A survey of experiences with surgery readiness assessment and gender-affirming surgery among trans people in Canada: Focus on British Columbia

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The Gender-Affirming Surgery Experience Survey received ethics approval from the Research Ethics Board at the University of British Columbia (certificate #H16-00800). The study was also reviewed and approved by the Interior Health Authority.

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Available online in pdf format at www.saravyc.ubc.ca
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Executive Summary

The Gender-Affirming Surgery Experience Survey is the result of a collaboration between the Stigma and Resilience Among Vulnerable Youth (SARAVYC) research centre at the University of British Columbia, and Trans Care BC, a program of the Provincial Health Services Authority. Trans Care BC’s role is to enhance the coordination and availability of trans health services and supports across the province.

The survey had 337 respondents and was open to anyone residing in Canada who had undergone assessment and/or surgery in the last five years. This means we captured people’s experiences since 2011. Due to our partnership with Trans Care BC (which began its work as a program in October 2015), we focused recruitment efforts on British Columbia for this first report. The survey asked trans people who were at various stages of accessing gender-affirming surgery about their experiences with this process, including their experiences with surgery readiness assessments and with various surgical and other procedures.

KEY FINDINGS

• When collecting data about the gender of patients or research participants, it is essential to give people an opportunity to describe their gender in their own words, in order to reflect the spectrum and complexity of experiences. One in five (19%) respondents described their gender with words that went beyond traditional binary labels such as man, woman, trans woman, or trans man. This also highlights the need to recognize non-binary genders.
• On the journey to gender-affirming surgery, time spent waiting varied greatly among respondents. This was true for the wait time between the initial referral and the assessment (in BC, people reported waiting as little as 1 day and as long as 1825 days), as well as for the wait time between assessment and surgery (people reported waiting as little as 1 month and as long as 108 months).
• In BC, most people (60%) easily or very easily got referred to an assessor, and half of people in BC did not have to spend any money on their assessment appointment(s). Almost 1 in 5 people paid for their assessment(s) with at least some of their own money.
• Most people (93%) only had one source of funding for their surgery. For 1 in 3 people, this sole source of funding was their own money, while nearly 2 out of 3 had their surgery funded entirely by a government health plan. Even when their surgery was covered, people still had to cover a number of costs out of pocket (such as travel costs, accommodation, aftercare facilities, aftercare supplies) and
the amounts of money people had to spend varied greatly.

- Over half of respondents (57%) were able to choose the surgeon they wanted for surgery. People who paid for surgery entirely out of pocket were much more likely to be able to choose the surgeon they wanted.
- Just over 60% of respondents had to travel 2 or more hours to their surgery appointments.
- Experiences with surgeons and their staff varied; however, a large majority of people (83%) agreed or strongly agreed that the surgeon created a space that was safe enough to ask questions and talk about the surgery process, and an even larger portion of people (89%) agreed with the same statement concerning the clinic staff.
- Self-reported complication rates after surgery varied depending on the surgery. They were highest for phalloplasty (83%), vaginoplasty (60%), and facial feminization (43%)*. Complication rates were higher for people travelling 2 hours or more to their surgery appointments, as well as for people whose surgery was funded solely through a government health plan.
- People scored on average 7 out of 10 on a support scale for post-surgery support, meaning that they had quite a bit of social supports available to them.

*We are not able to report percentages on certain procedures due to the low number of responses (i.e., voice feminization, liposuction, metoidioplasty, clitoral release, or pectoral implants).
Introduction

As awareness of gender diversity grows in Canada, so do options for gender-affirming care for many trans people in Canada. We use the word *trans* in this survey as an umbrella term for people whose gender does not match the sex and gender that they were assigned at birth. This includes trans men, trans women, and non-binary people, although many people use a wide variety of terms to talk about themselves and their gender.

Gender-affirming care is a broad category that includes routine care provided in a gender-affirming way, gender-affirming counselling, hormone therapy, and surgical interventions. Trans people may choose to access one, many, or none of these forms of gender-affirming care. This report is focused on access to gender-affirming surgery, which is considered medically necessary for many people, and is an effective treatment for ‘gender dysphoria’ as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). As a result, we focus on trans people who seek out these surgeries, but it is important to note that not all trans people desire or seek out medical interventions such as hormone therapy or surgery.

This survey is the first to provide a detailed overview of the experiences of trans people in Canada who are accessing, or have accessed, gender-affirming surgery. While we were running this survey, we also conducted an interview study that explores in more detail people’s experiences with gender-affirming surgery and can help illustrate and explain some of the findings from the survey. Findings from the interview have been published in a report entitled "The agency to choose what’s right for their body": Experiences with Gender-Affirming Surgery in British Columbia." You can find this complementary report on our website www.saravyc.ubc.ca.

**PURPOSE OF THE SURVEY**

This partnership between SARAVYC and Trans Care BC was created to improve the delivery of services to trans people who are interested in accessing gender-affirming surgeries. Because Trans Care BC is a new provincial resource, the intention was to get a better sense of people’s experiences with assessment and surgery in order to inform the program in its work provincially.

There is very little information in the academic and clinical literature on people’s experiences through the process of accessing gender-affirming surgery. We developed a survey that could provide information on how gender-affirming care is delivered in Canada, and how people navigate and experience the current health care system. It was a priority for us to make sure that the voices of trans people were heard in the process, and this survey is one of two projects whose results will be directly used to help efforts aimed at improving existing systems of care. The other project focused on in-depth interviews and the report will be released later this year.

Having clear and detailed information on the access to, and the delivery of, gender-affirming surgery is essential to inform future policy decisions and best practices for health care practitioners. This report will help improve existing systems of care for trans people in Canada.
METHODS

We developed the survey in partnership with the Trans Care BC team and a peer reference group, which includes members of the trans community from across the province. After the first draft of the survey was created, we met with the peer reference group in person to get their feedback on how questions could be improved or what other questions should be asked. This feedback was integrated into the survey and the peer reference group was invited to test out the survey and give further feedback ahead of its public launch.

Data for this report was collected from July 1, 2016 through December 31, 2016. Participants who had undergone a surgical readiness assessment and/or gender-affirming surgery as far back as 2011 were able to participate. People could respond to the survey online, either on a computer, tablet, or smartphone, as well as on the phone if they contacted us directly. We spread the word about the survey through the professional and interpersonal networks of the research team and of the peer reference group, and through advertisements via social media, websites, and cards distributed during public events aimed at trans communities. Our study received ethics approval from UBC’s ethics board as well as from Interior Health Authority.

The survey was anonymous, but we asked for participants’ province and postal code, and checked the country location of their IP addresses so we could exclude surveys from people who were not eligible to participate in the study.

Throughout the survey, we provided comment boxes for respondents to give us more detailed feedback on their experiences. The quotes included in this report are from those comments, and they include brief information on the person who wrote that comment: that person’s age and their gender (in their own words).
Who participated in the survey?

In order to be eligible for the survey, people had to be 18 or older, live in Canada, and fit into one of three groups:

- They had had a gender-affirming surgery in the past five years and/or
- They had had a surgery readiness assessment in the past five years and/or
- They were currently waiting for a surgery readiness assessment.

In total, 337 people participated in the survey. Estimates (based on British data) suggest that between 0.2%-0.5% of the population seek out medical transition. No numbers are available in Canada.

LOCATION

Our recruitment strategy was focused on British Columbia; as a result, the majority of our respondents (64%) were from there.

Based on the postal code that people reported, only a minority (9%) lived in rural and small towns (as defined by Statistics Canada).

1 Gender Identity Research and Education Society (GIRES) (2011). The Number of Gender Variant People in the UK-Update 2011.

SURGERY STATUS

Among survey respondents:

- 65% had completed a surgery readiness assessment as well as surgery in the last five years
- 18% had completed a surgery readiness appointment but had not had surgery in the last five years
- 8% people had completed gender-affirming surgery but had not completed a surgery readiness assessment in the last five years
- 9% had not yet completed a surgery readiness assessment but had been referred to an assessor and/or had an appointment set up

Among people who had surgery, we asked people to identify what procedure(s) they had.

