PROGRESS

for Phalloplasty and Metoidioplasty

Research Results Community Report

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2024

PROGRESS

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Please note that this report contains images and descriptions of sex-related content including depictions of genitals and discussion of sexual acts. This report is meant as a resource for adults considering undergoing or those who have undergone phalloplasty or metoidioplasty.

Sections

Introduction

PROGRESS was a community-based, participatory, patient-oriented research project about experiences with and outcomes of two gender affirming genital surgeries: phalloplasty and metoidioplasty

The project aimed to provide a platform for individuals who had undergone either phalloplasty or metoidioplasty to share their experiences and perspectives. The researchers involved in the project worked closely with community organizations and individuals who had undergone these surgeries to develop a research agenda that was meaningful and relevant to the community.

Participants were asked to a complete survey, and share their personal stories about their experiences with gender affirming surgeries. The findings of the project highlighted the diverse experiences of those who undergo these surgeries and the importance of patient-centred care in the process.

Overall, PROGRESS demonstrated the value of community-based research and the importance of centring the experiences and perspectives of those most impacted by the research topic. The project's findings have the potential to inform and improve healthcare practices for individuals seeking gender affirming surgeries in the future.

Art by: Ari Ganahl

Our Participants

In total, 215 individuals participated in our survey, with 33 respondents from Canada and the remaining 182 from the United States.

Demographics

Ethnicity: A significant majority of our participants, or 84%, identified as white. 8% identified as black, 3% as Indigenous, 4% as Asian, 1% as Middle Eastern and 8% identified as Latino(8%).

Age: Most commonly, participants were between the ages of 25 and 35 (52%). Next most common were the ages of 36-50 (23%). Only 14% were between 18 and 24 and 9% were over the age of 50.

Sexual Orientation: The breakdown of sexual orientations includes queer (37%), straight (27%), gay (21%), and bi (24%).

Education: About 30% of participants attended graduate school or obtained a graduate degree, indicating a high level of education among respondents.

Geographic location: The largest amount, making up 61%, resided in urban areas. About 20% lived in medium-sized cities. A smaller portion, around 8.6%, were from small cities. Finally, 9.6% lived in rural or remote areas.

Income: A substantial 40% reported an annual income exceeding $80,000 (CAD or USD), reflecting a notably high level of income.

Other characteristics

Almost half (40%) of our sample self-described as neurodiverse. Among those, 18% self-identified as autistic 32% of our sample self-identified as a person with a disability

A small subset (4%) of participants were intersex.

Surgery Types & Details

Type of Surgeries

Phalloplasty: Roughly half, or 51%, had exclusively undergone phalloplasty

Metoidioplasty: 38% had only meta.

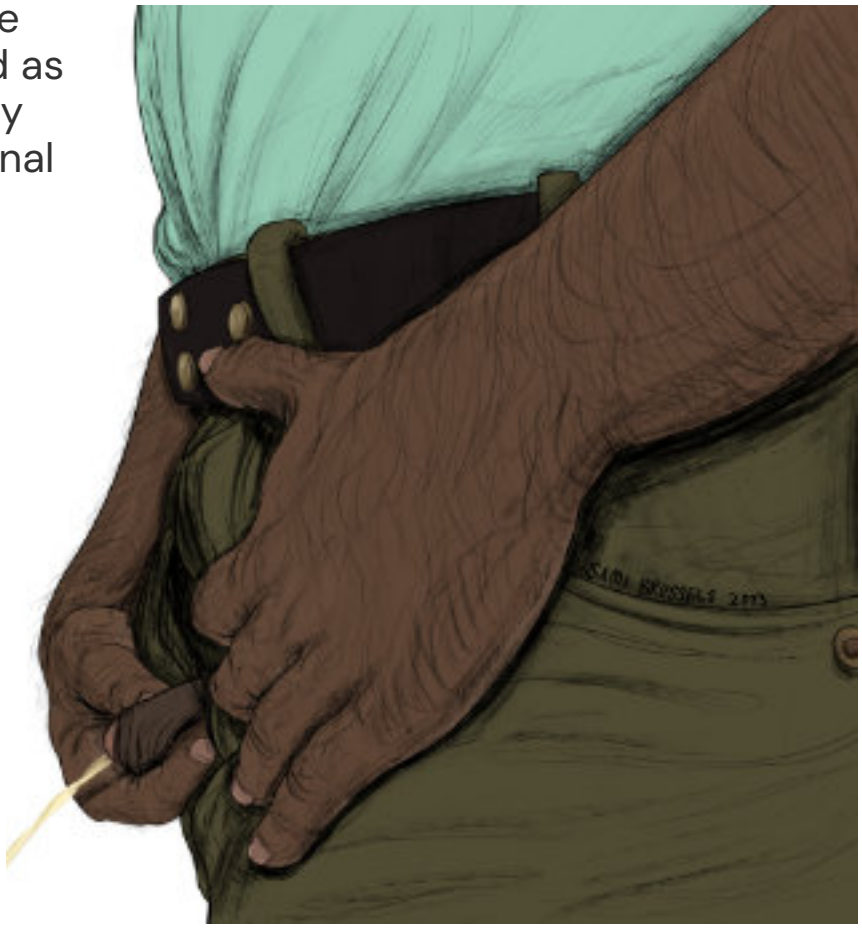
9%, underwent both procedures.

Urethral Lengthening: 71% of our sample had UL and 68% of participants had vaginectomy

Among those who had phalloplasty, 73% had radial forearm free-flap (RFF)

Timing of Surgeries: Only 40% of had their surgeries before 2020, but the majority (59%) underwent surgery between 2020 and 2022. This means at the time of survey completion, some participants only had surgery a few months ago, others many years ago.

Surgical Process Status: More than half (54%) were classified as 'active process,' indicating they were either waiting for additional surgeries or between planned stages.



