Created in
New York City
June 2022

THE TESTOSTERONE SURVEY ZINE

A Community Health Art Project

by Rena Yehuda Newman

TESTO

GEL

Rx

For Meg,

who taught me what it
means to love and protect
myself and each other.

Bibliography & Further Reading

Black Transmen Inc., "Local Resources for All Transgender People": https://blacktransmen.org/resources/

FTM Essentials, "Trans* Resource Guide": ftmessentials.com/pages/trans-resource-guide

Health Law, "Increasing Access To Testosterone To Improve the Lives of Transmasculine People"
healthlaw.org/increasing-access-to-testosterone-to-improve-the-lives-of-transmasculine-people/

HCP Live, "Mortality Rate Much Higher for Transgender People":
hcplive.com/view/mortality-rate-higher-transgender-people

Hudson's FTM Resource Guide: ftmguide.org

Johns Hopkins Medicine, "Transgender Resource Guide":
hopkinsmedicine.org/center-transgender-health/patient-resources/resources.html

National Library of Medicine, "The effect of testosterone on ovulatory function in transmasculine individuals": pubmed.ncbi.nlm.nih.gov/32044312/

PR Newswire Reporting on Boston IVF Study on Fertility in Transgender Men: prnewswire.com/news-releases/boston-ivf-announces-results-of-landmark-transgender-male-fertility-research-study-300982676.html

Scientific American History of Transgender Health Care:
blogs.scientificamerican.com/guest-blog/a-history-of-transgender-health-care/

"Stone Butch Blues" by Leslie Feinberg

"We Both Laughed In Pleasure" by Lou Sullivan

Williams Institute 2019 Study on LGBT Poverty: williamsinstitute.law.ucla.edu/publications/lgbt-poverty-us/

Rena Yehuda Newman (They/Them) is a transgender Jewish artist and writer living and working in NYC. You can find and follow Rena Yehuda's work on instagram (@rena.yehuda) or get in touch at rena.yehuda@gmail.com. They'd love to hear from you.

Share this zine! If you would like to use any information or images from this project, the author asks only that you cite it and reach out to let them know where this zine goes. You can read more of Rena Yehuda's zines and download a digital copy of this one for free or donation at renayehuda.gumroad.com.

FOLK WISDOM FROM TRANS FOLKS

Here's some wisdom that respondents learned from other trans folks & wanted to pass on to readers.

SWITCH SIDES EVERY OTHER INJECTION!

BOTTOM GROWTH CAN BE SUPER UNCOMFY- GET SOFT UNDERWEAR!

YOU CAN USE TOPICAL ESTROGEN FOR CRAMPS & ATROPHY.

ONE WORD: MOISTURIZE.

KEEP A LOG OF YOUR CHANGES.

RUB/MASSAGE YOUR INJECTION SPOT TO MAKE IT LESS SORE.

EVERY BODY RESPONDS TO TESTOSTERONE DIFFERENTLY! THERE'S NO GUARANTEED OUTCOME - OR 'RIGHT' WAY TO TRANSITION

BEING IN COMMUNITY WITH OTHER TRANS FOLKS IS SO IMPORTANT.

GET SOME BAND-AIDS YOU LIKE- FUN ONES!

BE PATIENT. TAKE YOUR TIME. YOU CAN ALWAYS STOP IF YOU NEED TO.

Table of contents

Author's Note 4
About The Data 6
The Survey & Its Respondents 8
How Respondents Take Their T 17
Doctors, Pharmacists,
and the Medical Establishment 41
Our Trans Bodies,
Our Trans Selves 45
Bibliography & Resources 59

Author’s note

This zine is a public health art project designed to empower people transitioning on testosterone with knowledge, help us ask vital questions about our bodies and needs, and hopefully, make us all feel a little less alone. This zine was also designed for doctors, educators, therapists, and all those who care for transgender people to learn more about our experiences, struggles, and needs as they relate to medical transition using testosterone (sometimes referred to as “T” within this zine).

This survey was created as an art project - not as a scientific study. I have no formal background in statistics or medical science; I am a transgender comics artist and writer. I encourage readers to view this zine as a community health artwork. That means I hope it will do what all good art does: inspire new questions and catalyze change.

In the year 2022, nearly 80 years after the first documented prescriptions of HRT (Hormone Replacement Therapy, sometimes also called GAHT, or “Gender Affirming Hormone Therapy”), there is still an unacceptable dearth of information about transgender bodies and outcomes for those of us who choose to medically transition. This is medical neglect - and medical neglect is a form of abuse. While we’re globally seeing a major increase in access to hormone therapies, this has not been followed by information and studies which allow us to make informed decisions for our health and safety. As private transitional healthcare providers crop up and make access easier, I worry for the ways that for-profit industry around transition (as with healthcare in general) may continue to neglect the needs of the trans people buying their services while profiting off of our vulnerability as a marginalized, under-researched group. While informed consent models of transition treatment grow more common than the often-abusive previous model of therapist letters determining if one is “trans enough”, I question how useful informed consent models are when there is hardly any information to consent to.

Other concerns, in order of frequency

Cardiovascular health ● Research specific to non-binary/gender conforming people ● Liver and Organ Health ● Skin changes & acne ● Acid reflux and Gastrointestinal health ● What’s the best way to assess the proper dose and method for one’s unique body? ● Bone density and osteoporosis ● Impacts on Dysphoria ● Premature menopausal symptoms ● Dose relative to body size Research specific to fat bodies ● Interactional with Birth Control ● Impact on joints and hypermobility ● Cholesterol ● Outcomes for people with autoimmune diseases ● Information on DHT blocks and other modes of controlling certain effects of Testosterone ● Musculature and changes in muscles & body composition ● Hydration & retaining water ● Life expectancy ● Headaches & hormonal migraines ● Outcomes from people with chronic illness or disability ● Predictions for health or transitional outcomes based on heredity ● Difference in transitional outcomes between intramuscular and subcutaneous injection methods ● Thyroid health ● Outcomes for Autistic people ● Changes in appetite ● Risk of blood clots? ● Pulmonary health ● Vaginal discharge ● Weight gain ● Change in Height/Hand/Foot Size ● Racial, ethnic, and sociological research ● Vision and eyesight ● Permanence of effects ● Why do some changes stop and restart abruptly, sometimes years apart? ● Blood sugar Risk of ovarian cysts ● Lactation ● Sleep apnea and insomnia ● Changes for tears and crying Research specific to Butch-identified people ● Pain tolerance ● Pelvic floor ● Impacts for eggs & IVF ● Difference between injecting every 1 versus 2 weeks ● Sublingual testosterone ● Scar tissue formation and prevention ● Risk for AMAB-specific diseases ● Blood pressure

11.Cancer (specifically breast and cervical cancers)

12. Impacts on existing mental illness & mood disorders

13. Bottom growth, changes to physical sensitivity, and sexual pleasure

14. Difference between methods of administration (shots versus gel, pellets, patch, Nebido v Cypionate etc.)

15. Relationship to other medications

16. Hysterectomies and how effects & experience of Testosterone change after Hysterectomy

17. Starting T later in life/at older age

18. Cramping & uterine pain

19. Effects of taking a break/starting or stopping Testosterone more than once

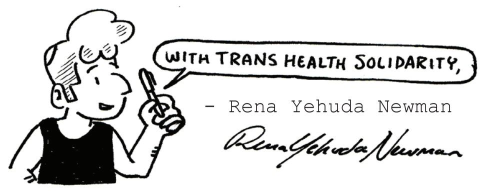
20. Interaction with Menopause

What questions does this survey raise for you?

We all have a right to accurate and current medical information about our decisions to start or continue HRT. As evidenced in this survey, many of us don't even know what questions to ask. The trans community has often been hesitant to engage in critical discussion about the dangers and risks of HRT for fear that the medical establishment may reduce the scarce, often life-saving care that trans activists have long fought to achieve. But as a growing number of people are choosing to medically transition, we can no longer ignore the absence of information. This survey and zine was created to help raise questions about the gaps in research and generate more knowledge, with the hopes of educating both trans people about our own bodies and needs, as well as doctors and other professionals who are responsible for giving us the care we deserve.

I have not drawn many conclusions from this dataset, but rather present it here for readers to engage with through their own questions, hoping that through the continued unknowns, we will learn how to ask better questions about trans health. I've tried to present the information as accessibly as possible, hand-drawing charts, graphics, and cartoons, wanting our data to be easy and enjoyable to read.

I am forever grateful to all of the people who helped make this project a reality. Thank you to those who shared this survey with their communities, and especially to those friends who helped bring this zine to fruition through editing, answering my many questions about data and excel, and celebrating this work enough to give me the energy to bring this zine to completion. Most of all, thank you to the respondents who trusted me with their personal information and stories. I hope I've been a good steward of all the experiences and wisdom you've shared in this survey. **May we continue to work towards more just, safe, and empowered healthcare outcomes for all trans people.**



- Rena Yehuda Newman

About the Data

This survey had **389 participants**. The survey was 73 questions long.

There will inevitably be information in this zine that either feels like it's missing or will be outdated in a few years. Hopefully, that will be because more of the gaps in our collective knowledge about transition, hormonal care, and trans bodies will be filled in. In many ways, this survey is an historical snapshot of some transgender lives in 2022, and should maybe be regarded as an historical document describing a moment in time. Even one percentage point represents potentially thousands of experiences beyond this survey.

In putting this zine together, I had to sort through an enormous amount of data and make difficult choices about how to group, sort, and organize it. Some of these decisions will contain bias, including the dataset itself. This survey was released over social media to my general following and community, which leans Jewish, white, and United States-based, mirroring the identities I hold. Though it was widely shared, the survey was more of a spur-of-the-moment experiment that evolved into a serious project, rather than a professionally produced (and professionally resourced) survey.

Unfortunately, this also meant I didn't have the budget to pay participants, which may have been prohibitive for some potential respondents in taking a whopping 73 question survey. I encourage all readers to reflect on who has the time and resources to fill out such a long survey for free, and be aware that this does influence the results and who is represented in them. Often, white wealthy trans people's voices are heard the loudest; while a wide range of economic class backgrounds are represented here, the respondents of this survey were overwhelmingly white.

Were I to do this project again, I would've created a budget to pay people for their labor and immensely valuable information. I would've done more diligence to seek out more Black and Brown respondents, rather

What Research Are We Missing?

So much research about the effects of Testosterone hasn't been done. This is part of a trend of historical neglect of transgender bodies. This is a list of research topics that respondents wished existed or that they had known, many of these inquiries related to actual changes experienced by respondents.