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaginoplasty</td>
<td>31%</td>
</tr>
<tr>
<td>Orchiectomy</td>
<td>8%</td>
</tr>
<tr>
<td>Labiaplasty</td>
<td>9%</td>
</tr>
<tr>
<td>Phalloplasty</td>
<td>4%</td>
</tr>
<tr>
<td>Metoidioplasty</td>
<td>3%</td>
</tr>
<tr>
<td>Clitoral release</td>
<td>1%</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>25%</td>
</tr>
</tbody>
</table>

**PERCENTAGE OF PEOPLE WHO HAD LOWER SURGERIES/PROCEDURES (N=88)**

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast augmentation</td>
<td>6%</td>
</tr>
<tr>
<td>Chest surgery</td>
<td>45%</td>
</tr>
<tr>
<td>Facial feminization*</td>
<td>4%</td>
</tr>
<tr>
<td>Voice feminization*</td>
<td>2%</td>
</tr>
<tr>
<td>Tracheal shave*</td>
<td>4%</td>
</tr>
<tr>
<td>Pectoral Implants*</td>
<td>0%</td>
</tr>
<tr>
<td>Liposuction*</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Electrolysis*</td>
<td>39%</td>
</tr>
</tbody>
</table>

**PERCENTAGE OF PEOPLE WHO HAD UPPER SURGERIES/PROCEDURES (N=104)**

Note: People could select more than one answer.
*Not publicly funded in British Columbia.
DEMOGRAPHICS

AGE

Age of respondents ranged from 18 to 69. The average age of survey respondents was 37 years old and the median age was 34 years old.

GENDER

To ask people about their gender, we used a two-fold approach. First, we asked people what their gender identity was, leaving space for people to be able to enter their specific identity(ies). The vast majority of people (87%) entered an answer. While a majority (81%) of participants who used the comment box wrote in binary gender identities, many people used this open-ended box to indicate not only non-binary identities but also a wide variety of identities and labels, such as “male, gender fluid,” “Two-Spirit,”
“genderqueer transmasculine,” etc. This diversity of answers suggests that it was important to make room for people to write in how they describe their gender, and that labels resonate in a variety of ways with different people. This is especially true for people with non-binary genders, since the English language is still limited in this respect.

Second, we asked people which terms best described them between the following three options:

- transfeminine/woman/MtF
- transmasculine/man/FtM
- non-binary/genderqueer

It was important to be able to categorize people within these broader labels so that we could contrast and compare findings among different populations. As the graph below indicates, 42% of people selected transfeminine, 47% selected transmasculine, and 12% selected non-binary.

Among respondents who identified as Aboriginal or Indigenous, 18% identified as Two-Spirit.

We also asked people to identify what sex they were assigned at birth. A small percentage (10%) of people did not answer the question. Of those who did, 44% were assigned male at birth and 56% were assigned female at birth. We also asked about whether or not people were born with an intersex body, and 4% said they were, with an additional 14% who were not sure if that was the case.
ETHNO-CULTURAL BACKGROUND

We asked people to identify their ethno-cultural background.

The low participation of people of colour should be cause for concern, but it is difficult to determine why this happened. It may reflect the higher barriers encountered by these populations in accessing gender-affirming surgery (making them ineligible for this study). It also may reflect higher barriers to participation in research. Both possible reasons suggest future research is needed that engages under-represented communities better, including studies that make these groups the focus of the research, so that we can better understand their specific experiences.

These low numbers means that we cannot meaningfully report on differences in experiences and outcomes based on ethno-cultural background. This does not mean that these differences do not exist.

<table>
<thead>
<tr>
<th>ETHNO-CULTURAL BACKGROUND OF PARTICIPANTS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal/Indigenous</td>
<td>4%</td>
</tr>
<tr>
<td>Black</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Filipino</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>East Asian (Japanese, Korena, Chinese)</td>
<td>2%</td>
</tr>
<tr>
<td>Central and South America</td>
<td>1%</td>
</tr>
<tr>
<td>South or Southeast Asian</td>
<td>1%</td>
</tr>
<tr>
<td>West Asian or Arab</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>White/European descent</td>
<td>80%</td>
</tr>
<tr>
<td>Other</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Multi-ethnic</td>
<td>10%</td>
</tr>
</tbody>
</table>
CITIZENSHIP AND INCOME

The vast majority (95%) of people who answered the survey were Canadian citizens while 3% were Permanent Residents. The remaining 2% had status in Canada as temporary residents, workers, or students.

The table below shows estimates of household incomes among our respondents. Just over half (55%) of people reported an annual household income of $40,000 or less. In comparison, the media Canadian family income in 2015 was $70,770. Additionally, just over 10% did not know or did not want to share their income. The majority of people (85%) indicated that their annual household income supports one or two people.

Three quarters of respondents reported they had access to some form of social assistance. More specifically, a quarter of people indicated that they had access to paid vacation, while only 1% reported they had access to paid sick leave and 4% to short-term disability benefits. Overall, 60% of respondents indicated that they had access to multiple forms of benefits.

**ESTIMATE OF HOUSEHOLD INCOME IN LAST 12 MONTHS**

<table>
<thead>
<tr>
<th>Income Range</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $30K</td>
<td>44%</td>
</tr>
<tr>
<td>$30K to less than $60K</td>
<td>25%</td>
</tr>
<tr>
<td>$60K to less than $100K</td>
<td>12%</td>
</tr>
<tr>
<td>$100K or more</td>
<td>7%</td>
</tr>
<tr>
<td>I'd rather not say/I don’t know</td>
<td>12%</td>
</tr>
</tbody>
</table>
A survey of experiences with surgery readiness assessment and gender-affirming surgery among trans people in Canada: Focus on British Columbia

Surgery readiness assessment

ASSESSMENTS IN BC: KEY HIGHLIGHTS

- Most people (85%) have only had to get one or two assessments overall, as per the World Professional Association for Transgender Health (WPATH) guidelines.
- Almost half (40%) of people had a challenge finding an assessor in BC.
- Half of respondents in BC traveled 45 minutes or less to their assessment, but there are wide disparities in how far people have to travel.
- Nearly 1 in 5 (19%) of respondents in BC paid out of pocket for at least some of their assessment(s), and there are wide disparities in how much they spent.
- A large majority of people (90%) who had at least one assessment in BC found that their assessor created a safe space to talk about their plans for surgery.
- The assessment appointment was not rated highly by respondents: 54% people found it at least somewhat stressful, 52% of people found it slightly or not at all helpful, and only 52% felt mostly or completely prepared for it.
- Almost half of respondents in BC (48%) waited less than a month to hear whether they had been approved for surgery. A third of respondents in BC did not have to wait at all: they learned right away at the appointment whether they had been approved.

In this section, we focus primarily on people who reported having had at least one surgery readiness assessment in BC. We refer to this group as “respondents in BC.” When the results from BC differ significantly from the results in the rest of the country, we mention it.

A surgery readiness assessment is an assessment conducted by a qualified health care professional to ensure that the person is prepared for the surgery, in order to have the best possible post-surgical outcomes.

It is distinct from other gender-related counselling respondents may have accessed otherwise. While most surgeons in BC adhere to the 7th version of the WPATH Standards of Care (SOC) for referral criteria, accepting a referral is up to the clinical judgment of the surgeon. The WPATH standards are simply guidelines and therefore requirements may differ from surgeon to surgeon.

Currently, there is variation in terms of what a surgical readiness assessment entails, what questions are asked, what information is provided, etc.
The latest version of the WPATH Standards of Care do provide some broad guidance around the role of the assessor, as well as the recommended content in a referral for surgery:

Mental health professionals can help clients who are considering surgery to be both *psychologically prepared* (for example, has made a fully informed decision with clear and realistic expectations; is ready to receive the service in line with the overall treatment plan; has included family and community as appropriate) and *practically prepared* (for example, has made an informed choice about a surgeon to perform the procedure; has arranged aftercare). If clients are of childbearing age, reproductive options (section IX) should be explored before undergoing genital surgery. (p. 26-27) (emphasize ours)

The WPATH SOC also emphasize a patient-centered informed consent model:

It is important for mental health professionals to recognize that decisions about surgery are first and foremost a client’s decisions – as are all decisions regarding healthcare. However, mental health professionals have a responsibility to encourage, guide, and assist clients with making fully informed decisions and becoming adequately prepared. (p. 27)

While the SOC allow for an individualized approach to best meet a patient’s health care needs, a criterion for all breast/chest and genital surgeries is documentation of persistent gender dysphoria by a qualified mental health professional. For some surgeries, additional criteria include preparation and treatment consisting of feminizing/masculinizing hormone therapy and one year of continuous living in a gender role that is congruent with one’s gender identity. (See p. 60 of the SOC for details.)

