



“In society I don't exist, so it's impossible to be who I am.”

Trans people's health and experiences of healthcare in Sweden

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Summary

This report describes the health of trans people and experiences in both general healthcare settings and in gender affirming healthcare. The current report is a more comprehensive version of the Swedish country report in “Overdiagnosed but under served” (Transgender Europe, 2017). 472 trans people responded to the Swedish survey, 35.6 % were trans men, 36.4 % non-binary, 23.3 % were trans women.

39 % of our respondents stated that their general health is bad. In the Swedish general population this number is 5 % (Folkhälsomyndigheten, 2016). Non-binary people have poorer health than respondents with other gender identities. People experiencing misgendering and people not being able to live according to their gender identity have worse self-reported health than other trans people, indicating that societal factors are impacting health. People with a lack of support from their families also report poorer health than others. Many of our respondents delay seeking healthcare even if they need it, with 62 % stating that they have done so in the past 12 months because of their gender identity. Delaying healthcare is connected to being treated badly, which many of our respondents have experienced in the last year (23.2 %). It is clear that practitioners in general healthcare need more knowledge about trans to be able to treat trans people properly, both when it comes to interpersonal relations and actual medical treatment.

The satisfaction with the Swedish trans care is generally low, with approximately 40 % of our respondents rating the care as bad. The respondents report problems in gender affirming healthcare with waiting times, the referral process and the actual treatment by the gender clinics. However, some (18 %) are satisfied with the gender affirming healthcare. Improvement of gender affirming healthcare is needed on many levels. A recent doctoral thesis on the subject concludes that “one way to reduce the risk that the healthcare *per se* induces stress is by working together with the transgender population and their organizations to improve care”(Dhejne, 2017).

9.7 % of all respondents in this study had attempted suicide within the last year, so for many people this problem is very acute. 54 % have had serious thoughts of ending their own lives during the past year. All participants regardless of gender identity have the same, very high, risk for suicide ideation and attempts.

In this study we reached 172 non-binary respondents. It is clear from our results that non-binary people have worse self-reported health, more self-reported disability and are less happy with how society perceives them than do the men and women in the study. It is impossible to know for sure that the frequent misgendering and inability to live according to one’s gender identity leads directly to bad health. The theory and research about minority stress (Meyer, 2003) does however imply that the environment is the main cause of ill-health

among sexual- and gender minorities and our research indicates that these factors do play an important part also for trans people's health. It is apparent that actions are needed to improve non-binary people's health both physically and psychologically.

Many measures are needed to improve trans people's health in Sweden. These measures include improving quality and access to gender affirming healthcare, changing the law on legal gender recognition, improving access and quality of mental health services for trans people, improving the support systems for people and families who need it and improving the knowledge on gender identity and expression in general healthcare.

Sammanfattning

Denna rapport beskriver transpersoners hälsa och erfarenheter i hälso- och sjukvården. Rapporten inkluderar erfarenheter både inom den generella sjukvården och inom den transspecifika vården. Rapporten är en längre version av kapitlet om Sverige i Transgender Europes rapport "Overdiagnosed but under served" (Transgender Europe, 2017). 472 transpersoner svarade på den svenska enkäten. 35,6 % var transmän, 36,4 % var ickebinära och 23,3 % var transkvinnor.

39 % av våra respondenter angav att de har dålig hälsa. I den generella befolkningen är motsvarande siffra 5 % (Folkhälsomyndigheten, 2016). Ickebinära har sämre hälsa än personer med andra könsidentiteter. Människor som ofta upplever att de blir felkönade och personer som inte kan leva i enlighet med sin könsidentitet har sämre hälsa än andra, vilket tyder på att samhällets bemötande påverkar hälsan. Personer utan stöd från sin familj har också sämre hälsa än de som upplever att de har stöd från familjen. Många av respondenterna anger att de drar sig för att söka sjukvård när de behöver den. 62 % anger att de har skjutit upp ett läkarbesök det senaste året på grund av sin könsidentitet. Personer som har upplevt dåligt bemötande eller diskriminering inom sjukvården senaste året skjuter oftare upp sina läkarbesök än andra. 23 % av alla respondenter anger att de har upplevt diskriminerande behandling inom sjukvården senaste året. Det är uppenbart att personal inom den generella hälso- och sjukvården behöver mer transkompetens för att kunna bemöta transpersoner på ett bra sätt och ge rätt medicinsk vård.

40 % av respondenterna anser att den könsbekräftande vården är dålig. De uppger problem med långa väntetider samt krångliga och utdragna processer för att få remiss. Många är också missnöjda med själva vården och bemötandet av teamen. Vissa (18 %) är också nöjda med den vård och bemötande som de har fått. Den könsbekräftande vården behöver förbättras på många olika sätt. En nyligen utkommen doktorsavhandling sammanfattar (översatt från engelska): "Ett sätt att reducera risken att vården i sig orsakar stress är att arbeta tillsammans med transpersoner själva och deras organisationer för att förbättra vården (Dhejne, 2017)."