Art by: Sami Brussels

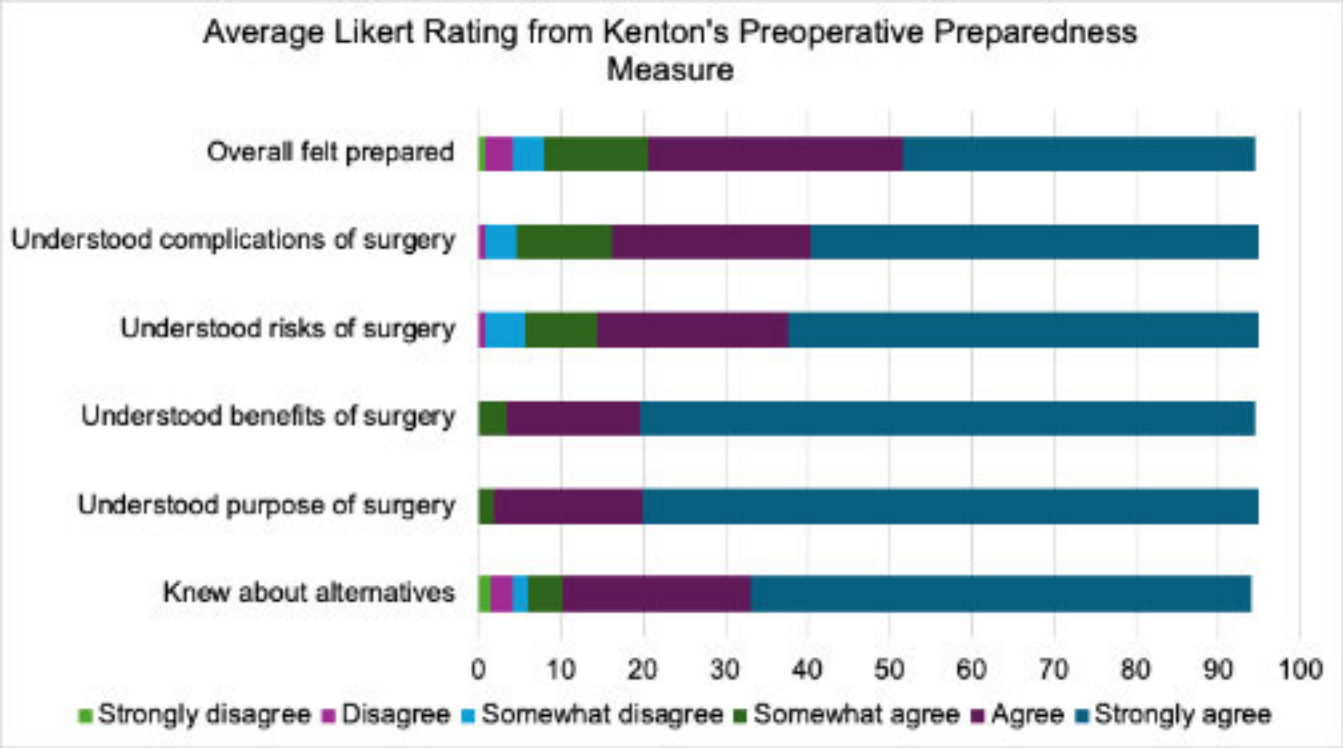
6

Pre-Surgical Experiences

Art by: Ari Ganahl

Preparing for Surgery

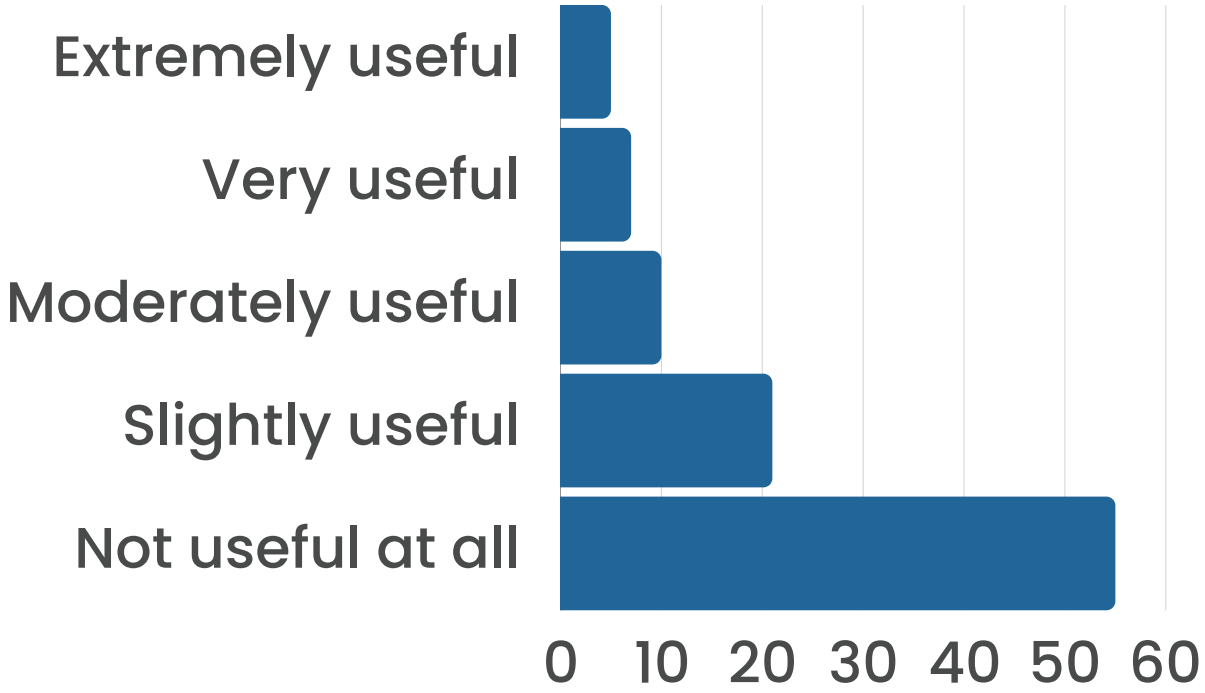
Preparing to undergo any surgery can be overwhelming and challenging. One important and under-studied aspect of phalloplasty and metoidioplasty is how people prepare to undergo these surgeries, including what resources are useful in preparing and how surgical care teams support preparation. We included several questions in our survey to understand how participants prepared and what was useful.



Readiness Assessments

We first asked what the process of surgical readiness assessment looked like for our survey respondents. Most commonly 73% (or 159), participants needed to obtain 2 letters attesting to their readiness from a mental health care provider, secondly, 45 participants only needed an interview by a readiness assessor. A few participants needed only one letter of support or had care teams which utilized workshops or other educational content as part of surgical readiness assessing.

We followed up this question by asking how useful this process was in preparing the participant to have surgery. For those who had the most common 2-letter readiness assessment, 88 (40%) said this was not useful at all to them.



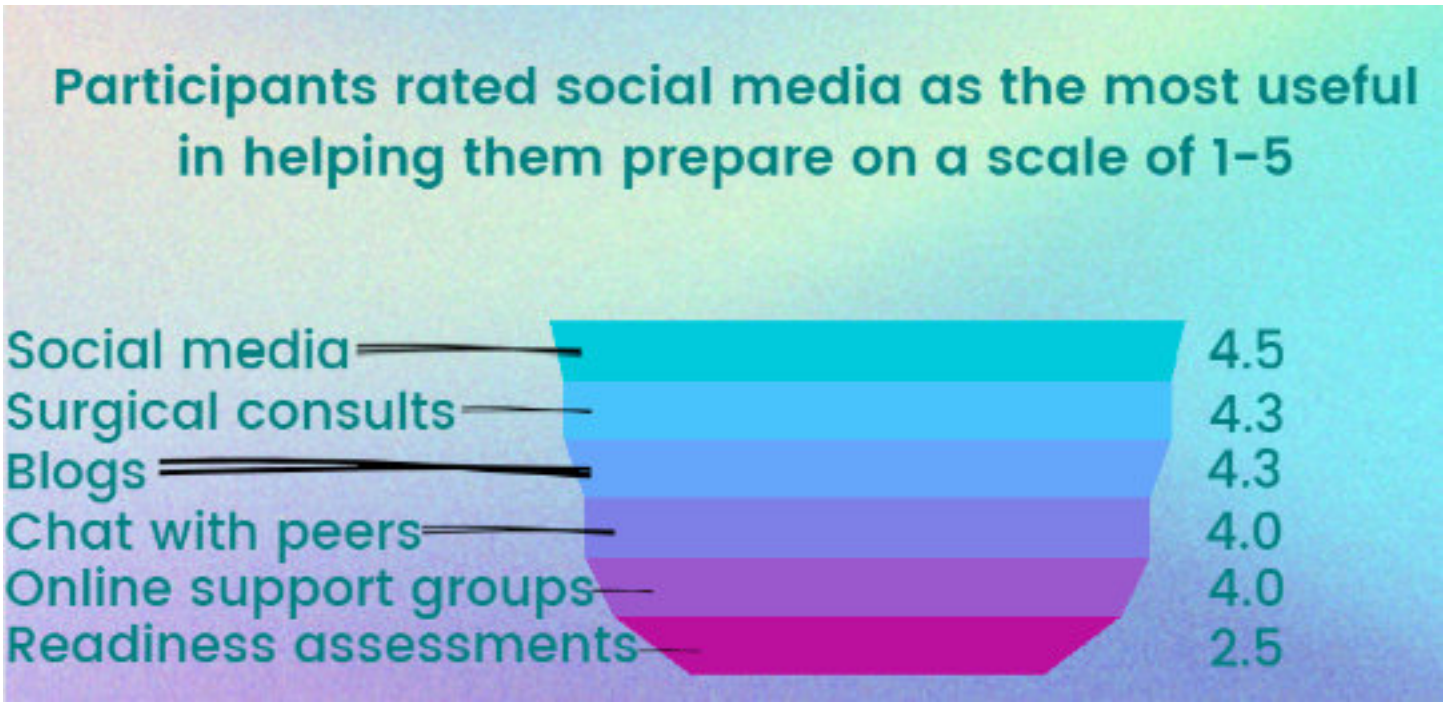
Most commonly, participants needed 2 letters from mental healthcare providers to access surgery. Among them, 55% said this was not useful at all for preparing

Usefulness of other resources

Beyond readiness assessments, we know people prepare for phallo or meta by looking at a lot of information online, talking to others who've had surgery and reading about experiences. We wanted to ask whether these were useful, and which were most useful.