Based on the feedback of respondents, practitioners in BC who perform readiness assessments generally appear to align with these SOC.

Professionals from a range of disciplines have been trained to do this work as qualified assessors – including psychiatrists, psychologists, nurse practitioners, and GPs. A single assessment is typically needed for chest or breast surgery while two assessments are needed for vaginoplasty, phalloplasty, and metoidioplasty. For hysterectomy/bilateral salpingo-oophorectomy and orchiectomy, 1 or 2 assessments may be needed depending on the requirements of the surgeon.

Some people may seek a readiness assessment for more than one procedure in one assessment process. Others may seek assessment for different procedures at different times. In BC, respondents had on average 2 surgery readiness assessments; people ranged from having 1 to 6 assessments, though most had only 1 or 2.
TOTAL NUMBER OF SURGERY READINESS ASSESSMENTS
(for people who had at least one assessment in BC)

- 57% 1
- 28% 2
- 6% 3
- 5% 4
- 1% 5
- 3% 6 or more

ACCESSING SURGERY READINESS ASSESSMENTS

We asked respondents how easy they found it to get a referral for their assessment. While most respondents in BC (60%) found it easy or very easy to do so, 11% found it very difficult to get a referral for a surgical readiness assessment.

“...the referral to assessment process was drawn out and the delays and lack of communication made one feel completely powerless. I’ve basically spent approaching five years with my life in limbo trying to get this surgery done.”
- 39, FEMALE

EASE OF GETTING A REFERRAL TO ASSESSOR IN BC

- 11% Very difficult
- 29% Difficult
- 45% Easy
- 15% Very Easy
WAIT TIMES

Overall, half of respondents in BC waited 150 days or less between the referral and their most recent surgery readiness assessment appointment. This compared to 180 days in the rest of the Canada. It should be noted that wait times varied greatly: in BC, people reported waiting as little as 1 day and as long as 1825 days (over 5 years).

Regardless of whether a procedure is publicly or privately funded, most surgeons require readiness assessments. For assessments in BC, respondents reported the highest wait times between referral and assessment for the following procedures: facial feminization, breast augmentation, tracheal shave, and phalloplasty.

AVERAGE TIME BETWEEN REFERRAL AND ASSESSMENT APPOINTMENT IN BC, BY TYPE OF SURGERY PLANNED

<table>
<thead>
<tr>
<th>Surgery</th>
<th>Time (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaginoplasty (n=59)</td>
<td>212</td>
</tr>
<tr>
<td>Labiaplasty (n=14)</td>
<td>255</td>
</tr>
<tr>
<td>Chest surgery (n=80)</td>
<td>318</td>
</tr>
<tr>
<td>Orchiectomy (n=12)</td>
<td>322</td>
</tr>
<tr>
<td>Hysterectomy (n=47)</td>
<td>336</td>
</tr>
<tr>
<td>Tracheal shave* (n=5)</td>
<td>364</td>
</tr>
<tr>
<td>Phalloplasty (n=6)</td>
<td>383</td>
</tr>
<tr>
<td>Breast augmentation (n=8)</td>
<td>572</td>
</tr>
<tr>
<td>Facial feminization* (n=6)</td>
<td>607</td>
</tr>
</tbody>
</table>

* Not publicly funded in British Columbia

"[We need] better explanations of how the process will unfold (ie. you get referred, then you wait, then you get assessment, then you wait, then phone call for scheduling and picking dates, etc). I didn’t understand this very well to begin with.

- 29, TRANS MASCULINE
TRAVEL TIMES

Respondents in BC reported having to travel an average of 74 minutes to get to their most recent surgery readiness assessment. Half of respondents in BC traveled 45 minutes or less.

Here again, the range of answers suggests that there are some large disparities: some respondents in BC reported having to travel as little as 5 minutes, while others reported having to travel as long as 12 hours.

KNOWLEDGE ABOUT SURGERY READINESS ASSESSMENT

We asked people what kind of information people had received when they were referred for a surgery readiness assessment appointment. We specifically asked them to tell us if they had received information about (1) the assessment process, (2) the criteria for surgery, (3) the surgery process, (4) travel, and (5) the aftercare process. The graph below shows what type of information respondents in BC received.

<table>
<thead>
<tr>
<th>Information Received</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment process</td>
<td>82%</td>
</tr>
<tr>
<td>Criteria for surgery</td>
<td>83%</td>
</tr>
<tr>
<td>Surgery process</td>
<td>69%</td>
</tr>
<tr>
<td>Travel</td>
<td>39%</td>
</tr>
<tr>
<td>Aftercare process</td>
<td>58%</td>
</tr>
<tr>
<td>I didn’t receive information about any of these</td>
<td>18%</td>
</tr>
</tbody>
</table>

Note: Respondents could select more than one answer.
Almost 1 out of 5 respondents who had an assessment in BC indicated that they had not received information about any of these topics. A minority of respondents also gave contradictory answers (they checked a type of information but also that they had not received any information).

Among respondents in BC who had received information, 87% of people indicated that they had received information on multiple topics. When they had received information on only one topic, it was most frequently information about the assessment process (63%).

We also asked who people had gotten this information from. The graph below shows an overview of the answers people gave. People who selected the ‘Other’ option most often mentioned obtaining information from their surgeon or assessor (4%), or from doing their own research (4%).

The majority of respondents in BC (58%) indicated that they had received information about assessments from one source, with another quarter of respondents in BC (26%) reporting that they had received this information from two sources. When people only had one source of information, it was most likely to be the doctor who referred them (63%).
FUNDING FOR ASSESSMENTS

Half of respondents in BC reported not spending any money on assessment appointments, while half of people outside of BC reported spending $115 or less. Again, there were some very large disparities among our respondents: some people reported spending several thousands of dollars.

Respondents in BC were significantly more likely to have their surgery covered at least partially by Medical Services Plan (MSP), the provincial government health plan, than people in the rest of Canada. The vast majority of respondents in BC (95%) received funding for their assessment from one source.

<table>
<thead>
<tr>
<th>Source of Funding</th>
<th>BC</th>
<th>Rest of Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government health Plan (e.g., MSP, OHIP)</td>
<td>80%</td>
<td>77%</td>
</tr>
<tr>
<td>Private insurance</td>
<td>6%</td>
<td>4%</td>
</tr>
<tr>
<td>Out of pocket/My own money/Private pay</td>
<td>19%</td>
<td>27%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>5%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Note: People could select more than one answer.
EXPERIENCE OF ASSESSMENT APPOINTMENT

WHO CONDUCTS ASSESSMENTS?

In BC, about half of the respondents (52%) had at least one of their surgery readiness assessment appointments with a healthcare provider they already knew.

Primary care providers (general practitioners, family doctors, and nurse practitioners) represented the largest proportion of assessors (34%). The “other” category included counsellors or mental health workers, other medical specialists (such as endocrinologists), or designated assessors whose credentials were not specified. Outside of BC, sexologists were also mentioned as part of this “Other” category and represented 2% of the assessors.

PROFESSIONS OF ASSESSORS IN BC

- Primary care provider: 34%
- Psychiatrist: 28%
- Psychologist: 23%
- Other: 12%
- I’m not sure: 3%
HOW PEOPLE FEEL ABOUT ASSESSMENTS

We asked people to rate their experience of their appointment for their surgery readiness assessment in terms of safety, preparedness, stress, and helpfulness.

Overall, assessors were successful at creating a space that was safe enough to talk about the person’s plans for surgery: only 10% of people disagreed or strongly disagreed with that statement.

Open atmosphere, people who genuinely cared how I felt and wanted to hear what I had to say. They were very knowledgeable in the process and let me know how difficult the recovery would be.