9,7 % av alla respondenter har försökt ta sitt liv det senaste året, så för många är detta ett väldigt närvarande och akut problem. 54 % har haft allvarliga självmordstankar det senaste året. Alla transpersoner i rapporten, oavsett könsidentitet, har samma höga risk för självmordstankar och självmordsförsök.

Denna studie nådde 172 ickebinära personer. Resultaten visar tydligt att ickebinära har sämre hälsa, mer självdefinierade funktionsnedsättningar och är mindre nöjda med hur samhället uppfattar dem än de män och kvinnor som har deltagit i studien. Det är omöjligt att veta om det är det konstanta felkönandet och svårigheter att leva i det kön som en identifierar sig med som orsakar den sämre

hälsan. Teorier kring minoritetsstress (Meyer, 2003) föreslår dock att omgivningens bemötande är den viktigaste förklaringen till hbtq-personers sämre hälsa. Det är uppenbart att insatser behövs för att förbättra ickebinäras fysiska och psykiska hälsa.

Många förändringar måste till för att förbättra transpersoners hälsa. Tillgängligheten och kvaliteten på den könsbekräftande vården måste förbättras. Könstillhörighetslagen måste förändras i grunden. Psykiatrin och andra instanser som jobbar med psykisk hälsa måste bli transkompetent och mer tillgänglig. Det måste finnas stöd för personer och familjer som behöver det. Sist men inte minst måste den generella hälso- och sjukvården bli mer transkompetent.

Background

Sweden established the law on gender recognition in 1972, making it the first country in the world that enabled trans¹ people to get legal gender recognition. The law has been updated since, removing requirements of sterilization and divorce as prerequisites for being eligible for legal gender recognition. The existing law states that you have to 1) have been identifying as the other gender for a long time,² 2) have been living in that gender role for some time, 3) be assumed to live according to that gender in the future, and 4) be over 18 years old. Additionally, you have to be a permanent resident of Sweden (SOU 2014:91, 2014) to be able to get legal gender recognition. There is no obligation to undergo genital surgery or other treatment to be able to change your legal gender.

Thus, the Swedish law does not per se have a diagnosis requirement, but in practice diagnosis is a prerequisite to get approval from the Legal Advisory Board (LAB), the body within the National Board of Health and Welfare that decide on legal gender recognition. The LAB requires the diagnosis F64.0 Transsexualism and a positive statement from a gender clinic to approve legal gender recognition (Socialstyrelsen, 2015b).

In 2015, guidelines on trans healthcare for adults and children were adopted, giving guidelines for the gender clinics on how to provide care for gender dysphoric individuals. The guidelines state that both binary and non-binary trans people should get medical help if needed and that the process should be tailored according to the patient's needs. It also gives guidelines for how young people under the age of 18 should be treated (Socialstyrelsen, 2015a, 2015b). However, these guidelines are not mandatory, resulting in varying procedures by the different gender clinics that are located in six parts of Sweden. This study is the first, to our knowledge, to be conducted after the guidelines were adopted.

At the gender clinics the person meets a multidisciplinary team consisting of psychologists, psychiatrists, counsellors and other staff members. One aspect of the assessment consists of sessions with a psychiatrist, with the task to exclude other reasons for the patient's discomfort than gender dysphoria and to give a diagnosis to be eligible for treatment. The treatments included in the Swedish health insurance are hormone replacement therapy, top and/or bottom surgery, hair removal (usually face and breast area), voice training and, if needed, reduction of the Adam's apple. Some clinics provide a penis prosthesis. Feminizing facial surgery and liposuction of hips is recommended to be provided under certain circumstances, but it is very uncommon and hard to

¹ For information about words describing gender identity and expression (in Swedish) go to www.transformering.se

² Direct translation of the law. "The other gender" is not a phrase RFSL would use.

access (Socialstyrelsen, 2015b). All treatments are available for non-binary persons, according to the persons needs, with the exception of bottom surgery. To receive bottom surgery, one needs the diagnosis F64.0 Transsexualism.

For minors, hormone blockers are provided. Hormone replacement therapy (HRT) and top surgery are generally available from age 16, even though there is no age limit regulated by law. However, non-binary minors are to a lesser extent able to access HRT or top surgery at the moment. At some gender clinics for minors, non-binary persons do not even get to undergo an assessment.

The number of persons seeking gender clinics is increasing dramatically, and the queues to access care are very long. Long waiting times to the gender clinics is a huge problem for trans people in Sweden, at some clinics the waiting time can be more than one year, and for some clinics close to two years. Another problem is the time the actual assessment takes, since waiting is used intentionally as a diagnostic tool, presumably to minimize the risk of regret (Bremer, 2011; Linander, Alm, Hammarström, & Harryson, 2017). However, the assessment time is individual and may vary greatly. To approve an application for legal gender recognition and bottom surgery the LAB requires the assessment period to be about two years long, thus prolonging the time the whole process takes for many persons.

