

PROGRESS for phalloplasty and metoidioplasty: A trans community-designed study

By

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We acknowledge and respect the Ləkʷəŋən (Songhees and Esquimalt) Peoples on whose territory the university stands, and the Ləkʷəŋən and W̱SÁNEĆ Peoples whose historical relationships with the land continue to this day.

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ABSTRACT

Some trans and nonbinary people access gender-affirming surgeries as part of their medical transition-related care. Patients undergo phalloplasty and metoidioplasty for a number of reasons which may relate to a desire for reduction of gender or body-related dysphoria or increases in gender-related euphoria. Literature on patient-reported experiences and outcomes is lacking for these surgeries, rather, the majority of research addresses complication rates, aesthetic appearance of genitals and the ability of the penis to function as intended.

This dissertation begins to fill these gaps in literature about patient experiences. Within the methodological chapter of this dissertation, I detail the community-based participatory nature of the project which showcases how research led by and for trans communities can be useful for collecting novel data; it also describes the value added to research when community input is centered in the research process.

The first empirical chapter presents data from this project about factors associated with self-reported feelings of being prepared to undergo phalloplasty or metoidioplasty. In a multivariable regression analysis, self-reported utility of readiness assessment was associated with perceived preparedness. The last empirical chapter documents improved self-rated mental health among our sample. In this analysis, self-rated mental health at the time of survey completion was statistically significantly higher than recalled mental health prior to undergoing surgery. In a multivariable model, self-reported preparedness and surgical satisfaction were associated with self-reported improved mental health. Lastly a concluding chapter summarizes both the novel contributions and significance of this work in context.

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DEDICATION

This dissertation is dedicated to all the trailblazers of the trans community who have, over the years, fought to access the care they needed and for our rights to make decisions about our own bodies. This project would not have been possible without all those who came before me and made progress for our community.

CHAPTER 1: INTRODUCTION

This chapter serves as an overview to this dissertation, which is focused on experiences and outcomes of two gender-affirming surgeries. Within it, the overarching goals of the dissertation project are listed before providing details on contents of all the chapters that follow. After this, I provide a background section that includes an introduction to trans and nonbinary people before detailing common gender-affirming care experiences. Lastly, I briefly describe the surgical procedures of phalloplasty and metoidioplasty to provide necessary context for readers. Following this introduction is a review of literature relevant to the topic areas of this dissertation.

The overall objectives of this project were: 1) to document patient experiences of surgical processes of phalloplasty and metoidioplasty, 2) to explore how self-reported health and well-being have been impacted by undergoing surgery, 3) to gather and formalize community knowledge and experiences to share with those considering having these surgeries, and 4) to lay a groundwork for further investigation into patient experiences with these surgeries. These overarching goals are reflected in the way this research was conducted, the knowledge translation activities (detailed in the methodology chapter), as well as the topical choices of the individual chapters of this dissertation.

This dissertation is divided into five chapters. This Chapter 1 will continue to provide background information on trans and nonbinary people's experiences of accessing gender-affirming care and information about phalloplasty and metoidioplasty. Chapter 2 presents a manuscript detailing the novel community-led process we utilized to design and carry out the research project PROGRESS. Chapter 3 presents results of an analysis focused on what resources participants found useful while preparing for phalloplasty and/or metoidioplasty.

Chapter 4 examines self-reported perceived mental health changes after phalloplasty and metoidioplasty are described and correlates are identified. Last, Chapter 5, summarizes the body of work, discusses the results broadly, and details implications of the overarching results.

BACKGROUND

Transgender (trans) people are a diverse population composed of people who have a gender identity not typically associated with the sex (or gender) assigned to them at birth (Meier & Labuski, 2013). Trans people can have a myriad of different gender identities. *Nonbinary* people are those whose gender identity does not fall under the binary categories of “man” or “woman” (Clark et al., 2018). Some nonbinary people consider themselves trans, while others do not. When using the umbrella term “trans” throughout this dissertation, for brevity, I include nonbinary people. Some trans people transition, which can be understood as a process through which a person comes to express their gender identity in ways that feel affirming. Trans people might only socially transition – meaning change their name, clothes, pronouns, and other aspects of their gender expression – whereas others seek various types of medical interventions as part of their process (Sineath et al., 2016).

Some trans people access gender-affirming healthcare; not everyone will seek all possible gender-affirming care (Thomas, 2020; Heston, 2019). Further, some seek gender-affirming care but cannot access it (Rotondi et al., 2013). One study found that 50% of their sample of trans men expressed interest in bottom surgery, including phalloplasty or metoidioplasty (Firouzi et al., 2022). Another reports a sample where 25% of trans people wanted bottom surgery but have not accessed it (Puckett et al., 2019). Among those who desire but have not undergone genital surgery, 62 (14%) of Trans PULSE Canada participants reported being on a waitlist (Scheim et

al., 2019). In the United States, one survey documented 50% of their respondents reporting being denied access to surgery (James et al., 2016). Additional barriers to accessing gender-affirming surgery notably include financial challenges/ affordability (Ebert et al., 2004; Puckett et al., 2019) and lack of resources available about accessing this type of care (Firouzi et al., 2022).

Often trans and nonbinary people access medical care to reduce gender- or body-related dysphoria and increase euphoria. Dysphoria has had many different definitions over time (Fraser, 2015) and its meaning has not been consistent in academic literature (Davy & Toze 2018). It can also be both gender-related or specific to certain areas of the body (Brecht et al., 2024). In using the term dysphoria here, I mean both gender-related or body-specific experiences. The Diagnostic and Statistical Manual of the American Psychological Association defines it as “incongruence between one’s experienced/expressed gender and assigned gender” and accompanying distress (DSM-5; 2013, p. 302.6) whereas the World Professional Association for Transgender Health (WPATH) Standards of Care Version 8 defines it as “discomfort or distress that is caused by a discrepancy between a person’s gender identity and that person’s sex assigned at birth” (Coleman et al., 2022). Further, some countries utilize the International Classification of Disease 11 (ICD-11) definition which includes CD-11 constitutes incongruence of an individual's sex assigned at birth and felt gender (World Health Organization, n.d.). Literature documents various ways in which dysphoria can be experienced or defined; according to a systematic review of qualitative literature about trans people’s experiences of gender dysphoria, the two most common ways this construct was described included “distress due to dissonance of assigned and experienced gender” and “negative consequences of gender identity” (Cooper et al., 2020 p10). Participants in these studies also described dysphoria occurring related to internalized transphobia and fear of rejection, both leading to distress (Cooper et al., 2020).

Rather than alleviating dysphoria, some trans people seek access to gender-affirming care (socially or medically) due to a desire to increase their gender or body-related euphoria (Beischel et al., 2022). Euphoria, typically an antonym for dysphoria, in this context can have many meanings and the language is still evolving since its introduction in 1976 (Kane, 1976). For some community members, euphoria involves positive emotions which occur because of gender-affirming experiences (Jacobsen & Devor, 2022). Several recent qualitative studies describe trans and nonbinary people's experiences of euphoria. One survey asked 47 participants how they define euphoria; results included feelings of rightness that can be internal, external, or social (Beischel, 2022). Another study interviewed 30 trans adults about their experiences with and understanding of gender-related euphoria. Participants described affirming experiences and thoughts, positive emotions, and improved quality of life as euphoria-related experiences (Austin et al., 2022).

Body-related changes can occur along with positive mental health changes while undergoing gender-affirming care. Overall mental health and the impact of accessing trans-affirming care has been explored by several studies. A few systematic reviews of literature or meta-analyses indicate that trans people as a population experience poorer mental health than cisgender people. For instance, one systematic review of studies in the United States of America (US) describes 77 published peer-reviewed papers that found trans people experience high levels of stress, stigma, and discrimination. This review further mentions that community connection and social support impact mental health in this community in positive ways (Valentine, 2018). Studies across Canada (TransPulse Canada, 2020) and the United States (James et al., 2016) have shown higher levels of depression and anxiety in trans and nonbinary people. Further, in a systematic review of 165 articles, Pinna (2022) found 22 studies which document poorer mental

health in the transgender community compared with cisgender people, including more depression and anxiety. Indeed, it has been estimated that trans people may have diagnoses of mental health disorders between 1.5 times to 3.9 times more often than the US population (Hanna et al., 2019).

Risk factors for trans people related to poorer mental health may include experience of abuse, discrimination, being socially isolated, and/or few peer connections (Tankersley, 2021). Further, there are higher rates of suicidality and suicide attempts (Bauer et al., 2013; Marshall et al., 2016) among trans populations compared with cisgender people. Variable rates of suicide attempts were noted in one systematic review of 30 studies about suicidality in this population. These lifetime suicide attempts varied from 9.8% to up to 44% in studies of both trans men and women; however, all rates were consistently higher than the general population (McNeil et al., 2017). Similarly, compared with the general population, trans people also may have lower quality of life according to a meta-analysis of 29 studies (Nobili, 2018).

One of the factors which influences mental health for trans people is the experience of dysphoria. Literature suggests that experiencing dysphoria and the stress that accompanies it contributes to negative mental health experiences including depression and anxiety (Leerdam et al., 2023). Some qualitative research describes dysphoria as causing suffering and negatively impacting multiple areas of a person's life (Austin et al., 2022). Access to gender-affirming care that reduces dysphoria is linked to improvements in mental health (Costa & Colizzi, 2016). One qualitative study of transmasculine people specifically documents body-related dysphoria as contributing to mental health challenges, which may be ameliorated by hormones (Martin & Coolhart, 2019). Authors note that participants also reported mental health improvements when experiencing less dysphoria (Martin & Coolhart, 2019). Indeed, for those who need certain gender-affirming care, accessing it may overall improve well-being.

While only a small portion of trans people want surgery, and a smaller amount actually undergo surgery on their genitals (Frey et al., 2017), some trans men pursue this option. For those who were assigned female at birth and desire more typically masculine genitals, current surgical options include *metoidioplasty* and *phalloplasty*. Phalloplasty has been described as “a modular set of procedures that can be combined, mixed and matched to meet the needs of each individual patient” (Heston, 2019 pg. 3) due to the numerous options of additional surgeries. Phalloplasty, with or without additional procedures, can be conducted in several different ways, with numerous variations evolving over time and by geographic region. Currently, *radial forearm free-flap* (RFF) phalloplasty is the most common type of phalloplasty across the world (Hadj- Moussa 2019). The first team to utilize this forearm-flap method was Change and Hwang in 1984 (Courtois, 2012; Rashid, 2013). This procedure uses a graft of tissue from the forearm, along with an artery rolled into a tube which is then attached to another artery in the groin as well as the mons pubis at the base of the pubic bone (Song, 2011). The forearm graft—typically referred to as the donor site—is then covered with a split-thickness graft from the thigh (Frey, 2016). *Anterolateral thigh flap* (ALT) phalloplasty is currently the second most common type of phalloplasty (Hadj-Moussa 2019). It uses a donor site from the thigh: one that is pedicled (rolled) into position while maintaining its connection to blood supply (Terrell, 2018). Using a pedicled approach decreases the chances of loss of the penis¹ due to blood supply issues and maintains tactile sensation to the area (Terrell, 2018).

¹ While some medical literature uses the term phallus or neo phallus to refer to penises created as a result of phalloplasty or metoidioplasty, I chose to use the word penis throughout this dissertation. This is for several reasons including more common usage of the word penis to refer to organs created via phalloplasty or modified by metoidioplasty in recent literature. More importantly, as a community-based participatory research project my work values community members lived experience and centres community-used language. Within community spaces the term penis is used commonly whereas the word phallus is not. For those who undergo phalloplasty or

This procedure does not leave scarring on visible locations such as forearms, unlike RFF phalloplasty (Terrell 2018). Several other types of phalloplasty exist and are used by some surgical teams across the world. These include the following flaps: scapular, thoracodorsal, suprapubic, deltoid, upper arm, inguinal, and fibular flaps (Courtois, 2012).

Metoidioplasty was created specifically for transgender men (Hadj-Moussa, 2019) who have experienced an increase in the size of their natal erectile tissue due to testosterone use (Bizic et al., 2020). Metoidioplasty is performed by releasing ligaments of the clitoris (Vukadinovic, 2014) and uses labia tissue to increase the bulk of the phallus. Then, the urethra can be extended beyond its natal position into the newly lengthened organ (Bizic et al., 2020). Unlike phalloplasty, a donor site is not needed, and therefore no major scarring occurs related to this procedure (Hadj-Moussa, 2019). Metoidioplasty preserves tactile and erogenous sensation (Vukadinovic, 2014) and continues to allow a natural erection of clitoral tissue (Bizic et al., 2020; Djordjevic, 2019). Metoidioplasty is also an option for people who are considering phalloplasty later (Bizic et al., 2020).

Due to the modular nature of gender-affirming genital surgeries described above by Heston (2019), phalloplasty and metoidioplasty can co-occur with several additional surgeries either during the first instance of genital surgery or at later times, depending on surgeon

metoidioplasty, many seek to align their felt sense of their body and the reality of it; and this includes having a penis. Whether entirely functional like that of a natal penis, or not, using this term recognizes the embodiment that community members have after undergoing one of these surgeries and validates their experiences of their genitals as a penis. Lastly, using a term other than penis to describe an organ that functions as such for many people may be perceived as an attempt to devalue or delegitimize the lived experience of those who have this organ and refer to it with this term.

preference and patient desire (Weyers, 2006). When a person undergoes phalloplasty or metoidioplasty, various combinations of procedures may be involved (Remington, 2017). Both metoidioplasty and phalloplasty can co-occur with a procedure called *urethral lengthening*, a type of *urethroplasty* (Santucci, 2018). This process, when successful, allows for urination through the penis and, therefore, the ability to stand to urinate (Hadj-Moussa 2019). Urethral lengthening is not a simple procedure, and several techniques have been developed and used by surgeons (Santucci, 2018). Urethral lengthening within a constructed phallus was first developed and performed by Gillies and Harrison in 1948 (Remington, 2017). The structural changes of this procedure re-route the urethra from its original natal position with an exit inside the labia minora to a new position inside the penis with an exit at the tip of the penile shaft (Santucci, 2018).

Other procedures that can occur with either phalloplasty or metoidioplasty include *vaginectomy* and *scrotoplasty*. Vaginectomy is the removal of the vagina, and associated tissues, with either complete closure of the opening using sutures or with a small hole left for drainage of potential tissues left behind (Thomas, 2020). It often co-occurs with urethral lengthening, with some surgeons requiring vaginectomy if urethral lengthening is desired (Heston, 2019). Some patients do not wish to have their vagina removed, just as some do not desire standing to urinate (Heston, 2019). In addition, some patients wish to have a scrotum to masculinize the appearance of their genitals. Scrotoplasty is the creation of a scrotum out of analogous labia majora tissue (Thomas, 2019). Creation of testicles within a scrotum occurs in another surgical procedure (Thomas, 2019). Scrotoplasty can be added to both metoidioplasty or phalloplasty and is often conducted at the same time as these rather than in additional stages. After phalloplasty only, erectile implants may be placed inside the penis to create rigidity that is similar to a naturally occurring erection (Young, 2017). There are two common types of erectile implants: one utilizes

a pump and fills a tube with saline to create rigidity (Hoebcke et al., 2009) while the other is a semi-rigid malleable rod (Pigot et al., 2020) that is attached to the pubic bone and allows the penis to be bent into an upright position (Kang, 2019).

LITERATURE REVIEW

Building on the background information provided in the introduction, this section will serve as a review of literature related to the topics of this dissertation, including patient preparedness for phalloplasty and metoidioplasty and mental health-related outcomes of these surgeries. In it, I first describe experiences related to preparation for surgical procedures, and second, I describe outcomes of surgical procedures. In both sections, I review broad literature about surgical experiences before focusing specifically on outcomes of the gender-affirming surgeries of phalloplasty/metoidioplasty. Last, I describe the theoretical approaches employed in understanding gender-affirming surgical outcomes while detailing the ways in which other theories and frameworks may be utilized for interpreting experiences of gender-affirming surgery.

It is estimated that the average person in the United States will undergo 9.2 surgical procedures in their lifetime (Lee et al., 2021). Surgery is inherently stressful physiologically and there are many ways people may prepare for this type of stressful life event; patients might learn more about the surgery, its risks, typical results, and what to expect during recovery (Wynter-Blyth & Moorthy, 2017). Some people plan to make use of caregivers or other social supports after surgery; others may change their diet, exercise, or reduce caffeine and alcohol consumption (Boehm et al., 2016). Generally, everyone who undergoes surgery needs to plan for some time to rest and recover (Stanford Health Care, n.d.). In the past, literature on preparing patients for

surgery was focused on how to mitigate risk factors that are known to result in poorer surgical outcomes or to increase the risk of complications (Levett, 2016). These factors included smoking cessation, reduction of alcohol intake, and limiting use of caffeine and other drugs (Levett, 2016). Some surgical fields utilize more holistic patient preparedness programs, which include a mental health focus, postoperative care planning, and pre-surgical well-being supports. However, ideal ways of preparing patients for surgery have generally not been documented in current literature (Wynter-Blyth et al., 2017).

Prehabilitation is a developing concept in patient surgical preparedness, it can be defined as a process that “prepares patients to weather the storm of their operation” (Durrand, 2019, p. 458) according to one systematic review. Patient prehabilitation programs vary, and one standard or best practice approach does not exist (Hijazi et al., 2017). At present, multimodal prehabilitation is an emerging practice that combines several interventions such as diet and exercise changes along with mental-health-related supports to affect patient outcomes (West et al., 2021). These programs are developing due to evidence that anxiety and depression contribute to poor outcomes for patients undergoing surgery (Levett et al., 2019; Scheede-Bergdahl et al., 2019) Preparing for surgery, then, can be conceptualized as a going beyond physical preparedness to also include mental and emotional health (Gillis et al., 2021).

Despite variation, a sizable body of literature documents efficacy of prehabilitation programs in improving patient outcomes. For instance, one umbrella review (a systematic review of other systematic reviews) looked at 55 papers which document the effectiveness of prehabilitation across several surgical disciplines. There was moderate evidence of improvement with prehabilitation for cancer-related surgeries and lower quality evidence of improvement for cardiovascular, mixed, and orthopedic surgeries (MacIsaac et al., 2022). This review overall

concludes that prehabilitation may be useful in increasing positive postoperative outcomes (MacIsaac et al., 2022).

Little research about gender-affirming surgery seems to focus on patient prehabilitation or preparedness. A literature search strategy including combinations of the words/phrases “preparedness,” “gender-affirming surgery,” “prehabilitation,” and “gender reassignment surgery” yielded only a few results. Most specifically, Poceta (2019) describes a patient education program designed for those undergoing gender-affirming genital surgery; the paper details a 4-hour workshop given to educate patients about phalloplasty or metoidioplasty and a post-intervention survey given to attendees. Of their 214 participants, a majority indicated feeling more informed and prepared to undergo surgery after attending the educational workshop (Poceta et al., 2019). Other research did not provide much information about patient preparedness. One study stated the importance of patients feeling prepared for gender-affirming surgery, but not what actually prepares patients (Scalia et al., 2021). Another article included a statement that patients should be prepared for gender-affirming surgery, however, how best to prepare patients “is part of an ongoing discussion” (Roblee et al., 2023 pg. 8).

Rather than preparedness, patient readiness has been the focus of pre-surgical assessments for gender-affirming care. While these constructs of preparedness and readiness are similar, their relationship to one another in the context of phalloplasty and metoidioplasty is not understood. Specifically, there is no research which asks about the difference of readiness versus preparedness experiences from a patient perspective. Literature more broadly suggests that readiness is usually as an indication of willingness or the desire to undertake an activity and preparedness is conceived of as having requires knowledge, skills or the information needed to take an action (Jin et al., 2024). While literature about preparedness for some surgeries exists,

based on the literature described henceforth, for gender-affirming surgeries, readiness is seemingly used as the sole indicator of both concepts.

Patients planning to undergo gender-affirming surgeries typically have their readiness addressed by an assessor following the World Professional Association for Transgender Health (WPATH) Standards of Care (SOC) guidelines (Coleman et al., 2022). These SOC have been utilized by various countries since the 1970s (Amengual et al., 2022) as a means for providers to document informed consent (Cavanaugh et al., 2016), assess readiness, and meet insurance requirements (Coleman et al., 2022). Initially, the SOC were created to ensure patients were receiving care that was safe and in line with best practices as well as to reduce risk to both patients and healthcare providers (Marrow, 2023). Readiness assessments have a goal of documenting stable mental health of a person who is seeking to access gender-affirming surgery (MacKinnon et al., 2020). These assessments are not required to address areas of preparedness such as exercise, diet, aftercare planning, or changes that may result from the surgery, although they may be addressed in addition to discerning mental health status (see *Phalloplasty: A guide to gender-affirming surgery*, n.d.). Some surgical centers or care teams are using combinations of readiness assessments and patient education within these processes (for examples see, Oregon State University Transgender Health Program, 2022; Trans Care BC, 2023, Kaiser Permanente Oakland California). What is included in this education is not well documented online or in academic literature. In addition, some care teams are now using the language of “surgical care planning” instead to refer to readiness assessment processes (PHSA, 2023).

Readiness assessments have been critiqued, in part, due to the reasons for their creation which include having criteria which reduce clinician liability and prevent regret (Marrow, 2022) rather than with the goal of ensuring preparedness. Indeed, some consider readiness assessment

to both not determine readiness and gatekeep certain patients from accessing surgery (MacKinnon et al., 2021). Patients report that readiness assessments do not help them make decisions and provide a barrier to accessing care (MacKinnon et al., 2020). Overall, the current processes of determining readiness of patients who wish to undergo phalloplasty and metoidioplasty varies greatly with some surgical centres relying solely on letters of support from mental healthcare providers and others using patient education programs. Whether these readiness assessments relate to patient self-reported preparedness has not yet been documented in academic literature.

Thus far, this literature review has identified gaps in understanding how trans patients prepare for phalloplasty and metoidioplasty, including lack of patient preparedness programs. Indeed, for patients preparing for one of these surgeries, there is limited information to access about how to prepare (Adams, 2019). While one study notes that information on websites about surgery outcomes is not sufficient to fully inform potential patients of their options and the risks of surgery (Karamitros, 2017), others point to social networking sites as places of knowledge sharing about surgery for trans people (Haimson, 2019; Horak, 2014). Current literature does not specifically document whether patients feel prepared to undergo these surgeries, what helps them feel prepared, or not, and how this preparedness may impact post-surgical experiences such as satisfaction with surgery.

Outcomes of Surgery

Contrary to a dearth of literature about how patients prepare for surgery and the impact of preparedness assessments and programs, there is much more information available regarding surgical outcomes. Surgical outcomes are changes in functioning or states of the patient (Carli &

Mayo, 2001). Surgical outcomes can be clinical, including signs of complications; additional surgical procedures; morbidity and/or mortality; or patient reported (Porter, 2010). Patient-reported outcomes are increasingly being used in surgical disciplines to measure perceived impacts of surgery. What outcomes should be measured or prioritized may be different for patients and surgeons (Feldman et al., 2015). Outcomes of surgery include any planned or unplanned changes as a result of undergoing surgery. This may mean improved health or well-being, increased quality of life, or surgical satisfaction; it also may include complications, new health issues, or mental health challenges (Chou et al., 2015). In this next section, I will first summarize the literature on complications with surgery broadly, then for phalloplasty or metoidioplasty specifically. Similarly, I will review other outcomes including surgical satisfaction and mental health generally, then specifically for these procedures.

All surgeries have the potential for adverse outcomes (Levett et al., 2016). These unanticipated issues or unexpected adverse outcomes of surgeries are usually considered complications (Sokol & Wilson, 2008). This includes any type of deviation from normal or expected outcomes, morbidity, and mortality (Sokol & Wilson, 2008). Commonly, instances or rates of complication for a particular surgery are reported by surgeons; these rates vary across procedure types (Veen, 1999). Complication rates are often used as a benchmark for determining how successful surgery or a specific surgeon is, with fewer complications equating to more favourable outcomes and, therefore, a successful surgery (Dindo & Clavien, 2008; Staiger, 2019).

Both metoidioplasty and phalloplasty have risks of complications associated with them and with optional procedures such as vaginectomy and urethral lengthening. Urethra-related complications are among the most commonly occurring (Fascelli et al, 2023). Urethral

lengthening is known to often result in certain complications, specifically *fistulas* and *strictures* (Santucci, 2018; Remington, 2017). A fistula is a hole that develops somewhere along the newly constructed urethra and causes urine to leak out of and/or pool within the body (Veerman et al., 2020). A stricture is a blockage caused by scarring or by the healing of the new urethra (Jackson, 2013); it either completely prevents the passing of urine or reduces the amount of urine able to exit the body (Jackson, 2013). Both of these complications may require additional surgical intervention to correct (Santucci, 2018).

For surgeries with urologic components, the Clavien-Dindo classification of complications has been used since the mid-2000s (Clavien et al., 2009). This classification is used by surgical care teams to document the severity of patient complications on a scale ranging from minor deviations of normal recovery to death of the patient (Dindo, 2004). Mitropoulos (2012) reviewed 907 articles that addressed surgical outcomes and found that 89% included this classification. These researchers further concluded that this classification system is not always used correctly (Mitropoulos et al., 2012). For these gender-affirming genital surgeries, literature does not indicate this reporting tool being used; instead, what is commonly included are only rates of specific complications. In one cohort study, urinary-related complications occurred with 73% of their sample requiring additional surgery to address urethral issues (Veerman et al., 2020). Morrison's (2016) comprehensive literature review found 248 articles which in total reported complications in 1,753 of 3,238 participants, which is just over 53% of patients who had undergone phalloplasty or metoidioplasty.

While complications that occur with phalloplasty and metoidioplasty are well documented in literature, their impact on patients is not commonly addressed. One study reports reduction in sexual function and quality of life among trans patients who experience

complications with phalloplasty (Fascelli et al, 2023). A second study suggests that multiple-staged urethral surgeries may result in fewer complications and therefore higher sexual function and patient satisfaction after phalloplasty (Morrison et al., 2016). Research about complications from other surgical disciplines has demonstrated a link between complications and mental health. A systematic review and meta-analysis of 50 studies found worse psychological outcomes among those who had any complications (Pinto et al., 2016). Further, half of the studies in this review documented continuing mental health challenges one year or more after surgery among those who had complications (Pinto et al., 2016). Further, another survey of 1,233 patients who underwent colorectal surgery found that those who experienced any complication rated their hospital care as lower quality and were less satisfied with their surgical experiences (Gurland et al., 2013). This literature about complications lacks use of any standardized measure, finds wide ranges in rates of complications and does not include patient self-reported complications of the effect these have from a patient perspective.

Satisfaction with surgical experience is complex due to its subjective nature and the possibility of many factors impacting feelings of satisfaction (Chow et al., 2009). Satisfaction in a surgical context can be defined as patient-reported feelings that outcomes, overall, are positive (Jackson et al., 2001). Healthcare satisfaction studies point to positive and negative judgements of aspects of a medical encounter, adding up to a feeling either of satisfaction or dissatisfaction (Gill & White, 2009). Additionally, literature relating to satisfaction with elective surgeries demonstrates the role that expectations play in relation to patient satisfaction with results (Batbaatar et al., 2015; Shirley & Sanders, 2013). Both Batbaatar (2015) and Shirley (2013) show that expectations being met indicates higher surgical satisfaction.

For phalloplasty and metoidioplasty, surgical satisfaction is reported as an outcome in several studies. In particular, several articles report on patient satisfaction with the overall surgical experience or with a particular aspect of the surgical outcome. One of these studies included a review of 24 patient charts after suprapubic phalloplasty as well as patient-reported surgical satisfaction; Terrier (2014) found 95% of these patients were satisfied with their surgical experience and aesthetic appearance of their genitals. Leriche's (2008) long-term follow up after forearm phalloplasty asked 56 patients how satisfied they were with the physical appearance of their genitals an average of 9 years post-surgery; 93% reported feeling satisfied. In addition, within a systematic review of 50 articles about outcomes of phalloplasty there were 25 articles addressing patient satisfaction with the procedure (Remington et al., 2017). Of the 495 patients asked about this surgical outcome, this review found 81.5% reported overall satisfaction with the procedure (Remington et al., 2017). While surgical satisfaction seems commonly addressed with literature about these surgeries, what factors are related to patient self-reported satisfaction is missing. Further, no literature documents the impact of complications, choice of surgery, or surgical technique on patient satisfaction.

In addition to surgical satisfaction a small body of literature documents changes related to mental health after undergoing gender-affirming surgeries. One literature review identified increases in quality of life, decreases in gender-related dysphoria, and decreases in depression for those who have undergone these procedures (Akhavan, 2021). Swan's (2023) systematic review echoes these results, finding that suicide attempts, anxiety symptoms, and depression symptoms decreased after surgery. This review also found that happiness and quality of life may improve after gender-affirming surgery (Swan, 2023). Further, Almazan's (2021) secondary analysis of the U.S. Trans Survey documented less distress and prior-year suicidal ideation among those

who had undergone any gender-affirming surgery. Specifically for trans men who undergo any type of gender-affirming surgery, several studies demonstrate improvements in quality of life and mental well-being after surgery (Defreyne, et al., 2017).

Only a few studies focus on mental health as an outcome of phalloplasty and metoidioplasty. Smith (2005) found improved mental health and overall fewer psychological challenges in their Dutch sample of trans men after gender-affirming genital surgery. Similarly, Wierckx et al. (2011) reported trans men who underwent genital surgery had no difference in mental health scores on the Short Form 36-question Health Survey as compared with the general Dutch population. Lastly, De Cuypere's (2006) survey of 27 trans men showed improved mental health after surgery and no significant mental health differences compared with the Dutch general population.

A few studies have reported no change or worsening mental health among their samples after undergoing any type of gender-affirming surgery. One reported no increase in quality of life among trans women who had undergone genital surgery up to five years ago (Lindqvist et al., 2017). Two others found no reduction in suicidality, and no improvements in mental health in a long-term follow up of trans women up to ten years after undergoing surgery (Dhejne et al., 2011; Bränström & Pachankis, 2020). Some of these studies have used proxies to measure mental health, such as number of mental health care visits (Bränström & Pachankis, 2020), hospital records (Dhejne et al., 2011), or they have utilized measures not validated for use in trans populations (Lindqvist et al., 2017). This small but burgeoning body of literature about mental health outcomes after phalloplasty and metoidioplasty has some limitations which are important to note. These include use of proxy measures such as treatments or diagnoses rather than utilizing either patient self-report or scales related to mental health experiences such as

depression or anxiety. Importantly, literature lacks descriptions of pre compared to post-surgical mental health among those who have these surgeries; this could be achieved either through cross-sectional studies which ask participants to recall times before undergoing surgery, or through longitudinal analyses.

Similarly to general mental health outcomes, gender-affirming surgeries have the possibility of altering experiences related to dysphoria and euphoria for trans and nonbinary people. Dysphoria changes after surgical intervention can be generally related to whole body image or focus on a particular aspect of the body, such as genitals (Milano et al., 2020). The literature describes overall reductions in dysphoria among trans and nonbinary patients who access the gender-affirming care they need (Kearns et al., 2020; Weissler et al., 2018). This includes one systematic review of 122 studies on the topic that describe overall increases in body-related satisfaction and reduction in dysphoria (Baspinar & Ozturk, 2023). Further, another review found increased quality of life and decreased dysphoria among both trans women and trans men after gender-affirming genital surgeries (Meyer et al., 2020). In addition, one cross-sectional study (Jahromi et al., 2021) found that patients who underwent gender-affirming surgery experienced reductions in gender dysphoria when their surgical goals were met.

With specific attention to outcomes of phalloplasty and metoidioplasty, less literature exists. One qualitative study (Goetz & Arcomano, 2023) interviewed one transmasculine person who had undergone gender-affirming genital surgery and 14 people who wanted to undergo one of these surgeries in the future. Most participants described reduction in dysphoria or promotion of euphoria as an important reason for wanting to undergo surgery (Goetz & Arcomano, 2023). Similarly, those who accessed any type of gender-affirming surgery described increases in mental health and body-specific euphoria (Goetz & Arcomano, 2023). Overall, literature related

to dysphoria changes is scant and no literature describes euphoria-related changes due to undergoing phalloplasty or metoidioplasty.

The literature reviewed thus far documents some experiences trans and nonbinary people in relation to surgical experiences and how they perceive outcomes. There are significant limitations to this work, however that demonstrate areas of potential growth for research on this topic. Further to the limitations described thus far, there are methodological aspects of this literature that are worth noting. Overall, samples sizes are small and recruited from specific surgical centers, by surgeons or surgical care teams. Larger sample sizes would present an opportunity for more nuanced data analysis and provide a better sense of common experiences. This would especially be the case if data were collected from more geographically diverse populations or those outside specific surgical centers.

Additionally missing based on the literature are nuanced understandings of correlates of experiences such as surgical satisfaction or mental health improvements. This includes whether patient expectations or preparedness predict surgical satisfaction, or whether other factors, such as complications or demographics, are related to satisfaction. Preparedness and surgical satisfaction may also be related to changes in quality of life after undergoing gender-affirming genital surgeries. Lastly, literature documents very few trans community-driven research initiatives. Indeed, very few studies have included trans community members in the design of research about these surgeries (Dy et al., 2022). This presents a missed opportunity to allow self-identification of important research topics that may benefit the broader community. If trans people are active participants in research about these surgeries, perhaps data collected could focus on more nuanced aspects of surgical experiences.

In summary, this literature review has demonstrated current gaps in published evidence about phalloplasty and metoidioplasty surgical procedures. While only some trans and nonbinary individuals wish to undergo gender-affirming genital surgeries; others desire but cannot access these or are faced with long wait times or experiences barrier such as insurance denial or financial challenges (Firouzi et al., 2022; Puckett et al., 2019; Scheim et al., 2019). Preparing for phalloplasty and metoidioplasty is complex and various resources are available to patients. However, there is no agreement on the best way to prepare patients for these surgeries. For individuals who do undergo these surgeries, some research indicates improvements may occur in mental health and quality of life. Surgical satisfaction rates are generally good for gender-affirming surgeries. However, complications may play an important, yet currently unrecognized role in this and other surgical outcomes. More research is needed to understand pre-surgical experiences of preparation and health-related outcomes of phalloplasty and metoidioplasty procedures. In this next section, I will provide an overview of theoretical frameworks to consider when conducting research on these topics.