- 28, Female

**ASSESSOR(S) IN BC CREATED SAFE SPACE TO TALK ABOUT PLANS FOR SURGERY**

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1%</td>
<td>9%</td>
<td>41%</td>
<td>49%</td>
</tr>
</tbody>
</table>

**HOW PREPARED PARTICIPANTS IN BC FELT FOR THEIR LATEST ASSESSMENT APPOINTMENT**

<table>
<thead>
<tr>
<th>Not at all prepared</th>
<th>A little bit prepared</th>
<th>Somewhat prepared</th>
<th>Mostly prepared</th>
<th>Completely prepared</th>
</tr>
</thead>
<tbody>
<tr>
<td>6%</td>
<td>21%</td>
<td>22%</td>
<td>32%</td>
<td>20%</td>
</tr>
</tbody>
</table>
In BC, over a quarter of respondents (27%) found the surgery readiness assessment not at all helpful, while only 9% of respondents found it extremely helpful. The table above shows that people had mixed experiences in terms of how helpful they found the process.

As we noted earlier, there is wide variation in practice standards for assessments; this lack of consistency may in part explain the widely different experiences that people reported in the survey in terms of safety, helpfulness, stress and preparedness.
RESULT OF ASSESSMENT AND APPROVAL FOR SURGERY

We asked people to tell us how they got the results of their surgery readiness assessment. In BC, most respondents (62%) indicated that the assessor had told them during their appointment.

HOW PARTICIPANTS IN BC GOT THE RESULTS OF SURGERY READINESS ASSESSMENT

- 62% Told at appointment
- 7% Told by primary care provider (who was not assessor)
- 21% Follow-up letter/email/phone call from assessor
- 6% Never told
- 4% Other

People who selected the ‘Other’ option indicated in comments that they had to follow-up themselves with their doctor or assessor to find out if they had been approved. Others also noted that they figured out that they were approved when they were contacted directly by the surgeon.

“[My assessment] was really just cursory gatekeeping, would have really liked to have more info given about what I was getting into with committing to surgery.

-22, FEMALE
We also asked people how long they waited to learn whether or not they were approved for surgery. Respondents in BC most often reported hearing they were approved right away at the appointment (33%) or within a month of the appointment (15%).

A number of people indicated that their assessor told them the result of the assessment during their appointment but also indicated that they waited to find out if they were approved for surgery. We wonder if this difference may be explained by the distinction that some respondents may have made between the moment they were told informally by their assessor that they would be recommended for surgery, and the moment that they got official confirmation that they were approved for surgery, for example once their primary care provider received the letter from the assessor’s office, or once the surgical center called them to confirm.

<table>
<thead>
<tr>
<th>Length of Wait in BC Between Assessment and Learning if Approved for Surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>No wait</td>
</tr>
<tr>
<td>Less than a month</td>
</tr>
<tr>
<td>1 month</td>
</tr>
<tr>
<td>2 months</td>
</tr>
<tr>
<td>3 months</td>
</tr>
<tr>
<td>4 months</td>
</tr>
<tr>
<td>5 months</td>
</tr>
<tr>
<td>6 or more months</td>
</tr>
<tr>
<td>Still waiting to hear</td>
</tr>
</tbody>
</table>
DETAILED FEEDBACK ON ASSESSMENT

Throughout the survey, we asked participants for feedback regarding their experience with surgery readiness assessments. We asked them what was surprising/unexpected about the assessment, what they wish they had known before their appointment, and what were positive aspects of the assessment. In line with the rest of the survey data, we found great variation among people’s answers, suggesting that there is little consistency in how assessments are conducted and how they are experienced.

POSITIVE EXPERIENCES OF THE ASSESSMENT

Some people reported having a good experience. This subset of respondents often communicated that they did not experience the assessment as a stressful process. A few key elements appeared to contribute to these positive experiences:

I don’t think anyone needs to ‘know’ anything [before the assessment], except why they want the surgery. The questions are completely personal. It is not a test.

-28, FEMALE

Knowledgeable assessors. People appreciated when their assessor(s) could provide clear and honest answers to any remaining questions that they had. People especially appreciated being able to obtain clear, detailed information about the surgery (risks, different procedures, outcomes, etc.) and the recovery process.

Affirming environment. Many people emphasized the importance of a supportive environment where the assessor was welcoming, respectful, and warm, listened carefully, and made it clear that they were an ally who was there to facilitate that process rather than someone there to evaluate whether they needed surgery.

I asked about some of the things that wasn’t that clear regarding the whole process, and my assessor fill[ed] me in on the missing information.

-40, FEMALE
The counsellor I saw was very supportive and friendly. She was very affirming of my identity and was able to answer some questions that I had been unable to find answers to online or elsewhere. She was infinitely more knowledgeable than my GP on all topics [...] She was able to make the process mostly painless.

-22, NON-BINARY/TRANS MASCULINE

- Previous relationship with the assessor(s). People often had positive experiences with the assessment process when they already knew their assessor (for example, their assessor may have been their counsellor) and had a positive, trusting relationship with that provider.

- Supportive of non-binary identities. For non-binary respondents, it was important to have an assessor who was explicitly inclusive of their identities.

- Timely and convenient to access. People who were able to access an assessor where they live or via telehealth appreciated that they could fit this process into their lives with relative ease. People also appreciated being able to book an assessment appointments in a timely manner.

While a number of people appreciated the opportunity that the assessment gave them to reflect and obtain information, for many people, the most positive aspect of the assessment process was simply having completed it, because it meant being one step closer to surgery.

CONCERNS ABOUT THE ASSESSMENT PROCESS

Many people also reported frustrations about the process of going through the surgery readiness assessment. Three major concerns were mentioned:

- Being uncertain about content and goal of the appointment. Many people commented on the lack of information that they had going into their appointment(s). Participants particularly mentioned wishing that they had known about who is qualified to be an assessor, what they were going to be asked, and how long they would have to wait afterwards before surgery.

- It felt like I had to answer lots of questions about my childhood and my stability. It was uncomfortable. [...] It wasn’t therapeutic so I felt like I had to just say things to advocate for myself.

-27, GENDERQUEER NON-BINARY TRANS MASCULINE
- Perceiving the assessment as a gate-keeping mechanism. Many people were worried that they could be prevented from accessing surgery if they did not provide the ‘right’ answers to the assessor. As a result, they felt that they could not open up during the assessment. People were not sure they had to go through this assessment, and wanted to know “what would disqualify [them] from having surgery” (33, gender neutral). Part of the concerns expressed about gate-keeping came from a perception that the surgery readiness assessment exists more for the benefit of the health care system than for the benefit of the respondents.

- Not obtaining enough information. Survey respondents also reported often walking away with still insufficient information about the process. This often left them feeling disempowered to make informed decisions about their health. People mentioned not having enough information in terms of eligibility criteria for surgery (such as BMI cut-offs), different surgeons and techniques available, and surgical results (including potential complications).

These concerns often created stress about the assessment ahead of time, which sometimes turned out to be unwarranted. One person noted, “[I wish I had known] that it wasn’t going to be as stressful as I thought it would be” (28, non-binary).

It was very useful to me to know that if I treated the appointment as what it purported itself to be (a safe, semi-therapeutic environment to receive advice and support), that I would be held off indefinitely from getting surgery, and that, instead, it was really about assuaging the fears of the assembled professionals and funding bodies.

- 34, MALE
Gender-affirming surgery

GENDER-AFFIRMING SURGERY: KEY FINDINGS

- Across all surgeries, most people (71%) had their surgery paid at least partially for through a government health plan.
- Over half of respondents (57%) were able to choose the surgeon they wanted for surgery. People who paid for surgery entirely out of pocket were much more likely to be able to choose the surgeon they wanted.
- Just over 60% of respondents had to travel 2 or more hours to their surgery appointments.
- Experiences with surgeons and their staff varied; however, a large majority of people (83%) agreed or strongly agreed that the surgeon created a space that was safe enough to ask questions and talk about the surgery process, and an even larger portion of people (89%) agreed with the same statement concerning the clinic staff.
- An important minority of respondents (17%) indicated that they had not received all the information they needed to understand what their surgery would involve.
- Complication rates were higher for people travelling 2 hours or more to their surgery appointments, as well as for people whose surgery was funded solely through a government health plan.
- People score on average 7 out of 10 on a support scale for post-surgery support, meaning that they had quite a bit of social supports available to them after they came home from surgery.

