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Impact of a Web-based Decision Aid for Gender Affirming Treatment

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Impact of a Web-based Decision Aid for Gender Affirming Treatment

A dissertation submitted in partial satisfaction of the

requirements for the degree

Doctor of Nursing Practice

by

Bianca Maria Salvetti

2022

ABSTRACT OF THE DISSERTATION

Impact of a Web-based Decision Aid for Gender Affirming Treatment

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University of California, Los Angeles

2022

Professor Nancy A. Pike, Chair

Background: The decision to begin gender affirming treatment (GAT), such as puberty blockers or hormone therapy, can be difficult and complex. Transgender and gender diverse youth (TGD) and their caregivers must learn and understand a large volume of information to participate in shared decision-making (SDM) regarding the decision to begin gender affirming treatment. One method to support SDM is the use of a decision aid (DA), to provide evidence-based information on treatment benefits, risks, and long-term effects. Currently, there are no DA to assist TGD youth and caregivers in the decision on whether to start GAT.

Objectives: The aim of this project was to develop, implement, and evaluate the impact of a web-based DA on GAT in a pediatric academic medical center.

Methods: Cross-sectional, pre- and post-intervention design. Participants included treatment naïve TGD youth aged 13-25 years or their caregivers. Eligible participants were evaluated for their pre-and post-intervention knowledge, fertility attitudes, and decisional conflict (DC), with acceptability of the intervention only being assessed post-intervention. Data were collected from March 2022 to May 2022 utilizing Research Electronic Data Capture (REDCap). Descriptive statistics were used to assess demographics and post-intervention survey responses and paired t-test to assess knowledge and DC pre- and post-intervention.

Results: A total of 10 [6 TGD youth (mean 16.5 years, SD=2.2) and 4 caregivers (mean 45.5 years, SD=7.5)] participated in the study. The majority were assigned female at birth (70%) and identified as white (40%) or Latino/a/e/x (40%). All participants had high mean GAT knowledge (7.8 [SD=1.3] vs. 7.4 [SD=1.8], p=0.509) and low mean DC (18.1 [SD=19.9] vs. 10.9 [SD=12.9], p=0.187) scores pre- and post-intervention, respectively, with no significant difference. Caregivers had higher GAT knowledge and DC scores then TGD youth. The DA had no effect on knowledge in either group but showed reduced DC scores in both groups. The majority of participants (80%) found the DA useful for their decision-making process for GAT.

Conclusion: This pilot study tested a newly developed web-based DA on GAT, which showed improved scores on DC but had no effect on knowledge among the users. The majority of participants found the DA information helpful in making their decision regarding GAT. Future studies are needed to verify findings in a larger, more diverse cohort of TGD youth and their caregivers.

The dissertation of Bianca Maria Salvetti is approved.

John Lazar

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Kristi Karin Westphaln

Nancy A. Pike, Committee Chair

University of California, Los Angeles

2022

DEDICATION

This dissertation is the culmination of my unwavering dedication to improving the health of marginalized youth. I would not have been able to achieve this without the help of my family, colleagues, and patients who have supported and encouraged me along the way.

To my mother, Mara: You found a way to learn another language, raise children as a single mother, and graduate from college all at the same time! Your dedication is inspiring. Non sarei qui senza i tuoi sacrifici, il tuo sostegno e la tua verità. Ti amo più di quanto possa descrivere.

To my sister, Camilla: You have literally taken care of me for the past 2 years. You made sure the house was clean, the dogs taken care of, and that I was fed. I would not have been able to accomplish this without your support!

To all the gender diverse youth I have cared for and who helped me with the development of this project: I am grateful that you have allowed me to be a part of your journey. I have learned so much from each one of you and I am excited to continue learning. I hope this project will be the beginning of a more interactive tool that can meet the needs of the community.

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And to my family, Mara, Camilla, Mateo, Mauro, Ella, Karen, and Keisha, thank you for supporting me through all my school adventures!

VITA

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1 Julian, J. M., **Salvetti, B**., Held, J. I., Murray, P. M., Lara-Rojas, L., & Olson-Kennedy, J. (2020). The impact of chest biding in transgender and gender diverse youth and young

adults. *Journal of Adolescent Healt*h, *68*(6), 1129-1134. https://doi.org/10.1016/j.jadohealth.2020.09.029

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ABSTRACTS

1 Pike, N. A., Toyoma, J., **Salvetti, B**., & Okuhara, C. (2015, March). *Weight gain, feeding mode and clinical variables associated with tube feedings in infants with hypoplastic left heart syndrome*. Poster presented at National Pediatric Nurse Practitioner Annual Conference, Las Vegas, NV.

2 Salvetti, B. (2017, Feb.). *Removing barriers to transgender youth healthcare: The role of nurses*. Abstract submitted to US Professional Association of Transgender Healthcare Conference, Los Angeles, CA.

3 Salvetti, B. (2019, March). *Transgender youth: What a PNP should know*. Abstract submitted to National Association of Pediatric Nurse Practitioners Annual Conference, New Orleans, LA.

4 Mounier, C., Holloway, R., **Salvetti, B.** & Lim, I. (2020, March). *Harm reduction, restorative justice, positive youth development, and structural competency: Intersecting concepts to transform medical, mental health and substance use services for youth and young adults experiencing homelessness*. Abstract submitted to Society of Adolescent Medicine Annual Conference, San Diego, CA.

5 **Salvetti, B**., Julian, J., & Held, J. (2020, March). C*hest binding in transgender and gender diverse adolescents: translating evidence-based research into care*. Abstract submitted to Society of Adolescent Medicine Annual Conference, San Diego, CA.

6 **Salvetti, B**., Julian, J., & Held, J. (2020, March). *Use your HEEADSSS: Getting the most out of a biopsychosocial assessment*. Abstract submitted to National Association of Pediatric Nurse Practitioners Annual Conference, Virtual Conference.

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CHAPTER ONE: INTRODUCTION

Nearly two percent of high school students in the United States (US) identify as transgender, a term used to describe the incongruence of one's sex assigned at birth and their gender identity (Gender Spectrum, 2019; Johns et al., 2019). In California, almost 800,000 youth aged 12 to 17 identify as gender diverse or with a gender identity that does not conform to societal binary gender norms (Gender Spectrum, 2019; Wilson et al., 2017). Some transgender and gender diverse (TGD) youth may experience gender dysphoria, or a feeling of unhappiness, uneasiness, or discomfort related to incongruence between one's gender identity and their assigned sex at birth (Gender Spectrum, 2019). These youth may seek gender-affirming treatment (GAT), such as puberty blockers and/or hormone therapy, to prevent adverse outcomes, such as suicidal ideation or discrimination for being identifiably transgender (Turban et al., 2020). Among TGD high school students, nearly 35% reported being bullied at school, 44% have considered suicide, and 35% have made a suicide attempt (Johns et al., 2019). Youth have been found to experience gender euphoria or joy when their gender identity is affirmed (Earl, 2019). Caregiver consent is required for youth under 18 years old, but young adults often involve their families in their decision-making (DM) process.

TGD youth and their caregivers are tasked with understanding a large amount of medical information before deciding on GAT. Research suggests that TGD youth often conduct independent research and deliberate before disclosure to caregivers. This discordance can result in DM timeline misalignment between youth and their caregivers and delayed access to medical care (Clark et al., 2020a). Youth and their caregivers often come to their initial appointments with different concerns and goals. These differences include the likelihood of TGD youth to endorse concerns about gender-affirming hormones, goals for transition, and surgical

interventions at their initial visit, while their caregivers' endorsed concerns around their child's mental health, safety, and acceptance from family (Lawlis et al., 2017). The decision to begin GAT is compounded by its potential impact on future fertility and irreversible physical effects.

TGD youth may not have clear goals for parenthood, making them more likely to prioritize initiation of medical treatment over the potential for future fertility (Chen et al., 2019). Caregivers may have concerns about their child's capacity to retain and apply medical information to make an informed decision. This may encourage caregivers to feel paternalistic by protecting their child from poor DM (Jeremic et al., 2016). Caregivers concerned about long-term medication risks and the persistence of the youth's gender identity are more likely to delay treatment initiation (Daley et al., 2019). Youth autonomy may be impacted by parental pressure to complete fertility preservation (FP) or delay treatment, widening the gap between the consenting parties (Chen et al., 2019). Providers must balance the immediate well-being of the youth with the overall goals and/or concerns of both the caregivers and the youth (Daley et al., 2019; Harris et al., 2019).

One potential method to provide TGD youth and caregivers education to make an informed decision on GAT is the use of a decision aid (DA). DAs provide an evidence-based approach to information delivery. DAs promote active patient engagement in order to make an informed choice in collaboration with their provider (International Patient Decision Aid Standards Collaboration [IPDAS], 2017). A well-designed DA provides balanced information on treatment benefits, risks, and potential long-term effects. Feasibility of DAs has been shown in other populations and settings. They differ from other patient education methods by helping users clarify their values regarding the decision and decision outcomes when evidence-based options are limited (IPDAS, 2017; Ottawa Hospital Research Institute [OHRI], 2020b; Stacey et

al., 2017). Little is known about the impact of DA use in assisting TGD youth and caregivers with GAT decision-making.

Statement of the Problem

Providers in a large gender health program had identified the need for a standardized tool to improve GAT knowledge and decisional conflict (DC) among TGD youth and their caregivers. During the one-hour initial visit, providers elicit the patient's gender journey from the youth and their caregiver to understand family values, goals, and concerns. Education detailing medication options, risks, and benefits is provided verbally during the consultation and written in a consent. Patients and/or families are encouraged to review the consent between the initial visit and the consenting visit to elicit any questions or concerns they may have prior to consenting to any medical interventions. Consenting to GAT typically occurs at a follow-up appointment that is scheduled anywhere from two weeks to several months from their initial visit depending on the needs of the youth. At the conclusion of the initial visit, take-home information would be beneficial to further reinforce the content discussed thus supporting the need for a DA in this population.

The long-term risks and benefits for GAT are not well researched, which make the DM process challenging. Current GAT treatment is guided by The World Professional Association for Transgender Health (WPATH) Standards of Care (version 7), University of California – San Francisco (UCSF) Transgender Care and Guidelines, and the Endocrine Society Clinical Practice Guideline for the treatment of gender dysphoric/gender-incongruent person (Coleman et al., 2012; Deutsch, 2016; Hembree et al., 2017). Other health organizations, such as the American Academy of Pediatrics (AAP), National Association of Pediatric Nurse Practitioners (NAPNAP), Society for Adolescent Health and Medicine (SAHM), American Medical Association (AMA),

American Academy of Family Physicians (AAFP), and American Psychiatric Association (APA), have issued position statements and an amicus brief advocating for timely, gender-affirming treatment for gender diverse youth (AAFP, 2020; AMA, 2019; *Brandt v. Rutledge*, 2021; Drescher et al., 2018; NAPNAP et al., 2019; Rafferty et al., 2018; SAHM, 2020)

Shared decision-making (SDM) is one method used to make medical decisions when evidence-based options are not well defined (Daley et al., 2019). Youth who have already begun GAT continue to have questions about GAT that were discussed during the consenting process, such as body development while on GAT and potential for future fertility. Some caregivers continue to have DC about GAT due to worry about their child having decisional regret in the future (Clark & Virani, 2021). SDM with youth seeking GAT and their caregivers can foster emerging autonomy, ongoing engagement in health care, and address disagreements between the deciding parties (Clark et al., 2020b). Hence, the aim of this project was to evaluate the effects of utilizing a DA to support GAT for gender dysphoria among TGD youth ages 13-24 years and their caregivers in a free-standing pediatric academic medical center.

PICOT Question

Among transgender and gender diverse youth and their caregivers deciding on gender affirming treatment for gender dysphoria (P), does an evidence-based web-based decision aid (I) compared to the current practice of providing non-standardized verbal counseling (C) increase knowledge and decrease decisional conflict (O) after the intervention over a 3-month period (T)?

Purpose and Objectives

The purpose of this project was to describe the impact of a web-based DA on GAT among TGD youth and their caregivers. The project had two objectives: (1) develop and

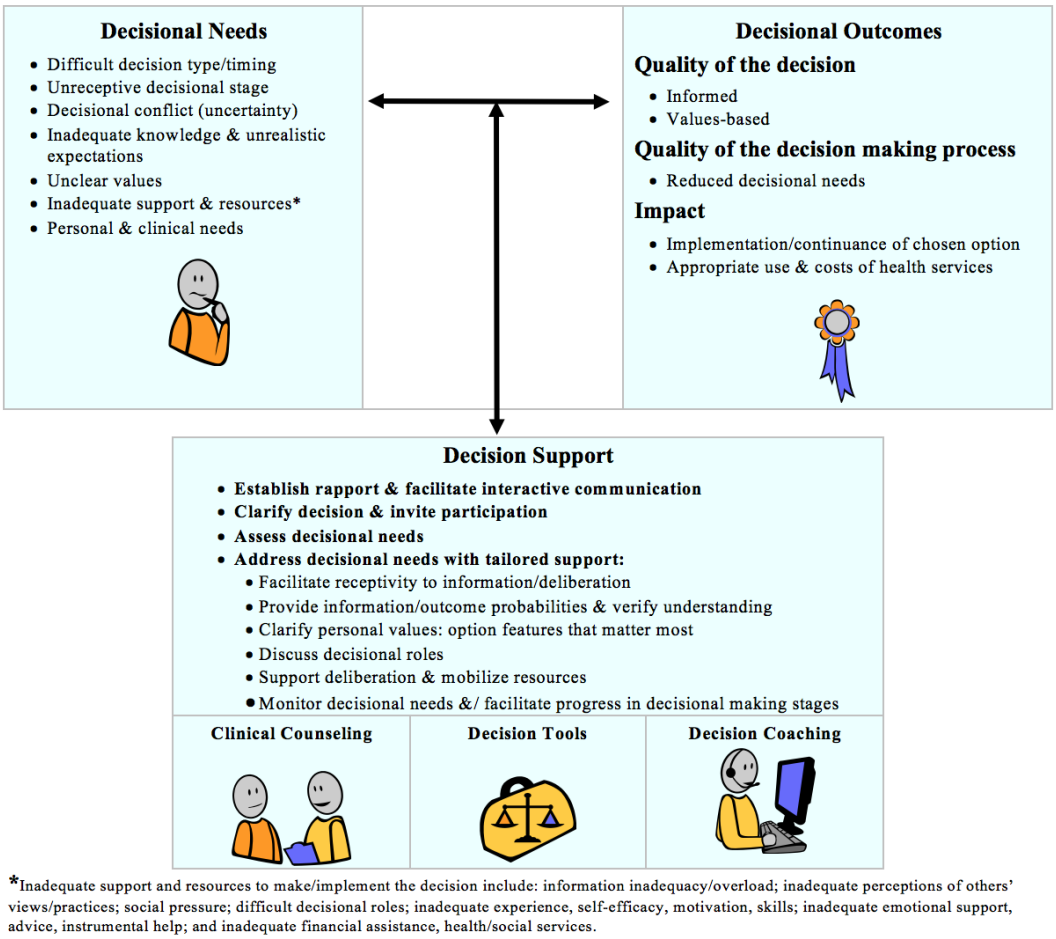
implement a web-based DA on GAT and (2) perform a pilot assessment of knowledge and DC regarding GAT before and after DA use among participants.

CHAPTER TWO: THEORETICAL FRAMEWORK

The Ottawa Decision Support Framework

The Ottawa Decision Support Framework (ODSF) (1998) was developed to facilitate DM and improve decision quality when faced with a difficult choice (see Figure 1) (O'Connor et al., 1998; Hoefel et al., 2020). The ODSF integrates concepts from several theories such as self-efficacy, DC, reasoned action, and social support to enhance SDM with all individuals involved (OHRI, 2020a). The ODSF process identifies decisional needs, provides tailored decision support, and assesses the DM outcomes. This framework recognizes the adverse impact unresolved decisional needs have on decision quality and health outcomes. Decisional support tools, like DAs, can be used to meet these needs. The ODSF supports DM by providing information and helping users clarify their values regarding the decision (OHRI, 2020a; Stacey et al., 2020).

Figure 1: *Ottawa Decision Support Framework*



Note. From "Ottawa Decision Support Framework (ODSF)" by Ottawa Hospital Research Institute, 2020a (https://decisionaid.ohri.ca/docs/develop/ODSF.pdf). Copyright 2020 by the Ottawa Hospital Research Institute.

Decisional Needs

The ODSF includes concepts that describe DM as being dependent upon the following characteristics of the deciding parties: level of knowledge regarding the decision options, feeling the decision aligns with family or social values, level of uncertainty regarding outcomes alignment with personal values, and deciding parties having access to supportive resources (O'Connor et al., 1998). The decision to begin GAT involves several options with various levels of risk and reversibility (Chen et al., 2019; Daley et al., 2019). TGD youth and their caregivers

may be at different stages of the DM process at their initial visit. Youth typically disclose their identity and desire for transition after they have completed a stage of discovery that includes identity awareness, research, deliberation, and evaluation. Caregivers of TGD youth begin their discovery process during a time where youth may feel ready to seek medical care (Clark et al., 2020; Daley et al., 2019). While TGD youth and caregivers frequently seek information online, this information may be inaccurate or difficult to understand (Cook et al., 2017; Daley et al., 2019; Vargas et al., 2017). People with low literacy levels may have difficulty accessing, reading, understanding, and evaluating online resources that are written at or above a 12th grade reading level (Vargas et al., 2017). Misinformation or misinterpretation of online data may mislead the reader, leading to delays in care and potentially invalidation of the youth's identity (Evans et al., 2017).

Personal values and social environment play important roles in the DM process. TGD youth have varying desires for future biological children and FP. These youth may feel pressured to complete FP if their family values biological parenthood over other options, such as adoption or being childless (Chen et al., 2019). The decision to transition and seek medical care is compounded by the fear and risk of stigma, discrimination, harassment, and/or violence. These real or perceived risks can cause TGD youth to delay disclosure and their caregivers to delay accessing care (Clark et al., 2020).