In order to access care at a gender clinic one often needs a referral from a psychiatrist within general healthcare. This referral can be hard to obtain, making the waiting time even longer. Often you need a referral from a general practitioner to even get to see a psychiatrist in the first place. Some gender clinics have started to accept referrals from the patients themselves, thus simplifying that part of the process, reducing waiting times and the stress the referral process might cause.

With the exception of minors, asylum seekers and undocumented people cannot access gender clinics. The Swedish healthcare system only grants “treatment that cannot be deferred” to people who are seeking asylum or who are undocumented, and gender affirming care does not fall into this category at this moment. However, for a person who already has started hormone replacement therapy before coming to Sweden, exceptions may be possible.

A recent Swedish study, with 800 trans respondents, showed that about half reported good health, and about a fifth reported poor health. Poor self-reported health was associated with having a history of negative healthcare experiences. So was needing, wanting or not having accessed legal gender recognition, as well as low income and insecure employment status (Zeluf et al., 2016). The survey also showed that about one fifth of the respondents had been subject to violence because of their trans identity. More than one third of the respondents had been subject to psychological violence in the year preceding the study, mostly in public spaces. Many have experienced sexual violence, and 30 % reported having been forced to sex against their will at some point in their lives.

More than half of the respondents had been subject to demeaning or abusive treatment in the previous three months, because of their trans identity (Folkhälsomyndigheten, 2015).

Suicide ideation and attempts are common within this group, with 37 % reporting having seriously considered suicide in the past year (Zeluf et al., 2017), compared to the general population where 3 % reported suicide ideation the past year (Folkhälsomyndigheten, 2016). Suicide ideation among the trans respondents within the past year was associated with unemployment or long-term sick leave, country of birth other than Sweden and alcohol risk consumption. Older age was associated with less suicide ideation. Also, having been subject to offensive treatment in the past 3 months, having been exposed to trans related violence, dissatisfaction with contacts with friends and dissatisfaction with psychological wellbeing was associated with suicide ideation. Problems with suicide ideation and attempts were equally common among people of all different trans experiences and gender identities, regardless of whether or not they had accessed legal gender recognition or not (Zeluf et al., 2017).

Method

Together with the partner organisations Transgender Europe (TGEU), Women's Initiative Supportive Group (WISG, Georgia), Trans-Fuzja (Poland), Daniela Fundación (Spain), Gayten LGBT (Serbia), the survey was co-constructed during intense research team meetings in 2016. The survey aimed at capturing the experiences of trans healthcare users in the five countries. In Sweden the survey was disseminated mostly through social media, including Facebook-groups for trans people, spreading it through the RFSL-page on Facebook and on the RFSL website.

Public health researchers from the University of Gent, Belgium performed the data analysis. During the analysis of the data, great consideration was placed on the possible effects of different socio-demographic variables such as gender identity groups, age, income, educational level, other minority status due to ability, ethnicity, religion, sexual orientation, and so on – acknowledging the cumulative effects of these social positions. The methods used and results from the five countries combined are presented elsewhere (Transgender Europe, 2017). As stated above, the current report is a more comprehensive version of the Swedish country chapter in the report “Overdiagnosed but under served”, by the same author, so partly the content is the same in both reports. The full survey can be found for download on www.rfsl.se.

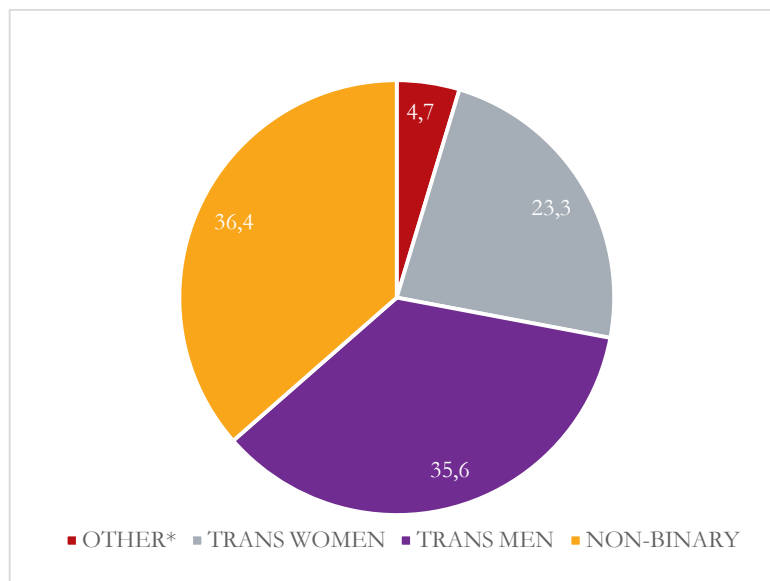
Results

The respondents

472 trans people responded to the Swedish survey. The other countries had fewer respondents, but all except Georgia (n=23) had enough respondents to compare between countries (Spain =276, Poland=76, Serbia=38).

