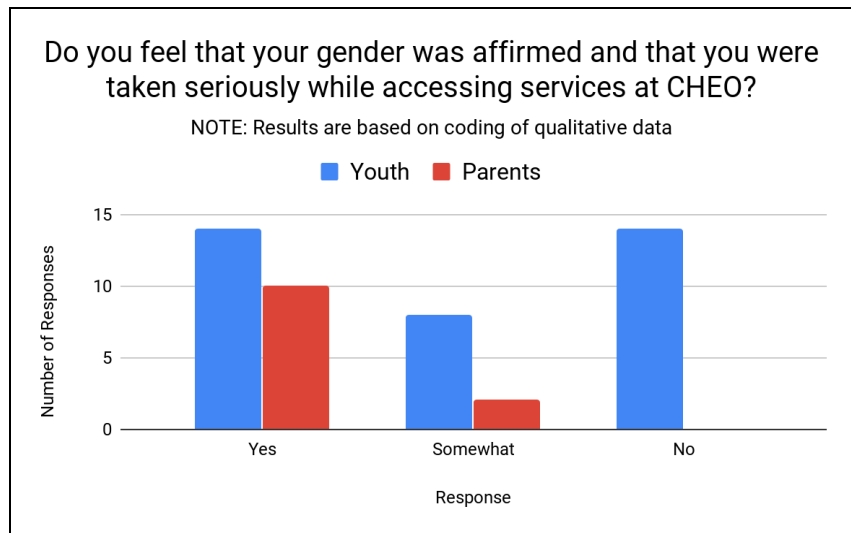
“I didn’t feel I was in a safe enough place to ask [clinic staff] to use they/them pronouns for me due to previous experiences in which they invalidated my nonbinary identity”

Some people described experiences where the wrong name or pronouns was listed in electronic systems which resulted in the wrong name being used in phone calls, letters or called over the speaker at the clinic. Some respondents also had the wrong name or pronouns used in case notes or in referral letters. Lastly, some described that staff at the front desk or providers who they were referred to by the clinic did not always use the correct name and pronouns.

“When going places at CHEO that the clinic referred me to, sometimes they don’t use the right name and pronouns. ... If the CHEO clinic is sending trans... youth there, the people... should know about the importance of proper use of names and pronouns.”

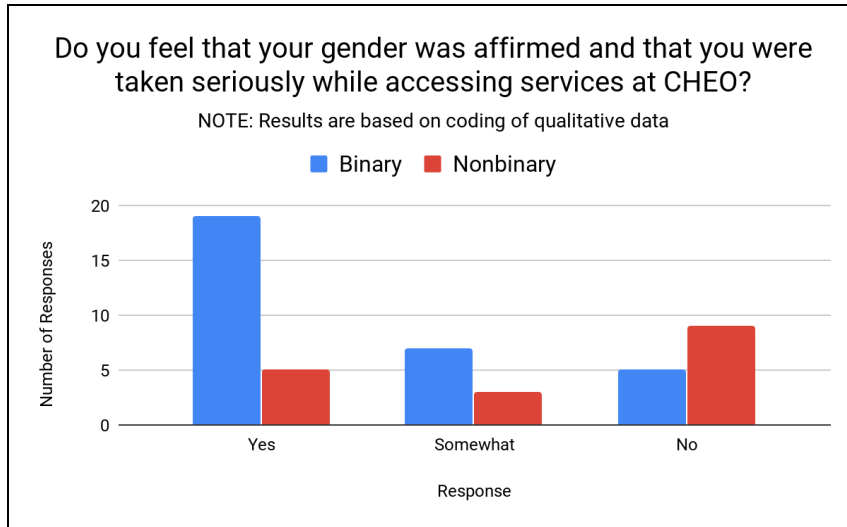
Gender Affirming Care

When asked if they felt that their gender was affirmed and that they were taken seriously while accessing services at CHEO, 49% of respondents answered yes, while 29% answered no. The last 20% indicated that this was the case at some times or with some providers. Some respondents had not initially felt affirmed when beginning to access the clinic but felt more positively now that they had progressed further in their medical transition.



Youth were less likely than parents to feel affirmed and taken seriously; 83% of parents responded yes to this question while only 39% of youth did. Among youth respondents, older youth and those who have been accessing the clinic for longer (i.e. since 2015) were less likely to feel affirmed. This

pattern may indicate that the clinic has improved for youth who have begun accessing it more



recently, or that those who have been in the clinic for longer have had more opportunities for non-affirming experiences or have different expectations for their care as they are older and have been transitioning longer. Nonbinary and genderfluid youth were also less likely to report feeling affirmed with only 15% answering yes to this question, and 70% answering no.

Those who felt that their gender was affirmed or that they were taken seriously while accessing services at the clinic explained that their names and pronouns had been consistently respected, and that they had been believed about their experiences with gender. Throughout the survey, respondents also indicated that they felt affirmed when they were able to access Lupron and HRT quickly, and receive all of the information that they needed from providers at the clinic.

“I’m able to get my blockers [and] hormones which is really important to me.”

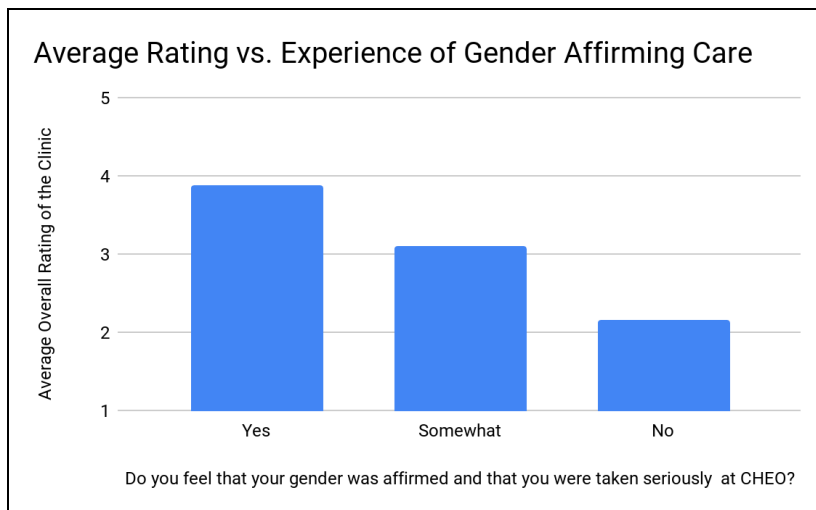
Those who did not feel that their gender was affirmed or that they were taken seriously while accessing services at the clinic had several explanations. A common theme throughout the survey was distress caused by long wait times to access services. Some respondents also described their nonbinary identities not being affirmed; feeling that mental illness was a barrier to accessing services; feeling patronized by or having to educate providers at the clinic; and not being taken seriously or feeling like they had to prove their gender to doctors, especially if they had not always expressed certainty about their gender identity.

“I felt I had to pretend I was 100% male-feeling to get referred to an endocrinologist.”

“My gender was taken seriously but I’m not sure I was at some points based off of the mental health struggles I was open about, I feel the staff took my pushing to receive my care in a timely manner as me being ‘an impatient teen with mental health issues’”

“I felt like the social worker took me seriously but I felt like I had to prove my gender to the doctor, which made me doubt my gender”

Respondents who felt that their gender was affirmed and that they were taken seriously when accessing the clinic also gave higher overall ratings for their experiences at the clinic on average, indicating that this is an important factor in clients' experiences.



Desistance

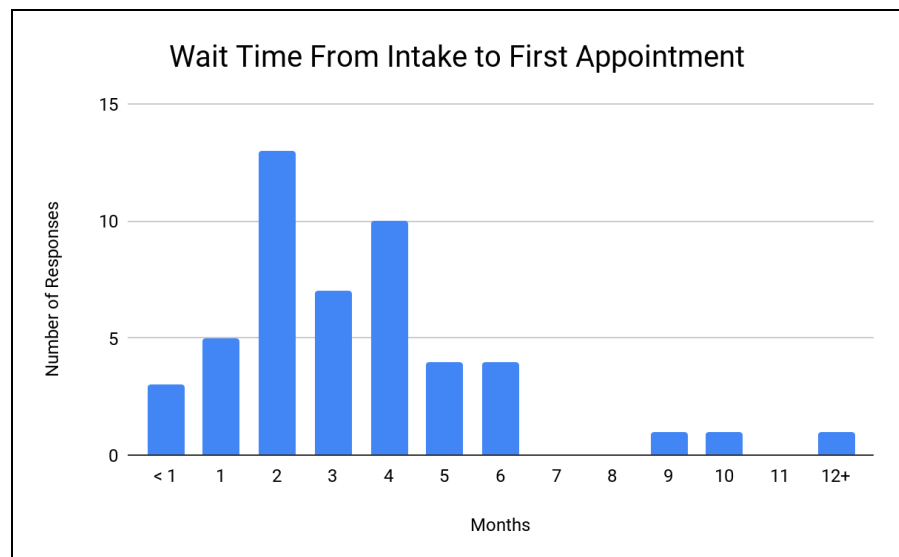
The term desistance is used in academic literature to describe children or youth who identify as trans and later identify as cisgender. Approximately 20% of respondents were told by a staff member at the clinic that "80% of prepubescent trans children do not identify as trans as adults." Respondents who have begun accessing the clinic more recently were

less likely to have been told this statistic; however some indicated being told this as recently as 2017, which is our most recent year of data. None of the respondents gave any indication that they had stopped identifying as trans.