THEORETICAL FRAMEWORKS

When reviewing the above literature about experiences preparing for surgery and surgical outcomes, theoretical frameworks were not commonly reported. This may be due to literature on these topics coming from disciplines that do not necessarily focus on theory as a basis for understanding research results. The supposed atheoretical nature of the extant literature on these topics does not provide ways of understanding how patient characteristics, qualities, and life experiences may impact surgical outcomes. Further, few theories are referenced in reviewed literature that relate to the ways in which gender-affirming surgery impacts health or well-being for trans and nonbinary people. More broadly, a few theories are utilized commonly to

understand the impact of gender affirmation on individuals in this population. These include Minority Stress Theory (Brooks, 1981; Meyer 2005) and the Gender-Affirmation Framework (Sevelius, 2013). Two additional theories, Life Course (Elder et al., 2003) and the Social Determinants of Health (Marmot & Wilkinson, 1999) have been recommended for use with research with the trans population by the Institute of Medicine (IOM, 2011). Within this section, I will first describe Life Course Theory and its implication for this work before detailing the Social Determinants of Health, Minority Stress Theory, and the Gender-Affirmation Framework. Last, I will overview how these theoretical approaches relate to this dissertation.

Life Course Theory or a life course perspective highlights the importance that certain factors have throughout an individual's life (Hunt, 2017). These include changes that occur throughout life related to age or shifts that occur due to stage of life, such as the transition from student to employee (Hutchinson, 2014). Life Course Theory posits that earlier life experiences relate to or impact later life experiences or outcomes (Halfon, et al., 2018). These changes in life are ideally understood over time and should be given context within research (Neale, 2015).

Several life course aspects have been shown to impact health and well-being broadly and are important to understanding an individual's unique experiences. These include the effect of cohorts and life transitions. Cohort effects point to possible similarities among groups of people close in age or those who have life changes around the same time (Scherger, 2009). Age for instance, might be related to likelihood to have a certain health condition (Wethington, 2005), or those who have a baby late in life may experience similar challenges. For those who have gender-affirming surgery around the same time and/or at similar ages these cohorts may have unique experiences of phalloplasty and metoidioplasty. These may include time-specific stressors, like the COVID 19 pandemic or advances in surgical techniques. Further, life

transitions, or changes in roles across the life span might include births, deaths, marriage or divorces, changes in job (Wright & Cullen, 2004), or retirement (Gettings, 2018); these may impact those who undergo phalloplasty or metoidioplasty. Similarly, for some people who are planning to undergo phalloplasty or metoidioplasty, transitional life events may play a role in preparing for or recovering from surgery. Related to Life Course Theory is another framework that is useful for understanding how life experiences relate to health outcomes, the Social Determinants of Health (Marmot & Wilkinson, 1999).

While Life Course Theory seeks to understand how changes over the life span impact individuals or groups, the Social Determinants of Health capture the way social and economic positions influence health (Ward et al., 2011). Social Determinants of Health are aspects of one's life related to sociocultural factors that influence health and include income, social status, employment and/or working conditions, education, the environment, social support, healthcare access, gender, race, and culture (Marmot & Allen, 2015). Social determinants of health have been shown to relate to health inequities, with some groups of people experiencing these inequities due to their lesser/lower social position (Baum & Friel, 2017). Trans people are known to experience health inequities compared with cisgender people, especially related to mental health and healthcare access (Blosnich et al., 2017).

With specific attention to phalloplasty and metoidioplasty, no research addresses how social determinants of health impact outcomes or experiences. Other surgical disciplines describe how determinants of health affect patient undergoing specific surgeries or more broadly in relation to surgery, however. Factors such as race (Taylor et al., 2023; Greene & Edwards, 2024), socio-economic status (Diaz et al., 2023; Malapati et al., 2024), education level (Greene & Edwards, 2024), and housing (Greene & Edwards, 2024) have each been shown to relate to

post-operative outcomes. These factors are thought to relate to access to healthcare (Diaz et al., 2023), quality of healthcare a person receives (Greene & Edwards, 2024), rates of complications and poor outcomes overall (Schmidt et al., 2023) Indeed, in one study, living in certain geographic locations, having less financial means and less education was associated with less positive patient outcomes overall (Schmidt et al., 2023). For those who undergo phalloplasty or metoidioplasty, then, social determinants described such as race, education, income, and housing stability likely impact patient experiences and outcomes. This has yet to be documented in literature on these surgeries.

Related to health disparities that some groups experience is Minority Stress Theory (Brooks, 1981; Meyer 2005). This theory focuses on the ways in which some groups are exposed to minority-specific stressors (Brooks, 1981; Meyer 2005). These may include distressing experiences which lead to negative mental health outcomes and health disparities (Frost & Meyer, 2023). The model of sexual minority stress was developed by Brooks (1981) to describe the impact of discrimination and oppression on health and well-being in sexual minority communities. It was later utilized in understanding trans and nonbinary experience of gender-related stress (e.g., Tebbe & Moradi, 2016).

Hendricks & Testa (2012) suggest that for trans and nonbinary people, experiences of discrimination and overall stigma produce unique minority stressors that may impact health. Unique stressful events such as violence, discrimination and transphobia are likely to produce negative mental health impacts, including increases in suicidality and depression (Hendricks & Testa, 2012, Pellicane & Ciesla, 2022). While resilience may ameliorate some of these negative impacts (Hendricks & Testa, 2012), lacking social support and stigma continue to relate to poorer health in these populations due to the impact of minority stressors (Hughto et al., 2015).

With regard to gender-affirming surgery, the experience of preparing for and undergoing gender-affirming surgeries, may create additional minority stressors; more research is needed to understand the minority stressors that may relate to surgical experiences among this population.

More specific to the experience of being trans or nonbinary, the Gender-Affirmation Framework (Sevelius, 2013) suggests that experiences which affirm and support a person's gender may relate to risk taking behavior. Further it recognizes that for trans and nonbinary people, experiences related to non-affirmation of gender identity and expression may further produce minority specific stress and lead to health disparities (Testa et al., 2015). Indeed, some research suggests that when trans people are accepted in their identities and can access needed healthcare, quality of life increases (King & Gamarel, 2021; Glynn et al., 2016).; this reiterates the importance of gender affirmation for trans and nonbinary people as a determinant of health.

Overall, these theoretical frameworks showcase the positive role gender-affirming experiences can have for trans and nonbinary people. Despite that, the literature does not appear to highlight how trans-specific minority stressors may impact individuals as they undergo or recover from gender-affirming surgeries. These theoretical frameworks should, however, be considered when describing surgical experiences and outcomes. As documented through the earlier literature review, some research indicates improved health and quality of life after undergoing gender-affirming surgery, Similar to literature on this topic described above, however, this dissertation is not focused on one particular theory related to trans and nonbinary people's experiences with gender-affirming surgical outcomes. In contrast to previous literature, this dissertation, its research aims, and interpretation of findings center trans community voices and lived experience as expertise. This represents an epistemological choice to value trans community members' expertise as essential in understanding surgical outcomes and experiences

(Black et al., 2013; Travers et al., 2013; Coombe et al., 2020). As such, individual manuscripts contained within this dissertation will address philosophical and theoretical foundations employed to interpret results and answer specific research questions. The methodology manuscript that follows next provides a more detailed overview of the community-based participatory research process undertaken for this dissertation project.

CHAPTER 2

Centering trans voices in community-based participatory research: A case study of how to form a trans community-driven research initiative

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ABSTRACT

Transgender and nonbinary people have rarely had the opportunity to lead community-based research project about our life experiences. This article documents a case study of the process of a research project about two gender-affirming surgeries designed, led, and conducted by trans community members with expertise of the research topic. The study, PROGRESS, focused on trans people's experience of phalloplasty and metoidioplasty and was led by those individuals with lived expertise. Within this paper, share our model of CBPR and compare the process we undertook with commonly reported approaches of other CBPR initiatives. The model showcases how the novel context surrounding the project led to greater trust within the community, equitable participant-researcher relationships and the ability to understand research participants in a nuanced way. Unlike much other research on the topic, which is conducted by non-community members, the project's partnership processes were built on foundation of mutual understanding through lived experience between the primary researcher, community members involved in the project and potential participants. Further, the outputs of this project include the development of much-needed resources for the trans community; this has rarely been a priority in past research. This community-led initiative demonstrates that prioritizing developing knowledge for communities is possible; this paper describes why this is beneficial. In short, this project demonstrates that research conducted by and for trans and nonbinary people has the potential to lead to more nuanced research that can be beneficial to our community's health and well-being.

INTRODUCTION

Community-based participatory research (CBPR) can be defined as an approach to research that is collaborative, involves community equitably, and values the strengths of community members (Minkler & Wallerstein, 2008). It is a research framework which provides clear ethical and practical standards for conducting research with a community (Holkup, 2004). As a type of action-orientation to research, it involves those with lived experience throughout the research process and has a goal to address inequities (Israel, 1998). CBPR's ontological paradigm is one that recognizes that individuals construct their reality through connection with other people (Reason, 1998). Epistemologically, it recognizes that experiences are a form of knowledge that can be considered of the same value as other types of knowledge (Holkup et al., 2004). This translates into a recognition of lived experience and community knowledge as valuable information that should be at the centre of research studies (Durrán et al., 2019).

There are several principles that guide CBPR. These include partnerships with communities that are genuine, that capacity or training opportunities are built into the project, and that dissemination of findings occurs in ways that are beneficial to everyone involved (Israel, 1998; Wallerstein & Durrán, 2006). When CBPR principles are followed, some research indicates positive outcomes are likely to occur (Durrán et al., 2019). Indeed, CBPR has been described as a way to create positive change for marginalized communities and ameliorate health disparities among these groups (Wallerstein & Durrán, 2006). It is a flexible approach which can be used with different research methodologies and has been utilized with many different marginalized communities (Collins et al., 2018). Further, CBPR has been used to address health disparities in racialized communities (Nguyen et al., 2021), with those who are underserved by health or medical services, and within sexual minority populations. The use of CBPR is

burgeoning with transgender and nonbinary people (Dickey et al., 2016), abbreviated as “trans” for brevity throughout this paper.

Transgender (here shortened to “trans”) people are those whose gender identity is dissimilar to the sex/gender assigned to them at birth. Its antonym is cisgender, which refers to people whose gender identity aligns with the sex/gender assigned at birth. Some trans people transition or make social or medical changes that affirm their identity. This can include using an affirming name or pronoun, non-medical changes to appearance such as clothing, or can include medical care. Gender-affirming care is any healthcare a trans person receives which positively supports their transition process (Lightfoot et al., 2021). It can include hormone replacement therapies and various surgical interventions (Lightfoot et al., 2021). Not every trans person wants or needs all possible types of gender-affirming medical interventions (Deutsch, 2019). Most trans people seek care that alleviates their gender- or body-related dysphoria (Kearns et al., 2021) and promotes overall euphoria or positive emotions (Austin et al., 2022). For those who do need them, gender-affirming surgeries can improve mental health and overall well-being (Almazan et al., 2021). Some trans and nonbinary people undergo genital surgeries. For those assigned female at birth two options exist to alter genital tissues to be more typically male: phalloplasty and metoidioplasty (Deutsch, 2016). These two procedures use existing and/or grafted tissues through a complex surgical process which enhances existing genitals or constructs a penis (Bizic et al., 2019; Morrison et al., 2016). A detailed overview of these surgeries is outside the scope of this paper; the description of these procedures as gender-affirming and complex is sufficient background for an understanding of what follows.

In research about trans and nonbinary people CBPR has not been a common approach, but it is occurring more frequently in recent years (Tebbe & Budge, 2020). Several research

projects that have focused on trans people’s experiences or well-being have utilized CBPR. These projects have addressed topics including mental health (Johnson et al., 2011) and suicidality (Smith et al., 2018), access to care (Tanner et al., 2014) or barriers to healthcare (Salkas et al., 2017), social support (Pinto, et al., 2008), and intimate partner violence (Ghanbarpour et al., 2018).

Less research utilizing CBPR approaches addresses the experience of trans individuals receiving gender-affirming care or outcomes of this care. Notably, two Canadian research projects have addressed topics inclusive of self-reported experiences of transition-related healthcare: Trans PULSE Ontario (see Travers et al., 2013) and Trans PULSE Canada (see Scheim et al., 2019). Manuscripts published from this research have included topics such as sexual healthcare (Bauer et al., 2013), and healthcare availability in Ontario (Giblon & Bauer, 2017, Scheim et al., 2021). Further, this research has documented unmet healthcare needs of trans people in Canada generally (The Trans PULSE Canada Team, 2020) and for gender-affirming surgeries in Ontario (Giblon & Bauer, 2017). To the author’s knowledge, however, no research projects utilizing CBPR specifically address outcomes of the gender-affirming genital surgeries of phalloplasty and metoidioplasty; this was the focus of the project we describe within this manuscript.

Project overview

Patient-Reported Outcomes of Genital Reconstruction and Experiences of Surgical Satisfaction or “PROGRESS” was a community-based, participatory project that utilized quantitative survey methods to understand the unique experience of trans people who undergo phalloplasty and metoidioplasty. The project included several community-determined research-

specific aims and goals. Goals of this project included community capacity building, collection of data about surgical outcomes important to the trans community and identifying important areas for future research. Based on the current literature and our team's goals, this project sought to fill gaps in knowledge by extending current understandings of the impacts of phalloplasty and metoidioplasty on health and well-being of trans and nonbinary people.

The research was led by a community-engagement committee and lead researcher from the trans community, all with lived experiences related to the topic of the project. This group of people formed the team primarily responsible for all aspects of the project; when using the words *we* or *our* within this paper, this is the group being referred to. The research process focused on centering community voices in our decision-making process, from research choices for data collection to planning knowledge product outputs and mobilization. We collected data online, via an anonymous survey which was only available in English and took about 45 minutes for the average participant to complete. We recruited 315 participants from April through July of 2022 utilizing convenience sampling from social media networks. Eligibility criteria used to screen potential participants included self-identifying as trans, non-binary or another related term, residing in the United States or Canada, having undergone phalloplasty and/or metoidioplasty, and being over the age of majority. Participants were initially offered an honorarium of \$20 for taking part in our survey, however, this immediately caused issues with robots and non-real participants taking part in the survey. After consulting with community, I amended our REB application to remove the honoraria from the survey. The funds that would have been used this way were re-directed to the knowledge mobilization process of the project.

Ongoing knowledge mobilization activities include community-facing reports, infographics, and a podcast featuring our data in addition to guests from the community. More

about all aspects of this project leading up to data collection, along with knowledge dissemination activities is provided in the following sections.

OUR CBPR MODEL

In this section, the CBPR model of PROGRESS is described (see Appendix 1) including detailing aspects of the project that were essential for successful partnership. Our research process can be understood based on an adapted theoretical model that was initially designed by Wallerstein and Durran (2010) and updated by Wallerstein and colleagues (2020). This model was developed based on literature reviews, community consultation, and experts within academia and community groups; it includes four domains. The first, context, describes the environment in which research is conducted, the policy landscape, funding and historical relationship between researchers and community. The second domain, partnering processes, refers to relationships and their dynamics between researchers and community members involved in the project. Third, the intervention and research design domain is inclusive of how communities participate in designing and carrying out research. Last, outcomes refer to short-term and longer-term impacts or realized goals of the work. Theories of CBPR processes demonstrate that effective partnerships and research outcomes are dependent on each of these four domains and the interactions between them. Each of these domains will be further discussed in this paper, first with commonly reported aspects of these domains in literature broadly, or with trans communities, then with specific attention to how the process of PROGRESS differs from other projects that use CBPR or address trans health.

Domain 1: Context

The context of a study, in a CBPR model, is usually inclusive of five themes: political landscapes and policy, social and structural factors, health issue importance, capacity and readiness, as well as collaboration and trust (Luger et al., 2020). This domain provides an understanding of the ways contextual factors relate to the research project. Each of these aspects are relevant to our CBPR process and are essential to understand how this research project was uniquely beneficial to the trans community.

Several research papers provide a historical overview of the ways in which trans communities have been negatively impacted and/or harmed by some research. A thorough review of this history is outside the scope of this paper, however, we will briefly summarize this literature to situate the mistrust that often occurs between trans communities and researchers. For many years, cisgender people primarily conducted research and were considered experts about transgender people (Ansara & Hegarty, 2021; Rosenberg & Tilley, 2021). Early research about trans experience was highly pathologizing with being trans viewed as a mental illness. This reified wide-spread stigma around being trans and led to research primarily taking a deficit-based approach to describing trans experiences (Streed et al., 2023) rather than describing positive experiences or aspects of trans individuals.

This early research on the trans community had an impact on all future research about transgender people, with cisgender views about trans lives (otherwise known as cisnormativity) shaping discourse about our experiences (Streed, 2023). With cisgender people creating discourse about the community, trans people have not often been considered to have expertise or valid knowledge about our own lives or well-being (Galupo, 2017). Further, trans people may distrust researchers due to these past negative experiences (Owen-Smith et al., 2016). Research

may be seen as potentially exploitative, and researchers viewed as suspicious, especially if those researchers are not transgender themselves (Asquith et al., 2021).

Cisgender people still sometimes conduct much research about trans people without inclusion of community. Some scholars in the trans community have felt as though this leads to harm or no benefits to health and well-being of this marginalized population (Marshall et al., 2022). Several papers point to a need for change towards trans voices being centered in research about our own health and well-being. Some have called for cisgender researchers to step back from trans-focused work while uplifting the voices of emerging trans scholars (Streed, 2023). Others suggest universities recruit trans students through additional funding and mentorship opportunities (Restar & Operario, 2019).

Several articles address ethical considerations of conducting work with trans people. One reiterates problems addressed above by detailing the negative impacts of cisnormativity, misrepresenting trans people's experiences, and not conducting research important to the community; it further suggests research conducted from a trans perspective is beneficial for this community (Marshall et al., 2013). Relatedly, a document written by the Canadian Professional Association for Transgender Health (CPATH) suggests researchers addressing trans people's experience at least consult, if not meaningfully engage the community in their work (Bauer et al., 2019, Adams et al., 2017). They also suggest considering social positioning and how this impacts research along with power dynamics that occur when cisgender people conduct research with trans people (Adams et al., 2017). Lastly, an article by several leaders in the field of trans health suggests that for research to be conducted ethically with the trans community, the expertise trans communities have should be recognized and harms to the community must be minimized while potential benefits should be maximized (Veale et al., 2022). These ethical considerations, in

addition to guiding principles of CBPR, were essential within our research project; this will be evidenced as we describe our processes.

With these considerations in mind, trans individuals may come to possible partnerships with concerns regarding the intentions of researchers, and may even mistrust them (Asquith et al., 2021). Trust has been documented as an essential part of all aspects of CBPR research (Belone et al., 2016). Indicators of trust typically reported for a researcher include qualities such as being authentic, listening skills, demonstrating commitment to community, valuing community voices, and taking actions that promote a community's well-being (Christopher, Watts, McCormick, & Young, 2008; Hora, Prochaska, Bolin, & Ory, 2007; Jones et al., 2008). These indicators can only come about once trust has been established and are dependent on the type of trust that exists (Belone et al., 2016). Several types of trust have been theorized to play a role in partnership and research processes, including trust due to being in a particular role, having common connections, or even trust deficits (Lucero et al., 2016). While researchers may assume that holding a position or title may lead to trust within marginalized communities, some research suggests that suspicion is actually more likely to occur in this instance (Lucero et al., 2016). Recognizing the power dynamics, suspicions, and trust challenges that exist, conducting research as a member of the community you are researching could help reduce many of these overarching power, control, and historical context challenges.

This context is important to foreground to showcase the ways in which the present project has recognized this history as harmful and moves towards ethical practice with the trans community. To further explain the context of our specific work, we first include a personal statement from the lead researcher and first author of this work; after this a summary of the study's unique context occurs.

A personal statement on the development of this project

PROGRESS first started as an idea and desire within the trans community for more research about outcomes of these surgical procedures. It then became a formalized research project with community members who agreed to be part of the work. In this way, it was a grassroots initiative that came up organically as a community-identified research priority. I (the lead author) approached this project first as a community member and second as a researcher; the drive to carry out this research has always been deeply rooted in a personal desire to better the lives of fellow trans people who have undergone or are considering phalloplasty or metoidioplasty.

As a person who was preparing for and undergoing phalloplasty myself, over five years ago, I found the experience stressful due to how difficult it was to find information about surgical experiences and outcomes. Similarly, for years prior to undertaking this work, community members involved in online spaces had been lamenting lacking research on both preparing for these surgeries and how lives are impacted from undergoing them. Indeed, much research focuses on a few surgical outcomes and has not involved community members in shaping the research questions. For most individuals within the community who raised a need for more research on these topics, leading or co-conducting research projects is out of reach or beyond their skill set. The opportunity to lead this research project emerged as I began my doctoral studies and became one of very few people with both personal knowledge of the topic and skills needed to conduct a community-based research project on the topic. With this unique opportunity, the possibility of a truly community-led research project became a reality.

Context of PROGRESS

Being led by a member of the community who has preexisting relationships within the sub community of individuals who seek information about these surgeries, the context of this project varied quite dramatically from cisgender-led research on the topic. Trust was already established between the lead researcher and some community team members, which prompted their involvement in the team. This was either due to pre-existing relationships or simply due to shared relevant identities and lived experiences of undergoing surgery that catalyzed trust. The challenge of having cisgender people involved, which can lead to distrust or suspicion (Freeman & Stewart, 2022; Ralston, 2023; Bassetti, 2020; Liampattong et al., 2020), was not of concern for us within our team. With trust in one another, and relationships founded in shared lived experience, we were able to focus efficiently and quickly on other important aspects of the work, including building capacity and designing a survey that would benefit our community. These relate to our partnership processes.

Domain 2: Partnership Processes

Within a CBPR model, partnership processes are often the second domain included. This aspect of the model contains information about the ways in which collaboration with communities occurs (Israel et al., 2017). Partnership processes are inclusive of how researchers work with community and are often dependent on the ways in which relationships with community members or organizations occur. In literature about CBPR, partnership process and evaluation of partnerships is a commonly reported aspect of research. Partnership processes refer to three specific sub-categories: partnership structure, relationships, and characteristics of individuals (Luger et al., 2020). The first, partnership structures, is inclusive of the makeup of

the research team, agreements between researchers and community members, principles of partnership, and the ways funding is used within communities (Greenhalgh et al., 2016). Second, relationships further address trust and safety, accessibility, capacity building, and mutual learning, conflict resolution, leadership skills, and decision making (Williamson et al., 2020). Lastly, individual characteristics may include positionality of researchers, motivations for participation, and values held by team members.

Partnership structures

Partnership structures are commonly described in literature about CBPR as researchers forming relationships with community organizations to reach a shared goal or objective through a research endeavor (Luger et al., 2020). Communities are engaged by researchers, in some cases through establishing a Community Advisory Board (CAB; Newman et al., 2011). The CAB then can act as representatives of the community throughout the research process. The level of community participation in research can vary from researchers primarily making decisions to community ownership in which power is placed entirely in community hands (Heany et al., 2007). Some researchers utilize community control within their studies; this allows community members to lead decision making and promotes collectively owning resources, particularly in response to inequity and inequality (Torres et al., 2020). Several studies have utilized this concept of community control to reflect how they engage with and give power to those involved with the project from marginalized communities. In particular, Trans PULSE, which was one of the first community-initiated CBPR projects about transgender health in Canada, described their project as community-controlled. In their work, research was designed with community members using shared decision-making processes, which gave all team members a vote and voice in research processes (Travers et al., 2013).

Principles of partnership and relationships

The lead researcher's commitment to centering the community was further demonstrated by the way partnership processes occurred. To create partnerships, CEC members were approached individually by the lead researcher and asked to join the team. They were chosen based on knowledge of surgery, clinical practice, policy, or if they were strong advocates for our community; this allowed for a team with a breadth and depth of expertise on the subject area. As mentioned in the context section, several team members had prior relationships with the lead and/or each other; others were recommended by various individuals in the community. In addition to being community members with lived expertise, most CEC members also worked within community organizations or as service providers. It was important to bring together team members with lived and professional experience of these surgical procedures to form a team that could speak on behalf of the community of trans individuals who have undergone these surgeries. The relationship dynamic between lead researcher and community members who took part in the CEC was then based on peerhood, shared lived experience and recognition of the importance of a project about this topic.

As a graduate student, the lead researcher also worked with research supervisors; while not part of a formal partnership, those researchers oversaw the work by providing guidance and direction and giving feedback on research processes. Those individuals include two trans community members and one cisgender person. These individuals were not specifically involved in initial decision making of research topics, survey questions, recruitment strategies or knowledge mobilization plans; they provided review of materials for scientific and methodological rigor after community decisions were made.

The partnership of the lead researcher and the CEC was governed by a Memorandum of Understanding, or MOU (see Appendix 2), which outlined the scope of the project, our shared goals and values, and how decision making occurs. This document clearly stated goals and objectives that, at the outset of the project, indicated a focus on creating research that will benefit the trans community. The stated objectives included documenting experiences and outcomes of these surgical procedures and gathering and formalizing community knowledge on the topic. Within the MOU we also included guiding principles of the project, which included centering trans voices, community control, a collaborative process, and focusing on capacity building for all involved. Our previously discussed decision-making process was also made clear in this document as well as a commitment to community-oriented knowledge sharing/mobilization. Further, the MOU described how CEC members could be paid for any time spent engaging in project-related activities. Each person who agreed to be paid was compensated at a rate of \$25 Canadian (CAD) an hour thanks to a research grant which provided a \$5,000 CAD research allowance a year; it also provided an annual stipend of \$50,000 CAD to the lead researcher. Compensating team members for their time allowed everyone to participate in the project and, importantly, reiterated a commitment to supporting our community.

Another aspect of community partnership for us included a focus on developing research skills for those within our community. Capacity-building and mutual learning are values that characterize CBPR approaches (Faridi, et al., 2007; Kwon et al., 2018) and another aspect of the partnership processes domain. Capacity building is increasingly recognized as important for all team members (Mason et al., 2013). A focus on capacity building has also been linked to stronger partnerships and a perception of sustainability within team relationships (Hacker et al., 2013). This is especially important when conducting CBPR with trans communities, who often

presently lack research skills as they have not been equitably engaged in much previous research (Spade, 2011; Mckendry, 2020).

Often, formal training is used to help community members gain research knowledge or skills. Examples include workshop series about how to collect data (e.g., Amico et al., 2011, Ramanadhan et al., 2021, Rubin et al., 2016). Resources for capacity building, including funding and access to formal training, have been identified as important facilitators (Mason et al., 2013). Further, hands-on experiences rather than only utilizing training of skills and practices has also been described as promoting capacity (Mason et al., 2013).

An essential goal of PROGRESS was to develop research-related capacity of team members and promote mutual learning as we believe this can develop more educated community members and work towards equity for our community. Through our capacity-building process, the goal was to support the community by promoting a culture of mutual learning and skill-building. We used a combination of formal training, Q&A with researchers, informal research design discussions, and hands-on experience as part of our mutual learning processes. Formal training included tutorials on research and less formal aspects include a meeting with senior researchers to discuss specific methods.

Several community members gained hands-on experience of designing surveys, developing qualitative data codebooks, creating infographics, and analyzing survey data. At the time of this writing, everyone who took part as a community engagement committee member has gained skills in planning a research project, grant writing, designing a survey, promoting a survey, collecting quantitative data, planning academic papers, and making decisions about ways to create knowledge products that are important and useful for the community. Community

partners and the lead researcher of this project have gained important skills from experiences directly associated with this project.

Domain 3: Intervention and Research Processes

This intervention and research processes section describes the third domain of this project's CBPR model. Intervention and research processes are inclusive of both research products and the outputs of research. Research processes, here includes how community knowledge is integrated into the research and the ways empowerment of communities might occur due to participation (Jull et al., 2017). Outputs are the results of these processes; they may include community priorities being a focal point of research and therefore research design and translation can occur that is beneficial within that community (Unertl et al., 2016). In this section, the processes by which community knowledge has been centered in PROGRESS is described before describing the empowerment that may occur as a result. Regarding outputs, we will describe how our project represents an example of how community-identified priorities can be centered in research about transgender people's health and well-being. After reviewing the outputs of the project, I describe outcomes (the fourth model domain) in the next section.

Decision making within PROGRESS uplifted community voices and empowered individuals involved. Trans community member voices and research priorities from our community drove our research process at each step. Our team, with essential knowledge of community priorities and needs, made decisions about all aspects of the work; this further reified our commitment to centering trans voices throughout the process. To ensure our project did focus on community priorities as we set out to do, we included a research process that robustly centered decision making about almost all topics on community. For example, each CEC

member, in addition to the lead researcher, was given ample opportunity to add topics to a list of items that were important for inclusion on our study survey. We then discussed this list in detail at a series of meetings, following which team members voted on what topics were most important to keep in the survey. Our voting system utilized a 1-vote per person approach, where a more than 50% majority needed to be reached for a vote to pass. For each of our votes, we easily reached a majority, and often a consensus with no decision failures.

Given that community-identified priorities are not commonly addressed in academic literature (Marshall et al., 2022), the importance of community members identifying research priorities is clear; had we not done so, an opportunity to create research most beneficial to this community would have been lost. The experiences we collectively had, and our insider knowledge of the sub-community of people who are interested in or have undergone these surgeries, formed the basis for all decisions about the research project. In this way, this project went beyond centering trans voices, to recognizing lived experience as a form of expertise. With the knowledge that their contributions are highly valued, community members involved can therefore feel empowered to share ideas and opinions. This empowerment was essential to create a survey from which the data we collected could ultimately benefit our community.

Data Collection

For data collection, we recruited trans and nonbinary individuals who had undergone phalloplasty and/or metoidioplasty from across North America. We chose to utilize a cross-sectional survey that collected primarily quantitative data for this project. This decision was made based on our collective knowledge of how research might benefit our community. We recognized that within our community, narratives of experiences of these surgeries are easy to

find in videos, blogs, books and conversations with peers. What has been lacking includes quantitative data about common experiences related to these surgeries and the frequency of those experiences among larger samples of participants who are not tied to surgical centers. In addition, more complex analysis of the relationships between individual factors or experiences and surgical outcomes are lacking in the literature and quantitative data could begin to fill this gap. Further lacking in current literature are some topic areas that are often discussed within trans communities yet little or no formal research exists on the topic. Broadly, these topics included how patients prepare for these surgeries and what was useful for them in preparing; what recovery experiences are like, including severity of complications; aftercare experiences; and self-reported changes due to undergoing one of these surgeries. For many topic areas included in the survey, we chose to create new questions which were designed to address a specific experience, rather than using pre-existing scales or measures. This is in part because many widely used scales are not validated for use in transgender populations (Dy et al., 2022); further, few measures exist to measure patient-reported outcomes of these specific surgeries. Designing new survey items based on lived expertise ensures those taking the survey would understand the questions and feel they reflect their own experiences.

Our recruitment of participants was also positively impacted by who was involved in our team. Our recruitment strategy focused on our strengths as a community-led and -organized project. Most notably, this included our connection to online spaces where cisgender people are not intended to be; those involved in these spaces had either undergone phalloplasty and/or metoidioplasty or are planning to have one of these in the future. In addition to having access to these community spaces, several CEC members are well-known within these forums; this made recruitment an easy process due to the level of trust this created within trans communities.

This recruitment experience is unlike many projects where community members are not involved in the process. Commonly, trans people are not considered easy to recruit for research projects. In part, due to historical or ongoing mistrust described above, but also due to being considered a “hard to reach” or “invisible” population (Ellard-Grey et al., 2015). Trans people are considered hard to reach due to the small size of the population and lack of concentration in a geographic area or other location, unlike many communities who may participate in research (Hughes et al., 2017). Overall, the team’s connections within the trans community, and more specifically with those who have undergone phalloplasty and metoidioplasty, positively impacted our ability to recruit participants.

Outputs: Knowledge Mobilization

Notably, knowledge mobilization for PROGRESS was designed to first benefit our community. From the outset, a central project focus was to create resources for trans community members considering undergoing phalloplasty and metoidioplasty. In part, this focus was due to lacking information about these surgeries that is widely accessible to the average reader. In addition, we recognized that existing research on the topic is primarily disseminated via medical academic journals and conference presentations that are not accessible to the average trans person. Without making research about a community into accessible formats, the community cannot easily utilize research results to advocate for needed change. Since research has rarely been conducted with the goal of creating knowledge or outputs for the trans community, it was important for this project to consider trans people when creating research outputs.

When deciding on knowledge mobilization plans, we first asked ourselves what kinds of products or outputs might reach our community and make research more accessible. We decided

that community reports and infographics were both essential for a few reasons. In easy-to-understand language, community reports share large amounts of data and individuals or organizations can use these reports in academic, policy and clinical work. Infographics are more concise and represent quantitative data in visual form, making these outputs easy to share on social media which we hoped would help get our results back to those who participated. In addition to these outputs, we decided to produce a podcast series on our findings and interviews trans community members about their experiences with phalloplasty or metoidioplasty in relation to our results. As of October 1, 2024, our podcast had been downloaded over 350 times and reached listeners in at least 10 countries. As of this writing, a zine, community report, three infographics, and three podcast episodes have been released; see Appendix 4 and 5 for the zine and community report we produced; the podcast is freely available at pod.link/1652577729 or by searching for PROGRESS podcast in any browser.

Domain 4: Outcomes

Choices about knowledge mobilization necessarily impact the ways in which project goals can be met and influence outcomes that occur from the research. Outcomes refer to changes that occur due to the research project and/or its processes; these can be short term, intermediate, or longer-term and can include systems- to individual-level changes (Belone et al., 2016). Specific examples of short or intermediate outcomes might include policy changes, increased capacity within community organizations, dissemination of works, and sustainability of partnerships (Hacker et al., 2012). Generally, long-term outcomes represent improved health, increased social justice and/or equity for marginalized communities (Wallerstein et al., 2020).