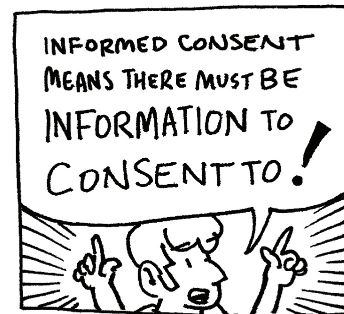
Top Twenty Topics for Further Research

1. Impacts on the reproductive system, uterus, fertility, menses, and pregnancy

2. Long-term impacts on general health

3. Emotional, mood, and mental health outcomes

4. Difference between "low" and "high" doses, dose variation, and microdosing



5. Hair loss and gain (including 5-Alpha inhibitors such as Finestide, Minoxidil, etc. to prevent hair loss)

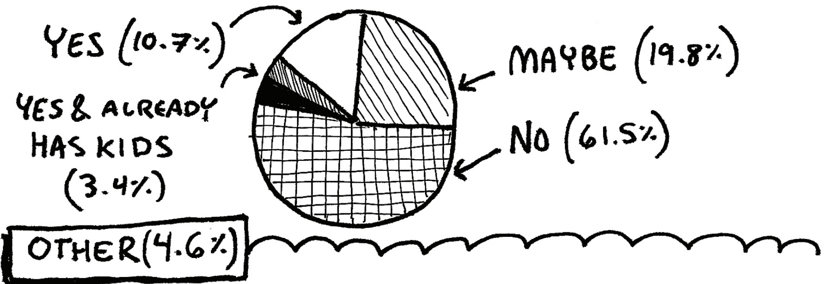
6. Effects on sexual health and sexuality

7. Genital atrophy, changes to uterine/vaginal lining, PH, and endometriosis

8. Speed of transition and more detailed timelines, especially varied by dose and body composition

9. Relationship to AFAB-specific health conditions (including PCOS and PMDD)

10. Vocal changes & how to keep range for singers, including trans vocal training best-practices



Over one third of respondents expressed interest or potential interest in bearing children biologically. While pregnancy is a complicated question for a lot of people taking testosterone, it's far from out of the question. Some respondents reported that they'd been told by doctors that testosterone would definitely make them infertile, which is false medical information. According to a 2019 study conducted by Boston IVF, "based on 8 years of patient data, found that trans men who had begun the transition process via testosterone therapy had similar egg yields as those of cisgender female patients. More than one-half the transgender male patients had been on testosterone therapy before undergoing ovarian stimulation cycles, and all had discontinued testosterone for an average of 4 months before starting their treatment cycle."

People transitioning on testosterone can and do get pregnant. There are also options for egg freezing and other measures for folks with fertility concerns. It's also worth stating that even if you're not getting your period, **testosterone shouldn't be used as birth control** (and certainly doesn't protect against STDs). Use protection!

than leaving it to whoever organically found the survey online. I also would've included more questions about disability. Had I known there would've been such a large response, I may have crowdsourced questions before launching the survey (anyone interested in creating future surveys, take note).

Additionally, it would be meaningful to have had more specific geographical data; state laws and rural versus urban divides may be predictors in the kinds of care that respondents did or did not recieve, and shouldn't be ignored as a demographic factor for trans health.

In spite of the lack of compensation, this survey garnered 389 responses over three weeks, from December 21st 2021 to January 10th, 2022 - significantly more than many of today's official transgender medical studies. I attribute this both to the rise of the COVID-19 Omicron wave, which meant a lot of people suddenly had a lot more time & interest in virtual activities, but most significantly to the truth that this survey is responding to a serious community need: We want and need more information about how HRT impacts our lives.

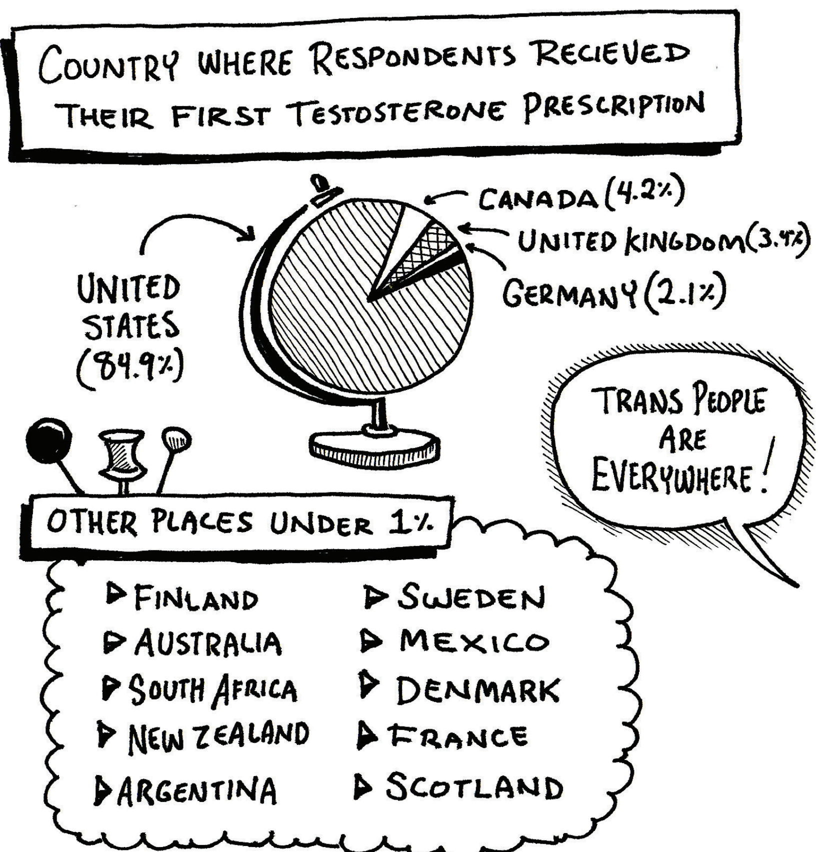
Readers of this zine should be aware that while the data may speak for certain percentages of transition outcomes, it can't predict or determine what someone's experience of testosterone will be; rather, this is a collection of anecdotal information about what others' experiences have been. The young ages of most respondents also means there's less data about longterm effects of T, especially beyond ten years of dosage.

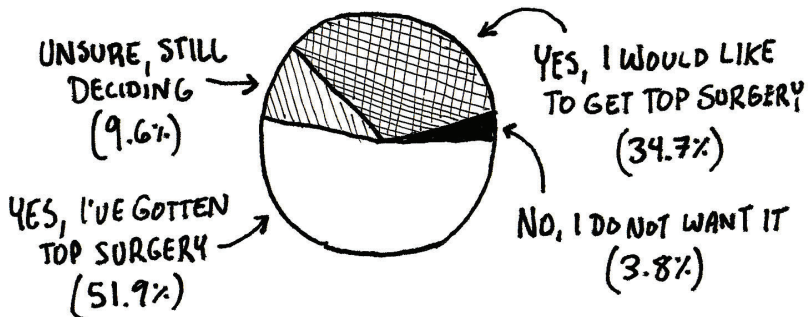
As a transmasculine, non-binary person who has been on HRT for three years at the time of publication, I decided to limit this survey to experiences of testosterone, feeling that a focus related to my own experience would be the most effective project. Similar projects and professional research should and must exist for those who are transitioning using Estrogen and Progesterone. I also believe that someone with that experience is the best person to lead that project. I hope to support any future efforts in generating more information for transfeminine people and all those who transition using hormones other than testosterone.

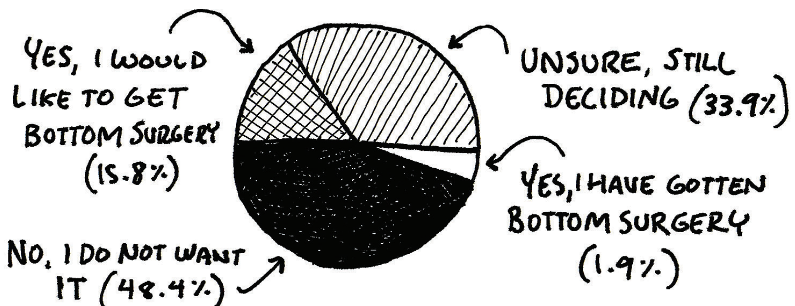
The Survey & Its Respondents

389 respondents participated in this informal, 73 question google survey over three weeks, from December 21st 2021 to January 10th, 2022. Responses came from participants worldwide, with the majority of respondents from the United States. The survey was disseminated through Instagram and Facebook, with respondents usually learning about it through their newsfeeds or from friends. The survey was open to all who at some point have taken testosterone and did not identify as cisgender men.

Here's where respondents recieved their first prescriptions:



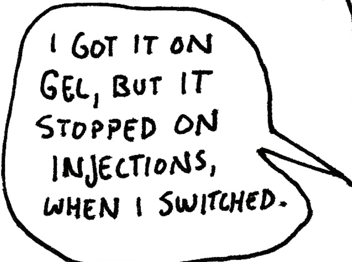




All trans people are different and want different things from their transitions - and not all people who take testosterone and took this survey identify as trans! There is no "right" way to transition. Though desiring to take testosterone may correlate with other aspects of medical transition, such as top and bottom surgery, **many respondents were either ambivalent about, not able, or did not want to get transitional surgeries.** All medical transition decisions can be complicated (personally and financially), can take years to make, and may or may not always be directly related to gender dysphoria.

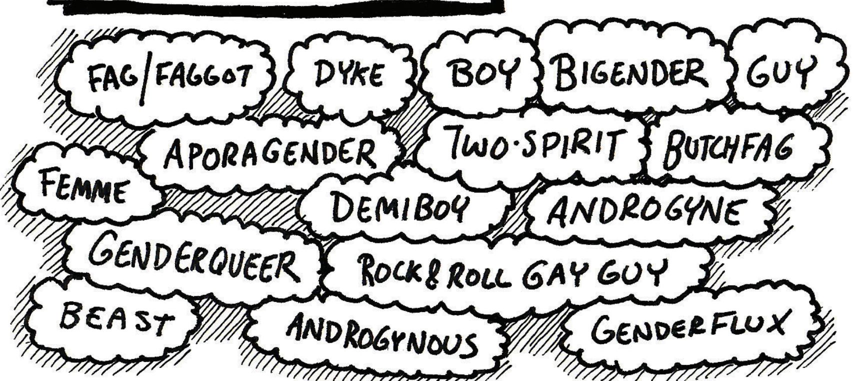
How Does Menstruation Change on Testosterone?

For those who still menstruate on testosterone...

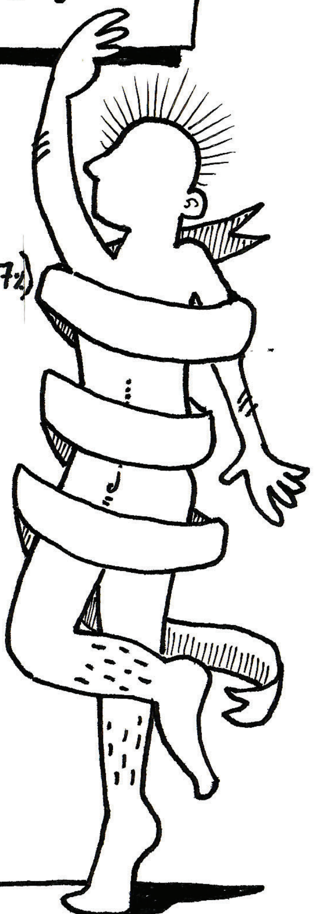


What Terms Did Respondents Use to Describe Their Identities?