Timelines and the Assessment Process

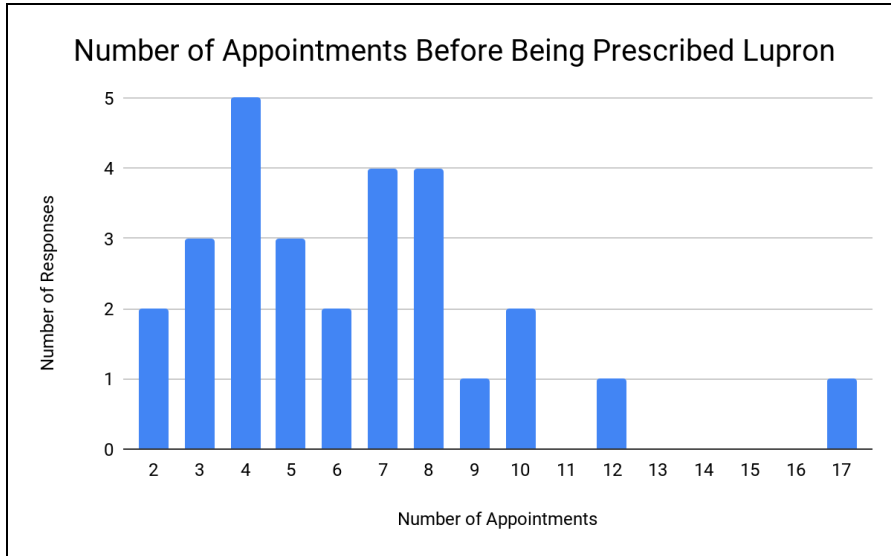
Intake

Respondents waited between less than one month and more than twelve months from the time of their referral to Clinic C5 until their first appointment at the clinic. The average wait time was 3.5 months, with approximately 60% of respondents reporting waiting between two to four months.



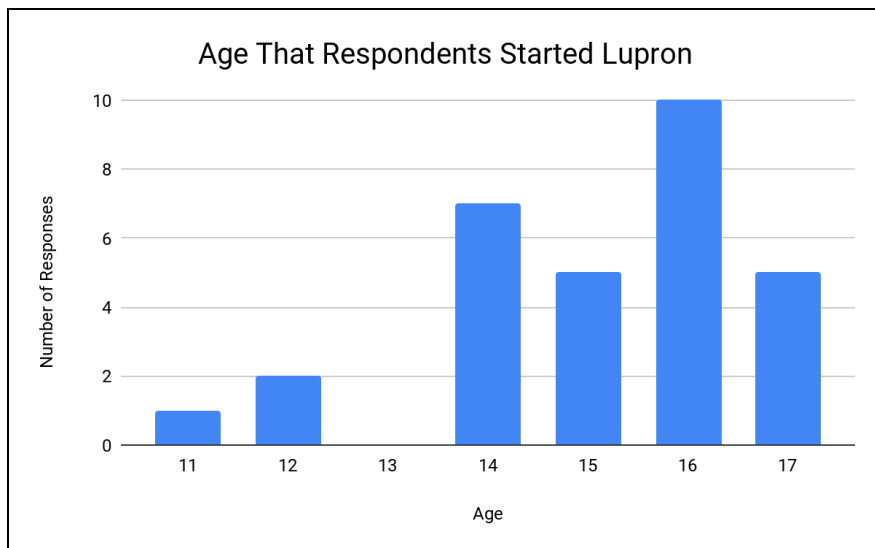
Hormone Blockers

Respondents had between two and seventeen appointments before being prescribed Lupron, with an average of 6.4 meetings. There did not appear to be any obvious reasons for the wide variation. Respondents were between the ages of 11 and 17 at the time that they received hormone blockers, with an average age of 15 years. At least one person's wait time was elongated to the point that they reported completing puberty before receiving Lupron. Another



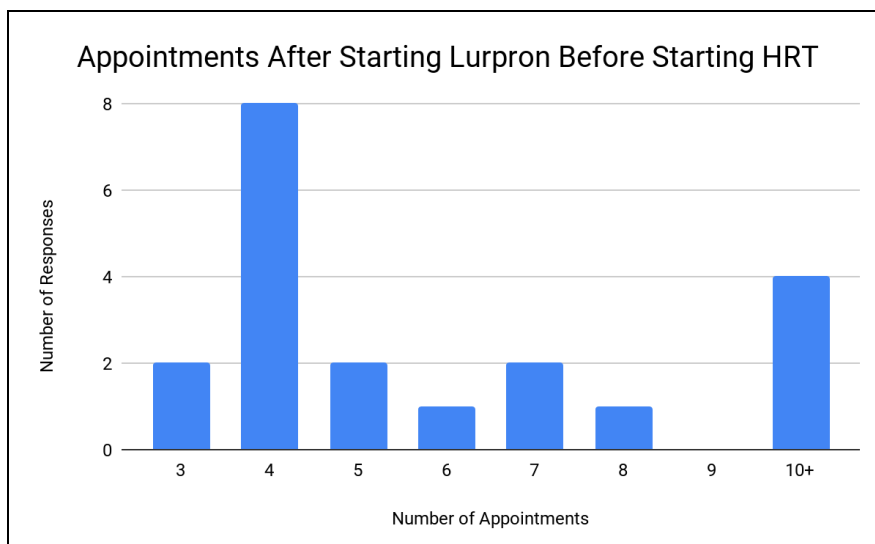
participant reported being told that they needed to have reached Tanner Stage II for a couple months before starting hormone blockers so that the physician could be sure that they would experience distress when beginning puberty. Tanner Scale refers to the scale used to measure development based on external primary and secondary

sex characteristics. Tanner Stage II, as mentioned previously, is the second stage that indicates the beginning of puberty.



Although the survey did not ask specifically how long it took between respondent's initial appointment and the time that they started Lupron, the majority of respondents were one year older at the time of beginning Lupron compared to their initial intake at the clinic.

Hormone Replacement Therapy

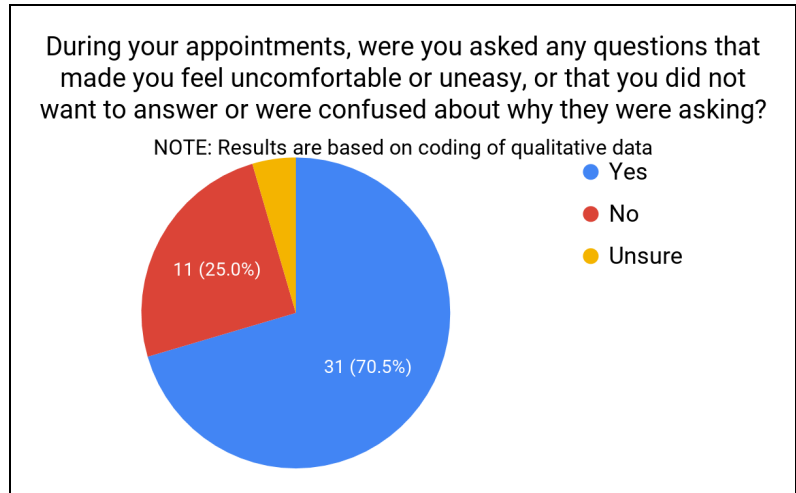


After receiving hormone blockers, respondents reported having between 3 and 10+ additional appointments before beginning HRT, with an average of 4.8 appointments. There did not appear to be any clear