Within other sections of this manuscript is documented the ways in which we built capacity among our team, empowered community members and created knowledge outputs to benefit the larger trans community. One of the goals well achieved by our work includes developing educational materials useful to our community. By collecting data about topics important to our community and creating knowledge outputs designed specifically for them, we have provided much-needed information to our community. This will, in turn, produce more educated and thus empowered prospective and current patients. With these actions, along with sharing community focused outputs in online spaces, we believe our community can benefit long term from this research project.

Other longer-term changes that may occur as a result of our work include changes to policy or healthcare service delivery and reduction in health disparities experienced by trans people. While many CBPR projects include policy change as a short-term outcome of their work, creating policy change for gender-affirming care is complex and multifaceted. With the information generated and translated to our community through PROGRESS, we are hopeful that community-organized efforts to affect policy are undertaken. As opportunities arrive, we will support such initiatives through access to our data in a dynamic online data dashboard (forthcoming), advocacy based on lived experience and research results, and through continuing to provide resources to the trans community. In the long term we also aim to promote well-being among trans communities. A central aspect of PROGRESS, and a research aim listed in our MOU, included a goal of bettering the lives of trans people. While this represents the grandest long-term goal of this project, our partnership will be ongoing, and our results will continue to be used to educate patients and service providers and promote needed change for our community.

The overall success or not of CBPR projects seems to be a culmination of the context, partnership processes, research projects, and their outputs. While a formal evaluation of PROGRESS has not yet occurred, this manuscript offers a reflection of our partnership and processes. Recognizing the importance of context and partnering processes we consider PROGRESS to be exemplary in utilizing CBPR principles to engage the trans community in this project. Below is a summary of key differences in aspects of PROGRESS that we believe are contributing to success.

The context of this research project differed from many other projects in that outsiders to the community were not actively making decisions about research design and knowledge mobilization. Centering of trans voices ameliorated potential trust issues and our peer-based relationships promoted level-ground rather than power-over dynamics. The lead researcher approached decision making in a way that empowered community members to freely express opinions and know their voices (and votes) mattered. The research process, outputs, and outcomes were then positively impacted. In our research process, we were able to identify novel topics to address in our survey due to our lived experiences and intimate knowledge of community. We also had a keen sense of how research results could benefit our community and designed knowledge outputs to advance these ideas. Due to our close proximity to the community of potential participants and their knowledge of several community members as activists or trustworthy individuals, we successfully recruited a large number of respondents from a 'hidden population'. Recruiting hard-to-reach individuals allowed us to share results that may be more broadly relevant than if recruitment focused within a surgical center or care team. The outcomes of research are potentially the most greatly impacted by our community-led design. Due to our focus on community-identified research priorities and knowledge

mobilization for community members, our results promote both the education and well-being of trans communities.

LIMITATIONS AND CHALLENGES

While our CBPR process was novel and had many strengths, there are limitations to this work and challenges we experienced along the way. These included funding and time-related issues, community burden and limitations based on the lack of evaluation of the process. The process of obtaining our funding was not easy and only occurred after several failed attempts. Ultimately, the project received a small amount of funding which was enough to cover costs associated with public-facing materials (flyer, website), knowledge translation, and community member time spent on the project. Community members who indicated in our MOU that they would like an honorarium for their work were paid at a rate of \$25/hour for meetings, review of documents, meeting preparation and time spent voting. While this compensation was useful, it may not have entirely ameliorated some burdens placed on community, namely the time commitment.

The process of creating our survey and recruiting participants was lengthy and occurred over many months. During that time, we met over 10 times and the CEC was asked to spend additional time voting or considering project design. This placed a significant time burden on community members who each had their own full-time commitments elsewhere. This burden of time was exacerbated by my lack of awareness of how long the process would take at the outset. The community members involved in the work thus were additionally burdened due to the time commitment potentially lasting longer than I had led them to expect.

Related to this challenge of time was the experience of completing this project within a PhD program and dissertation. Balancing a desire to complete my PhD in a timely fashion with a

strong commitment to doing CBPR well was not easy. I chose to prioritize community-led decision making which, of course, took more time than if I had made decisions unilaterally. Further, developing several community-facing knowledge translation outputs while completing a dissertation was a challenge and required much more time than I had expected. Overall, conducting a CBPR project within a PhD program was challenging to balance.

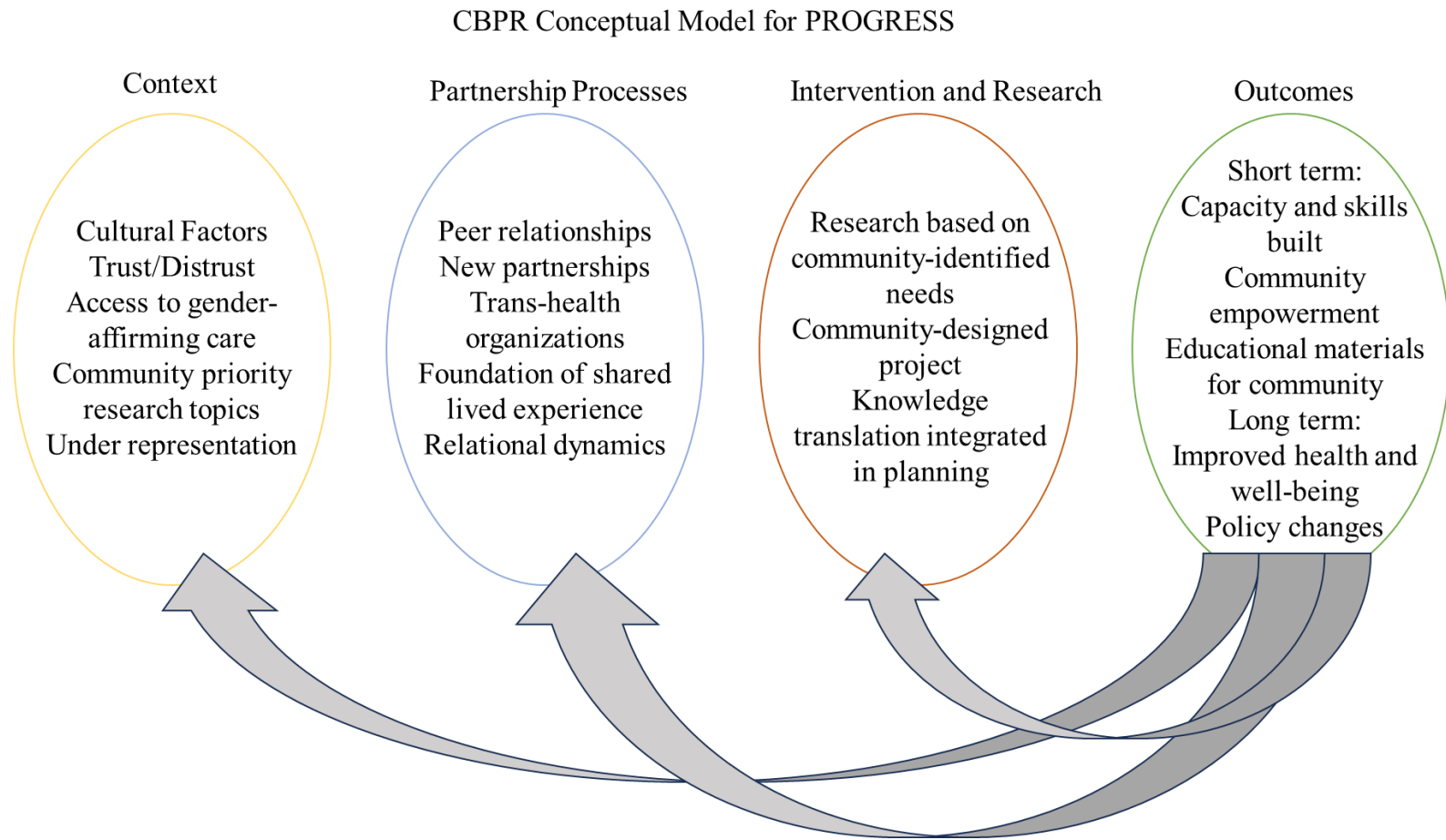
While the KT outputs of the work have the potential to positively impact trans communities, we have not formally evaluated the process we undertook to conduct the PROGRESS study or determine its impact. An informal evaluation has not occurred either. This is a limitation of the CBPR process outlined within this paper since we cannot speak to how our project compares with other projects on similar topics or with a comparable community-led design.

CONCLUSION

While much research about trans people has occurred by cisgender people with little inclusion of trans community members, more research is recently being led by and for trans communities. Historical harms created by research that did not center trans voices, research priorities, or accessible knowledge can begin to be rectified by trans-centric initiatives. In alignment with CBPR principles and ethical consideration for research with trans people, PROGRESS was successful in implementing a trans-led research project with robust inclusion of community members and focus on research priorities deemed important to our community. The context of the project, as well as our partnership processes and outcomes of the work, was unique due to our team's composition and knowledge of both subject matter and the community. As a project designed by and for trans people, we were able to collect data about novel research topics and create research outputs, which directly benefit our community. Future research should

continue to seek equity for trans communities by uplifting trans voices in research and ultimately building the capacity of trans scholars who can then lead discourse about trans people's health and well-being.

Figure 1: CBPR conceptual model of PROGRESS



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Chapter 3

Promoting trans patient autonomy in surgical preparation for phalloplasty and metoidioplasty:
Results from a community-based cross-sectional survey and implications for preoperative
assessments

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ABSTRACT

Background

Some transgender and nonbinary people undergo phalloplasty and/or metoidioplasty as part of their medical transition process. Across surgical disciplines, a variety of resources are used to assist patients who are preparing for surgeries, including educational materials, workshops, peer support, and lifestyle changes. For gender-affirming surgeries, patients undergoing assessments to discern whether they are ready to undergo the surgery, and to assist them in achieving preparedness when needed. Little research investigates what resources are useful in helping patients to feel prepared to undergo phalloplasty or metoidioplasty, and how assessments and resources can promote patient autonomy in the process. Respect for patient autonomy is one of the central tenets of ethical healthcare, yet historically, scholarship related to pre-surgical assessments for gender-affirming surgery has focused determining the ideal surgical candidate rather than respecting patient autonomy and ascertaining individual patient needs.

Methods

This study sought to fill this gap by utilizing data from PROGRESS (Patient-Reported Outcomes of Genital Reconstruction and Experiences of Surgical Satisfaction), a cross-sectional, community-based survey of trans and nonbinary adults from the United States of America and Canada who had undergone one or more of these surgeries.

Results

Results revealed most participants (86%, n=186) felt prepared to undergo surgery, though the majority of our sample (53%, n=105) did not find referral letter assessments to be helpful. Peer support such as online resources/blogs were rated as highly useful, along with surgical consults.

In a multivariable logistic regression, higher perceived preparedness was associated with identifying as queer (inclusive of gay, bi and pansexual compared to being straight), and feeling that one's assessment process was useful (as opposed to not useful). Type of assessment was not significantly associated with preparedness; therefore, what is most useful when preparing for surgery may vary across individuals.

Conclusion

Healthcare professionals who interact with preparing patients should develop new, or utilize existing, resources to assist patients in identifying their preparation needs and achieving preparedness. Our data supports assessments that center surgical care planning rather than assessing level of gender dysphoria. Future longitudinal research could further refine which assessment processes are most effective in helping patients who are preparing for these surgeries. Assessments should ensure that patients are appropriately prepared to undergo and recover from surgery through a robust process of informed consent.

KEYWORDS

Transgender, readiness, preparedness, gender-affirming surgery, informed consent, patient autonomy, CBPR

BACKGROUND

For some transgender and nonbinary (henceforth referred to as “trans”) people, gender-affirming surgery is an important part of their transition. Gender-affirming surgeries can include chest surgery (e.g., top surgery/mastectomy, breast augmentation), reproductive system surgeries (e.g., hysterectomy/oophorectomy, orchiectomy), and genital surgeries (e.g., metoidioplasty, phalloplasty, vaginoplasty). For trans people assigned female at birth, genital surgery options include phalloplasty and metoidioplasty. Not all trans people desire gender-affirming genital surgeries (1) and not everyone who wants these surgeries has access to them, (2) though here, we will focus on those who do.

Phalloplasty was originally designed to reconstruct a penis after physical trauma, cancer, or disease, and has since been used to create a penis for trans people who desire one through use of non-genital flaps.(3,4) It has been described as a “modular set of procedures that can be combined, mixed, and matched to meet the needs of each individual patient.”(5) Phalloplasty, with or without additional procedures, can be performed in several different ways, with numerous variations occurring over time and geographic region. Currently, radial forearm free flap (RFF) phalloplasty is the most common type of phalloplasty globally,(6) though other types of phalloplasty, such as anterolateral thigh flap (ALT) and abdominal flap, among others, are also performed.

Metoidioplasty is an adaptation of surgeries to resolve hypospadias,(7) which is a condition where the urethral opening is located somewhere other than the tip of the penis. In trans individuals, metoidioplasty utilizes the hypertrophied clitoris resulting from testosterone therapy.(8) Metoidioplasty is performed by releasing ligaments of the clitoris (9) and uses labia

tissue to increase the bulk of the phallus/penis. Unlike phalloplasty, a donor site is not needed, and therefore this procedure causes no major scarring.(6)

Various types of patient preparedness programs exist across surgical disciplines, yet the ideal patient preparation program has not been identified in most fields, nor is a universal best practice agreed upon.(17) In some surgical fields, several interventions have been demonstrated to impact patient feelings of preparedness.(18) Aftercare and planning for recovery are also major considerations when undergoing surgery that are addressed in some surgical preparation programs.(19) Some evidence suggests that patient preparedness may lead to positive surgical outcomes, higher quality of life after surgery,(20) and fewer surgical complications. In contrast, feeling unprepared for surgery has been associated with patient dissatisfaction.(21)

A paucity of literature documents how patients prepare for phalloplasty and/or metoidioplasty. In one qualitative study, participants reported spending a large amount of time and energy preparing themselves and highlighted relationships with their care team as important to their preoperative process.(22) Other research suggests that social media may also be a source of content that helps patients prepare for, or ask questions after, surgery; one analysis found that patients used social media to ask questions about post-operative scarring and wound care, medical supplies, recovery, and general appearance.(23) There are data which indicates that, out of a variety of methods used by patients before and after surgery to improve their experiences with their genitals, peer/social support was found to be one of the most helpful methods both before and after surgery.(24)

While preparing to undergo phalloplasty or metoidioplasty, a patient will likely be working with a surgeon or surgical care team which utilizes the World Professional Association

for Transgender Health (WPATH) Standards of Care (SOC) guidelines for assessments prior to gender-affirming surgery.(25) The SOC require patients undergo one assessment external to their surgical team (often called “referral letters”(27)) by a “qualified healthcare provider” in order to undergo surgery.(25) Previous iterations of the SOC required two referral letters for genital surgery.(25,28) For many patients, these referral letters are then given to their surgical team and/or their health insurance company in order for them to be surgically cleared for surgery, and to receive insurance approval.(25) Referral letter assessments are usually conducted by a mental healthcare provider, social worker, and/or medical provider.(25,26)Such assessments typically do not focus on aspects of preparation such as hair removal (specifically prior to phalloplasty), exercise, diet, aftercare planning, or physical and psychological changes that may result from the surgery; sometimes, these topics are addressed in educational materials from some surgical teams and service providers (29) who work with patients preparing for phalloplasty and metoidioplasty, but these practices are not required as per the WPATH SOC.(25) The content and thoroughness of the assessment is similarly non-standardized, and depends largely on who is conducting the assessment, the procedure in question, the assessment tools used, and the goals of the assessment.(27) This is consistent with direction in the WPATH SOC version 8, which directs that “no single assessment process will fit every person or every situation.”(25, p. S31) There is evidence indicating that referral letters serve as barriers to care, rather than facilitators.(27)

In addition to these referral letters, some surgeons and/or surgical teams provide patient education as part of readiness/preparedness documentation prior to surgery.(29,30) The content of this education or resource provision is similarly non-standardized and not stipulated by the WPATH SOC,(25) and again varies depending on who is providing it. Further, some surgical

teams do not require letters of support or assessments of any kind, unless required by the patient's insurance provider. Instead, these providers focus on patient education and the informed consent process.(31) Indeed, some service providers have begun to recognize the need for more comprehensive patient education and planning prior to phalloplasty and/or metoidioplasty, and have shifted to defining their readiness assessment procedures in terms of "surgical care planning".(32) Surgical care planning then, will typically include obtaining a letter of support in line with the WPATH SOC, but will also provide more comprehensive educational and resource support in line with the other elements of preparedness discussed above.(32)

In addition to there being no standardized assessment model, there is little guidance on what credentials the assessor should have. For instance, according to the WPATH SOC, assessors do not have to be mental health professionals and need only have a Master's-level degree and sufficient knowledge to enable them to perform a competent assessment.(25) However, neither "sufficient" nor "competent" are terms defined within the SOC. Provider knowledge levels are vary, which makes it more difficult to evaluate the helpfulness and legitimacy of the required assessment. Indeed, if the assessors have little knowledge of the surgery, these assessments may fail to help patients make informed decisions about what is best for their own bodies. If this informed decision-making process fails and patients are not able to make the best decisions for their own bodies, patient autonomy is compromised; this is discussed next in further detail.

Respect for patient autonomy is one of the foundational principles of biomedical ethics; as described by Beauchamp and Childress.(33) It underlines the need to allow individuals to make decisions and take actions based on their own beliefs and values.(33) One of the ways in which autonomy is respected in healthcare is in the informed consent process, through which a

patient is provided with the information necessary to understand and voluntarily consent to the planned medical intervention.(33) A readiness assessment can enable this process by ensuring that the patient has adequate understanding of the surgery they are about to undergo.

Elliot Marrow talks about the inception of pre-surgical assessments in the 1950s in a recent article, describing how few surgeons were willing to provide gender-affirming care to trans people, though some providers did create their own pre-surgical criteria to try to prevent postoperative regret and clinician liability.(34) Initially, this involved ensuring that patients would blend-in with cisnormative culture by being heterosexual and looking a certain way (or passing as cisgender).(35) Psychologists and clinicians felt they needed justification beyond patient desire to undergo surgery, and, further, feared backlash from patients and the media if they allowed the ‘wrong people’ to access surgery.(34) These early clinician experiences lead to the creation of the WPATH SOC (then called the Harry Benjamin Standards of Care for Gender Identity Disorders) and clinicians began to assess patient surgical readiness.(36) This process was designed, in part, to protect medical teams and additionally, out of fear of regret from patients (37); it was not designed to support patients in choosing what they wanted for their own bodies, nor to promote patient autonomy or informed consent.(34) The gatekeeping nature of these original assessments led trans people to feel as though assessment processes are not designed to support them or their decision making (38); this feeling is still pervasive today and described in recent literature.(37)

Though gender-affirming surgery assessments have shifted in recent years to be oriented more explicitly toward serving both the patient and surgeon, they may still be informed by fear.(34) The lack of a standardized assessment model can restrict patient autonomy if they are based in cisnormativity or fear of patient backlash, rather than intent on providing a robust

process of informed consent by adequately informing the patient and ascertaining understanding of the desired procedure.

Overall, the current process of determining readiness of patients who wish to undergo phalloplasty and metoidioplasty varies greatly, with some surgical centres relying solely on letters of support from mental healthcare providers and others using patient education programs. To our knowledge, no published research has investigated what factors are associated with patients feeling prepared to undergo these surgeries, or whether any one type of preparedness process leads to better readiness overall. Given this lack of literature on trans patient preparedness, it is essential to not only understand the factors associated with perceived preparedness for surgery, but also for services to be built and delivered to bolster patient preparedness. The aim of this investigation was to utilize data from a community-based cross-sectional sample of trans individuals who had undergone phalloplasty and/or metoidioplasty to examine factors associated with feeling prepared for these surgeries and argue for the creation of more patient-centered and autonomy-promoting preparedness programs based in evidence.

METHODS

Patient-Reported Outcomes of Genital Reconstruction and Experiences of Surgical Satisfaction (PROGRESS) was a community-based, patient-oriented, and cross-sectional survey. The study questionnaire was developed by a team of seven trans community members with lived experiences of phalloplasty and/or metoidioplasty, and was led by the first author. A full copy of the survey is available to view in the Supplementary Material. Survey responses were collected online from April to July 2022. Eligibility criteria included adults identifying as trans, nonbinary or other related terms; having had phalloplasty or metoidioplasty; living in the United States of America or Canada; and being able to self-complete the questionnaire in English. We posted

recruitment flyers on trans community-identified social media channels, Facebook groups, and Reddit forums, and shared flyers in trans-related listservs. The survey was cross-sectional, online, self-completed, and anonymous, and included questions about demographics, preparing for surgery, recovery experiences, perceived changes in mental health, gender dysphoria and euphoria, and overall surgical satisfaction. Participants were not provided with an honorarium for taking part in the survey. This study was jointly approved by the University of Victoria and University of British Columbia's Human Research Ethics Boards (certificate number 21-0033). Informed consent to participate was secured online prior to any data collection.

Measures

The primary outcome variable for this analysis was perceived preparedness for surgery. This was measured using responses to a single question adapted from Kenton's Preoperative Preparedness Questionnaire.⁽²¹⁾ This single item was chosen instead of the whole scale due very little variance and non-linearity when testing responses to the overall scale for assumptions of logistic regression. The item asks participants to rate how much they agree with the statement "Overall, I felt prepared to undergo surgery." Originally, this item was part of a measure designed for use prospectively before surgery; however, all items in this questionnaire were adapted by our team to use past tense language. In both versions, response options include a 6-point Likert scale ranging from "strongly disagree" to "strongly agree," which we then dichotomized into 'disagree' versus 'agree' for logistic regression analyses.

Exposure measures

Demographic characteristics included age, ethnoracial identity, education, income, sexual orientation, and country. Other exposures of interest included type of gender-affirming assessment, mental health in the year leading up to surgery, access to community support or resources prior to surgery, and self-reported usefulness of assessments. To determine the type of assessment, participants were asked a question created by our team which read, “What did the process of obtaining approval to have surgery look like for you?”. Response options included: two letters (from a therapist or mental health care provider), one letter, interview by an assessor, a combination of letter(s) and something else, a workshop or training, and ‘other.’ This variable was dichotomized into ‘two letters’ and all other response categories for the regression analysis. A follow-up question asked, “how useful was this method of approval in preparing you to have surgery?”. Responses to the question included a 5-point Likert scale ranging from ‘not at all’ to ‘extremely useful’. These responses were also dichotomized into ‘not useful’ versus ‘useful,’ where ‘useful’ included all responses other than ‘not at all.’

We adapted the Canadian Community Health Survey’s single-item measure of mental health (39) to be used in the past tense and added a time qualifier to determine mental health in the year prior to surgery. The item asked, “How would you describe your mental health in the year before you had phalloplasty or metoidioplasty?”. Response options were unchanged from the original measure and included a 5-point Likert ranging from ‘poor’ to ‘excellent.’ Categories were dichotomized into ‘poor or fair’ versus ‘good, very good, or excellent’.

Accessing community in the time before surgery, either for support or information, was measured by creating a derived variable from responses to the question, “When deciding to have surgery, where did you access information about surgery options and outcomes?” Respondents were invited to select all that apply. Those who selected any of the following were placed in the

‘accessed community’ category: conversation with peers, Facebook or reddit groups, online virtual support groups, or in-person support groups and/or reading blogs by post-op trans men. Those who did not select one or more of these were categorized in the ‘did not access community’ groups. This question was followed by another asking how helpful each of those resources were in preparing the participant to have surgery. Responses to this question included a 5-point Likert ranging from ‘not helpful at all’ to ‘very helpful’.

We created a variable derived from three questions to discern who was ‘active process’ or between planned surgeries, stages, or awaiting revisions; this is a commonly used and understood phrase within trans community. We categorized participants that reported fewer numbers of completed than planned surgeries as active process. Additionally, if they stated a planned surgery was indefinitely put on hold or that they were waiting for revisions, we placed them in the active process category. Lastly, if a participant wrote in any open text box within the survey that they are between stages or active process, they were placed in this category.

Analysis

Data were cleaned to remove eight survey responses which did not meet our eligibility criteria. Four other responses were removed due to having completed less than 10% of our survey. All questions in the survey were optional resulting in varying amounts of missingness. Twelve participants who did not answer the question about preparedness, which was the dependent variable used in the analysis, were not included in the multivariable logistic regression. Several other variables in our analysis that contained missing counts larger than ten were coded as a separate category to ensure those participants were still kept in regression analyses. The final analytic sample, which excluded those who did not answer the dependent variable questions, included 203 responses.

The analysis in this paper includes descriptive statistics, bivariate analyses, and a multivariable binary logistic regression; all analyses were conducted in SPSS version 29. First, we prepared descriptive statistics for variables of interest followed by cross-tabulations with chi square tests between the outcome variable and all exposure variables ($p < 0.05$ considered statistically significant). Next, we conducted an automatic, backwards selection binary logistic regression with preparedness as the outcome variable with all categorical explanatory variables. Our multivariable logistic regression utilized an automatic backwards conditional selection process, which removed the least statistically significant items while finding the model's best fit, and did not force demographic variables into the model. We tested age, ethnoracial identity, income, education level, sexual orientation, and country of residence as covariates. This regression method was chosen due to the exploratory nature of the research and because extant literature cannot indicate what may be associated with patient preparedness for these procedures.

RESULTS

Table 1 presents descriptive statistics of all demographic and exposure variables, stratified by our outcome variable of surgical preparedness. Chi square results are not displayed as only one item statistically significantly varied by self-reported preparedness. Most of our participants self-identified ethnoracially as white (84%). Participants described their sexual orientation as queer (37%), straight (27%), gay (21%), and bi (24%). Our participants mostly had high levels of education with 30% having attended graduate school or achieving a graduate degree. Additionally, participants had high personal income levels with 40% making more than \$80,000 annually (CAD or USD depending on their location).

In terms of surgeries, about half (51%, $n=103$) had solely phalloplasty, 83 (38%) had solely metoidioplasty, and 21 (9%) had both procedures. Only 40% ($n=85$) of our sample had

surgery prior to 2020, whereas 59% (n=124) had surgery in the past two years. Over half (54%, n=110) of our respondents were identified as ‘active process’ meaning either they were waiting for additional surgeries or between planned stages of surgeries. Participants typically traveled outside of their state or province of residence for surgery (42% n=85), but only 10% (n=20) traveled outside their country. However, 14% (n=28) of participants had surgery within their city of residence.

Overall, participants reported high levels of preparedness, with 86% (n=186) feeling prepared. Results of the full Preoperative Preparedness Questionnaire can be found in **Table 2**; for all items in the measure, participants largely agreed with statements related to aspects of preparedness. The item in which participants rated their lowest level of agreement was whether they felt prepared to cope with a catheter at home after leaving the hospital.

Regarding assessment types, about half underwent two external assessments for referral letters from mental health providers (51.7%, n=105). The participants underwent two referral letter assessments as our survey took place prior to the updated SOC version 8, which removal the second letter assessment requirement. Approximately another half had a different type of assessment (48.2%, n=98). Overall, 53% (n=105) of our sample reported that their assessment was not at all useful in preparing them for surgery. Based on a Chi Square test using Fisher’s exact test, whether participants self-reported their readiness assessment as useful was statistically significantly associated with self-reported preparedness at a $p < .05$ level. Among those who received two letters, half (55%, n=88) said this was not at all useful in preparing them to have surgery. Only 13% (n=26) reported feeling that two letters were very or extremely useful in preparing them for surgery.

While preparing for surgery, 92.1% (n=187) of our sample accessed community supports or resources, including conversation with peers, support groups or community-created resources. The resources most highly rated as helpful included social media, including Facebook groups and reddit forums, with 47% (n=101) participants indicating these were ‘very helpful’ in preparing them for surgery. Similarly, participants rated conversations with peers as very helpful (n=48, 22%) or helpful (n=34, 15%) in preparing for surgery. Outside of peer-created content or resources, consults with surgeons were also rated highly as helping people prepare, with 40% (n=87) stating these were ‘very helpful’, and 24% (n=52) rating them as ‘helpful’. No demographic or other characteristics were significantly associated with feeling prepared in bivariate analyses.

Correlates of surgical preparedness

The multivariable logistic regression analyses resulted in a final model with 2 statistically significant factors: sexual orientation and usefulness of assessment processes. More specifically, those who self-identified as queer were more likely to report feeling prepared for surgery than non-queer participants. We conducted a post-hoc chi-squared test looking at sexual orientation and self-reported access to community in the time leading up to surgery. We found that queer participants were statistically significantly more likely to have access community in the time leading up to surgery ($p < .05$), which may have contributed to greater feelings of preparedness, as compared to non-queer participants. **Table 3** presents odds ratios (adjusted and unadjusted), and 95% confidence interval results for the logistic regression.

DISCUSSION

Our results add to a growing body of literature about the experiences of access to gender-affirming surgery and ethical considerations regarding bodily autonomy. This analysis revealed

high rates of perceived preparedness among a community-based sample of trans individuals who had undergone phalloplasty and/or metoidioplasty. Participants who felt that their assessment process was useful were more likely to report feeling prepared to undergo surgery. Which type of assessment process a person underwent, however, was not statistically related to whether participants felt prepared. The following discussion showcases these results in relation to the existing literature on surgical preparedness for phalloplasty and metoidioplasty, with specific attention paid to critiques of current assessments within context of informed consent and patient autonomy.

Participants in our study reported feeling prepared to undergo phalloplasty and/or metoidioplasty and had high scores on the individual items of the Preoperative Preparedness Questionnaire (21) and the general question of overall preparedness. The resources ranked by our participants as most highly useful in preparing were Facebook and Reddit groups. Social media spaces like these are frequently places where community members ask questions about outcomes or experiences, get support from peers and share experiences of surgical teams. It is well-known within the trans community that prospective patients preparing for gender-affirming surgery spend a large amount of time preparing themselves, outside of their relationships with their surgeons/surgical teams, by seeking out community information or support to help them feel ready.(24,40) Other literature documents peer support and shared experiences as useful to patients who are recovering from surgery,(41) experiencing a health concern,(42) or undergoing medical treatments for cancer.(43) While accessing community support or resources was not a statistically significant correlate of feeling prepared, participants' responses clearly indicated the utility of these resources. It is likely that there was a lack of statistical significance related to

community support due to the small number of respondents who did not access community support (8%, n=16).

Our participants also rated surgical consults as highly useful while preparing for surgery. These consults often deliver important patient education and address questions or concerns.(30) Along with surgical consults, in many other surgical fields, patients are now being helped by social workers or other practitioners to develop care plans or for pre-surgical preparation.(44) Some literature suggests that patients given resources by care teams are more likely to feel prepared, so long as they judge those resources to be beneficial.(45) This type of care planning is beginning to occur for gender-affirming surgeries but, for our participants, was likely not standard. If patients are not being assisted to prepare by surgical care teams or other providers outside of surgical consultations, then peer support and accessing other resources become essential to achieve preparedness.

Another important finding from our results was that overall feeling of preparedness was more likely among those participants who found their assessment process useful. Overall, however, referral letter assessments were ranked as low in utility for preparing for surgery. For most participants, assessment processes involved obtaining letters from mental healthcare providers documenting the stability of their mental health.(25) While less common, a small proportion (2%) of our participants received education or workshops as processes of determining readiness. If, indeed, many patients are not being provided educational materials or coached by surgical care teams about how to prepare, referral letter assessments may be the only time in which a patient has interactions with a healthcare provider specifically about whether they are prepared to undergo surgery or not. With a primary goal of evaluating the mental health of patients, these types of assessments may present a missed opportunity to truly understand

whether a patient feels ready to undergo surgery and to develop a care plan to address needed preparation. Instead, referral letter assessments may provide little value to patients who are seeking access to complex surgical interventions.

Our research adds to other literature critiquing referral letter assessments as not useful to those accessing gender affirming care.(27) While one study noted prospective patients feeling that they wouldn't be considered ready for surgery if they have any mental health concerns,(46) another noted that many patients feel assessments are simply gatekeeping processes.(47) Still another has critiqued assessments as not offering information needed for patients to be fully informed about what to expect postoperatively.(48) For our participants, type of assessments did not impact self-reported preparedness but the perceived utility of these did. The current version of the WPATH SOC suggests only one letter of readiness for genital surgeries (25); this may be a step towards reducing barriers to care, but any letter requirements may also reinforce an unhelpful process for those preparing for surgery. This suggests that, along with the other literature previously mentioned, assessments often do not uphold patient autonomy if they do not serve the process of informed consent by assessing patient knowledge and providing education regarding the procedure. Our results suggest that needs for pre-surgical preparation vary between patients. This may mean that individualized approaches to helping patients better prepare are needed for these surgeries.

In contrast with other literature, among our sample retrospective self-reported mental health in the year leading up to surgery was not significantly associated with the likelihood of participants feeling prepared to undergo these surgeries. Yet, mental health is one of the primary focuses of assessments within current standards of care.(25) While mental health has been documented to impact surgical outcomes across a range of disciplines,(49) it is not clear whether

mental health prior to surgery plays a role in whether a trans patient feels prepared for phalloplasty or metoidioplasty. Gender dysphoria may also negatively affect mental health and may be associated with anxiety and depression, which surgery might help resolve.(50)

Assessments or surgical care planning that recognizes mental health as influencing outcomes but focuses on other aspects of surgical preparation may, therefore, lead to more readiness among prospective patients. More research is needed to understand how mental health plays a role in promoting preparedness for these procedures.