The vast majority of the Swedish respondents had Swedish citizenship or a valid residence permit in Sweden (99.2 %). The age range of the respondents was 16-77 years old and the mean age was 27 years. 35.6 % were trans men, 36.4 % non-binary, 23.3 % were trans women and 4.7 % other. The last group, "other", contains only 22 respondents. Therefore, the group is too small to be used for analysis. 69.7 % were assigned female at birth and 30.3 % were assigned male at birth.

Figure 1. **Gender identity of the respondents (%)**



Question: How do you describe your gender identity at the current moment? Please select the option that fits you best

We asked about identifying as belonging to different minority groups. 9.7 % state that they belong to an ethnic minority and 9 % that they belong to a religious minority. 89 % state that they belong to a sexual minority, identifying as gay, bisexual, lesbian, pansexual, queer, asexual etc. As many as 33.9 % reported identifying as pansexual and 33.4 % as queer. 35.9 % belong to a minority group due to ability status. 58.7 % of the respondents had a low level of education, while 41.3 % had a high level of education

Figure 2. **Sexual orientation/sexuality (%)**

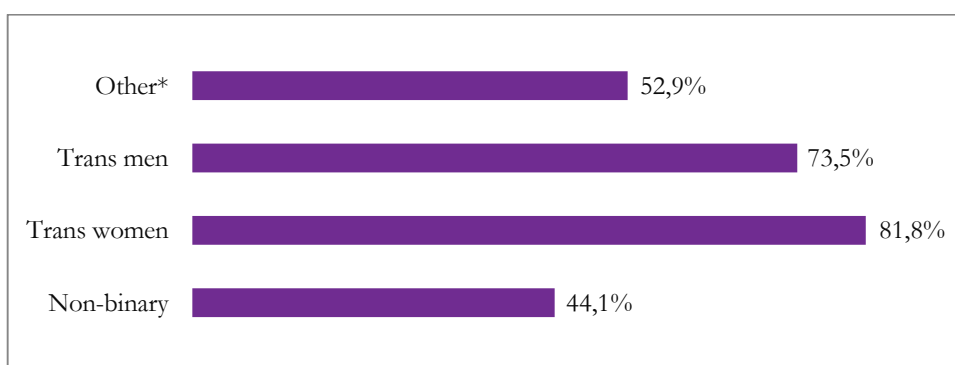
SEXUAL ORIENTATION OR SEXUALITY	%
BISEXUAL	27.3 %
GAY	10.0 %
LESBIAN	16.7 %
ASEXUAL	17.4 %
PANSEXUAL	33.9 %
QUEER	33.4 %
STRAIGHT OR HETEROSEXUAL	12.1 %
DON'T DEFINE, NOT SURE OR OTHER	34.1 %

Question: Below are some terms that describe different sexual orientations and sexualities. Please select all that apply to you.

Legal gender recognition

41.1 % of the respondents had changed, or were in the process of changing, their legal gender marker at the time of the survey. 69.1 % of trans women, 60.7 % of trans men and 6.4 % of non-binary people had done so or was currently in the process. Out of the 58.9 % who had not changed their legal gender marker, 57.2 % were interested in doing so in the future.

Figure 3. **Would like to change legal gender marker, by gender identity (% Yes)**



Question: Would you like to change your legal gender marker?

Among the respondents who did not want to change their gender marker, the two main reasons were that they didn't feel the need for it (42.9 % of cases) and more than half (53.8 % of cases) said that the gender they would want is not available. Among the people who had other reasons for not wanting to change

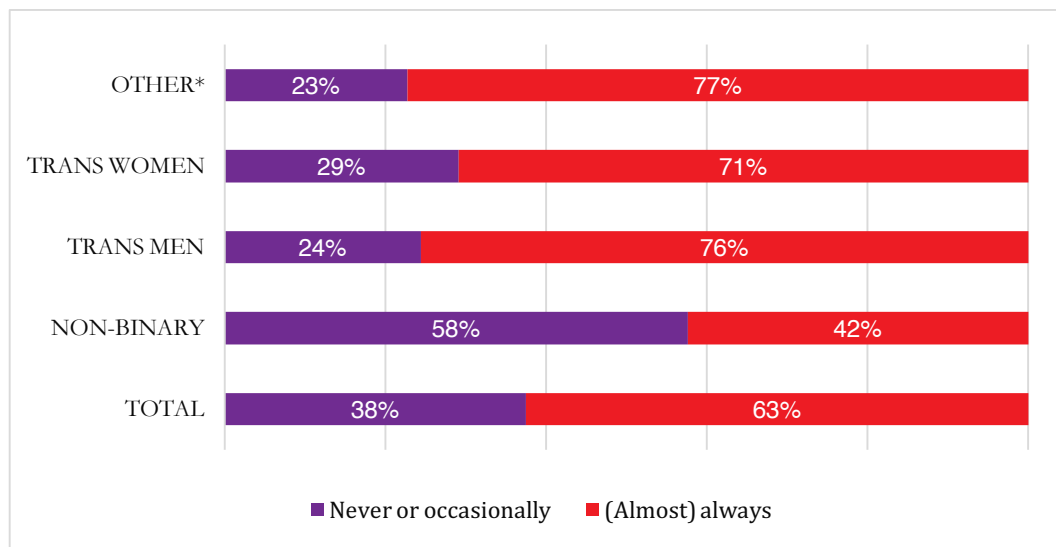
their legal gender marker, quite a few stated in their comments that they think legal gender should be abolished.