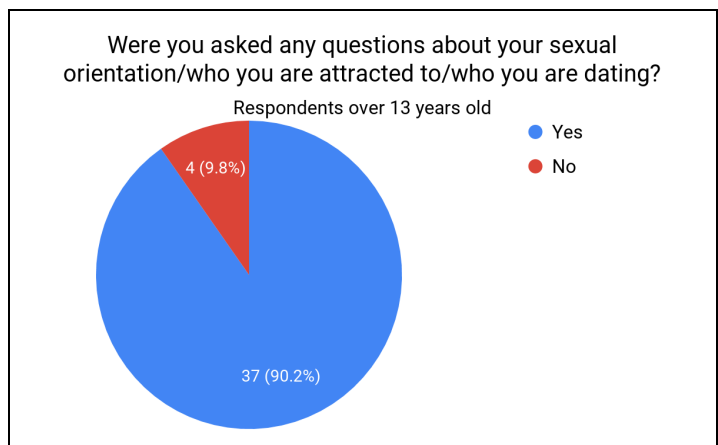
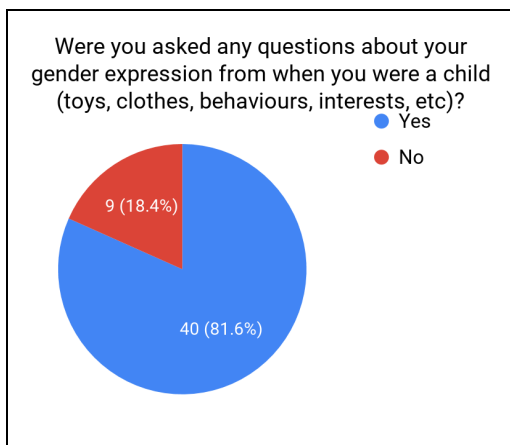
data trends explaining the reasons for this range. Overall, there was an average of 11 meetings between initial intake and starting HRT. Youth reported starting HRT between the ages of 14 and 17 with an average age of 16. Although we did not ask specifically how long it took between respondents starting Lupron and the time that they started HRT, about half of respondents were one year older at the time of starting HRT compared to when they started Lupron. Some of the other respondents were two years older at this time, while many were the same age.

The Assessment Process

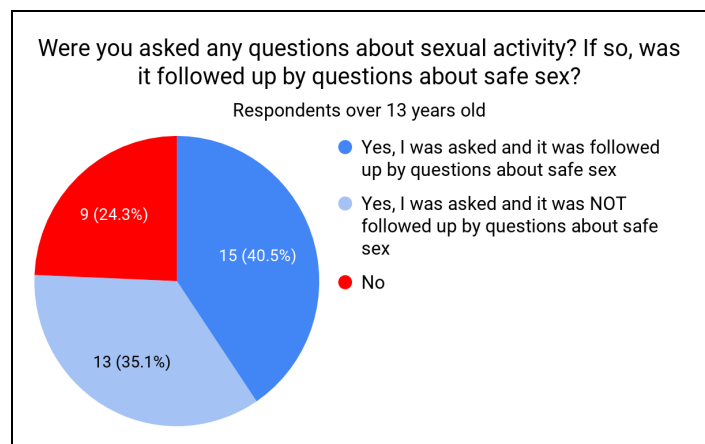
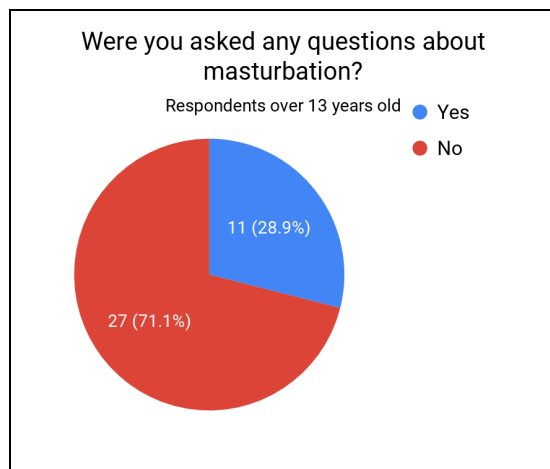
Of the respondents, 70% indicated that during appointments they were asked questions which made them uncomfortable or uneasy, or that they were confused by or did not know why they were being asked. We asked about a few specific questions based on stories that we have heard through informal conversations with youth and families about uncomfortable questions that they have been asked when accessing care in the past.



Over 80% of respondents were asked about their gender expression as a child. Of those over 13 years old, 90% were asked about their sexual orientation, who they are attracted to, or who they are dating; 27% were asked questions about masturbation; and 76% were asked about their sexual activity. Youth who were 13 years old or younger were not asked any of these questions. Transfeminine people were significantly more likely to be asked about masturbation, with 66% indicating that they had been. Of those asked about their sexual activity, 59% were asked follow up questions about safe sex while the other 41% were not.



When we enquired how respondents felt about the questions they were asked, 87% indicated that they were upset by them. Words that they used to describe their feelings included “dysphoric,” “uncomfortable,” “confused,” “weird,” “horrible,” “angry,” “awkward,” “objectified,” “ashamed,” “very bad,” “unwelcome,” “suicidal,” “dehumanized,” “embarrassed,” “disappointed,” or like they were not being listened to. Despite these feelings, several respondents described feeling pressured to answer anyway. Respondents also described that the questions seemed irrelevant, leading, or invasive and felt like they were coming from the doctors curiosity rather than medical necessity. Some people reported lying about the answers, because they felt uncomfortable.



“I didn’t understand why they felt it was important to know what toys I played with as a kid and it felt invalidating when I mentioned anything in my life that was remotely feminine (when I identify as transmasculine.)... I was worried that if I said I still enjoyed painting my nails I would be viewed as something other than trans.”

“I didn’t understand why they need to know my sexual orientation, as that does not really correlate with gender identity.”

“Some of the questions made me feel like I was being led to conclusions that they wanted to draw, like they were phrased to get specific answers.”

“[The questions made me feel] uncomfortable and objectified, like I was something to study or a spectacle”

“When I’m asked most of these questions I feel awkward because it’s not stuff I like to talk about but I do because I want to be taken seriously so I feel like I need to tell them about everything.”

In addition, we asked respondents what other questions, if any, they had been asked that stood out to them or made them uncomfortable. The responses fit into two broad categories:

questions that youth felt were being used to judge or prove their transness, and questions that are often used to determine the potential cause of young people's trans identities. Results also indicated repeated questions being asked about disordered eating when this was not a relevant concern to the client.

Questions that appear to be used to judge or prove clients' trans identities include:

- Do you want to keep living as a girl? If you had to live as a girl, would you kill yourself?
- Do you pee sitting or standing?
- What gender are your friends?
- Do you crossdress?
- Do you wear male underwear?

Respondents also described being asked about what dysphoria they experienced and how it impacted them. Youth described that these questions were asked in ways that made them feel like providers expected them to experience significant dysphoria about all aspects of their bodies and that this was expected to have a significant impact on them. Youth reported feeling judged or invalidated if they expressed that this was not the case.

"I had said something about not being too dysphoric about below the belt stuff at the time and I felt very judged, so I lied and said that yes I knew I wanted bottom surgery because I didn't want to be invalidated for not knowing."

Questions that appear to be used to prove the cause of clients' transness include:

- Why don't you want to be a girl anymore?
- Do you have friends who are trans?
- Questions about family life and parental conflict
- Questions about childhood trauma and sexual assault
- Asking youth what they think made them trans or if they feel that it is linked to mental illness

Gatekeeping

Throughout the survey, respondents described many barriers which they felt prevented or delayed their access to Lupron or HRT. A significant barrier identified by many youth was gatekeeping by providers, providers expressing concern or uncertainty, or providers seeming less willing to refer a client for transition related care as a result of a specific identity or experience that they had. Several clients described being able to access the services they needed only after advocating significantly for themselves.

"When I said I could not wait a full year for T I was taken seriously and they pushed down the wait to 6 months. I deeply appreciate that. But to have to advocate so firmly for myself at 16 over a semi- arbitrary time frame shouldn't be necessary."

Mental illness and nonbinary identities were the most significant and recurring barriers identified as resulting in delays to accessing care. Other experiences that respondents identified include: being uncertain about answers to some questions that they were asked or not always having been certain about transition goals, being overweight, parental conflict or lack of support, not being out to everyone in their life or being young when seeking access to services.

“[CHEO] threatened to not allow me HRT because I was suicidal. Knowing full well that 90% of my suicidal ideation had to do with dysphoria”

“Mental health is definitely a barrier because when I came in initially I was doing well and they said I would be on hormones soon, but then when I had a decline in mental health they refused to give me an estimated date of when I would finally receive care.”

“I believe telling [the staff] I was nonbinary delayed my access to hormone blockers because once I began telling them I identified as strictly male (even though I was lying), the process sped up noticeably.”