Together, our results paint a picture of those who undergo phalloplasty and/or metoidioplasty as highly prepared patients who are most likely to feel well-prepared when they have access to assessments or preparation programs that they find useful. Preoperative processes may best assist patients if they are designed with resources patients have identified as helpful. Without other preparation programs or educational materials, many patients are left to prepare themselves for these very complex surgical procedures. While assessment processes do not always have the goal of assisting patients to prepare for surgery, this is changing with more clinicians offering surgical care planning or education tools for patients. For those without access to formalized education or preparedness programs, patients are put in a position to rely on peers and other information they can access online to get information and feel ready. While our participants felt peer-created resources were very useful in preparing them to have surgery, patients should not primarily be responsible for preparing themselves for complex surgeries like phalloplasty or metoidioplasty.

Limitations

Our results are not without limitations. This cross-sectional study asked participants about a range of experiences that for some happened many years ago. This introduces the risk of

potential recall bias. However, over half of our participants were ‘active process’ or between stages of surgeries, and a similar proportion had surgery in the two years prior to our recruitment. The recentness or the timing of their particular surgeries may relate to our findings, including a potential for increased access to care in recent years or increases in uses of informed consent models. Positively, this may have lessened the impact of recall bias in our data.

Our sample is majority white (83.7%, n=170) and young, with 65% being between the ages of 18-24 (n=133), as well as formally educated, as the majority had a college/university degree (48.3%, n=98) or a graduate/professional degree (31.5% ,n=64). A substantial amount of participants (63.1%, n=128) also made \$50,000 or more per year. Participants belonging to these demographic groups may have had an easier time accessing community support and online resources, and faced less barriers to surgery, such as financial/insurance barriers, lack of housing, and so on. Our results do not capture the experiences of participants who are less resourced or face increased stigma and barriers in healthcare environments. In addition, the majority of our participants came from the United States, with only a small portion from Canada. These results may, therefore, be less applicable in a Canadian context. We are further unable to draw conclusions about people outside of these geographic locations.

Most questions in our survey and in this analysis were developed by the patient-oriented research team, which provided increased face validity, but lacked psychometric validation. Kenton’s Preoperative Preparedness Questionnaire (21) has not had its psychometric properties evaluated; however, the content of the questionnaire is relevant for the surgeries of interest in this paper and will allow us to compare our results with the results of others who use it. Additionally, we did not ask qualitative questions that would have further clarified or given

context to some responses that participants provided; such questions could have explained why some resources were more useful than others when preparing for surgery.

Implications

The results presented in this paper are novel and have far-reaching implications for the fields of medicine, counseling, and social work, for policy makers and academics, and for those who create standards of care. We demonstrate that current processes of preparing patients for surgery (e.g., referral letter assessments/clinical assessments) may not be adequate for some patients. It is therefore essential to discern what types of readiness processes are useful to patients. It may be useful to borrow from other surgical disciplines developed to holistically support the post-surgical recovery of patients undergoing other surgeries. In addition, individualized preparedness programs might better suit patient needs. For these surgeries community support provided goes beyond the preparation that is currently provided through assessments. Future research should seek to understand what specifically is most useful for patients preparing for surgery and make recommendations to policy makers and clinicians about patient preparedness programs that may be more effective than current processes.

CONCLUSION

Healthcare professionals who interact with preparing patients should develop new or utilize existing resources to assist patients in identifying their preparation needs and achieving preparedness. Our data supports assessments that center surgical care planning rather than assessing level of gender dysphoria. This can ensure the necessary flexibility so that such assessments are based in the evidence of what will be most helpful for patients and, ultimately, that patient autonomy is upheld through a robust informed consent process. While it is important to adjust as needed for individual patients to ensure their needs are met, the educational and

planning content of assessments should be standardized throughout gender-affirming care so that all patients can benefit from high-quality care. Future research should further investigate what patients need from assessments in order to feel prepared for surgery.

Phalloplasty and metoidioplasty are complex surgical procedures that can be challenging to prepare for as a patient. Ensuring patients are prepared to undergo these procedures is essential to ensuring informed consent is upheld and since feeling prepared may impact surgical outcomes and overall satisfaction. The standard approach of determining readiness through meeting a therapist or mental health care provider and obtaining two letters in support of having surgery may not be useful for some patients who are preparing to undergo these complex surgeries. Accessing community resources and surgical consults remain incredibly important to patients in this process. Ultimately what an individual patient finds useful may vary and individualized approaches to developing preparedness should be supported. Patient preparedness should be the collective responsibility of the care team, readiness assessors, and patients. Readiness processes should support patients in evaluating what they need to feel ready and provide those needed supports or resources. Assessments should serve as a way to respect autonomy by ensuring patients are appropriately prepared to undergo and recover from surgery through a robust process of informed consent.

LIST OF ABBREVIATIONS

CBPR	Community-Based Participatory Research
PROGRESS	Patient-Reported Outcomes of Genital Reconstruction and Experiences of Surgical Satisfaction
RFF	Radial forearm flap
ALT	Anterolateral thigh flap
WPATH	World Professional Association for Transgender Health
SOC	Standards of Care

DECLARATIONS

Ethics approval and consent to participate

This study was jointly approved by the University of Victoria and University of British Columbia's Human Research Ethics Boards (certificate number 21-0033). All participants consented to study participation. Study activities were conducted in accordance with relevant guidelines and regulations.

Consent for publication

Not applicable.

Availability of data and materials

Data collected is confidential and stored only on University of Victoria servers; it is not available elsewhere.

Competing interests

Not applicable.

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Author's contributions

Authors L.R., N.A., L.B., L.J., A.S., A.D., and N.L. each made substantial contributions to the design and conception of the study. Authors L.R., N.L., and A.S. also made substantial contributions to the interpretation of the data and preparation of the tables. Authors L.R. and E.C. wrote the manuscript text. All authors have approved the submitted version of the manuscript.

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Table 1. Participant Demographics by Self Report of Being Prepared or Not for Surgery

	Not prepared (n = 17)		Prepared (n = 186)		Total
	<i>n</i>	%	<i>n</i>	%	<i>n</i>
Country					
Canada	5	29.4	24	12.9	29
United States	12	70.6	162	87.1	174
Age group					
18-24	2	11.8	24	13.0	26
25-35	9	52.9	98	53.0	107
36-50	4	23.5	44	23.8	48
50-65	2	11.8	17	9.2	19
Sexual Orientation					
Queer	6	35.3	72	38.7	78
Straight or Asexual	11	64.7	114	61.3	125
Person of Color					
Yes	3	17.6	23	12.4	26
No	14	82.4	156	83.9	170
Year of surgery					
Before 2020	9	52.9	74	39.8	83
2020 or after	8	47.1	112	60.2	120
Education					
High school diploma or less	1	5.9	10	5.4	11
Some college or university	1	5.9	29	15.6	30
College or university degree	8	47.1	90	48.8	98
Graduate or professional degree	7	41.2	57	30.6	64
Personal annual income (currency unspecified)					
<\$20,000	3	17.6	18	9.7	21
<\$20,000 - >\$50,000	2	11.8	38	20.4	40
<\$50,000 - >\$80,000	5	29.4	45	24.2	50
<\$80,000 - >\$100,000	2	11.8	21	11.3	23
\$100,000 +	4	23.5	51	27.4	55
Person of color					
Yes	3	17.6	23	12.4	26
No	14	82.4	156	83.9	170
Accessed community support or resources before surgery					

No	1	5.9	15	8.1	16
Yes	16	94.1	171	91.9	187
Mental health, year before surgery					
Poor or fair	9	52.9	87	46.8	98
Good, very good or excellent	8	47.1	94	50.5	102
Active Process					
No	8	47.1	78	41.9	86
Yes	9	52.9	108	58.1	117
Type of readiness assessment	14	6.5	7	4.1	177
Two letters	12	70.6	147	79.0	159
Other	5	29.4	39	21.0	44
Usefulness of readiness assessment					
Not useful	13	76.5	92	49.5	105
Useful	3	17.6	89	47.8	92

Table 2: Average Likert Rating from Kenton's Preoperative Preparedness Measure

	<i>n (%)</i>					
	Strongly disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly agree
I knew about the <i>alternatives</i> to the planned surgery.	3 (1.4)	5 (2.8)	4 (1.9)	9 (4.2)	49 (22.8)	131 (60.9)
I understood the <i>purpose</i> of the planned surgery (what this surgery could accomplish).	-	-	-	4 (1.9)	39 (18.1)	161 (74.9)
I understood the <i>benefits</i> of the planned surgery (how it could help me).	-	-	-	7 (3.3)	35 (16.3)	161 (74.9)
I understood the <i>risks</i> of the planned surgery (what the chances are of something not going the way my doctor and I want it to go).	-	2 (0.9)	10 (4.7)	19 (8.8)	50 (23.3)	123 (57.2)
I understood the <i>complications</i> of the planned surgery (what problems can come from this surgery).	-	2 (0.9)	8 (3.7)	25 (11.6)	52 (24.2)	117 (54.4)
I felt prepared about what to expect after surgery <i>while I am in the hospital</i> .	3 (1.4)	13 (6)	19 (8.8)	30 (14.0)	67 (31.2)	60 (27.9)
I felt prepared about what to expect after surgery <i>when I am at home</i> .	3 (1.4)	9 (4.2)	22 (10.2)	51 (23.7)	68 (31.6)	49 (22.8)
I felt prepared to cope with a catheter after the surgery <i>while I am in the hospital</i> .	7 (3.3)	15 (7.0)	14 (6.5)	33 (15.3)	53 (24.7)	59 (27.4)

I felt prepared to cope with a catheter after the surgery <i>when I am at home</i> .	10 (4.7)	17 (7.9)	20 (9.3)	40 (18.6)	48 (22.3)	42 (19.5)
My doctors and nurses spent enough time preparing me for my upcoming surgery.	10 (4.7)	11 (5.1)	15 (7.0)	38 (17.7)	60 (27.9)	69 (32.1)
Overall, I felt prepared for my upcoming surgery.	2 (0.9)	7 (3.3)	8 (3.7)	27 (12.6)	67 (31.2)	92 (42.8)

Table 3: Results of Logistic Regression of Correlates of Surgical Preparedness

	<i>OR</i>	95% CI	<i>AOR</i>	95% CI
Country*				
Canada	Ref	Ref	-	-
United States	4.85	.831-28.3	-	-
Age group*				
18-24	Ref	Ref	-	-
25-35	1.47	.221-9.86	-	-
36-50	3.80	.362-39.0	-	-
50+	1.87	.107-32.9	-	-
Sexual Orientation				
Queer	Ref	Ref	Ref	Ref
Straight or Asexual	5.40	1.28-22.8	3.71	1.23-11.1
Person of Color*				
Yes	1.08	.145-8.06	-	-
No	Ref	Ref	-	-
Year of surgery*				
Before 2020	2.55	.510-12.7	-	-
2020 or after	Ref	Ref	-	-
Education*				
High school diploma or less	Ref	Ref	-	-
Some college or university	6.67	.144-310	-	-
College or university degree	4.28	.240-76.7	-	-
Graduate or professional degree	1.68	.394-7.23	-	-
Personal annual income (currency unspecified)*				
<\$20,000 - >\$50,000	Ref	Ref	-	-
<\$50,000 - >\$80,000	.681	.149-3.10	-	-
<\$80,000 +	.649	.124-3.39	-	-
Accessed community support or resources before surgery*				
No	Ref	Ref	-	-
Yes	1.20	.083-17.4	-	-

Mental health, year before surgery*					
Poor or fair	Ref	Ref	-	-	-
Good, very good or excellent	.849	.210-3.44	-	-	-
Active Process*					
No	Ref	Ref	-	-	-
Yes	.802	.215-2.99	-	-	-
Type of readiness assessment*					
Two letters	Ref	Ref	-	-	-
Other	.927	.231-3.71	-	-	-
Usefulness of readiness assessment					
Not useful	Ref	Ref	Ref	Ref	
Useful	12.6	.032-498	5.61	.284-110	

**item was not included in the final multivariable model built using automatic backwards selection*

CHAPTER 4

Perceived mental health improvements after phalloplasty and metoidioplasty: Results from a community-based survey of trans and nonbinary people

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ABSTRACT

Trans and nonbinary people experience mental health-related challenges such as depression and suicidality more often than cisgender peers. Research has demonstrated that social support and accessing needed gender-affirming care have positive impacts on the mental health of trans people. For the gender-affirming surgeries of phalloplasty and metoidioplasty, little research exists that documents whether patients perceive improved mental health after undergoing one of these procedures. Our data come from a cross-sectional, community-based survey entitled Patient-Reported Outcomes of Genital Reconstruction and Experiences of Surgical Satisfaction (PROGRESS). We had 215 participants complete our survey from April to June of 2022. Criteria for eligibility included living in the United States or Canada, having undergone phalloplasty and/or metoidioplasty and identifying as trans, non-binary or another related (non-cisgender) term. Over 80% of participants self-reported that their mental health improved due to undergoing phalloplasty or metoidioplasty surgery. Goals for surgery being met, feeling prepared for surgery, and surgical satisfaction were associated at the bivariate level with reported mental health improvements. In a multivariable model, surgical satisfaction and feeling prepared for surgery were significantly associated with perceived mental health improvement. In summary, data from this novel, community-based study indicate that, for those who undergo phalloplasty and metoidioplasty, self-rated mental health may improve, which may be attributable to decreased dysphoria and increased gender euphoria.

INTRODUCTION

Transgender (abbreviated to trans throughout this paper) is an umbrella term which describes a group of people whose gender identity does not match the sex assigned to them at birth; nonbinary people may fall under this umbrella, but not all nonbinary people identify as trans (Monro, 2019). It is estimated that trans people make up about 1.6% of the United States population (Brown, 2022). In Canada, the most recent census found 0.3% of the population identified as trans or nonbinary, with higher proportions in a few urban areas (Statistics Canada, 2022). Many studies have identified that trans people as a population experience poorer mental health than cisgender people (Anderssen et al., 2020; Clements-Nolle et al., 2006; Rotondi et al., 2012). Studies across Canada (Trans PULSE Canada, 2020) and the United States (James et al., 2016) have shown higher levels of depression and anxiety in trans and non-binary people as well as much higher rates of suicidality and suicide attempts (Bauer et al., 2013; Marshall et al., 2016).

Some theories utilized to understand these disparities that trans and nonbinary people experience include Minority Stress Theory and the Gender Affirmation Framework. Brooks (1981) developed the sexual minority stress model to describe the impact of homophobia on lesbian women; others have applied this theory to trans populations (Hendricks & Testa, 2012). Both distal (external) and proximal (internal) stressors are hypothesized to impact health and well-being. The impact of these distal or external stressors, such as discrimination may be lessened by social support and resilience factors (Testa et al., 2015). For trans and nonbinary people, minority stress such discrimination, transphobia, and violence results in minority

stressors that impact health or well-being. These stressors can result in poor mental health and increases in both depression and suicidality (Pellicane & Ciesla, 2022).

Further, the Gender Affirmation Framework has specifically addressed gender affirmation and the importance of this for trans individuals' health. Specifically, Sevelius (2013) suggests that non-affirmation, including stigma and oppression may contribute to risk taking behaviour among trans women. Other research documents affirming experiences, such as identification that matches one's gender, peer support and transition-related care as contributing to positive health and well-being (Baker et al. 2021; Bauer et al. 2015; Bradford, Rider, and Spencer 2019; Glynn et al. 2016; Hughto et al. 2020; Lelutiu-Weinberger, English, and Sandanapitchai 2020; Matsuno and Israel 2018; Scheim, Perez-Brumer, & Bauer, 2020).

To support gender affirmation, some trans people socially transition and some access hormones; it is important to note that not all trans people pursue all available transition-related care (Puckett et al., 2017; Kennis et al., 2022). For trans and nonbinary people who need gender-affirming health care such as hormones or surgeries, accessing this has been associated with decreases in depression, anxiety and suicide attempts (Hughto & Reisner, 2016; Hughto et al., 2020; Tomita et al., 2019).

Some trans and non-binary people assigned female at birth undergo the gender-affirming genital surgeries of phalloplasty and/or metoidioplasty. Phalloplasty, originally designed for cisgender men requiring penile (re)construction, has been described as, "a modular set of procedures that can be combined, mixed and matched to meet the needs of each individual patient" (Heston, 2019 pg. 3). Phalloplasty, with or without additional procedures, can be conducted in several different ways, with numerous variations evolving over time and

geographic region. Metoidioplasty was created specifically for transgender men (Hadj-Moussa, 2019) who have experienced an increase in clitoral size due to testosterone treatment (Bizic et al., 2020); it is performed by releasing ligaments of the clitoris (Vukadinovic, 2014).

Research on outcomes of phalloplasty and metoidioplasty surgeries is sparse. A few studies have found surgical satisfaction to be high in clinical samples of trans individuals who undergo these surgeries (Bordas, et al., 2021; Terrier, et al., 2014). Some research has demonstrated links between undergoing phalloplasty or metoidioplasty and increases in sexual satisfaction (Javier et al., 2022), positive body image, and overall quality of life (McNicols et al., 2020). Few studies have looked at mental health-related outcomes of these procedures. Some literature about phalloplasty and metoidioplasty points to overall positive changes in mental health (Almazan & Keuroghlian, 2021), including reduction in depression and anxiety and suicidality (Wernick et al., 2019). In addition, decreases in gender dysphoria have been reported (van de Grift, 2018).

Several research studies have demonstrated that gender-affirming surgeries improve the lives of trans people who need them (Jokic-Begic et al., 2014), including improvements in overall quality of life and well-being (Hughto & Reisner, 2016) and reductions in gender-related or body dysphoria (Kelly et al., 2023; van de Grift et al., 2017). Several studies have found reductions in suicidality and mental health conditions like depression and anxiety after undergoing gender-affirming surgery (Akhavan et al., 2021; Baker et al., 2021; Swan et al., 2021; Wernick et al., 2019).

A few studies have reported no change or worsening mental health among their samples after undergoing gender-affirming surgeries. One reports no increases in quality of life among

trans women who underwent genital surgery up to five years prior to the study (Lindqvist et al., 2017). Two other studies found no reduction in suicidality and no improvements in mental health in long-term follow up (Dhejne et al., 2011; Bränström & Pachankis, 2019). Some of these studies have used proxies to measure mental health such as number of mental health care visits (Bränström & Pachankis, 2019), hospital records (Dhejne et al., 2011), or have utilized measures not validated for use in trans populations (Lindqvist et al., 2017).

Rationale

Research on mental health after gender-affirming surgery is a growing area of inquiry, but mental health outcomes specific to phalloplasty and metoidioplasty are less reported. Further, little research on these topics utilizes patient self-rated, perceived mental health as a surgical outcome. Self-report measures of mental health have been demonstrated to serve as appropriate proxies for validated mental health measures and, more broadly, as indicators of overall health (Ahmad et al., 2014). In addition to these challenges with collecting meaningful data about trans experiences, little research has included patients or those with lived experience in designing research or measures (Dy et al., 2022). While most studies use ad hoc measures created for their particular project, rarely are these developed with or by trans members (Dy et al., 2019; Kamran et al., 2023). This is important because measures designed without input from trans people may miss important topics, may not ask questions in inclusive ways, and may not account for unique trans-specific experiences.

The purpose of this study was to understand patient self-reported changes related to mental health after undergoing gender-affirming phalloplasty and/or metoidioplasty. This paper seeks to answer two research questions: 1) Do those who undergo gender-affirming genital

surgeries experience improvements in self-reported mental health?, and 2) What factors are associated with self-reported improvement of mental health after undergoing phalloplasty or metoidioplasty?

METHODS

The project was a community-based research study in which data collection tools and planned knowledge mobilization were designed by a group of trans community members with lived experience of these surgeries. We used a voting system to collaboratively make decisions about all aspects of the project from survey topics to potential journals for publication. The community-focused nature of the project was chosen to center trans voices in the project and support our communities with much-needed research. We used a cross-sectional study design with a retrospective self-completed questionnaire.

We collected responses to our online survey from April to June of 2022. Criteria for eligibility included living in the United States or Canada, having undergone phalloplasty and/or metoidioplasty, and identifying as trans, non-binary or another related term. Recruitment primarily occurred online in social networking spaces like Facebook and Reddit where those who have undergone these surgeries commonly share experiences. Eligible participants were provided with the online consent form and provided individual informed consent to participate before continuing on to complete the survey. Our survey was comprehensive of many aspects of the patient experience and included topics related to preparing for, recovering from, and self-reported changes after undergoing these surgeries. All original survey questions were designed by trans community members, based on personal and professional expertise. Participants were not provided with any honoraria for taking part in this study. This study was jointly approved by

the University of Victoria and University of British Columbia Human Research ethics boards (H22-00492).

Measures

Demographics and Surgery

We measured country of residence, age, being a person of colour or not, sexual orientation, education level, annual income, urban or non-urban living, year of surgery, and whether a participant was ‘active process’, meaning between surgeries or planning to undergo additional surgical procedures. Countries included Canada or the United States. Age was categorized for all analyses, which included 18-24, 25-35, 36-55 and over 55 years of age. We used responses to the question “are you treated or perceived as a person of colour” as our racialization variable as a dichotomized variable in the analysis with ‘yes’ versus ‘no’ or ‘not sure’. Participants were able to select multiple sexual orientations, which included queer, gay, bi, straight, pansexual, asexual, heteroflexible, and other. These categories were dichotomized into ‘queer’ versus not, with the first category including those who selected queer, gay, bi, pansexual, and heteroflexible; those who only selected asexual and/or heterosexual were categorized as ‘not queer’. Education level was a categorical variable and included the following categories: not having graduated from high school or receiving a high school diploma, having some university or college experience or having a college degree, having gotten to graduate school or having a graduate degree. Annual income categories included less than \$50,000 a year, \$50,000 to \$80,000 and above \$80,000 (currency was not specified in the survey). Size of city was a categorical variable collapsed into the dichotomy of urban (and midsize city of more than 50,000 people) versus non-urban (small city, rural, remote of smaller than 50,000).

For the year of surgery, dates were dichotomized into after 2020 or prior to 2020; this year was chosen due, in part, to changes in healthcare related to COVID-19 and also since most patients complete their surgical stages in about two years. Relatedly, we included a variable which denotes whether a participant had completed their planned surgeries or not; not having completed all planned surgeries was referred to as ‘active process’. Whether a participant was active process was derived from several variables. If participants reported fewer numbers of completed than planned surgeries, we categorized them as active process. Additionally, if they stated a planned surgery was indefinitely put on hold, or they were waiting for revisions, they were placed in this category. Lastly, if a participant wrote in any open text box of the questionnaire that they were between stages or active process, they were placed in this category.

Surgical experiences

In addition to demographics, surgery timing, and active process status, several other variables were included in this analysis as potentially related to whether a participant may have experienced positive or negative changes in their mental health after initially undergoing phalloplasty or metoidioplasty. Surgical complications were assessed by asking participants whether they experienced any complication, defined as “any deviation from normal, planned healing or recovery”. Responses included “yes”, “no” and “not sure”; the “not sure” category was collapsed into the “yes” response to ensure those who remained in the “no complications” category truly did not experience complications. For goal attainment, we asked participants how well their surgical goals were met. Responses were originally on a 5-point Likert scale and collapsed into the categories of “not well through moderately well met (which included 3 points on the scale)” and “very or extremely well met” for the purpose of analyses. Surgical satisfaction

was also originally rated on a 5-point Likert scale and re-coded into the categories “extremely dissatisfied through neutral” (which also included 3 of the 5 Likert scale options) and “somewhat satisfied through extremely satisfied”. How challenging participants perceived their recovery to be was dichotomized into the categories of “not very challenging” (not at all, a little bit, or somewhat) versus “very challenging”.

Life events around the time of surgery that could impact mental health were assessed by asking participants whether they had a life event (e.g. loss of job, death, loss of partner) around the time of surgery. Responses included “yes”, “no”, and “not sure”. Responses of “not sure” were collapsed into the “yes” category to ensure those who remained in the “no” category truly did not experience any event that may have negatively impacted their mental health. Self-reported mental health before surgery was determined based on the Canadian Community Health Survey’s single-item measure of self-rated mental health (Statistics Canada, 2012). It was adapted to be past tense, and we added a time qualifier to determine mental health in the year prior to surgery. The newly adapted item asked, “how would you describe your mental health in the year before you had phalloplasty or metoidioplasty?” Responses were unchanged from the original measure and included a 5-point Likert ranging from “poor” to “excellent”. Categories were collapsed into a dichotomy of “poor or fair” mental health or “good, very good, or excellent”. Overall surgical preparedness was determined by responses to a question which asked participants to agree or disagree with the statement, “Overall, I felt prepared to undergo surgery”. These responses were dichotomized into the categories “agree (prepared)” and “disagree (not prepared)”.

Outcome variables

Primary outcome

The primary outcome variable of interest for this analysis was self-reported change in mental health following surgery. The question read “Has your mental health changed due to undergoing phalloplasty or metoidioplasty”? Responses included “yes it has improved a lot”, “yes it has improved a little bit”, “no nothing has changed”, “yes it got a little bit worse”, and “yes it got a lot worse”. For regression analyses, responses were dichotomized as “mental health improved” (a lot or a little bit) vs. “mental health did not improve” (including nothing has changed, a little bit worse, and a lot worse).

Secondary outcomes

To measure both pre- and post-surgical genital dysphoria, we created two questions. The retrospective item read “Thinking back to the year before surgery, how much dysphoria did you have about your genitals?” and the post-surgical question read “how much dysphoria do you have about your genitals now”? Both questions utilized a 5-point Likert scale ranging from “none at all” to “a lot”. For analyses, these were collapsed into one category containing responses of “none at all” through “some” and another category containing “moderate” through “a lot”. We assessed overall pre-surgical euphoria in a similar way, with a newly designed question that read “Thinking back to the year before surgery, how much euphoria (happiness or joy) did you experience related to your body, generally?” The post-surgical equivalent asked “how much euphoria (happiness or joy) do you have now?” The same 5-point Likert scale from the dysphoria items was used for these two questions, which were dichotomized the same way. The Canadian Community Health Survey’s (CCHS) single-item measure of mental health was

used to assess current (at the time of survey) mental health for participants. This item asked participants, “Overall, how would you rate your mental health?” Responses include a 5-point Likert scale which was collapsed into a dichotomy of “poor or fair” mental health, and “good, very good, or excellent” as described above.

Analysis

All analyses conducted for this paper used SPSS version 29 (IBM, 2023). First, we prepared descriptive statistics for variables of interest for these analyses, followed by cross-tabulations with chi square tests and odds ratios between the primary outcome variable and all exposure variables. All variables used for bivariate analysis and subsequent regression were categorical. Crosstabulations with chi square using McNamar’s test (Sundjaja & Krishan, 2023) were also performed to assess differences in pre- and post-surgical genital dysphoria, euphoria and self-rated mental health using the CCHS scale. Next, we ran a binary logistic regression with the mental health improvement variable as the outcome variable and all categorical variables. The regression utilized an automatic backwards, conditional selection process and included all demographics mentioned above as covariates at the start of the regression. Backwards automated selection was chosen for our multivariable model to reduce potential bias. Rather, this model-building process ensured the fit was based on statistical significance. In choosing this approach, the potential for bias as a result of manual variable selection was reduced. Only variables associated with the outcome at $p < 0.10$ were retained in subsequent steps of the model before the final model was reached. (IBM, 2109). This method was chosen to utilize statistical significance as a determinant of which variables should be retained in the model rather than building it based on theory (Chowdhury & Turin, 2020).

RESULTS

In total, 215 people responded to the survey, 33 were from Canada and the other 182 from the United States. **Table 1** shows the descriptive statistics for all variables by outcome variable of mental health improvement.

Overall, 82% of our analytic sample reported their mental health improved as a result of undergoing phalloplasty or metoidioplasty. Looking back at the year prior to undergoing surgery, about half (51%) reported having “good, very good or excellent” mental health whereas 48% reported their mental health as “poor or fair”. At the time of taking the survey, 77% reported their mental health as “good, very good or excellent” and 22% reported their mental health as “poor or fair”. The difference between pre- and post-surgical self-rated mental health was statistically significant ($p < .001$).

In the year before undergoing surgery, 87% of our sample reported they had moderate or a lot of genital-specific dysphoria and only 13% reported having none or some. After surgery only 12% of our participants reported having moderate or a lot of genital-specific dysphoria and 88% experienced none or some dysphoria; these differences were statistically significant ($p < .0001$). Similarly, participants also experience statistically significant ($p < 0.001$) increases in euphoria after undergoing surgery. In the year leading up to surgery, 80% of participants reported no or some euphoria and 20% reported moderate amounts or a lot. At the time of survey completion, 7% of our sample reported moderate or a lot of euphoria and 28% experienced none or some. In contrast, 89 (41%) of our sample self-reported experiencing postoperative depression whereas, 29 (13%) reported “maybe” experiencing postoperative depression, 58 (27%) of participants reported they did not experience it, and 10 reported being “unsure”.

Table 1 contains demographic and exposure variables by mental health improvement or not, with p values and 95% confidence intervals. The results of all bivariate and multivariable analyses related to the primary outcome are reported for only our analytic sample of 184. To determine whether there were differences among those who answered the ‘mental health improvement’ question, we ran a chi square test with this outcome variable and all exposure variables included in Table 1. Participants did not statistically significantly vary across any of the exposure variables included in this analysis. Differences among participants may still be reflected in the model due to this missing data, however.

Correlates of Mental Health Improvement

Participants who reported surgical satisfaction (Adjusted OR = 27.04 95% CI 6.55-111.67) and reported feeling prepared for surgery (Adjusted OR = 4.49 95% CI 1.08-18.69) were more likely to report mental health improvements (Table 2). Two items with significant bivariate associations, goal attainment and being active process, were not significant in the final multivariable model. Of note, a portion of participants (n= 31) who did not answer the outcome question were dropped from the analysis; due to using complete case analysis, the final analytic sample was 184 for the model.

DISCUSSION

The present study aimed to investigate the impact of undergoing phalloplasty and/or metoidioplasty on self-reported mental health, and identify factors associated with self-reported mental health improvement after surgery. Our results are among the first to look at self-reported, perceived changes in mental health due to undergoing these gender-affirming surgeries.

Achieving desired surgical outcomes, feeling adequately prepared for the procedure, and having

a high level of surgical satisfaction were factors associated with self-reported mental health improvements in our sample. Being between surgical stages or active process may also impact the self-reported mental health outcomes of patients. These findings add to growing evidence that gender-affirming surgeries can improve mental health for those who undergo and/or need them.

Few quantitative data exist with which to compare our findings; to our knowledge, this was the first study to ask participants to subjectively assess whether their mental health improved because of undergoing these surgeries. Using this subjective measure of perceived change, we can understand a nuanced experience that is unique to trans people who access these gender-affirming surgeries.

Overall, a large portion of our participants reported that their mental health improved; pre-surgery mental health was rated lower than current mental health. Our sample most commonly reported “good” or better (77%) mental health on the CCHS single-item question. Compared with two other samples using the same self-reported mental health question, our participants reported more favourable mental health. In results from the Trans PULSE Canada survey (Trans PULSE Canada Team, 2020), 44% of trans and non-binary participants across Canada reported ‘good’ or higher mental health, and 56% reported “fair” or “poor” mental health. While there may be many differences between Trans PULSE participants and our own, these differences might relate to having accessed gender-affirming care. While all of our sample has undergone at least some gender-affirming care they need, including phalloplasty or metoidioplasty, not all Trans PULSE participants had, however. Trans PULSE reports that 26% of their sample underwent all the gender-affirming care they needed, and 32% were in the

process of completing needed care (Trans PULSE Canada Team, 2020); this was not broken down by what type of care participants had accessed so comparisons specific to those who underwent genital surgery is not possible.

Further, our participants reported similar levels of mental health to the overall Canadian population surveyed around the same time through the Canadian Social Survey. In the 2023 Canadian Social Survey, 80% of Canadians rated their mental health as ‘good’ or better while almost 20% rated their mental health as “fair” or “poor” (Statistics Canada, 2024). Taken together, our results provide support for the idea that mental health improvements occur when trans and nonbinary people are able to access the gender-affirming care they need.

We also found self-reported decreases in genital dysphoria and self-reported increases in euphoria among our sample after surgery; other research describes reduction in dysphoria when needed gender-affirming care or surgeries are accessed (Owen-Smith et al., 2018; Park et al., 2022). Our results add to this work by further providing evidence that undergoing gender-affirming surgeries may contribute to decreases in self-reported genital dysphoria and increases in self-reported body-related euphoria (Reisner, et al., 2023; Goetz & Arcomano, 2023).

Our multivariable model revealed significant associations between being prepared for surgery and mental health improvement. This finding is important to consider for several reasons. First, current readiness assessments have been critiqued for serving as a gatekeeping process rather than supporting patient readiness (Ashley, 2020; MacKinnon et al., 2021; Verbeek et al., 2022). If this is the only pre-surgical readiness process involved in a patient’s preoperative care, they may not be receiving necessary information or resources to know what to expect after surgery, or to plan for aftercare (Mitchell, 2015; Poletti et al., 2024; Oswald, 2018). In addition,

if patients are not well-informed about what to expect after undergoing surgery, their expectations may not be met, and mental health may not improve (Giardina et al., 2020; Khorfan et al., 2019; Blöndal et al., 2022). Further research could discern more specifically what contributes to feeling prepared for one of these surgeries.

In our sample, surgical satisfaction was highly correlated with self-reported mental health improvement. In other surgical disciplines, surgical satisfaction has also been linked to health improvements (Tevis et al., 2015). Our results about surgical satisfaction can also be interpreted along with our findings about preparedness. Patients who are well-prepared and know what to realistically expect after surgery may feel more satisfied with the outcomes or experience of their surgery. This suggests that when patients are supported to be well-prepared and their surgical goals are met, along with experiencing surgical satisfaction, they are also more likely to have improvement in their mental health.

While not significant in the multivariable model, those who were not active process, or had finished all planned surgeries, were more likely to report mental health improvements. This may be explained by the stress of waiting for additional surgeries, surgical goals or ideals not being met, undergoing those procedures and the overall impact that any surgery can have on mental health (Cushnie et al., 2021). While recovering from surgeries, a person may not be able to engage in their usual physical activities or interact with their communities in the same way as usual; this can contribute to negative emotional states or reduce overall well-being (Mutran et al., 1995; Brembo et al., 2017; Luiten et al., 2016; Rodríguez-Fernández et al., 2017).