Decision Support

The ODSF stresses the use of decision support tools to improve DM and the quality of the DM process by facilitating communication and rapport, encouraging patient participation, defining personal values, and supporting access to resources (O'Connor et al., 1998; O'Connor et al., 2021). Decision support is provided using clinical counseling that can be supplemented with

decision coaching and/or decision tools, such as a DA (O'Connor et al., 2021). DAs can assist users in clarifying the value they place on the risk and benefit of each option by providing information and realistic expectations of outcomes (IPDAS, 2017; O'Connor et al., 1998).

The decision to begin social and/or medical transition is complex and impacted by personal and social values. SDM can improve communication between the deciding parties and lead to improved trust and reduced stigma among TGD patients (Lambert et al., 2022; Scalia et al., 2021). A DA supporting GAT may help bridge the gap between TGD youth and their caregivers by providing standardized counseling, which meets health literacy needs, and highlights the impact of GAT on immediate and long-term health outcomes (Kolbuck et al., 2020; Scalia et al., 2021).

Decisional Outcomes

The ODSF identifies three decisional outcomes: quality of the decision, impact of the decision, and quality of the DM process (O'Connor et al., 2021; Stacey et al., 2020). A high-quality decision is defined as being informed and consistent with personal values. Decision support enhances the quality of the DM process by reducing decisional needs. The ODSF postulates that improving the quality of decisions and DM will impact the implementation and continuation of the chosen option, improve the utilization of health services, and decrease costs of care (O'Connor et al., 1998; O'Connor et al., 2021; OHRI, 2020; Stacey et al., 2020).

TGD youth and their caregivers may experience information overload at their initial visit, creating a need for ongoing conversations regarding fertility, the timing of effects, and potential risks (Chen et al., 2019; Stacey et al., 2020). An online DA can be used to address overload by layering information from simple details to more complex concepts (Stacey et al., 2020). Research suggests that decision support tools for TGD youth and their caregivers that focus only

on medical risks and benefits may not be sufficient to support quality DM (Daley et al., 2019). Personal narratives from TGD youth and caregivers that discuss the youth's gender identity awareness, SDM process, and experience with starting GAT may be more useful in supporting DM (Lambert et al., 2022). Evidence supports the idea that decisional outcomes are impacted by caregiver acceptance of their child's gender identity, uncertainty regarding persistence of their child's asserted gender identity in the future, and their fear of regret if GAT were to be initiated (Daley et al., 2019). Therefore, a DA that includes the risks and benefits of GAT options, exploration of various gender journeys, personal narrative, and caregiver acceptance may improve quality decisions and DM (Daley et al., 2019; Kolbuck et al., 2020; Lambert et al., 2022; Scalia et al., 2021).

CHAPTER THREE: REVIEW OF LITERATURE

Search Strategy

A comprehensive literature search was developed using PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and University of California-Los Angeles (UCLA) ArticlesPlus databases. Key search terms included: *child, adolescent, youth, parent, caregiver, education, decision aid, decision support, counseling, online, web-based, digital, knowledge,* and *decision conflict*. Key search terms were searched using * and " " to provide a wider search for relevant studies. Medical Subject Headings (MeSH) terms included: *decision support technique, adolescent, child, parent, and knowledge*. Boolean operators of parentheses, AND, and OR were used to encompass a wider yield. The Cochrane Library was searched for relevant systematic reviews. Grey literature was searched utilizing Open Grey and Grey Literature Report using key search terms of *decision aid and decision support*. Due to the paucity

of literature specific to TGD youth, the search was expanded to include similar populations and/or conditions, such as fertility decisions or with adults considering gender affirming surgery.

Selection of Evidence

Inclusion criteria for the review of literature required that the manuscript be published from 2017-2022 and written in English. The initial search yielded 804 peer-reviewed journal article and 37 Cochrane Reviews (N=841). No articles met the criteria within the Grey literature. After assessing for content relevance and removing duplicates (n=767), a total of 74 abstracts (and 1 Cochrane review) were eligible for further review.

Included abstracts were limited to those that provided outcome analysis of knowledge or decision conflict. Abstracts that did not implement an intervention, implemented a DA that was not web-based, and interventions that did not target youth, caregivers, or transgender people were excluded from full text review.

Synthesis of the Literature

Seven research studies were critically appraised and documented in a Table of Evidence (see Appendix A). The research designs among the articles included three randomized controlled trials (Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017), three cross-sectional study designs (Allingham et al., 2018; Chen et al., 2022; Mokken et al., 2020), and one qualitative focus group study (Ozer et al., 2018).

Population Characteristics

Population characteristics were limited and reported findings were inconsistent among the studies. One study included TGD youth and caregivers of TGD youth who were considering or had been prescribed GAT (Chen et al., 2022). The remaining studies included female-identified participants considering fertility preservation (Allingham et al., 2018; Ehrbar et al.,

2018; Ehrbar et al., 2019; Garvelink et al., 2017) or trans men who previously underwent or were considering genital surgery (Mokken et al., 2020; Ozer et al., 2018). Most studies implemented a DA involving parents (Allingham et al., 2018; Chen et al., 2020) or participants over the age of 18 (Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020; Ozer et al., 2018). Four out of seven studies reported most participants had obtained a college degree or higher (Allingham et al., 2018; Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017), which is associated with higher health literacy compared to people with lower school attainment (Office of Disease Prevention and Health Promotion [ODPHP], 2022). Additionally, people who identify as a person of color, speak English as a second language, and/or have lower income levels may also be at risk for lower levels of health literacy (ODPHP, 2022). The health literacy level of all participants (decision makers) is essential context for the development and implementation of a successful DA.

One cross-sectional and one qualitative study found the DA intervention to be acceptable and feasible among healthcare providers, but neither provided quantitative data (Allingham et al., 2018; Ozer et al., 2018). These results suggest the implementation of a DA could be feasible and accepted among healthcare providers. Generalizability of these findings may also be limited given that the setting for a majority of the selected studies was outside of the US: The Netherlands (n=3; Garvelink et al., 2017; Mokken et al., 2020; Ozer et al., 2018), Germany (n=2; Ehrbar et al., 2018; Ehrbar et al., 2019) and Australia (n=1; Allingham et al., 2018).

Intervention Methodology

Interventions varied among the appraised studies. Most studies utilized an online website as the study intervention (Allingham et al., 2018; Chen et al., 2022; Ehrbar et al., 2018; Ehrbar et al., 2019; Mokken et al., 2020; Ozer et al., 2018). For example, one study compared the use of a

DA using an online website with printed brochures to printed brochures alone which provided nearly identical content (Garvelink et al., 2017). While all participants had low total Decisional Conflict Scale (DCS) scores at baseline, those who received the DA with brochures alone had lower scores on effective DM subscale six weeks after the intervention and higher levels of DC six months post-intervention compared to the control group (Cohen's d = 0.34). Both groups reported a significant improvement in knowledge, but no difference was found between the groups (Garvelink et al., 2017).

One study conducted five qualitative focus groups to identify themes and content for a DA for genital surgeries in trans men (DA_GST) (Ozer et al., 2018). Each focus group lasted 3 to 4 hours and was led by an independent moderator. All participants endorsed that a DA-GST should include a range of information regarding options, aid users in clarifying values and limit the depth of medical information. Data analysis revealed five main themes to inform the development of a DA-GST: outcome, environment, beliefs, sexuality, and quality of life. The DA-GST pilot was then evaluated by two focus groups, feedback was incorporated to create a final product (Ozer et al., 2018), and the final product was ultimately tested in a separate study (Mokken et al., 2020). Overall participants scored high on the Measures of Informed Choice scale (median=94, range 50-100), indicating participants were confident in making an informed decision after using the DA-GST (Mokken et al., 2020).

Most studies that implemented a DA provided a one-time intervention (Allingham et al., 2018; Chen et al., 2022) or allowed participants to access the DA through the entirety of the study (Ehrbar et al., 2018; Ehrbar et al., 2019; Mokken et al., 2020). One study did not describe how long participants had access to the online DA (Garvelink et al., 2017). The timing of DA implementation and standard GAT counseling varied among the studies. Studies implemented

the DA before counseling (Mokken et al., 2020), after counseling (Allingham et al., 2018; Ehrbar et al., 2018; Ehrbar et al., 2019), or among participants at various stages of counseling (Chen et al., 2022; Garvelink et al., 2017; Ozer et al., 2018). Studies that implemented a DA before or after GAT counseling reported improvements in knowledge and DC (Allingham et al., 2018; Ehrbar et al., 2018; Ehrbar et al., 2019; Mokken et al., 2020). Most studies which were implemented among users with different levels of counseling reported no significant difference in targeted outcomes or did not assess these outcomes (Garvelink et al., 2017; Ozer et al., 2018). However, one study found use of a web-based DA significantly improved knowledge among TGD youth and their caregivers (Chen et al., 2022). Therefore, a DA implemented at varying stages of counseling may inhibit data analysis and limit the impact of the desired effects.

Evidence Synthesis

Sample characteristics of the appraised literature were commonly described using descriptive statistics (Allingham et al., 2018; Chen et al., 2022; Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020). Most participants were assigned female at birth (Chen et al., 2022; Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020; Ozer et al., 2018) and with a mean age greater than 29 years old (Allingham et al., 2018; Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020). Many participants spoke a language other than English (Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020; Ozer et al., 2018) and had obtained a college degree (Allingham et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017).

To compare group means, four studies used t-tests (Allingham et al., 2018; Chen et al., 2022; Ehrbar et al., 2018; Ehrbar et al., 2019) and two studies used analysis of variance (ANOVA) (Ehrbar et al., 2018; Ehrbar et al., 2019). Dropout rates varied between 9-55% across

studies, with trans male participants having the lowest dropout rate (Allingham et al., 2018; Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020).

Most of the appraised literature assessed the intervention's impact on knowledge (Allingham et al., 2018; Chen et al., 2022; Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020). These studies primarily used knowledge questionnaires that were developed for the study and did not describe their validity. However, two studies used validated questionnaires: the Fertility Preservation Knowledge Scale (FPKS) (Allingham et al., 2018) and the Measures of Informed Choice Scale (MICS) (Mokken et al., 2020). These studies reported some improvement in knowledge after the intervention, however only three studies reported statistical significance ($p = 0.04$) (Allingham et al., 2018; Chen et al., 2022; Ehrbar et al., 2018). The lack of significant improvements may be due to small sample sizes and use of unvalidated questionnaires. A validated tool to evaluate knowledge about GAT among TGD youth and their caregivers has not yet been developed and would be instrumental in reliably assessing the relationship of the intervention to knowledge acquisition.

Many of the studies utilized the DCS to evaluate DC (Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al, 2020). Half of the appraised literature found use of a DA decreased the mean DCS score (Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020). One study reported a statistically significant improvement in DCS scores among DA users when compared to the control group ($p=0.008$) (Ehrbar et al., 2019). Another study found a medium effect on DC over time (T1, Cohen $d=0.264$; T2, Cohen $d=0.637$; T3, Cohen $d=0.569$) (Mokken et al., 2020). Studies that collected retrospective data assessed regret using the Decision Regret Scale (DRS) (Allingham et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017). One study found statistically significant improvements in DRS among participants ($p=0.04$)

(Allingham et al., 2018). Given that the proposed project was implemented in real time versus (vs.) using retrospective data, the DCS was an appropriate fit.

Personal values regarding the decision through the values clarity subscale of the DCS were commonly evaluated by the majority of the appraised studies (Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al, 2020). Few studies reported an improvement in the values clarity subscale and none of the studies reported statistically significant results (Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017). The lack of statistical significance may be related to small sample sizes or due to varying baseline counseling or DA exposure in the selected literature. Three studies provided a Values Clarification Exercise (VCE) to assist participants in identifying the importance one places on an option's risks and benefits (Allingham et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017). Two studies reported participants used the VCE often (54-80%) (Ehrbar et al., 2019; Garvelink et al., 2017) and one found the VCE useful for participants' DM process (Allingham et al., 2018). With regard to values, the findings from these studies suggest that combining a VCE with the values clarity subscale of the DCS may help aid users in making decisions that align well with personal values. An online DA for TGD youth and their caregivers should include just enough information to improve DM, clarify values, and address decisional needs.

Gaps in the Literature

There is a paucity of research addressing best practices in improving knowledge and decreasing DC among TGD youth and their caregivers when deciding on GAT. Overall, implications to the practice problem suggest that an evidence-based digital decision aid may improve knowledge and decrease DC within the target population. The appraised literature supports the use of DAs to impact knowledge and DCS scores among diverse populations across

multiple types of decisions (Allingham et al., 2018; Chen et al., 2022; Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020; Ozer et al., 2018). Future research should seek to validate a GAT knowledge questionnaire for TGD youth and their caregivers and assess the acceptability, feasibility, adaptation, and sustainability of the DA across multiple sites. A validated knowledge tool would be useful in evaluating the impact of a DA among the target population nationally.

DNP Leadership

The development and implementation of this Doctor of Nursing Practice (DNP) project integrates systems thinking and transformational leadership practices. Transformational leaders inspire themselves and others towards a shared vision to improve patient safety. They exhibit courage and vulnerability by empowering interdisciplinary collaboration to develop and try new solutions supported by evidence. Transformational leadership is operationalization through systems thinking (Ash & Miller, 2021; Chism, 2019; Dolansky, 2020).

Systems thinking is a leadership practice that considers the interaction between systems to identify appropriate interventions to improve the delivery of high-quality patient care. Systems thinking leaders use evidence to support engagement from key stakeholders and a shared vision for any intended changes. These changes are assessed for impact and sustainability. Transformational leaders are willing to challenge systems to implement changes that reflect core values and strive for excellence (Ash & Miller, 2021; Dolansky, 2020; Petersen, 2020).

These leadership practices align with the American Association of Colleges of Nursing's (AACN, 2006) DNP Essential II: Organizational and Systems Leadership for Quality Improvement and Systems Thinking. This essential highlight the importance of DNP graduates developing and applying the skills of organizational and systems leadership to impact health

disparities and patient safety. Mastery of this essential is demonstrated by the DNP leader's ability to develop sustainable, innovative care delivery models based on nursing science with consideration of the different systems that impact and will be impacted by the practice change. This project aimed to address the health needs of the practice population by developing and implementing a practice-level change to improve care delivery (AACN, 2006).

Interprofessional Practice

The conceptualization and implementation of this DNP project were inspired by current best practices for SDM, in partnership with an interprofessional team (in a high-impact clinic setting) and community advisory board (CAB) consisting of community members that reflect the target population. The clinical practice site for the project has a core value to enhance SDM among adolescents and young adults (AYA), their caregivers, and the healthcare provider. There has also been a call for healthcare providers to improve collaboration with TGD community members when developing or implementing population-focused programs, research, and/or education (Ashley & Dominguez, 2021; Howard Brown Health's Center for Education, Research, & Advocacy Series, 2021).

The DNP project idea was formed with a team-based approach rooted in the idea that the ability to share power is rooted in the team being founded with a shared purpose (Ash & Miller, 2020; Brown, 2018). Input was collected from program staff, department medical director, division medical director, and administrative leadership during the developmental stages of the project to identify important practices and organizational context. To ensure that the intervention remained useful and relevant for users, ongoing feedback from team members and the CAB regarding the content of the decision aid was collected.

Technology holds the capacity to either improve or hinder communication. This project aimed to improve communication between the consenting parties by improving knowledge about treatment options and providing the opportunity to explore personal values regarding the decision. To accomplish this, effective team communication was implemented to ensure the sustainment of the improvement. Eliciting feedback from others promoted self-reflection and positive change toward daring leadership practices (Ash & Miller, 2020; Brown, 2018; Jenkins, 2020). Leaders must be able to recognize their areas of weakness and find opportunities to collaborate with people who have strengths in those areas. The project team was constructed to reflect a wide variety of expertise, including data analysis and REDCap survey development.

Ethical Implications

GAT and parental acceptance have been shown to diminish the many negative effects of gender dysphoria, such as an increased risk of depression, violence, sexually transmitted infections, and suicide (Kimberly et al., 2018; The Trans Pulse Project, 2012). The principles of beneficence, nonmaleficence, and autonomy are weighed when considering GAT's mitigating effects compared to the lack of extensive, high-quality research on long-term outcomes (Kimberly et al., 2018). Caregiver rejection or indifference, such as not meeting the gender-care needs of their child, may elicit feelings of uncertainty and lead to psychological distress in trans youth (Pariseau et al., 2019).

Clinicians should promote parental acceptance to limit conflict among youth and their caregivers. Understanding the experience of grief among caregivers caused by the disruption of an envisioned future for their child is critical in fostering a healthy environment for TGD youth (Ashley, 2019a; Ashley, 2019b). Supporting the family through narrative disruption and narrative reconstruction can shift families from non-acceptance to advocacy (Ashley, 2019a).

Psychoeducation, such as emphasizing the importance of active acceptance and the negative impact of caregiver indifference, may be necessary for collaborating with the caregiver to increase involvement with their transgender child while holding space for their values (Pariseau et al, 2019). This project aimed to provide psychoeducation using a tool to improve SDM, foster collaboration between the deciding parties, and enhance value-aligned DM.

CHAPTER FOUR: METHODS

Study Design

The project used a cross-sectional, pre- post-intervention design. The pre- post-intervention design was selected as participant characteristics could not be ensured to be similar in a 2-group comparison project design across the data collection period. A one-group design helped to establish internal validity as changes in test scores were likely to be due to the intervention and not a difference in participant characteristics (Melnyk et al., 2019).

Setting and Sample

The gender health program is situated in the Division of Adolescent and Young Adult Medicine at an urban pediatric teaching hospital. With nearly 1800 active patients and over 300 new patient visits annually, it is one of the nation's largest youth gender health programs in the nation. The program cares for youth aged 3-25 years who are seeking various levels of GAT.

Inclusion criteria were treatment naïve TGD youth aged 13-25 years or their caregivers who had the ability to read and understand English and had completed an intake appointment. Exclusion criteria included past or current use of GAT and inability to read and understand English. Although utilization of the DA required an electronic device with internet access, this was not an inclusion criterion as participants were able to use a clinic-provided device as needed.

Measures / Instruments

Pre-screener

A screening questionnaire was created to identify eligible participants based on inclusion and exclusion criteria (See Questionnaire A1).