“I don't want to stand behind the legislation as it is today. The day you apply at the Swedish Tax Agency and the issue is handled in the same way as name change or change of home address, that day I'll change my legal gender.”

Ability to live according to one's gender identity

Far more trans men (75.6 %) and trans women (70.9 %) stated that they were able to always or almost always live according to their gender identities than did non-binary people, of which only 42.4 % were able to. Only 3.5 % of the non-binary respondents state they can always live according to their gender identity.

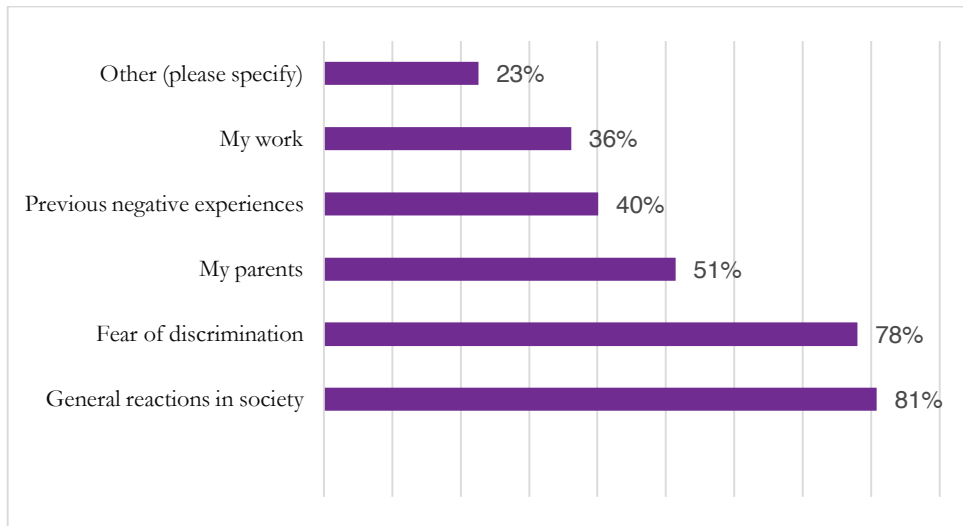
Figure 4. ***Being able to live according to one's gender identity (%)***



Question: At the present time, how often are you able to live according to your gender identity?

The three main reasons that people state for not being able to live according to their gender identity are general reactions in society (81 %), fear of discrimination (78 %) and parents' reactions (51 %).

Figure 5. ***Reasons for not living according to one's gender identity (%)***



Question: What are your reasons for not (always) living according to your gender identity? Please select all answers that apply to you.

Comments from people on reasons for not always living according to one's gender identity include:

“As non-binary it's hard that so many people don't know that there are more than two gender identities. Every time you come out it has to be followed by a lesson about your identity and having to 'prove' that your identity is real, which is very difficult.”

“Fear of violence. Going out on weekends is the worst.”

“Haven't been able to start transitioning because I have to undergo other assessments before I can undergo gender assessment.”

“In safe trans rooms I can. In society I don't exist, so it's impossible to be who I am. I am misgendered in ALL situations.”

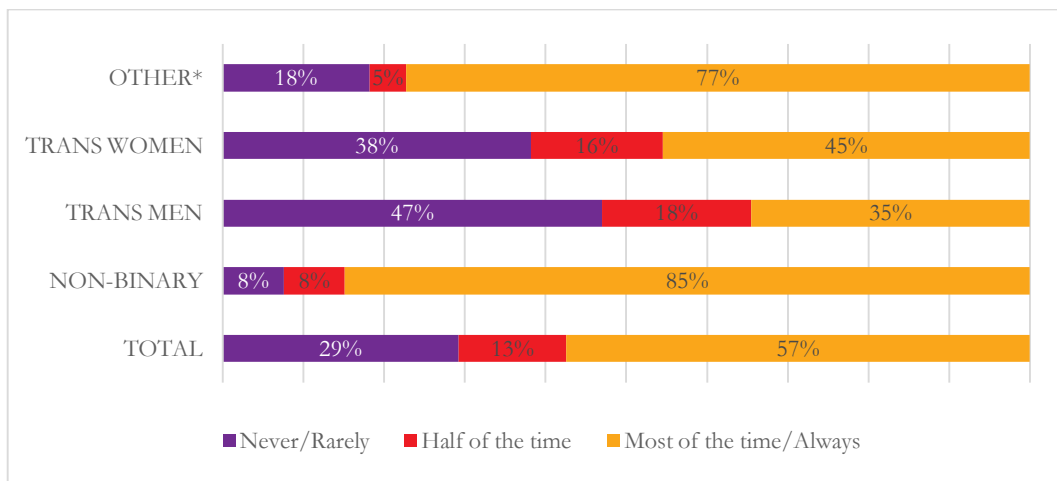
“I am 8 months pregnant (I'm usually treated with testosterone, but haven't taken it in a long time because I wanted to try and have a baby).”