Our results include one non-significant finding that is worthwhile to mention and interpret with caution. Self-reported mental health in the year leading up to surgery was not

significantly associated with improvements in mental health post-surgery in bivariate or multivariate analyses. While mental health has been documented to impact surgical outcomes, across a range of surgical types (McBride et al., 2021), for the trans-specific experience of undergoing phalloplasty or metoidioplasty, mental health before surgery may not be predictive of changes in mental health afterwards; other factors like surgical satisfaction as discussed above may play more of a role.

Overall, the results from our survey appear to indicate that self-reported mental health improves for people who undergo gender-affirming genital surgeries of phalloplasty and metoidioplasty. Additional research is required to understand fully what factors impact self-reported mental health improvements; these may include whether patient preparedness or surgical goal attainment predict improvement. However, we found that surgical preparedness and surgical satisfaction were strongly related with self-reported mental health improvement post-surgery.

Limitations

Our results build upon other literature which documents improvement in mental health when trans and non-binary people undergo needed gender-affirming surgery. As an exploratory analysis about an under-researched area, our results are not without limitations. First, we used a cross-sectional study design, and future evidence on this topic would be strengthened with prospective cohort or longitudinal designs, or the use of matched controls. This community-based sample cannot be generalized to the broader trans communities and our participants' experiences may not be representative of trans men overall due to our sample being made up of mostly people who had relatively recently had genital surgery, were mostly from the United

States, were mostly white, and reported higher income and education levels than the broader population. Further, over half of our participants were *active process* or between stages of surgeries and may not have had their surgical goals met or had time to fully recover from surgery. This may lead to our sample reporting experiences that are atypical among those who are finished their surgical journey rather than active process. What these differences may be are unclear due to lacking current literature on the topic; these differences may relate to changes in mental health or dysphoria.

Another limitation relates to self-report of events that have occurred in the past, which is subject to recall bias. As most of our participants underwent surgery recently this may be less of a concern, however, participants may not accurately remember or report these experiences. Nonetheless, self-reported feelings of increased mental health are important to take at face value due to the value of patient's subjective experience of what constitutes positive outcomes of these surgeries (Dinkel & Jahnen 2024; Mendlovic et al., 2022).

Most questions in our survey used in this analysis were developed by the research team and not validated; this may have contributed to measurement error. Given the community-focused nature of the project, however, our questions likely allowed participants to more accurately describe their experiences than questionnaires not designed with communities' input would have.

Implications

Clinicians and surgeons helping to prepare patients for surgery should be aware of the ways in which patient preparedness, goal attainment, surgical satisfaction and mental health outcomes may be interrelated. When counseling patients about how to prepare for surgery,

realistic goal planning can help expectations for surgery be met and may lead to more surgical satisfaction. Our results provide arguments for patient preparedness programs that are unlike current readiness assessments, but rather, are programs designed to support patients to be prepared for surgery. Individualized approaches to patient recovery planning and follow-up care may be the best way to support each patient as they prepare, given the lack of literature about what best prepares patients for these surgeries.

In addition, future research should account for the role of patient self-reported preparedness and satisfaction with surgery when reporting on mental health outcomes of gender-affirming care. Current literature on the topic has rarely, or not at all, accounted for the role of patients feeling prepared for surgery in relation to mental health afterwards. Our findings suggest this may be a limitation of extant literature, which should be considered when making policy or clinical decisions based on past research.

CONCLUSION

In summary, data from this novel, community-based study indicate that for trans and non-binary people who underwent phalloplasty and metoidioplasty, self-reported mental health overall improved while self-reported dysphoria decreased, and self-reported euphoria increased. These changes were more likely to occur when patients felt prepared to undergo surgery and when they found the outcomes of their surgery satisfactory. While preparing for surgery, patients should be educated about the possibility of postoperative depression and create a responsive care plan. Overall, our findings showcase improvements in mental health after undergoing gender-affirming genital surgeries and provide support for continuing to provide access to needed gender-affirming care for trans and non-binary people.

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Table 1. Frequency of self-reported mental health improvements after phalloplasty and metoidioplasty among PROGRESS participants.

Variable	Overall sample		Mental health improved		Mental health did not improve		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Overall	-	-	184	82.6%	32	17.4%	
Country of Residence							0.268
United States	182	84.7	132	71.7%	25	13.5%	
Canada	33	15.3	20	10.8%	7	3.8%	
Age group							0.209
18-24 years	27	12.6	22	11.9%	4	2.1%	
25-35 years	111	51.6	78	42.3%	15	8.1%	
36 – 50	48	22.3	42	22.8%	13	7.0%	
Over 50	22	10.2					
Racialization							0.427
White (not a person of color)	183	85.1	135	73.3%	27	14.6%	
Person of color	29	13.5	17	9.2%	5	2.7%	
Active process or not							<0.05
Active process	118	54.9	85	46.2%	25	13.5%	
Finished all planned surgeries	97	45.1	67	36.4%	7	3.8%	
Sexual orientation							.842
Queer	134	62.3	99	54.7%	21	11.6%	
Not queer	74	34.4	50	27.6%	11	6.0%	
Education level							0.311
Some high school or graduated high school	13	6.0	7	3.8%	1	0.5%	

Some college or university	31	14.4	27	14.6%	2	1.0%	
College or university degree	103	47.9	68	36.9%	19	10.3%	
Graduate school or graduate degree	65	30.2	50	27.1%	10	5.4%	
Income level							0.652
Up to 50,000	65	30.2	47	27.3%	11	6.4%	
Over 50,000	143	61.9	95	55.2%	19	11.0%	
Complications							0.686
Yes, experienced	126	58.6	97	52.7%	22	11.9%	
No complications or not sure	69	32.1	55	29.8%	10	5.4%	
Preparedness for surgery							<.001
Agreed to being prepared	186	86.5	144	78.2%	24	13.0%	
Disagreed to being prepared	17	7.9	8	4.3%	8	4.3%	
Goal attainment							<.001
Not well-moderately well met	57	26.5	39	21.4%	18	9.8%	
Very or extremely well met	127	59.1	113	62.0%	12	6.5%	
Level of informed of surgical risks							0.105
Not well informed	46	21.4	31	17.0%	11	6.0%	
Well informed	151	70.2	121	66.4%	21	11.5%	
Life events around the time of surgery that may have impacted mental health							0.111
No, did not experience any	116	54.0	90	49.4%	24	13.1%	
Did experience some or not sure	70	32.6	62	34.0%	8	4.4%	
Surgical satisfaction							<.001
Extremely dissatisfied – neutral	21	9.8	8	4.4%	13	7.1%	
Somewhat satisfied – extremely satisfied	163	75.8	144	79.1%	17	9.3%	

Table 2: Results of Logistic Regression of Correlates of Self-Reported Mental Health Improvement Among PROGRESS Participants

Variable	<i>OR</i>	<i>95% CI</i>	<i>AOR</i>	<i>95% CI</i>
Country of Residence*				
United States	Ref	Ref	-	-
Canada	1.19	0.22-6.47	-	-
Age group*				
18-24	Ref	Ref	-	-
25-35	0.22	0.01-2.75	-	-
36-50	0.07	0.00-1.30	-	-
50+	0.93	0.00-94.2	-	-
Education*				
Some high school or graduated high school	0.28	0.06- 1.30	-	-
Some college or university	0.16	0.26- 40.17	-	-
College or university degree	0.74	0.38- 12.67	-	-
Graduate school or graduate degree	Ref	Ref	-	-
Personal annual income (currency unspecified)*				
<\$20,000 - >\$50,000	Ref	Ref	-	-
<\$50,000 - >\$80,000	1.06	0.24-4.67	-	-
<\$80,000 +	1.45	0.36-5.90	-	-
Racialization*				
Not a person of color	Ref	Ref	-	-
Person of color	0.42	0.07-2.46	-	-
Sexual Orientation				
Queer	Ref	Ref	Ref	Ref

Straight or Asexual	0.17	0.035-.843	-1.17	0.66-3.15
Active Process*				
Not active process	Ref	Ref	-	-
Active process	0.42	0.11-1.64	-	-
Complications*				
Yes	Ref	Ref	-	-
No or not sure	24.5	1.16-5.17	-	-
Life events around time of surgery*				
Yes	Ref	Ref	-	-
No or not sure	0.17	0.00-3.42	-	-
Mental Health Before Surgery*				
Poor or fair	Ref	Ref	-	-
Good through excellent	0.42	0.12-1.43	-	-
Goal Attainment*				
Goals not met	Ref	Ref	-	-
Goals met	1.95	0.46-8.29	-	-
Surgical Satisfaction				
Extremely dissatisfied to neutral	Ref	Ref	Ref	Ref
Somewhat to extremely satisfied	22.9	3.29-15.91	27.04	6.55, 111.62
Preparedness				
Not prepared	Ref	Ref	Ref	Ref
Prepared	8.16	1.41-47.2	4.49	1.08, 18.60

*Item was not included in the final, automatically built model.

CHAPTER 5: CONCLUSION

The purpose of this concluding chapter is to provide a summary of the research conducted as part of this dissertation and situate its results within a larger context. Since three chapters were written as manuscripts meant for publication and to stand alone, in this chapter I will interpret the findings of the analytic papers with a broader scope and address the implications of the body of work. In the first section of this chapter, I will briefly review the key points from each previous chapter or manuscript before detailing their contributions and implications as a body of work. Last, I will suggest future areas of work that can build upon the research conducted for this dissertation.

As described in the introduction, the overall objectives of this project included to document trans patients' experiences of surgical processes of phalloplasty and metoidioplasty, and to explore how self-reported health and well-being have been impacted by undergoing surgery. In addition, this project sought to gather and formalize community knowledge and experiences to share with those considering having these surgeries and to lay a groundwork for further investigation into patient experiences with these surgeries. Further, the community-focused approach and manuscript-specific empirical research were discussed in earlier chapters and will be briefly summarized next.

Manuscript 1: Centering trans voices in CBPR

Chapter 2 detailed the novel methodological processes used to develop this research project. With PROGRESS being led by and for trans people, partnerships were grounded in trust and shared experiences. These experiences were considered essential expertise when developing a data collection tool. Due to the proximity of the CEC and myself to the sub-group of the trans

community we hoped to engage, our recruitment resulted in 215 participants. Further, the CEC and I developed knowledge mobilization outputs based on consensus about what is important for our community. These unique factors each led to a project that was successful in implementing CBPR principles and benefiting the trans community.

Manuscript 2: Promoting trans patient autonomy in surgical preparation for phalloplasty and metoidioplasty: Results from a community-based cross-sectional survey and implications for preoperative assessments

The goal of this paper was to understand what factors were most useful (retrospectively) to those who underwent these surgical procedures. This analysis utilized responses to questions about what resources participants accessed, which resources were useful, and overall, how prepared they felt they were to undergo surgery. Results of our regression analysis included statistically significant relationships between whether a participant felt their readiness assessment was useful and overall perceived preparedness. The implications of these findings include a suggestion that healthcare providers and policy makers ensure patients are prepared to undergo surgery by giving resources that are useful to them. To do so, research first needs to document what is most useful to various patients and what is commonly useful for all patients; this further research will allow service providers to create more useful preparedness programs.

Manuscript 3: Perceived Mental Health Improvements After Phalloplasty and/or Metoidioplasty

The third manuscript's focus includes whether participants self-reported changes in their mental health after undergoing phalloplasty and/or metoidioplasty. The survey questions used in this analysis were created and/or modified by the CEC and I to understand retrospective and current mental health as well as pre- and post-surgical dysphoria and euphoria levels. Overall,

most participants reported increased mental health and euphoria, and decreased dysphoria attributed to undergoing surgery. Surgical satisfaction and self-reported preparedness were significantly associated with increased mental health after surgery. These findings suggest that ensuring preparedness and a satisfactory surgery according to a patient may be important to improving mental health. Implications of this paper include a suggestion that surgeons and those who prepare patients consider patient goals, expectations, and preparedness as important for postoperative outcomes.

Analysis

All regression analyses presented in this dissertation utilized automated backwards-elimination model building. This was chosen for several reasons including avoiding the impact of potential collinearity if variables were forced into the model. We identified many variables that could be related to our dependent variables and chose to utilize a process that relied on statistical significance to determine which variables remained in the final models. In doing so, the potential for collinearity was reduced as was the possibility of the variables being perceived as cherry-picked. As a trans researcher conducting a CBPR project, it was important to utilize a statistical approach that reduced the potential for others to consider the work as personally biased. Using a statistics-driven approach to model building may additionally increase the credibility of our findings to those who have biases against community-based research or research conducted by/for trans people. This also may lead to the process being seen as transparent or objective and therefore increase the uptake of the research.

Summative Contributions

Taken together, the results of these papers include novel findings predicated on robust CBPR processes that are important for prospective and current patients, researchers, surgeons, and other service providers who work with trans people undergoing phalloplasty and/or metoidioplasty. The results of this project especially highlight the significance of patient self-reported preparedness and what factors relate to improved mental health after these surgeries. Both topics are areas in which there is little to no extant academic literature; the results of this dissertation then comprise a significant contribution to the field.

In both empirical papers, patient preparedness became a topic addressed. While in the first, preparedness was chosen as an outcome variable specifically, in the second paper, preparedness was highlighted due to its significant relationship with mental health outcomes in our analysis. In previous literature, patient preparedness for these surgeries is rarely addressed and literature does not clearly document how patients are preparing for phalloplasty and metoidioplasty. Rather, it focuses on readiness, which does not include considerations of whether an individual has needed knowledge or skills. Survey participants reported accessing community resources often and rated these as highly useful; in contrast, readiness assessments were not considered very useful by our participants yet were common among the overall sample.

If community resources are very useful while preparing for surgery, patients may spend time seeking online resources to feel prepared for these complex procedures. Despite spending time online, there may be a lack of patient-facing or lay content about outcomes of these surgeries, which may leave patients under-educated about what will occur after undergoing them (Karamitros, 2023). If not well-informed about what may happen as a result of undergoing surgery, patients' mental health may suffer. Certainly, if mental health after surgery is improved

when patients feel prepared, as one analysis indicates, then preparedness may be an important indicator of positive surgical outcomes.

Further highlighted by these results is the role of surgical satisfaction in mental health-related outcomes. While surgical satisfaction is one of the more commonly addressed outcomes of gender-affirming surgeries in current literature, the relationship between surgical satisfaction and other outcomes is rarely addressed. In one analysis, surgical satisfaction was related to self-report of improved mental health. Considering trans people typically access gender-affirming care to alleviate dysphoria and/or promote euphoria, another goal may be mental health improvement. It is possible that the relationship between surgical satisfaction and mental health centers on whether expectations of changes in dysphoria or euphoria are met. If so, this further reifies the importance of preparedness being inclusive of realistic education materials about outcomes related to dysphoria. While further research is needed to understand these relationships, the results of this dissertation provide a necessary first look at factors that may be related to self-reports of preparedness and mental health improvements among those who undergo phalloplasty and metoidioplasty.

Implications

The findings and contributions of this dissertation have important implications for community members, healthcare service delivery, and policy. The unique CBPR process of this work showcases the ways in which trans voices can be centered in research about our own health and well-being. I hope it serves as an example of exemplary community partnership to those interested in research with trans communities. In addition to our methodology, the results of the two empirical papers presented within this dissertation point to needed changes in healthcare

service delivery and policy. Further, our research and results point to a need for more nuanced research projects into trans people's experiences of health and with health care systems.

The results of the analysis presented within this dissertation are important in that they recognize a need for a shift away from a predominant focus on assessing readiness before surgery towards ensuring comprehensive patient preparedness, especially if a goal of gender-affirming care is improved mental health. Indeed, achieving preparedness involves having requisite knowledge or skills to undergo an experience unlike readiness which simply can be thought of as willingness to undertake an action (Jin, 2024). Previous literature does not document whether patients feel they have enough knowledge to feel prepared instead this literature relates to readiness. Currently, interested patients access a referral for gender-affirming surgery through healthcare providers who discern whether an individual qualifies to undergo surgery based on the WPATH Standards of Care (Coleman et al., 2022). These readiness assessments traditionally focus primarily on evaluating the stability of current mental health (MacKinnon et al., 2020). In this analysis, however, mental health before surgery (albeit retrospectively self-reported) did not relate to whether mental health was self-reported to improve after surgery, while self-report of feeling prepared did. With readiness assessments focusing so heavily on mental health in the time leading up to surgery, whether patients feel prepared may not be determined. Indeed, patients can ultimately determine, by themselves whether they *feel* prepared to undergo a surgical procedure. Our results demonstrate support for this self-reported feeling being important for positive surgical outcomes.

For those who work with patients preparing for surgery, including mental healthcare providers, social workers, and surgical care teams, our results provide a suggestion to reflect on potential change to practice and service provision. Since it is unclear how best to prepare

patients, supporting patients individually to discern what they find useful while preparing for surgery, and providing resources to fit this need may be the best way to ensure preparation. While this may take more time than offering one set of resources for all patients within a practice, or only utilizing readiness assessments, it may be more effective in creating prepared patients and circumstances that lead to positive mental health-related outcomes. If further research adds to knowledge of what types of patient preparation materials are generally most useful for patients, this too could be integrated into practice.

The results in this dissertation provide timely information that can be utilized in clinical practice for phalloplasty and metoidioplasty, or for the care of trans patients more broadly. Specifically, the results provide support for shifts in clinical guidelines and the way care is provisioned, including the way readiness assessments are conducted and what information is shared with prospective patients. First, our findings provide information for clinicians to consider about patient preparation as important, different from readiness, and possibly related to improved mental health outcomes. With this information in mind, those who work with patients seeking these surgeries could work to address preparation more holistically and develop novel patient preparation strategies. Little literature suggests alternatives to the current readiness assessment process, but a consistent approach designed to maximize benefits to patients may be useful both to patients and clinicians.

Based on our findings, I suggest a process that is designed to benefit patients by providing necessary information and supports for patients to feel prepared (whatever prepared means to them). I suggest this looks like a check-in system with a social worker or other clinician in which a prospective patient is first able to request information about surgical options, discuss pros and cons of the options, and learn everything they need to feel informed about the surgery they plan to undergo. Next, patients can be aided by clinicians to prepare for undergoing a

challenging surgical experience. This should include personalised aftercare planning, any mental health support the patient solely feels they need, and a plan for how to deal with complications as they arise. The goal of this care should not be for a clinician to determine whether a patient is ready or prepared, but rather to assist the patient in whatever way the patient feels is needed. Some patients will want large amounts of support whereas others will be happy to learn from peers and do all the necessary work to prepare themselves for surgery. Every patient should have the opportunity to access this care to help them prepare, or to decline it.

Alternative approaches to readiness assessments could also be included in future iterations of the WPATH Standards of Care as ways to support patient preparation. Truly, with the original intention of the SOC being to protect patients from harm and reduce risks for both providers and patients (Marrow, 2023), a process designed to increase preparedness would uphold this value and intention. Further, as the SOC are being developed more collaboratively with trans and nonbinary people (Coleman et al., 2022), the results presented within this dissertation provide a starting point for conversation between these groups about how clinical guidelines can best support patients today. Indeed, the creation of an updated SOC that suggests patient-focused pathways for developing preparedness would be invaluable in creating both clinical change and influencing policy makers.

The results of this dissertation have implications not just for clinical practice or guidelines but for related policy. In the U.S. and Canada, policies regarding phalloplasty and metoidioplasty vary based on country of residence, state or province, and what healthcare insurance a person has. Each of these may have differing policies about what type of care a person can receive and from which surgeon, what is paid out-of-pocket or covered, and what is required before undergoing surgery (Goldenberg, 2020; Almazan et al., 2020; Downing et al.,

2022; Cohen et al., 2020). While a thorough overview of these policies is outside the scope of this dissertation, these results provide useful information for policy makers at any level.

Through this dissertation, I documented that readiness assessments, as they currently are, may provide little utility to prepare patients for phalloplasty and metoidioplasty. Further, since preparedness was found to be associated with improved mental health in this sample, policy makers should work with clinicians to ensure that patients have access to resources that support preparedness. Governments in Canada, and health insurance companies in the United States may consider dropping the requirement for these assessments or allowing alternatives to document patients' readiness. Relatedly, policies could be adapted to support patients in accessing supports that do help them feel prepared. Insurance or publicly-funded programs could pay for peer-mentoring programs, support groups, or educational programs designed to support patient preparation. Social workers could be paid by insurance to meet with patients preparing to undergo surgery to support aftercare planning or challenges that arise during the surgical journey.

I urge those who work in policy to consider the ways in which trans people's mental health can be supported, overall. Since my findings include that mental health improves for those who undergo this needed care, policy makers should work to improve access to these surgeries and this quality of care. The sample of participants who participated in our study rated their current mental health (after undergoing gender-affirming genital surgery) as about the same as the average Canadian population in 2022. This is in stark contrast with several other studies of trans people's mental health where consistently poorer mental health than the general population is found. It therefore appears that accessing needed gender-affirming healthcare may reduce mental-health related disparities for trans and nonbinary people. Despite this, many people lack access to these surgeries due to barriers related to income, insurance exclusion or lack of in-

network providers, inability to take time off work or school, and a myriad of other reasons.

Policies could be enacted which support all patients who need this type of care to access it. This could be done by increased coverage from insurance, government policies that mandate coverage or require this coverage to be provided.

Future Research

The analyses conducted as part of this dissertation and presented within these papers constitute an important step towards advancing knowledge about surgical outcomes of phalloplasty and metoidioplasty. Further, the way in which the research was conducted is valuable in how the CEC and I centered and empowered trans community members and focused on topics they voiced as important. Much more research is still needed to understand many aspects of patient experience with phalloplasty and/or metoidioplasty.

The results of this study raise questions that should be included in future research endeavors. First, patient preparedness is a complex self-reported experience; while the participants highly rated community-created resources and surgical consults as useful, more information is necessary to discern what resources patients generally find most useful and how services can best prepare them. Additionally, factors associated with increased mental health after gender-affirming care are rarely addressed in current literature

With a community-led focus the CEC and I have chosen to allow individuals interested in data from PROGRESS to request use of our findings for papers and other knowledge mobilization materials they would like to produce. Presently, further analysis is occurring with the PROGRESS data set based on additional community-identified questions and areas of

concern. Ongoing analysis is being conducted related to changes in sexual behaviors after phalloplasty and metoidioplasty. In addition, a paper about binary, compared to nonbinary people in our sample is being finalized and prepared for journal submission. Further data analysis based on PROGRESS is going to continue, based on other community-led analyses or topics identified by individuals within our community.

While this project has been a useful start to developing trans-led research on this topic, much more is needed to develop nuanced understandings of these patient experiences. Other researchers should carefully consider both their community engagement plan and methodological choices about these topics. Developing projects collaboratively with patients or community members seems to be an ideal way to ensure research can directly benefit trans and nonbinary people. Qualitative research may lead to more in-depth literature about individual experiences and provide nuance that quantitative data cannot. Contrarily, longitudinal or prospective cohort studies might provide insight into changes over time or due to accessing a particular type of care. Research about phalloplasty and metoidioplasty is burgeoning; this presents a unique opportunity to center trans and nonbinary people in this work and focus on community-identified priorities within studies. I hope other researchers work towards creating equitable partnerships and developing research programs that center trans voices to create much-needed progress for our communities.

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Appendix 1: PROGRESS Memorandum of Understanding (MOU)

PROGRESS Study

Memorandum of Understanding

Draft date- October 20, 2021

Project Full Name : Patient Reported Outcomes of Genital Reconstruction and Experiences of Surgical Satisfaction (**PROGRESS**) for Phalloplasty and Metoidioplasty

What is a memorandum of understanding?

A memorandum of understanding is a document that includes principles, goals and processes to which a group of people will agree as part of a project; it represents a kind of group consensus. The document may need adaptation or editions over the project's life cycle. While the terms within this document are not binding, it is expected that group members keep the spirit of its contents in mind as we navigate our work together. This MOU is between Leo (myself, a doctoral candidate) and the Community Engagement Committee (you) for my dissertation.

Description of the project. PROGRESS is an international, cross-sectional study of outcomes of phalloplasty and metoidioplasty for trans and non-binary people that is comprehensive and driven by patient experience.

Team Structure

Community-based research within a university is complex and political. There are a number of parties engaged in this project in order to provide collectively all of the necessary resources for its success. Here is an outline of the various roles in the project, what responsibilities they have, and who fills them:

Principal applicant: Leo Rutherford

Leo (myself), a PhD Candidate at the University of Victoria. Leo will use this project to write his PhD dissertation, which will be published online and is required to complete his program. Because Leo Rutherford is a PhD student being supervised at the University of Victoria, one of his professors must be the Principal Investigator for the research ethics application because that professor is ultimately responsible to the University of Victoria for ensuring that the study is done in an ethical manner.

Leo's research is funded by the Canadian Institute of Health Research's Patient-Oriented Research fellowship and includes \$5,000 of research expense funding per year

for two (2) years. His application for this fellowship was supported by the British Columbia SUPPORT (SUpport for People and Patient-Oriented Research and Trials) Unit and TransCare BC.

Leo's supervisory committee is made up of 2 professors at the University of Victoria, Aaron Devor, [Nathan Lachowsky](#) and 1 professor from Drexel University, [Ayden Scheim](#). Together, this supervisory committee has expertise in trans studies, epidemiology, LGBTQ2S+ health, survey design, community-based research, and knowledge translation. See more about each of these individuals by clicking the links in their names.

The Community Engagement Committee (CEC) will be made up of up to six trans or non-binary people with lived experience of either phalloplasty or metoidioplasty.

The CEC is responsible for assisting with the decision-making process of this project by providing input on research design, data collection materials and research outputs such as papers and presentations. We will hold 3-4 meetings over the course of the year (2021) in which we will decide on important aspects of this research including: when to collect data, who to collect data from, what instruments should be included in a survey about phalloplasty or metoidioplasty and how research data should be given back to the community. Between meetings, there will be draft documents to review and provide feedback on; all the tools needed to provide feedback will be provided.

Proposed project objectives:

1. To characterize the demographics of a sample of trans and non-binary people who have undergone phalloplasty and/or metoidioplasty.
2. To estimate the frequency of these types of surgical interventions and rates of patient-reported complications for a sample of individuals.
3. To document patient experiences of surgical processes
4. To explore patient expectations prior to surgery, and whether expectations were met through the surgical process
5. To explore how self-reported health and well-being have been impacted by undergoing surgery
6. To gather and formalize community knowledge and experiences to share with those considering having these surgeries
7. To lay a groundwork for further investigation into patient experiences with these surgeries

Project Goals

The ultimate goal of this project is to support the well-being of trans and non-binary people who undergo the gender-affirming genital surgeries of phalloplasty and/or metoidioplasty. Within the present study, our aim is to conduct one-time data collection through an online survey developed by and for those who have had phalloplasty and/or metoidioplasty. Results of the study will be used to inform community members, doctors, other healthcare providers, and academics about patient experiences of surgical outcomes.

Guiding principles of the project

This project uses two frameworks to approach research: Community-based participatory research (CBPR) and Patient-Oriented Research (POR).

CBPR is an approach to research that recognizes the expertise of community members or those with lived experience and seeks to co-create research and knowledge about community experiences. At its core, CBPR promotes mutual respect and understanding between researchers and those being researched while building skills for both researchers and community members.

POR developed due to a lack of patient input about healthcare experiences and ways to improve health services. Similarly to community-based research, POR recognizes that those who have experience of healthcare (or 'patients') should be involved in research about their health and service delivery.

For more information on these approaches to research please see the following links:

CBPR- <https://pacificaidnetwork.org/research-and-evaluation/what-is-cbr/>

POR- <https://cihr-irsc.gc.ca/e/48413.html>

Based on POR and CBPR frameworks, we will use the following principles to guide our work together:

Community control and collaboration

Being community-based and patient-centred allows research to be nuanced and to provide more direct benefit to the people whose lives are impacted by the research. By centering the voices of those with lived experience of these surgeries, we will ensure our work is more focused on the needs of our community. Decisions about this research project will be made by the CEC and myself to support equal power in decision making whenever possible.

Action-orientation to research

Research by and for trans communities is best suited to understanding our experiences and advocating for our needs. Not only will we collect data, but we will ensure community members have access to our results, and we will use the information we collect to benefit the community. We commit to long-term action based on the results of our survey.

Capacity building

Building capacity within the trans community is essential to the development of leaders who can make positive change for the future. Team members on this project will gain skills related to the research process and knowledge translation of academic data. There will be opportunities for everyone to gain skills related to data collection and analysis, if desired. We value co-learning and recognize that experience is valuable knowledge.

Honoraria

In order to ensure everyone can participate in this project, all CEC members can be compensated for their time at a rate of \$25 an hour for meetings and time spent reviewing / giving feedback on project materials. These funds are in Canadian Dollars (CAD) and will be delivered via cheque or interac e-transfer. The payments are not automatic, so please keep track of the amount of time it takes you to complete tasks for this project, and email me this information so I can forward the request to our administration. If you do not desire compensation, the funds will be put towards honoraria for survey participants.

One research assistant (RA) position is available to support an individual who wishes to be more involved in the project. This position would be 20-30 hours over the course of 2021 -- more details about this position are available upon request. There may be tax implications for funds received if they exceed \$500 over the course of a year; this can be explained in further detail if needed.

Please inform Leo as soon as possible if:

- 1) you would like to receive the honorarium: YES / NO***
- 2) if you are interested in the RA position : YES / NO***

Accessibility

Given the current pandemic, all of our meetings and interactions will be virtual for the time being. This may present barriers to participation in the project for some people.

We will be using email, Zoom, and Basecamp as our primary meeting and communication platforms. In light of screen fatigue and other computer-based challenges, we can be flexible with how these platforms are used. Emails may be handwritten and sent as a photograph attachment instead of typed. Zoom calls may be treated as phone calls; no one is required to use video on Zoom. If you experience challenges using or posting to Basecamp, Leo can transcribe or post on your behalf.

While we hope to have anticipated your accessibility needs, there may be other supports needed to ensure everyone can fully participate in the team. If the online environment or communication platforms we use present challenges for you, Leo is happy to adapt alternative means of communication. Please let Leo know if there is anything else he can do to remove barriers to your participation.

Team communication

Our team will utilize an online platform such as Slack or Basecamp in addition to email as our primary means of communication and will be using an excel sheet or Google poll for voting and providing feedback on various aspects of project planning.

Communications should be in plain English that avoids jargon and is easily understandable.

It will generally be expected that email and materials sent for review be returned within two weeks (14 days) of receipt. If you require more time in general, or for a specific period of time, please let us know as soon as possible. This extension may or may not be able to be accommodated.

Information shared, or details discussed during team meetings through email or other online platforms, is to be considered confidential and not to be shared outside of the team unless agreed upon by the entire group. This includes draft survey items, plans for knowledge translation, and all project progress.

You can speak personally about your involvement in the project and aspects including who is a part of the team, what our goals are and that we are planning to conduct a community-based, patient-oriented research project looking at outcomes of phalloplasty and metoidioplasty. If you receive a request from the media for more information than described above about the project, please inform the rest of the team. In the future, a media response guide will be integrated into this MOU document to further support the team in responding to media.

Authorship and Acknowledgement

All CEC members will automatically be included as authors on all non-academic publications such as community reports, one-page project briefs, media stories, and outputs made for social media. All CEC members will be acknowledged on all publications for which they are not an author.

For academic publications, such as scholarly journal articles, we will use an international standard for authorship guidelines in health/medical research called the ICMJE guidelines.

ICMJE guidelines can be found here:

<http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html>

These guidelines recommend the following criteria be met in order to be listed as an author:

- 1) Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- 2) Drafting the work or revising it critically for important intellectual content; AND
- 3) Final approval of the version to be published; AND
- 4) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

We use these criteria because they will be required for us to follow for any journal articles arising from this project. All CEC members will meet the first criterion as a result of their role on the CEC. The other criteria are dependent on what roles you are willing to play in future work.

With these agreements in mind, if you review any publications and provide feedback AND give your final approval AND agree to be accountable for all aspects of the work, THEN you can be listed as a co-author on a manuscript. Leo reserves the ability to be listed as last author on all publications if he has not led the writing of the manuscript. Leo will be first author on all publications arising from his dissertation.

The above mentioned ICMJE authorship guidelines will apply to all others who wish to be co-authors on academic publications.

If, for any reason, Leo is unable to finish his dissertation or publish on data collected, Leo's program permits his supervisors to publish using these data with his inclusion as co-author. They will honour this agreement in terms of CEC members serving as co-authors.

Decision making

Community based research decision making seeks to ensure all voices are heard in the decision-making process. We will use a voting process to make decisions. All CEC members and Leo will have one vote. Decisions made should be done transparently and each voter should be given a sufficient amount of time to share their thoughts and vote. For any materials I send for CEC feedback you will have two weeks (14 days) to review and cast your vote via our online platform. If you need more time due to other factors, please let me know. This extension may, or may not, be able to be accommodated.

Decisions made should reflect a simple majority vote. This means that for a decision to pass, more than half of the votes need to agree - so if there are 6 CEC members (i.e. 7 voters including Leo) at least 4 members need to vote yes for an item to be approved. If the vote is split entirely 50% in favour and 50% not in favour, then the decision will not pass.

Given this project is Leo's dissertation, it is essential that he fulfill his program requirements in order to obtain his degree and graduate in a timely fashion--Leo may make decisions about the project unilaterally. This will only occur in situations where Leo's progress in his program would otherwise be hindered.

Conflict resolution

Conflict is a normal part of life and may arise in personal or project-related activities during our time working together. To that end, it is important to consider how to address conflict when it arises.