Demographics

A demographic questionnaire was developed using best practices in data collection methodology (Hughes et al., 2016; The Trevor Project, 2021) (See Questionnaire A2) to describe the project sample, such as sex assigned at birth, gender identity, and socioeconomics, and identify any relationships between participant identities and outcome measures (Hughes et al., 2016).

GAT Knowledge Questionnaire

The OHRI Knowledge evaluation tool was adapted into 10-item GAT knowledge questionnaire (O'Connor, 2000). The tool instructs participants to score each item as true, false, or unsure. Items answered correctly are given a score of 1. Items answered incorrectly or as unsure equal 0. These scores are totaled and calculated into a mean score. The questionnaire was used to assess basic knowledge of GAT, including but not limited to medication names, benefits, and side effects. The knowledge scale is a reliable tool ($\alpha \geq 0.82$) that measures the user's awareness of a clinical issue's treatment options, risks, and benefits. To ensure validity of the adapted OHRI Knowledge evaluation tool for this project, expert providers, and youth CAB (YCAB) reviewed and provided feedback of the tool to ensure clarity and that it captures the main concepts of DA (O'Connor, 2000) (See Questionnaire A3). The YCAB was an already formed monthly group which informs various projects at the clinical site. The tool has been used to develop knowledge questionnaires for hormone replacement therapy (HRT) in

postmenopausal women but has not yet been studied in TGD youth and/or caregivers (O'Connor, 2000).

Transgender Youth Fertility Attitudes Questionnaire (TYFAQ)

The 16-item Transgender Youth Fertility Attitudes Questionnaire (TYFAQ) was developed, and pilot tested in a sample of TGD youth living with and without autism and their caregivers (see Questionnaire A4). The tool was designed for TGD youth who are contemplating medical treatment that could impact fertility. It uses a Likert scale where strongly disagree = 0 and strongly agree = 4. The TYFAQ can be used as a research tool to understand fertility attitudes of TGD youth and compare youth and caregiver dyads on parallel themed items. The tool can also be used clinically to facilitate SDM. As a clinical tool, each item is scored as an individual theme and not added into a total score (Strang et al., 2018). The project used the TYFAQ as a VCE. The reliability and validity of the TYFAQ have not been established.

Low Literacy Decisional Conflict Scale

The 10-item Low Literacy Decisional Conflict Scale (DCS-LL) was used to ensure that patients of all literacy backgrounds could participate effectively with the intervention. The DCS-LL begins with an unscored option preference question. The 10 scored items use three response categories where yes = 0, unsure = 2, and no = 4. These scores were summed, divided by 10, and multiplied by 25 to obtain a total score. Scores can range from 0 (no decisional conflict) to 100 (high decisional conflict). Subscale scores were calculated by summation of subscale items, divided by the number of items in the subscale, and multiplied by 25. Subscale scores range from 0 (feeling informed, clear about personal values, certain about choice, or supported in DM). DCS-LL scores under 25 are correlated to implementing decisions whereas delayed decisions are associated with scores over 37.5. The DCS-LL has been tested in low literacy adult populations

in English and Spanish located in Canada, Chile, and the US (O'Connor, 1993). There is limited research on its use in pediatrics (Hulin et al., 2016). Literature using the DCS-LL in TGD youth and caregivers has not been published. It is a reliable tool ($\alpha \geq 0.8$) correlated to constructs of knowledge, regret, and discontinuance (Garvelink et al., 2019; O'Connor, 1993) (See Questionnaire A5).

Acceptability

The OHRI Acceptability evaluation tool was used to evaluate comprehension, amount and balance of information, length, and its ability to enhance DM (O'Connor, 1996). The Acceptability questionnaire uses rating scales (poor to excellent), yes/no, best choice, and open-ended questions. Participant responses are reported as proportions of negative and positive answers. The validity and reliability of the tool had not been established. The tool has been tailored to guide the development and evaluation of various DAs, including HRT and prenatal testing. The tool had been used to develop acceptability questionnaires for patients and providers. Its use in TGD youth and their caregivers had not been established (O'Connor, 1996). (See Questionnaire A6).

Data Collection

This study was approved by the institutional review board at Children's Hospital Los Angeles (CHLA) (IRB # CHLA-21-00362) and deemed exempt at University of California Los Angeles (UCLA). A convenience sample of eligible patients and caregivers from a large gender health program situated in the Division of Adolescent and Young Adult Medicine at an urban pediatric teaching hospital were recruited via flyer distribution by a provider or by scanning a QR code located on posted flyers within the clinical site.

Participants were pre-screened, and exclusion criteria was applied to ensure participants reflected the target group. Selected participants were given a pre-test to assess baseline knowledge and DC regarding GAT. Upon completion of the pre-test, eligible participants were given access to the DA to review in the order of the users' choosing. Development of the DA was guided by current intake counseling, published treatment guidelines, and published expert consensus on the content for a fertility preservation DA (AAFP, 2020; AMA, 2019; *Brandt v. Rutledge*, 2021; Coleman et al., 2012; Deutsch, 2016; Drescher et al., 2018; Hembree et al., 2017; Kolbuck et al., 2020; NAPNAP et al., 2019; Rafferty et al., 2018; SAHM, 2020). The DA included baseline trans-inclusive sexual and reproductive health and development content. Medication options, including no treatment, were described, and compared using the best available evidence at the time. Links to recommended outside organizations and resources, such as social support groups were also included. The DA expanded upon the counseling provided during the 1–2 hour intake appointment (see Appendix B). To accommodate the amount and depth of the content, participants were able to access the DA until completion of the post-test. The pre-and post-test included the same measurement tools with the acceptability measure only being assessed post-intervention. Participants completed all measures utilizing their own internet enabled digital device in a location of the participant's choosing, on the Research Electronic Data Capture (REDCap) database over a two-week period. Data were collected from March 2022 to May 2022.

Outcome Measures

The project aimed to increase knowledge and decrease DCS scores regarding GAT among DA users. Target outcome measures included answering greater than or equal to 9 out of 10 knowledge questions correctly and scoring less than or equal to 25 on the DCS post-

intervention. Evaluation of the outcome measures was conducted bi-weekly, and findings were disseminated to program staff during scheduled weekly huddles over the 2-month project period. Providing dedicated time during huddles to explain current project implementation issues allowed program staff the opportunity to offer feedback regarding sustainable improvements (Scholl et al., 2016; Scoville et al., 2016).

Statistical Analyses

Descriptive statistics (means, standard deviations [SD], and frequencies) were used to assess the demographic characteristics of the participants. Chi-square was used to measure the distribution of categorical variables. A paired t-test was used to compare differences between the pre- and post-intervention outcomes (Polit, 2010). Statistical significance was set at $p \leq 0.05$. The Statistical Package for Social Sciences (SPSS) version 27 (IBM; Somer, NY) was used to analyze the data.

CHAPTER FIVE: RESULTS

Demographics

A total of 16 participants completed the pre-test. Six participants or 37.5% did not return to complete the post-test and were not included in the analyses. The final study sample included 10 participants (6 TGD youth and 4 caregivers) who completed both the pre- and post-intervention (See Table 1). The mean age was 16.5 years (SD=2.2 years) for TGD youth and 45.5 (SD=7.5 years) for caregivers. Most of the study sample identified as white (40%) or Latino/a/e/x (40%). Most participants were assigned female at birth (70%) and identified as female (60%) or on a masculine spectrum (40%). The majority of participants had less than high school education (60%) and were students or not working (60%). Insurance type was equally distributed between public and private insurance (50%).

Table 1: *Sample Characteristics [n=10]*

Characteristic	Mean [SD] or n [%]
Age [years]	
• Child [n=6] (range 14-20)	16.5 [2.2]
• Caregiver [n=4] (range 40-56)	45.5 [7.5]
Sex [assigned at birth]	
• Female	**7 [70%]**
• Male	3 [30%]
Gender Identity	
• Female	**6 [60%]**
• Male	3 [30%]
• Non-binary, trans masculine	1 [10%]
Ethnicity	
• Black	2 [20%]
• Hispanic / Latinx	**4 [40%]**
• White	**4 [40%]**
Highest Level of Education	
• < High School [HS]	**6 [60%]**
• HS Graduate or Some College	2 [20%]
• Bachelor or Graduate Degree	2 [20%]
Insurance	
• Public	**5 [50%]**
• Private	**5 [50%]**
Annual Income	
• Do not work – student	**6 [60%]**
• < $20,000	1 [10%]
• $20,000 - $30,000	1 [10%]
• > $100,000	2 [20%]

GAT Knowledge and DCS-LL Questionnaires

The pre- and post-intervention GAT and DCS scores by group are shown in Table 2. All participants had high mean GAT knowledge (7.8 [SD=1.3] vs. 7.4 [SD=1.8], p=0.509) and low mean DCS (18.1 [SD=19.9] vs. 10.9 [SD=12.9], p=0.187) scores both pre- and post-intervention, respectively, but did not reach statistical significance.

The pre- and post-intervention GAT and DSC scores by participant type are shown in Table 3. Caregivers had no change in pre- and post-intervention mean GAT knowledge scores

(8.7 out of 10), while youth showed a decreased in mean scores post-intervention (7.1[SD=1.1] vs. 6.5[SD=1.8], p=0.501). Caregivers had higher baseline mean DCS scores compared to baseline youth scores (33[SD=24] vs. 8.1 [SD=7.7]). Though scores did not reach statistical significance, both groups had a decrease in mean DCS scores post-intervention.

Table 2: *Pre- and Post-Intervention Questionnaire Scores by Group [n=10]*

Questionnaires	**Pre-Intervention Mean [SD]**	**Post-Intervention Mean [SD]**	***p*-value**
Gender Affirming Treatment [GAT] Knowledge	7.8 [1.3]	7.4 [1.8]	0.509
Decisional Conflict Scale [DCS]	18.1 [19.9]	10.9 [12.9]	0.187

paired sample *t*-test; $p < 0.05$

Table 3: *Pre- and Post-Intervention Questionnaire Scores by Caregiver and Child*

Questionnaires	**Caregiver [n=4] Mean [SD]**		***p*-value**	**Child [n=6] Mean [SD]**		***p*-value**
	Pre	**Post**		**Pre**	**Post**	
Gender Affirming Treatment [GAT] Knowledge	8.7 [0.9]	8.7 [0.5]	1.00	7.1 [1.1]	6.5 [1.8]	0.501
Decisional Conflict Scale [DCS]	**33 [24]**	16 [19]	.227	8.1 [7.7]	7.5 [5.5]	0.766

paired sample *t*-test; $p < 0.05$

TYFAQ Questionnaire

All participants reported a positive response to the importance of learning about the effects of GAT on future fertility (n=10) (Table 4). While all participants reported being aware that GAT could impact future fertility, youth were more likely to strongly agree (83.3%) with this statement compared to caregiver who mostly agreed (75%). Most participants learned about the effects of GAT on future fertility from a medical provider (Youth=100%, Caregivers=75%) or from the internet (Youth=66.6%, Caregiver=50%). Half of the caregivers did not feel they had someone to talk to about what their child could do to have biological children while taking GAT. Most youth did not want to adopt or have biological children (66.7%), whereas caregivers had

more diverse perspectives regarding their desire for their child to have kids someday (positive response=50%, unsure =25%, negative response=25%). Youth were more likely to negatively respond to the importance of having biological children compared to caregivers (83.3% vs. 50%). Caregivers all agreed that their child's feelings about wanting biological children could change in the future, whereas youth were equally split between positive and negative responses. All participants reported awareness of available options for having biological children while on GAT. Overall, youth did not feel pressured by their families to have biological children (66.7%) or to undergo cryopreservation (83%). However, 75 percent of caregivers reported wanting their child to preserve eggs or sperm. Half of all participants reported cost as a barrier to cryopreservation. Youth reported delayed access to GAT (83.3%) and discomfort with the cryopreservation process (83.3%) as additional barriers to preserving eggs or sperm.

Table 4: *Transgender Youth Fertility Attitudes Questionnaire - Youth and Caregiver Version Responses*

Youth [Caregiver] Questions		**Youth Response [n=6] n [%]**		**Caregiver Response [n=4] n [%]**	
1	It is important to learn about how hormone treatment might affect my ability [child's ability] to have my [their] own biological children.	**Strongly Agree**	**3 [50%]**	**Strongly Agree**	**1 [25%]**
		Agree	**3 [50%]**	**Agree**	**3 [75%]**
		Disagree	0 [0%]	Disagree	0 [0%]
		Strongly Disagree	0 [0%]	Strongly Disagree	0 [0%]
2	I am aware that hormone treatment could cause issues with my ability [child's ability] to have my [their] own biological children.	**Strongly Agree**	**5 [83.3%]**	**Strongly Agree**	**1 [25%]**
		Agree	**1 [16.7%]**	**Agree**	**3 [75%]**
		Disagree	0 [0%]	Disagree	0 [0%]
		Strongly Disagree	0 [0%]	Strongly Disagree	0 [0%]
3	How did you learn that hormone treatment could make it difficult [for your child] to have your own biological children? **(Check as many that are true)**	**Medical Provider**	**6 [100%]**	**Medical Provider**	**3 [75%]**
		Internet	**4 [66.6%]**	**Internet**	**2 [50%]**
		Parent/Caregiver	2 [33.3%]	Other Parent	1 [25%]
		Peers	2 [33.3%]	Other	1 [25%]
4		**Strongly Agree**	**2 [33.3%]**	**Strongly Agree**	**1 [25%]**

	I feel I have people to talk to (like my doctor or therapist) about how hormone treatment could affect my ability [my child's ability] to have my own biological children	**Agree**	**3 [50%]**	**Agree**	**3 [75%]**
		Disagree	0 [0%]	Disagree	0 [0%]
		Strongly Disagree	1 [16.7%]	Strongly Disagree	0 [0%]
5	I feel I have people to talk to (like my doctor or therapist) about what I can do [my child can do] to have my own biological children if I'm taking hormones.	**Strongly Agree**	**2 [33.3%]**	**Strongly Agree**	**1 [25%]**
		Agree	**3 [50%]**	**Agree**	**1 [25%]**
		Disagree	0 [0%]	**Disagree**	**2 [50%]**
		Strongly Disagree	1 [16.7%]	Strongly Disagree	0 [0%]
6	I want [my child] to have kids someday. (This could be either your own biological kids or adopted kids).	Strongly Agree	1 [16.7%]	**Strongly Agree**	**1 [25%]**
		Agree	1 [16.7%]	**Agree**	**1 [25%]**
		I don't know	0 [0%]	**I don't know**	**1 [25%]**
		Disagree	**4 [66.7%]**	**Disagree**	**1 [25%]**
		Strongly Disagree	0 [0%]	Strongly Disagree	0 [0%]
7	If I [my child has] have kids, it would be important to me that they are my [child's] biological kids.	Strongly Agree	0 [0%]	Strongly Agree	0 [0%]
		Agree	1 [16.7%]	**Agree**	**2 [50%]**
		Disagree	**2 [33.3%]**	**Disagree**	**1 [25%]**
		Strongly Disagree	**3 [50%]**	**Strongly Disagree**	**1 [25%]**
8	I [am open to my child] would consider adoption someday.	**Strongly Agree**	**1 [16.7%]**	**Strongly Agree**	**1 [25%]**
		Agree	**3 [50%]**	**Agree**	**3 [75%]**
		I don't know	2 [33.3%]	I don't know	0 [0%]
		Disagree	0 [0%]	Disagree	0 [0%]
		Strongly Disagree	0 [0%]	Strongly Disagree	0 [0%]
9	My [child's] feelings about wanting my [their] own biological child might change when I'm older [in the future].	Strongly Agree	0 [0%]	**Strongly Agree**	**2 [50%]**
		Agree	**3 [50%]**	**Agree**	**2 [50%]**
		Disagree	2 [33.3%]	Disagree	0 [0%]
		Strongly Disagree	1 [16.7%]	Strongly Disagree	0 [0%]
10	I would be angry if the doctor didn't tell me that hormone treatment could affect my [child's] ability to have my [their] own biological children.	Strongly Agree	0 [0%]	**Strongly Agree**	**2 [50%]**
		Agree	0 [0%]	**Agree**	**2 [50%]**
		Disagree	**4 [66.7%]**	Disagree	0 [0%]
		Strongly Disagree	**2 [33.3%]**	Strongly Disagree	0 [0%]
11	I am aware that there are options that would allow me [my child] to have my [their] own biological child even if I'm [they are] on hormones	Strongly Agree	0 [0%]	**Strongly Agree**	**1 [25%]**
		Agree	**6 [100%]**	**Agree**	**3 [75%]**
		Disagree	0 [0%]	Disagree	0 [0%]
		Strongly Disagree	0 [0%]	Strongly Disagree	0 [0%]

12	I feel pressured by my family to have my own biological child someday. [I would like my child to have their own biological child someday]	Strongly Agree	0 [0%]	**Strongly Agree**	**1 [25%]**
		Agree	2 [33.3%]	**Agree**	**1 [25%]**
		I don't know	0 [0%]	**I don't know**	**1 [25%]**
		Disagree	**1 [16.7%]**	**Disagree**	**1 [25%]**
		Strongly Disagree	**3 [50%]**	Strongly Disagree	0 [0%]
13	I would feel that I'm disappointing my family if I could not have my own biological child [I would be disappointed if my child could not have their own biological child.]	Strongly Agree	1 [16.7%]	**Strongly Agree**	**1 [25%]**
		Agree	1 [16.7%]	**Agree**	**1 [25%]**
		I don't know	1 [16.7%]	I don't know	0 [0%]
		Disagree	**1 [16.7%]**	Disagree	0 [0%]
		Strongly Disagree	**2 [33.3%]**	**Strongly Disagree**	**2 [50%]**
14	I would [want my child to] consider medical procedures that would allow me [them] to preserve my [their] eggs or sperm to be able to have my [their] own biological children in the future.	Strongly Agree	1 [16.7%]	**Strongly Agree**	**1 [25%]**
		Agree	0 [0%]	**Agree**	**1 [25%]**
		Disagree	**3 [50%]**	Disagree	0 [0%]
		Strongly Disagree	**2 [33.3%]**	**Strongly Disagree**	**2 [50%]**
15	My family wants me [I want my child] to preserve my eggs or sperm.	Strongly Agree	1 [16.7%]	**Strongly Agree**	**1 [25%]**
		Agree	0 [0%]	**Agree**	**2 [50%]**
		Disagree	**3 [50%]**	**Disagree**	**1 [25%]**
		Strongly Disagree	**2 [33.3%]**	Strongly Disagree	0 [0%]
16	Is there anything that would get in the way of your [child] preserving your eggs or sperm? **(Check as many as are true)**	Not enough info	1 [16.7%]	Not enough info	0 [0%]
		Cost of preserving	3 [50%]	**Cost of preserving**	**2 [50%]**
		Scheduling appointment slow down start of treatment	**5 [83.3%]**	Scheduling appointment slow down start of treatment	1 [25%]
		Preserving egg and sperm make me feel uncomfortable	**5 [83.3%]**	Preserving egg/sperm make me feel uncomfortable	1 [25%]

Acceptability

Overall, participants rated the information provided on the DA website as good or excellent (positive response range: 70-90%) (See Table 5). Some participants rated the 'Terms & Definitions' and 'Fertility Preservation & Family Planning' pages fair (10% each page). A majority of participants rated the length of the DA site to be 'just right' (60%), although 30% reported it to be 'too long'. Participants felt the amount of information provided was 'just right'

(80%) or ‘too little’ (20%). Most participants felt the DA provided balanced information (80%), with the right level of complexity (90%) that will help them decide about GAT (80%). While most participants used the DA site alone (60%), many utilized the site with another person (40%). Participant antidotal comments included feeling the “information was clear” and that the DA site “tried…to acknowledge the many different options and resources…in a very understandable way”. Feedback for improvements included using a simplified version of J Bruin, providing links to external resources, and improving the graphic design of the site.

