## **Client/Participant Information Sheet:**

## **Risks and Benefits of Testosterone**

**The goal of this form is to provide the most up to date information about the expected effects of hormone therapy, including both the desired effects as well as possible unwanted side effects. You should have the information you need to make decisions about your care. Please do not hesitate to ask questions and talk about any concerns you have at any time.**

Testosterone treatment results in certain changes to the body that some people find affirming, including lowering the pitch of the voice, possible increased facial and body hair, fat redistribution, and increased muscle mass. Each person responds to hormones differently, and it is difficult to predict some aspects of how your body might change.

Hormone therapy will not change some body features. A person’s bone structure or height will not change. Breast/chest size will not decrease or go away. Hormone therapy is not the only way to achieve your goals - we can always talk about other options (such as non-medical affirming products, other medications, and/or surgeries) that might be right for you.

Your medical provider will help decide which formulation and dose of testosterone (injections, topical gels or creams) may be best for you based on your gender affirmation goals, personal needs, and any medical or mental health conditions you might have. As part of this treatment, you agree to take the medications only as prescribed and to talk with your clinician before making any changes in your medication. You and your clinician can work together to best support your goals for care as safely as possible.

Tapestry has worked with gender diverse people for many years. Our approach to gender affirming care is based on scientific evidence whenever possible, national and international guidelines, and the feedback and experience we get from our own gender diverse community. Research on gender affirming hormone therapy provides us with information on the safety and effectiveness of these medications in helping you to achieve your goals. Despite the available research, the long-term effects of hormone therapy across the lifespan are not yet fully understood. This document outlines what we currently know about these medications. We will pass along any new information or research we learn, especially as it affects your health and wellbeing.

**Expected Physical and Emotional Effects of Testosterone Therapy**



The changes in your body may take several months to become noticeable and may take 3 to 5 years to progress fully.

Some changes are **PERMANENT** and will not go away, even if you decide to stop taking testosterone or take a lower amount:

* Deepening of the pitch (sound) of your voice.
* Growth, thickening, and darkening of hair on the body.
* Growth of facial hair, including beard and mustache. The ability to grow facial hair is not unlike a cisgender male, some will have the ability to grow a thick beard and in a short time, whereas others may have scant growth or facial hair that takes years to come in.
* Possible hair loss at the temples and crown/top of the head (androgenic alopecia) with the possibility of complete baldness. This may resemble and be affected by the hair patterns of cisgender men in your family. However, some do note that this form of hair loss is seen more commonly in those taking testosterone.
* Growth in the size of the phallus/clitoris. Some may also experience increased sensitivity of the phallus/clitoris as this early growth occurs.

Some changes are **NOT PERMANENT** and will likely return to how your body looked or worked before treatment if you stop taking testosterone. This may take a few weeks to months or longer depending on the change:

* Menstrual/monthly bleeding stopping, usually within a few months.
* There may be changes to the inside lining of the frontal canal/vagina (thinning, dryness). For some, this dryness can cause symptoms of discomfort with sex, can lead to increased risks of injury or infections if you are sexually active, and may make routine genital screening exams more challenging.
* Changes where fat is stored in the body; if you gain weight, the fat will tend to localize to the abdomen and mid-section, rather than the buttocks, hips and thighs. You may lose fat from chest/breasts, buttocks, and thighs if you lose weight.
* Muscle mass and upper body strength increase.
* Some people feel more energy, more active, or more short-tempered and angry. Some people experience improvement in their mental health; feeling better or calmer and more focused.
* Many people experience skin changes including acne on the face and back that may need medical treatment to manage. This may last months to a few years, like in puberty.
* Most people experience a significant increase in their sex drive or interest in sexual activity. Some people experience changes in who they are attracted to physically.

**Possible Fertility Effects of Testosterone Therapy**



* Possible loss of fertility; you may not be able to get pregnant after being on testosterone therapy for some time. How long this might take is unknown. Some people choose to harvest and bank eggs before starting testosterone.
* Testosterone is not reliable birth control. Even if menstrual periods (bleeding) stop, you could get pregnant; if you are having genital sex with a partner who produces sperm, discuss using some form of birth control with your clinician.
* If you get pregnant while taking testosterone, the high levels of testosterone in your system may cause harm and even death to the developing fetus.
* Other effects of testosterone on the ovaries and on ova (eggs) are not fully known.