Conflict occurs when two or more parties (people or groups) have a disagreement that results in challenges to their relationship. If the individuals who experience a conflict are unable to address it by speaking with the others involved in the conflict, the issue can be brought up to me or another member of the team. If conflict cannot be addressed through further conversation with the team, formal mediation may be requested by any party. One or more mediators can then attempt to resolve the conflict with the effected parties. I will suggest a mediator that is outside the project and has experience with managing teams or with conflict resolution.

This definition of conflict and processes to resolve it does not include harassment, discrimination, transphobia, racism, homophobia, xenophobia or misogyny. These will not be tolerated within the team. Any acts of 'phobias' or 'isms' should be reported to the team immediately and may result in an individual's removal from the project. If you experience harassment or discrimination, or witness another team member experiencing it, please report this to me.

If you have issues with the conduct of the researcher (Leo), please voice your concerns to those overseeing my work-- email any or all of my supervisors: Nate Lachowsky (nlachowsky@uvic.ca), Aaron Devor (ahdevor@uvic.ca) or Ayden Scheim (ais63@drexel.edu)

Violating group agreements, such as this MOU is not a conflict per se but should be brought to the attention of the team, Leo, or Leo's supervisors if it occurs.

Participating in our survey

Leading up to data collection we will have been working on this survey for some time and some of us might be excited to take part in data collection but there are unique considerations for us as potential participants. While the survey is anonymous and therefore it is possible for us to take part in, please carefully consider the following before choosing to take part in our survey.

Those of us who analyze the data (Leo and anyone else who is given access) may be able to identify your individual survey response. This is especially true if you have unique characteristics or experiences (such as having a surgeon at a certain time/place or having unique complications). While it's not generally problematic that we might be able to see your individual survey responses, it may make you feel uncomfortable or worried what we might think of your responses. Please consider carefully how you might feel if your responses are recognized before deciding to participate in the survey.

Leo will never know if you choose not to take the survey, so feel free to do whatever you are most comfortable with. We will get plenty of participants even if the 8 of us do not participate in the survey.

In addition, as researchers, we should not receive compensation for taking the survey. So, while 200 participants can be compensated for taking the survey, we should not include ourselves in that pool, nor should anyone include time taking the survey in their billable hours for work on this survey.

Data collection and recruitment

When recruitment for our study opens, we will need to share calls for participants (including flyers, email and social media posts) that are consistent with the details approved by the research ethics board (REB). Please see the highlighted recruitment plans in the REB application for details about how recruitment should occur.

Data storage and sharing

The data we will collect through this project is novel and very important to the community of trans and non-binary folks who have genital surgery. For that reason, it is essential to make data as freely available as possible while protecting confidentiality. This also supports our project's aim of bringing vital information to the community.

While data collection is occurring, due to human research ethics protocols, it will be stored on University (of Victoria) servers that are encrypted and only accessible to those with University of Victoria login credentials. If any CEC member is involved in data analysis we can share data in order for analysis to occur.

After data are collected and de-identified (meaning the removal of anything that could mean a specific person is identifiable), our data will be shared in an online data dashboard. On the dashboard, any person could look at descriptive statistics from our sample and make basic cross-tabulations. A colleague created https://www.cbrc.net/ourstats_dashboard, a data dashboard from a Canada-wide study of gay men's health; our data dashboard can mirror this or take a different direction.

Knowledge Translation

Knowledge translation (KT) is any activity or product with a goal of sharing research results. Most often, research knowledge is translated through academic publications and conference presentations. While these share knowledge to some groups, those who are not involved in academia are left out and may not receive information about current research and results. For us, then, it is essential to focus KT activities on giving the trans community this much-needed information. Many trans folks interested in surgery use social media, including Facebook, YouTube, Reddit and (previously) Tumblr. These platforms should therefore be places where we focus our KT efforts.

Built into the budget of this project is support for conference presentations and open-access academic publications of manuscripts. In addition, a video series or podcast has been suggested as an accessible format to share our work with the community.

During our group CEC meetings we will decide on what exactly these outputs will look like. This MOU section will then be updated based on our decisions.

One KT tool I am committed to is an open-access data dashboard where community members can view and conduct simple statistics on the data. What results are included will be revisited once we collect data, and this section will be updated once we make those decisions.

Future considerations

As this MOU document evolves with the project's life cycle, the following items will be updated or added:

- How to handle media requests
- How to handle requests for access to our full dataset
- What data we will include in an online dataset
- Additional items as needed

PROGRESS - final

Start of Block: Introduction and informed consent

Q1.1 Thanks for your interest in our study!

Please carefully read the following information about our study before continuing on to the survey; it contains important information that you need to consider as a potential participant. After reading this, you will be asked whether you want to continue to the survey (participate) or leave this site and not participate in the research (exit the survey).

We are currently recruiting for our survey about gender-affirming phalloplasty and metoidioplasty. Those eligible include anyone who is trans, non-binary, Two-Spirit, has transitioned or has transition experience or is post transition and has had either phalloplasty or metoidioplasty.

You are invited to participate in a study entitled PROGRESS (Patient-Reported Outcomes of Genital Reconstruction and Experiences of Surgical Satisfaction) for phalloplasty and metoidioplasty.

This research is part of a dissertation for the Social Dimensions of Health program at the University of Victoria. It is funded by the Canadian Institutes of Health Research's Strategy for Patient-Oriented Research Transition to Leadership Award. Our research partners include TransCare BC and the Community- Based Research Centre (CBRC).

Description of the study: PROGRESS is an international, cross-sectional study of outcomes of phalloplasty and metoidioplasty for trans and non-binary people that is comprehensive and driven by lived experience. The ultimate goal of this project is to support the well-being of trans and non-binary people who undergo the gender-affirming genital surgeries of phalloplasty and/or metoidioplasty. Within the present study, our aim is to conduct an online

survey developed by and for those who have had phalloplasty and/or metoidioplasty. Results of the study will be used to inform community members, surgeons, other healthcare providers, and academics about patient experiences of surgical preparation and outcomes.

The primary researcher is Leo Rutherford- a PhD candidate at the University of Victoria who is a community member with lived experience of phalloplasty. Leo uses community-based participatory research and patient-oriented approaches in his work and believes community members are experts on their lives and experiences. Along with Leo, 7 community members who have also undergone one or more of these surgeries have worked together to design the survey and recruitment materials. Some of these members of the research team are featured on our website: www.progresscolab.net

As a doctoral student, Leo is supervised by 3 faculty member researchers:

Dr. Nathan Lachowsky is an Associate Professor in the School of Public Health and Social Policy at the University of Victoria. He holds a PhD in epidemiology and conducts communitybased research in the field of sexual health and HIV/AIDS.

Dr. Aaron Devor is a Professor of Sociology at the University of Victoria and the world's first Chair in Transgender Studies. He is the founder of the Transgender Archives and the Moving Trans History Forward conferences.

Dr. Ayden Scheim is an Assistant Professor in the School of Public Health at Drexel University. He is a social epidemiologist who advances the field of trans research by leading communityengaged surveys in Canada.

Project objectives:

To characterize the experiences of people who have undergone gender-affirming phalloplasty and/or metoidioplasty surgery.

To document patient goals and experiences of phalloplasty and/or metoidioplasty surgery, and whether expectations were met through the surgical process

To explore how self-reported health and well-being have been impacted by undergoing phalloplasty and/or metoidioplasty surgery To gather and formalize community knowledge and experiences to share with those considering having phalloplasty and/or metoidioplasty surgeries

To lay a groundwork for further investigation into patient experiences with phalloplasty and/or metoidioplasty surgeries

Who is this study for?

We are looking for folks who are able to complete a survey in English, are over the age of majority in their state or province, are trans, non-binary, Two-Spirit or have transitioned and have had any kind of phalloplasty or metoidioplasty from either Canada or the United States.

Why is this study important?

For some trans and non-binary people, having surgery to alter their genitals is a necessary aspect of their medical transition process. To date, research has mostly focused on outcomes of these surgeries that are most useful to surgeons who conduct them. So, many aspects of surgery important to patients are not well-documented. To fill this gap, and, more importantly, gather information that our community needs about typical outcomes, we created this survey.

What's involved?

The survey includes a series of questions about you, how you prepared for surgery, your surgical experiences, your mental health, body image, sexuality and other surgery-related experiences. The survey will take approximately 45-60 minutes to complete. All questions are optional; you can skip any question you don't want to answer. All responses are anonymous, no personal contact information or details like your name, address, phone number or email will be collected.

How will my responses be used?

This survey uses Qualtrics as a data collection tool which has many security features to keep your data safe and ensure fraudulent data are not collected. You can read more about the security of data collected by Qualtrics at <https://www.qualtrics.com/security-statement/>. Our Qualtrics account is licensed to Dr. Nathan Lachowsky, one of Leo's supervisors. All the responses collected will be stored together in aggregate form, meaning all responses are grouped together. The study will not look at individual responses but rather how groups of people responded to our questions. Data will be stored on encrypted servers at the University of Victoria and only members of the research team will have access to the data.

We will use the results for community-oriented paper and media content and academic papers and publications. On our website and through social media, we will release infographics with some statistical results such as averages and percentages. We will also create reports for community members that interpret the results and provide information about common themes in our data. We may create media content such as YouTube videos or a podcast showcasing our findings. We will publish academic papers and give conference presentations based on the results as well.

We may use your information for an anonymous data dashboard, similar to the one created by TransPulse Canada <https://covid.transpulsecanada.ca/transpulsedash/>. Data dashboards allow members of the community to do basic statistical analyses on their own or look at information about how groups of people responded to survey questions. Data dashboards put research data in the hands of community members more readily. Future data analysis may

be conducted on data included in the dashboard. Again, all data will be completely anonymous, and no individual responses will be viewable by the public on this dashboard.

Inconvenience and potential risks:

This survey may take about 45-60 minutes to complete and asks questions that may bring up memories about mental and physical health challenges and stressful times such as hospital stays or recovering from surgery. If any survey content causes you distress feel free to take breaks and/or skip questions. In several places throughout the survey, information about accessing mental health supports is provided should you need it.

Benefits

Participating in this study will contribute to expanding knowledge about preparing for, undergoing and recovering from phalloplasty and metoidioplasty that is useful for community members who have undergone surgery, those considering surgery, surgeons who perform gender-affirming surgery, primary care doctors, counselors, and academics.

Compensation

We are not offering any compensation to those who participate in this survey. With the small budget this project has, we are focusing our funds towards knowledge translation activities that will benefit the trans community.

Voluntary Participation

Your participation in the research must be completely voluntary. If you decide to participate, you can withdraw at any time during the survey. However, if you stop taking the survey or do not submit it at the end, the responses you provided will still be recorded, as data. This is because once you provide responses in the survey, there is no way to remove them since we cannot identify your particular survey response. All information you enter in the survey, then, may be included as part of our data set. This survey is completely anonymous, meaning no identifiable data will be collected by us or the survey platform, Qualtrics.

Researchers' Relationships to Participants

Researchers who are also community members involved in the creation and promotion of this survey may have relationships with you. The community of people who have gender-affirming phalloplasty and metoidioplasty is small and you may know one or more members of the research team. Researchers and community members involved in this project have been instructed merely to share calls for participants through email listservs and on social media sites and not ask specific individuals to participate. While we may know one another personally, please do not feel pressured to participate in this research due to this relationship. If anyone involved in this research project directly asks you to take the survey or pressures you to participate in any way, please contact one of the three research supervisors for this

project or the Research Ethics Board that approved this study (see contact information below).

Disposal of Data

Data will be stored on the University of Victoria's password-secured, encrypted servers for at least 7 years. Leo Rutherford will be the owner of the data collected and Nathan Lachowsky will hold it on UVic's servers until the time Leo completes his PhD. After Leo's PhD is complete, data will either continue to be held by Dr. Lachowsky on UVic servers or move with Leo to another institution via a data transfer agreement. Data stored on UVic's servers will be destroyed after 7 years if it is not transferred to another institution with Leo. If a data dashboard is created, anonymized data will be stored there indefinitely.

Questions about this research may be directed to Leo at leorutherford@uvic.ca or by using the

'contact us' form on our study's website.

You may also contact Leo's supervisors with questions or concerns at the emails below:
Nathan Lachowsky- nlachowsky@uvic.ca Aaron Devor- ahdevor@uvic.ca

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria, 250-472-4545 or ethics@uvic.ca

By continuing on to take the survey, your free and informed consent is implied and indicates that you understand the above conditions in this study, and that you have had the opportunity to have your questions answered by the researchers.

Feel free to keep a copy of this informed consent letter for your reference.

Q1.2 After reading the informed consent information above, click 'continue to survey' below to go to the survey. If you do not wish to participate, select 'exit' or leave the site.

Continue to survey (1)

Exit (2)

End of Block: Introduction and informed consent

Start of Block: Screening questions

Q2.1 Keeping in mind that the following list may not capture all identities but is an attempt to be as inclusive of as many identities as possible, please answer the following:

Do **ANY** of the following describe you: transgender, trans, transsexual, Two-Spirit, non-binary, have trans experience, transitioned, or post transition?

Yes (1)

No (2)

Q2.2 Have you had any type of phalloplasty or metoidioplasty as part of your medical transition?

Yes (1)

No (2)

Q2.3 Which of the following countries do you currently live in?

Canada (1) The United States (2) Neither of the above (3)

Display This Question:

If Q2.1 = 1

And Q2.2 = 1

And If

Q2.3 = 1

Or Q2.3 = 2

Q2.4 You are eligible to participate. Please click the button below

End of Block: Screening questions

Start of Block: Demographics

Q3.1 This next section will ask some questions about you. Please note that all of the questions in this survey are optional; you may skip any questions you don't wish to answer for any reason.

Display This Question:

If Q2.3 = 2

Q3.2 What state do you currently live in?

▼ Alabama (1) ... Wyoming (52)

Display This Question:

If Q2.3 = 1

Q3.3 What province or territory do you currently live?

- Alberta (1) British Columbia (2) Manitoba (3)
- New Brunswick (4) Newfoundland and Labrador (6) Nova
- Scotia (5) Ontario (7) Prince Edward Island (8) Quebec
- (9) Saskatchewan (10) Northwest Territories (11)
- Nunavut (12)
- Yukon (13)
-

Q3.4 Which of these best describes the place you live?

- Urban (large city) population of 100,000 or more (1)
- Medium size city of 30,000- 99,999 (2) Small
- city of 10,000- 29,999 (3) Rural - less than 10,000
- (4) Remote (5)
-

Q3.5 What is the highest level of formal education you have

completed? Some high school, no diploma (1) GED or

similar (2) High school graduate (3)

Some college or trade school, no degree (4) College or

trade school graduate (5) Some university, no degree (6)

Bachelor's degree (7) Some graduate work, no degree (8)

Master's degree (e.g. MA, MS, MBA) (9) Some Doctoral or

professional work, no degree (10) Doctoral or professional

degree (e.g. PhD, MD, JD) (11)

Q3.6 Which of the following best describes you? Select all that apply

- Black (2)
- Indigenous (ex. First Nations, Native American, Metis, Inuit, Alaska Native) (3)
- East/Southeast Asian (4)
- South Asian (13)
- Middle Eastern (12)
- Native Hawaiian or Pacific Islander (5)
- Latino or Latinx (14)
- White (1)
- Other (6) _____

Display This Question:

If Q3.6 = 3



Q3.7 Are you Two-Spirit?

- No (0)
- Yes (1)



Q3.8 Are you perceived or treated as a person of color?

- Yes (1) No (0) Not sure (2)
-

Q3.9 What is your best estimate of the total income from all members living in your household including yourself, before taxes and deductions, from all sources in 2020? (include any money your household received from any person or organization). By household members, we mean people with whom you share income and resources, or who

share income and resources with you. Less than \$10,000 (1) \$10,000 - \$15,000

(2) \$15,000 to less than \$20,000 (3) \$20,000 to less than \$30,000 (4)

\$30,000 to less than \$40,000 (5) \$40,000 to less than \$50,000 (6) \$50,000 to

less than \$60,000 (7) \$60,000 to less than \$80,000 (8) \$80,000 to less than

\$100,000 (9) \$100,000 to less than \$150,000 (10) \$150,000 or more (11)

Unsure (12)

Q3.10 What is your current employment/student status? Select all that apply

Full-time employment (1)

Part-time employment (2)

Receiving Employment Insurance (EI) or unemployment (3)

- Receiving disability (4)
 - Receiving retirement or pension (5)
 - Stay at home parent or homemaker (9)
 - Full-time student (7)
 - Part-time student (8)
 - None of the above (6)
-

Q3.11 Which of the following words do you use to describe yourself? Select all that apply

- Man (8)
- Male (9)
- Transgender (1)
- Trans (2)
- Transitioned (6)
- Post transition (11)
- Two-Spirit (10)
- Non-binary (3)
- Genderqueer (4)

Transsexual (12)

Agender (5)

Something else (7) _____

13. transmasculine



```
Q3.12 /* Tooltip container */ .tooltip { position: relative; display: inline-block; } /* Tooltip
text */ .tooltip .tooltiptext { visibility: hidden; background-color: Yellow; color: #000;
text-align: center; padding: 5px 0; border-radius: 6px; top: -5px; left: 105%; font-
size: 20px; /* this changes your hover text font size */ } /* Show the tooltip text when you
mouse over the tooltip container */ .tooltip:hover .tooltiptext { visibility: visible; } Are you
```

intersex? Yes (1) No (0) Unsure (2)

Q3.13 What is your current relationship status?

Single and not dating (1) Single and dating (2)

In a monogamous relationship (3) In a non-

monogamous (open) relationship (4) In a

polyamorous (multiple people) relationship (5)

Q3.14 Which of these describe you? Select all that apply

Asexual (4)

- Bisexual (2)
- Gay (1)
- Heteroflexible (6)
- Pansexual (5)
- Queer (3)
- Straight or heterosexual (7)
- Prefer to self-describe as: (8)
- 9, other_____



Q3.15

Are you neurodivergent? Examples include being autistic, on the spectrum or having ADD/ADHD

Yes (1)

No (0)

Maybe (2)

Display This Question:

If Q3.15 = 1

Q3.16 Which of the following describe you? Select all that apply

- Autistic (1)
- ADHD (4)
- ADD (5)
- Tourettes (6)
- Another neurodiversity (7)



Q3.17 Do you have a disability or chronic health condition?

Yes (1)

No (0) Not

sure (2)

Q3.18 How old are you?

▼ Under 18 (86) ... 100 (85)

Q3.19 When did you first undergo phalloplasty or metoidioplasty?

Month

Year

Please select: (4)

▼ January (1 ... September
(9)

▼ 1922 (1 ... 2020 (99)

Q281 Are you currently between stages or 'active process'?

Yes (1)

No (2) Not

sure (3)

Q3.20 How did you hear about our survey? Select all that apply

Facebook (1)

Twitter (2)

Instagram (3)

Reddit (4)

Word of mouth (5)

My doctor/surgeon's office (7)

End of Block: Demographics

Start of Block: Before Surgery

Q4.1 Next, we are going to ask questions about your experiences before surgery. This includes the time you spent thinking about having surgery, deciding on surgical procedures or your surgeon, and preparing for the surgery itself. All questions in this survey are asking questions about your experiences with phalloplasty and metoidioplasty, unless otherwise specified.

Q4.2 When deciding to have surgery, where did you access information about surgery options and outcomes? Select all that apply

- Conversation with peers (1)
- Facebook or reddit group (2)
- Online virtual support groups (3)
- In person support groups (4)
- Surgeon's social media (7)
- Talking to a counselor or therapist (not for readiness for surgery assessments) (9)
- Surgery readiness assessment (10)
- Consults with surgeons (11)
- Talking to your primary care doctor (12)
- Talking to a social worker or nurse (13)
- Reading blogs by post-op trans men (14)
- Books on the topic (eg. Hung Jury) (15)

Academic texts including journal articles and case studies/clinical trials (16)

Resources prepared by a LGBTQ advocacy, education or outreach group (17)

None of these (18)

Skip To: Q4.4 If Q4.2 = 18

Skip To: Q4.4 If Q4.2 = 18

Display This Question:

If Q4.2 = 1

Or Q4.2 = 2

Or Q4.2 = 3

Or Q4.2 = 4

Or Q4.2 = 7

Or Q4.2 = 9

Or Q4.2 = 10

Or Q4.2 = 11

Or Q4.2 = 12

Or Q4.2 = 13

Or Q4.2 = 14

Or Q4.2 = 15

Or Q4.2 = 16

Or Q4.2 = 17

Carry Forward Selected Choices from "Q4.2"

X+

Q4.3 How helpful were each of the following in **preparing** you to have surgery?

	Not helpful at all (1)	A little helpful (2)	bitSomewhat helpful (3)	Helpful (4)	Very helpful (5)
Conversation with peers (x1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Facebook or reddit group (x2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Online virtual support groups (x3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In person support groups (x4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Surgeon's social media (x7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talking to a counselor or therapist (not for readiness for surgery assessments) (x9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Surgery readiness assessment (x10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consults with surgeons (x11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talking to your primary care doctor (x12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talking to a social worker or nurse (x13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Reading blogs
by post-op
trans men
(x14)

Books on the
topic (eg.

Hung Jury) (x15)

Academic
texts including
journal articles

studies/clinical and case
trials (x16)

Resources
prepared by a
LGBTQ



education or advocacy,

outreach
group (x17)

these (x18) None of

Page Break

Q4.4

Imagine an ideal world where there were no risks or complications associated with phalloplasty or metoidioplasty, where all costs were covered, and where you would have unlimited paid time off school or work. In this ideal world, which of the following would you have chosen? Select all that apply

- Radial forearm free-flap (RFF) Phalloplasty (1)
- Anterolateral thigh flap (ALT) Phalloplasty (2)
- Musculocutaneous latissimus dorsi (MLD) Phalloplasty (3)
- Abdominal Phalloplasty (4)
- Other type of phalloplasty (5)
- Simple metoidioplasty (6)
- Ring metoidioplasty (7)
- "Centurion" metoidioplasty (8)
- Other type of metoidioplasty (9)
- Urethral lengthening (10)

- Vaginectomy (11)
 - Scrotoplasty (15)
 - Glansplasty (12)
 - Erectile implants (13)
 - Scrotal implants (14)
-

Q4.5 Which of the following did you consider as part of deciding which surgeries you would have? Select all that apply

- Risk of urethra-related complications (1)
- Risk of implant-related complications (3)
- Risk of other complications (4)
- Worry about scarring (6)
- Cost (5)
- Not wanting another surgery (10)
- Needing to travel for a(nother) surgery (7)
- Sex-related worries (8)
- Recovery time (9)

- Personal safety (ex. in public bathrooms) (14)
- Aftercare (12)
- Surgeon competency (13)
- None of the above (11)

Page Break



Q4.6 This question is an attention check. It is used to ensure participants are reading questions before choosing responses. In the following list, please select the word '**cat**'.

- Dog (0) Cat (1) Horse (0)
- Bird (0)

Page Break

Q4.7 The next set of questions asks you to rate **how strongly you agree** with statements related to being prepared for surgery

	Strongly disagree (1)	Disagree (2)	Somewhat disagree (3)	Somewhat agree (4)	Agree (5)	Strongly agree (6)	Not applicable (7)
I knew about the alternatives to my surgery (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I understood the purpose of my surgery (what this surgery could accomplish) (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I understood the benefits of my surgery (how it could help me) (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I understood the risks of the surgery (what are the chances of something not going the way my doctor and I want it to go) (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I understood the complications of the surgery (what problems can come from the surgery) (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I felt
prepared
about what to
expect after
surgery while

I was in the
hospital (6)



I felt
prepared
about what to

expect after surgery when

I was at home
(7)

I felt
prepared to
cope with a

catheter after surgery while

I was in the
hospital (8)

I felt
prepared to
cope with a

catheter after surgery while

I was at home
(9)

My surgical
team spent
enough time

preparing me for surgery (10)

Overall, I felt

prepared for surgery (11)

Page Break

Q4.8

The next few questions are about procedures that you may or may not have had to preserve fertility. In this section, when talking about fertility preservation we mean anything

you did to ensure you might be able to have biological children in the future such as egg freezing or retaining part of your reproductive organs.

Q4.9 Have you had any of the following surgeries? Select all that apply. If this does not apply to you because you were born without these reproductive organs please respond with 'none of the above'

- Hysterectomy (1)
- Oophorectomy (2)
- Partial oophorectomy (4)
- None of the above (3)

Display This Question:

If Q4.9 = 1

Or Q4.9 = 2

Or Q4.9 = 4



Q4.10 Before you had your hysterotomy or oophorectomy, did any doctors talk to you about your fertility preservation options?

- Yes (1)
- Not sure (2)
- No (0)
- I was not
fertile before this surgery (3)

Skip To: End of Block If Q4.10 = 3

Display This Question:

If Q4.9 = 1

Or Q4.9 = 2



Q4.11 Did you have any fertility preservation?

Yes (1)

No (0)

Display This Question:

If Q4.11 = 0



Q4.12 Do you wish you had done any fertility preservation?

Yes (1) No (0) Not sure (2)

End of Block: Before Surgery

Start of Block: Around surgery time

Page

Break

Q5.1

How well do you remember the **few weeks leading up to** your first surgery?

Not well at all (1)

A little bit (2) Some (3) A fair

amount (4) Very well (5)

Page Break



Q5.4 Did you get to choose your surgeon?

- Yes (1)
- No (0)

Skip To: Q5.7 If Q5.4 = 0

Display This Question:
If Q5.4 = 1

Q5.5 Was this surgeon your first choice?

Yes (1) No, they were my second choice

(2) No, they were my third choice or lower

(3)

Display This Question:
If Q5.4 = 1

Q5.6 How **important** were each of the following for you when choosing your surgeon?

	Not important (1)	Slightly important (2)	Moderately important (3)	Very important (4)	Extremely important (5)
Short wait time (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Location (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

A particular procedure that surgeon performs (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The surgeon's reputation (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The number of procedures the surgeon performed previously (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship or rapport with surgeon (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bedside manner (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coverage by insurance or public plan (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Minimizing costs (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q5.7 Did you experience any of the following barriers or challenges while trying to access surgery? Select all that apply

- BMI or weight restrictions (1)
- Insurance issues (2)
- Discrimination (examples: race, gender expression, being neurodivergent) (4)
- Quitting smoking or vaping (5)

Feeling like you needed to lie about mental health (6)

Feeling like you needed to lie about an eating disorder (7)

Feeling like you needed to lie about substance use (8)

A real life test (9)

Page Break

Q5.8

The next question will ask you about your mental health. Remember you can skip any question for any reason.

If any questions in this survey bring up emotional or mental health challenges, consider visiting one of these websites to find resources near you.

<https://mindyourmind.ca/help/where-call> (Canada and USA)

<https://checkpointorg.com/global/> (Canada and USA)

If you experience a mental health crisis considering reaching out to one of the following services:

Thrive lifeline – text “THRIVE” to +1 (313) 662-8209 from anywhere to begin your conversation 24/7/365 (Canada and USA)

Trans Lifeline – (877) 565-8860 Crisis Text Line – text “START” to 741-741 from anywhere in the USA to text with a trained Crisis Counselor (USA only)

The Trevor Project – (866) 488-7386 for youth up to 24 (Canada and USA)

If you experience any suicidal thoughts or ideation, please reach out to one of the following:
National Suicide Prevention Hotline - 24/7 hotline, staffed by trained individuals 1-800-273-8255 (USA only)

Canada Suicide Prevention Service – available 24/7/365 at 1-833-456-4566 or text 45645 from

4 pm - Midnight ET (Canada only)

Or find a suicide hotline at <https://www.opencounseling.com/suicide-hotlines>



Q5.9 How would you describe your mental health **in the year before** you had phalloplasty or metoidioplasty? Excellent (5) Very good (4) Good (3) Fair (2)

Poor (1)

Page Break



Q5.10 Thinking back to the year before surgery, how much dysphoria did you have about your **body, generally**?

A lot (4) A

moderate amount (4)

Some (2) Not much

(1) None at all (0)



Q5.11 Thinking back to the year before surgery, how much dysphoria did you have about your **genitals**?

A lot (4) A

moderate amount (3)

Some (2) Not much

(1) None at all (0)



Q5.12 Thinking back to **the year before** surgery, how much euphoria (happiness or joy) did you experience related to your body, generally?

A lot (4) A

moderate amount (3)

Some (2) Not much

(1) None at all (16)

Page Break _____

Page Break

Q5.13 The next section will ask you questions about your sex life including masturbation and partnered sex in the year before your surgery. In this section, we use terms commonly used in the trans community to refer to genitals.

Page Break



Q5.14

In the year leading up to your surgery, did you have any sexual partners? By sex we mean any type of act you would do with a partner and consider to be sexual.

- Yes (1)
- No (0)

Skip To: Q5.17 If Q5.14 = 0

Q5.15 In the year leading up to your surgery, what kinds of partnered sex did you have? Select all that apply

- Mutual masturbation (1)
- Oral sex (2)
- Fingering (sex using fingers) (3)
- Fisting (sex using fists) (4)
- Anal sex as bottom (receptive partner) (5)
- Anal sex as top (insertive partner) (6)
- Sex in my front hole (7)
- Sex in my partner's front hole (8)
- Sex with prosthetics or sex toys (9)



Online sex (camming, sexting) (10)

Group sex (12)

Q5.16 In the year leading up to surgery, how satisfied were you with your sex life, overall?

Not at all (0) A little bit (1)

Somewhat (2) Quite a bit (3)

Very (5)

Page Break



Q5.17 **In the year leading up to surgery how often did you masturbate (alone)?**

Never (0) Rarely (1)

Sometimes (2) Often (3)

Daily (4)

Skip To: Q5.19 If Q5.17 = 0

Q5.18 **In the year leading up to surgery how did you masturbate? Select all that apply**

Touching external genitals (1)

Using 'front hole' or internal genitals (with toys or fingers) (2)

Using toys externally (3)

Anal penetration (4)

I didn't masturbate (5)

I'm not sure (6)

Something else: please specify (7)

8 clothed genital

touching _____

X→

X→

Q5.19 **Before** surgery, did you ever have a Sexually Transmitted Infection or STI (example, gonorrhea)? Yes

(1) No (0) Not sure (2)

Page Break

Q5.20 In the next section, we are going to ask a few questions about your preparation and surgical readiness processes.

What did the process of obtaining approval to have surgery look like for you? Select all that apply

- Two letters from a therapist (1)
- One letter from a therapist (2)
- Interview by readiness assessor (3)
- A combination of letters and a class/workshop or training (4)
- Workshops or training (5) Something else: specify (6)



Q5.21 How useful was this method of approval for preparing you to have surgery? Extremely useful

(5) Very useful (4) Moderately useful (3) Slightly useful (2) Not at all useful (1)



Q5.22 How **well informed** were you about the risks and potential complications associated with your surgery?

Extremely well (5) Very well (4) Moderately well (3) Slightly well (2) Not well at all (1)



Q5.23 Before you had phalloplasty or metoidioplasty how much **knowledge** would you say you had about each of the following:

	None at all (0)	Very little (1)	A bit (2)	A fair amount (3)	A lot (4)
The way the procedure is conducted (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The rates of complication or risks associated with the procedure (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to prepare for surgery (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What to expect while in the hospital (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What to expect for the first weeks after leaving the hospital (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What recovery would be like (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What normal healing from your surgery looks like (6)

What to do if complications occur (8)

The potential for post-operative depression or other mental health challenges (9)

The amount of pain to expect at various points in surgical recovery (10)

End of Block: Around surgery time



Start of Block: After surgery

Q6.1 This question is an attention check. It is used to ensure participants are reading questions before choosing responses. In the following list, please select the word 'rabbit'.

- Pig (0) Frog (0) Cat (0)

- Rabbit (1)

Page Break _____ Q6.2 The next set of questions asks about your surgical experiences, recovery and other experiences after surgery. All questions in this survey are asking questions about your experiences with phalloplasty and metoidioplasty, unless otherwise specified. Remember, you can skip any question for any reason.

Q6.3 How well do you remember the few **weeks just after** surgery while you were recovering?

- Not well at all (1)
- A little bit (2) Some (3)
- A fair amount (4) Very well (5)
-

Q6.4 At the time of your surgery, how long had it been since you started to medically transition? Less than a year

- (1) One to two years (2) Two to three years (3) Three to five years (4) Five to 10 years (5)
- More than 10 years (6)
-



Q6.5 How long was the wait (**in months**) from your first referral to the time you had surgery? Leave blank if you do not remember.

Q6.6 How many stages were **planned** for your surgery(ies)? (Not including hysterectomy) Only one (1)

Two (2) Three (3) Four or more (4)



Q6.7 In total, how many surgeries have you had? (Including to address complications or planned surgeries like implants)

Q6.8 Did COVID 19 impact your plans for phalloplasty or metoidioplasty, or planned additional procedures like implants in any of the following ways? Select all that apply

A planned surgery was rescheduled for a later date (1)

A planned surgery was delayed for longer than 6 months (2) A planned surgery was

indefinitely put on hold (3)

None of the above (4)



Q6.9 Did you pay out of pocket for your surgery(ies), including travel and accommodation if applicable?

- Yes, all of it (1) Yes, a portion of it (2) No, none of it (0)
- Not sure (3)

Display This Question:

If Q6.9 = 1

Or Q6.9 = 2

Q6.10 How much did you spend in total (estimate if unsure)?

Q6.11 How far did you travel for surgery?

Within my city or town (1)

Outside my city or town (2)

Outside my state, province or territory (3)

Outside my country (4)

Display This Question:

If Q6.11 = 4

X+

Q278 To which country did you travel to have your surgery?

▼ Afghanistan (1) ... Zimbabwe (1357)

Page Break

Q6.12 Which of the following procedures have you had? Select all that apply

- Metoidioplasty (1)
- Erogeous tissue release (also known as clitoral release) (2)
- Phalloplasty (3)
- Urethral lengthening (4)
- Vaginectomy (5)
- Scrotoplasty (6)
- Glansplasty (7)
- Erectile implant(s) (8)
- Testicular implants (9)
- Other, specify: (10) _includes like hysto, oopho and tissue expanders_____

11. debulking

12. monsplasty

7777. poor data quality

13. revisions and repairs

Display This Question:

If Q6.12 = 3

Q6.13 Which donor site was used?