“I felt like I had to stretch my trans story to fit a stereotype”

“I was told that I was going through a phase and after that I didn’t want to reach out again”

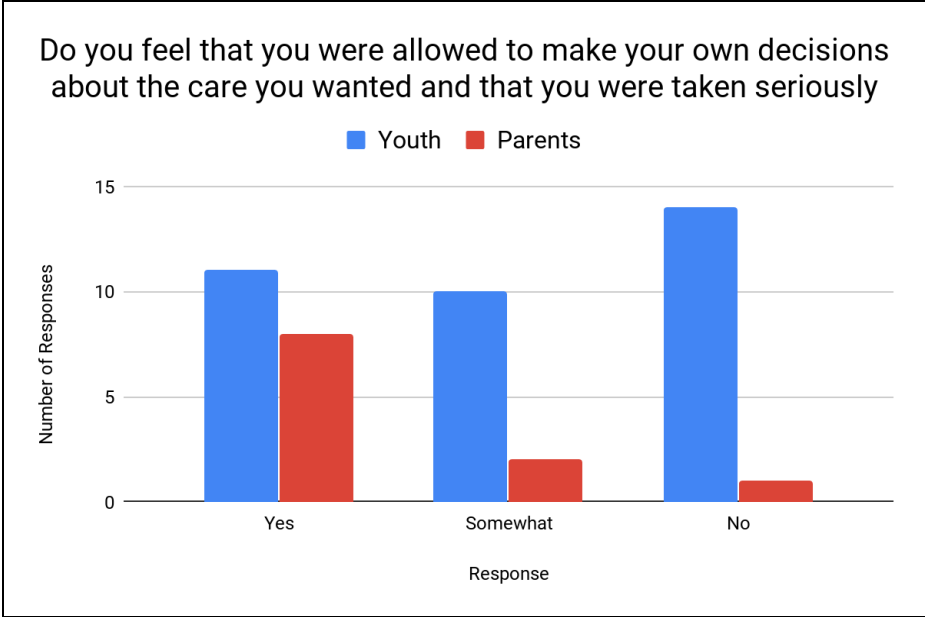
“I didn’t feel comfortable telling the doctor I might want biological kids so I lied so my services wouldn’t be delayed. I spent weeks crying because of it but I didn’t feel safe enough to tell anyone.”

Best Practices for Client-Centered Care

For the purpose of this report, client centered care refers to care that focuses on meeting the needs of the client. This may or may not be related to their trans identity specifically, but may also refer to more general aspects of their experience in the clinic.

Autonomy in Decision Making

Respondents were asked if they felt that they were allowed to make their own decisions regarding the care that they wanted and that their concerns were taken seriously. This could include making decisions about services that they did or did not want, such as Lupron, hormones, or surgery; making decisions about when they wanted to receive services; or making decisions about how they wanted to receive services, such as different dosages of hormones, different forms of administering hormones or different surgery techniques or surgeons. When responding to this question, 40% of respondents felt that they were able to make their own decisions, while 33% did not. Youth were significantly less likely than parents to answer this question positively with 73% of parents indicating that their decisions and concerns were taken seriously whereas only 31% of youth felt the same way. Among youth respondents, older youth and those who have been accessing the clinic for longer (i.e. since 2015 or 2016) reported

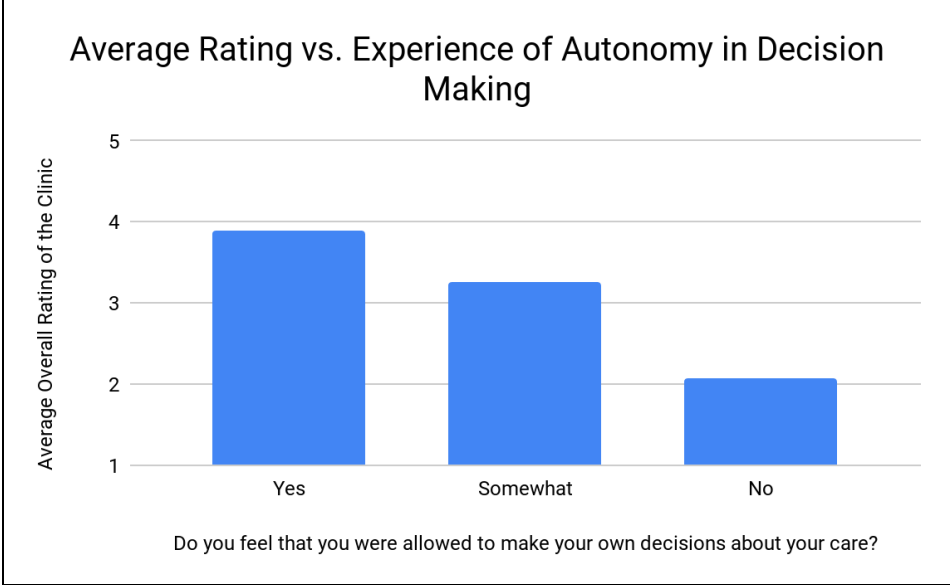


feeling that they have less autonomy over their care.

This pattern may indicate that the clinic has increased the autonomy that is granted to youth who have begun accessing it more recently, that experiences vary as clients progress through the clinic or that older youth or those who have been transitioning for longer

have different expectations for their care.

Respondents who felt that they had autonomy over their care described feeling that they were able to access HRT when desired and that they felt in control, listened to and that they were



able to make their own decisions. Those who felt that they had more autonomy over their care also gave significantly higher overall ratings for their experience at the clinic on average.

“My doctor listened to me and helped me problem solve.”

Many people who felt as though they had limited autonomy over their care described feeling pressured to follow a stereotypical transition path. Many respondents also described the process required for gaining access to endocrinology services as unnecessarily long. Additionally, respondents described feeling that they had to be mentally healthy and advocate strongly to gain access to services they needed. Some respondents described that they were given hormone doses that were too small to create change in the timeline they desired or that

they did not feel heard by their providers. In addition, some people felt pressured to start Lupron when they would have preferred to start HRT right away or were prevented from accessing Lupron when they felt it would help them. At least one young person indicated that they were considering using non-prescribed hormones as a result of the barriers they had encountered.

“I was forced to wait four months, and I am now on the lowest possible dose of estrogen (¼ of standard) and will be on this dosage for the next six months. This is not acceptable and I am highly considering moving to DIY grey market hormones.”

“Time and time again people told me that I would be put on Lupron, however that wasn’t what I wanted and no one listened to me for weeks.”

Experiences of Client Centered Care

Throughout the survey, respondents described many experiences, both positive and negative, related to client centered care. Many people specifically reported having good experiences with the endocrinology department as well as with a social worker.

“The endocrinologist was very affirming, explained everything clearly and in appropriate language. Assured my child more than once that she believed her gender. ... I felt listened to, not rushed and reassured.”

Many people felt that staff were kind, encouraging, supportive, affirming, and respectful and reported feeling like the staff genuinely care. Other positive experiences reported included feeling a sense of community and appreciating that the staff at the clinic knew and recognized them, and having staff who are honest about what they can and can’t do for them and when.

“When my doctor sent in my top surgery referral they let me hit the send button. I know this seems like such a small thing but it made my day.”

“Everyone was always very nice to me and I felt like they cared about me.”

“My doctor very clearly saw me as a guy, it was very affirming.”

Experiences that respondents described to indicate a lack of client-centered care included:

- Not feeling listened to or taken seriously;
- Having providers insist on talking to their parents against the youth’s wishes;
- Providers focusing too much on the desires of unsupportive parents at the expense of the needs of youth;
- Long wait times and being given inaccurate timelines regarding when they would be able to start Lupron or HRT;
- Having difficulty getting appointments at the clinic;
- The lack of trans staff at the clinic;

- Feeling pressured to make decisions based on provider assumptions about the needs of trans people, rather than their own needs and desires.

“At every appointment I always asked for a timeline of when things would be done. I was always lied to.”

Some respondents also reported feeling uncomfortable having a medical student in the room with them, but many people did not feel comfortable saying no to or disagreeing with their providers.

Supporting Letters, Referrals and Aging Out

The survey asked respondents if they have ever required supporting letters or referrals from CHEO for services outside of the clinic (e.g. referrals for surgery or other transition related services, letters for gender marker changes, etc.) and what their experience was in getting these documents. Almost half (45%) of respondents described having good experiences getting these referrals or letters, while 35% had negative experiences and 20% had mixed experiences.

In general, respondents had very good experiences getting supporting letters for name and gender marker changes and found that these were completed quickly and efficiently. Some people described having more difficulty getting other kinds of letters and referrals (e.g. surgeons and endocrinologists) and that, in some cases, they had to follow up multiple times before the referral was completed. Some people also described having the wrong name or pronouns used in their letters or referrals or that the letters were incomplete or included negative or irrelevant information.

“[In my top surgery referral] I was misgendered, they said I had a “comorbid” disorder, and mentioned completely irrelevant information that made my mental health challenges seem like a great concern to my surgeon (even though it does not in anyway affect my capacity to consent to surgery). Because of these letters I had to have a follow up appointment with my psychologist and get another letter to say that I was actually capable of consenting to surgery. This delayed my care with the surgeon greatly.”

“Even after I was told the referral had been sent in by CHEO, it hadn’t, so I [waited] an extra three weeks for a simple fax.”

“[Letters or referrals] were provided quickly when requested and they provided all the necessary information and were successful in getting the result.”