Note: The entire sample includes data about voice feminization, liposuction, metoidioplasty, and clitoral release. We are not able to report on these procedures separately due to the low number of responses.
ACCESS TO SURGERY

FUNDING FOR SURGERY

We asked people how their surgery was paid for. Across all surgeries, most people (71%) had their surgery paid at least partially for through a government health plan.

The vast majority of people (93%) only had one source of funding for their surgery. Nearly 7 out of 10 people had their surgery funded solely through a government health plan, but 1 in 3 people had their own money as their single source of funding for surgery.

Even when their surgery was covered, most people still had to cover a number of costs out of pocket, including travel costs, accommodation, aftercare facilities, and aftercare supplies. Although on average, people had larger out-of-pocket costs when they had paid for surgery with their own money, these costs were still high when the surgery had been covered by a government health insurance plan.

Out-of-pocket costs for things other than surgery and aftercare facilities varied greatly across respondents and across surgeries. Some people reported spending none of their own money while some people reported paying as much as $58,000. Looking specifically at the two most common surgeries (vaginoplasty and chest surgery), half of the respondents reported spending $2,500 or more of their own money for vaginoplasty (approximately the cost of aftercare, which is covered by Trans Care BC since December 2015); for chest surgery, half of the respondents reported spending $1135 or more of their own money.

To see the surgeon I wanted to, I had to pay around 10,000 dollars. To do this I had to put myself into debt which I am still paying back, several years later. […] This surgery was a life or death situation for me. I couldn’t [bear] to wait on unending wait lists.

-24, NON-BINARY, GENDERQUEER, EFFEMINATE TRANS GUY

<table>
<thead>
<tr>
<th>HOW WAS YOUR SURGERY PAID FOR?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Government Health Plan</strong> (eg., MSP, OHIP)</td>
</tr>
<tr>
<td><strong>Private insurance</strong> (group insurance)</td>
</tr>
<tr>
<td><strong>Out of pocket/My own money/Private pay/Crowd-sourcing</strong></td>
</tr>
<tr>
<td><strong>Don’t know</strong></td>
</tr>
</tbody>
</table>

Note: People could select more than one answer.
**INELIGIBILITY FOR SURGERY**

When people indicated that they were ineligible for a surgery that they wanted, we invited them to explain why they were ineligible. In addition to people who were ineligible due to medical conditions that made general anesthesia risky for them, two primary concerns were raised: breast augmentation and BMI (Body Mass Index).

**BREAST AUGMENTATION CRITERIA**

The current criteria for coverage by MSP specify that the attending surgeon needs to confirm that the person has been on hormones for at least 18 months (unless contraindicated), and that there has been less than an AA cup of breast growth or asymmetric breast growth of greater than 1 and ½ cup size difference.

> Current criteria for breast augmentation specify zero development in spite of hormones. I have a bit of development but not nearly enough to look female enough for my peace of mind.
> -68, TRANS WOMAN

There was a recurring theme among respondents that these criteria are inadequate for trans women because even though the breast tissue growth that they had experienced was ‘sufficient’ by MSP standards, it was not always enough for them to look feminine and/or feel good about their body.

**BMI CUT-OFF**

A number of people reported being ineligible for the surgery they needed or wanted due to being over a particular body mass index (BMI).

> The assessor pointed me toward surgeons who had BMI cutoffs that I was over. This caused a lot of struggles getting access to surgeries. There should be better communication through the whole process as to what the limitations are so realistic expectations are created and unique cases such as mine can start being managed and issues mitigated early in the process.
> -27, MALE

Although researchers and clinicians have questioned its appropriateness as a measure of weight or health, BMI is still commonly used to categorize people as underweight, normal weight, overweight, or obese. Many surgeons have eligibility criteria that includes BMI of 35 and under. Based on this BMI cut-off, they will not operate on a person over a certain BMI; reasons given include restrictions imposed on them by the facility or concerns around clinical safety and patient outcomes.
Our survey found that BMI-related criteria changes from surgeon to surgeon, which created additional difficulties for people as they navigated the process and tried to figure out if they had other options for accessing gender-affirming surgery. People also expressed concerns over the impact on both their mental and physical health of having to lose weight in order to access surgery as this is difficult or unattainable for many people.

**WAITING FOR SURGERY**

**BEING REFERRED FOR SURGERY AND CHOOSING A SURGEON**

The vast majority of participants (84%) did not have any problem getting a referral to a surgeon for gender-affirming surgery. Procedures where more than 10% of people reported having problems getting a referral include vaginoplasty, orchiectomy, phalloplasty, and chest surgery.

The majority of BC residents (90%) had no problems getting a referral to a surgeon. In comparison, only 7 out of 10 respondents in the rest of Canada said they had no problems getting a referral to a surgeon.

Over half of survey respondents (57%) reported that they were able to choose the surgeon they wanted for their surgery. We compared people whose sole source of funding was a government health plan versus people whose sole source of funding was private pay. People who paid for surgery entirely out of pocket were much more likely to be able to choose the surgeon they wanted (86% versus 28% for those who were funded entirely by a government health plan).

<table>
<thead>
<tr>
<th>PERCENTAGE OF PEOPLE ABLE TO CHOOSE THE SURGEON THEY WANTED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast augmentation</td>
</tr>
<tr>
<td>Phalloplasty</td>
</tr>
<tr>
<td>Orchiectomy</td>
</tr>
<tr>
<td>Chest surgery</td>
</tr>
<tr>
<td>Labiaplasty</td>
</tr>
<tr>
<td>Hysterectomy</td>
</tr>
<tr>
<td>Vaginoplasty</td>
</tr>
<tr>
<td>Facial feminization*</td>
</tr>
<tr>
<td>Tracheal shave*</td>
</tr>
</tbody>
</table>

* Not publicly funded in British Columbia.
WAIT TIMES

Among people in BC, the wait time between approval and surgery date was 12 months or less for half of the surgeries. In the rest of Canada, the wait time was 8 months or less for half of the surgeries. There may be other factors aside from health care system capacity that contributes to the length of time waiting, but the comments given by respondents provided no examples of such factors.

The range of experiences was very wide: some people waited as little as one month while others waited as long as 108 months (9 years). Respondents reported the widest range of wait times for orchiectomy, breast augmentation, phalloplasty, and chest surgery.

Additionally, at the time they took the survey, half of the people who were currently waiting for their surgery and had a scheduled surgery date had been waiting for at least 17 months. Half of the people who were currently waiting for surgery but did not have a scheduled surgery date had been waiting 11 months or more at the time they took the survey.
MANAGING STRESS WHILE WAITING

We asked people about their experience during the time that they were waiting for surgery. Respondents who had already had surgery varied greatly in how stressful they found it waiting for surgery. As the graphic below shows, 20% found the experience extremely stressful while a similar portion (19%) found the experience not at all stressful. These numbers also varied quite a bit depending on what surgery people were waiting for.

<table>
<thead>
<tr>
<th>Surgery</th>
<th>Stress Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phalloplasty</td>
<td>2.3</td>
</tr>
<tr>
<td>Chest surgery</td>
<td>2.4</td>
</tr>
<tr>
<td>Vaginoplasty</td>
<td>3.0</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>3.2</td>
</tr>
<tr>
<td>Orchietomy</td>
<td>3.3</td>
</tr>
<tr>
<td>Facial feminization*</td>
<td>3.5</td>
</tr>
<tr>
<td>Labiaplasty</td>
<td>3.7</td>
</tr>
<tr>
<td>Breast augmentation</td>
<td>3.9</td>
</tr>
<tr>
<td>Tracheal shave*</td>
<td>3.8</td>
</tr>
</tbody>
</table>

* Not publicly funded in British Columbia.