- Forearm (1) Thigh (2) Back (3) Bicep (4) Abdomen (5) A combination of the above (7)

Other, specify (6) _____

Display This Question:

If Q6.12 = 4

Q6.14 To where was your urethra extended? The tip of my penis

(1) Base of penis (2) Along the shaft but not to the tip (3)

Display This Question:

If Q6.13 = 1

Or Q6.13 = 2

Q6.15 How many weeks of laser hair removal or electrolysis did you have? (write 0 if you did not have this)



Q6.16 Have you had medical tattooing on your penis or scrotum?

Yes (1)

No (0)

Display This Question:

If Q6.12 = 1



Q6.17 After your metoidioplasty, did you have monsplasty (or a pubic lift)? Yes (1)

No (0)

Page Break _____



Q6.18 Did you experience any physical health issues or complications (meaning anything that required medical attention) because of your surgery?

- Yes (1) No (0) Not sure (2)

Skip To: Q6.35 If Q6.18 = 0



Q6.19 Did you experience any infection?

- Yes (1) No (0) Not sure (2)

Display This Question:

If Q6.13 = 1

And Q6.13 = 2



Q6.20 Did you experience any necrosis on your donor site(s)?

- Yes (1) No (0) Not sure (2)

Display This Question:

If Q6.12 = 3

X→

Q6.21 Did you experience necrosis (death of skin or tissues) on your penis?

- No (0)
- Yes (1)

Display This Question:

If Q6.12 = 4

X→

Q6.22 Did you experience a urethral fistula?

- Yes (1) No (0) Not sure (2)

Display This Question:

If Q6.12 = 4



Q6.23 Did you experience a urethral stricture?

- Yes (1) No (0) Not sure (2)

Display This Question:

If Q6.12 = 5



Q6.24 Did you experience a fistula around where your front hole used to be?

- Yes (1) No (0) Not sure (2)

Display This Question:

If Q6.12 = 1

Or Q6.12 = 2



Q6.25 Did you experience retraction (reduction of the length of your penis)?

- Yes (1) No (0)

Not sure (2)

Display This Question:

If Q6.12 = 8

X+

Q6.26 Have you experienced any protrusion (puncturing of skin) from an erectile implant?

Yes (1) No (0) Not sure (2)

Display This Question:

If Q6.12 = 8

X+

Q6.27 Have you experienced any infection of an erectile implant?

Yes (1) No (0) Not sure (2)

Display This Question:

If Q6.12 = 8

X+

Q6.28 Have you needed an erectile implant removed for any reason? Yes, due to a complication or other issue (1) Yes, due to regular wear and tear after several years (2) No (0)

Display This Question:

If Q6.12 = 9

X→

Q6.29 Did you lose a testicular implant or need to have it removed?

Yes (1)

No (0)

X→

Q6.30 Did you have any additional surgeries to address complications (not including any planned surgery)?

Yes (1)

No (0)

Display This Question:

If Q6.30 = 1

X+

Q6.31 Did your original surgeon perform this surgery(ies)?

Yes (1)

No (0)

Display This Question:

If Q6.30 = 1

Q6.32 How long was the wait from your original surgery to your first surgical revision? Less than 3

months (1) Between 3 and 6 months (2) Between 9 months and a year (3) Between a year

and year and a half (4) 1.5 to 2 years (5) Over 2 years (6)



Q6.33 Are you still waiting for revisions (whether scheduled or not)?

Yes (1)

No (0)

Page Break



Q6.34 Next, we are going to ask you about how **severe** your complications were. Carefully read the following options and **choose one that best fits** the experience you had. 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) (1) Complications needing the use of medication for infection or other serious issue (for example, a bladder infection) (2) 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) and does not require general anesthesia (3.1) 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 and does require general anesthesia (3.2)



Any life-threatening complication and/or any single organ dysfunction (for example, needing dialysis for kidney failure). This includes any additional stays in ICU (not the planned time spent in ICU after phalloplasty) (4.1)



Any life-threatening complication and/or any multi organ dysfunction. This includes any additional stays in ICU (not the planned time spent in ICU after phalloplasty) (4.2)

Page Break _____



Q6.35 Did anything happen during your surgery that you did not expect or did not consent to but was not a complication? (for example, a change in donor site, removal of tissues or organs)?

Yes (1) No (0) Not sure (2)

Page Break _____

Q6.36 After leaving the hospital, what kind of care did you receive? Select all that apply.

- Recovery house (1)
- An in-home nurse (2)
- My spouse, partner or significant other took care of me (3)
- Family took care of me (4)
- Friends or roommates took care of me (5)
- I cared for myself (8)
- Something else (6)



Q6.37 How much support do you feel you had, **generally**, while recovering from surgery?

- A lot (4) A fair amount (3) Some (2) Not much

(1)

None (0)

Display This Question:

If Q6.11 = 2

Or Q6.11 = 4

Or Q6.11 = 3

X→

Q6.38 Did you have a care team that was local(close to your home) you could access if needed (example: a urologist or other surgeon)?

Yes (1)

No (0)

Display This Question:

If Q6.38 = 1

X→

Q6.39 Was your local care team set up before surgery?

Yes (1) No (0) Not sure (2)



Q6.40 How easy was it to follow aftercare instructions given to you?

- Extremely easy (1) Somewhat easy (2) Neither easy
nor difficult (3) Somewhat difficult (4) Extremely
difficult (5) I was not given aftercare instructions (0)

Q6.41 How challenging was your recovery?

- Not challenging at all (1) Slightly challenging (2)
Moderately challenging (3) Very challenging (4)
Extremely challenging (5)
-

Page Break



Q6.42 What was the **biggest** challenge you experienced during recovery?



Q6.43 What is **one** tip or piece of advice about recovery you would give to others planning to have surgery?

Page Break

Q6.44 How much time did you take off from school or work for your initial surgery? Less than 4 weeks

(1) 4-6 weeks (2) 7-8 weeks (3) 9-12 weeks (4) More than 12 weeks (5) Not

applicable (6)

Skip To: Q6.46 If Q6.44 = 6



Q6.45 Was this enough time off work or school?

Yes (1) No (0) Not sure (2)

Page Break

Q6.46 During recovery, were you ever **denied** the following healthcare when you needed it? Select all that apply

Emergency care (1)

Urgent care (2)

Primary care (3)

Specialist care (4)

Mental health care (5)

A(another) surgeon's care (6)

Display This Question:

If Q3.17 = 1



Q6.47 Earlier, you said you have a disability or chronic health condition. Did this impact your surgery or recovery in any way? Yes (1) No (0) Not sure (2)

Page Break _____ Q6.48 The next questions are about your experiences talking with your surgeons and doctors at the clinic who provided your surgical care for phalloplasty or metoidioplasty. Thinking back to the time when you interacted with this surgical team, please answer the following questions. If you had more than one care team, answer these questions based on the team who conducted your first surgery.

How often did someone from the surgical team speak too fast?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.49

How often did someone from the surgical team use words that were hard to understand?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.50

How often did someone from the surgical team ignore what you told them?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.51 How often did someone from the surgical team appear to be distracted when they were with you?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.52 How often did someone from the surgical team seem bothered if you asked several questions?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.53 How often did someone from the surgical team really find out what your concerns were?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.54 How often did someone from the surgical team let you say what you thought was important?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.55 How often did someone from the surgical team take your health concerns very seriously?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.56 How often did someone from the surgical team explain results of tests (blood tests, X ray, CT, etc)?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.57 How often did someone from the surgical team clearly explain the results of a physical exam?

- Never (1) Rarely (2) Sometimes (3) Usually (4) Always (5)
-

Q6.58 How often did someone from the surgical team tell you what could happen if you didn't take a medicine that they prescribed for you?

- Never (1) Rarely (2) Sometimes (3) Usually (4)

- Always (5)
-

Q6.59 How often did someone from the surgical team tell you about the side effects you might get from a medicine?

- Never (1) Rarely (2) Sometimes (3) Usually (4)

- Always (5)
-

Q6.60 How often did someone from the surgical team ask if you would have any problems following what they recommend?

- Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.61 How often did you and someone from the surgical team work out your surgical plan together?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.62 If there were surgical choices, how often did someone from the surgical team ask if you would like to help decide your treatment?

Never (1) Rarely (2) Sometimes (3) Usually (4) Always (5)

Q6.63 How often was your surgical team compassionate?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.64 How often did your surgical team give you support and encouragement?

- Never (1) Rarely (2) Sometimes (3) Usually (4)
- Always (5)

Q6.65 How often was your surgical team concerned about your feelings? Never (1)

- Rarely (2) Sometimes (3) Usually (4)
- Always (5)

Q6.66 How often did your surgical team really respect you as a person?

- Never (1) Rarely (2) Sometimes (3) Usually (4)
- Always (5)

Q6.67 How often did your surgical team treat you as an equal?

- Never (1) Rarely (2) Sometimes (3) Usually (4)
- Always (5)

Q6.68 How often did your surgical team make assumptions about your level of education?

- Never (1) Rarely (2) Sometimes (3) Usually (4)
- Always (5)

Q6.69 How often did your surgical team make assumptions about your income?

- Never (1) Rarely (2) Sometimes (3) Usually (4)
- Always (5)

Q6.70 How often did your surgical team pay less attention to you because of your race or ethnicity?

- Never (1) Rarely (2) Sometimes (3) Usually (4)
- Always (5)

Q6.71 How often did you feel discriminated against by your surgical team because of your race or ethnicity?

- Never (1) Rarely (2) Sometimes (3) Usually (4)
- Always (5)

Q6.72 The next four questions ask about the front office staff, meaning the receptionist or the person you talk to on the phone (or email with) to make an appointment.

How often were office staff rude to you?

- Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.73 How often did office staff talk down to you?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.74 How often did office staff give you a hard time?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)

Q6.75 How often did office staff have a negative attitude towards you?

Never (1) Rarely (2) Sometimes (3) Usually (4)

Always (5)



Q6.76 How often were you misgendered by staff at the surgeons office or hospital?

Never (1) Sometimes (2) About half the time (3) Most of the time

(4)

Always (5)

Page Break

Q6.77 The next question will ask you about your mental health. Remember you can skip any question for any reason.

If any questions in this survey bring up emotional or mental health challenges, consider visiting one of these websites to find resources near you. <https://mindyourmind.ca/help/where-call> (Canada and USA)
<https://checkpointorg.com/global/> (Canada and USA)

If you experience a mental health crisis considering reaching out to one of the following services:

Thrive lifeline – text “THRIVE” to +1 (313) 662-8209 from anywhere to begin your conversation 24/7/365 (Canada and USA)

Trans Lifeline – (877) 565-8860 Crisis Text Line – text “START” to 741-741 from anywhere in the USA to text with a trained Crisis Counselor (USA only)

The Trevor Project – (866) 488-7386 for youth up to 24 (Canada and USA)

If you experience any suicidal thoughts or ideation, please reach out to one of the following:

National Suicide Prevention Hotline - 24/7 hotline, staffed by trained individuals 1-800-273-8255 (USA only)

Canada Suicide Prevention Service – available 24/7/365 at 1-833-456-4566 or text 45645 from 4 pm - Midnight ET (Canada only)

Or find a suicide hotline at <https://www.opencounseling.com/suicide-hotlines>



Q6.78 Do you think your mental health has **changed** as a result of surgery?

Yes, it improved a lot (1) Yes, it

improved a little (2) No, nothing has

changed (3) Yes, it got a little worse

(4) Yes, it got a lot worse (5)

I'm not sure (0)

X→

Q6.79 Did you experience any life events **around the time** of your surgery (job loss, marriage, loss of partner) that impacted your mental health?

Yes (1) No (0) Not sure

(2)

Display This Question:

If Q6.79 = 1

Or Q6.79 = 2

Q6.80 Which of the following did you experience? Select all that apply

A break-up or divorce (1)

Loss of employment (2)

- Death of close family member, friend or partner (3)
 - A marriage (4)
 - Starting a new job or educational program (5)
 - A financial hardship (7)
 - Something else (6)
-



Q6.81 Did you experience post-operative depression? Post-op depression can look and feel different for everyone, an example might be “feeling more depressed than usual due to stress of surgery and recovery”. Answer this question based on what post-op depression means to you.

- Yes (1) Maybe (2) No (0)

 - Not sure (3)
-

Page Break



Q6.82 This question is an attention check. It is used to ensure participants are reading questions before choosing responses. In the following list, please select the word **'whale'**.

Octopus (0) Dolphin (0) Whale (1)

Fish (0)

End of Block: After surgery

Start of Block: Recent experiences

Page Break

Q7.1 This next section is about how you feel **right now**. Answer all the following questions about the present unless they ask about a different time period. Remember you can skip any question for any reason.

Q7.2

Overall, how satisfied are you with your surgery? Extremely satisfied

(6) Somewhat satisfied (7) Neither satisfied nor dissatisfied

(8) Somewhat dissatisfied (9) Extremely dissatisfied (10)

Q7.3 How **well** would you say your surgical goals were met? Extremely well (6)

Very well (7) Moderately well (8) Slightly well (9) Not well at

all (10)

Page Break _____ Q279 **The next few questions will ask you about your mental health. Remember you can skip any question for any reason.**

If any questions in this survey bring up emotional or mental health challenges, consider visiting one of these websites to find resources near you. <https://mindyourmind.ca/help/where-call> (Canada and USA)
<https://checkpointorg.com/global/> (Canada and USA)

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Or find a suicide hotline at <https://www.opencounseling.com/suicide-hotlines>



Q7.5 In general, would you say your mental health is... Excellent (5)

Very Good (4) Good (3) Fair (2)

Poor (1)



Q7.6 Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way **during the past week** by checking the appropriate box for each question.

	Rarely or none of the time (less than 1 day) (1)	Some or a little of the time (1-2 days) (2)	Occasionally or a moderate amount of time (3-4 days) (3)	All of the time (5-7 days) (4)
I was bothered by things that usually don't bother me (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had trouble keeping my mind on what I was doing (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt depressed (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that everything I did was an effort (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt hopeful about the future (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt fearful (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My sleep was restless (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I felt happy (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt lonely (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I could not 'get going' (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.7 Overall, how much social support would you say you have right now?

- A lot (2) A fair bit (3)
- A little bit (4) None (6)

Page Break _____

Q7.8 Do you think having surgery changed your experience of dysphoria (**overall**)? Yes, my

dysphoria decreased (1) No, it did not change (2) Yes, my dysphoria increased (3) I

never had dysphoria (4) Not sure (5)

Q7.9 How much dysphoria (generally) do you have now?

A lot (1) A moderate amount (3) Some

(4) Not much (5) None at all (6)

Q7.10 How much dysphoria do you have about your **genitals** now?

A lot (1) A moderate amount (3) Some

(4) Not much (5) None at all (6)

Q7.11 How much euphoria (happiness or joy) related to your body do you have now?

A lot (1) A moderate amount (3) Some

(4) Not much (5) None at all (6)

Page Break _____



Q7.12 Next, we are going to ask some questions about your satisfaction with your genitals. Please tell us how much you agree with each of the following.

	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)
I feel positively about my genitals (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with the appearance of my genitals (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would feel comfortable letting a sexual partner look at my genitals (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with the size of my genitals (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My genitals work the way I want them to (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am not embarrassed about my genitals (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I feel
comfortable
letting a
healthcare
provider
examine my
genitals (7)



Page Break

Q7.13

	Extremely dissatisfied (1)	Very dissatisfied (2)	Somewhat dissatisfied (3)	No feeling one way or the other (4)	Somewhat satisfied (5)	Very satisfied (6)	Extremely satisfied (7)	Not applicable (8)
Length of your penis (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Girth (width) of your penis (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Color of your genitals (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shape of glans (regardless of whether you had glansplasty or not) (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Location of urethra (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Texture of skin (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Curvature of
penis
(whether
your penis
curves or
bends,
when erect
or not) (7)

Size of
scrotum
(8)

Genital veins
(or

Using the following,
rate how satisfied you
are with each of these
aspects of your
genitals.

lack of
veins,

of
you've
tattooing

Amount

pubic hair

Amount
ejaculate,
pre-cum,
cum, any

fluid from
the penis

Scent of
genitals

regardless
whether
had
or not) (9)

of

of

(11)

(10)

(12)



Q7.14 What is **one** thing that makes you feel euphoria (or happy) about your genitals since you had surgery?

Page Break _____

Page Break _____



Q7.15 Next, we are going to ask questions about your experiences with masturbation since surgery.

Since surgery, have you masturbated?

Yes (1)

No (0)

Display This Question:

If Q7.15 = 1

Q7.16 Since surgery how do you masturbate? Select all that apply

- Stimulating external genitals (1)
- Using 'front hole' or internal genitals (with toys or fingers) (2)
- Using toys externally (3)
- Anal penetration (4)
- Something else (5)

Not sure (6)

Display This Question:

If Q7.15 = 1

- Q7.17 Since surgery, on average, how **often** do you masturbate? Daily (5) 4-6 times a week (4) 2-3 times a week (3) Once a week (2) One or two times a month (6) Less than once a month (7) Rarely (8)
- Never (1)

Display This Question:

If Q7.15 = 1

Q7.18 How satisfied do you feel with your masturbation?

- Extremely satisfied (6) Somewhat satisfied (7) Neither satisfied nor dissatisfied (8) Somewhat dissatisfied (9) Extremely dissatisfied (10)

Page Break



Q7.19 Next, we are going to ask you about your sexual experiences since surgery.

Since surgery have you had any sexual partners?

Yes (1)

No (0)

Q7.20 How long were you told to wait after surgery until you had partnered sex again? Less than 6

weeks (6) 6 - 7 weeks (1) 8-9 weeks (2) 10-12 weeks (3)

More than 12 weeks (3 months) (4) More than 6 months (7) Not sure (5)

Display This Question:

If Q7.19 = 1

- Q7.21 How long after surgery did you actually wait until you had partnered sex again? Less than 6 weeks (7) 6 - 7 weeks (1) 8-9 weeks (2) 10-12 weeks (3) More than 12 weeks (3 months) (4) More than 6 months (5) Not sure (6)

Display This Question:

If Q7.19 = 1

- Q7.22 Since surgery on **average**, how often do you engage in partnered sexual activity? Daily (5) 4-6 times a week (4) 2-3 times a week (3) Once a week (2) One or two times a month (6) Less than once a month (7) Rarely (9) Never (1)

Display This Question:

If Q7.19 = 1

Q7.23 **Since** your surgery, what kinds of partnered sex have you engaged in? Select all that apply

- Mutual Masturbation (1)
- Oral Sex (receiving) (2)
- Oral Sex (giving) (14)
- Fingering (sex using fingers) (3)
- Fisting (sex using fists) (4)
- Anal sex as bottom (receptive partner) (5)
- Anal sex as top (insertive partner) (6)
- Sex in my front hole (7)
- Sex in my partner's front hole (8)
- Sex with prosthetics or sex toys (9)
- Online sex (camming, sexting) (10)
- Group sex (12)



Other (13)

Display This Question:
If Q7.19 = 1



Q7.24 How satisfied do you feel with your partnered sex?

- Extremely satisfied (5) Somewhat satisfied (4)
- Neither satisfied nor dissatisfied (3) Somewhat
dissatisfied (2) Extremely dissatisfied (1)

Display This Question:

If Q6.18 = 1

And Q7.19 = 1



Q7.25 Have your surgical complications ever impacted your ability to have partnered sex?

- Yes (1) Maybe (2)
- No (0)

Page

Break

Q7.26 Now we are going to ask about experiences related to sex in the **past 30 days**.

How interested have you been in sexual activity?

- Not at all (1) A little bit (2)
- Somewhat (3) Quite a bit (4)

Very (5)

Q7.27

In the past 30 days...

How often have you felt like you wanted to have sexual activity?

Never (1) Rarely (3) Sometimes (2)

Often (4)

Always (5)

Q7.28 There are many reasons why people may not have had sexual activity during the month.

What are the reasons why you did not have sexual activity in the past 30 days?

Please read the list carefully and select every reason that applies to you, even if it happened only one time during the past 30 days.

Was not interested in having sexual activity (1)

Difficulties with orgasm/climax (2)

Don't enjoy sexual activity (3)

Health condition (4)

No partner (5)

Partner was away (6)

Partner was not interested in sexual activity (7)

Partner's health condition (8)

COVID 19- related reasons (10)

Some other reason (9)



Q7.29

In the past 30 days...

How often have you been able to have an orgasm/climax when you wanted

to? Have not tried to have an orgasm/climax in the past 30 days (0)

Never (1) Rarely (2) Sometimes (3) Often (4) Always

(5)



Q7.30

In the past 30 days...

How satisfying have your orgasms or climaxes been?

Have not had an orgasm/climax in the past 30 days (0)

Not at all (1) A little bit (2)

Somewhat (3) Quite a bit (4)

Very (5)

Q7.31

In the past 30 days...

How satisfied have you been with your sex life?

Not at all (1) A little bit (2)

Somewhat (3) Quite a bit (4)

Very (5)

Q7.32

In the past 30 days...

How much pleasure has your sex life given you?

Not at all (1)

A little bit (2) Some (3) Quite a bit (4)

A lot (5)

Page Break _____

Display This Question:

If Q7.19 = 1



Q7.33 Since surgery, do you disclose that you had phalloplasty and/or metoidioplasty to new sex partners? Yes, always (1) Yes, sometimes (2) No (0) I haven't had a new sex partner since surgery (9998)

Skip To: Q7.35 If Q7.33 = 9998

Display This Question:
If Q7.19 = 1



Q7.34 Since surgery, do you disclose that you are not a cisgender man to new sex partners? Yes, always (1) Yes, sometimes (2) No (0)

Page Break

Q7.35 Next, we are going to ask about worries you might have related to sex. Select how strongly you agree with each of the following statements. When I think about sex, I worry....

	Not at all (1)	Slightly (2)	Somewhat (3)	Moderately (4)	Very (5)
That other people think my body is unattractive (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
That there are very few people who would want to have sex with me (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About feeling ashamed about my body (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

That once I
am naked,
people will
not see me
as the gender
I am (5)

That I can't
have the sex I
want until I
have another
surgery (2)

Page

Break

Q7.36 Since surgery, has a doctor or nurse ever talked to you about your risk for STIs?

Yes (1)

Not sure (2)

No (3)

Display This Question:

If Q7.19 = 1

Q7.37 How much **risk** do you think you have for getting an STI?

None at all

(1) A

little (2)

A moderate amount (3)

A lot (4)

Not sure (5)



Q7.38 Since surgery, have you ever been tested for an STI?

Yes (1)

No (0)

Not sure (2)

Display This Question:

If Q7.38 = 1

Q7.39 What type of STI test did you have? Select all that apply

A urine test (1)

A urethral swab (2)

A throat swab (3)

A front hole swab (4)

An anal swab (5)

A blood test (6)

Q7.40 Since surgery, have you had any of the following STIs? Select all that apply

Syphilis (1)

Warts (genital or anal) (2)

Chlamydia (3)

Herpes (genital or anal) (4)

Gonorrhea (5)

Non-specific urethritis (6)

Other(s) (7)

None of these (8)

Not sure (9)

Display This Question:

If Q7.40 = 1

Or Q7.40 = 2

Or Q7.40 = 3

Or Q7.40 = 4

Or Q7.40 = 5

Or Q7.40 = 6

Or Q7.40 = 7

Q7.41 Where did your STI occur? Select all that apply

- Urethra (1)
- Front hole (2)
- Penis (3)
- Scrotum (4)
- Anus (5)
- Not sure (6)

Page

Break

Q7.42 The next two questions are about experiences you may have had since surgery.

Q7.43 **Since your surgery** have you experienced any of the following? Select all that apply

- Had counseling related to your surgery (1)
- Attended a support group for those who have had surgery (2)
- Consulted with another surgical team about your genitals (3)
- Participated in online groups or discussions about phalloplasty or metoidioplasty (4)
- Feeling compelled to share photos of your genitals (5)
- Feeling compelled to share information about your surgical experience with others (6)

Been asked invasive or unnecessary questions about your surgery by a healthcare provider (7)

Been asked invasive or unnecessary questions about your genitals by a healthcare provider (8)

Been asked invasive, unnecessary questions about your genitals by a trans community member (9)

Experienced negativity within the trans community because you had surgery (10)

Feeling more comfortable in a locker room (11) Feeling

more comfortable in public bathrooms (12)

Page

Break

Q7.44 Where do you get support related to your surgical experiences? Select all that apply

Online social groups (eg. Facebook) (1)

Online discussion boards/forums (eg. Reddit) (2)

Friends (3)

Family (4)

- Partner or spouse (5)
- A counselor or therapist (6)
- A nurse or doctor (7)
- Something else (8)
- I don't have a place to get support about this aspect of my life (9)

Page Break

Display This Question:

If Q281 = 1

Q282 Earlier, you said you were between stages or 'active process'.

How much do you anticipate the following to change based on future surgeries...

	Not at all (1)	A bit (2)	Somewhat (3)	A fair amount (4)	A lot (5)
How well met your surgical goals are (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Satisfaction with your genitals (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Satisfaction with your sex life (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall surgical satisfaction (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Recent experiences

Start of Block: Reflecting back

Q8.1 The next two questions are going to ask you to reflect on choices you made before surgery, keeping in mind the knowledge and experience you have now after undergoing phalloplasty and/or metoidioplasty. Remember you can skip any questions you don't want to answer.

Looking back, would you have made any different choices based on your experiences or the knowledge you have now? Select all that apply

- Yes, I would have opted to add an additional procedure(s) (1)
 - Yes, I would have not included one or more procedures that I had (2)
 - Yes, I would have picked a different surgeon (3)
 - Yes, something else. (4)
 - No (5)
-

Q8.2 Do you think your care team adequately prepared you for surgery?

Definitely not (1)

Probably not (2) Not

sure (3) Probably

yes (4) Definitely

yes (5)

End of Block: Reflecting back

Start of Block: COVID questions and wrap up

Page Break



Q9.1 Last question! Is there anything we should have asked you in this survey but didn't?

Page Break

Q9.2 You've made it to the end! Thanks so much for taking this survey.

End of Block: COVID questions and wrap up

Appendix 3: PROGRESS REB Approval Certificate



University of Victoria

Certificate of Ethical Approval: Renewal for Harmonized Minimal Risk Behavioural Study

University of Victoria
 Human Research Ethics Board
 Michael Williams Building, R. B202 PO Box 1700
 STN CSC
 Victoria, BC V8W 2Y2
 Tel: 250-472-4545

Also reviewed and approved by:

- Children's and Women's Research Ethics Board

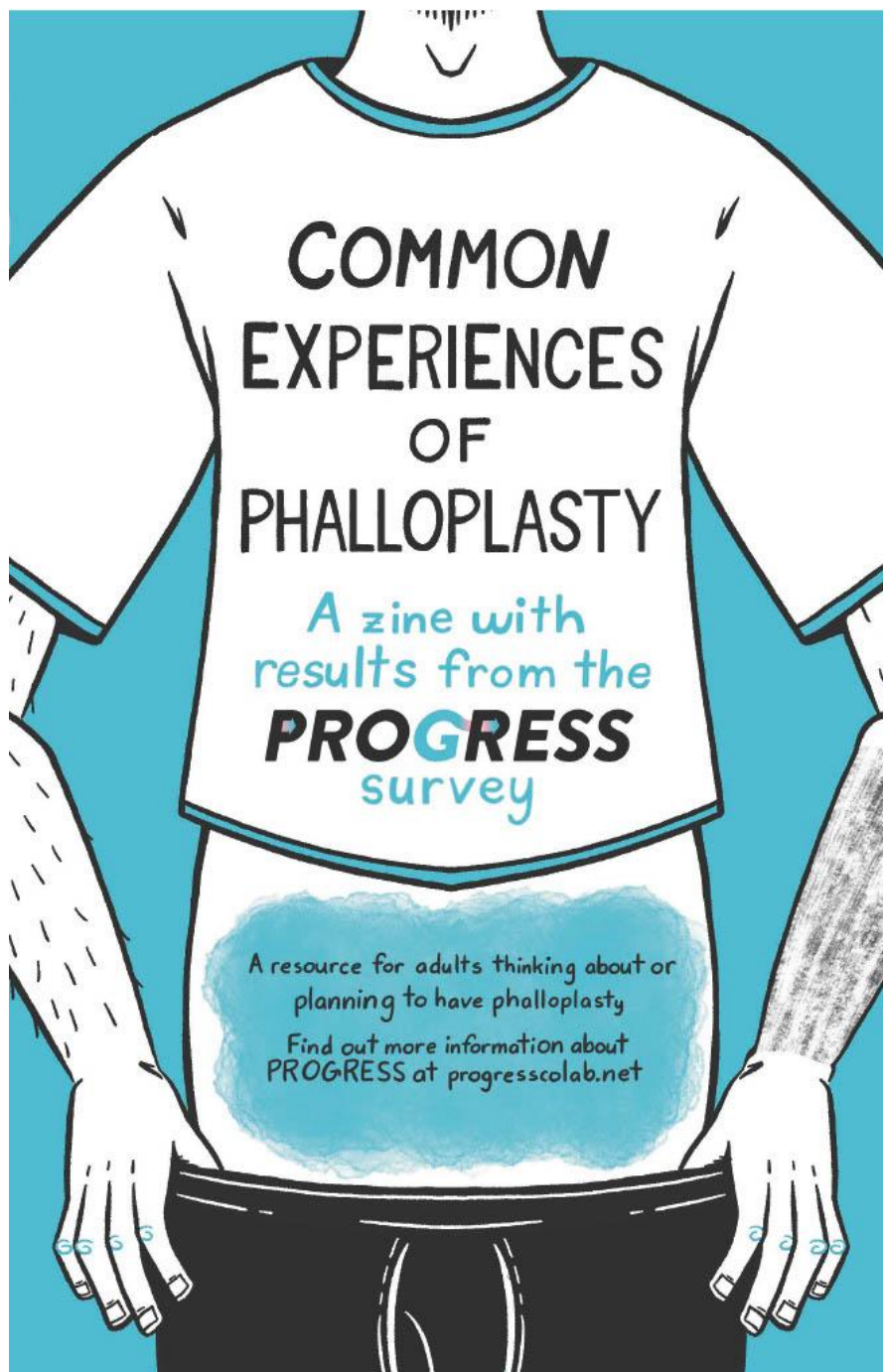


Principal Investigator: Nathan Lachowsky	Primary Appointment: University of Victoria	Board of Record REB Number: BC22-0164	REB Number: H22-00492 PAA #: H22-00492-A008
Study Title: PROGRESS (Patient-Reported Outcomes of Genital Reconstruction and Experiences of Surgical Satisfaction)			
Approval Date: October 9, 2024		Expiry Date: October 9, 2025	
Research Team Members:	Aaron H Devor (Faculty, UVic); Leo Rutherford (Student worker, UVic); Anya Slater (Research assistant, UVic); Lucas Wilson; Aeron Stark (Data analyst, UVic); Ayden Scheim (Drexel University) Community Engagement Committee members: Noah Adams, Linden Jennings, Logan Berrian, Gaines Blasdel		
Sponsoring Agencies:	- Canadian Institutes of Health Research (CIHR) - "Health after gender-affirming genital surgery: a patient-guided study (UVic #FN-6022, closed)" - Canadian Institutes of Health Research (CIHR) - "Trans Healthcare Research Co-lab (UVic #FN-11464)" - Michael Smith Health Research BC - "Transgender Healthcare Research Co-lab: A patient-oriented, community-based research program (UVic #FN-9469)"		
Documents included in this approval:	N/A		
Document(s) acknowledged with this submission:	Summary Report(s) There are no items to display		
This ethics approval applies to research ethics issues only and does not include provision for any administrative approvals required from individual institutions before research activities can commence. The Board of Record (as noted above) has reviewed and approved this study in accordance with the most recent requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2). The "Board of Record" is the Research Ethics Board delegated by the participating REBs involved in a harmonized study to facilitate the ethics review and approval process.			
The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.			

This study has been approved either by the Board of Record's full REB or by an authorized delegated reviewer.



Appendix 4: PROGRESS Zine



Hi, I'm Miles* (he/him)

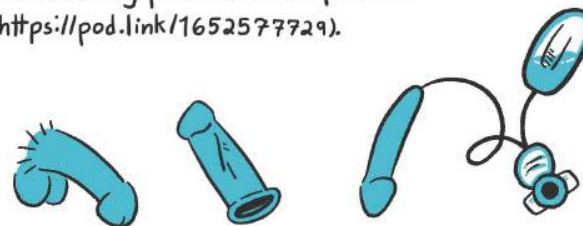


I was a participant in the PROGRESS study, and this zine explains my experience getting phalloplasty. A little bit about me: I'm 25, white, queer, and from Chicago. I had surgery in 2022, including a radial forearm phalloplasty (RFF), glansplasty, scrotoplasty, urethral lengthening (UL), and a vaginectomy. I hope this zine helps you understand what the experience is like and maybe figure out if you want to have surgery.

*Miles isn't a real person, but he does represent the average of the 215 participants from the PROGRESS Study (e.g. age, ethnicity, timeline of surgeries, satisfaction, etc).

PROGRESS was a survey designed and conducted by trans people that have lived experience of phalloplasty (phallo) or metoidioplasty (meta). We used our experiences to create a study that covered topics that are important to people who have had these surgeries or are interested in learning more about them.

This zine shows the results that are most common among our 215 participants, including how people prepare for surgery, what resources were useful to them, how challenging recovery was, and what changed as a result of undergoing surgery (like dysphoria or sex). We focus on phalloplasty because that was what most respondents had. Check out our website for more information and infographics (<https://progresscolab.net/>). You can also listen to our podcast from any major podcasting platform via podlink (<https://pod.link/1652577729>).