“[My doctor] will not write [a referral] without having another appointment with me.... It has been extremely frustrating to get this letter and it feels like [my doctor] has not taken my request very seriously.”

While a few respondents had negative experiences with aging out of the clinic, many respondents who had aged out of care reported that they had been given a referral to an external endocrinologist and that their care had continued smoothly.

Best Practices for Trauma Informed Care and Research Ethics

“Trauma Informed Care is an organizational structure and treatment framework that involves understanding, recognizing, and responding to the effects of [...] of trauma. Trauma Informed Care also emphasizes physical, psychological and emotional safety for both consumers and providers, and helps survivors rebuild a sense of control and empowerment (Trauma Informed Care Project, n.d.)”

Trauma Informed Care

We asked respondents who had experienced sexual assault how, if at all, they felt that their experiences impacted their services at the clinic. Although there was a relatively small sample size of only seven respondents, all but one reported negative experiences when sexual assault was relevant to their experiences at the clinic. Many people described that they were not comfortable talking about their experiences and did not receive any support when they did. One parent indicated that the clinic “could be stronger at working from a trauma-informed perspective.”

“I felt uncomfortable when asked about it [sexual assault] and didn’t like the fact that it was recorded in my file. ... I didn’t get support or resources for it.”

Physical Exams

We also asked respondents if they had ever received a physical exam at the clinic, what it involved, and how their experience was. Slightly over half (52%) of respondents described that their experience had been adequate while 48% described having a negative experience. Transmasculine youth and those who had been accessing the clinic for longer were more likely to report having negative experiences with physical exams.

Many transfeminine youth reported having their testicular volume measured to determine their Tanner stage before starting Lupron. The majority of the transfeminine respondents felt that their boundaries had been respected and that exams were done professionally. However some were confused about why the exam was necessary if they were older and therefore had clearly begun central puberty. From informal conversations that the SAEFTY team has had with families of younger youth who are not yet ready to start Lupron, it is clear that many families are extremely uncomfortable with this practice and do not want their child to undergo this exam.

Transmasculine youth reported a wide variety of physical exams, examining both their chests and genitals, including before starting both blockers and testosterone and while on testosterone. This was extremely varied and respondents did not seem to have consistent experiences regarding when physical exams were required. One young person reported that:

“[I]n the endocrinology dept they always measure my clitoris (since starting T) and it’s always awful but they say they have to no matter what.”

Those who reported having a physical exam before starting Lupron described that this was to determine their Tanner Stage. Respondents appear to be unsure why these exams were taking place before starting testosterone or while on testosterone. Many reported not understanding why the exam was needed and not being given advanced warning more than a few minutes ahead of time.

While some respondents described being given the choice to refuse a physical exam, the majority indicated that they were not given an option or that they were explicitly told that it was mandatory. Many people describe not being asked about their boundaries and being extremely uncomfortable and dysphoric. A few people described particularly disturbing experiences, including, 1) having a student look around a curtain to watch a patient's exam, after the client requested that the student not be present, and 2) a patient being asked by a staff member whether they masturbate with their clitoral growth after it was examined during a physical exam while on testosterone.

“I remember it so vividly even though I completely shut down. I didn’t feel I could say no because I felt like they wouldn’t let me get blockers.”

“[T]he specialist...asked if I masturbated with it after observing clitoral growth.... I understand it came from a place of professional curiosity but it strikes me as inappropriate to ask a 17 year old when the answer doesn’t affect anything other than curiosity.”

Research

Based on informal conversations, many youth and families have heard about research being done by CHEO on trans and gender diverse youth. There is limited information within the community about the research that is being done, but many people are concerned by the potential for their information to be used in research studies without their explicit knowledge or consent.

Some youth have reported being under the impression that physical exams that they have been asked to undergo or questions that they have been asked during their assessments are being used for research purposes or to fulfill “professional curiosity”. There is also uncertainty regarding the fact that young trans children, who do not yet require hormone blockers or other medical services, are nonetheless asked to have regular appointments at the clinic. Some families question whether this decision is for the purposes of longitudinal research studies and are extremely concerned by this. The trans and gender diverse community indicates a desire for more transparency when it comes to their personal data being used in research studies, given the potential impact of this on them as individuals and as a community.

Youth have also reported concerns after requesting their medical records from the clinic when there were aspects of their assessment that they were concerned about or uncomfortable with. In some situations, questions or comments made by their providers that stood out to the client were not recorded in their medical records and youth were confused or concerned by this and felt that it reflected a lack of accountability.

“I got a pat down when starting testosterone and the endo insisted on looking at my junk... I don’t appreciate that they ‘had’ to do it for research purposes”

“[CHEO] really just record[s] data on me that they don’t need.”

Discussion and Potential Solutions

Below we discuss the survey results for each section where the survey results reflect concern, along with some suggestions that may improve client's experience. The SAEFTY team looks forward to discussing these suggestions with the CHEO clinic staff to better understand the current practices in the clinic and work together to identify potential future steps.

Gender Affirming Care Model and its Application to Practice

Nonbinary Identities

Youth should not be expected to conform to binary identities or stereotypical gender expressions in order to access care. Many nonbinary youth wish to access medical transition that is similar or identical to that of their binary identified peers, and should be able to do so just as easily. As one young person said:

“Don’t treat nonbinary people differently”

Additionally, youth, regardless of their gender identity, may desire a medical transition path that does not follow conventional expectations. This could include wanting to access HRT but not surgeries or vice versa, requesting hormone doses that are different from the standard prescribed dose, or wanting to take hormones for a period of time and then stop. These are all valid options that youth should be able to access without additional scrutiny or difficulty. The Centre of Excellence for Transgender Health supports this variation in available paths, stating that “[h]ormone levels for genderqueer or gender nonconforming/nonbinary patients may intentionally lie in the mid-range between male and female norms (Deutsch, n.d.)” SAEFTY adds that this may be the desire of any youth, not only those identifying as nonbinary, as well as that this may not be desired by all nonbinary clients.

Preferred Name and Pronoun Use

Using the correct name and pronouns when referring to trans and gender diverse youth is a core aspect of gender affirming care and has a significant impact on the experience of clients. While this can be difficult to navigate with electronic systems that are not designed with preferred names or pronouns in mind, below are some recommendations for ensuring the consistent use of clients names and pronouns throughout their interaction with the clinic:

- Ensure that all clients are asked about their preferred name and pronouns when accessing the clinic for the first time and that they know that it is okay for this information to change at any time.
- Ensure that all pronouns are respected by clinic staff and make it clear to new clients that this is the case. This means that all staff are comfortable using any pronouns, including gender neutral pronouns, regardless of the gender expression of the client.
- Ensure that requested names and pronouns are used consistently. Providers can also model sharing their own name and pronouns when meeting clients and families and giving them the opportunity to do the same.
- Ensure that external providers, who clients are referred to by the gender clinic, are aware of the client's preferred name and pronouns and, whenever possible, that the outside providers are known to be trans-affirming. This can be accomplished by developing relationships with providers who the clinic refers to frequently or calling ahead of time to inquire about policies or practices related to preferred names, pronouns or trans affirming care when referring to new providers. In situations where this information cannot be ensured, providers can inform the client that they are unsure of the trans-competency of the provider they are being referred to and encourage the client to report back to the CHEO clinic for support if they have any issues or concerns. This feedback can also be noted for future clients. When possible, check in with clients at their next follow-up appointment to ask about their experience with the provider they were referred to.
- Ensure that the correct name and pronouns are recorded in electronic systems and are used in all case notes, referral letters, and other forms of communication and are used in the clinic at all times. The American Academy of Pediatrics policy statement on affirming care for trans youth indicates that a "patient asserted name and pronouns are used by staff and are ideally reflected in the electronic medical record without creating duplicate charts" (Rafferty, AAP Committee on Psychosocial Aspects of Child and Family Health, AAP Committee on Adolescence, AAP Section on Lesbian, Gay, Bisexual, and Transgender Health and Wellness, 2018). SAEFTY supports this standard and encourages CHEO to take measures to be able to implement these standards.

Gender Affirming Care

According to the American Academy of Pediatrics policy statement on affirming care for trans youth, gender-affirmative care should convey the message that "if a mental health issue exists, it most often stems from stigma and negative experiences rather than being intrinsic to the child (Rafferty et al., 2018)." Based on this, mental illness should not delay clients' access to transition related services unless there is clear reason to believe that it impacts their ability to consent to care. Delaying access to transition related care based on mental illness causes further harm and perpetuates the "stigma and negative experiences" that lead to poor mental health outcomes (Rafferty et al., 2018).

Some recommendations that may improve clients' experiences of gender affirming care include:

- Clients being included in discussion about all aspects of their care and their input being taken seriously. Youth are the experts of their own experience and know best what they need. It is important to work collaboratively with them to ensure that everyone is on the

same page about transition steps. Providers should be able to reasonably justify to either the client or their family what steps are occurring, and why, so that all parties are informed and in agreement about the process and next steps.