Table 5: *Acceptability with the Decision Aid - Participant Post-Intervention Evaluation [n=10]*

Questions	**Responses n= [%]**	
Question # 1 - How you think information was presented on: • Terms and definitions	Fair Good **Excellent** N/A	1 [10%] 1 [10%] **6 [60%]** 2 [20%]
Question # 1b • Basic Sexual and Reproductive Development	**Good** Excellent N/A	**5 [50%]** 4 [40%] 1 [10%]
Question # 1c • Trans Identity, Presentation & Transition Journey	Good **Excellent** N/A	3 [30%] **6 [60%]** 1 [10%]
Question # 1d • Gender Affirming Medical Intervention	Good **Excellent** N/A	4 [40%] **5 [50%]** 1 [10%]
Question # 1e • Fertility Preservation & Family Planning	Fair Good **Excellent** N/A	1 [10%] 3 [30%] **5 [50%]** 1 [10%]
Question # 2 • Length of Decision Aid Website	Too Long Too Short **Just Right**	3 [30%] 1 [10%] **6 [60%]**
Question # 3 • Amount of Information	Too much Too Little **Just Right**	0 [0%] 2 [20%] **8 [80%]**
Question # 4	Too complex	0 [0%]

• Quality of the Information	Too Simple	1 [10%]
	Just Right	**9 [90%]**
Question # 5 • I found the Decision Aid Website	Slanted toward GAT	2 [20%]
	Slanted towards delaying GAT	0 [0%]
	Balanced	**8 [80%]**
Question # 6 • The Decision Aid Website include information to help make a decision about GAT	**Yes**	**8 [80%]**
	No	0 [0%]
	Unsure	2 [20%]
Question # 7 • I used the Decision Aid Website (check all that apply)	**Alone**	**6 [60%]**
	With my child	2 [20%]
	With my parent or caregiver	1 [10%]
	With my friend [not related]	1 [10%]
Question # 8 [Narrative] What did you like about the Decision Aid Website? **Caregivers** – *"The information was clear", "The breakdown of GAT treatment, average cost, and potential side effects".* **Youth** – *"…it tried its best to acknowledge the many different options and resources it provided in a very understandable way", "it was very educational", "it talked about things I'm more interested in", "I really liked the ease of use and the unbiased nature"*		
Question # 9 [Narrative] What suggestions do you have to improve the decision aid website? **Caregiver** – *"The J Bruin graphic could be simplified for clarity. Also, it would be useful to provide links to external resources related to GAT treatment, community forums for trans youth and their parents."* **Youth – "***More graphic design, and more in depth looks about the types of testosterone hormone replacement therapy (HRT) people can and can't use, and the types of estrogen HRT people can and can't use", "N/A everything was perfect", "I honestly don't have any suggestions you did well"*		

CHAPTER SIX: DISCUSSION

The main findings of this study suggest that a web-based DA was feasible and beneficial to TGD youth and caregivers in deciding on GAT. This supports the DA literature in similar populations or in other clinical conditions (Allingham et al., 2018; Chen et al., 2022; Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020; Ozer et al., 2018). All participants had high mean baseline GAT knowledge, with many participants reporting that they

learned about the effects of GAT on future fertility online or from a medical provider. These findings are consistent with previous literature which suggests TGD youth and caregivers conduct extensive research prior to DM and seeking care (Clark et al., 2021; Halloran et al., 2022; Lambert et al., 2022). Post-intervention GAT knowledge scores either decreased or remained consistent compared to pre-intervention scores. These results may reflect participants not thoroughly reading each post-test question. In addition, results may reflect the age and developmental stage of the youth participants. Adolescents may have more ambivalence or inability to consider the future based questions as they move from concrete thinking towards mastery of abstract thought (Halloran et al., 2022; Strang et al., 2017).

Overall, the study sample had low baseline levels of DC. Caregivers had mean baseline DCS scores consistent with delayed decision making, whereas youth had very low levels of DCS scores consistent with making a decision aligned with personal values (O'Connor, 1993). Similar to previous findings, TGD youth and their caregivers may have completed a large portion of the DM process prior to attending an initial appointment (Clark et al., 2020a; Daley et al., 2019). This suggests access and use of a web-based DA prior to seeking medical care, may provide better decision support for individuals who are in the discovery phase of the DM process (Clark et al., 2020a).

Our demographic findings were consistent with previous studies in which the majority of individuals were assigned female at birth and identified as white or Latino/a/e/x (Daley et al., 2019; Halloran et al., 2022; Lawlis et al., 2017; Strang et al., 2018). Studies suggest that youth assigned female at birth face lower levels of stigma related to cross-gender behaviors compared to youth assigned male at birth, leading trans feminine people to be more likely to seek GAT as adults (Aitken et al., 2015; Leinung & Joseph, 2020; Quinn et al., 2017). Though the majority of

youth who participated in this study were still in high school, similar studies included participants from higher socioeconomic status and educational attainment, suggesting that a web-based DA can be useful among participants from various educational and sociodemographic backgrounds (Chen et al., 2019; Daley et al., 2019; Halloran et al., 2022). However, recruitment strategies are needed to capture more youth assigned males at birth to assess the generalizability and feasibility of the DA in a group of more diverse TGD youth, regarding gender identity and ethnicity, seeking GAT and fertility preservation.

Although all of the participants indicated that learning about the effects of GAT on future fertility was important, the findings of this study support previous literature suggesting TGD youth may prioritize GAT over the risk to future fertility (Chen et al., 2019; Daley et al., 2019; Halloran et al., 2022; Harris et al., 2019). Most youth study participants did not want to have a child, regardless of the parenthood method. This finding is congruent with other literature which has found a majority of TGD youth report future parenthood as not being significantly important to them or their DM process (Halloran et al., 2022; Strang et al., 2018). Most youth and half of the caregiver participants in this study indicated that having biological children or their child having biological children is not important. Consistent with other studies, these responses may be impacted by participants' reported barriers to cryopreservation, such as lack of insurance coverage, out-of-pocket costs, the need to delay GAT, and non-affirming clinical practices (Boguszewski, et al., 2022).

Most participants rated the DA information positively, with overall scores indicating the DA provided the right length, amount, and quality of information to support DM. These findings are similar to results from Chen et al. (2022), which found the implementation of a web-based decision aid to be acceptable and feasible among TGD youth and caregivers. Additionally, web-

based fertility preservation DAs have been found to be acceptable and feasible in supporting DM among women or parents of youth diagnosed with cancer (Allingham et al., 2018; Ehrbar et al., 2018; Ehrbar et al., 2019). While overall feedback was positive, participants suggested the need for additional resources regarding GAT and more interactive features to support DM. Studies have suggested use of personal stories may be more impactful than only discussing medical risks and benefits of GAT (Daley et al., 2019; Kolbuck et al., 2020; Lambert et al., 2022; Scalia et al., 2021). While links to personal videos and resources were included in the DA, these resources may not have been accessible due to a lack of interactive design format or participants did not find the provided resources sufficient to support quality DM.

Limitations

The biggest limitation of this pilot study was the small sample size, contributing to the lack of statistical significance in the outcome measures. The timeframe of the study was also a significant limitation to the sample size, as the study occurred over a 2-month period. Another potential reason for the smaller sample may be related to a moderately high attrition rate with 37.5 percent of the participants that completed the pre-testing did not return to complete the post-testing. Despite this, attrition was consistent with the appraised literature which reported dropout rates as high as 55% (Allingham et al., 2018; Ehrbar et al., 2018; Ehrbar et al., 2019; Garvelink et al., 2017; Mokken et al., 2020). While the findings of this study did not reach statistical significance, the findings were clinically significant in supporting SDM among participants.

In addition, there were limitations with the study design. The youth and caregivers were unrelated making it difficult to assess agreement or disagreement based on dyad responses. Despite this difference, valuable information was obtained to assist in modifying the DA per participant feedback. Furthermore, the start-stop feature in the DA was meant to provide

participants flexibility in the completion of the study measures and allow viewing with other people who did not attend the intake appointment which may be important to the DM process. However, this flexibility in access could cause concerns for testing validity, as participants could obtain assistance from others online.

Though many of the study questionnaires lacked validation in a similar population, the measures were evaluated by the YCAB to assess content validity. Similar to other youth gender health clinics, the participant demographics skewed towards Caucasian or Latino/-a/-e/-x individuals who were assigned female at birth, limiting its generalizability to other populations and clinical settings. In addition, sample selection bias may have occurred due to the recruitment of more participants with higher GAT knowledge either through prior appointments with medical providers or internet searches. A future study using a modified DA, in a larger, more diverse cohort is needed to validate findings and assess the DM process. Despite these limitations, the information gleaned from this project contributes important implications to improving SDM among TGD youth, their caregivers, and their treatment team.

Future Implications

Findings from this study identified caregivers with a desire for their child to have children while TGD youth recognized that their feelings regarding parenthood could change in the future. However, both youth and caregivers recognize potential barriers to fertility preservation being delays in starting GAT and feelings of discomfort in the cryopreservation process. Providers caring for the TGD youth population should be knowledgeable on fertility planning best practices for TGD youth and identify local gender-affirming resources for cryopreservation. The cost of cryopreservation was seen as another significant barrier to cryopreservation. While there are no studies evaluating long-term decisional regret regarding not

undergoing cryopreservation in TGD youth, clinicians should advocate for medical insurance to make fertility planning a covered benefit to limit this potential risk.

This pilot study lays the foundation for larger, more diverse multi-site studies. Future research should seek to understand the impact of the DA on individuals who are at the beginning stages of exploration and identify best practices in the implementation of a DA in relationship to provider counseling. In addition, longitudinal studies are needed to assess the impact of the DA on values-aligned DM related to GAT and decisional regret.

CONCLUSION

In conclusion, the purpose of this project was to develop and pilot test a newly developed web-based DA on GAT. Findings suggest the use of a DA can improve DC scores and help users with DM regarding GAT. The DA had no effect on knowledge among the users. This could reflect a more educated study population on GAT before the use of the DA. Modifications to the DA are needed based on participant feedback related to terms and definitions, figures and graphics for consistency, and fertility preservation and family planning. The implementation of web-based DAs into clinical practice is becoming more widely used to provide information in an easily digestible platform to assist with informed decision making. There is still much work to be done to enhance SDM to reduce DC and champion equitable, age-appropriate access to GAT. Future studies are needed to verify findings in a larger, more diverse cohort of TGD youth and their caregivers.

APPENDICES

Appendix A: Questionnaires

Questionnaire A1: Pre-Screener

1. Have you or your child completed an intake or 1st appointment with the Center for Trans Youth Health and Development at Children's Hospital Los Angeles?
    a. No (ends survey with message to return after completing their appointment)
    b. Yes

Patient Pathway

2. Select PATIENT if you are thinking about starting gender-affirming treatment (GAT) for yourself, such as puberty blockers or hormone therapy. Select CAREGIVER if you are the parent or caregiver of someone who is considering GAT
    a. Patient
    b. Caregiver (starts Caregiver branching – see below)
    c. I am NOT considering GAT and I am NOT a caregiver of someone considering GAT (survey ends)
3. What is your current age (in years)? (<12 or 25> survey ends)
    a. < 12 years (survey ends)
    b. 13-17 years (branches to consent/assent for TGD minor)
    c. 18-25 years (branches to consent/assent TGD adults and caregivers)
    d. > 25 years (survey ends)

Caregiver Pathway

2. Select PATIENT if you are thinking about starting gender-affirming treatment (GAT) for yourself, such as puberty blockers or hormone therapy. Select CAREGIVER if you are the parent or caregiver of someone who is considering GAT

a. Patient (Starts Patient branching – see above)

b. Caregiver

c. I am NOT considering GAT (survey ends)

3. What is your current age (in years)? _____

4. How old is the person considering GAT?

a. 12 or younger (survey ends)

b. 13-18

c. 19-25

d. 26 or older (survey ends)

Questionnaire A2: Demographics

1. What is your sex assigned at birth?

a. Female

b. Male

c. Intersex

2. What is your current gender identity?

a. Female

b. Male

c. Non-binary, trans feminine

d. Non-binary, trans masculine

e. Prefer not to answer

3. Which of the following best describes you? (Select all that apply.)

a. Asian

b. Black or African American

c. Hispanic, Latinx, or Spanish Origin

d. White

e. Other _____

4. Highest level of education:

    a. Less than high school

    b. Completed high school (earned GED or diploma)

    c. Some college

    d. Completed Bachelor degree

    e. Completed Graduate degree

5. Insurance status:

    a. Public (Medi-cal, California Children's Services (CCS), Champus, Disability or SSI)

    b. Private (HMO, PPO)

    c. No insurance, out-of-pocket, self-pay

6. Annual Income:

    a. I do not work or student

    b. < $20,000

    c. $20,000 to less than $30,000

    d. $30,000 to less than $50,000

    e. $50,000 to less than $80,000

    f. $80,000 to less than $100,000

    g. > $100,000

h. Prefer not to answer

7. What is your email address?

Questionnaire A3: GAT Knowledge

	Question	True	False	Unsure
1	Most children know their gender identity by age 5 years old.	X		
2	Being gay or lesbian is the same as being transgender.		X	
3	You can tell what pronouns someone uses by how they express their gender (through clothes, makeup, hairstyle, etc.).		X	
4	Being transgender or gender diverse is not a mental health illness.	X		
5	All bodies make some testosterone and some estrogen.	X		
6	Someone must go to therapy or get a letter from a therapist before beginning GAT.		X	
7	Being transgender is caused by parenting or trauma.		X	
8	People who transition must start with social transition (change name, pronouns, clothes, etc.) before beginning medical treatment (gender affirming treatment)		X	
9	Some GAT options (puberty blockers and/or hormone therapy) may make it impossible or difficult to get pregnant or get someone pregnant.	X		
10	Before starting GAT, people must freeze eggs or sperm.		X	

* Correct answers marked with "X"

Questionnaire A4: Transgender Youth Fertility Attitudes Questionnaire

TYFAQ – Youth Self Report

Please answer the following questions. Please note: "Biological children" means children born with your eggs or sperm.

1. It is important to learn about how hormone treatment might affect my ability to have my own biological children.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

2. I am aware that hormone treatment could cause issues with my ability to have my own biological children.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

3. How did you learn that gender affirming treatment, such as puberty blockers and/or hormone therapy, could make it difficult to have your own biological children? (Check as many as are true)

- Medical provider
- The internet
- Parent, caregiver, or guardian
- Peers (other young people your age)
- Other (fill in the blank): _____

- I did not know that gender affirming treatment could make it difficult to have my own biological children prior to this questionnaire

4. I feel I have people to talk to (like my medical provider or therapist) about how hormone treatment could affect my ability to have my own biological children.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

5. I feel I have people to talk to (like my my medical provider or therapist) about what I can do to have my own biological children if I’m taking hormones.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

6. I want to have kids someday. (This could be either your own biological kids or adopted kids).

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

7. If I have kids, it would be important to me that they are my biological kids.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

8. I would consider adoption someday.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

9. My feelings about wanting my own biological child might change when I’m older.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

10. I would be angry if the doctor didn’t tell me that hormone treatment could affect my ability to have my own biological children.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

- I don’t know

11. I am aware that there are options that would allow me to have my own biological child even if I’m on hormones.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

12. I feel pressured by my family to have my own biological child someday.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

13. I would feel that I’m disappointing my family if I could not have my own biological child.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

14. I would consider medical procedures that would allow me to preserve my eggs or sperm to be able to have my own biological children in the future.

- Strongly agree

- Agree
- Disagree
- Strongly disagree
- I don’t know

15. My family wants me to preserve my eggs or sperm.

- My family hasn’t talked about this
- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

16. Is there anything that would get in the way of your preserving your eggs or sperm? (Check as many as are true)

- I don’t have enough information to know how to preserve eggs or sperm
- Cost of preserving eggs or sperm
- Scheduling the appointment could slow down starting puberty blockers, hormones, or other medical treatments
- The procedure of preserving eggs or sperm would make me feel uncomfortable or embarrassed
- Other (please describe):

TYFAQ – Parent Report

Please answer the following questions. Please note: “Biological children” means children born with your child’s own eggs or sperm.