Most commonly, conversation with peers, surgical consults, and blogs/ vlogs, were the most highly rated resources in helping participants prepare for surgery.

Overall, almost all of our participants said they were prepared for surgery, with 92 (42%) even strongly agreeing that they felt prepared.



Generally participants felt prepared to undergo surgery but their readiness assessment was not useful for preparing them. Community spaces and surgical consults were most useful instead. This means patients put a lot of effort into preparing themselves for surgery. More supports should be given by surgical care teams to help patients prepare.

10

Post-Surgical Experiences

Complication Rates*

When it comes to complication rates, academic literature shows various rates of complications based on surgery type, whether someone underwent urethral lengthening and/or vaginectomy or not. Here we show the complication rates among our sample based on surgery type and whether they underwent urethral lengthening

	Phalloplasty	**Metoidioplasty**
Had Urethral Lengthening	70% had complications	65% had complications
No Urethral Lengthening	11% had complications	22% had complications

In total, 58% (or 126) of our participants reported some type of complication. Complications were highest among those who had phalloplasty and urethral lengthening.

*Complications can occur for a number of reasons including individual factors such as chronic illness or other health conditions. It is important to note that complication rates among our sample may not represent the true number of complications that occur for anyone undergoing these surgeries.

Complication Severity

Instead of just asking our participant whether they had complications, we wanted to understand how severe their complications were. To do this, we adapted a measure of complication severity, called the Clavien-Dindo Classification of Complications. Usually, surgeons rate the severity of a patient's complications using this measure, but we asked our participants to self-report this. We couldn't find literature where gender-affirming surgery outcomes included complication severity to compare our results to.

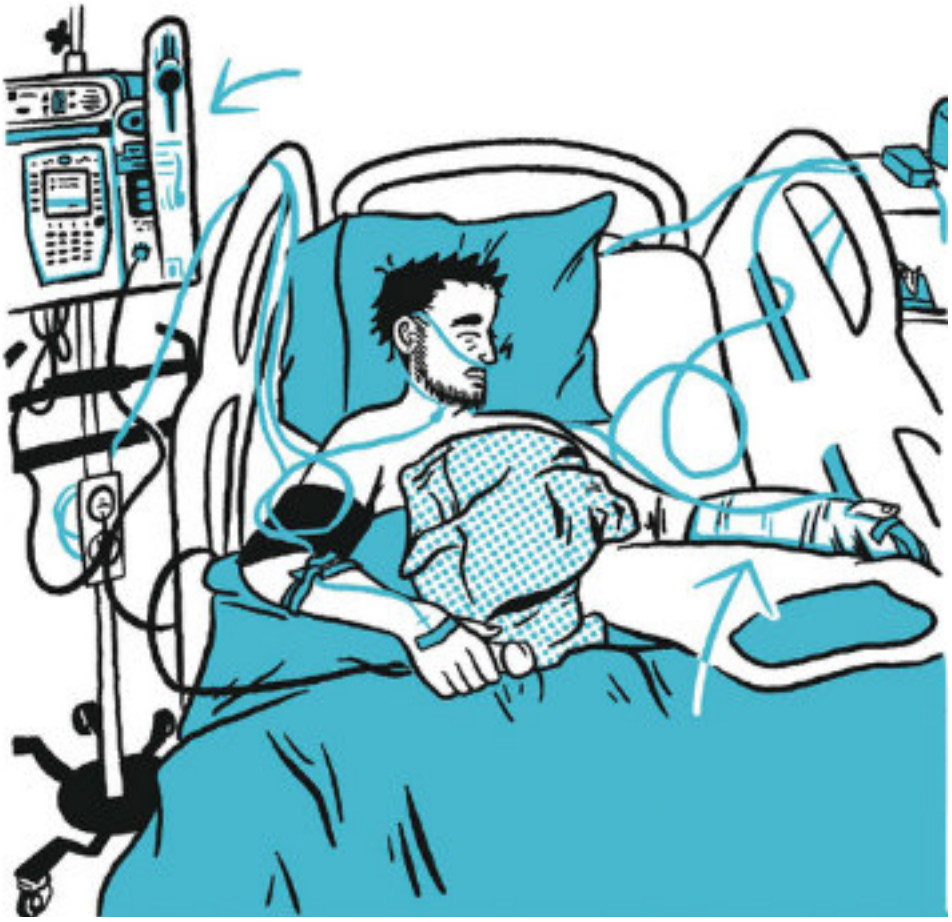
Complication severity (by grade)	Percent of participants that reported this level
1. Any change to normal, planned recovery or healing that requires medical attention but does not require surgery or unanticipated medication (for example, a fistula that closes on its own, a wound separation)	9.8%
2. Complications needing the use of medication for infection or other serious issue (for example, a bladder infection)	7.0%
3. Any complication that requires an additional surgery, x ray, CT or MRI, or a procedure where a tool is used to see inside the body (for example, a stricture repair surgery)	33.4%
4. Any life-threatening complication and/or any single organ or multi organ dysfunction (for example, needing dialysis for kidney failure).	6.8%

Most commonly, participants reported mid-grade complication severity. Recovering from surgery and dealing with these level of complications can be very challenging and impact multiple areas of a person's life.

How challenging was recovery?

Overall, 32% of our sample reported their surgery was very or extremely challenging to recovery from (on a scale of 1-5 with 5 being 'extremely challenging' and 1 being 'not very challenging at all'). Most rated their surgery as moderately challenging. Among those who had phalloplasty only, 36% said surgical recovery was very or extremely challenging, compared to 24% of those who had meta only reporting this.

For those who have phalloplasty, the surgery can include several surgical sites, and the urethral lengthening process can be complex. Coupled with higher risks of complications, recovery from phalloplasty may be perceived as more challenging than metoidioplasty. Either surgery, however, might feel challenging to recovery from; it's important to prepare as best you can and have support during recovery.



Art by: Ari Ganahl

Mental Health *Before* Surgery

We used a question from the Canadian Community Health Survey to ask survey participants about their mental health in the year before surgery. It read "In the year before surgery, how would you have rated your mental health on scale of 1 to 5, with 5 being 'excellent' and 1 being 'poor'"?

Looking back to the year before surgery, nearly half (49%) of participants said their mental health was poor or fair. About 45% of participants said their mental health was good or very good, and less than 10% of participants said their mental health was excellent.