Being read as someone of the gender you were assigned at birth by strangers, here translated roughly to misgendering, is a problem for many of the respondents in this survey. Misgendering is the process where other people address or read a person as a gender they do not themselves identify with. 45 % of the trans women,

35 % of the trans men and 85 % of the non-binary people say misgendering by strangers happens always or most of the time. Misgendering by strangers is, not surprisingly, more common for non-binary people than for trans men and trans women. 51 % of non-binary trans people state that strangers always address them as someone of the gender they were assigned at birth.

Some trans men (27 %) and trans women (14 %) state that they are never read as someone of the sex they were assigned at birth. 2 % of the non-binary people experience this.

Figure 6. ***Being addressed by sex assigned at birth, by gender identity (%)***



Question: At the present time, how often do strangers (shop assistants, people on the street, etc.) address you as someone of the sex you were assigned at birth?

Family support

66 % have support from their close family, 14 % have had disapproving reactions from close family and 20 % have had neutral reactions. With close family we mean parents, siblings, partners and children. There is no significant difference in family support between the different gender identity groups. However, 18 % of non-binary people say that they don't know yet if their family will be supportive, indicating that they have not yet come out to their close family (which is true for 15 % of the respondents, see figure 7). People with lower education and people with bad health have less current support from family than other respondents. There were not enough respondents from Sweden alone to analyse differences about having a disability or belonging to ethnic minority, but among all respondents from all countries combined we see that these report far lower levels of current support from their families (Transgender Europe, 2017).

Many respondents state different adverse family reactions as reasons for not being open, not seeking gender recognition, not seeking healthcare etc.

“I have told my parents but they don't care and keep addressing me according to binary gender. Many friends want to support but "forget" to address me correctly.”

“I haven't legally changed my name yet. So it's not 'for real' yet, according to for example my family.”

“I was living in a psychologically abusive relationship with my parents for many years until I slowly started to distance myself from them.”

“My dad has broken contact with me related to me being trans, but among other close family members and especially the ones I've chosen myself I feel very supported.”

“My family doesn't like trans people.”

“I live with people who don't support me and will therefore wait [with contacting gender affirming healthcare] until I'm independent.”

We asked how open people are about their gender identity in different settings. This data has not been statistically analysed so differences between gender identity groups might not be statistically significant, however the data gives some insight in the differences in openness about one's gender identity in different parts of life.

64 % state that they are fully open with their gender identity to their close family. Non-binary people seem to be less open than other gender identity groups with 15.1 % saying that they are not open at all to their close family, while only 5.5 % of trans women and 4.2 % of trans men say the same.

Figure 7. *Openness to close family (%)*

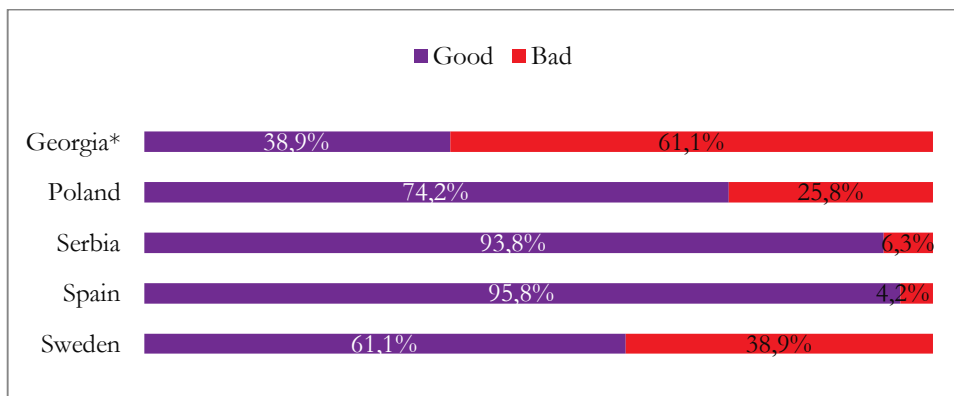
	FULLY OPEN	PARTIALLY OPEN	NOT OPEN AT ALL
TRANS WOMEN	73.6 %	20.9 %	5.5 %
TRANS MEN	78.0 %	17.9 %	4.2 %
NON-BINARY	43.6 %	39.0 %	15.1 %
OTHER	59.1 %	27.3 %	9.1 %
TOTAL	63.6 %	26.7 %	8.7 %

Question: At the present time, how open are you about your gender identity around the following people? In each case, please select the option which is most applicable to your life nowadays

Self-reported health

We asked about general health, where 61 % of the respondents stated they have good health, and 39 % say their health is bad. Trans people in Sweden reported significantly worse health than people from the other countries, see figure 8.