HOW STRESSFUL WAS IT WAITING FOR THIS SURGERY? (AVERAGE ACROSS ALL SURGERIES)

<table>
<thead>
<tr>
<th>Stress Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely stressful</td>
<td>20%</td>
</tr>
<tr>
<td>Very stressful</td>
<td>22%</td>
</tr>
<tr>
<td>Somewhat stressful</td>
<td>23%</td>
</tr>
<tr>
<td>Slightly stressful</td>
<td>15%</td>
</tr>
<tr>
<td>Not at all stressful</td>
<td>19%</td>
</tr>
</tbody>
</table>
In contrast, people who were currently waiting for their surgery (and may or may not have a scheduled surgery date) reported slightly higher levels of stress: 28% were finding this waiting period extremely stressful while only 10% were finding it not at all stressful. This difference may be explained by the fact that, for those who have already had surgery, the stress of waiting has been dampened a bit by time and distance from that experience, while this stress is very present for those who are currently waiting.

We asked people what resources they had – or wish they had – that are helpful while waiting for surgery. People primarily mentioned:

- **Support from peers, friends, and/or the broader trans community**, especially the ability to talk to people who have been through the same surgery
- **Online resources** such as blogs, websites with information, YouTube channels, etc.
- **Support from health care providers**, including the ability to contact with the surgical centre to answer any questions that arise

All these resources point to the need that people expressed for having information as they wait for their surgery. People expressed distress and frustration when they felt like they had little access to information – for example because they could not talk to someone who has had the same surgery, with the same surgeon – and it contributed to making them feel less well-prepared for the next step.

“I have a support group but I am not able to determine anything else about the surgery, like whether or not I’ll be approved or what options are available and so on.”

-30, TRANSFEMALE

“I just look online to YouTube videos. [I am] currently the only trans person in my community.”

-48, FTM, MALE, TWO SPIRIT, TRANS MAN
The long journey home was difficult, and being so far from the clinic (several thousand miles) meant effectively that once I was home, there was no way of going back for follow-up care when questions arose. That meant I was relying on my GP, who had not taken a patient through the transition process before, so in many cases, I was the one educating him.

-67, female

PRE-OPERATIVE EXPERIENCE
DISTANCE FROM SURGERY CENTRE

Overall, 61% of respondents had to travel 2 or more hours to their surgery appointments. This was most often the case for the following procedures: phalloplasty (100%), vaginoplasty (84%), and labiaplasty (83%).

PERCENTAGE OF PEOPLE WHO HAD TO TRAVEL 2 OR MORE HOURS TO THEIR SURGERY APPOINTMENT

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phalloplasty</td>
<td>100%</td>
</tr>
<tr>
<td>Vaginoplasty</td>
<td>84%</td>
</tr>
<tr>
<td>Labiaplasty</td>
<td>83%</td>
</tr>
<tr>
<td>Tracheal shave*</td>
<td>67%</td>
</tr>
<tr>
<td>Facial feminization*</td>
<td>63%</td>
</tr>
<tr>
<td>Breast augmentation</td>
<td>63%</td>
</tr>
<tr>
<td>Orchietomy</td>
<td>62%</td>
</tr>
<tr>
<td>Chest surgery</td>
<td>62%</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>17%</td>
</tr>
</tbody>
</table>

* Not publicly funded in British Columbia.
We also asked respondents if they had encountered any problems with travel to and from appointments related to your surgery. Over half of respondents (56%) reported encountering problems. However, people getting hysterectomies were less likely to encounter problems. As the graph below shows, cost and time were the most commonly reported problems.

In the ‘Other’ section, people commented primarily on difficulties caused by travelling shortly after a major surgery, such as pain, stress, or extreme discomfort. These difficulties can be amplified by disabilities or typical travel inconveniences such as flight cancellations or delays.

**PROBLEMS ENCOUNTERED WITH TRAVEL TO AND FROM SURGERY-RELATED APPOINTMENTS**

<table>
<thead>
<tr>
<th>Problem</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost</td>
<td>49%</td>
</tr>
<tr>
<td>ID</td>
<td>5%</td>
</tr>
<tr>
<td>Time</td>
<td>38%</td>
</tr>
<tr>
<td>Other</td>
<td>19%</td>
</tr>
</tbody>
</table>

Note: People could select more than one answer.

**INFORMATION AND CONSENT**

The vast majority of respondents (83%) indicated that they had received all the information they needed to understand what their surgery would involve. However, that number was much lower for vaginoplasty (75%) and phalloplasty (34%).

"Not much time was spent with medical team or surgeon. It was very rushed and there was a lot of down time without information readily available. I would’ve appreciated a more informative environment with support."

-39, Woman
Almost all respondents (94%) indicated that the surgeon met with them before the surgery to answer their questions. While this number remained high across all surgeries, there were some types of surgeries (i.e., vaginoplasty and phalloplasty) for which more than 10% of people were not able to meet their surgeon before their surgery.

Similarly, the majority of people (85%) indicated that all of their questions about their surgery were answered by the surgeon and their team. This still leaves a large minority who felt that all their questions were not answered. Among respondents who had had vaginoplasty and phalloplasty, more than 20% of people felt that all their questions had not been answered.

Nearly all respondents (96%) indicated that they had signed a consent form prior to surgery. Fewer than 1% of respondents had not signed a consent form, and 3% were unsure.

The vast majority of people (92%) reported having enough time to review the consent form before signing. However, in the case of some lower surgeries (vaginoplasty, labiaplasty, and phalloplasty) as well as tracheal shave, more than 15% of people indicated that they did not have enough time to review the consent form.

**INTERPERSONAL EXPERIENCES WITH SURGEON AND CLINIC STAFF**

We asked respondents to tell us how much they agreed with the following statement: “the surgeon created a space that was safe enough to ask questions and talk about the surgery process.” A large majority of people (83%) said that they agreed or strongly agreed with this statement.

However, in the cases of vaginoplasty, tracheal shave, and phalloplasty, over 20% of respondents indicated that they disagreed or strongly disagreed with this statement.

“The surgeons are very knowledgeable and experienced, and understand how to deal with trans patients. The staff involved in the procedure are too very comforting, and all ensure that you are feeling calm and prepared for the surgery.”

-20, MALE
We have included a summary graphic for the two surgeries where we had the most respondents, vaginoplasty and chest surgery.

![SURGEON CREATED SAFE SPACE TO TALK ABOUT THE SURGERY PROCESS]

Note: People could select more than one answer.

“[The clinic staff] have requested an undue amount of documentation regarding my gender presentation from my doctors, simultaneously violating my privacy and delaying my paperwork. They offer me no explanations and will speak only with my doctors. They do not treat me as an interested party. The clinic’s ostensible continued adherence to archaic standards of care limits access to life-saving surgery.”

-29, FEMALE

We also asked respondents to tell us how much they agreed with the following statement: “the clinic staff created a space that was safe enough to ask questions and talk about the surgery process.” An even larger portion of people (89%) said that they agreed or strongly agreed with this statement.
The staff and surgeon that I had were fantastic and made sure to ask about what pronouns I used before discussing anything with me.

-24, NEUTRAL

Only in the cases of phalloplasty and hysterectomy did 20% or almost 20% of respondents indicate that they disagreed or strongly disagreed with this statement.

We have included a summary graphic for the two surgeries where we had the most respondents, vaginoplasty and chest surgery.

In comments, people’s experiences varied quite a bit. While some reported excellent interactions with staff, including some surgeons and most nursing staff, many reported feeling rushed through interactions with surgeons and were surprised by how little time they spent meeting, and interacting with, their surgeon. Many people who spent a few nights in recovery facilities were appreciative of the staff there. However, there were still a number of people who experienced instances of misgendering and other upsetting interactions with staff.

I expected it to be my (recently changed) legal name appearing on the files and clinic bracelet. It wasn’t; they claimed that they couldn’t change my name once the file was started.

-30, MAN

CLINIC STAFF CREATED SAFE SPACE TO TALK ABOUT THE SURGERY PROCESS

Note: People could select more than one answer.
SELF-REPORTED COMPLICATIONS

We asked people about their experiences of complications during and after surgery. There are complications that are commonly associated with any kind of surgery, but there is no systematic data that would allow us to compare typical complication rates for gender-affirming surgery with what our respondents reported. It is also difficult to make comparisons without knowing precisely what procedures people underwent.