- Transgender (73.4%)
- Transmasculine (64.1%)
- Non-binary or Genderqueer (57%)
- Man (42.7%)
- FTM (38.8%)
- Genderfluid (13%)
- Butch (10.2%)
- Agender (7%)
- Woman (1.3%)
- Transsexual (1.3%)

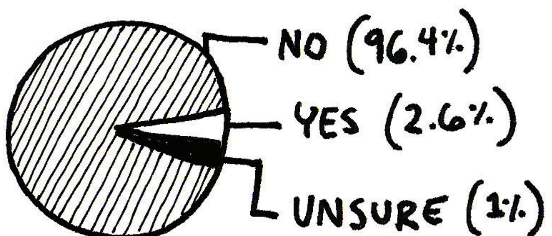


Other Terms Used >1%

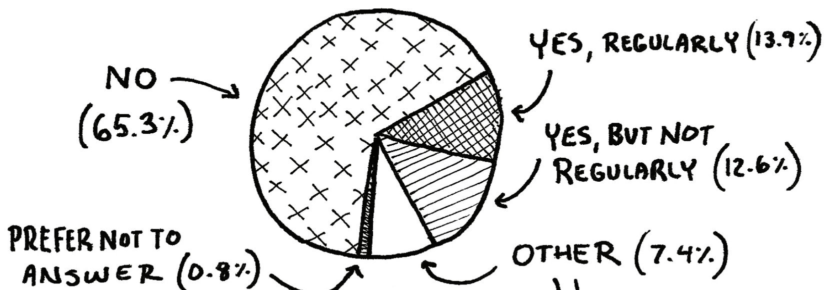


Though this survey was largely taken by transgender people, respondents identified themselves using a range of terminology. Many chose more than one label. The wide number of terms used to self-identify demonstrates the true diversity of people who and reasons why someone may choose to start testosterone, going beyond a single narrative of transition.

In today's world of gender and sexuality, where terminology has become so central, this survey does something different: it focuses on shared experience rather than shared language. Many people who took testosterone before even the 1990s largely used terms like "FTM" rather than "transgender"; yet, if we're focusing on unity, it makes more sense for us to talk about what we do have in common (i.e., a bodily transitional experience) rather than limiting ourselves to terms and definitions, which are subject to change - and may not actually describe our individual experiences without flattening them.



Intersex identities and healthcare needs are an important part our collective of understanding of transgender health, as there are often overlapping health questions for intersex and transgender communities. 2.6% of respondents identified as intersex, and many of those who indicated that they were unsure noted that they had PCOS and wondered if this could be included under an intersex banner.



The majority of people taking testosterone stop menstruating. However, many folks who take testosterone do continue to menstruate or experience a change in menstruation. The higher the dosage, the less likely one is to have a period. However, this varies depending on your body; some people on high doses of testosterone menstruate or occasionally menstruate. Unfortunately, there's little information on the variables that impact testosterone and menses.

PHYSICALITY

Respondents were asked "After I started testosterone, physically I noticed..." and given the chance to write in their answers. While physical changes are better documented in trans medical literature, these are some physical changes that were highlighted multiple times.

APPETITE 7.5% mentioned increased hunger or appetite.

HAIR 51.4% mentioned body hair growth, or in some cases, hair loss on their heads.

BOTTOM GROWTH 23.9% mentioned experiencing significant bottom growth and other changes to genitalia.

PHYSICAL STRENGTH 28.8% mentioned increase in muscle mass and physical strength.

SMELL 3.1% mentioned a change in their smell, whether their body odor, urine, genitals, or ejaculate and discharge.

ENERGY 9.3% mentioned increased energy

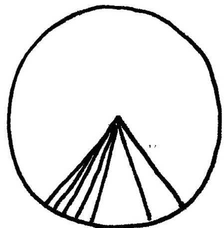
SKIN 10% mentioned oilier, thicker, or rougher skin texture, and acne.

TEMPERATURE 5.7% mentioned higher body temperature, feeling warmer or experiencing hot flashes.

FACE 8.7% mentioned facial changes; squared jawlines and changes in shape.

VOICE 21.6% mentioned vocal changes and voice drops. 2.6% mentioning experiencing sore or scratchy throat during voice drops. (Some reported vocal coaching helped.)

RACIAL IDENTITY

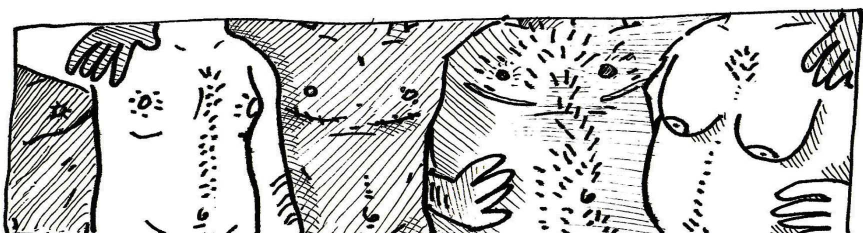


White: 78.9%
Not specifed: 8.0%
Multiracial or other: 6.7%
Asian or Pacific Islander: 2.3%
Latinx: 1.8%
Black: 1.3%
Native American: 0.8%
Southwest Asian or North African: 0.3%

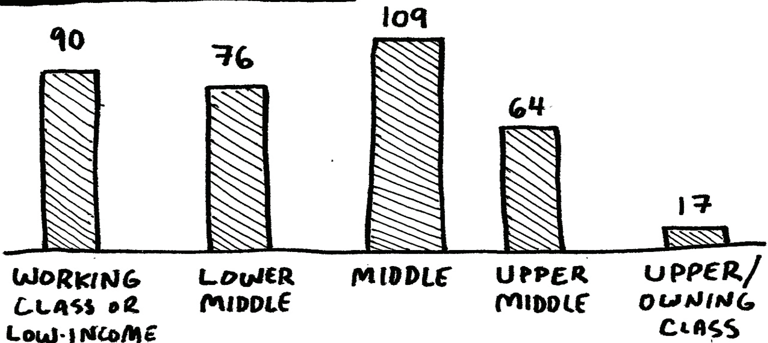
At the end of the survey, respondents were asked to self-identify their race, and in a separate question, their ethnicity.

The majority of respondents to this survey identified as white. It's important to note that the whiteness of this survey means that this data should be examined critically with this in mind: testosterone healthcare outcomes for people of color are not properly represented, as is unfortunately true in many healthcare studies. This is one of the most significant shortcomings of the data gathered in this survey; further surveys that specifically focus on healthcare outcomes and experiences of people of color on testosterone are absolutely necessary, especially in the United States.

It's worth asking if the overwhelming whiteness of the survey indicates that white people are more likely to have access to transitional care than people of color.



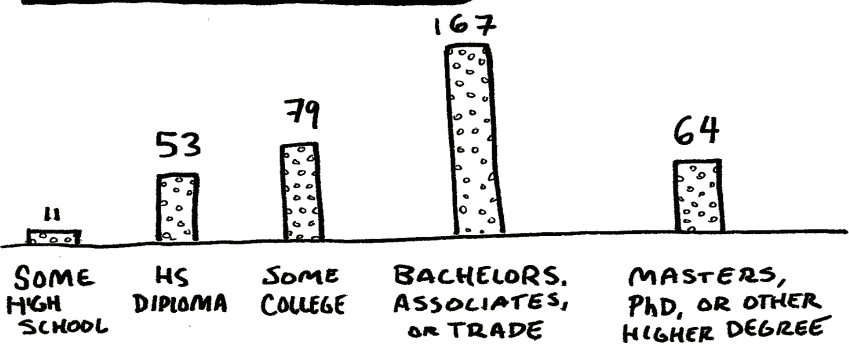
CLASS BACKGROUNDS



Also at the end of the survey, respondents were asked to self-identify their economic class background. While these identifiers are subjective and may mean different things geographically and interpersonally, it's worth noting that **nearly half of respondents identified as working class, low income, or lower middle class**.

According to a 2019 study by the Williams Institute at UCLA, 29.4% of transgender people live in poverty, with significantly higher rates when specified for transgender people of color, transgender people living in rural areas, and transgender people with disabilities. This is due to the immense discrimination faced by transgender people particularly in employment, housing, and healthcare.

EDUCATION BACKGROUNDS



SPIRITUALITY

Respondents were asked "After I started testosterone, spiritually I noticed..." and given the chance to write in their answers. Though many responded "none" or that they did not identify as having a spiritual identity, here are some of the responses of those who wrote in about spiritual changes in their own words.

"A better access to my spiritual roots and the search for more."

"A deeper connection to the trans community."

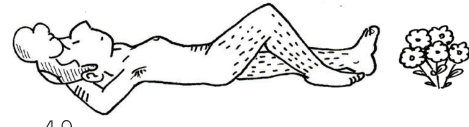
"A solid throughline, an anchor almost, to my place in physical space and my body, that is rooted in my autonomy. Sensual joy in my body and honest engagement with my sexuality, not hiding in a dissociative state during sex. A sense of correctness and alignment with regard to others, and a corresponding sureness of how to act in accordance with it. This isn't constant of course, but I feel more honest with myself and therefore more honest and open to others, less preoccupied with avoiding feeling wrong. This has produced in me greater harmony with everything around me."

"Feeling a lot more connected to my body and grounded in myself. After years of being agnostic, started to believe in God and my own intentional creation again."

"Greater peace, understanding of my gender as spirituality transcendent, great appreciation for my uniqueness."

"More in touch with my ancestors."

"So much connection to other people of all genders and way more aware of the distance I had. That I feel very "in my skin" in a way that helps me feel bad, neutral and good about different parts of myself while before I usually just didn't notice my physical self. That I feel more divine."

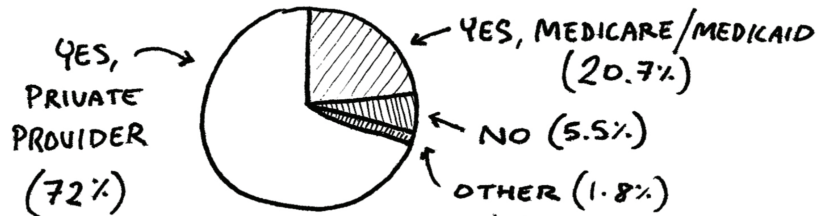


Emotions On T: Quotes from Respondents

There's no singular emotional experience of people who begin taking testosterone. Here are some quotes from the survey, in respondents' own words.

- "I felt further from emotions - felt more fiery than watery."
- "I was more stable and happy, I cried less but could still cry if I needed to. I got more angry for a short while, but that passed."
- "My emotions were closer to the surface and it was harder or impossible to hold them back."
- "I felt at peace with myself and no longer cared as much if people used the wrong pronouns for me; I felt more even-keeled and present."
- "A state of contentedness, whereas I could not clear my mind previously."
- "My emotions became much more physical, I was able to get angry."
- "I had a reason to live for the first time in my entire life."
- "I was more grounded."

IF YOU LIVE IN THE UNITED STATES, DO YOU HAVE INSURANCE?



- MILITARY INSURANCE OR VETERANS COVERAGE
- ON PARENTS' INSURANCE BUT AM NOT OUT TO THEM & MUST PAY OUT OF POCKET
- SCHOOL HEALTHCARE

For many, access to transitional care is contingent on access to insurance. In the United States, without insurance, the out-of-pocket cost of HRT can be prohibitively expensive, especially for a population that is more likely to be low-income. Costs and healthcare coverage can also vary state by state, which can make maintaining a prescription while moving locations into a nightmare. According to the Nat'l Health Law Program, "many people in Medicaid and private coverage can only fill their prescription for 30 days at a time, requiring monthly pharmacy visits," making access far more difficult.