- It is imperative that providers approach a client without the goal of requiring them to prove their gender identity or prove they deserve puberty suppressants or HRT, even if the clients have not always been certain about their gender identity or transition goals. Hidalgo *et al.* (2013) describe that

“[W]e understand gender identity, both in its match and mismatch with assigned natal sex, as primarily informed by a child’s cognitions and emotions, rather than by genitalia and observable external sex characteristics. Gender identity is then to be differentiated from gender expressions: the manner in which a child presents gender to the world – physical appearance, toys chosen, preferred playmates and activities. The category ‘gender nonconforming children’ embraces all children exploring, questioning, or asserting their gender identities and/or their gender expressions outside of cultural expectations. By differentiating gender expressions from gender identities, we have a tool for sorting out the children who are insistent, persistent, and consistent in their affirmation of a cross-gender identity from those children who are either asserting or exploring gender-nonconforming expressions within acceptance of their natal gender assignment.”

Based on this explanation, it seems clear that the only way to know if a child or youth is truly trans is to believe them when they assert their gender identity. Questions related to their gender expression are not relevant to determining or verifying their trans status. The assessment process is discussed in more detail below.

Desistance

The statistic that 80% of pre-pubescent trans and gender diverse children do not identify as trans as adults is one that is frequently cited and extremely harmful. This statistic is frequently used to justify a “wait and see” approach to caring for trans youth which was popularized by Dr. Kenneth Zucker (Drummond, Bradley, Badali-Peterson and Zucker, 2008) and the Amsterdam Gender Clinic (Steensma, McGuire, Kreukels, Beekman, and Cohen-Kettenis, 2013), and which is considered to be harmful by proponents of the gender affirming model. A recent article published by Newhook *et al.* (2018), of which Dr. Feder is a co-author, discusses this in detail.

Despite this, youth and families report being told this statistic by staff in the clinic as recently as 2017, which is our most recent year of data. This is unacceptable.

We recommend that all staff in the clinic stop using this statistic immediately and receive detailed information about why it, and discussions of desistance in general, are inaccurate and harmful. It is also recommended that information explaining why the statistic is untrue and

harmful be posted in the clinic and online in order to ensure that youth and families are made aware that it is false.

Timelines and the Assessment Process

Long wait times are the most frequently cited concern that survey respondents had regarding their experiences at the CHEO Gender Diversity Clinic. Many respondents described that long wait times had extremely negative impacts on their mental health, including increased dysphoria, anxiety, depression and suicidality.

“It really impacted my mental health having my care delayed so much.... By the time I saw my new endocrinologist in the community [outside of CHEO], she told me blockers would not help me because my puberty had advanced too much. If I had been able to access blockers a year earlier, I believe it would have been different. That statement had been soul crushing, because while the effects of Lupron are reversible, puberty is not to a great extent.”

“Not moving ahead fast enough may kill kids, and that isn’t an exaggeration, because I have lived it and my experience is not in isolation.”

It is recognized that a lack of funding and staffing capacity is a primary factor in limiting the clinic’s capacity to significantly reduce wait times of clients accessing care. While acknowledging that this is a long term concern, respondents and members of SAEFTY propose some other suggestions for reducing wait times that do not require increased funding or staff.

Respondents were required to have numerous appointments at the clinic with significant wait times in between appointments, before being able to access both hormone blockers and hormones, which was a significant source of delay.

While it is important to build rapport and assess client readiness for intervention, it is recommended that this process be accomplished in fewer appointments wherever possible. This reduction would significantly reduce the negative impact of delays on clients. Some respondents also indicated that they felt that they were required to continue seeing a social worker beyond their initial intake and that they did not feel the need for this. They recommended that, after an initial intake, social work appointments be available to those who desired them but not be required.

Many respondents also reported other concerns with the assessment process they underwent, as discussed in more detail below. Altering this process may also reduce the number of appointments required for each client, leading to reductions in the clinic waiting list and faster timelines for those in the clinic who want to access services more quickly.

“The doctors wanted to be sure that I actually am trans which took a long time.”

Hormone Blockers

“Make blockers in particular easier to access”

Long wait times to access hormone blockers was identified as a significant source of distress by many respondents. As described by the American Academy of Pediatrics in their policy statement on comprehensive care and support for trans and gender diverse youth, “children who are prepubertal and assert [an] identity of [trans or gender diverse] know their gender as clearly and as consistently as their developmentally equivalent peers who identify as cisgender and benefit from the same level of social acceptance (Rafferty et al., 2018).” They describe this “in contrast to the outdated approach in which a child’s gender-diverse assertions are held as ‘possibly true’ until an arbitrary age (Rafferty et al., 2018).” The policy statement also describes that pubertal suppression is “reversible” and “creates an opportunity to reduce distress that may occur with the development of secondary sexual characteristics” and “provide time... for the individual and the family to explore gender identity... and further define appropriate treatment goals (Rafferty et al., 2018).”

When assessing clients for puberty suppressants, it is important to consider the outcomes of all actions. Delaying access to Lupron is not a neutral action. In many cases, the changes that accompany young people’s natal puberty are irreversible and known to cause significant harm, both mentally and physically when access is delayed. When youth are able to access Lupron more easily, there is then more time to make decisions about their future pubertal development without irreversible and unwanted changes to their bodies.

Access to hormone blockers is extremely important to many youth and families accessing services at CHEO and has important implications for health and wellness outcomes of youth. It is recommended that:

- Any youth who have reached Tanner Stage II should be able to access hormone blockers upon request, when provided with the necessary information to provide their informed consent.
- Youth should not be required to complete an assessment of their gender identity in order to access hormones blockers, given that this treatment is entirely reversible and that its purpose is to relieve distress and allow additional time for thought and exploration.

The American Academy of Pediatrics policy statement also states that “rather than focusing on who a child will become, valuing them for who they are, even at a young age, fosters secure attachment and resilience, not only for the child, but also for the whole family (Rafferty et al., 2018).” If a child or youth’s trans identity is believed, it is difficult to justify subjecting them to unwanted pubertal changes while assessing the validity of their gender identity and their need to transition. This statement supports providing reversible hormone blockers which alleviate the distress described by respondents throughout the survey. In rare cases where a client does not continue to identify as trans or chooses not to continue with HRT, they are able to discontinue the use of hormones blockers with no adverse effects.

Hormone Replacement Therapy

Several respondents reported being frustrated by the need to take Lupron before being able to start HRT. In particular, many older youth reported wanting to start HRT as soon as possible and some found Lupron to be simply another barrier delaying their access to hormones.

It is recommended that older youth who would prefer to start HRT directly, without being on Lupron first, be given the option to do so, similarly to the process for adult care. This recommendation is supported by the American Academy of Pediatrics policy statement on affirming care for trans youth, which describes puberty suppression “[can be prescribed] up *until 16 years of age* (Rafferty et al., 2018; emphasis added).” If youth who are 16 years of age or older want to be administered Lupron, SAEFTY fully supports their bodily autonomy and right to make this decision; however, it is recommended that it not be required.

The Assessment Process

Many respondents described being asked questions that made them feel uncomfortable, or like they had to prove their trans identity to their providers. While it is important to get to know each client and build a relationship with them, it is vital that this trust be accomplished through conversations that affirm, not challenge, their gender identity, expression and their transition needs.

Regardless of the intention of providers, many of the questions described in the results section of this report may be perceived by youth or families to challenge clients’ gender identity or their readiness to access transition related services. Many respondents also described that they sometimes felt the need to lie to their providers and give the answers that they thought would be expected of them related to their gender identity or gender expression. This has been a common experience of trans and gender diverse people for many decades and many trans people of all ages learn to give the responses that providers are looking for, regardless of their truthfulness, in order to access the services they need (Stone, 1992). Evidently, this is neither helpful to clients nor providers and contributes to further mistrust of the medical system by many trans and gender diverse people and communities. Respondents most frequently mentioned feeling the need to lie or give only partially true answers in reference to questions about present or past gender expression. For example, many transmasculine youth described feeling the need to express that they played with stereotypically masculine toys or wore stereotypically masculine clothes. When asked questions of this scope, many respondents described feeling that these questions were not relevant to determining their readiness for transition related services and that they perpetuated cissexist³ and binary understandings of gender.

When youth are asked questions about gender dysphoria or distress related to their trans bodies or identities, many people experience the need to emphasize or perform distress in order

³ Cissexist: Prioritizing cisgender views of gender as superior and not taking into account transgender experiences.

to prove that they are trans enough and to access medical transition. The expectation that trans and gender diverse youth must experience significant dysphoria, discomfort or distress related to their bodies or genders is rooted in the pathologization of trans identities and perpetuates the idea that transition is an undesirable outcome rather than a natural expression of human diversity.