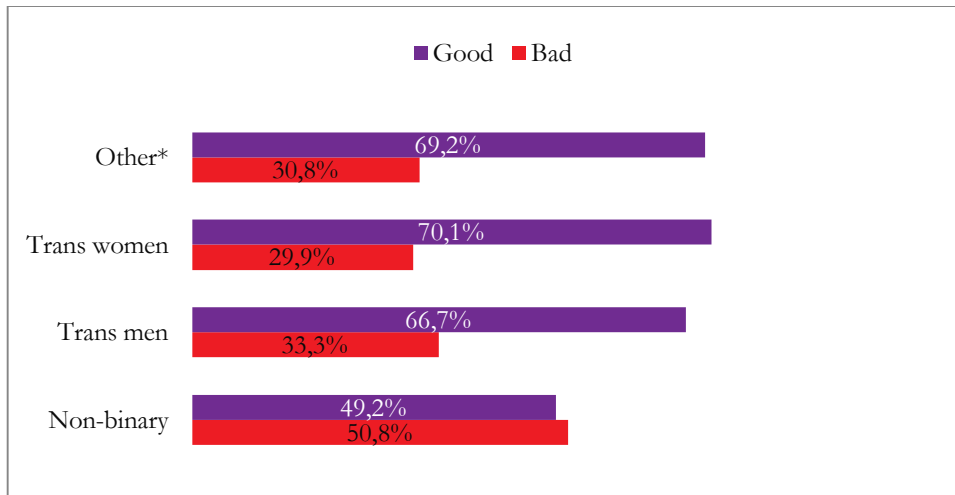
Figure 8. *Health status, by country (weighted %)*



Question: In general, would you say your health is...

The difference in health between people with different trans experiences is significant, with non-binary respondents more often reporting bad health ($p=.009$), as shown in figure 9.

Figure 9. **Health, by gender identity (%)**



Question: In general, would you say your health is...

Our results show that trans people with supportive families have significantly better health. 50.0 % of people who did not have their family's support stated having bad health, which is a significantly higher percentage than those who did (31.7 %, $p=.003$). People who experience misgendering always or most of the time have significantly worse health than people not experiencing this. 46.2 % of people who experience much misgendering have bad health, compared to 20.7 % of people who do not get misgendered that often ($p=.00003$). People who feel that they cannot live according to their gender identity have significantly poorer health, with 56 % reporting bad health, compared to people who can, where 24 % report bad health ($p<0.001$).

Looking at the respondents from all the five countries it is also clear that respondents with low education, respondents belonging to an ethnic, religious, sexual minority group and people with disabilities reported significantly more often bad health. Additionally, respondents feeling discriminated against in healthcare settings during the past 12 months reported worse health than did other respondents (Transgender Europe, 2017).

We also asked about chronic (long-standing) physical or mental health problems, illnesses and disabilities. 65 % of the Swedish respondents said that they were experiencing one or more of these health problems. Of the non-binary people 74 % had these problems, compared to 56 % of the trans women and 63 % of the trans men.

Mental health and well-being

Well-being was measured by the 5-item World Health Organization Wellbeing Index (WHO-5), where a score below 48 indicates a risk for poor mental health. When we compare the country scores from the trans respondents with the scores on the WHO-5 in the European Quality of Life Survey of 2012 (Sándor, E; Ahrendt, D; Kuenzi, 2012) it is clear that the score for trans people of this survey is lower (43) than the score for the general Swedish population (64), indicating that trans people in Sweden generally are at risk for poor mental health. The index shows that approximately 30 % of the respondents are likely to have an on-going depression, about a third are generally in a low mood and about 40 % have an average or positive mood, see figure 10 (Transgender Europe, 2017).

We also asked an open question about mental health, and got 172 answers, long and short. When quickly analysing the text, there are a few words that stick out. The words depression, depressed and antidepressants are used in total 72 times, the word anxiety is used in total 47 times.

Here are some of quotes from our participants:

“I've suffered from depression and panic disorder for 2-3 years, but it's starting to subside.”

“For long periods of time I feel very anxious and depressed, this strongly affects how I feel about my gender identity.”

“Had my worst depression while I still wasn't out to myself. Now I feel better when I acknowledge myself as I am, but my mental health is still affected by how society treats me.”

“I'm very ok with myself and love my near and dear. It's the contact with the outside world I don't have the energy for. I'm sick of all people who don't understand, that don't want to understand. I'm sick of having to live up to other's expectations, sick of being perceived as something I'm not. I'm sick of the mean things people can say, I'm sick of not feeling secure in all feminist rooms I have access to, I'm sick of how hard it is to date without feeling like a cheater. A lot has to do with my gender and it drives me insane. Wish I didn't have to think about it, wish that I too could be for real.”