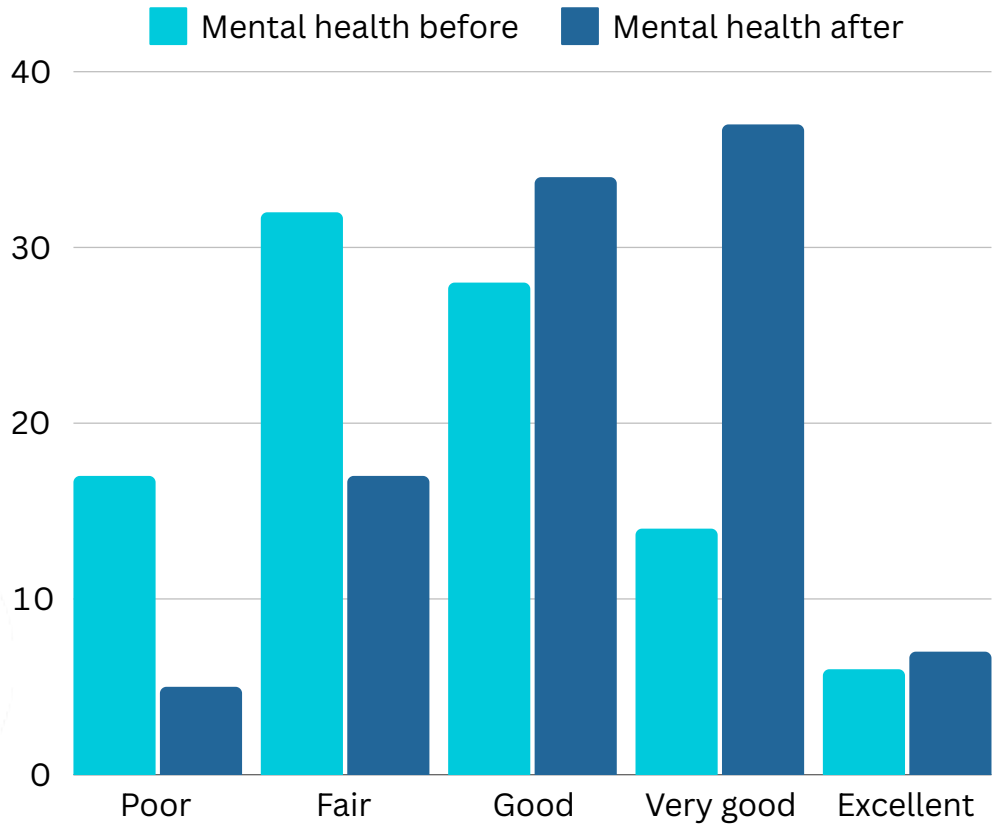
As a comparison, in Canada overall, 14% of Canadians say their mental health as poor or fair, while most say their mental health is very good or excellent. There are many reasons why mental health differs between the general Canadian population and those waiting for phalloplasty or metoidioplasty. Trans, non-binary, and gender-diverse people in Canada face high rates of violence due to their gender identity, and have many healthcare needs that are not met. Trans people may also experience body dysphoria and genital dysphoria, which can explain why their mental health might be worse in the year before surgery.

Mental Health *After* Surgery

After genital surgery, most participants (51%) said their mental health was much better. Some participants (32%) said their mental health was a little better. Less than 10% said their mental health stayed the same, or they weren't sure if it got better.

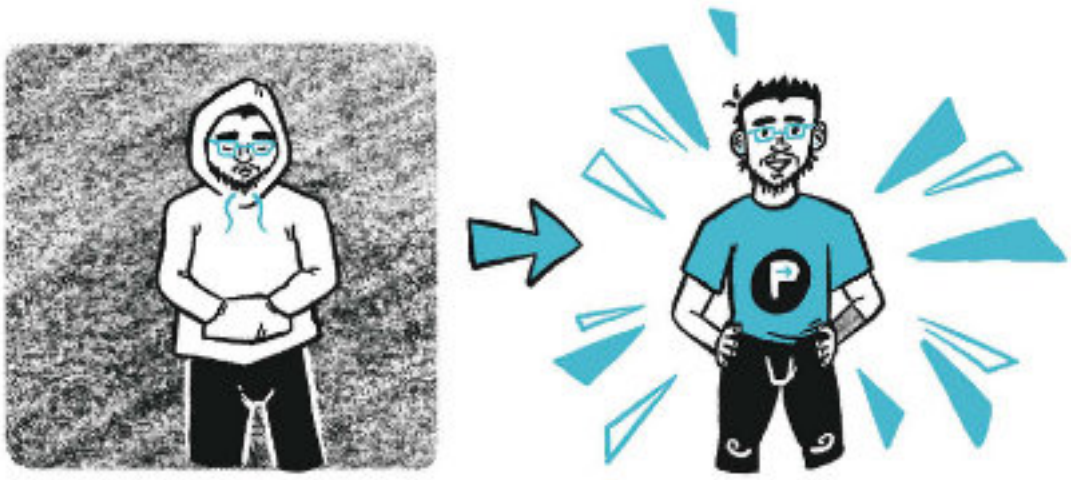
To compare our sample's self-report mental health after surgery, we looked at the self-rated mental health, among those who participated in the Trans PULSE Canada project. In the Trans PULSE sample, 27% of trans and nonbinary participants rated their mental health as fair or poor and 37% rated their mental health as very good or excellent.

Based on these data, our participants rated their mental health after phalloplasty and/or metoidioplasty more highly than the average trans or nonbinary person in Canada. This is likely due to the positive impact that having surgery had on their mental health, dysphoria and euphoria. When trans people are able to access gender affirming care that they need, mental health is likely to improve as dysphoria decreases and more positive body-related feelings take place.



Participants with high surgical satisfaction were *27x* more likely to report mental health improvements

Participants who felt prepared for surgery were *5x* more likely to report mental health improvements



Art by: Ari Ganahl

Most people who undergo metoidioplasty and phalloplasty reported an improvement in mental health. Improvements were more likely to occur if a person is satisfied with their surgery and felt prepared for surgery.

Before experiencing these improvements, about 41% of our sample said they experienced post-operative depression.

In addition, it's important to remember that half of the participants recently had genital surgery. This means some participants may still be healing and might not yet see improvements in their health. Additionally, some participants might not have had all the surgeries they want, so they might not have reached their surgical goals yet. This may explain the differences in participant responses.

Dysphoria

Dysphoria (sometimes referred to as gender dysphoria) can happen when your gender identity doesn't match the sex you were assigned at birth or your sex-related traits. It's a broad term that can include body dysphoria, genital dysphoria, and social dysphoria. Body dysphoria is a feeling of discomfort that can occur when your whole body doesn't match your gender identity. Genital dysphoria is a feeling of uncomfortability or distress that can occur when your genitals don't match your gender identity.

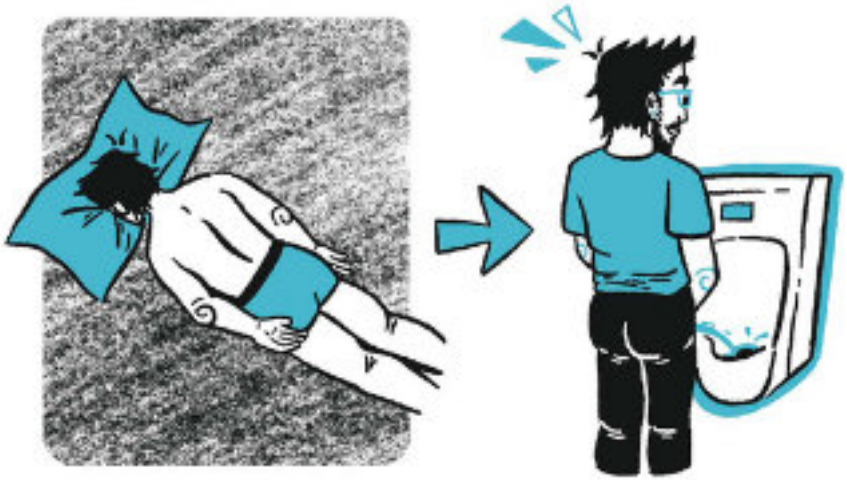
Before surgery

We asked participants how much body dysphoria they had in the year before surgery. The question read "In the year leading up to surgery, how much dysphoria did you have, overall?"

Most participants (90%) said they experienced a lot or some body dysphoria, while almost 10% said they had little or none at all. Similarly, when we asked about genital dysphoria during the same period, most participants (66%) said they experienced a lot of genital dysphoria. 21% said they felt a moderate amount, and 13% said they experienced some, little, or no genital dysphoria.