A significant number of respondents were under the age of 18, meaning they are reliant on their parents or other caregivers for healthcare, insurance, and access to medical care. Ensuring transgender youth are able to get the transitional care they need (including puberty blockers) must be part of our vision for accessible transgender healthcare.

RELIGIOUS IDENTITY

None/Not affiliated: 45.6%
Jewish: 17.6%
Not specified 11.6%
Christian (Protestant): 7%
Spiritual: 5.2%
Pagan: 4.9%
Catholic: 3.6%
Buddhist: 1.0%
Multireligious: 1.0%
Satanic: 0.8%
Hindu: 0.5%
Quaker: 0.5%
Muslim: 0.3%
Unitarian Universalist: 0.3%

Though many queer people have difficult experiences with institutional religion, it's not unusual that respondents had strong religious or spiritual identities! A majority of those marked "none/non-affiliated" also indicated that they were raised Christian. A significant number of respondents also self-identifed as "spiritual".

The disproportionately large number of Jewish respondents is likely a reflection of my following and social media algorithms, as I am an Ashkenazi Jewish artist.

EMOTIONS

On the survey, respondents were asked "After I started testosterone, emotionally I noticed..." and given the chance to write in their answers. These are some emotional changes that came up multiple times.

CRYING
19.8% mentioned difficulty crying or a significant change in their ability to cry.

ANGER
10% mentioned experiencing more noticeable anger, frustration, or irritation.

CONFIDENCE
9% mentioned increased confidence and self-comfort.

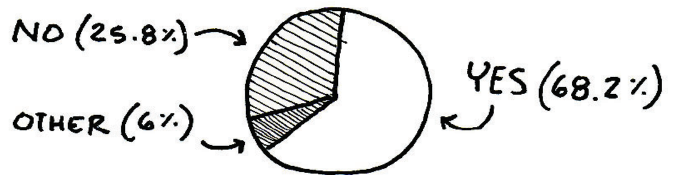
CALM
13% mentioned increased stability, calm, and inner peace.

JOY
16.9% mentioned a significant feelings of joy, happiness, or euphoria.

NO CHANGE
1% mentioned they experienced no emotional changes.

Some respondents reported experiencing mood swings and increased emotional intensity after starting T, but found that over time, the extremes evened out. More research needs to be done on how T interacts with mood disorders.

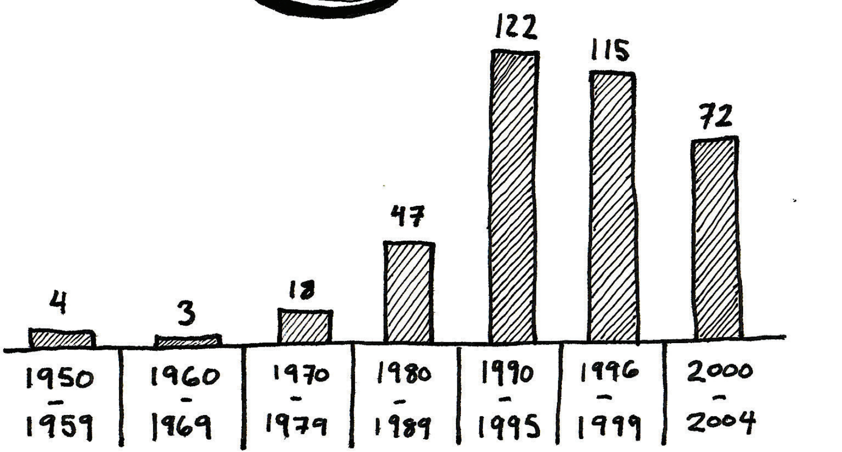
SINCE STARTING T, HAS YOUR EXPERIENCE OF SEXUALITY CHANGED IN ANY SIGNIFICANT WAY?



Changes in sexual orientation were very normal. Respondents expressed a range of feelings about these changes; experiencing new attractions may have ramifications for personal identity, community, and even gender presentation.

Combining and comparing all sexual orientation data before and after T, there was a **21.3% increase** in respondents reporting attraction to men, a **5.9% decrease** in reporting attraction to women, and a **32% increase** in identifying as "T4T," or attracted to other trans & non-binary people. There was also a **6.9% increase** in reporting as bisexual or pansexual, and a **19% increase** in reporting as queer. It's worth noting that all combinations of changes (or lack of changes) were present in the dataset. **These numbers can't predict what someone's experience of sexuality will be after T.**

BIRTH YEAR



LESLIE FEINBERG BORN 1949

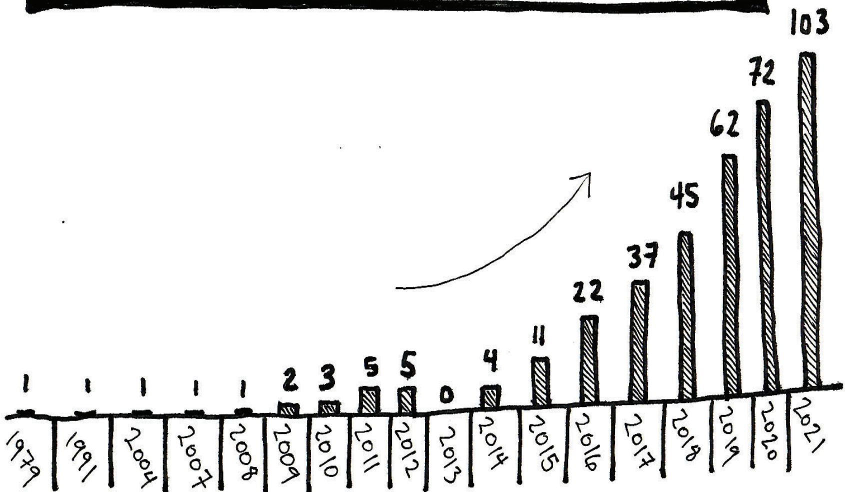
LOU SULLIVAN BORN 1951

Oldest Respondent: Born in 1950
Youngest Respondent: Born in 2004
Average Respondent: Born in 1994

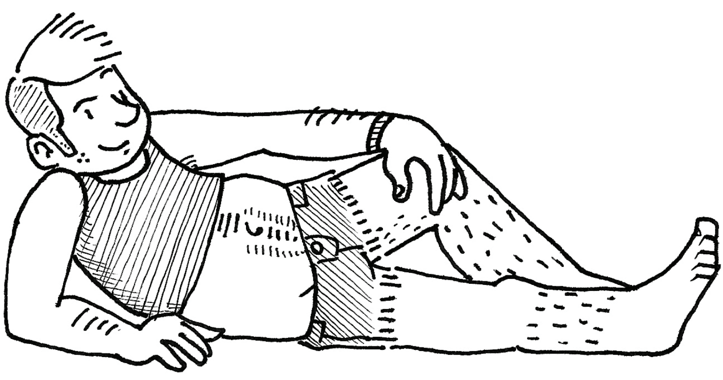
The majority of respondents were born in the 1990s. It's unclear if this age range is reflective of the broader population of people taking testosterone for transitional purposes, or if that's simply a bias of the social media populations and algorithms used to spread the word for the survey. **The average age of respondents was 28.**

Still, it's not an underestimation to say that queer elders who have taken testosterone are in scarce supply. Some of this may be because in the past decade, thanks to the activism of many, transitional care has become significantly more accessible, especially as "informed consent" models of access become more widely practiced, so most people taking testosterone are younger or began more recently. Unfortunately, the paucity of elders in our community may also be because fewer of them survived: trans men have a lower life expectancy than cisgender men or women.

Year Respondents Started Testosterone



Though age and likelihood of taking this survey (which most people found through social media) definitely influences the range of years represented in the chart above, it's clear that the last decade, especially the last five years, has seen major changes in the availability of transitional care, with many more people of a variety of gender identities and ages able to access HRT. There is little data on the longterm effects of testosterone, and this survey doesn't adequately represent experiences of those who have taken T for longer than 10 years, or before the year 2000.



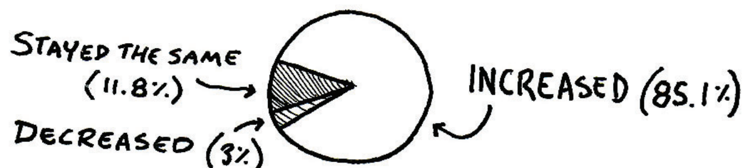
Our Trans Bodies, Our Trans Selves

Medical transition on testosterone has impacts for many aspects of a person's well-being: body, sexuality, emotions, spirituality, and social life. Repeatedly, respondents expressed a desire to know more about the bodily and emotional impacts of going on testosterone, particularly with regards to reproductive health and other conditions specific both to people assigned female at birth and intersex folks.

Sex Drive & Sexuality

Most people who took the survey experienced an increase in sex drive, describing it as easier to experience arousal, feeling attraction more physically and viscerally. "What feels good" also changed, with a handful of folks writing in that they had to relearn and explore new types of sexual experience, sometimes due to bottom growth (clitoral enlargement that often occurs from testosterone). Many reported feeling more comfortable to explore aspects of their sexuality that were either dormant or new, whether related to kink, body, or sexual orientation.

Since Starting T, Has Your Sex Drive Changed?



Among respondents who identified as asexual pre-T (6.3%), the majority continued to identify as asexual or on the ace spectrum after taking T, though the majority of all ace respondents reported an increase in sex drive. 2.3% of respondents began identifying as asexual after T. A small but notable percentage experienced a significant decrease in their sex drive.

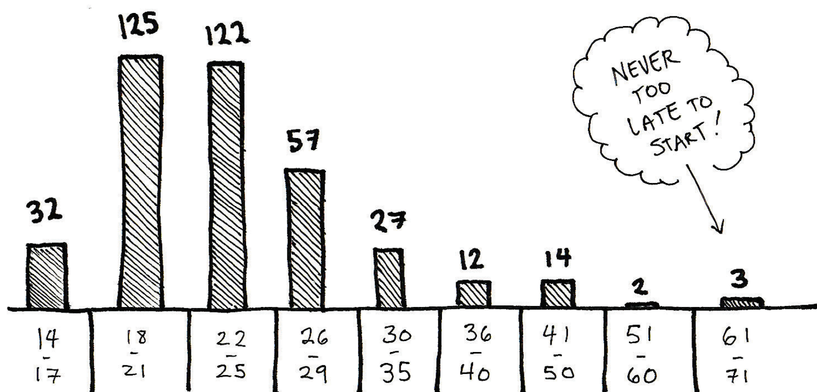
More Difficulties and Questions

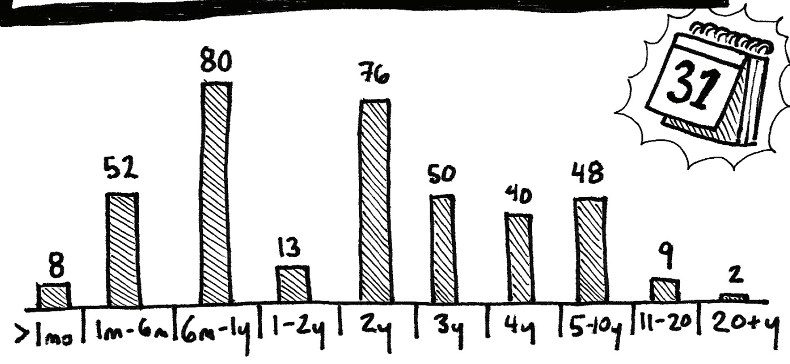
Respondents describe challenging experiences with doctors in their own words.