For some surgeries (such as phalloplasty), it is important to remember that only a few respondents provided data. This makes it difficult to be confident our findings represent an accurate estimate of complications and highlights the need for further research.

CONTACT IN CASE OF COMPLICATION

Almost all respondents (95%) indicated that they were given contact information in case of questions or complications. Among those who received this information, almost half (45%) used it. The people most likely to use that contact information were people who had had the types of surgeries that were most likely to experience complications, namely vaginoplasty (80%) and phalloplasty (100%).

DURING SURGERY OR BEFORE DISCHARGE

We asked people about their experiences with complications during surgery, before they were discharged from the surgery centre, and after they were discharged from the surgery centre. The numbers reported below are based on people’s personal understandings of complications; this may lead to over- or under-reporting depending on the circumstances.

Most respondents (82%) did not have any complications during surgery or before they were discharged, meaning that the reported complication rate was 18%. The complication rate was higher for people who had had vaginoplasty (33%), phalloplasty (67%), and facial feminization (25%).

One way of classifying the severity of complications is the Dindo-Clavien classification. Complications reported by respondents ranged from Type 1, which requires limited medication and health interventions, to Type 2, which requires medication, and Type 3 which requires further surgery or other significant treatments.

Among the people who provided details about their complications during surgery or before discharge, 93% reported experiencing one type of complication, and 7% reported experiencing two types of complications.

Almost half (47%) of the reported complications were Type 1 complications, while Type 2 represented 12% of reported complications, and Type 3 represented 12% of reported complications. More than 1 in 4 people (29%) reported complications that we classified as non-surgical because they did not require further surgical interventions (such as stitches not dissolving).

Within BC, we looked separately at complication rates for surgeries that took place in Vancouver (15%), the rest of the lower mainland (25%), Victoria (29%), and the rest of BC (0%).
A survey of experiences with surgery readiness assessment and gender-affirming surgery among trans people in Canada: Focus on British Columbia

AFTER DISCHARGE

Complications after being discharged from the surgery centre were more common. 40% of respondents indicated that they experienced complications after they were discharged. As with complications before discharge, the most common types of surgeries where people experienced post-discharge complications were vaginoplasty (60%), phalloplasty (83%), metoidioplasty (80%), and facial feminization (43%).

Among the people who provided details about their complications, 70% reported experiencing one type of complication, 25% reported experiencing two types of complications, and 4% reported experiencing three types of complications.

Well over half (60%) of the reported complications were Type 1 complications, while Type 2 represented 20% of reported complications, and Type 3 represented 9% of reported complications.

Just over 1 in 10 people reported complications after being discharged that we classified as non-surgical/medical complications. These included: improper hair growth on reconstructed genital tissue, unclear post-op instructions, and pain management. People also reported having difficulties with follow-ups due to distance from their surgeon and a lack of available trans competent health care providers in their area.

Within BC, we looked separately at complication rates in Vancouver (49%), the rest of the lower mainland (38%), Victoria (29%), and the rest of BC (10%).

FACTORS IN COMPLICATIONS

We looked at how distance from home might affect complication rates after someone has been discharged. Complication rates were 34% when the person had to travel less than 2 hours to their surgery appointments, and 44% when the person had to travel more than 2 hours to their surgery appointments.

I had a lot of pain about 3-5 days later that the meds couldn’t control. It seemed to be related to attempting to go to the bathroom. It went away on its own, but at the time I seriously considered going to the ER, except I didn’t really want to go through the extreme hassle of explaining everything to an ER Dr. and potentially being discriminated against.

-34, MALE

We also looked at how source of funding might impact complication rates. When surgeries were funded only through a government health plan, 30 people (or 25%) reported complication before discharge and twice as many (52%) reported complications after discharge. When surgeries were funded only out of pocket, 9 people (13%) reported complications before discharge and 23 (34%) reported complications after discharge.
POST-OPERATIVE EXPERIENCES

RECOVERY

We asked people if their surgeon had talked to them after their surgery. The majority of them (76%) said yes.

Nine out of ten people also indicated that they were given post-op care instructions in writing, and 84% of respondents felt that the post-op care instructions were clearly explained and that all questions were answered before they were discharged.

Although we did not ask specific questions about post-operative recovery centres, many people who had spent time in these centres after surgery before heading home shared positive stories about places where they could recover surrounded by both medical staff and other trans people who had just gone through major surgeries as well.

SOCIAL SUPPORT

We used an established social support scale to measure how much support people had while they were recovering from surgery. We specifically asked people if they had someone who could take them to the doctor, help change their bandages, help them with daily chores, listen to them, and get their mind off things.

On average, people score a 7 out of 10 on that support scale, meaning that they had quite a bit of support available to them.

The surgical team (and I stress “team”) were amazing, caring, and supportive. They listened to what I wanted and did everything they could to make it happen. The aftercare facility is staffed by (again) wonderful, amazing, and caring support workers. [...] We were also surrounded by other trans folk, both men and women, whose experience we shared, and we were able to support each other when needed, and to rejoice in each other’s minor (and major) triumphs as well. I had been told ahead of time that it would be an emotionally intense time, but I was unprepared for just how intense it would be. I left grateful more than words could tell for all I had been given.

-67, FEMALE
About two thirds of respondents (68%) indicated that they were told about the possibility of surgery revisions. This percentage was higher for labiaplasty (82%) as well as phalloplasty (100%).

The vast majority of respondents (86%) had not had any surgery revisions. The only surgery that had a much higher rate of revisions was phalloplasty. About a quarter of respondents (26%) indicated that they would like to have (further) surgery revisions, with another 37% indicating that they were not sure if they wanted revisions.

<table>
<thead>
<tr>
<th>PERCENTAGE OF PEOPLE WHO HAD SURGERY REVISIONS</th>
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<tbody>
<tr>
<td>Phalloplasty</td>
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<tr>
<td>Chest surgery</td>
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<tr>
<td>Facial feminization*</td>
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<tr>
<td>Breast augmentation</td>
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<td>Vaginoplasty</td>
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<td>Orchiectomy</td>
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<tr>
<td>Labiaplasty</td>
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<td>Tracheal shave*</td>
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* Not publicly funded in British Columbia.
Conclusion

I am able to continue on forward with my life.
-48, FEMALE

When asked to reflect on positive aspects of surgery process, people primarily emphasized their satisfaction with the result of the surgery and how much it meant to them to have been able to access surgery: they felt happier, more comfortable in their body, able to live their lives more fully.

This whole experience [with surgery] was terrible. The flight costs should have been covered. I should have had a pre-surgery consult by phone/skype months in advance and then the opportunity to meet the surgeon prior to the surgery.
-43, MALE

When they had good experiences with the clinical and surgical staff along the way, they praised them generously; and it was clear that having the experience of knowledgeable, supportive medical team could make all the difference in the person’s experience of navigating their access to gender-affirming surgery, even when other elements (such as lengthy wait times) were difficult.

However, some important disparities exist when people seek out gender-affirming surgery. We pointed out wide differences in terms of wait times, their ability to choose one’s surgeon, whether or not people felt properly informed before they had surgery, their interactions with surgeons and their staff, whether they experienced complications or not, and how supported they were during their recovery. Some of these disparities are impacted by where people live, how far they have to travel to their surgery, whether they are able to pay out of pocket for certain or all expenses, and what surgeries they want to have.
Additionally, although small sample size does not allow us to report on these experiences in detail, the small subset of people who tried to access gender-affirming surgery from the Yukon consistently reported difficulty accessing care, with unclear pathways to surgery, especially when they needed to have it covered by a government health plan. These experiences suggest that particular attention needs to be paid to gender-affirming care for patients from the territories.

I feel great after the surgery. It looks almost exactly how I hoped and I feel much better about myself and my body. The surgery itself was an experience, and I am very thankful for everyone who supported me.

-29, TRANS

These negative experiences rarely represented the majority of our sample, but they were frequent enough that they point to recurring issues and gaps in the current model of access to gender-affirming surgery.

“We need] less treating medically necessary surgeries like elective surgeries. More holding surgeons accountable when they treat patients terribly.