It is recommended that providers keep this in mind when asking questions about youths' experiences with gender and transition needs and that youth not be expected to express significant distress in order to access services. It may be more beneficial to ask questions that focus on clients' experience of gender euphoria, or expressions of their gender that bring them comfort and joy. Asking questions about the things that make clients feel most comfortable in their gender or the aspects of transition that they are most looking forward to may give a more accurate picture of young people's experience with gender while allowing youth to experience joy in their gender diversity, rather than only distress.

Some of the questions described in the Results section were identified by respondents or members of the research team as questions that may be perceived to be attempting to determine the cause of a client's trans identity. These questions are felt by many trans and gender diverse people and families to be highly inappropriate and invalidating of a person's trans or gender diverse identity.

It is recommended that these types of questions be avoided whenever possible. It may also be beneficial for providers to explain to clients why they are asking each question and that client responses are not being used to assess a client's trans identity. This clarification may make youth feel more comfortable being truthful with their providers about their needs and their experiences with gender, knowing that their identity and expression are not being challenged.

Respondents who were asked questions related to masturbation or sexual activity frequently described that these questions made them very uncomfortable and that they did not feel that the information was relevant to their care. Some respondents described feeling that these questions came from a place of professional curiosity rather than medically necessary which is considered to be highly inappropriate.

TransCare BC provides some helpful suggestions of questions which may be more appropriate for gathering information related to a clients gender identity and experience of gender dysphoria (Trans Care BC and Provincial Health Services Authority [PHSA], 2017). Some of these questions are listed below. Please see the Trans Care BC resource for a complete list.

1. How would you describe your gender identity? If prompting is needed: For example, some people identify as a man, a trans man, genderqueer, etc.
2. Do you remember the time when you realized that your gender was different from the one you were assigned at birth? Or: Do you remember when you first started to see your gender as _____?

3. Have you taken any steps to express your gender differently/to feel more comfortable in your gender? If prompting is needed: Some people ask others to use a different name and pronoun, or make changes to their hair or clothing styles.
4. If they have taken steps to express their gender differently: What was that like for you? How did that feel?
5. Are you hoping to take any [transition related] other steps in the future?
6. Have you thought about how you will manage the changes in your appearance and gender expression at work or school?
7. What changes from hormones are you most looking forward to?
8. Are there any potential [transition related] changes that you are not sure of?
9. Do you know about the potential impact that taking hormones can have on your fertility? Would you like me to refer you to a fertility clinic to talk about fertility preservation options?
10. Some people find it helpful to have the support of a counsellor for either decision making or ongoing support after beginning hormone therapy – would you like a referral to a trans competent counsellor?

Gatekeeping

It is considered a best practice within both trans and gender diverse and medical communities that providers should aim to support trans and gender diverse clients in accessing the care that they need and should avoid acting as gatekeepers as much as possible. Below are a few recommendations that may help to accomplish this:

- Ensuring that youth, as well as supportive families, understand and are a part of all decisions and that they feel in control of the transition process from the start to end.
- Recognizing and acknowledging the power differential between services providers, families and youth and working to mitigate this as much as possible.
- Carefully considering and clearly communicating what criteria allow or prevent youth from accessing care. It is recommended that factors such as being nonbinary, mentally ill, uncertain about end goals of transition, not having parental support, not being out to everyone, age, or other similar factors should be discussed with youth, but should not necessarily prevent youth from accessing care. If there are factors such as these or others that are used to determine a client's readiness to access services these should be clearly communicated to youth and families along with the reasons for this requirement.
- Providing counselling or referrals to counselling by providers who are not a part of the assessment process. Many youth may not be comfortable being open with providers knowing that the information they share may be used to prevent or delay their access to services that they need. It appears that many respondents currently view all staff in the clinic as gatekeepers to their access to care.

Best Practices for Client-Centered Care

Autonomy in Decision Making

As described above, trans and gender diverse people follow many different transition paths, all of which are equally valid. The gender affirming model supports the fact that “variations in gender identity and expression are normal aspects of human diversity, and binary definitions of gender do not always reflect emerging gender identities” (Rafferty et al., 2018). As a result, it is important that youth and families be supported to make decisions about their medical transition that reflect their own needs. Youth should not feel pressured to follow a stereotypical transition path through overt or covert messages and should be supported equally in whatever path they choose. The development of the assessment process is an important part of this, which is discussed further above.

Several respondents felt that they had to advocate a lot within the clinic in order to receive the care that they needed. While this advocating works for some youth, being able to strongly self-advocate should not be a requirement to accessing care, especially given the power differential that exists between clients and services providers as well as the power that providers at CHEO hold as the only source of care for trans and gender diverse youth in Ottawa. Providers should be attentive to listening to the needs and desires expressed by youth at all times and these should be recorded to ensure that all staff in the clinic are helping each person to work towards their own needs, rather than a preset transition path.

Finally, several youth described being prescribed HRT in dosages that are significantly smaller than that administered by most other endocrinologists. While it is acknowledged that there is some literature that supports the idea of beginning HRT with a very small dose to simulate the start of biologically induced puberty, it is typically standard practice for individuals who have already begun puberty at the time they begin hormones to start briefly on a small dose which is increased over time based on client needs and response to a standard maintenance dose, as described in Rainbow Health Ontario's Hormone Guidelines and Protocols for Hormone Therapy and Primary Health Care for Trans Clients (Bournes, 2009). Many youth were extremely frustrated by their low hormone doses, and some indicated that they were considering taking non-prescription hormones as a result. It is recommended that hormone doses be discussed in collaboration with youth and families and that doses be prescribed that best meet the needs of each client. If a young person expresses a strong need or desire for changes associated with HRT in a timely manner, then a higher, more standard starting dose is recommended. In addition to this recommendation, talking through hormone levels and results of blood work with clients should be a common practice. This may help youth and families to better understand their hormone dose and the effect of hormones in their body.

Experiences of Client Centered Care

The goal of client centered health care is to focus on the needs of clients and to work alongside them to meet these needs. In this context, SAEFTY considers the client to be the trans and gender diverse youth accessing care at CHEO. It may also be important to consider the needs of caregivers and family members of youth, but this concern should be determined based on the needs of the youth themselves. For example, if a youth is encountering difficulties due to their

parents lack of understanding of their identity, and wishes for their parents to receive more information, it would benefit the youth for providers to spend time with parents discussing their concerns and providing them with information when possible. There may be some situations where a young person wishes to access transition related services as quickly as possible, and their parents wish for them to wait longer before doing so. In these cases it is recommended that providers work with the youth to provide them with the care they need, while making this process as smooth as possible, even without the full support of their parents or guardians.

This distinction may mean following the lead of youth who require access to care even without the full support of their parents or guardians, if it will best meet the needs of the youth, particularly for youth who are older. In Ontario there is no minimum age of health care consent (Health Care Consent Act, 1996).

The needs and experiences of trans and gender diverse youth vary greatly, making it vital to ask questions and listen to youth articulate their own transition goals in order to work with them to meet their goals. There is no one standard pathway that will meet the needs of all youth.

“Go at the speed with which the child is comfortable - so faster than you think but still in accordance with the rule of informed consent.”

Some things that may improve respondents' experiences of client centered care include:

- Hiring trans staff to work in the clinic.
- Shorter wait times to access services.
 - This can be influenced by greater funding and staff when possible.
- Ensuring that it is easy for clients to contact the clinic outside of appointments, including updating the webpage to include basic information about services provided at the clinic and information how youth and families can self refer to the clinic and book appointments.
- Ensuring that appointment scheduling is well organized and that appointments are not cancelled at the last minute and are rescheduled as quickly as possible when necessary.
- Not requiring social worker appointments beyond the initial intake unless desired by youth.
- Providing information to new clients about what to expect at the clinic, including approximate timelines based on actual average timelines so that they are as accurate as possible.
- Making data on average timelines in the clinic and information about what to expect at the clinic publically available online so that current and potential clients know what to expect.
- Ensure that timelines and approximate wait times given to youth and families are adhered to as closely as possible and that there is open communication between providers and youth regarding timelines.

“Stop giving false hope/expectations. When you say someone can start something in two weeks and they wait two months and it’s still not done, that has a HUGE mentally/emotionally damaging impact”

Supporting Letters, Referrals and Aging Out

A few solutions that may help to improve client experiences with referral letters or aging out include:

- Employing strategies to organize communication within the clinic to ensure that clients do not need to ask more than once for a letter or referral.
- Discussing with clients ahead of time what name and pronouns they would like to have used in letters or what information will be shared in referrals. This step may help to ensure that clients confidentiality is respected and that gender affirming care is consistent across providers. If there is a specific name or pronoun that must be used or specific information that must be shared, discussing this in advance may help to ensure that the reason for this is clearly communicated and that everyone is on the same page.
- When youth age out of CHEO, ensuring that they are referred to an endocrinologist or other provider to continue their care and follow up with them to ensure that this transition is smooth, to assist if there are any difficulties or to collect information that may be useful to share with other clients in the future.