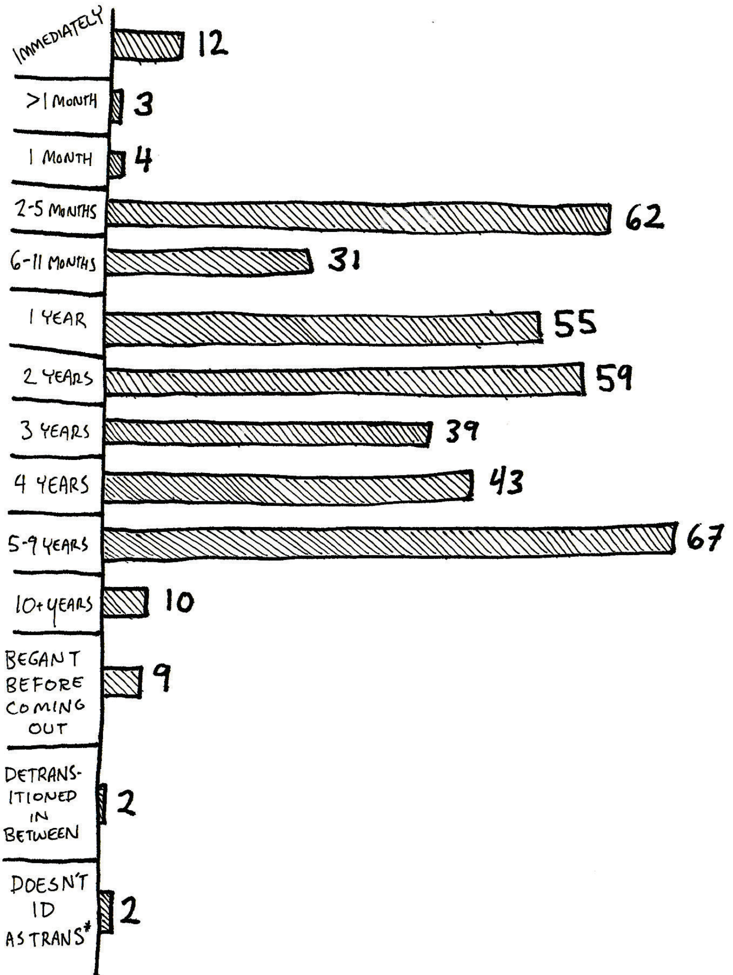
- "My psychiatrist LOVES to say that me transitioning is the reason I have an Anxiety Disorder, even though I've been seeing him about my anxiety long before even coming out as trans."
- "I just feel they didn't really have an idea of gender beyond the binary or supporting/understanding gender and the journey of it. I came in with most/all of the information and an idea of what they could do for me and it was just transactional."
- "My initial NHS doctor refused to answer any questions and asked me to transfer to a new surgery as she did not want to provide me with trans healthcare."
- "They didn't take my blood before so I don't have any initial levels."
- "They couldn't answer lots of questions that trans people know about anecdotally, but doctors do not research. Like change in sexuality, mood stabilizing effects."
- "Doctors answered all the questions I had. But even still, there have been effects (mostly minor ones) that nobody told me about - like hot flashes!"
- "Can my insurance cover vocal coaching? Will a hysterectomy be necessary? What can I do about hair loss? (I started finasteride last year after doing my own research but wish I had known sooner)."
- "Practically all of my questions were met with 'we don't have enough research to know for sure.'"
- "My PCP could not tell me really definitively the risk of infertility on T."
- "No one understood how bad my junk was hurting until I got a trans man doctor. I also have PCOS and there wasn't really much doctors could explain to me as to how that would play out long term."

How Respondents Take Their T

Here's some information about respondents' relationships to testosterone; how long they've been taking it, their dosages, and information about prescriptions.





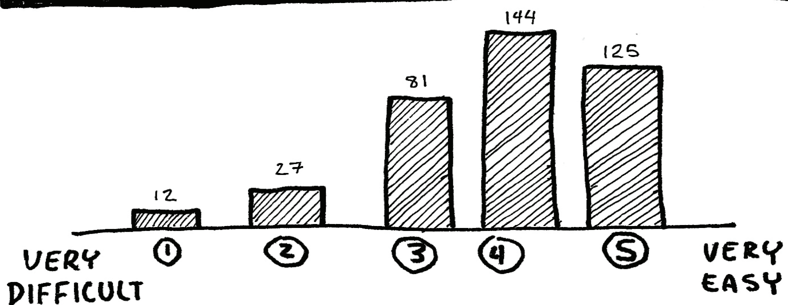


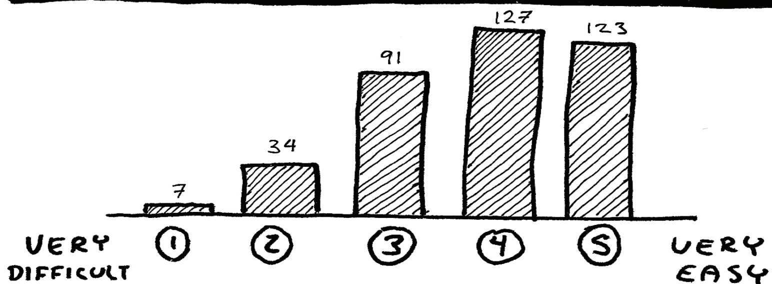
Trans defined here as identifying with a gender other than gender assigned at birth, including genderqueer or nonbinary.

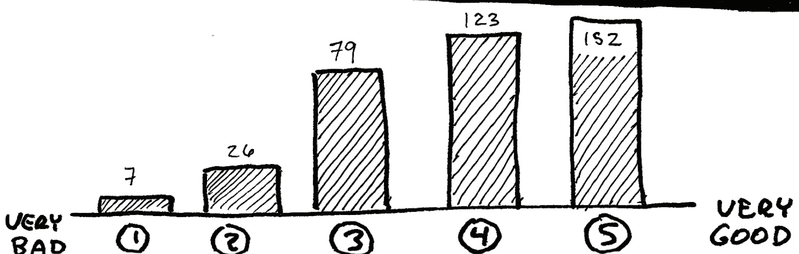
Not all respondents began testosterone immediately upon coming out. In fact, for a variety of reasons, most waited a year or longer to begin HRT.

(Mis)information from Doctors

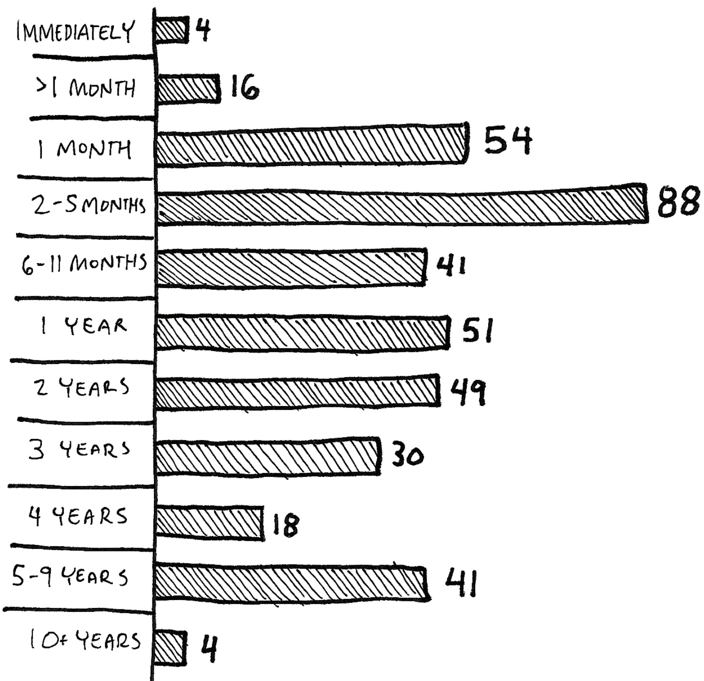
Many respondents noted that doctors either couldn't adequately answer their questions and even gave them incorrect or inaccurate information about health outcomes on testosterone.







The lower the rated quality of experience, the more likely the respondent was to also identify as low income or living in poverty. **Class inequalities persist in terms of trans healthcare quality.**



After respondents made the decision to take testosterone, **most people experienced delays** in acquiring prescription to actually start HRT. Testosterone is considered a controlled substance the United States, making it more difficult to acquire than certain other synthetic hormones. This means that people who use testosterone need to have more frequent contact with their prescribing provider to ensure a consistent supply. While currently in the U.S., a prescription is good for six months, states and health plans may impose additional restrictions.

Main Reasons For Delays Between Respondents Deciding To Take Testosterone and Actually Getting a Prescription

Many of reasons are overlapping and interrelated, with respondents citing more than one reason there was a delay in accessing testosterone. Reasons are listed in order of frequency, from most to least common.

---

1. Difficulty or long wait times to see a trans-affirming doctor, endocrinologist, or other transitional health-care professional

2. Being a minor or not having parental approval

3. Family or romantic partner pressures not to transition

4. Uncertainty, fear, or needing more time

5. Needing therapist letter of approval

6. Lack of financial resources

7. Lack of information or knowledge

8. Health insurance issues or barriers

9. Wanting or needing to either come out or socially transition before beginning HRT

10. Reliant on others for housing or finances & transition would risk this

11. Discrimination, gatekeeping, prohibited by medical professionals, therapists, and/or pharmacies, or being deemed “not trans enough”

12. Legal/state restrictions on transitional access

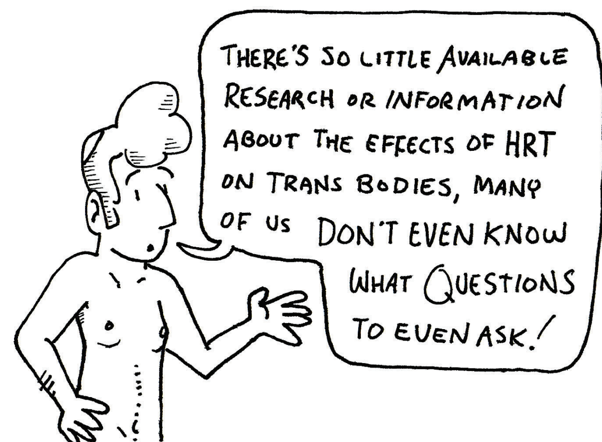
13. Location difficulties accessing care

Doctors, Pharmacists, and The Medical Establishment

For many people, one of the most difficult parts of transition is dealing with transphobia in the medical profession or navigating medical beauracracy.

In the survey, respondents were asked to rate their ease of access to getting prescriptions, getting those prescriptions filled at a pharmacy, and the overall care they’d recieved from doctors and endocrinologists. While the majority of respondents had neutral or positive experiences, quality of care declined directly along class lines. The vast majority of negative experiences were from low-income respondents who identified as lower-middle class, working class, or living in poverty.

Respondents frequently reported misinformation, misgendering, lack of knowledge, intrusive questions, inappropriate comments, and discrimination from healthcare providers. As access to HRT becomes more widely available, more trans people are interacting with doctors about transitional care - and more doctors, regardless of their area of practice, are likely to have trans patients. The stakes are high. These interactions must help heal us rather than cause more trauma and damage.