After Surgery

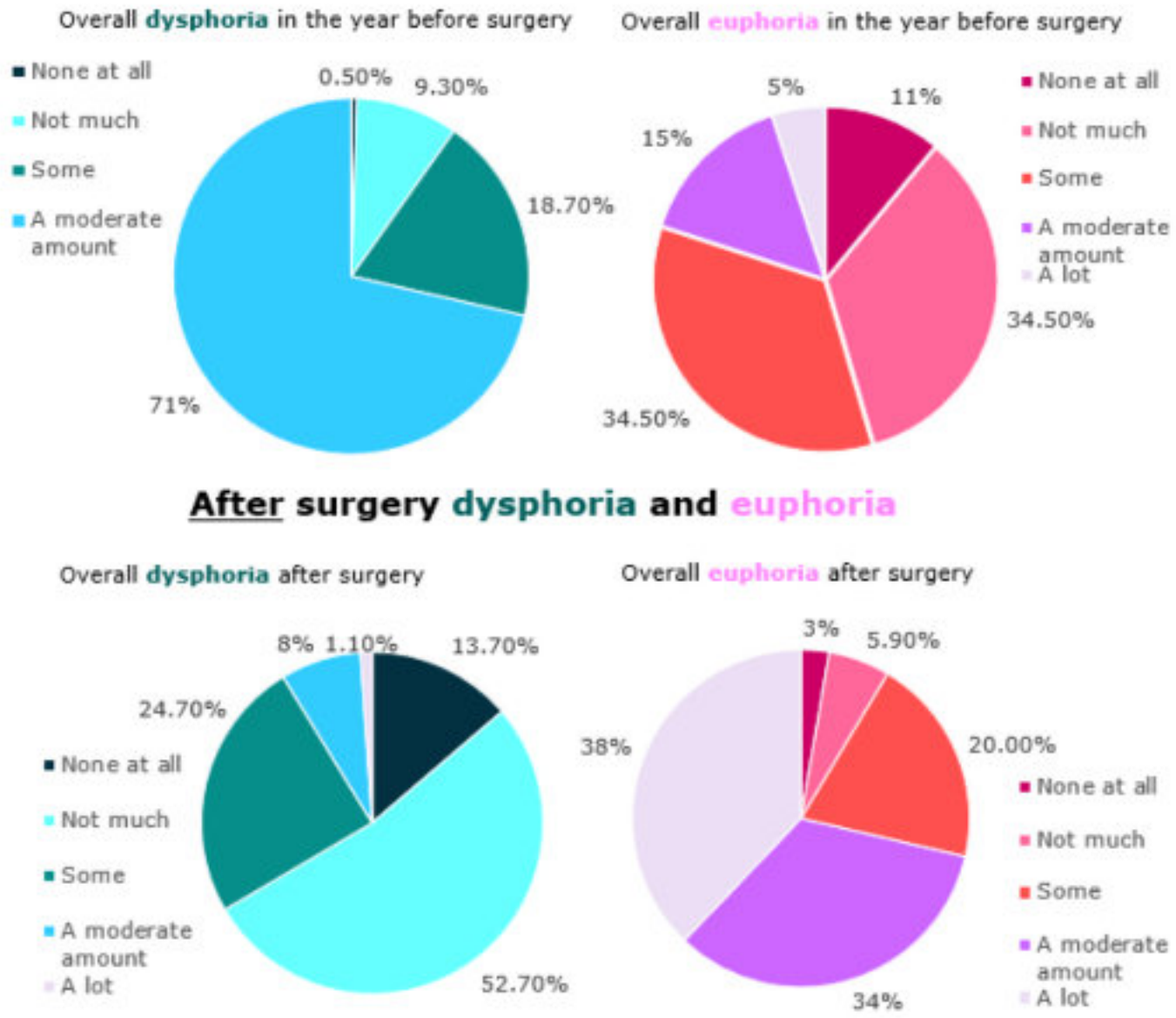
After surgery, only 12% of our participants reported having moderate or a lot of genital-specific dysphoria, and 88% experienced none or some dysphoria Most participants (67%) said they generally have not much, or no dysphoria after surgery. 25% said they have some dysphoria, and less than 10% said they have a moderate amount or a lot of dysphoria.



Art by: Ari Ganahl

Changes in Dysphoria and Euphoria

We asked participants if having phalloplasty or metoidioplasty changed their overall experience of dysphoria. Most participants (94%) said their dysphoria decreased. Only 6% said their dysphoria did not decrease, they weren't sure, or they never had dysphoria.



Euphoria

We asked participants about their body euphoria (positive feeling or joy or ease) **after** receiving genital surgery. Most (71%) reported having a lot, or a moderate amount of euphoria. 20% reported some euphoria, while less than 10% reported not much or no euphoria.

Having genital surgery is a personal choice, and trans people decide to have genital surgery for different reasons. For some, receiving genital surgery may decrease their genital dysphoria, increase their sense of comfort and joy, or a combination of these reasons and more. Everyone's experience is unique.

Based on themes from an open text box asking about euphoria, overall, we found the following brought up euphoria:

31% of participants said having a penis or scrotum.

26% of participants liked how their genitals looked.

23% of participants were happy with how their genitals worked.

11% of participants enjoyed the sensation from their genitals.

Art by: Ari Ganahl

Satisfaction with Surgical Outcomes

We asked participants if their surgery achieved their goals. Most (69%) said their goals were met very well or extremely well. About 21% said their goals were met moderately well, and less than 10% said their goals were met slightly well or not at all.

Overall, you might be curious about what it means to "meet surgical goals." We looked at studies on surgical goals, but found information mostly about what surgeons aim to achieve. This doesn't really tell us about how patients feel or if they reach their own goals through surgery.

When we asked people about their surgical goals, we wanted to understand their feelings about the whole experience. Surgical goals can vary from person to person. For example, some people might want surgery so they can stand to pee, have penetrative sex, or have less dysphoria about their genitals. Everyone has their own unique goals for surgery.

We think this question is important because it focuses on what patients themselves go through and how they feel about their surgery. When we understand what patients want and if it was achieved, we can use that information to improve gender-affirming care and make the journey through surgery better.

Art by: Erik Persson - @artsofep.

Genital Satisfaction

In addition to dysphoria and euphoria considerations post surgery, we wanted to compare our sample's feelings about their genitals with those of other men. To do so, we included The Male Genital Self-Image Scale in our survey. This included several questions about satisfaction with appearance of genitals. Below are some of the items and their scores both for phallo and meta and cis men in another research study. Each question asked participants to rate on a scale of 1-4 where 1 is strongly disagree and 4 is strongly agree.

*See Herbenick et al., 2013 for more details about this measure and the cis sample	Phalloplasty, average rating (standard deviation)	Metoidioplasty, average rating (standard deviation)	Cis Men in the U.S. average rating (standard deviation) *
I feel positively about my genitals	3.39 (.632 SD)	2.93 (.915 SD)	3.17 (0.74 SD)
I am satisfied with the appearance of my genitals	3.20 (.705 SD)	2.55 (.902 SD)	3.18 (0.75 SD)
I am satisfied with the size of my genitals	3.28 (.734 SD)	2.19 (.826 SD)	3.05 (0.83 SD)
My genitals work the way I want them to (Our participants) / I think my genitals work the way they are supposed to (Cis men in the U.S.)	2.54 (.797 SD)	2.67 (.825 SD)	3.25 (0.75 SD)

As you can see in this table, among our sample, those who had phalloplasty rated their genitals satisfaction the highest across all questions. Compared to cis men in the U.S., our participants who had phalloplasty reported higher genital satisfaction on all items except whether their genitals worked they wanted to. Based on our findings, those who have phalloplasty may be more happy with their genitals than the average cis man.

Sexuality Before and After Surgery

In this section, we will talk about the results from the sex and sexuality-related questions asked in the PROGRESS survey. While there is some published academic literature which talks about things like the possibility of increased libido/sex drive and sexual satisfaction after metoidioplasty and phalloplasty, overall there is still a limited amount of data about sex and sexuality for people who have had these surgeries. This is especially true for research that is designed and run by people with lived experience of undergoing metoidioplasty and/or phalloplasty.