-27, MALE
Recommendations

We asked people what recommendations they had both for the surgery readiness assessment and for gender-affirming surgery in general. We have summarized these recommendations here, along with our own recommendations based on the data that we have presented in this report.

We gave Trans Care BC the opportunity to read a draft of the report and provide an update on early steps and actions taken to address the recommendations from the reports. Some of the recommendations identified through our research had also been raised during Trans Care BC’s community consultation process.

Surgery Readiness Assessment

**Recommendations**

**Transparent, streamlined assessment process, with reduced wait times**

People should have a clear sense of next steps and how long each step might take (this includes a clear idea of wait times between the referral and the assessment, and between the assessment and surgery). The priority should be on significantly reducing wait times by training more assessors, as well as on creating a streamlined process from referral to surgery.

**Recent Actions**

- In December 2015, Trans Care BC implemented a streamlined referral process for surgeries that removed the requirement of a central provincial chief assessor. Referrals can be made directly to surgeons, which has reduced wait times in the assessment and referral process.
- Trans Care BC has created a surgical assessment infographic outlining the steps for assessment. It is accessible at: [http://transhealth.phsa.ca/wp-content/uploads/sites/15/2014/05/Trans-Care-BC_Surgical-Assessment-Infographic_FINAL.pdf](http://transhealth.phsa.ca/wp-content/uploads/sites/15/2014/05/Trans-Care-BC_Surgical-Assessment-Infographic_FINAL.pdf)
- Trans Care BC is developing a new website that will include more surgical information for clients. In the meantime, some information can be found on the Trans Health Information Program site at [http://transhealth.phsa.ca/medical-options/surgeries](http://transhealth.phsa.ca/medical-options/surgeries)

“"If, and I stress the “if,” we are to have psychiatric assessments before surgery, those psychiatrists need to bring that basic respect and curiosity into the interview with them. [...] Whatever happened to “informed consent?” If I am a competent adult, surely, the decision to pursue surgery is (or should be) a matter for me and my doctor to decide."”

-FEMALE
More consistency in the assessment process

Our research suggests the current assessment process is not helpful for many people. There are discrepancies in terms of what information people are able to obtain on the assessment process, and who can perform assessments. People also do not obtain enough consistent, helpful information during the assessment. When people did find their assessment(s) helpful, it was because they were able to obtain information on next steps, on different surgical procedures and outcomes, and on the healing process. There needs to be more systematic training of assessors in order to ensure more consistency across practitioners regarding assessment practices – what should happen, and what should not happen, in an assessment.

RECENT ACTIONS

Trans Care BC is increasing training for more publicly funded assessors to reduce wait times and develop a consistent process that is modelled on a patient-centred, strengths based, trauma-informed approach:

- Prior to Trans Care BC’s start in 2015, there were 14 publicly funded assessors across the Province. This figure has increased to 26.
- Trans Care BC will be publishing a list of trained, publicly funded assessors in fall 2017. In the meantime, clients can call our Care Coordination team for further information: 1-866-999-1514
- TCBC’s Care Coordination team also provides surgical assessments via telehealth to patients across the province.
In the spring of 2016, Trans Care BC established a Care Coordination team of health navigators, nurses and a part-time primary care physician. Some of the supports the team can offer are to:

- Provide patient navigation support through the system of care
- Increase support for pre and post-surgical care, as well as training for other health care providers
- Provide surgical readiness assessments through tele-health (secure video) for patients who have difficulty finding an assessor in their community
- Provide help with surgical care coordination for clients seeking lower surgeries like vaginoplasty, phalloplasty and metaoidioplasty.

Informed consent
The assessment process was useful when it helped people plan for surgery and aftercare and gave them a space to explore fears, questions, and concerns without feeling like this might jeopardize their chance to access surgery. Emphasizing a patient-centered, informed consent model would ensure that people have all the information they need to make the best decision for themselves.

Transparent, streamlined assessment process, with reduced wait times

More consistency in the assessment process

Cost coverage
If assessments remain mandatory, their cost should be fully covered by government health plans to avoid disparities between those who are able to pay out of pocket for services, and those who cannot.

“I was lucky and was able to be connected to all the right and best doctors. I was scared that I would have to fit into the trans narrative of being born in the wrong body and knowing my whole life that somethings wasn’t right and being binary trans, but that wasn’t the case.”

-42, NON-BINARY
**Transparent, streamlined path to surgery, with reduced wait times**

As with assessments, people need to have easy access to a clear outline of the different pathways to surgery. Clearly understanding next steps and expected wait times would help people better plan and manage their stress. Additionally, because waiting is often a time of high stress, wait times should be reduced as much as possible by increasing the numbers of surgeons available to perform surgeries.

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**Increased choice of surgical options**

People’s lack of ability to choose their surgeon when their surgery is funded through a government health plan is a concern. People need to have access to more trained surgeons locally for those surgeries that can currently only be performed out of province or out of country. Finding ways to have care be closer to where people live would help address some of the concerns and issues that arose from having to travel large distances (such as higher complications rates, which may be linked to difficulties with follow-up and reduced support). This would likely reduce wait times as well.

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**RECENT ACTIONS**

Trans Care BC is working to increase the number of new surgeons performing upper surgeries:

- Trans Care BC is supporting work to train new surgeons across BC so that patients can obtain surgery closer to home.
- A central intake model through Trans Care BC will be in place in the fall 2017 so that communication with patients about their status on the wait list will be improved.
- The current list of surgeons who are working with Trans Care BC as part of the central upper surgery wait list can be found here: [http://transhealth.phsa.ca/services/service-directory/surgeon-profiles](http://transhealth.phsa.ca/services/service-directory/surgeon-profiles). As new surgeons become trained and part of the process, their information will be available here as well.

- Trans Care BC has submitted recommendations to the Ministry of Health on how a comprehensive surgical program could provide lower surgeries in BC to bring procedures closer to home.
Trans-affirming healthcare is still all sourced by word-of-mouth - there is no way to discover who is willing to treat you without applying over and over again. [...] A centralized resource list for trans-affirming surgeons, that is kept current, would be a godsend.

-40, WOMAN

**RECOMMENDATIONS**

**Clearer pathway to surgery for people with a high BMI**

Given that gender-affirming surgery is medically necessary for many people, there should be work done to improve the experience for patients with higher BMIs so that they have a clear sense of their options for care. Ways to remove barriers to surgery due to BMI should be explored so that those who are able to safely access surgery can do so.

**Greater number of trans-competent local primary care providers**

Having trained and well-informed health care providers that are accessible locally would both help people navigate the process of getting gender-affirming surgery and would help with aftercare in the case of surgeries that have to be done out of province/out of country.

**RECENT ACTIONS**

- Currently all surgeons working with Trans Care BC have a BMI cut-off rate of 35. Trans Care BC is working with these surgeons to develop a standard and clear process for patients with a BMI of 35 or higher.

-I was VERY fortunate to have had access to an incredibly supportive and professional health care team, starting and ending with my family doctor/GP. That has made all the difference for me in comparing my surgery/transition experience to others.

-35, MALE/FTM

- Trans Care BC’s education team is working to enhance primary care providers’ knowledge to provide safe and supportive primary care for trans patients, as well as hormone initiation, monitoring and surgical assessments. An informed consent model is a key part of this training.
### RECOMMENDATIONS

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<tr>
<th>Better coverage of travel and aftercare costs</th>
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<td>This will reduce inequities between those who can afford to pay for care out of pocket, and those who cannot.</td>
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<th>Broader access to surgeries that facilitate participation in society</th>
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<td>Some procedures that are still considered primarily cosmetic (such as tracheal shave, electrolysis, facial feminization, etc.) are sometimes key for people to feel like they can more happily and confidently, safely navigate everyday life. These surgeries should also be covered to increase access for those who need them.</td>
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### RECENT ACTIONS

- Since October 2015, Trans Care BC funds aftercare funding for medically required, live-in, post-operative care after complex lower (genital) surgeries.

- Trans Care BC is conducting an environmental scan on existing models to inform recommendations about expanding coverage of other medically necessary affirming procedures.

- Trans Care BC is working with the Ministry of Health to review the current criteria of breast construction and augmentation to improve publicly funded access for trans people seeking this procedure.