14. Physical health concerns or waiting on physical tests (bloodwork, etc.)

15. Fear of certain effects of T

16. Unsafe location or situation to transition / concerns for physical safety

17. Moving locations at time of decision

18. Fear of social or sexual rejection

19. Pandemic-related difficulties

20. Internalized transphobia

21. Friend, peer, or other person dissuading them from transition

22. Not a minor but otherwise reliant on parents or other caregivers to help access care who refuse to do so

23. Mental health or executive functioning-related difficulties getting in the way of respondent seeking care

24. Reproductive health or fertility concerns

25. Body image issues

26. Pharmacy issues

27. Lack of community

28. Fear of "not being trans enough"

29. Denial

30. Medical trauma

Others: Mental health concerns, detransition, pressure from employers not to transition or fear of unemployment

METHODS OF TESTOSTERONE ADMINISTERING

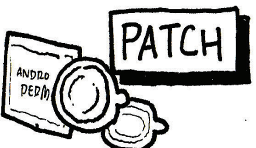
Over the years, methods of testosterone administration have changed. There are a handful of options. Today, injections and gels are currently considered the most safe, effective, and widely used.

INJECTION

Injected testosterone is the most widely used method, as it's often cheapest and most effective. Common types include Testosterone Cypionate (Depo-Testosterone), Testosterone Enanthate (Xyosted), Testosterone Undecanoate (Nebido/ Aveed). Recommended time between doses varied widely depending on the type.

GEL

Gels are the second most common method, usually available in a pump bottle or packets, applied daily or every other day, taking about 3-4 hours to dry. Common brands include AndroGel, Testogel, and Testim.



PATCH

Patches are applied directly to the skin, with the brand name AndroDerm. This method is less common, as doses are more difficult to adjust and physical changes occur more slowly.

PILLS

While testosterone supplement pills are sometimes available, they are considered unsafe and not recommended for medical transition. Not available in the U.S.

PELLET IMPLANTS

Testosteone Pellets, known by the brand name Testopel, are small cylandrical pellets containing crystalline testosterone implanted under the skin which release slowly over time.

CREAM

Testosterone cream and gel are essentially the same substance. They are both topical forms of testosterone, applied to the skin. There are currently no mass-manufactured T creams in the U.S. - only gel.

Pharmacist told me there was a shortage. My transmasc roomie and I bought supplies bulk online and haven't had that problem since

I was working at a sleep away camp in a different state and couldn't get a prescription across state lines one time.

my pharmacy
frequently gives me the wrong combination of needles so I've mail ordered them.

Having to restart care in new cities and needing to go thru the same sort of intake process as new patients for trans care clinics.

I didn't have an official prescription and ran out of T 1. when the pandemic shot down injection sharing get togethers, 2. when there were shortcomings due to the Brexit, 3. when the person I got the gel from didn't get their prescription any more because they switched to injections.

I couldn't get into the doctor for blood work required

I collected and used the bits of T left in the old bottles. You're not supposed to, because of risk of infection, but like.

My shipment of supplies was missing injection needles, shipping delays in replacing it

My old pharmacy was really passive aggressive toward me being trans, always dead naming me and such. They would never order in my prescription on time and I would have to call over and over for them to do it.

The local CVS was not equipped with the right needles, so I missed a week or two transferring to another place.

Injection mishaps

Doctor didn't process my refill request in time before I ran out

If you have run out of supplies before a refill, describe what happened and why.

Forgot to renew prescription, change in insurance, courier/pharmacy delay

Funds, switching providers, switching pharmacies.

Bottle didn't have enough testosterone in it for all four doses, as some of it got wasted in the syringes over time.

The pharmacy refuses to keep 10ml vials in stock and requires a no-substitutions special order for it

A needle broke

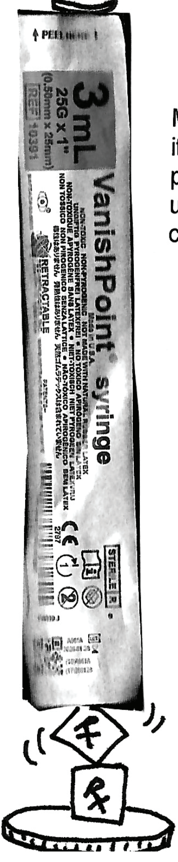
My insurance stopped covering T gel very suddenly and it cost $600 out of pocket. I had to try multiple pharmacies and doctors to figure out a solution, and ultimately I decided to switch to injection because it was covered.

not supplies but the actual hormone as my doctors didn't put it on repeat and don't really ever stock it

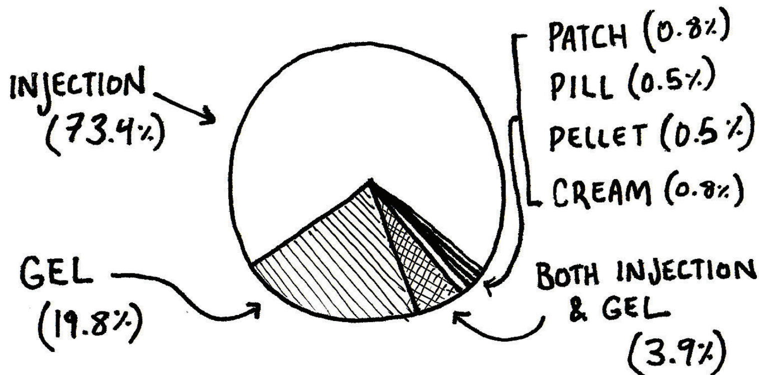
I was having insurance issues and was unable to afford my T without it.

I was getting care at an LGBTQ clinic and they were always so overloaded and underfunded that it took forever to do simple things like get prescription refills sent to the pharmacy. I also had trouble with my insurance because they would only cover me getting the single dose vials rather than the larger 10 mL bottle. And then they would think I was getting more T than I should because the single dose vials were 1 mL, so they thought it should last me 3-4 doses. But my doctor said to never use the single dose vials more than once. It was a mess.

Pharmacy logistics, bad brain



HOW DO RESPONDENTS ADMINISTER TESTOSTERONE?

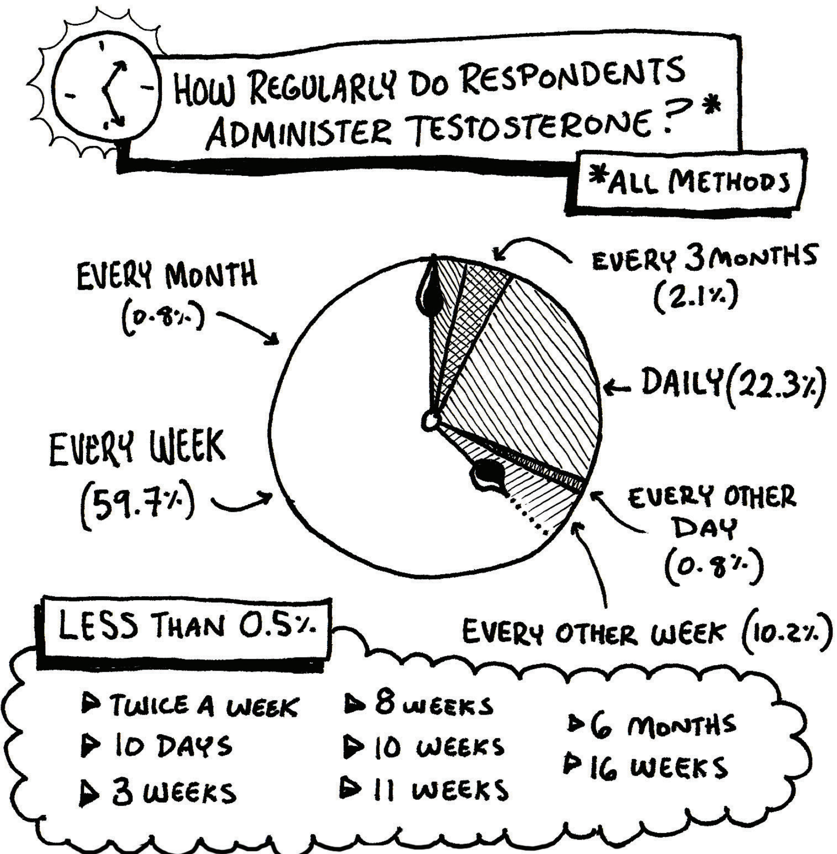


Injection was by far the most common method of taking testosterone. It's usually the cheapest, most widely available method, with some reporting desired changes happening most quickly. Injections can be intramuscular (thigh, arm) or subcutaneous (belly, butt).

Gels were the second most commonly used method. There seemed to be some popularity of gel among non-binary respondents, who may prefer the day-to-day control over dosing and the potentially longer timeline for changes to occur. Plus, for some, fear of needles made gels/creams a much better option, even though they can take time to dry.

A significant number of respondents replied that they used both gel and injection, though it was unclear if (but unlikely that) they were using both at the same time. **A notable number of respondents had tried more than one method**, switching from gel to injection (or vice versa), or changing methods over time as more options became available.

Pellets and patches were far less common, but viable alternatives to injections and gel/cream. Pills, however, are considered unsafe to use for medical transition. To those who responded that they were using pills, I urge you to find another method!



Frequency of dosage is directly related to the type of testosterone one is taking. People who inject testosterone cypionate or enanthate take 20-200mg doses every week or every other week. People who inject testosterone undecanoate (which is considered to be slow release) will take a 1000mg dose every 10-16 weeks. According to responses, cypionate is most commonly used in the United States, while undecanoate is most commonly used in the U.K. and Europe. It's unclear if there are benefits/downsides to one as opposed to the other beyond quantity and dose length.

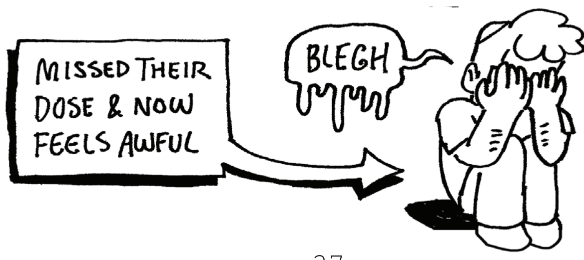
Those who use gel applied it daily, or sometimes every other day.

Common Symptom Experiences of Withdrawal from Testosterone

Ranked in order of most to least common, these are the symptoms that respondents described experiencing when they had either delayed taking or went off of Testosterone. Some of these symptoms could be felt within a day or two of missing a dose.