We hope that the data here will help give you some more information about sex/sexuality and body image for people who are pre- and postop metoidioplasty and/or phalloplasty.

Preop vs active process vs. postop

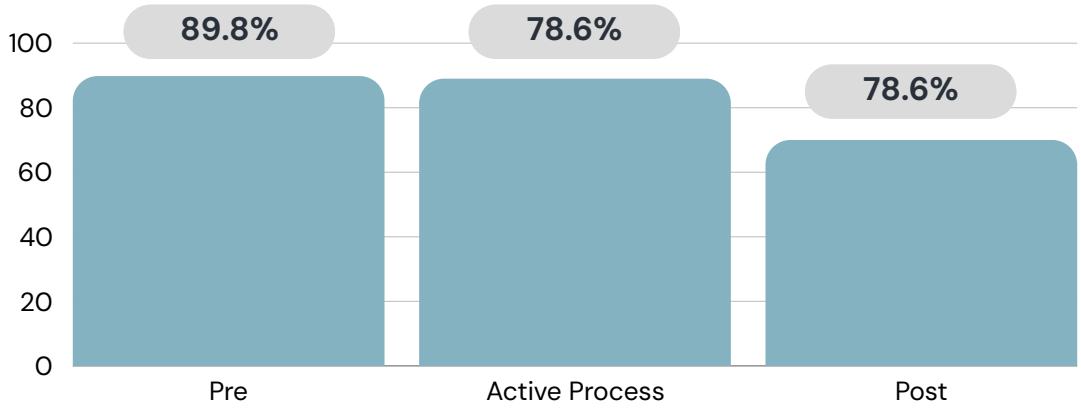
Throughout this section of the report, we will look at the participant data in three different groups. We will look at the questions people asked about their sexual lives and experiences before surgery (''preop"). All of the participants (n=215) answered the preop questions. Our participants were at varied stages of having had surgery. 105 (49%) of our participants were completely finished with all planned surgeries ("postop"). 110 (54%) participants had undergone at least one planned surgery, but were not finished with all planned surgeries ("active process"). So now, when you see these terms, you'll know what we're referring to.

Pre- vs. postop sex and sexuality

Here, we will look at sexual behaviours and experiences with sex and sexuality for participants before and after they had surgery.

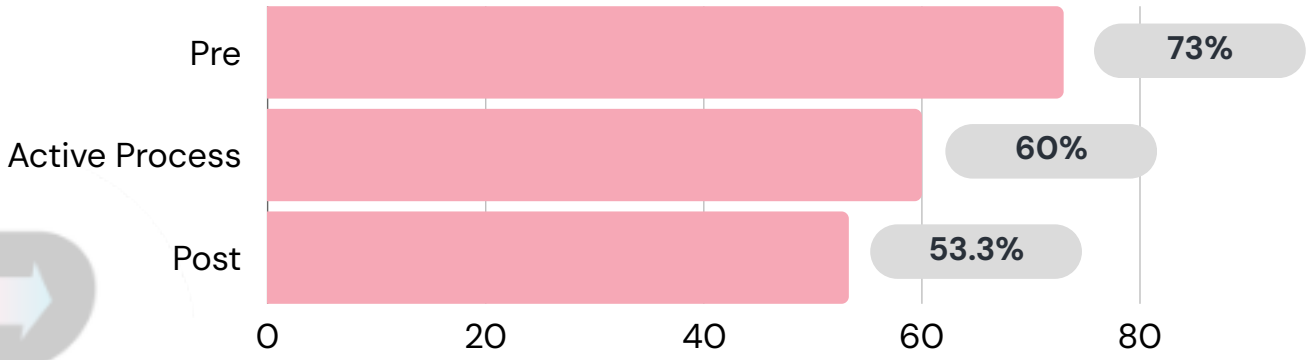
Before surgery, 89.8% (n=193) of participants reported masturbating alone sometimes, often, or daily. Out of those who were active process, 89.1% (n=98) reported masturbating alone. For those who were postop, 69.5% (n=73) reported masturbating alone. Out of those who masturbated on their own who were active process or postop, 32% (n=54) had metoidioplasty and 69.2% (n=117) had phalloplasty.

Table 1. Masturbation (alone) preop vs. active process vs. postop



Before having surgery, 73% (n=157) of participants reported having any sexual partners in the year leading up to surgery. After surgery, 60% (n=66) of those who were active process and 53.3% (n=56) of those who were postop stated they had any sexual partners. Here, sex was defined as, “any type of act you would do with a partner and consider to be sexual,” so it was an expansive definition that allowed participants to determine what sex is for themselves.

Table 2. Presence of sexual partners in each surgical stage



Out of the participants who reported having a sexual partner in the year leading up to surgery, as well as after surgery, we asked them some questions about the kinds of sex they were having. Here is an overview of the types of partnered sex participants reported having, separated by sexual activities reported before surgery, as well as those reported by those who were active process and postop:

Table 3a. Type and frequency of partnered sexual activities: preop

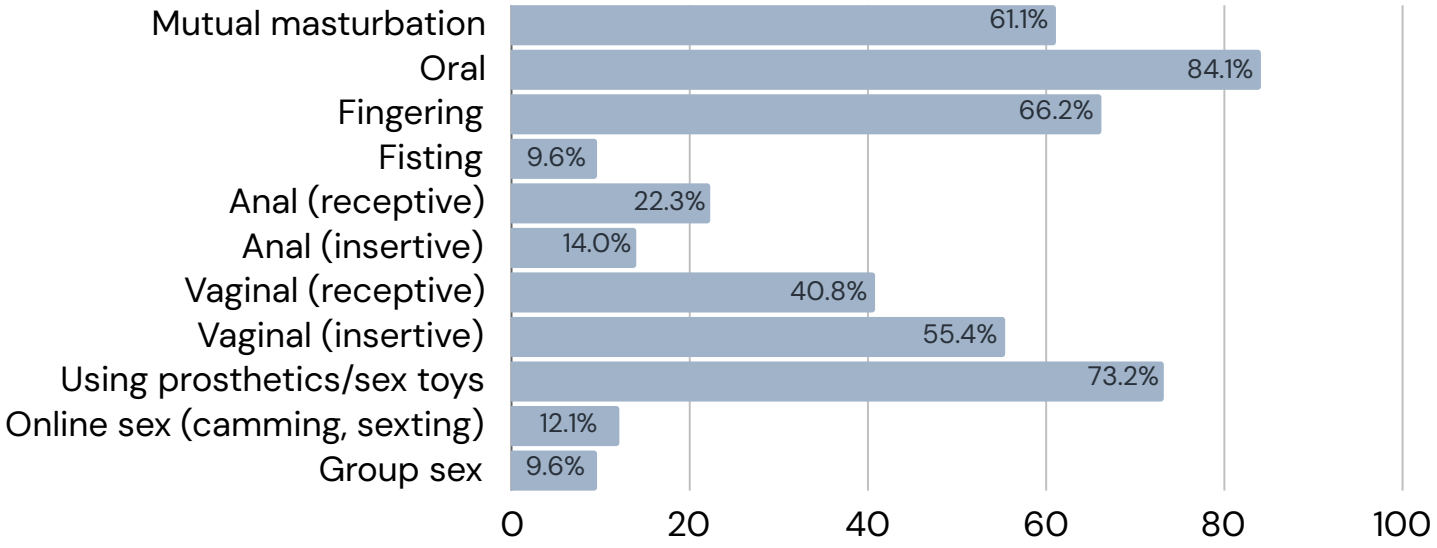


Table 3b. Type and frequency of partnered sexual activities: active process

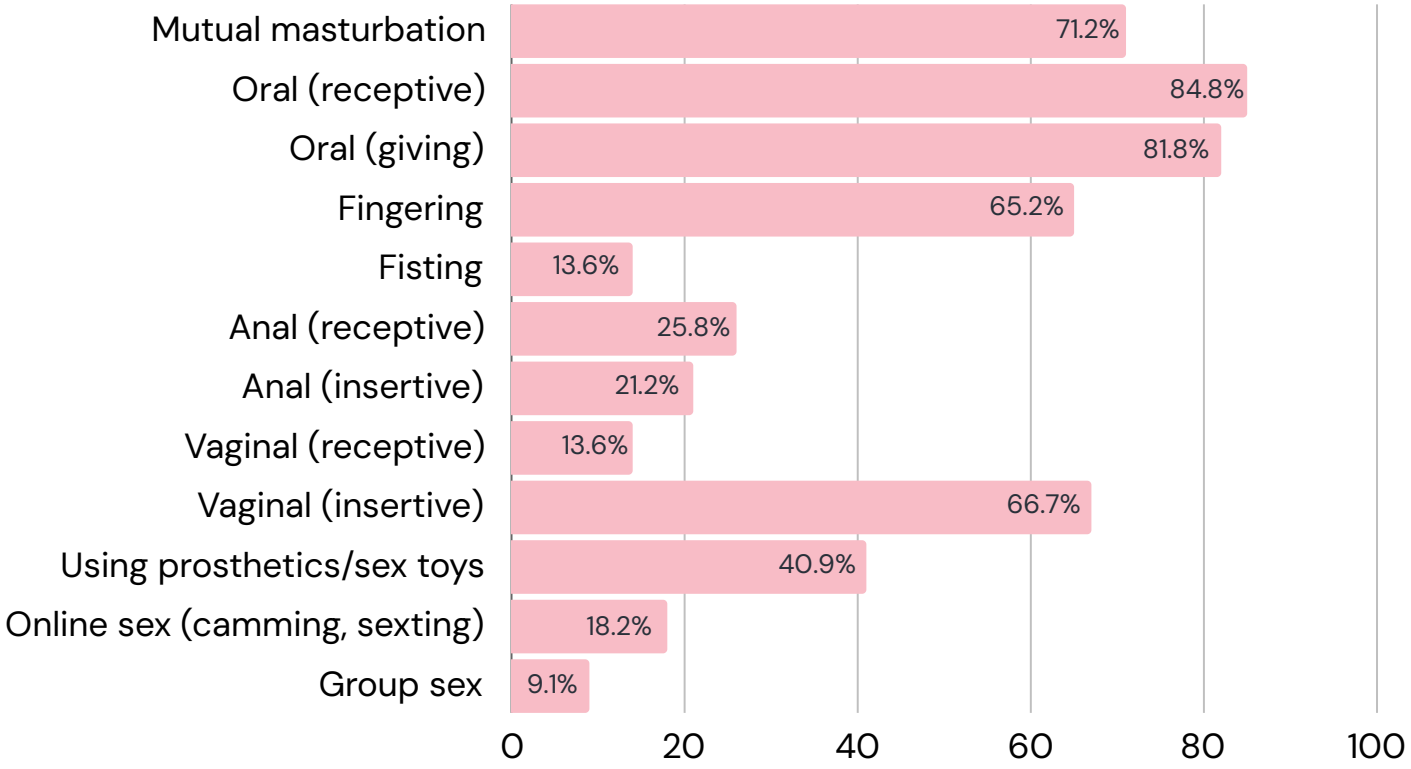
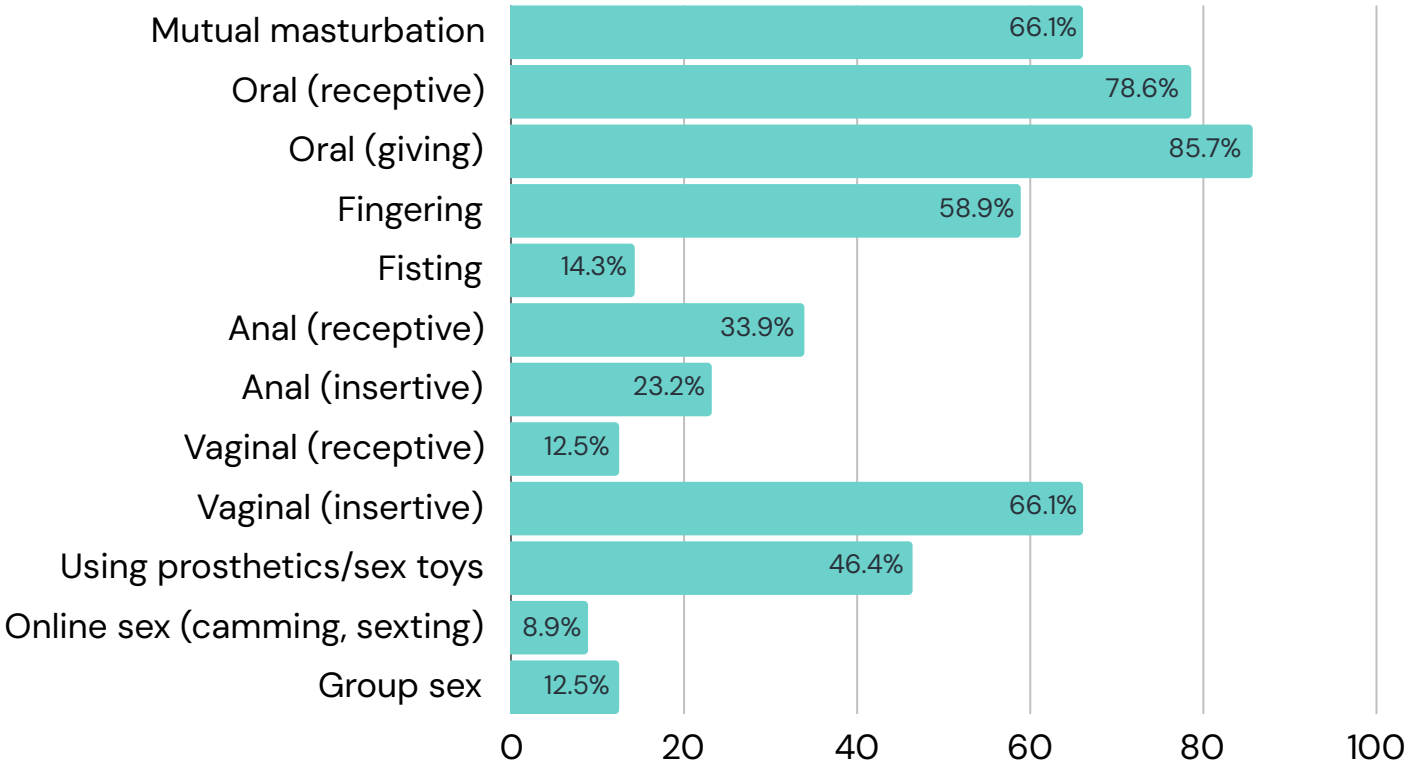


Table 3c. Type and frequency of partnered sexual activities: postop



Out of the 157 participants (73%) who were having partnered sex (sex with 1 or more people) before surgery, the 3 most common activities were giving or receiving oral sex (n=132, 84.1%), sex with prosthetics/sex toys (n=115, 73.2%), and fingering (n=104, 66.2%).

For those who were having partnered sex who were active process, the 3 most common activities were receiving oral sex (n=56, 84.8%), giving oral sex (n=54, 81.8%), and mutual masturbation (n=47, 71.2%).

For those who were postop, the 3 most common activities were giving oral sex (n=48, 85.7%), receiving oral sex (n=44, 78.6%), and tied between mutual masturbation and insertive vaginal sex (n=37, 66.1%).

For those who were either active process or postop and had metoidioplasty, the 3 most common activities were:

1)	Oral (n=41, 93.2%)
2)	Fingering (n=34, 77.3%)
3)	Mutual masturbation (n=32, 72.7%)

For those who were either active process or postop and had phalloplasty, the 3 most common activities were:

1)	Oral (n=59, 75.6%)
2)	Tied between mutual masturbation and insertive vagina/front hole sex (n=52, 66.7%)
3)	Fingering (n=42, 53.8%)

39 total participants (18.1%) reported that surgical complications impacted their ability to have partnered sex at some point after surgery, with 35.9% (n=14) of these participants having had metoidioplasty and 64.1% (n=25) having had phalloplasty.