**Possible Side Effects and Risks of Testosterone Therapy**



* After being on testosterone for a number of months, some people may develop pelvic pain. Some experience this pain with sexual arousal/orgasm and some for no apparent reason. The level of pain varies in the people who experience this effect. For some the pain resolves on its own after several months. For others the pain may persist. For a few the pain seems to go away only with removal of the uterus (hysterectomy). The cause of this pain is unknown.
* The cervix and walls of the frontal canal may become drier and more fragile (thinner). This may cause irritation and discomfort. It also may make you more vulnerable to sexually transmitted infections and HIV if you have unprotected sex using the frontal canal/vaginal opening.
* Testosterone will not protect against cervical, ovarian, uterine, or chest/breast cancer. Current research indicates there may be no increased risk for these cancers above the risks already present for any individual based on genetics. Please check with your provider regarding recommendations for routine cancer screening.
* Possible elevation of cholesterol, increased blood pressure, and other changes to the body may increase risk of cardiovascular disease (heart attacks, strokes and blockages in the arteries) when on testosterone therapy long-term. However, current research indicates that individuals taking gender-affirming testosterone do not have increased rates of cardiovascular events than those seen in cisgender men. Family history may reveal a specific genetic risk for heart disease, which should be discussed with your provider.
* Possible changes in the body that might increase the risk of developing diabetes.
* Increased appetite is common and may result in weight gain.
* Increased risk of sleep apnea (breathing problems while you are sleeping) appears related to testosterone treatment.
* Possible increase in the hemoglobin and hematocrit (the number of red blood cells). If this increases to higher levels, it may cause problems with circulation, and increase the risk of blood clots, strokes, and heart attacks.
* Increased sweating.
* Increased risk of tendon injury.
* Possible worsening or triggering of headaches and migraines.
* Possible increase in frustration, irritability or anger; possible increased aggression and worsened impulse control.
* Possible destabilization of bipolar disorder, schizophrenia and psychotic disorders or mood disorders.
* Brain structures respond differently to testosterone and estrogen. Testosterone therapy may have long-term effects on the functioning or structure of the brain that we do not yet fully understand. Some limited research suggests a decrease in verbal fluency (talkativeness or using lots of words).

*Smoking cigarettes may increase some of the risks of taking testosterone therapy.*

**Expectations, Rights, and Responsibilities**



* Take testosterone only at the dosage and in the form prescribed.
* Taking testosterone in doses that are higher than recommended may increase risks from testosterone. There is no evidence that higher doses will work better or faster. The body converts (aromatizes) testosterone into estrogen, and this may occur at increased rates if testosterone levels are higher than recommended, which may lead to undesired effects.
* Suddenly stopping testosterone after a long time on the medication may have negative physical and mental health effects. It is recommended to speak to your clinician before stopping the medication.
* You may choose to stop hormone therapy at any time and for any reason. You are encouraged to discuss this decision with your clinician prior to making any changes in your medication. It is best to make a plan for stopping the treatment with a clinician familiar with hormone therapy.
* If you have or develop any condition, you think may cause harm or worsen while taking hormone therapy, work with your clinician to evaluate and manage that condition.
* Inform your clinician if you are taking or start taking any other prescription drugs, dietary supplements, herbal or homeopathic drugs, street/ recreational drugs, or alcohol. Being honest about what you are taking/using will help your clinician prevent or reduce potentially harmful reactions or interactions.
* Inform your clinician of any new physical or emotional symptoms and any medical conditions that develop before or while you are taking hormone therapy.
* Inform your provider if you think you are having bad side effects from the medication.
* Your provider may recommend decreasing the dose of or, on rare occasions, stopping testosterone because of medical reasons and/or safety concerns. You can expect the clinician to discuss all treatment decisions with you. Some people may also need to change, decrease, and/or stop hormone therapy as they age.
* Keep appointments for follow-up monitoring and other preventative health care needs, as recommended by your clinician.
* Blood testing may be recommended to monitor your health and hormone treatment. Your clinician will discuss which tests are necessary and any recommendations for ongoing care and monitoring.
* Hormone therapy is not the only way to affirm your gender. Your clinician and/or a mental health provider are able to talk with you about other options if you are interested.