1. Lethargy/fatigue
2. Mood swings/emotional instability
3. Depression/sadness
4. Anger/irritability
5. Cramping
6. Dysphoria
7. Lowered sex drive
8. Resumed periods, spotting or abnormal bleeding
9. Anxiety
10. Headaches
11. Crying/tearfulness
12. Physical aches
13. Acne Breakouts
14. Suicidal thoughts
15. Hot flashes
16. Low-self esteem/sense of failure
17. Worsened other medical conditions (including PCOS, PoTS, IBS, PMDD, and ADHD)

Other symptoms listed (with fewer than five instances mentioned in responses): Insomnia, brain fog, skin changes, social isolation, dissociation, inability to focus, hair loss, appetite loss, bloating, vulnerability, sweatiness, fat redistribution, sugar cravings, stopped periods, joint instability, increased sex drive, generally feeling ill, urine smell change, panic attacks



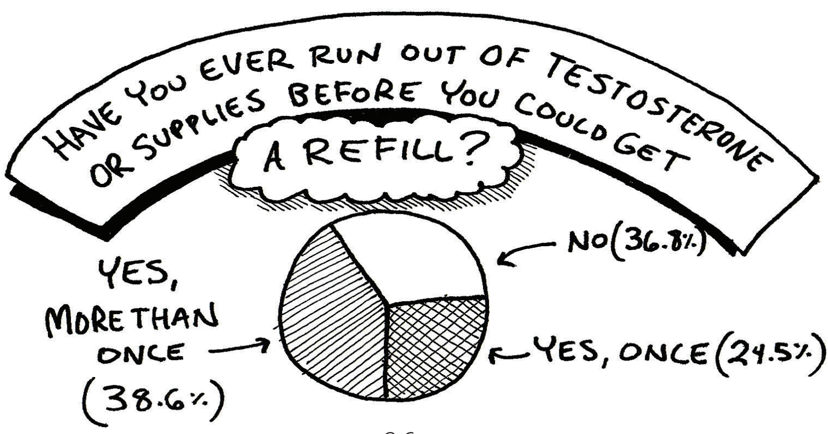
WITHDRAWAL

AMONG RESPONDENTS WHO HAVE EVER DELAYED ADMINISTERING OR GONE OFF OF TESTOSTERONE...

37% HAD EXPERIENCED WITHDRAWAL

24% WERE UNSURE IF THEY'D EXPERIENCED WITHDRAWAL

There isn't a lot of discussion about what happens when one misses a dose or stops taking T. Like any hormone shift, a change in T levels can result in physical and emotional changes or disruptions. Over a third of respondents reported experiencing some kind of withdrawal symptoms after ever delaying or stopping dosage - and more than two thirds of respondents had once run out of supplies before they could get a refill. Though testosterone isn't considered to be an addictive substance, bodies seem to adjust to increased testosterone levels - and some experienced its absence in ways that were uncomfortable, confusing, or even destabilizing. For this reason, some people who inject testosterone may prefer to dose weekly rather than biweekly, since a more regular dose can prevent withdrawal-related ups-and-downs. More research should be done about T withdrawal and if there are ways to mitigate these effects, especially for those who have had hysterectomies.



Dosage Data Note & How to Measure Your Testosterone

The survey results revealed that the majority of participants didn't properly know how to indicate their dosage, making much of the data unusable. This is partially my fault; by allowing respondents to write in their dosage without guidenace, much of the data was difficult to understand. All data that either ambiguously or didn't properly indicate dosage had to be thrown out.

Because so much of the survey data on dosage was unusable, it is clear that too many people on T were not educated by their doctors or prescribers about how to properly describe their doses. **When describing your dosage, always describe the milligrams (mg) of testosterone you're taking and the frequency with which you're taking it.**

Sample Injection Dose:
50mg Testosterone Cypionate, 200mg/mL 1mL bottle
Using 1mL syringe, fill to 0.25mL line.
Intramuscular. Weekly.

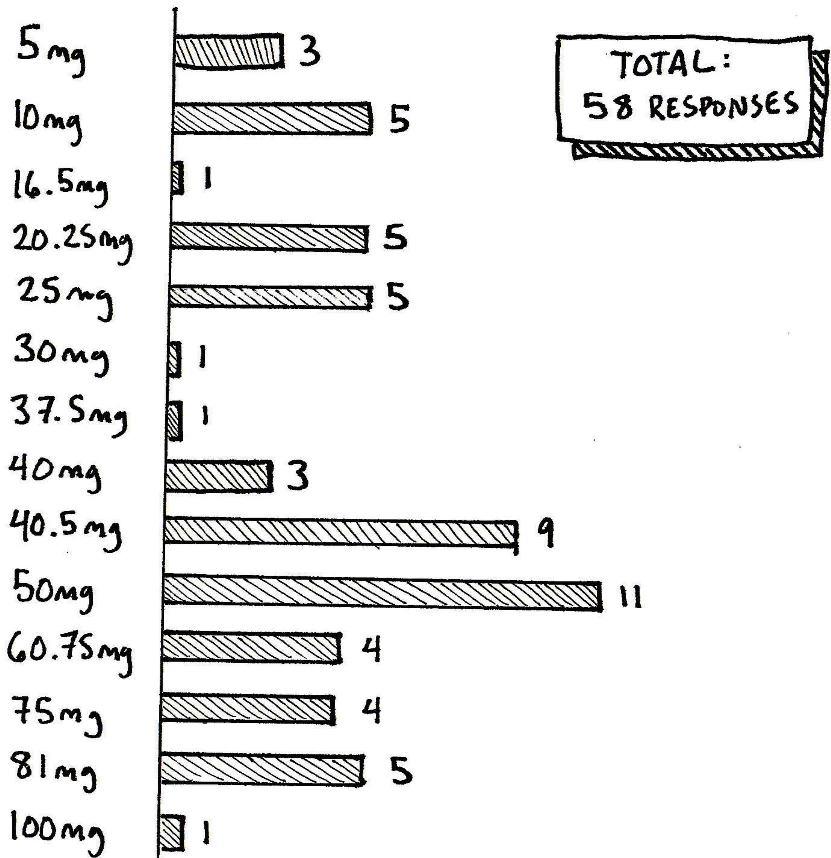
Sample Gel Dose:
40.5mg Testosterone, 2 pumps Androgel 1.67%. Daily.

Injectable testosterone comes in different concentrations & bottle sizes. Testosterone Cypionate is commonly found in concentrations of 100 mg/mL and 200 mg/mL. Your dosage is the number of milligrams (mg) you take. For example, someone who takes 50mg would take 0.5mL of a 100mg/mL substance, or 0.25mL of a 200 mg/mL substance. Instead, on the survey, many respondents wrote the number of milliliters (mL), which is denoted by the line on the syringe but is not the actual quantity of T.

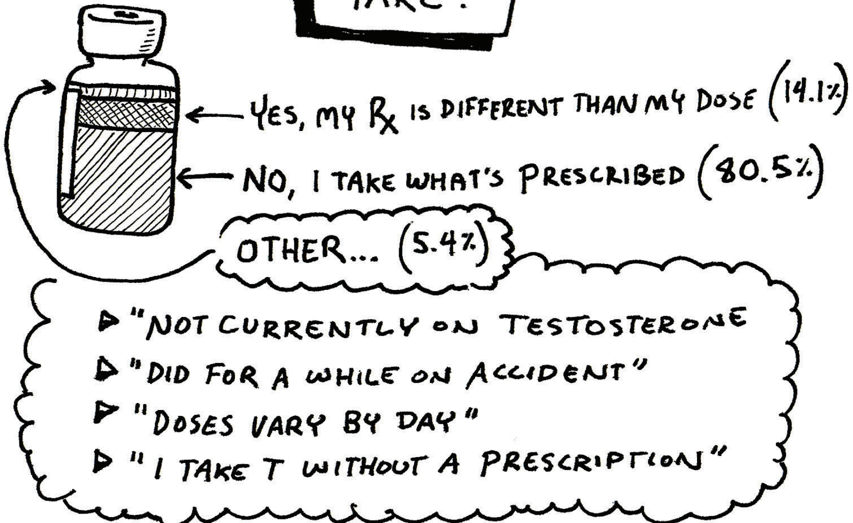
Gels also come in different concentrations, including 1%, 1.67%, and 2%. Many people wrote the number of pumps or packets they took without specifying the concentration of T in the gel.

DOSAGE

From the usable data, here were the results for those taking gel daily & injections weekly.

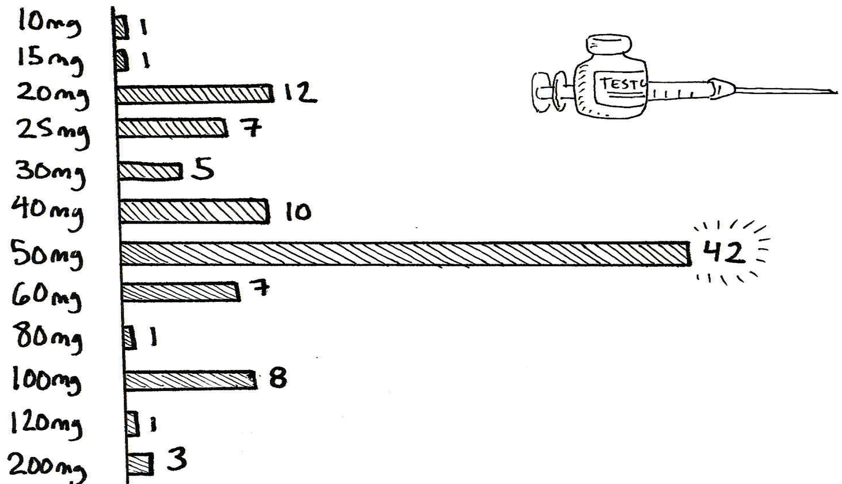


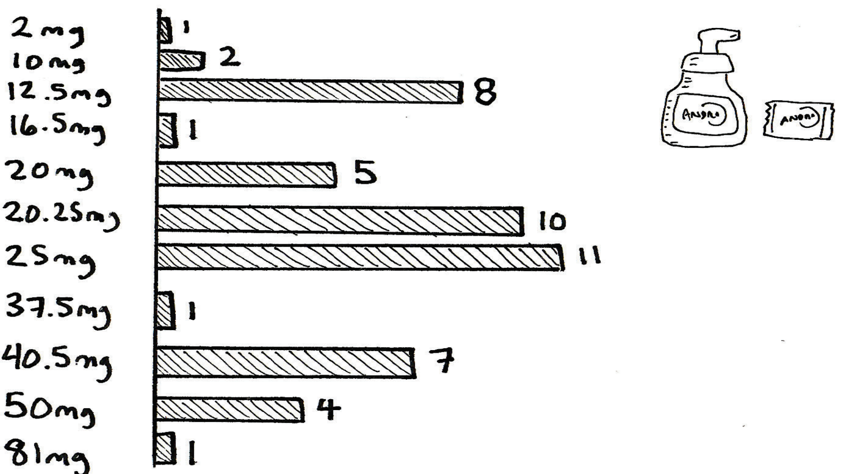
Gel doses tend to be, on average, lower than injection doses - however, they're given more frequently. It would be useful to know what the average T blood levels are for these doses and comparing them to the dose levels of those who inject.