1. It is important to learn about how hormone treatment might affect my child's ability to have biological children.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don't know

2. I am aware that hormone treatment could cause issues with my child's ability to have their own biological children.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don't know

3. How did you learn that hormone treatment could make it difficult for your child to have their own biological children? (Check as many as are true)

- Medical provider
- The internet
- Other parents
- Other (fill in the blank): _____
- I did not know that hormone treatment could make it difficult for my child to have their own biological children prior to this questionnaire

4. I feel I have people to talk to (like a medical provider or therapist) about how hormone treatment could affect my child's ability to have biological children.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don't know

5. I would like to talk to someone about what my child can do to be able to have biological children if they are taking hormones.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don't know

6. I want my child to have kids someday. (This could be either their own biological kids or adopted kids)

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don't know

7. If my child has kids, it is important to me that they are my child's biological kids.

- Strongly agree

- Agree
- Disagree
- Strongly disagree
- I don’t know

8. I am open to my child adopting someday.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

9. My child’s feelings about wanting their own biological child might change in the future.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

10. I would be angry if the medical provider didn’t tell me that my child’s treatment could affect their ability to have biological children.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

11. I am aware that there are options that would allow my child to have biological children in the future (even if on hormones).

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

12. I would like my child to have their own biological child someday.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

13. I would be disappointed if my child could not have their own biological child.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

14. I want my child to consider medical procedures that would allow them to preserve their eggs or sperm to be able to have their own biological children in the future.

- Strongly agree
- Agree

- Disagree
- Strongly disagree
- I don’t know

15. I want my child to preserve eggs or sperm.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I don’t know

16. Is there anything that would get in the way of your child preserving their eggs or sperm? (Check as many as are true)

- I don’t have enough information to know how to help my child preserve eggs or sperm
- Cost of preserving eggs or sperm
- Scheduling the appointment could delay my child starting puberty blockers, hormones, or other medical treatments
- The procedure of preserving eggs or sperm would make my child feel uncomfortable or embarrassed
- Other (please describe):

Questionnaire A5: Low Literacy Decisional Conflict Scale

1. Which Gender Affirming Treatment (GAT) option do you prefer? (check all that apply)
    a. Puberty Blockers (Histrelin or Leuprolide)

b. Feminizing Medications (Estrogen, Androgen Antagonists or "T" Blockers, Progesterone)

c. Masculinizing Medications (Testosterone)

d. Cycle Suppression (hormonal or non-hormonal contraceptives)

e. Other (Specify) _____

f. Unsure

2. Considering the option you prefer, please answer the following questions:

		Yes (0)	**Unsure (2)**	**No (4)**
1	Do you know which options are available to you?			
2	Do you know the benefits of each option?			
3	Do you know the risks and side effects of each option?			
4	Are you clear about which benefits matter most to you?			
5	Are you clear about which risks and side effects matter most to you?			
6	Do you have enough support from others to make a choice?			
7	Are you choosing without pressure from others?			
8	Do you have enough advice to make a choice?			
9	Are you clear about the best choice for you?			
10	Do you feel sure about what to choose?			

Questionnaire A6: Acceptability

1. Please rate each section to show what you think about the way the information was presented on:

1	Terms & Definitions	Poor	Fair	Good	Excellent	N/A (did not review)
2	Basic Sexual/Reproductive Development	Poor	Fair	Good	Excellent	N/A (did not review)
3	Trans Identity, Presentation, & Transition Journeys	Poor	Fair	Good	Excellent	N/A (did not review)
4	Gender Affirming Medical Interventions	Poor	Fair	Good	Excellent	N/A (did not review)
5	Fertility Preservation & Family Planning	Poor	Fair	Good	Excellent	N/A (did not review)
6	Resources	Poor	Fair	Good	Excellent	N/A (did not review)

2. The length of the decision aid website was
    a. Too long
    b. Too short
    c. Just right
3. The amount of information was
    a. Too much information
    b. Too little information
    c. Just the right amount of information
4. The quality of the information was:
    a. Too complex or used words I did not understand
    b. Too simple
    c. Just the right amount of depth

5. I found the decision aid website
    a. Slanted towards starting gender affirming treatment
    b. Slanted towards delaying or not using gender affirming treatment
    c. Balanced
6. The decision aid website included enough information to help me make a decision about GAT.
    a. Yes
    b. No
    c. Unsure
7. I used this decision aid website (check all that apply):
    a. Alone (by myself)
    b. With my child
    c. With my parent or caregiver
    d. With a family member (not a parent or caregiver) if so who:
    e. With my partner/spouse/significant other
    f. With my friend (not related)
8. What did you like about the decision aide website?
9. What suggestions do you have to improve the decision aid website?

Appendix B: GAT Decision Aid Content

Introduction

Gender affirming treatment (GAT), such as puberty blockers and/or hormone therapy, can be a hard decision. This website was made to help users understand gender dysphoria and treatment options. Please review the pages related to your or your child's gender journey.

Terms and Definitions

Common terms used in DA (alphabetical)

1. **Cisgender** - People whose assigned sex at birth and gender identity are the same.
2. **Gender** – How the world expects a person to look, think, or act based on cultural beliefs.
3. **Gender affirming treatment** (GAT) – Using medicine(s), like puberty blockers and/or hormone therapy, for medical transition
4. **Gender binary** – The thought that there are only two genders (male and female).
5. **Gender creative/diverse/diversity/expansive** - Describes people who refuse or do not connect with expected gender roles.
6. **Gender dysphoria** – The feeling of unhappiness, stress, or tension between how someone sees themselves compared to expected gender roles. It can range from mild discomfort to severe distress. This can be different for each person.
7. **Gender euphoria** – A sense of joy or rightness related to one's gender.
8. **Gender expression** - This is how we present our gender to the world, using things like clothing, hairstyles, etc. Gender expression can change and may not be the same as someone's gender identity.

9. **Gender identity** - A person's inner feeling of being male, female, both, neither, or something else (Ex. non-binary, gender fluid, agender, etc.). It may be the same or different as their assigned sex at birth.
10. **Pronouns –** A word or phrase used in place of a noun, like someone's name. Pronouns used by most people include she/her/hers, he/him/his, they/them/theirs, and ze/zir/zirs. There are several other pronouns that someone may use, so it is best to ask which pronouns they use rather than to assume. (May also be called "gender pronouns" or "asserted pronouns").
11. **Romantic orientation** – Describes who someone has romantic feelings towards. This may or may not be the same as their sexual orientation.
12. **Sex assigned at birth** - The sex (male, female, or intersex) given to a baby at birth. It is usually based on the baby's genitals and sometimes through chromosome (DNA) testing.
13. **Sexual orientation** – Describes who a person has physical feelings towards (Ex. Gay, Lesbian, Bisexual, Pansexual, straight/heterosexual, etc.). It may or may not be the same as a person's romantic orientation. It is different from a person's gender identity.
14. **Transition** – Describes a process of change that is different for each person. For many transgender people, this process is continuous.
    a. Social Transition – The process of changing one's gender expression. May include changing names, pronouns, clothing, hair style, etc.

b. Medical Transition – The process of changing one's body and/or preventing the body from going through puberty using medications.

15. **Transgender or trans** (adj) - Describes a person whose assigned sex at birth and gender identity are different.
    a. Trans boy/man - A person who was assigned a female sex at birth and has a male gender identity
    b. Trans girl/woman - A person who was assigned a male sex at birth and has a female gender identity.
    c. Nonbinary person – A person whose gender is not binary (girl/woman or boy/man). This can be an umbrella term for other identities such as genderqueer, agender, or genderfluid.

Gender Identity

At birth, babies are typically assigned male, or female based on the baby's genitals and/or chromosomes. Some babies have sex or reproductive traits that do not fit these labels, this is also called intersex. Intersex differences occur in 1 out of 2000 births. Once a sex is assigned at birth, we assume a child's gender identity will match. Some people's gender identity matches their assigned sex at birth, but some do not.

How Does Gender Identity Develop?

A child's ability to know their gender happens over time. It is clear for most children by age 4 or 5. However, they might not have the words or feel safe enough to tell others.

- **2 to 3 years:**

    - Children notice differences between people's bodies and their own, like genitals. These differences are often reinforced by things other people say. Ex. "Boys have a penis" or "Girls have a vagina"
    - Most children can easily label their gender identity. They may tell this to other people. Ex. "I'm a girl" or "I'm a boy"
- **4 to 5 years:**
    - Children are aware of gender roles and expectations (*"things that boys do"* or *"things that girls do")*. This can cause distress if a child's gender identity does not match expectations.
    - Most children have a gender identity that is consistent. This may change later in life as someone has more language and understanding of their feelings.
- **6 to 7 years**:
    - Children may have anxiety when their gender identity does not match their assigned sex at birth. This can be caused when a child wants to be like their peers but realizes they do not feel the same way.
- **8 years and older**:
    - Gender identity grows as a person thinks about their own feelings. This can be impacted by comments from peers, family, and friends.
    - As puberty starts, some youth realize that their gender identity is not the same as their assigned sex at birth.
    - Most children will have a gender identity that matches their assigned sex at birth.

Gender Expression

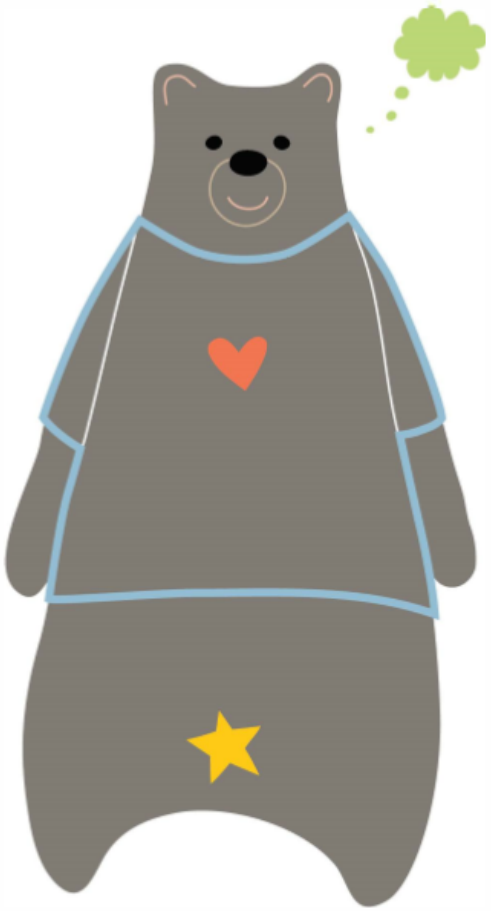
A person's environment can impact how they show their gender to others. Gender identity cannot be changed. People may express their gender identity in the following ways:

- Clothing, makeup, or hairstyle
- Their name, nickname and/or pronouns
- Choice of toys, games, and/or sports
- The relationships they have with other people

Sexual Orientation

Sexual orientation is a word used to describe who a person has physical and/or romantic feelings towards. A person may have physical feelings but not romantic feelings for a person. Or they can have romantic feelings but not physical feelings for someone. A person's gender identity and/or expression does not influence their sexual orientation. A person's gender expression does not tell others their sexual orientation and/or gender identity.

People often mix up gender and sexual orientation. This can make it hard for a young person to understand and articulate aspects of their own gender. It is common for transgender and gender diverse youth to think or talk about their sexual orientation before their gender identity. How each person comes to know their gender and sexual orientation is a unique journey.



J BRUIN: AN INTRO TO GENDER, SEXUALITY, & EXPRESSION

SEX ASSIGNED AT BIRTH

The classification of an infant's sex. This has biological, social, and legal implications.

- Female
- Male
- Intersex

GENDER IDENTITY

A person's concept of their own gender.

Agender →
- Woman
- Man
- Genderqueer, Nonbinary

GENDER EXPRESSION

The ways that a person expresses their gender.

Masculine ← Androgynous → Feminine

SEXUAL AND/OR ROMANTIC ATTRACTION

A person's romantic and/or sexual attraction to another person(s) based on their sex/gender.

Asexual, Aromantic →
- Different Gender than self
- Same Gender as self
- Multiple Genders

Created by Kevin Medina and Megan van der Toorn & Designed by Syd Rein, LGBTQ Campus Resource Center, 2017.

Sexual & Reproductive Development

Puberty is when the body changes from being a kid to an adult. These changes may give a person the ability to make a baby (reproduction). Puberty starts when a part of the brain, called the hypothalamus, begins making a hormone called gonadotropin-releasing hormone (GnRH). This happens at different ages and speeds for each person. GnRH tells the pituitary gland to start releasing puberty-related hormones (Luteinizing Hormone (LH) and Follicle Stimulating Hormone (FSH)). The increase of LH and FSH causes the gonads (testicles or ovaries) to make hormones that cause the body to change. People who have testicles start making more testosterone. People with ovaries start making more estrogen and progesterone. However, all people make some testosterone, estrogen, and progesterone. These hormones impact puberty changes such as body hair, bone growth, genital growth, etc. Changes like acne, pubic or armpit hair are caused by other hormones.

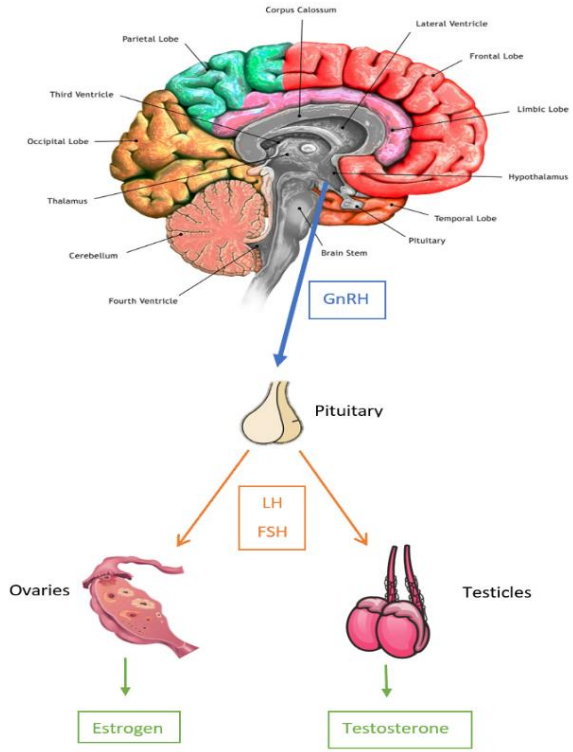
Changes during puberty for all bodies:

- Increase acne
- Increase sweating and body odor
- Hair growth in genital area and armpits

- Growth spurts and growing pains

Body changes in people with testicles (without puberty blockers)

- Testicle and penis grow
- Increase hair on face, chest, and back
- Voice deepens
- May have bump on throat grow & becomes visible (“Adam’s apple”)
- Chest and shoulders broaden



Body changes in people with ovaries (without puberty blockers)

• Breast changes/chest development

• Changes in body shape, including wider hips

• Menstrual cycle starts (usually more than 2 years after chest development)

Once puberty starts, people with testicles usually make sperm cells and people with ovaries usually make egg cells. But not all bodies with testicles make sperm and not all bodies with ovaries make eggs. Usually, people with ovaries also have a uterus or a place

inside the abdomen where a baby can grow. When a sperm cell and egg cell come together and get into a uterus, a baby can develop. This can happen in many ways depending on the needs of the people involved.

Physical Changes of Puberty

↑ Estrogen

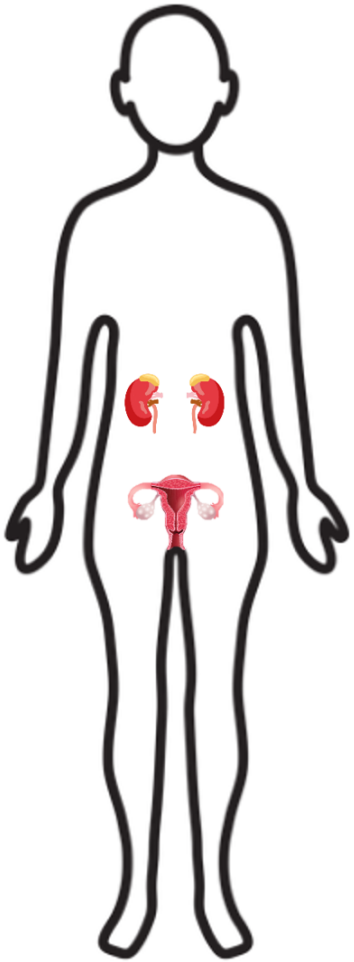
Face Stays Round

Growth of Chest

Wider Hips

Period/Cycle

Skin Stays Softer



Androgens

Everyone makes some androgens from their adrenal glands (on top of the kidneys)

Slight Voice Change

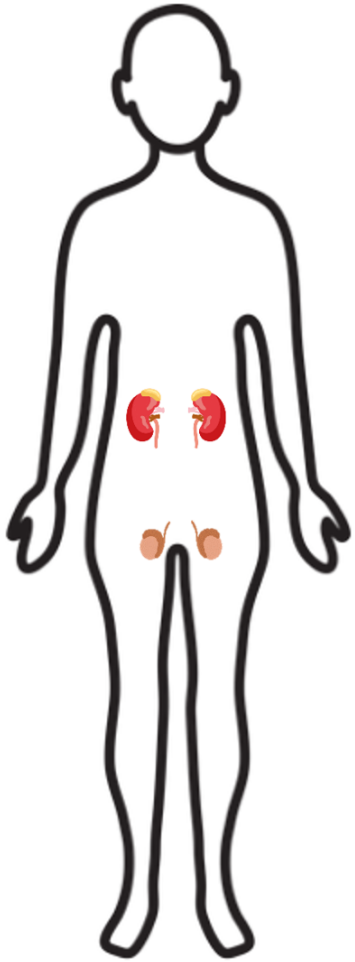
Body Odor

Armpit Hair

Some Arm Hair

Pubic Hair

Some Leg Hair



↑ Testosterone

Prominent Brow
Angular Jaw
Facial Hair

Deeper Voice
"Adam's Apple"

Wider Shoulders
Increased Muscles

Overall Thicker Body Hair
Thicker Skin Texture

Hand/Feet Growth
Increased Height

Growth of Testicles & Penis
Erections

Trans Identity & Transition Journeys

Gender diverse people have been around since the beginning of time. This includes indigenous communities in the United States and Mexico (Two-spirit, Muxes), Africa (Okule & Agule), and India (Hijras), to name a few. We do not know why some children identify as transgender or gender diverse. Research suggests that gender is something a person is born with, and it cannot be changed by others.