Best Practices for Trauma Informed Care and Research Ethics

“Trauma Informed Care is an organizational structure and treatment framework that involves understanding, recognizing, and responding to the effects of all types of trauma. Trauma Informed Care also emphasizes physical, psychological and emotional safety for both consumers and providers, and helps survivors rebuild a sense of control and empowerment (Trauma Informed Care Project, n.d.).”

Trauma Informed Care

Many trans and gender diverse youth have experienced trauma and it is important for all care to be trauma informed. Some ways to accomplish this include:

- Ensuring that all clients know that they have the right to say no to anything they are uncomfortable with, including having a medical student in the room during their appointments or answering questions or discussing things that they are uncomfortable talking about.
- Explaining things in detail to clients whenever possible to ensure that they understand what is happening and why. This could include explaining what will happen at each appointment, explaining why tests are needed or why certain questions are being asked.
- Not asking about experiences of trauma or sexual assault for the purpose of readiness assessments.
- Providing resources or support related to trauma or sexual assault if requested.

Physical Exams

Many trans and gender diverse youth experience dysphoria or significant discomfort related to many different parts of their body. While physical exams can be uncomfortable for many people, it may be particularly important to keep this in mind when working with trans and gender diverse youth. When performing physical exams, there are a few things which may help to ensure that clients have the most comfortable experience possible:

- Do not perform physical exams unless they are medically necessary or requested by a client.
- Consider the purpose for the exam and communicate this purpose clearly to the client. It is important for clients to understand why the exam is needed or beneficial and the medical consequences of having or not having it. For example, if it is necessary to determine that a client has reached Tanner Stage II before they begin Lupron, explain what this means, how it will be tested and why it is important to know. In addition, if the client desires, the practitioner should explain the results of the exam after it is completed.
- Give clients advanced notice if a physical exam will be performed. This could be discussed at the appointment before the exam to ensure that the client is prepared and knows what to expect.
- Ensure that clients know that they have the right to say no to an exam or to ask for it to stop or pause at any time. If there is a medical consequence to refusing the exam let them know this and allow them to make their own decision. For example, if they are not able to start Lupron until it has been confirmed that they have reached Tanner Stage II, explain all of the options for testing this and allow them to determine what they would be most comfortable with.
- Explain ahead of time what the exam will involve. Give clients a chance to articulate their boundaries and let providers know if there is anything they are uncomfortable with or would like changed. Ensure that clients boundaries are respected.
- Offer to explain procedures as they are carried out if the client would like.
- Avoid making comments or asking questions about a client's body during or after a physical exam unless it is directly related to the test that being done, and offer to explain the results of the exam if the client would like. For example, a provider might inform the client that they have reached Tanner Stage II and are able to begin Lupron. Avoid commenting on specific aspects of their physical development unless necessary and relevant.

“They were nice about it and tried to make me feel comfortable but I hated it. There was two of them and while they were examining me they talked back and forth and picked numbers to describe how developed things were and I was fixated on those numbers and what they meant whether they were good and bad and I hated that the numbers were what they were. I also remember being terrified for a few months every time I had to go to any doctor that they were going to give me an exam.”

Research

Based on the concerns expressed by trans youth and families, it is recommended that CHEO communicate clearly to the community about their research practices and any research that is currently occurring. When doing research about clients in the clinic, it is recommended that youth and families be asked explicitly if they would like to participate and given information about what participation will entail and what the final research will be used for. This includes research that is done based on retrospective chart reviews. Based on the marginalized status of trans and gender diverse youth and the power differential that is inherent between medical professionals and clients, youth and families informed consent should be given for any use of their information regardless of whether it is identifying.

It is also recommended that participation in any form of formal or informal research should not be a requirement for accessing services. Youth and families should only be asked questions or undergo tests that are medically indicated for their personal care unless they consent to participating in other activities. As a result of the lack of other sources of transition related care for children and youth, ethical considerations should note that many people have no options outside of CHEO for accessing the care that they need and this should not require them to consent to participation in research of any kind.

Additionally, when formal or informal research is produced by or about the clinic, it is recommended that studies be conducted in partnership with trans and gender diverse communities and that results be made available to clients of the clinic and trans and gender diverse communities more broadly. Research can be important to the wellbeing of trans and gender diverse communities and working together to make this information available to community members can help to reduce the power differential between services providers and the community.

Lastly, it is recommended that providers be intentional about the information that is recorded in clients' medical records. It is recommended that providers check in with clients when discussing anything that may be sensitive for clients and ask if they would like this information recorded in their file. For some people, it is important to be able to look back on their file and see a record of the conversation as they remember it, while others may prefer that the information not be recorded for other providers to see.

Suggestions for the Future

When asked about what suggestions they would give to the clinic, survey respondents gave a few recommendations that may be helpful to clients and families. These suggestions included:

- Playing a role in providing training to doctors outside of the clinic so that other providers in and around Ottawa are able to prescribe Lupron and HRT and make transition related surgery referrals for youth or families who are not able to or would prefer not to access services at CHEO

- Hiring or partnering with a trans affirming psychologist so that youth who require more robust mental health services are able to receive this in conjunction with their transition related services and have easier access to a provider who they can be confident will be trans affirming
 - Hiring a system or family navigator so that youth or families are able to meet with another trans or gender diverse person who can assist them in navigating the sometimes confusing and complex pathways to accessing transition related health care and social services
 - Develop relationships with other hospitals in and close to Ottawa to improve transitions to adult care as well as surgical care that is not available at CHEO. In particular, several people indicated that they would prefer not to be required to travel to Montreal in order to access bottom surgery.
 - Improving the website page on Clinic C5 to contain more up-to-date information as well as including contact information to make the clinic easier to reach.
 - Continuing to work with clients and gather more information on how best to improve the clinic to meet the needs of the clients accessing transition related services. This could take the form of a client advisory committee, client feedback surveys or other feedback methods. It is recommended that all members of trans and gender diverse communities who are being consulted with by the clinic be appropriately compensated for their time.
-

References

- Bourns, A. (2009) Guidelines and Protocols for Hormone Therapy and Primary Health Care for Trans Clients. Sherbourne Health Centre.
- Canada, S. (n.d.). Population estimates on July 1st, by age and sex. Retrieved from <https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000501>
- Deutsch, M.B. (n.d.). Overview of masculinizing hormone therapy. Centre of Excellence for Transgender Health. University of California, San Francisco. Retrieved from <http://transhealth.ucsf.edu/trans?page=guidelines-masculinizing-therapy>
- Drummond, K. D., Bradley, S. J., Badali-Peterson, M., & Zucker, K. J. (2008). A follow-up study of girls with gender identity disorder. *Developmental Psychology*, 44, 34–45.
- Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A.
- Hidalgo, M., Ehrensaft, D., Tishelman, A., Clark, L., Garofalo, R., Rosenthal, S., Spack, N., & Olson, J. (2013), "The Gender Affirmative Model: What We Know and What We Aim to Learn", *Human Development*, 56, 285-290
- Hoffman, J. (2016, June 30). Estimate of U.S. Transgender Population Doubles to 1.4 Million Adults. Retrieved from <https://www.nytimes.com/2016/07/01/health/transgender-population.html>
- Newhook, J.T., Pyne, J., Winters, K., Feder, S., Holmes, C., Tosh, J., Sinnott, M-L., Jamieson, A., & Pickett, S. (2018) A critical commentary on follow-up studies and "desistance" theories about transgender and gender-nonconforming children, *International Journal of Transgenderism*, 19:2, 212-224, DOI: 10.1080/15532739.2018.1456390
- Rafferty J, AAP Committee on Psychosocial Aspects of Child and Family Health, AAP Committee on Adolescence, AAP Section on Lesbian, Gay, Bisexual, and Transgender Health and Wellness. (2018). Ensuring Comprehensive Care and Support for Transgender and Gender Diverse Children and Adolescents. *Pediatrics*.;142(4): e20182162
- Steensma, T. D., McGuire, J. K., Kreukels, B. P. C., Beekman, A. J., & Cohen-Kettenis, P. T. (2013). Factors associated with desistance and persistence of childhood gender dysphoria: A quantitative follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 52, 582–590.
- Stone, S. (1992). The "empire" strikes back: A posttranssexual manifesto. *Camera Obscura*, (29), 151.

Trans Care BC & Provincial Health Services Authority. (2017). Gender-affirming Care for Trans, Two-Spirit, and Gender Diverse Patients in BC: A Primary Care Toolkit. <http://www.phsa.ca/transgender/Documents/Primary%20Care%20Toolkit.pdf>

Trauma Informed Care Project. (n.d.). What is TIC? <http://www.traumainformedcareproject.org>