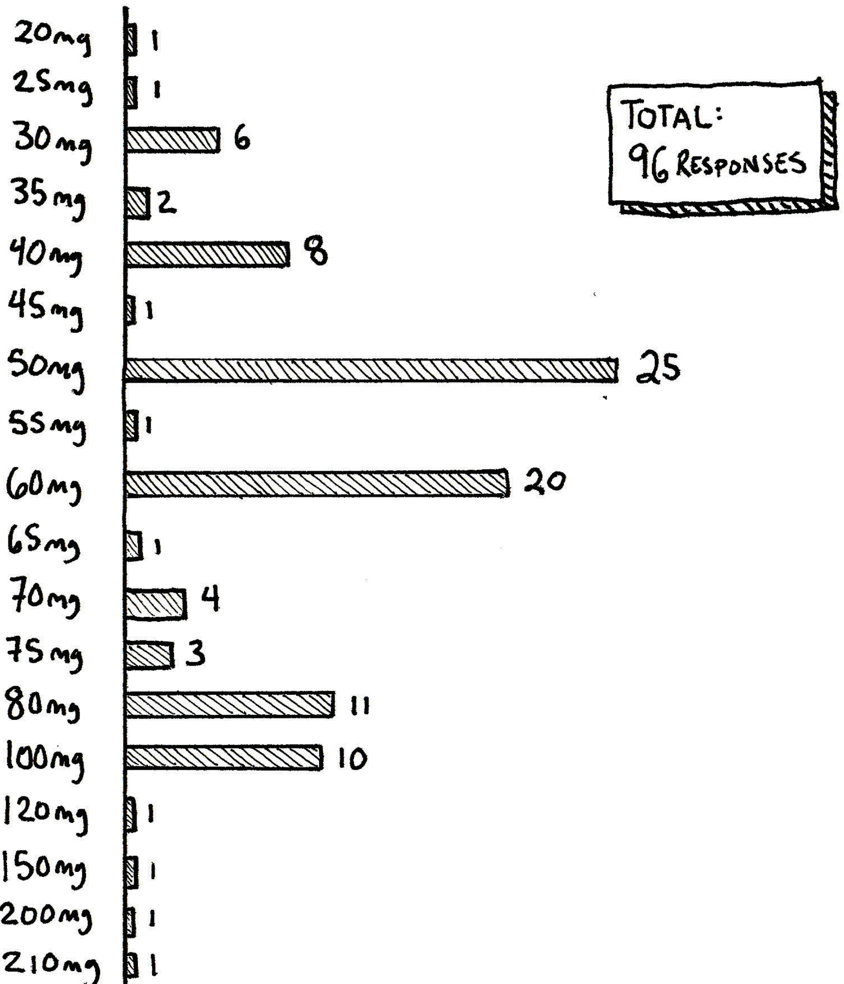
At least 14% of respondents reported that they take a different amount of testosterone than they're technically prescribed. For many, this is because changing their dosage on paper would make them more likely to run out of supplies before they're able to get a refill; usually, they're taking less than what's on paper. For others, it may be because they've changed their dose independently, and haven't wanted or been able to see a healthcare professional in order to document this change.

A small handful of respondents answered that they did not have a formal prescription for testosterone. For people who cannot access HRT through institutional methods, especially people living in poverty or youth whose parents/guardians will not support their transitions, they may acquire medication through friends or other means.





These are the initial or “starting” doses of respondents using gel or injections. The majority of U.S. respondents who injected were initially prescribed a 50mg dose. Those who started with gel had more variable starting doses. Though some doses are lower than others, there’s no official or uniform “low dose.”



The most common doses for those administering weekly were 50mg, 60mg, 80mg, and 100mg. Among those who administered every other week, respondents were more likely to have a dose of 80mg or higher, with the majority of biweekly doses being 80mg, 100mg, or 200mg. Injection responses were limited to U.S. participants (who largely take cypionate). Most non-U.S. respondents used Nebido (undecanoate) in ~1000mg/every 10-16 weeks.

INJECTIONS!

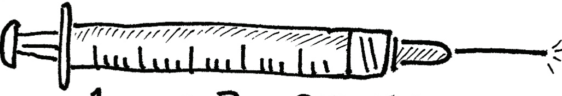
ACCORDING TO RESPONDENTS, MOST PEOPLE USE...

COTTON BALLS

BAND-AIDS

ALCOHOL SWABS

...



1mL OR 3mL SYRINGE WITH CHANGEABLE NEEDLE

LARGER NEEDLE FOR DRAWING UP TESTOSTERONE

18G – 22G DRAWING UP

SMALLER NEEDLE FOR ADMINISTERING

18G – 27G ADMINISTERING

AVERAGE: 25G NEEDLE

Subcutaneous SUBQ → 5/8" • 1" • 1.5" ← IM Intra-muscular

NEEDLE LENGTH VARIABLE FOR SUBCUTANEOUS v. INTRA-MUSCULAR, AS WELL AS BODY SIZE & COMPOSITION.

NOT EVERYONE SELF-INJECTS!

WHETHER BY INJECTION, GEL, PATCH, PILL, OR PELLET, MOST PEOPLE STAY WITHIN 25MG OF THEIR INITIAL DOSAGE.

AMONG THOSE WHO DECREASED DOSAGE...

79.3% DECREASED BY 25MG OR LESS

20.7 DECREASED BY MORE THAN 25MG

AMONG THOSE WHO INCREASED DOSAGE...

56.3% INCREASED BY 25MG OR LESS

43.7% INCREASED BY MORE THAN 25MG

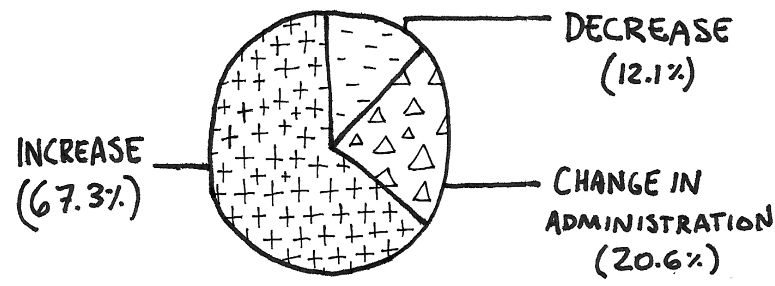
PEOPLE OFTEN ADJUST THEIR DOSAGES AFTER THEY BEGIN TESTOSTERONE.

MANY PEOPLE INCREASE + FROM THEIR INITIAL Rx

WHILE SOME DECREASE − ACCORDING TO THEIR NEEDS.

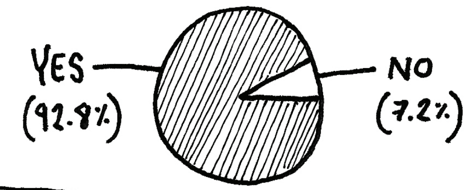
STILL OTHERS MAY CHANGE THE FREQUENCY WITH WHICH THEY ADMINISTER OR THE METHOD OF ADMINISTRATION (GEL → PATCH ETC.

AMONG RESPONDENTS WHO CHANGED THEIR DOSE, HOW MANY INCREASED, DECREASED, OR CHANGED METHODS?*



* INCLUDING THOSE WHO CHANGED FREQUENCY OF DOSE

AT THE TIME OF THIS SURVEY, ARE YOU CURRENTLY TAKING TESTOSTERONE?



MOST TIME RESPONDENT WAS ON T BEFORE STOPPING: 6 YEARS

LEAST TIME RESPONDENT WAS ON T BEFORE STOPPING: 2 WEEKS

AVERAGE TIME RESPONDENTS TOOK TESTOSTERONE BEFORE STOPPING: 1.5 YEARS

THERE ARE LOTS OF REASONS FOLKS STOP TAKING T!

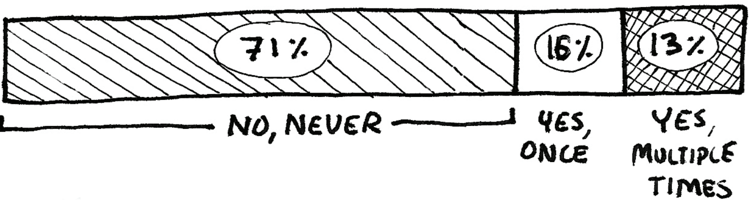
- ACCESS PROBLEMS
- MEDICAL REASONS
- REACHED TRANSITION GOALS
- IT'S NOT FOR ME, BUT I NEEDED TO TRY IT!

14% of respondents who stopped taking T identified as butch

86% of respondents who stopped taking T identified as non-binary, genderqueer, and/or genderfluid

Not all people who took the survey were currently taking testosterone; some respondents had previously taken it, or were taking a break from dosage. Some people who decide to transition using testosterone only take it for a limited amount of time, rather than as a lifelong medication. A majority of people who chose to take testosterone for limited number of time identified as non-binary, genderqueer, butch, or genderfluid - perhaps because their transitional goals didn't require longterm dosage.

HAVE YOU STOPPED & RESTARTED TAKING T?

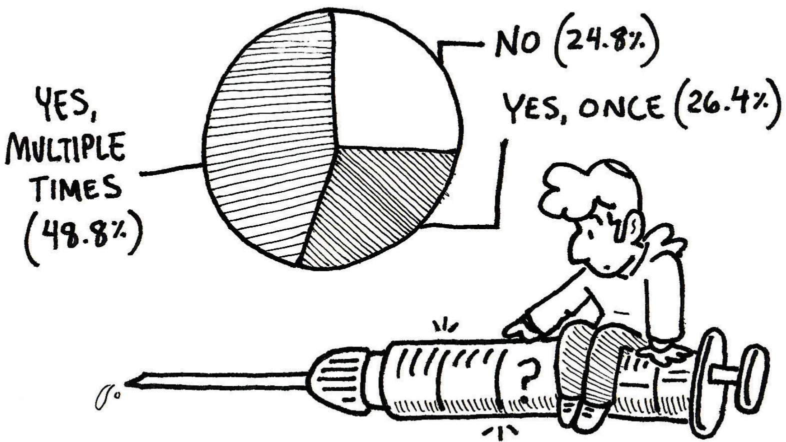


It's not unusual for folks to begin using testosterone, stop using it, and then restart dosing later. Though this question didn't ask respondents to specify how long their breaks were, nearly 30% said that they'd "gone off" of testosterone at least once, then began to use it again at a later time. For some, that may be because they needed to see how they felt without it, or that at the time they'd stopped dosing, they had reached a point of comfort or a personal goal with their transition. For others, that might be because they were no longer able to access testosterone, and so were required to stop treatment because of circumstance.

People also regularly change their dosage, sometimes with the help and guidance of doctors, sometimes independently, according to their felt need. In fact, the vast majority of respondents reported that they'd changed their dosages at least once since beginning testosterone, with nearly half indicating that they'd changed their dosage multiple times.

There's very little research to indicate best practices about changing dosages. It's unclear what (if any) health outcomes may result from changing one's dose frequently, by small or large quantities - or if particular methods of administration/types of testosterone have safer or more effective outcomes than others.

SINCE BEGINNING TESTOSTERONE, HAVE YOU CHANGED OR ADJUSTED YOUR DOSE?



Just like some folks start, stop, and resume taking testosterone, **most people adjust their dosage at least once during the time they take it.** Some people even reported adjusting their dose bit by bit each time they administered. There isn't a standard "starting dose," especially when factoring in for non-binary transitions that may have different goals than those of some transgender men, so the process of figuring out what dose is right for each individual's body and transitional needs often requires some experimentation. Sometimes this happens without medical oversight. Whether you're changing your dose with a doctor's help or not, getting your bloodwork done (analyzing T levels, liver and kidney function, etc.) is an extremely important routine health measure for anyone on HRT.

Some people not only change their dosage but also their method and/or frequency of administration, finding that different methods of testosterone (gel, injection, patch, etc.) work better for their lifestyles, or may be more readily available or affordable.