Differences in identity and/or expression are normal parts of human development. Youth need a safe space to explore gender. This can be difficult as gender norms, expectations, and assumptions are in all areas of our society. Examples: pink, dolls, and house-play toys are for girls and blue, trucks, and action figures are for boys. Youth may feel pressure to fit into these norms, which can cause depression, anxiety, and isolation if they do not fit into these norms.

Each child has different needs about their gender identity and expression. It is normal for youth to explore their gender expression and present different than their assigned sex at birth. Some youth will identify with a gender that matches their sex assigned at birth (cisgender). Some youth will identify with a gender that does not match their assigned sex at birth (transgender). The language a person uses to talk about their gender identity can change as they gain more vocabulary.

How a person wants to express their gender can vary. Some youth may only want to socially transition. Some youth may also want to pursue medical transition, such as puberty blockers or hormone therapy. Gender journeys do not all start with social transition. Some people are uncomfortable changing their gender presentation before starting hormone therapy due to harassment, physical violence, or rejection. Youth who do not identify with a binary gender may only want to use non-medical ways to express their gender

identity, such as wearing makeup or legally changing their gender marker. Some people may only want surgery, like male chest reconstruction surgery. Some people use hormone therapy for a short amount of time or at low dose. There is no one way for someone to transition.

	Example	Reversibility
Social Transition	Change clothing, makeup, hair/hairstyle, name, pronouns	Reversible
Legal Transition	Change gender and/or name on legal documents	Reversible
Puberty Blockers	Gonadotropin-releasing hormone analogs (GnRHa). Ex. Histrelin implant or leuprolide injection	Reversible
Gender-affirming hormone therapy	Estradiol with or without an androgen blocker (for those assigned male at birth) Testosterone (for those assigned female at birth)	Partially Reversible
Gender-affirming surgeries	Includes all types of surgeries used to enhance gender expression. Ex. facial feminization, male chest reconstruction	Most Not Reversible

A child's ability to talk about their gender depends on how their family reacts to gender diversity. Before puberty, some children who show gender diverse traits may start a social transition. Others may not. Gender dysphoria that lasts through puberty or is

increased by puberty will likely not stop. Not all transgender or gender diverse people will have a history of gender diverse traits in childhood.

Being transgender is not a mental health disease. If a mental health issue exists, it often comes from other factors, such as bullying, discrimination, and/or genetics. Being transgender is not contagious. Some youth may feel more comfortable talking to classmates or online friends before their parents or family. When a youth's gender expression does not fit into societal or cultural norms, they may feel rejection from their family.

Family Acceptance

Children should be allowed to try activities and interests that are different from expected gender roles (ex. "things girl's do" and "things boys do"). This exploration is a normal part of development. It does not define a person's gender identity. There is no evidence that parenting style, childhood trauma, or peer influence can cause gender diversity.

Research shows that family support and acceptance can prevent negative health outcomes. Youth who are not supported in their gender (i.e., waiting or preventing transition), have higher rates of suicidal thoughts and attempts. However, youth who are supported in their gender do not have higher rates of depression than their cisgender peers (Olson et al., 2016). No matter how a child identifies, they each have their own strengths that may not always fit expectations. The best thing a family can do is love, support, and accept their child for who they are.

What family members can do:

- Follow the youth's lead regarding their gender expression. Set limits as necessary for safety.

- Advocate for safe spaces that are affirming of gender diversity.
- Ensure the environment reflects diverse people and perspectives.
    - Books that include diverse gender roles.
    - Offer a wide range of toys and activities.

Non-Medical Options

Some people use non-medical ways to match their gender expression (how they look) with their gender identity (who they are). Each person will have a different timeline for when or if they use non-medical options. People may use all these options, some of these options, or none.

Name and/or Gender Marker Change

Changing one's name and/or gender marker can be done whenever they feel ready. A person can change their name and/or gender without ever using medicine. Some people may change legal documents before or after starting medicine.

In California, a person does not need a doctor letter to change their name and/or gender marker. A letter may be needed if a person was born in another state. The United States federal government no longer needs a letter or other items (ex. updated birth certificate or identification (ID)) to change federal documents. In California, a person can select a male (M), female (F), or non-binary or intersex/non-binary gender marker (X). These gender marker options are also available for U.S. passports. However, this may disclose your identity to others. Some countries may not be affirming of an X gender maker or maybe discriminatory towards those who are identifiable as transgender.

These forms can be completed with or without help from an organization. Regardless of income, everyone is encouraged to submit a fee waiver form. If approved, the court fees can be reduced or made free.

Voice Therapy

A person's voice can be an important part of expressing their gender. Estrogen and progesterone do not have a big impact on voice. Testosterone will thicken vocal cords and lower or deepen the voice. Some people use vocal therapy or have surgery to change the tone, pitch, and pattern of their voice. These options may be covered by insurance. Speak with your medical provider to find out more.

Clothing

Clothing allows a person to express themselves. They can be used to improve a person's gender expression. However, it may not be safe or feel comfortable for someone to change how they dress before they are ready. A person does not need to change their clothing before they begin GAT. Some people change their clothing without, before, or after using GAT.

Hair & Makeup

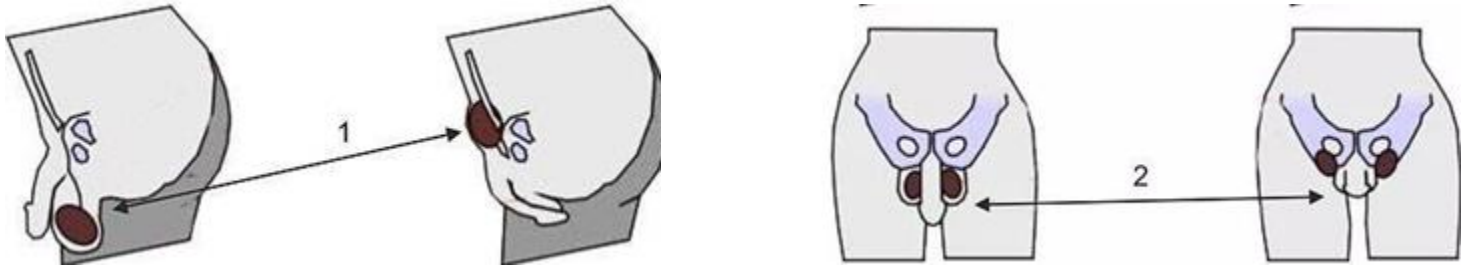
Some people may change their hairstyle and/or length to enhance their gender expression. Some people may also use makeup to appear more feminine or masculine. These things can help with dysphoria for some people.

There are three main kinds of wigs: hard fronts, lace fronts, full lace.

Type	Features	Pros	Cons
Hard Front	• Commonly comes with bangs	• Affordable	• Not easily styled • More unnatural looking
Lace Front	• Uses fine lace with individual hairs tied to front • "Wefting" or hair tracks on sides and back	• Natural appearance • Mimic the look of scalp • More variety compared to hard front	• More expensive than hard front
Full Lace	• Entirely made with lace, with fine hairs tied to it. • No wefts (tracks) used	• Most variety in style options • Can be styled into ponytails, braids, etc.	• Most expensive option

Tucking

Tucking describes the practice of putting one's genitals between and behind one's legs, so that it is not visible from the front of the body. Some people push their gonads (or testicles) back as well. Others move them upward and rest them on the lower part of their abdomen before securing them in place. It is best to use tucking gear rather than tape or very tight underwear to avoid pain or discomfort.



Note. From "Tucking" by Hour Glass Figure, 2019. (https://www.hourglassfigure.co.uk/tucking-32-w.asp). Copyright 2019 by Little Red Ruby Ltd.

Tucking Gear

Options	What is it?	Avg. cost
Control Briefs	• Use of "tummy control" briefs (like Spanx)	$10-30
Layering Undies	• Layering or wearing more than 1 pair of underwear • Use cotton panties instead of other options to avoid irritation	$10-30
Gaffs	• Compression underwear made for tucking	$20-30

Breast Forms

Breast forms are prosthetic breasts which are secured onto the chest or worn within a bra to increase chest size. They are usually made from silicone for a soft, life-like feel. They come in different sizes and colors. Some people choose to wear them before, in addition to, or instead of hormones and/or surgery.

Packers & Stand-to-Pee devices

A packer is a device or object that is worn to give the appearance of having a penis or bulge. They can also be called a “packer”, “packy” or an "STP packer" (if it can also be used to pee through while standing up (STP= Stand To Pee)). Packers can vary from a rolled-up sock to more expensive options.

There are many reasons someone might want a packer. The act of packing can help some people improve or alleviate their “bottom dysphoria”. The goal of packing differs depending on the person. Some people do not feel the need or want to pack. Some may wear one on certain occasions and others will never leave home without it.

Given the choice, most people would want to go big. But, if the packer is too big, it could look unusual and draw attention. These products are usually non-returnable, so be careful when ordering. Try to pick one that fits one’s overall body frame. When in doubt, go for medium or whatever size is in the middle range for that brand.

Packer Material	Pros	Cons
Sock/fabric	• Cheap • Easy to clean • Easy to obtain	• Not as versatile
Silicone	• Most popular • Hypoallergenic • Durable • Easy to clean	• If surface breaks can lead to tears • Expensive
Cyberskin	• Blend of rubber & mineral oil • Mimics feel/look of human skin • Low-cost	• Porous – hard to keep clean • Can show discoloration & shrink over time

Chest Binding

Chest binding is the act of flatting chest/breast tissue using a binder, compression, or wrap. It can help some people improve distress or dysphoria related to having a chest that others see as female. Youth who do not have access to a binder are more likely to use options that can increase negative side effects such as trouble breathing, rib fractures, or rashes.

A recent study found that 95% of youth who had negative side effects from binding continued to bind to feel more comfortable in public. Youth who bind report higher levels of life satisfaction and ability to engage in life activities, like school (Julian et al., 2021).

Best Practices for Chest Binding

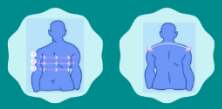
It is best to use a medical grade or commercial binder from a trusted binder company. Some people may be able to use TransTape© or sports bras to create a flatter appearing chest.

Do not use:

- Binders with clasps, hooks, or ribbing (i.e., corsets)
- Ace bandages
- Household tapes (ex. duct tape, scotch tape, etc.)
- More than 1 binder or compression item at a time
- Items that are too small, too tight, and/or not stretchy

Best Practices for Chest Binding

RIGHT SIZE



Measure around:

1. Underams
2. Largest part of chest
3. Under chest

Also measure:

1. Shoulders from point-to-point

RIGHT FIT

Compare measurements to each company's sizing chart.

Each company has different sizing & fits.

Different styles may work better for different chest sizes.

COMFORT

The binder should be snug but not too tight.

One should be able to breathe and move comfortably.

Do not wear a binder for more than 9 hours/day.

Take breaks when you can.

SUPPORT

Talk with your healthcare provider if you have questions or experience chest pain, trouble breathing or skin irritation.

RESOURCES

These are some of our favorite binder companies!

gc2b TRANSITIONAL APPAREL

Flamt

Images reprinted with permission from gc2b©, a trans-owned binder company

Mental Health & Social Support

Therapy or a letter of support is not required before starting GAT. However, mental health and social support can be important parts of a person's transition journey. It can be helpful for the youth and/or their family to find support individually or in groups. Many people may only want or need mental health support for things not related to their gender. At this time, one or two letters of support from licensed mental health provider(s) are still needed for insurance to approve payment.

Medical Options

Puberty Blockers

Puberty blockers are medicines that stop the hormones (Luteinizing Hormone (LH) and Follicle Stimulating Hormone (FSH) that start puberty. These medicines (also called GnRH agonist) stop puberty by blocking gonadotropin-releasing hormone (GnRH). The body cannot make LH and FSH without GnRH. Stopping LH and FSH causes the body to not make estrogen and testosterone. This puts a 'pause' on changes that come from testosterone and estrogen.

A person can only use a puberty blocker after puberty has started. There is no specific age when someone can begin using a puberty blocker, as puberty starts at different ages for each person. These medicines are reversible if used alone. If you stop the medicine, puberty changes of a person's assigned sex at birth will start. Puberty changes that have already happened will not be changed by these medicines. But any further puberty changes will stop. Puberty blockers can give youth and/or caregivers time to make decisions about more permanent choices, like hormones.

Puberty blockers can come in different ways. They can be expensive but may be covered by insurance. How much is covered depends on many things, such as the type of insurance plan or deductibles.

Puberty Blocker Type	**How is it Given?**	**Puberty Blocker Name**	**Estimate Cash Price**
Intramuscular Injection (leuprolide acetate)	A shot that is given in the muscle (arm), every 3 months.	Lupron Depo-Ped 11.25MG/ 3 months	$ 4 - 5,000/every 3 months
Subcutaneous Injection (leuprolide acetate)	A shot in that is given in fat (abdomen or thigh), every 3 months.	Eligard Kit 22.5mg/3 months	$ 2 - 4,000/ every 3 months
Implant (histrelin)	A small plastic rod placed under the skin for 1-2 years.	Vantas 50mg Implant (2-year average)	$ 5 - 15,000/each *
		Supprelin 50mg Implant (2-year average)	$ 20 - 50,000/each*

* Does not include insertion or hospital fees. Prices vary depending on the dispensing pharmacy.

There are some risks with using a puberty-blocker. In some people, blocking puberty can lower bone density or make bones weaker. This may get better when puberty blockers are stopped or if hormone therapy starts. Taking vitamin D, calcium, and doing activities that make bones strong like jumping rope and walking can improve bone health. These medicines may lower the need for

future procedures such as hair removal or surgeries (ex. male chest reconstruction or “top” surgery). But they can make surgeries that use genital tissue (ex. vaginoplasty or “bottom” surgery) more complex.

When used alone, puberty blockers do not impact a person’s ability to have children in the future (fertility). Future fertility can be impacted if a person stays on a puberty blocker and starts hormone therapy (testosterone or estrogen). Puberty blockers can be used for about 2-4 years without starting hormone therapy or stopping them to allow puberty to resume.

Hormone Therapy

Hormone therapy includes medicines that a person can take to change the amount of sex hormones in their body. This can help make the body match a person’s gender identity. Feminizing hormones can help the body look and feel less “masculine” and more “feminine”. Masculinizing hormones can help the body look and feel less “feminine” and more “masculine".

Hormone therapy can lower anxiety and depression as a person’s body and mind start to match. It may not get rid of anxiety or depression, especially if symptoms get worse by things not related to gender.

There is no way to know how a person will respond to hormone therapy. The changes that happen from hormone therapy are different for each person depending on their age and genetics (how sensitive they are to hormones and the number of receptors they have). You cannot pick the changes you want. Taking more hormones than prescribed may not increase or speed up changes and can increase other risks, like blood clots or diabetes.

Medications for Trans Feminine Youth

Feminizing hormone therapy is different for each person. A person may use one, some, or all the following medicines depending on their goals, health, and insurance coverage.

- Estrogen
- Androgen antagonist ("T-blocker)
- Progesterone

Estrogen

Estrogen is the main hormone that causes "feminine" traits of the body. Estrogen can lower testosterone over time. Some changes may be noticed within several months or much longer. Some of the changes from taking estrogen are permanent (if medicine is stopped, changes will remain). Some of the changes are reversible (if medicine is stopped, changes will go back to how they were before medicine was used).

Effect	Avg. Timeline*	Max. Effect*	Reversibility
Skin softening	1 - 6 months	Unknown	Reversible
Decrease muscle mass		1-2 years	
Redistribution of fat to hip, thighs, & breasts		2-3 years	

Decrease sex drive		3-6 months	
Decrease in ability to have erection		3-6 months	
Decrease in ability to make sperm		> 3 years	
Growth in nipples and breasts	3 –12 months	2-3 years	Not Reversible
Slower hair growth on face & body		> 3 years	Reversible
Slower head hair thinning or loss		1-4 years	
Decrease in genital size		2-3 years	

* Average timeline and Maximum effect if on full-dose, low-dose may extend timing.

Feminizing medicines will make facial hair less noticeable, but it will not go away completely. These medicines will not change a person's voice or get rid of the bump on the throat that is sometimes called an "Adam's apple". Feminizing medicines do not help people grow a uterus or ovaries.

Estrogen can be taken in several different ways:

Types of Estrogen	How do you take it? (Route of Administration)	How often? (Frequency)	How much? (Avg. cost without	Considerations

			insurance coverage*)	

Estradiol tablets (pills)	Swallow whole tablet (oral) or place under tongue to dissolve for a few minutes, then swallow remainder (sublingual)	Daily	≈ $ 7- 15/month, depending on dose.	• Tablets won't dissolve completely.
				• Prescription bottles may not say to dissolve under tongue. Ask your provider if you have questions.
				• Some people take them twice or three times a day
				  • May feel less ups and downs, by keeping levels stable.
				  • Maybe harder to remember or fit into schedule
				• Some people take them all at once
				  • Easier to remember
				  • May increase nausea

Estradiol Valerate	Intramuscular (in the muscle) injection	Every 1-2 weeks	5ml vial ≈ $100 **	• Can be more painful/ sore muscle for several days • May see changes faster than with tablets • Can take every 2 weeks

	Subcutaneous (in fat) injection	Every 1 week (7 days)	5ml vial ≈ $100**	• Typically, less painful than IM • Can have bump or irritation after injection • Use same medication as IM injection • May see changes faster than with tablets
Estrogen patches	Transdermal Patch with medication that is applied to skin for a certain number of days, then removed and replaced with a new patch.	Change patch(s) once or twice a week	≈ $20 – 100/ month, depending on dose	• Useful for those with fear of needles • Can cause skin irritation • May not be covered by insurance without trial of tablets and/or injections first.

* As of September 12, 2021, from goodrx.com

** Not including injection supplies (syringes and needles)

Androgen Antagonists

Androgen antagonists (also called, anti-androgens, testosterone blockers, or "T-blockers") work by stopping the body from making or using testosterone. They reduce "masculine" physical traits. They can also have some "feminizing" effects. There are different types of androgen antagonists.

These medicines are often used in addition to estrogen. Taking testosterone blockers lowers the amount of estrogen a person needs to have the same effects. This can lower the health risks associated with estrogen. Testosterone blockers can be used alone for a more androgynous look because it is less "feminizing" than estrogen.