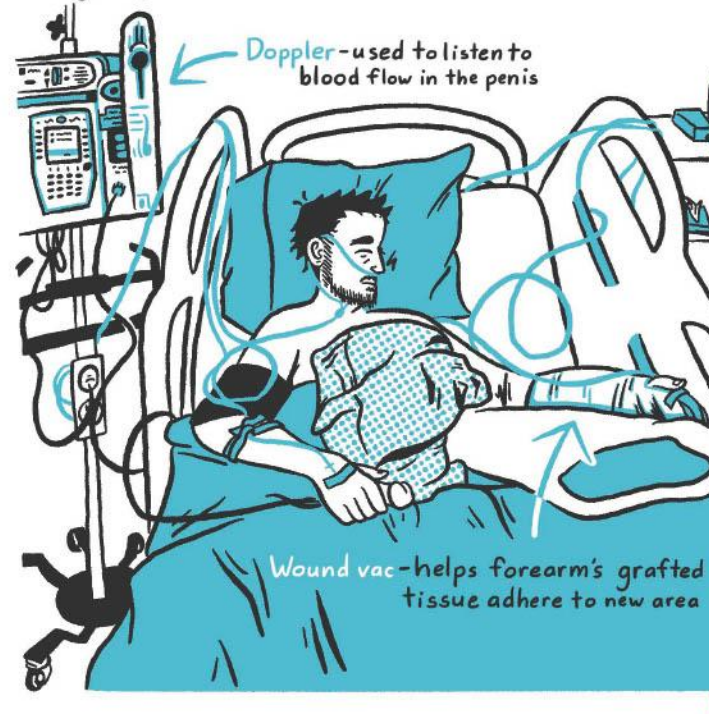
It was about 2 years from my consultation to when I actually had surgery, so I had lots of time to prepare.



To get ready, I had conversations with others who'd had surgery, both in person and on Facebook and Reddit. I also checked out a lot of blogs and vlogs and had a few surgical consults as well. All of these were super helpful in making me feel prepared for surgery. However, the readiness assessment I had was not helpful at all and only provided the two letters I needed to access surgery.

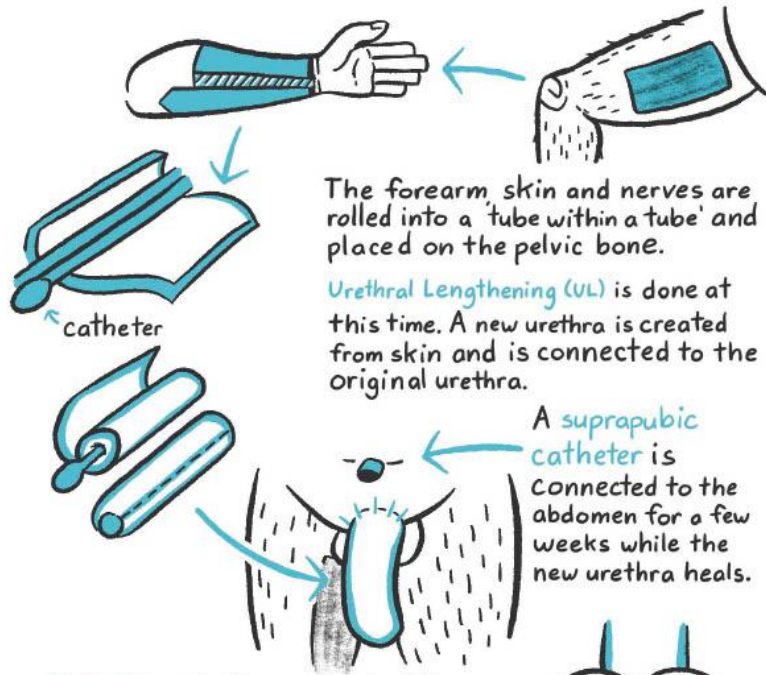


I knew that I wanted to have urethral lengthening, which means that they extend my old urethra to the tip of my penis, which meant that the risk of my having urethra-related complications would be high. I did end up having a fistula (an extra hole where urine was coming out) and had to have an additional surgery to fix this. Originally, I had planned to have 3 surgeries, (1) RFF with vaginectomy and scrotoplasty, (2) glansplasty, and (3) the implant. However, I've already had to have surgery to fix the fistula since getting phallo 8 months ago. Overall, I'd say that my recovery was moderately challenging, like a 3 on a scale from 1 to 5. It really helped that I took 8 weeks off of work.

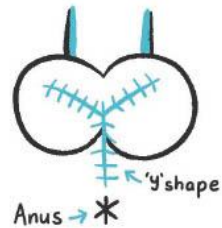


Surgery 1* - RFF, Vaginectomy, & Scrotoplasty

Radial Forearm Flap (RFF) Phalloplasty is the most common type of phalloplasty. Skin is taken with an artery from the forearm. The skin here is thin, flexible, and relatively hairless, making it ideal for surgical construction and erogenous sensation. A split-thickness skin graft from the opposite thigh replaces this skin on the forearm.



Vaginectomy is the removal of the vagina, and **scrotoplasty** is the creation of the scrotum. These are usually done together, with the scrotum created using tissue from the labia majora and placed behind the penis.



Surgery 2* - Glansplasty

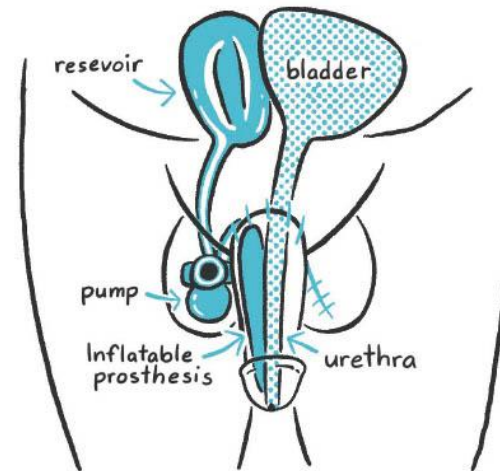
Glansplasty is a surgery to sculpt a ridge onto the phallus, making it look like a circumcized penis.



Surgery 3* - Implant

One last surgery is done to place the erectile implant.

Post-Phalloplasty Anatomy with Inflatable Erectile Implant

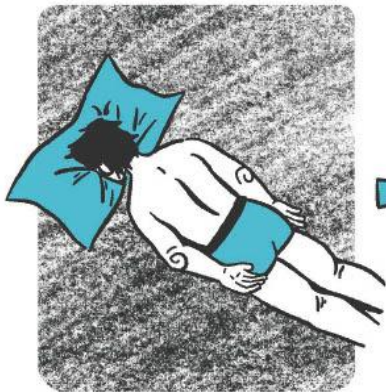


*Staging, or the order of surgeries, will depend on your surgeon. The information on this page depicts one common example, but you will need to check in with your surgeon to understand what your process will be like.

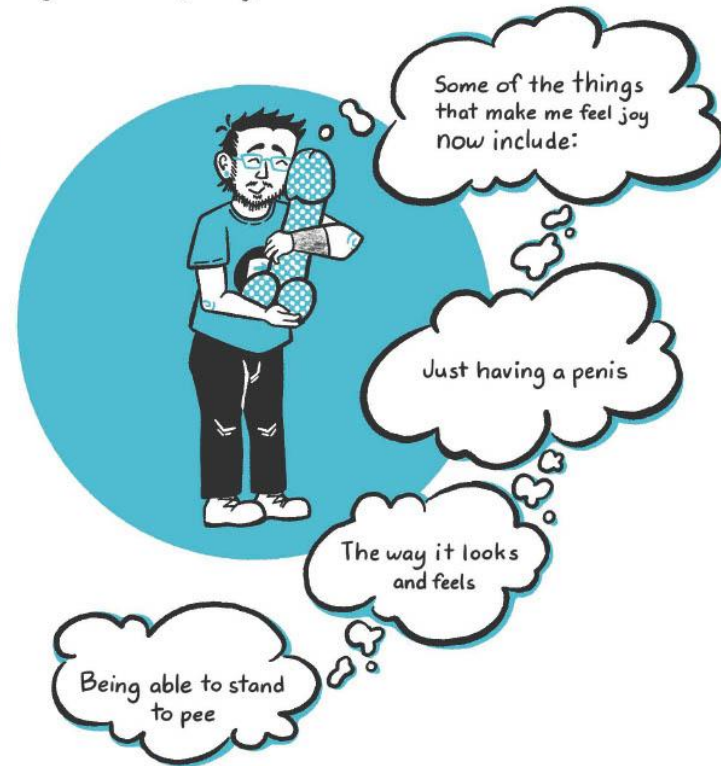
Overall, I'm really happy with the results of my surgery. Before, I would have rated my mental health as about a 2 on a 5 point scale, but now I feel much better—more like a 4.



I had a lot of trouble with dysphoria before, too, with a lot of genital-related dysphoria especially. Whereas I would have said my dysphoria was a 4 out of 5 before, now it's more like a 2.



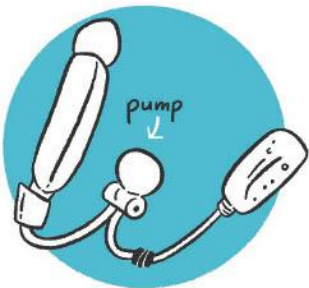
My feelings of gender-related and genital specific euphoria (feelings of happiness or joy) have also increased a ton since surgery! Before, I would have rated my euphoria about my genitals as especially low.





My surgeon just cleared me to have sex again, which has been awesome! I'm having more sex than I ever did before, even trying new things like having penetrative sex with my partner (it's tough without an erectile implant, but I got a penis sleeve that helps!). I'm much more satisfied with my sex life than I was before surgery! I'm really looking forward to getting an erectile implant so things can be even better in the bedroom??

Penis Sleeve- A hollow sheath that goes over the penis during sex.



Inflatable Erectile Implant- Implant filled with sterile saline. The pump/valve in the scrotum is used to fill/release the erection.

Here are a few pieces of data based on our average participant's experience:

73% of those who had phalloplasty had **Radial Forearm Free-Flap Phalloplasty (RFF)**, **71%** had **Urethral Lengthening (UL)**, and **68%** had **vaginectomy**

78% of participants felt they were **well-prepared** for surgery

58% of our sample experience some type of **complication**, and **57%** percent had a **fistula** after **UL**

Reflecting back to **before surgery**, **51%** rated their **mental health** as good or better than good

After surgery, **77%** said their **mental health** was good or better than good

After surgery, only **1%** reported a lot of **dysphoria** as compared to **65%** reporting it **before surgery**

For **euphoria**, only **5%** reported experiencing a lot **before surgery**, but **37%** reported it **after surgery**

75% of participants who had phalloplasty reported feeling really **satisfied with their sex life** after surgery

To read even more statistics from our survey findings, check out our **community report**, it shares our results and what they mean. You can find it here-

<https://progresscolab.net/studyresults/>

Created in
2024 by:

Ari Ganahl
Leo Rutherford
Noah Adams
& the PROGRESS Project
progresscolab.net

The PROGRESS study was conducted at the
University of Victoria and approved by the
University's research ethics board
(certificate # H22-00492-A007).

Thank you to our funder, the Canadian Institutes of
Health Research, the Strategy for Patient-Oriented
Research, and to The University of Victoria



Appendix 5: PROGRESS Community Report



PROGRESS

Thanks to our funders, the Canadian Institutes of Health Research (CIHR) and the Strategy for Patient-Oriented Research (SPOR) and to our partners, the University of Victoria, Trans Care BC and the Community-Based Research Centre.

This research was reviewed by research ethics board at both the University of Victoria and University of British Columbia - certificate number . If you have questions you can contact them at

Cite this report using the following suggested citation:
Rutherford, L., Adams, N., Castle, E. R., Lewis, A., and the PROGRESS team. 2024. PROGRESS for phalloplasty and metoidioplasty community report. <https://progresscolab.net/community-report/>

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

01

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02

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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 complete a 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-centered care in the process.

Overall, PROGRESS demonstrated the value of community-based research and the importance of centering 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 and 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

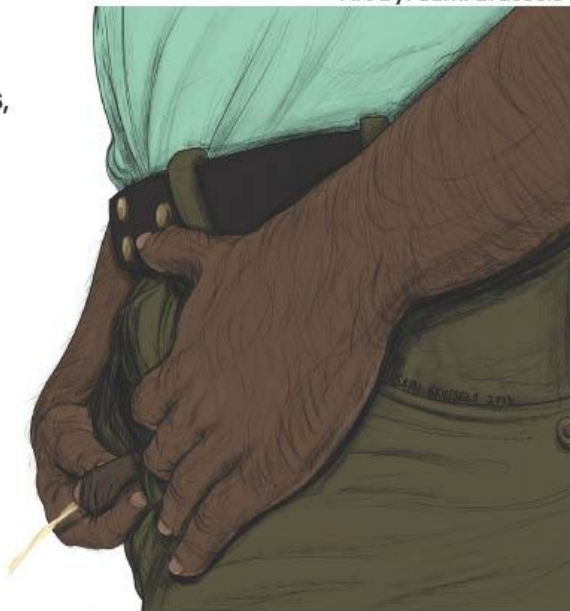
Among those who had phalloplasty, 73% had radial forearm free-flap (RFF)

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





Pre-Surgical Experiences

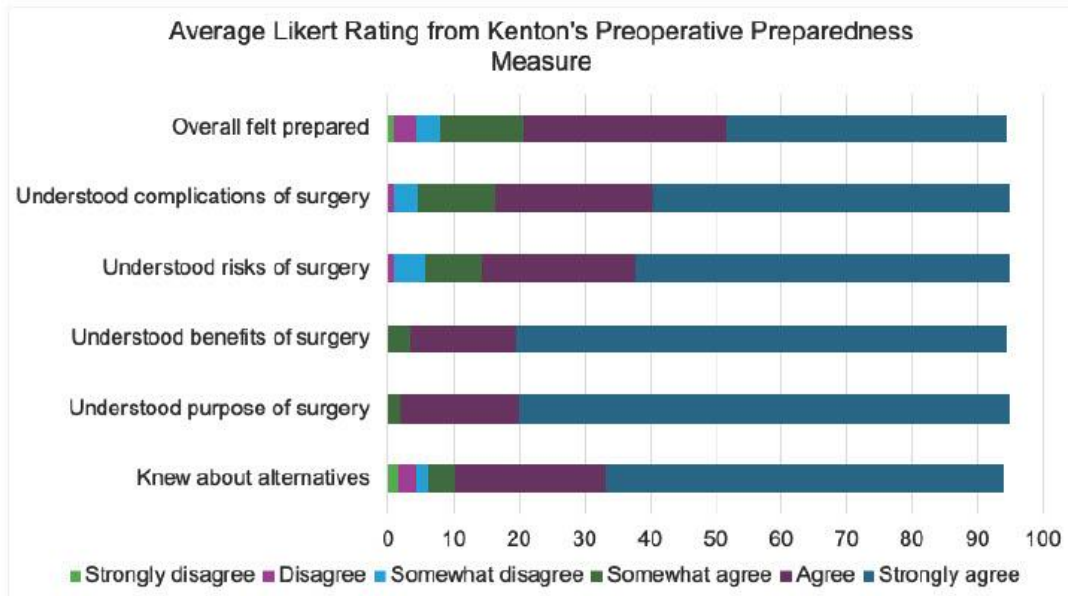


Art by: Ari Ganahl



Preparing for Surgery

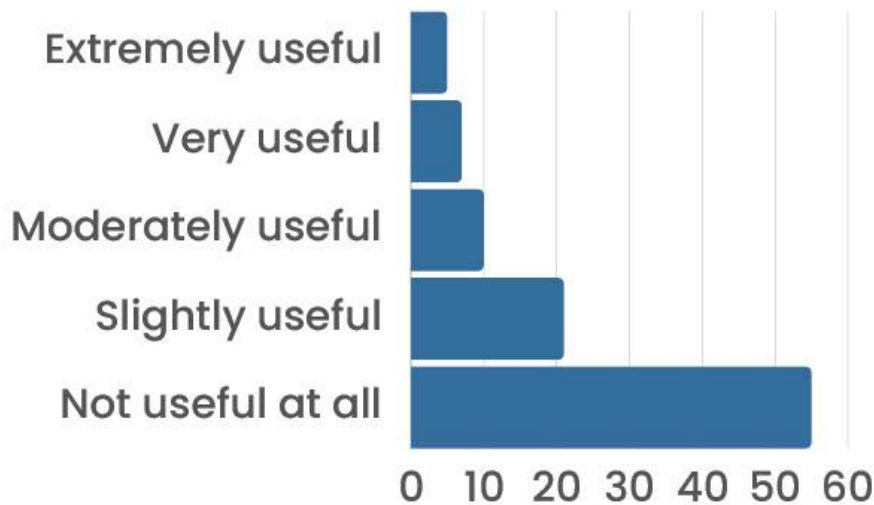
Preparing to undergo any surgery can be overwhelming and challenging. One important and under-studied aspect of phalloplasty and metoidioplasty is how people prepare to undergo these surgeries, including what resources are useful in preparing and how surgical care teams support preparation. We included 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 (x%) said this was not sure 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

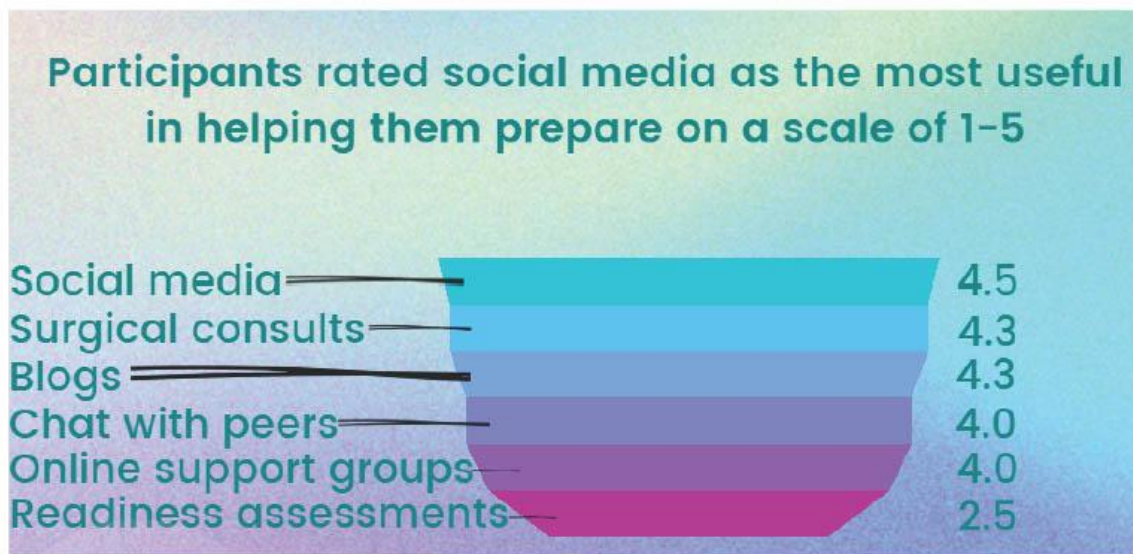


Usefulness of other resources

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.



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.

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.

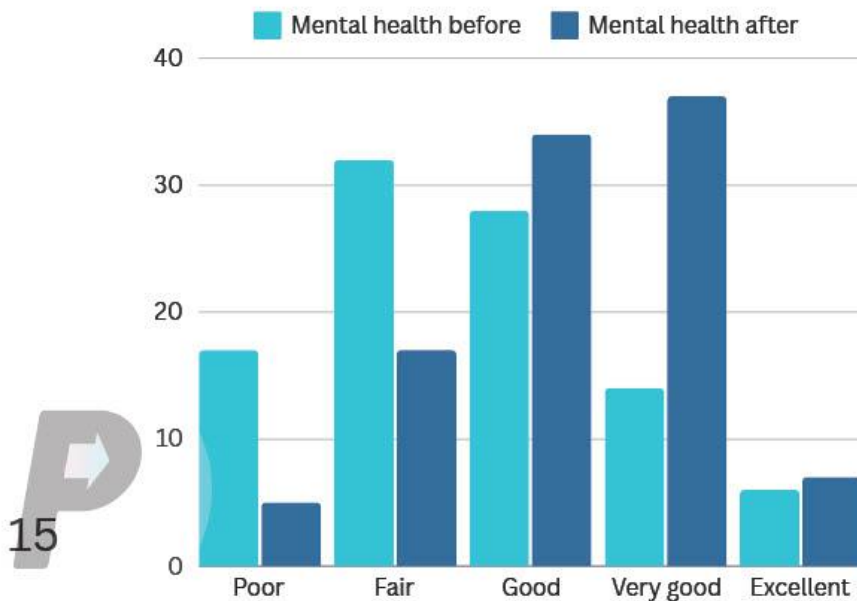


Mental Health After Surgery

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.



15 P

**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.



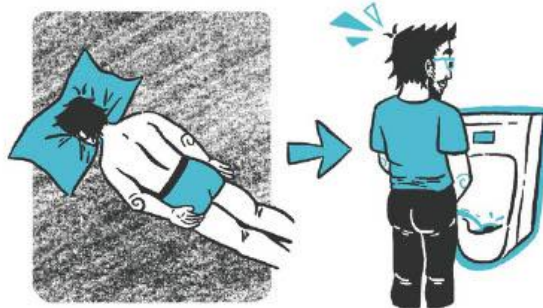
Dysphoria

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 uncomfotability 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.



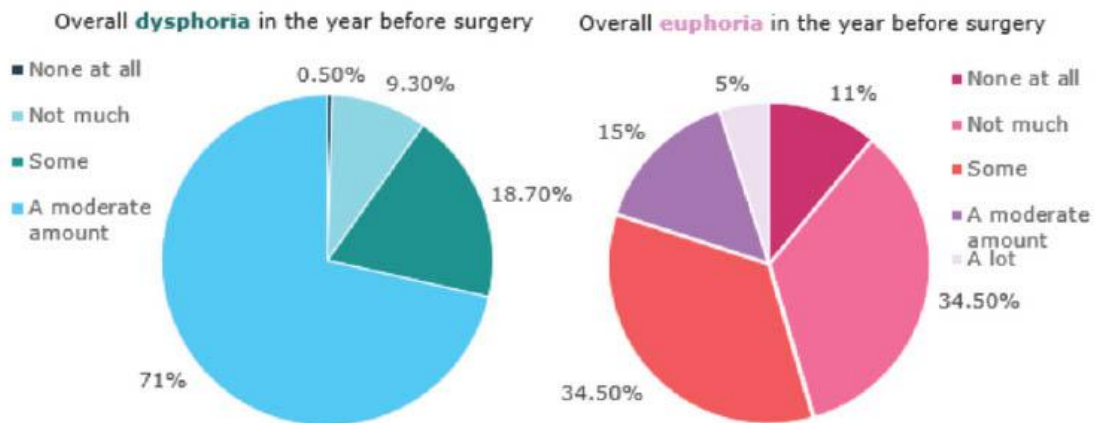
Art by: Ari Ganahl

After Surgery

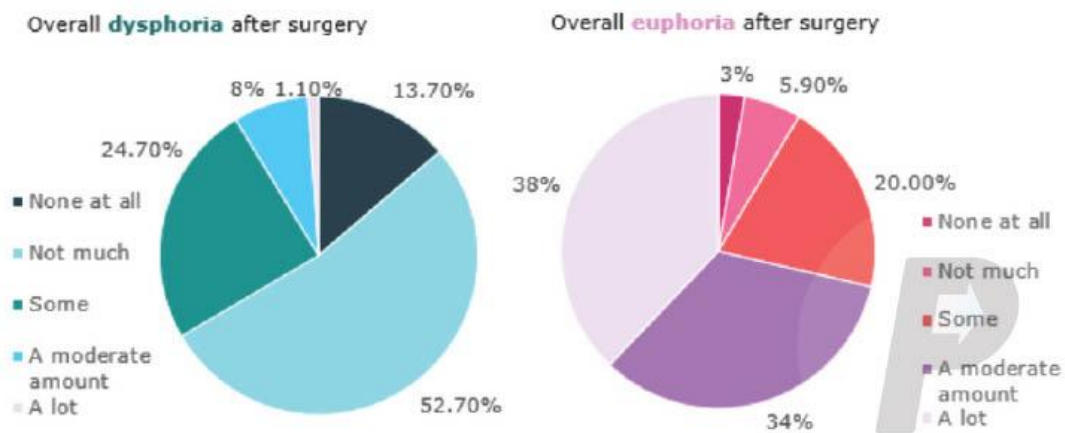
After surgery, only 12% of our participants reported having moderate or a lot of genital-specific dysphoria, and 88% experienced none or some dysphoria. Most participants (67%) said they generally have not much, or no dysphoria after surgery. 25% said they have some dysphoria, and less than 10% said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

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.



After surgery dysphoria and euphoria

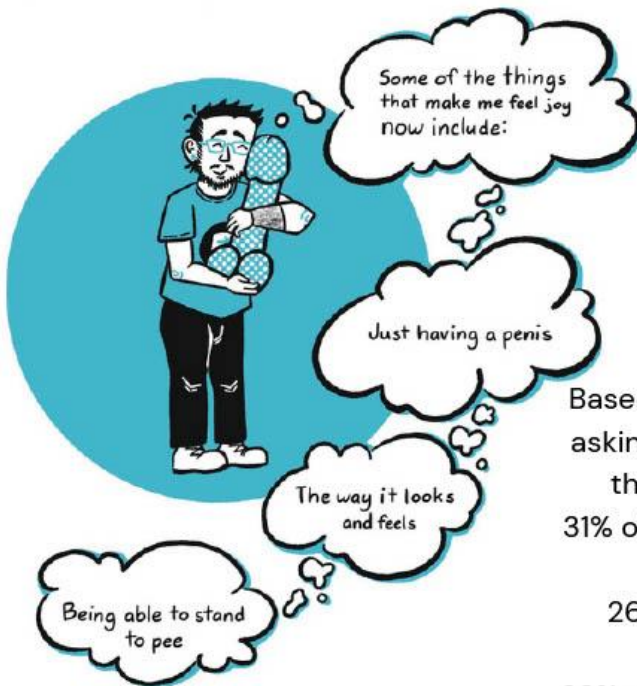


Euphoria

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.



Art by: Ari Ganahl

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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.

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.

<i>*See Herbenick et al., 2013 for more details about this measure and the cis sample</i>	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 genital 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 the way 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.

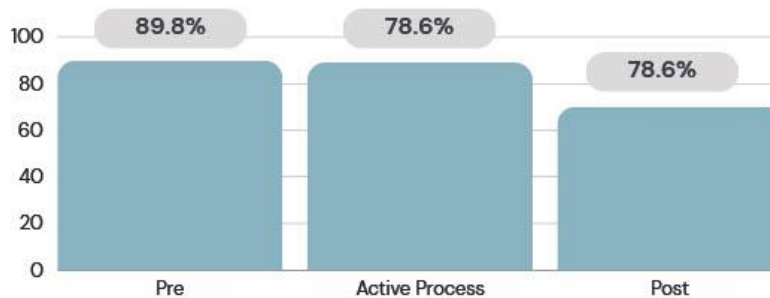


Pre- vs. postop sex and sexuality

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

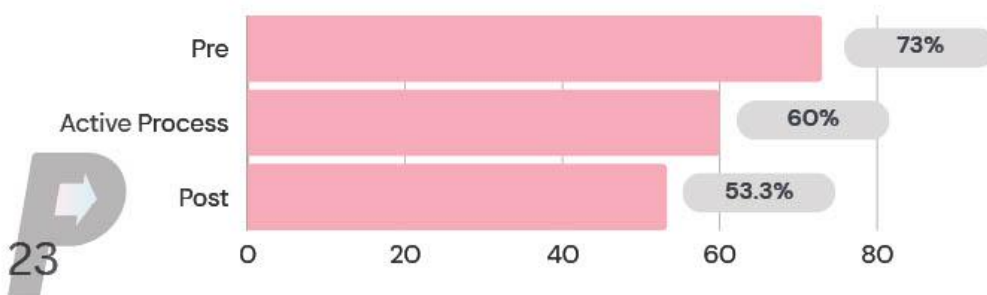
Before surgery, 89.8% (n=193) of participants reported masturbating alone sometimes, often, or daily. Out of those who were active process, 89.1% (n=98) reported masturbating alone. For those who were postop, 69.5% (n=73) reported masturbating alone. Out of those who masturbated on their own who were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

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

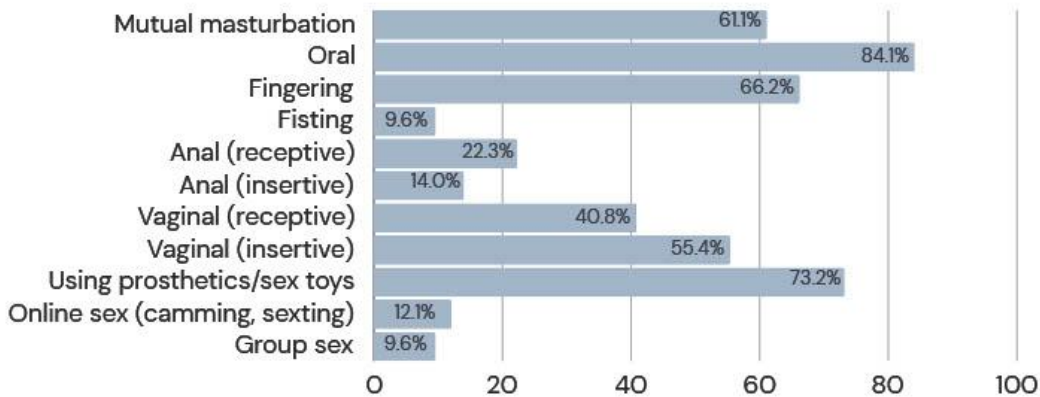


Table 3b. Type and frequency of partnered sexual activities: active process

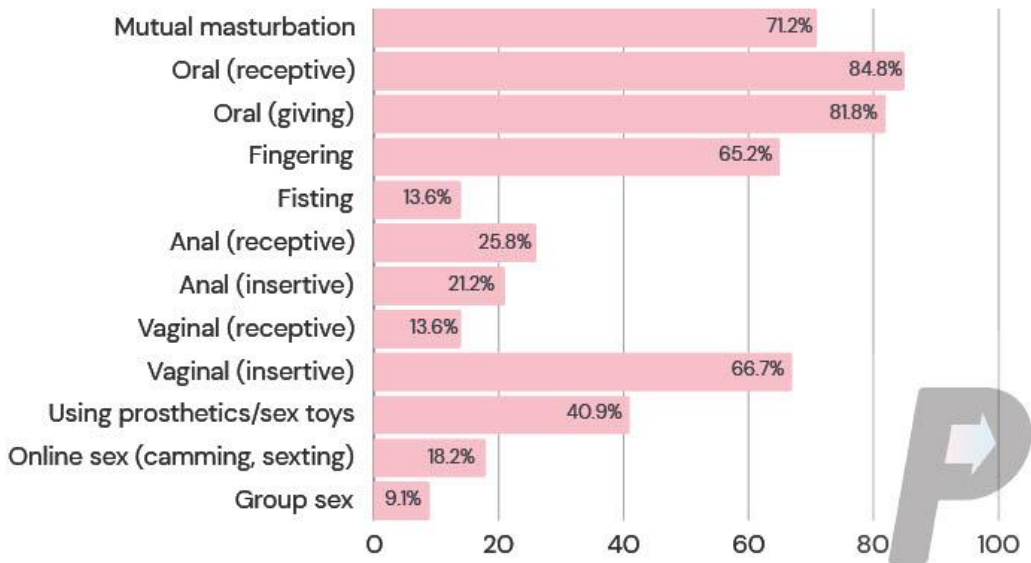
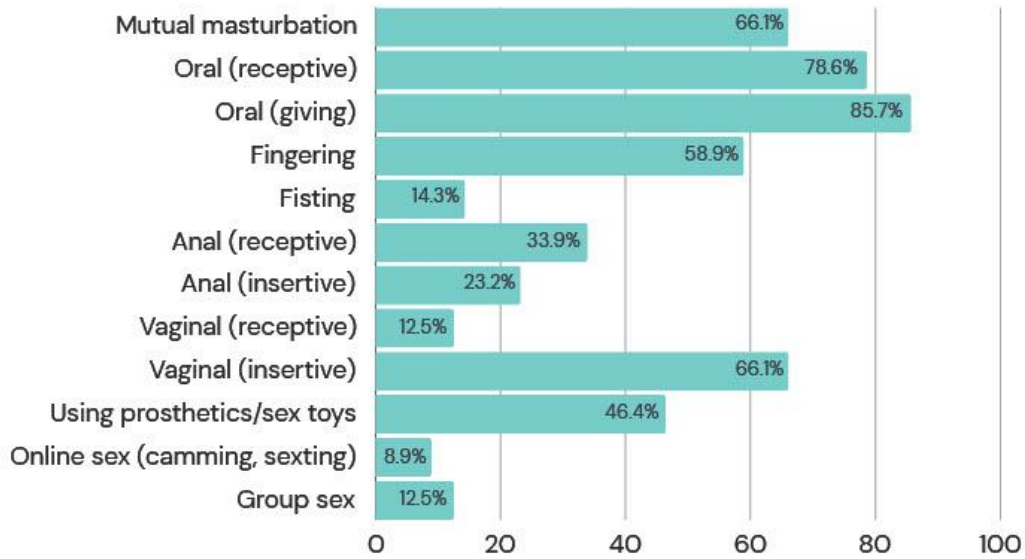


Table 3c. Type and frequency of partnered sexual activities: postop



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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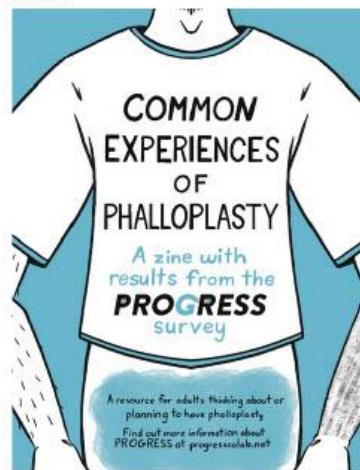
Infographics



PROGRESS Podcast



Zine



Art by: Ari Ganahl.

You can find the zine at: progresscolab.net/zine