Satisfaction with sex life

Participants were most commonly "somewhat satisfied" (n=48, 30.6%) with their sex lives overall in the year leading up to surgery. This was the most commonly selected rating for satisfaction with partnered sex after surgery as well, both for those who had metoidioplasty (n=20, 45.5%) and phalloplasty (n=36, 46.2%). After surgery, 75% (n=33) of those who had metoidioplasty and 75.6% (n=59) of those who had phalloplasty were "extremely" or "somewhat" satisfied with the partnered sex they were having.

For those who were active process and postop, 69.7% (n=46) and 82.1% (n=46) respectively were "extremely" or "somewhat" satisfied with the partnered sex they were having.

Sex-related body image worries

Table 4. Sex-related body image worries, comparison of PROGRESS results and TransPULSE Canada's transmasculine sample

When I think about sex I worry...	M (SD) PROGRESS participants (n=183)	M (SD) TransPULSE transmasculine participants (n=171)
That other people think my body is unattractive	3.09 (1.36)	2.22 (1.34)
That there are very few people who would want to have sex with me	2.90 (1.46)	2.05 (1.41)
About feeling ashamed about my body	2.52 (1.39)	2.06 (1.43)
That once I am naked, people will not see me as the gender I am	2.03 (1.25)	2.72 (1.42)
That I can't have the sex I want until I have another surgery	2.77 (1.65)	1.42 (1.53)
Overall mean	2.06	2.09

In the PROGRESS survey, we also asked participants about their body image using the Transgender sex-related body image worries scale (or, the T-Worries scale), developed by TransPULSE Ontario. You can see that PROGRESS participants had a lower mean score for body image worries as compared to the TransPULSE participants.

However, you can also see that PROGRESS participants had higher mean scores for all statements except for "When I think about sex I worry that once I am naked, people will not see me as the gender I am."

These data should not necessarily be taken to mean that surgery does not help improve body image. As these questions are mainly about others' perceptions of participants' bodies, it is helpful to keep in mind the prominent anti-bottom surgery stigma and general anti-trans stigma and antagonism toward trans people that is quite common today. We hope that this study, among other work, will help to destigmatize bottom surgery so that those of us who have had surgery or want to have surgery will have less worries about how other people perceive our bodies and how desirable we are.

Conclusion

You may have noticed that there were less participants having partnered sex and masturbating alone after surgery (while in active process and postop) as compared to before. Some people may not want to masturbate or have sex while waiting for surgery. Participants were also varied in how long ago they had surgery. Some participants were recently postop, and others had surgery over a decade ago. Most postop participants (57.7%) had surgery between 2020-2022. It is possible that, being so newly postop, participants also had not yet wanted to or had the chance to engage sexually with their bodies.

Regardless, participants were at least somewhat satisfied with the partnered sex they were having after surgery. Participants were also less concerned about not being seen as their actual gender when having sex, as compared to a general sample of transmasculine participants.

Sex and sexuality are complicated, and having surgery can further complicate things, especially in the short-term. It's normal for it to take a while to get used to our new genitals, especially in sexual contexts, both by ourselves as well as with one or more partners. We believe that, for most people, sexual satisfaction can improve after surgery with time and some effort – and we hope you have fun along the way!

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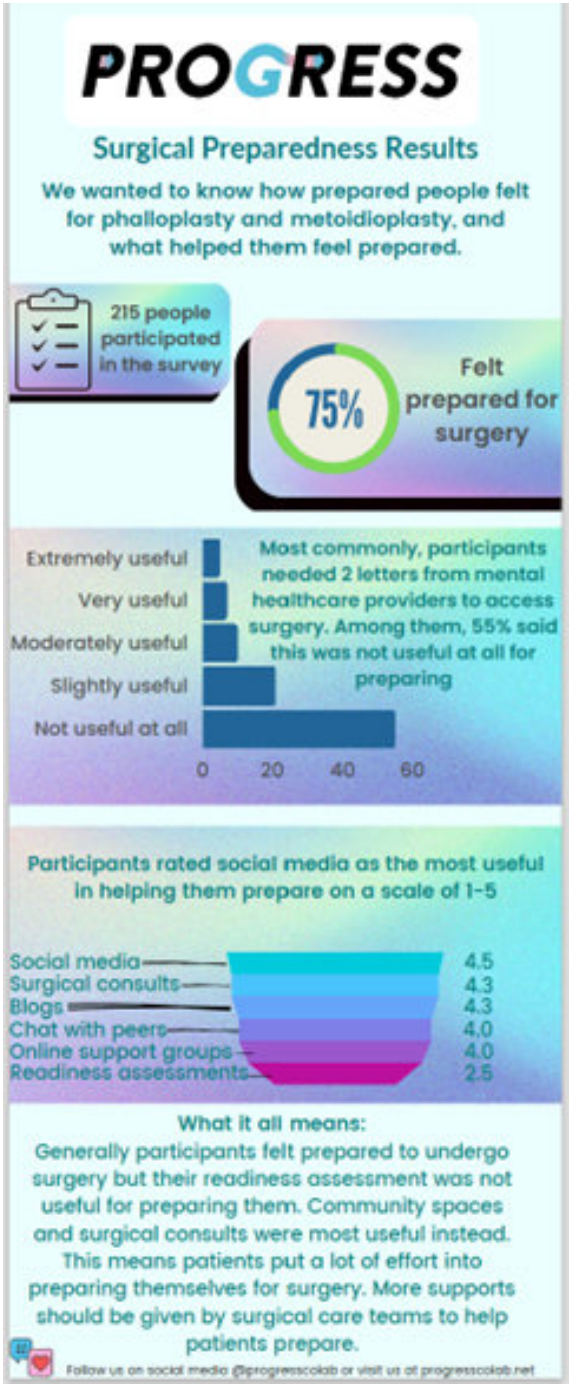
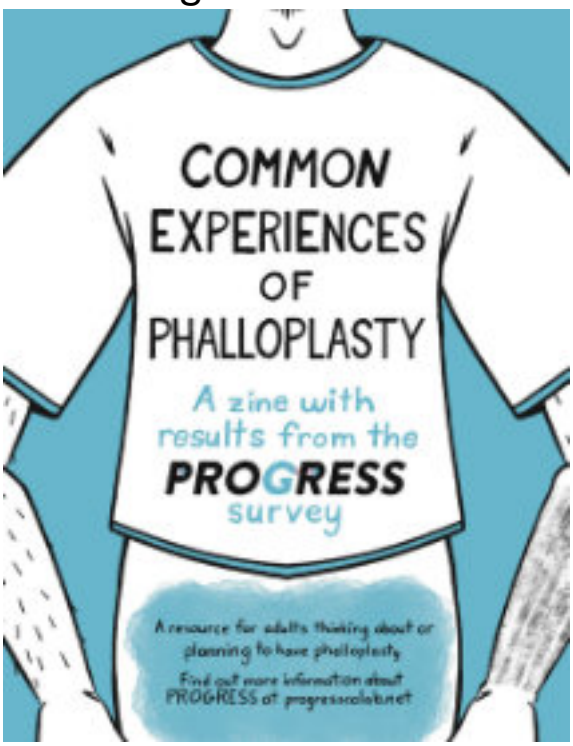
To share this study knowledge with your community, and to learn more about the study, visit progresscolab.net. You'll find sharable infographics, a zine, a podcast, and academic papers & presentations

Infographics



Podcast

Zine - English & French



Art by: Ari Ganahl

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for Phalloplasty and Metoidioplasty

Acknowledgements

A big thank-you to those who completed our survey and all those community members who take a big leap of faith undergoing a surgery they needed.

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