Most of the changes are reversible. If a person stops taking it, the body will go back to how it was before the medicine was started. These medicines affect the whole body. You cannot pick the changes you want.

Testosterone Blockers (Androgen Antagonists)	How do you take it? (Route of Administration)	How often? (Frequency)	How much? (Avg. cost without insurance coverage*)	Considerations
Bicalutamide	By mouth (oral)	Once a day	≈ $ 10 – 25/ month, depending on dose.	• Blocks testosterone receptors (used to treat prostate cancer) o **May have permanent breast development** o Slow head hair loss o Decreased muscle mass o Increased fat redistribution o Lower libido • Risks o Hot flashes o Nausea, vomiting, or constipation

				○ Sensitivity to sunlight/tanning beds ○ **Rarely causes liver problems**
Spironolactone	By mouth (oral)	1-2 times/day	≈ $12 – 25/ month, depending on dose.	• Decrease testosterone production (used in prostate cancer, acne, high blood pressure, & more) ○ Decreased body/facial hair growth ○ Slow head hair loss ○ Lower libido ○ Decrease in genital size ○ **May have permanent breast development** • Risks ○ Increase peeing (urination) ○ Lower blood pressure ○ Dizziness/ Lightheaded ○ Increased thirst ○ **Dangerous levels of potassium in the blood**

* As of September 12, 2021, from goodrx.com

Progesterone

After about 6 months of using feminizing hormones, some people may take progesterone. Progesterone is another hormone that is used with estrogen to improve feminization. The long-term effects and risks of this medicine are not known. The risks of taking this medicine are worsening mood and increased risk of heart disease or stroke.

	How do you take it? (Route of Administration)	How often? (Frequency)	How much? (Avg. cost without insurance coverage*)	Considerations

Progesterone	By mouth (oral)	Once a day (at night preferred)	≈ $12 – 25/ month, depending on dose.	• Benefits
				  ○ Increase breast & nipple development
				  ○ Weight gain
				  ○ Increase libido
				  ○ Enhance fat redistribution
				• **Take before bed**
				  ○ Can make some sleepy/tired
				• Risks
				  ○ Worsening mood
				  ○ Increase risk of heart disease & stroke

* As of September 12, 2021, from goodrx.com

Medications for Trans Masculine Youth

A person who identifies as male or masculine may use masculinizing hormone therapy, such as testosterone, or medicine to stop their menstrual cycle. A person may use one or both of the following options depending on their goals, health, and insurance coverage.

- Testosterone
- Cycle management

Testosterone

Testosterone (sometimes called "T") is the main hormone that causes "masculine" traits of the body. Testosterone can lower estrogen over time. Some changes may be noticed within several months or much longer. Some of the changes from taking testosterone are permanent (if the medicine is stopped, changes will remain). Some of the changes are reversible (if the medicine is stopped, changes will go back to how they were before medicine was used).

Effect	Avg. Timeline	Max. Effect	Reversibility
Increased hair growth, coarseness, & thickness on arms, legs, chest, back, stomach, & butt	1-3 months	4-5 years	NOT Reversible

“Bottom” growth or growth of clitoris (1-3 cm)		1-2 years	
Fat redistribution (more in waist/stomach & less in hips/thighs)		2- 5 years	Reversible
Increase oily skin and acne		1-2 years	
Increased sex drive		-	
Increased muscle mass		2- 5 years	
Genital Dryness		1-2 years	
Cycle stops	1- 6 months	-	
Voice cracking & deepening	3 – 6 months	1-2 years	NOT Reversible
Facial Hair	Gradual over the 1st year	4-5 years	
Head hair loss or thinning		-	

* Average timeline and Maximum effect if on full-dose, low-dose may extend timing.

Masculinizing hormones do not help people grow a penis or testicles.

Testosterone can be taken in several different ways:

Type of Testosterone	How do you take it? (Route of Administration)	How often do you take it? (Frequency)	How much? (avg. cost without insurance coverage*)	Considerations
Testosterone cypionate (mixed in cottonseed oil)	Subcutaneous (SC) (in fat) injection	Every 1 week	1ml vial ≈ $10 – 20 **	• Maybe less painful than IM injection • May have bump or irritation after injection • Use same medication as IM injection • May see changes faster than gel • Weekly dosing may help keep hormone levels stable
	Intramuscular (IM) (in the muscle) injection	Every 1-2 weeks	1ml vial ≈ $10 – 20 **	• May be more painful than subcutaneous injections • Can take every 2 weeks • May have more fluctuations in hormone level • May see changes faster than gel
Testosterone enanthate (mixed in sesame seed oil)	Subcutaneous (SC) (in fat) injection	Every 1 week	5ml vial ≈ $30 – 50 **	• Maybe less painful than IM injection • May have bump or irritation after injection • May see changes faster than gel • Typically used if allergy or sensitive to cottonseed oil
	Pre-filled syringe for subcutaneous (SC) injection (Brand name: Xyosted)	Every 1 week	4 autoinjectors ≈ $500 – 600/ month	• Maybe helpful for those with fear of needles • Maybe less painful than IM injection • May have bump or irritation after injection • May see changes faster than gel • Less likely to be covered by insurance

Testosterone gel	Apply gel to skin (topical)	Daily	Packets ≈ $ 100 – 300/ month depending on dose Pump ≈ $ 100 – 600/ month, depending on dose	• Useful for those with fear of needles • May see changes slower than injections • **Must wash hands after applying to avoid transferring to others**
Testosterone patches	Patch with medication that is applied to skin, then removed and replaced with a new patch (transdermal)	Daily	≈ $600 – 1000 / month, depending on dose	• Useful for those with fear of needles • May cause skin irritation

* As of September 12, 2021, from goodrx.com

** Not including injection supplies (syringes and needles)

Cycle Management

Some trans masculine youth may only want to stop their cycle/period. This can be done using a progesterone-only medicine. Medicines that have estrogen are usually avoided but can used for some people. Progesterone-only medications are not guaranteed to make the cycle stop completely. Many may cause spotting. These medicines may also be used to prevent pregnancy (birth control). They can be used with or without testosterone. Medicines used to stop the cycle may be covered by insurance or programs such as Family Planning, Access, Care, and Treatment (Family PACT).

Method	Medication Name	How do you take it? (Route of Administration)	How often do you take it? (Frequency)	Chance for cycle to stop	Considerations
Implant	Nexplanon	A small plastic rod placed under the skin in the upper arm.	Stays in arm for 3- 5 years	30%	• May cause spotting • May decrease cramps • May impact mood
Intra-uterine device (IUD)	Progestin IUD (Mirena, Skyla, etc.)	Inserted in the uterus by a medical provider.	Can stay in place for 5-7 years	50% after 1 year, 60% after 5 years	• May cause spotting • Mirena used to treat heavy cycles ○ May decrease cramps

Pill	Norethindrone (Aygestin)	By mouth (oral)	Once a day	Up to 76% with high doses after 2 years	• **Must be taken at the same time every day**
					• If taken every day (skipping placebo pills), may stop cycle
					• May cause
					  ○ spotting
					  ○ depression
					  ○ hair or skin changes
					  ○ bloating

Injection	Depo-Provera	Intramuscular or subcutaneous injection	Every 3 months (12 weeks)	50-60% after 1 year, 70% after 2 years	• May cause
					  ○ spotting
					  ○ stop cycle
					  ○ **weight gain**

					○ depression ○ hair or skin changes • **May impact bone density**

Fertility Preservation and Family Planning

Gender-affirming treatment may impact a person's ability to get pregnant or to make someone pregnant. It is normal for young people to not want children or be unsure if they want children. This may or may not change in the future. Some people may want to have biological children using their eggs or sperm. Some people may want to become a parent using other methods that do not use their sperm or eggs, such as adoption or choosing someone else to carry the pregnancy (surrogacy).

A person should know how these medicines can affect their fertility in the future. A person who starts puberty blockers at the beginning of puberty and then starts hormones, may not develop sperm or eggs. This means the person may not be able to have biological children. If the puberty blocker is stopped and hormone therapy is not started, pubertal development would continue, and fertility would be maintained.

The long-term effects of hormone therapy alone on fertility are not well studied. While using hormone medications, fertility may be reduced. Many hormone medicines do not prevent pregnancy. People using hormone therapy have gotten pregnant or someone else pregnant. The ability to have biological children may or may not come back even after stopping hormone therapy. A recent study found transgender men who had used testosterone (avg. length of hormone therapy = 3.7 years; max. length = 17 years) had similar fertility outcomes as cisgender peers (Leung et al., 2019).

Some people may want to save their sperm or eggs before starting medications (fertility preservation). People who have already begun medicines may be able to preserve their fertility but will need to stop hormones for several months before doing so. Stopping or delaying gender affirming treatment, as well as the process for collecting eggs or sperm, can increase dysphoria in some people.

Insurance does not usually cover the cost of fertility preservation. You may have to pay for the cost of collecting and freezing your sperm or eggs (preservation process). There is also a yearly storage fee to keep your sperm or eggs at the fertility clinic. Ask the fertility clinic about the costs and what is included when you call them.

Procedure	Avg. Cost*
Egg Freezing	$10 – 15,000
Egg Storage	$300 - 500/ year
Sperm Banking	$500 - 1000
Sperm Storage	$140-500/ year

* As of Sept. 2021, from allianceforfertilitypreservation.org

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2. Silverberg, C. (2012). What makes a baby. ZoBall Press.

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1. Personal Journey Videos
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    b. MTV. (2016 August 6). Laverne Cox Presents: The T Word Full Documentary (video). https://www.youtube.com/watch?v=mDy0DhfuxfI&t=68s

c. BuzzFeedVideo. (2016 July 16). Trans Teens Talk about What It's Like to be Trans (video). https://www.youtube.com/watch?v=umM1fu8-q50

d. Self-Made Man. (2019 December 16). How I Knew I Was Trans? (video). https://www.youtube.com/watch?v=7-UQbm38nSI

e. Jackson Bird – Am I Really Trans? (video). https://www.youtube.com/watch?v=-teBenVDyOU

f. Ryan Jacob Flores – How Did I Know I Was Trans? (video). https://www.youtube.com/watch?v=DoTp0m7ZKLU

g. Audrey Mason-Hyde. (2018 January 19). Toilets, bowties, gender and me (video). https://www.youtube.com/watch?v=NCLoNwVJA-0&t=169s

2. Family Acceptance Videos

a. Parents of Transgender Youth Have Important Advice for New Parents Starting Their Journey (video)- https://www.youtube.com/watch?v=ihkEf1Tk1e4

b. Truth: Meet Zoey (video). https://www.youtube.com/watch?v=zUus5XDIX4A

c. The Miles Family (video) - https://www.youtube.com/watch?v=azhauAuHlhc

d. The Berman-Ruth & Wylie Families (video) - https://www.youtube.com/watch?v=XIEvdXRKW8k

e. Supporting Trans & Non-binary Youth: HRC Youth Ambassador Panel 2021 (video)- https://www.youtube.com/watch?v=Pmg8z0we7Yw

3. Family Acceptance Project. (2009). Supportive families, healthy children: Helping families with Lesbian, Gay, Bisexual, & Transgender children. https://familyproject.sfsu.edu/sites/default/files/FAP_English%20Booklet_pst.pdf
4. Parents for Transgender Equality National Council Resources - https://www.hrc.org/resources/parents-for-transgender-equality-national-council
5. Rafferty, J. (2021 June 7). Gender-diverse and transgender children. https://www.healthychildren.org/English/ages-stages/gradeschool/Pages/Gender-Diverse-Transgender-Children.aspx

Non-Medical Options

Name & Gender Marker Change

1. Self-Help
    a) CA Courts Change Gender Marker - https://www.courts.ca.gov/genderchange.htm
    b) How to: Name and Gender Marker Change in California (Video) https://www.youtube.com/watch?v=UAjXaNckaIE
    c) Lambda Legal Birth Certificate State-By-State Guideline - https://www.lambdalegal.org/know-your-rights/article/trans-changing-birth-certificate-sex-designations
    d) National Center for Transgender Equality - https://transequality.org/documents
    e) Transgender Law Center – A Guide to Changing California & Federal Documents https://tlcenter.app.box.com/s/3da7afk3p7dn1ngoxcz3tuy18q3u1dco
    f) Trans Lifeline - https://translifeline.org/resource/id-change-library/

2. Organizations
    a) Bet Tzedek – Contact: Steven Friday 323-549-5894 sfriday@bettzedek.org
    b) The Center in Long Beach - 562-434-4455 info@centerlb.org https://www.centerlb.org/legal-clinic/
    c) LA Gender Center - https://www.lagendercenter.org/ (under services)
    d) Transgender Economic Empowerment Project - 323-860-3713 teep@lalgbtcenter.org
    e) Trans Wellness Center - 3055 Wilshire Blvd #360, Los Angeles, CA 90010 323-993-2900 TransWellness@LALGBTCenter.org
3. Funding Programs
    a) Trans Lifeline Microgrants - https://translifeline.org/microgrants/

Voice Therapy

1. Callen-Lorde Finding your voice: A short guide to vocalization. http://callen-lorde.org/graphics/2018/09/HOTT-Voice-Brochure_Final.pdf
2. Transgender Voice Therapy - https://www.tgvoicetherapy.com/
3. The Voice Lab - https://thevoicelabinc.com/
4. UCLA Voice Therapy & Surgery - https://www.uclahealth.org/gender-health/vocal-surgery
5. Speaking Boldly - https://www.speakingboldly.com/
6. True to You Voice Therapy - https://truetoyouvoicetherapy.godaddysites.com/

7. TransVoiceLessons. Youtube channel. https://www.youtube.com/c/TransVoiceLessons/featured

Clothing

1. Aqua Underwear - https://www.aquaunderwearslc.com/
2. Haute Butch - https://hautebutch.com/
3. Outplay - https://outplaybrand.com/
4. Origami Customs - https://origamicustoms.com/
5. Rebirth Garments - http://rebirthgarments.com/
6. The Phluid Project - https://thephluidproject.com/

Hair & Makeup

1. Project Q - https://www.projectq.me/
2. Aphrodite Project - https://theaphroditeprojectusa.org/
3. Salon Benders - https://www.salonbenders.com/
4. Strands for Trans (Gender affirming salons) https://www.strandsfortrans.com/ - https://www.google.com/maps/d/u/0/viewer?mid=1CRAKdWRl_rvqST3sBRoLKUO60JA&ll=33.46769648903217%2C-117.12981046279354&z=7

Tucking

1. En Femme Style - https://enfemmestyle.com/

2. Unclockable - https://unclockable.com/

Packers & Stand-to-Pee devices

1. Youth Packers
    a. Tranz Wear - www.tranzwear.net
        i. Best Boi Packer
        ii. Best Boy Bump
2. Stand-to-pee (STP) & Packers
    a. Tool Shed Toys - www.toolshedtoys.com
        i. STPs
            1. The Model D STP by Number One Labs STP-FITZ
            2. The Model A STP by Number One Labs
            3. The Model D Sport STP by Number One Labs
            4. The Number One STP Hugo and Tomas
        ii. Porous Soft Packers
            1. Mister Softie Elastomer Packer
            2. The Sailor aka GV Soft Pack
            3. Pack It Light/Pack It Heavy

iii. Non-porous Soft Packers

1. Pierre Uncircumcised Packer
2. Archer Packer
3. Mr. Right Shilo
4. Hugo and Tomas

b. Peecock - www.peecockproducts.com

i. Pee-Cock 3-in-1 Packer

c. Free Tom - www.freetomprosthetics.com

i. FreeToM Prosthetics 2-in-1

d. Transthetics Prosthetics - https://transthetics.com/

Chest Binding

1. Gc2b - https://www.gc2b.co/
2. Flavnt - https://www.flavnt.com/
3. Underworks - https://www.underworks.com/tri-top-chest-binder or https://www.f2mbinders.com/
    1. Tri-top chest binder
4. T Kingdom - http://www.t-kingdom.com/index.php
5. TransTape - https://transtape.life/

Mental Health

Youth Social Support

1. Qchatspace.org - https://www.qchatspace.org/
2. LA Gender Center - https://www.lagendercenter.org/
3. LGBT Center – Trans Lounge - https://www.lagendercenter.org/
4. Trans Wellness Center - https://mytranswellness.org/
5. FEDUP (Fighting Eating Disorders in Underrepresented Populations: A Trans+ & Intersex Collective) - https://fedupcollective.org/
6. Gender Spectrum - https://www.genderspectrum.org/articles/gender-spectrum-groups
7. Solace App (Personalized resource guide for gender transition) - https://solace.lgbt/
8. LA LGBT Center Trans Lounge - https://translounge.org/

Family/Parent/Caregiver support

1. Transforming Family - https://www.transformingfamily.org/
2. Trans Family Support Services - https://transfamilysos.org/
3. Trans Families - https://transfamilies.org/
4. Gender Spectrum - https://www.genderspectrum.org/articles/gender-spectrum-groups

Individual Therapy

1. LA Gender Center - https://www.lagendercenter.org/
2. Colors LGBTQ Youth Counseling Services- https://colorsyouth.org/
3. Therapy Den - https://www.therapyden.com/causes/trans-community-support/
4. National Queer & Trans Therapists of Color Network - https://nqttcn.com/en/

Crisis & Suicide Support

1. Hotlines
    a. Trans Lifeline - (877) 565-8860 https://translifeline.org/
    b. Trevor Project - (866) 488-7386 https://www.thetrevorproject.org/
    c. Crisis Text Line - Text HOME to 741741 https://www.crisistextline.org/
    d. LGBT National Youth Talkline – 800-246-7743 https://www.glbthotline.org/talkline.html
2. Exodus Mental Health Urgent Care Clinic (24hr Walk-In program)
    a. Westside 310-253-9494 11444 W Washington Blvd, Suite D, Los Angeles, CA 90066-6024
    b. Eastside 323-276-6400 1920 Marengo Street, Los Angeles, CA 90033

Medical Options

Puberty Blockers

1. Seattle Children's. (2019). *Puberty blockers (Video)*. https://www.youtube.com/watch?v=-_ldEpFoJCI&t=1s

2. Seattle Children's. (2019). *Puberty blockers (English)*. https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe2572.pdf

3. Solorzano, C. B. & Davidge-Pitts, C. (2019). *Gender nonconformity in children and adolescents.* Hormone Health Network. https://www.hormone.org/your-health-and-hormones/transgender-health/gender-nonconformity-in-children-and-adolescents

Hormone Therapy

Medications for Trans Feminine Youth

1. Seattle Children's. (2020). *A guide to feminizing hormones* (handout). https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe2706.pdf
2. Seattle Children's. (2020). Feminizing hormone therapy (video). https://www.youtube.com/watch?v=8_gdLCXKl5Y
3. Davidge-Pitts, C., Safer, J., & Sarvaideo, J. (2020 May). *Feminizing hormone therapy.* Hormone Health Network. https://www.hormone.org/your-health-and-hormones/transgender-health/feminizing-hormone-therapy

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1. Jammidodger. (2017). Everything Testosterone Changes (video). https://www.youtube.com/watch?v=MGwW6M_Tyy8
2. Reproductive Health Access Project. (2021 July). *Birth control across the gender spectrum*. https://www.reproductiveaccess.org/wp-content/uploads/2018/06/bc-across-gender-spectrum.pdf
3. Seattle Children's. (2020). *A guide to masculinizing hormones* (handout). https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe2707.pdf

4. Seattle Children's. (2020). *Masculinizing hormone therapy* (video). https://www.youtube.com/watch?v=dmjSEf2og1A
5. Seattle Children's. (2020). *Menstrual suppression for adolescents* (handout). https://www.seattlechildrens.org/pdf/PE2675.pdf
6. Davidge-Pitts, C., Sarvaideo, J., & Safer, J. (2020 May). *Masculinizing hormone therapy.* Hormone Health Network. https://www.hormone.org/your-health-and-hormones/transgender-health/masculinizing-hormone-therapy

Fertility Preservation and Family Planning

1. Education/Support
    a. Trans Fertility Co. - https://transfertility.co/resources
    b. Family Equality – Trans Family Building - https://www.familyequality.org/family-building/trans-family-building/
    c. Birthing and breast or chestfeeding Trans people and Allies (Facebook group) - https://www.facebook.com/groups/TransReproductiveSupport/
2. Providers/Fertility Programs
    a. UCLA Gender Health Program - https://www.uclahealth.org/gender-health/reproductive-health
    b. USC Fertility – LGBT Fertility - https://uscfertility.org/same-sex-family-building/
    c. California Cryobank (Ask for PRIDE discount)- https://www.cryobank.com/lgbtq-families/
    d. Cryochoice (At home sperm banking option) - https://cryochoice.com/store-semen-before-transgender-transition-hrt/

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Gender Affirming Non-Medical Interventions

Name & Gender Marker Change

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Clothing

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Tucking

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2. Hour Glass Figure. (2019). *Tucking*. https://www.hourglassfigure.co.uk/tucking-32-w.asp

Chest Binding

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TABLE OF EVIDENCE

CITATION	PURPOSE	SAMPLE/SETTING	METHODS (Design, Interventions, Measures)	RESULTS	DISCUSSION, INTERPRETATION, LIMITATIONS
Allingham, C., Gillam, L., McCarthy, M., Zacharin, M., Jayasuriya, S., Heloury, Y., Orme, L., Sullivan, M., Peate, M., & Jayasinghe, Y. (2018). Fertility preservation in children and adolescents with cancer: Pilot of a decision aid for parents of children and adolescents with cancer. *Journal of Medical Internet Research Pediatrics and Parenting, 1*(2). http://doi.org/10.2196/10463	Develop & assess feasibility, usability & acceptability of DA. Assess impact of DA on knowledge & decisional regret. Assess clinician acceptability of DA.	Parents of youth diagnosed with cancer, age 0-18, between Dec. 2010-Dec. 2015 (N=15). Mean age= 42.6 yrs. Most were married (n=13) and had been born in Australia (n=8). 53% were parents of children assigned female at birth (n=8). 11 clinicians completed post-DA survey. Clinicians involved FP consultation (N=9). Setting: The Royal Children's Hospital, Australia.	Retrospective, cross-sectional, pre/post survey. Demographics, Fertility Preservation Knowledge Scale, Decision Regret Scale (DRS). Likert scales used to assess emotional impact, satisfaction, and perceived knowledge. Values Clarification Exercise (VCE). Web-based decision aid administered one time, after FP counseling. Descriptive statistics (means, range, SD), *t*-tests.	67% parents were satisfied with DA & found useful (86%). Many had prior FP counseling (n=13), usually with an oncologist (n=5). FP knowledge mean score increased by 1.5 in all parents (P=0.04). Mean scores on the DRS increased by 1.9 in all parents (P=0.54).	Tool useful & acceptable in parents. DA increased parents' FP knowledge, regardless of prior education. No significant increase in decisional regret. Parent reported better understanding of fertility risks a & expectations of future fertility. Limitations: Small sample size. Retrospective study, limiting study measures.

CITATION	PURPOSE	SAMPLE/SETTING	METHODS (Design, Interventions, Measures)	RESULTS	DISCUSSION, INTERPRETATION, LIMITATIONS
Chen, D., Kolbuck, V. D., Sajwani, A., Shen, E., Finlayson, C., & Gordon, E. J. (2022). Feasibility, acceptability, and preliminary efficacy of AFFIRMED (aid for fertility-related medical decisions), a web-based fertility decision aid for transgender and non-binary youth and their parents. *Journal of Adolescent Health*, *70*(4), S27-18. https://doi.org/10.1016/j.jadohealth.2022.01.164	Evaluate feasibility, acceptability, and efficacy of DA regarding fertility knowledge & decisional self-efficacy.	TGD youth ages 8-24 (n=8) eligible for or prescribed GAT & parents (n=7). Most youth were transmasculine (63%) or transfeminine (25%), and white (37.5%). Parents were mostly white (71%) and mothers (86%). Setting: Not identified.	Cross-sectional, pre/post survey Demographics, fertility knowledge test, Decisional Self-Efficacy Scale, Feasibility of Intervention Measure, Acceptability of Intervention Measure, & System Usability Scale. In-person or online video research visit to complete pre- & post-test after using web-based fertility preservation DA for TGD youth & caregivers	Youth: improvement in knowledge (pre-52.7% to post-84.1%, $t(7)= -3.8$, $p=0.003$) & decisional self-efficacy (pre-64.0 to post-82.8), $t(6)= -3.1$, $p=0.01$). Parents: knowledge improved significantly (pre-69.3% to post-93.7%, $t(6)= -12.7$, $p<0.001$) but improved self-efficacy not significant (pre-85.7 to post-91.6), $t(6)= 1.6$, $p=0.08$). Both groups rated DA high acceptability (M youth (SD)=4.1(1.2), M parents (SD)=4.9(0.3)) & feasibility (M youth (SD)=4.3 (0.9), M parents (SD)=4.1(1.1). Usability scores were above avg. score 68 (M youth (SD)=79(23), M parents (SD)=86(10)).	Knowledge had significant increased post-intervention in both groups. Significant improvement in self-efficacy among youth. Both cohorts rated DA as acceptable, usable, & feasible. Limitations: small sample size, limited data reported.

CITATION	PURPOSE	SAMPLE/SETTING	METHODS (Design, Interventions, Measures)	RESULTS	DISCUSSION, INTERPRETATION, LIMITATIONS
Ehrbar, V., Urech, C., Rochlitz, C., Dallenbach, R. Z., Moffat, R., Stiller, R., Fah, M., von Wolff, M., Nawroth, F., Dangel, A., Germeyer, A., Findeklee, S., & Tschudin, S. (2018). Fertility preservation in young female cancer patients: Development and pilot testing of an online decision aid. *Journal of Adolescent and Young Adult Oncology*, *7*(1), 30-36. https://doi.org/10.1089/jayao.2017.0047	Development of online DA in German on FP. Assess user satisfaction with DA, impact on FP knowledge & decisional conflict (DC).	Women with a recent cancer diagnosis & using treatment with potential for infertility, aged 18-40 years, German speaking, with access to an internet-enabled device (N =40). Mean age = 29.23 yrs. Settings: Swiss fertility centers/hospitals (n=5) & German fertility centers/hospitals (n=3), between July 2014- June 2016.	Prospective consecutive intervention study. Online questionnaire completed right after counseling, 1 m post-intervention and 12m. Included knowledge about FP options, DCS, and user satisfaction. Online fertility preservation DA, accessible by intervention group after counseling, through entirety of study. Descriptive statistics (mean, SD), ANOVA, *t*-test, Mann-Whitney *U*-test, Fisher's exact test, chi square test. Two tailed *p* value <0.05 statistically significant.	Most participants were aware of the most common FP options; 92.5% freezing ovarian tissue, 92.5%, freezing egg cells, & 77.5% hormonal protection of the ovaries. Significant difference in knowledge confidence regarding freezing egg cells in intervention (p=0.047). Overall moderate level of DC (DCS mean score=27.92, SD=13.27). Intervention group had higher DCS mean score compared to control (28.64 vs. 27.19). Users were satisfied with DA (M=3.25, SD=1.09), reported it to be useful in decision-making (DM) process (M=3.20, SD=1.36), & would recommend it to others (M=3.95, SD=1.09)	DA acceptable to users & would recommend to others. Fertility-related knowledge & confidence regarding options was high. No significant difference in DCS. Limitations: Small sample size. Consecutive study design can cause sample bias. Sample had prior access to comprehensive information about FP.

CITATION	PURPOSE	SAMPLE/SETTING	METHODS (Design, Interventions, Measures)	RESULTS	DISCUSSION, INTERPRETATION, LIMITATIONS
Ehrbar, V., Urech, C., Rochlitz, C., Dallenbach, R. Z., Moffat, R., Stiller, R., Germeyer, A., Nawroth, F., Dangel, A., Findeklee, S., & Tschudin, S. (2019). Randomized controlled trial on the effect of an online decision aid for young female cancer patients regarding fertility preservation. *Human Reproduction, 34*(9), 1726-1734. https://doi.org/10.1093/humrep/dez136	Assess impact of online DA with standard counseling on DC & FP knowledge compared to counseling alone.	Females aged 18-40, with recent cancer diagnosis, scheduled for cancer treatment. German speaking with internet access (N=51). Mean age = 29.31 yrs. Setting: Recruited from 8 fertility centers in Switzerland & Germany, between July 2016- Dec. 2017.	Randomized controlled trial. Sociodemographic, FP options knowledge, attitude & willingness for preservation, DCS, Decisional Regret Scale. Online questionnaire administered at 3 time points: directly after counseling, 1m after, & 12m after. Online fertility preservation DA, accessible by intervention group after counseling, through entirety of study. Descriptive statistics (mean, SD), ANOVA, *t*-test, chi square test. Confidence interval 95%. Two tailed *p* value <0.05 statistically significant.	Lower mean DCS scores in intervention compared to control after counseling (13.49 vs. 17.27; P=0.008) & 1m after (13.99 vs. 15.19; P=0.043). Information (45%) & values clarification exercise (40%) were most viewed content pages. 80.8% completed values clarification exercise. DA was reported as satisfying (M=3.79) & helpful (M=3.54). Over 80% recommend to others (M=3.96).	DA useful to reduce decisional conflict. DA helps make decision in less time. Values clarification & information most important for decision making. Limitations: Impact on knowledge not reported. Small sample size. High education level of participants, limits application to lower literacy levels.

CITATION	PURPOSE	SAMPLE/SETTING	METHODS (Design, Interventions, Measures)	RESULTS	DISCUSSION, INTERPRETATION, LIMITATIONS
Garvelink, M. M., ter Kuile, M. M., Louwe, L. A., Hilders, C. G. J. M., & Stiggelbout, A. M. (2017). Feasibility and effects of a decision aid about fertility preservation. *Human Fertility*, *20*(2), 104-112. https://doi.org/10.1080/14647273.2016.1254821	To assess feasibility & impact of DA compared to brochures about FP on DC, knowledge, regret & concerns.	Dutch-speaking, female breast cancer patients, ages 18-40, likely to receive chemo & eligible for FP (N=26). Brochure group mean age=32.9yrs (range=28-39). DA group mean age=35.8yrs (range=30-40). Setting: Oncology (n=13) & gynecology (n=3) departments of medical centers in Netherlands. Data collected between June 2011 & Dec. 2012.	Randomized controlled trial Web-based comprehensive DA compared to 4 brochures. Web-based included all information from brochures plus more background, Values Clarification Exercise (VCE), & question prompts. Feasibility assessed by proportion of eligible, invited, & recruited participants after 16m & proportion completed questionnaires after 18m. Detailed website statistics measured time spent on DA. Participants self-reported time spent on brochures. Online self-report data collected at baseline (T0), 6wks after when decision likely made (T1), & 6m after T0 when able to reflect	Participants randomized after baseline questionnaire, brochure (n=13) or DA (n=13). Both groups 12 completed T1. DA groups lost a participant at T2 (n=11) compared to brochure group (n=12). In brochure group, most used all brochures & reported reading them thoroughly (n=8). DA group – many logged into DA (n=7) & some used VCE (n=6). Users of DA spent avg. 29 mins (range=1-74 mins), viewed 15 out of 26 pages (range=0-53), & viewed all VCE pages (9 out of 9; range=0-21). 62% had preference for FP at T0, 88% at T1, 100% at T2. Changes in total DCS were not significant	Participants had low levels of DC. Brochures were previously available publicly. Brochure group had slightly better outcomes compared to DA. Information overlaps in both formats. Brochure could be considered a DA. Recommended to keep both formats, with additional guidance in DM for DA. Limitations: Small sample size, difficulty recruiting, both formats could be considered a DA.

CITATION	PURPOSE	SAMPLE/SETTING	METHODS (Design, Interventions, Measures)	RESULTS	DISCUSSION, INTERPRETATION, LIMITATIONS
			(T2). Data collect on socio-demographic & medical information (T0), FP preference (T0/T1/T2), FP decision (T1/T2), DCS (T1/T2), knowledge (T0/T1/T2), reproductive concerns (T0/T1/T2), & decisional regret (T1/T2). Descriptive analysis. Non-parametric tests used due to small sample. Missing data used Multiple Imputation – data imputed 5 times & combined using Rubin's rules for multiple imputation.	between groups at T1 (p=0.256) & T2 (p=0.115). Significant change in knowledge between T0 & T1 (ΔM=1.35 out of 10) & T0 & T2 (ΔM=1.25, p=0.004). No difference between groups at T0 (p=0.772), T1 (0.668), & T2 (0.264).	

CITATION	PURPOSE	SAMPLE/SETTING	METHODS (Design, Interventions, Measures)	RESULTS	DISCUSSION, INTERPRETATION, LIMITATIONS
Mokken, S. E., Ozer, M., van de Grift, Tim C, Pigot, G. L., Bouman, M., & Mullender, M. (2020). Evaluation of the decision aid for genital surgery in transmen. *Journal of Sexual Medicine, 17*(10), 2067-2076. https://doi.org/10.1016/j.jsxm.2020.06.017	To evaluate the effect of a DA on genital surgery in transmen (DA-GST) on decisional confidence & conflict.	Trans men, aged 19-51 (Mean age = 31.2 yrs.) considering genital surgery, understand Dutch (N=51). Qualitative interviews from a subset of study population (n=15). Setting: Amsterdam University Medical Center	Mixed methods, cross-sectional study. Sociodemographic, Dutch translation of Ottawa Preparation for Decision-Making Scale (PrepDM Scale), DCS, & Measures of Informed Choice (MMIC) administered before group consult (T1), before personal consultation (T2), & after personal consultation (T3). Online DA-GST available publicly. Exposure to DA varied, link provided by medical provider before study or during study. Mean scores, Cohen *d* & descriptive statistics. Statistical significance set *p* value <0.05. Qualitative data analyzed descriptively & thematically, coded into themes, theme map developed.	DC decreased over time (p=0.008) & lower in DA users but did not reach significance (p=0.141). PrepDM Scale scores ranged 21-100 (median = 71). MMIC scores ranged 50-100 (median =94). Knowledge was not directly measured. Interviewees report knowledge attainment from personal stories over clinician information sessions.	Time decreased DC. Users of DA had lower DC across study compared to non-users. Limitations: Many study participants had used DA prior to study. Time between assessments was long, impacting participant recollection. Possible attrition bias. Small sample size.

CITATION	PURPOSE	SAMPLE/SETTING	METHODS (Design, Interventions, Measures)	RESULTS	DISCUSSION, INTERPRETATION, LIMITATIONS
Ozer, M., Pigot, G. L. S., Bouman, M. B., van de Grift, T. C., Elfering, L., van Mello, N. M., Al-Itejawi, H. H. M., Buncamper, M. E., & Mullender, M. G. (2018). Development of a decision aid for genital gender-affirming surgery in transmen. *The Journal of Sexual Medicine*, 15, 1041-1048. https://doi.org/10.1016/j.jsxm.2018.04.644	To develop DA for genital surgery in transmen (DA-GST) to improve SDM between transmen & health care providers (HCP).	Transmen (n=12) who underwent or considering genital surgery & HCPs (n=9) who care for individuals with gender dysphoria. Setting: Transmen recruited from all over The Netherlands. HCPs from Center of Expertise on Gender Dysphoria of the VU University Medical Center, Amsterdam, The Netherlands.	Qualitative focus groups (n=5), lasting 3-4 hrs., led by moderator. Participants wrote down answers or issues about specific topic before all participants shared. Suggestions were translated into common Dutch. Process was repeated until saturation. Themes were identified & developed into first draft of DA. This was tested using 2 focus groups to refine and clarify content, then a final DA was developed. Data analyzed through thematic analysis.	All attendants state DA should assist in identifying important values, include broad range of information regarding options & motives, & should not include extensive medical information. Focus group 1 identified main themes: outcome, quality of life, environment, sexuality, and beliefs. Content was refined by remaining focus groups & developed in online format.	Gender variance is increasing creating a need for varying treatment options. A DA for GST was developed using input from transmen & HCPs. Use of DA-GST can remind HCP to address identified themes to support DM aligned with personal values. Limitations: Selection bias, small sample

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