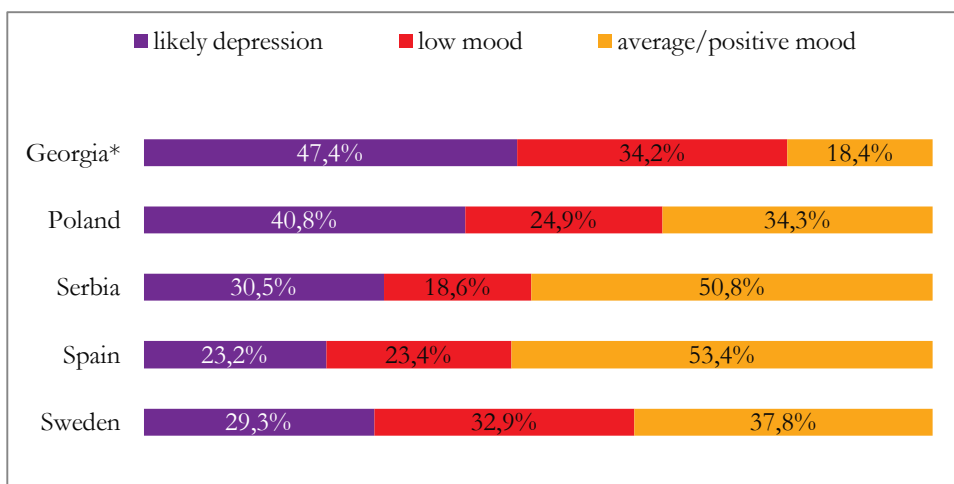
“I have just come out of a long depression, since my assessment was finally finished and I got to start medical transition. The assessment has been incredibly tough mentally and I hated every second. I'm glad to be rid of them today and only have to deal with

the endocrinologist, who's not part of the team. It's worked wonders for my mental health.”

“I'm not interested in any 'reconstructive' care and don't see myself as ill and therefore don't want to be diagnosed as such but would like to get counselling and help with my mental health in relation to what I've been subject to as a trans person.”

From the international report data about well-being, it is clear that among respondents from all five countries non-binary people, people with low educational level, respondents belonging to a sexual or ability minority group, younger respondents and respondents with great difficulties to make ends meet financially, had significantly lower well-being scores than other respondents (Transgender Europe, 2017).

Figure 10. **Well-being, by country (weighted %)**



Question: Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks.

Suicide ideation and attempts

The respondents were asked questions about suicide attempts and suicide ideation. 79.2 % of all Swedish respondents report having had serious thoughts about ending their own life. Of those, 68 % (N=255) reported having had these thoughts the previous year. 24.8 % of all respondents report having attempted suicide at least once during their lifetime. 9.7 % of all respondents had attempted suicide the previous year. There were no significant differences according to identity groups for lifetime suicidal thoughts or attempts, however people of young age are significantly more prone to suicide ideation.

We asked about where people turned for help about their suicidal thoughts and attempts, and of the people with suicide ideation or attempts, 59 % responded that they didn't seek any help at all. 36 % sought help from friends, peers or

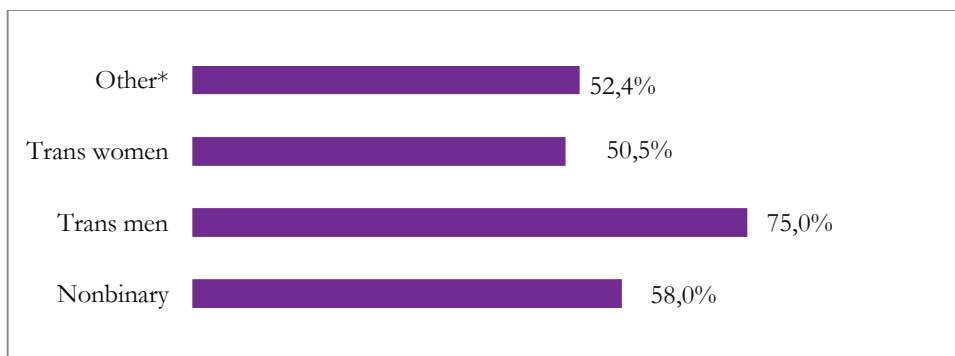
family. 48 % responded that they had sought professional help through mental healthcare services. People could choose more than one option, in case they turned for help differently at different times when they needed help for suicidal thoughts or attempts.

Factors like gender identity, family support, experiences of misgendering or if one can live according to one's gender identity did not differ significantly in experiences of suicide ideation or attempts.

Experiences of general healthcare

In total, 62.1 % report to have delayed going to a general healthcare practitioner – ranging from sometimes to all the time. A significant difference in gender identity groups was found, with trans men delaying going to a general healthcare practitioner more frequently when compared to other identity groups.

Figure 11. ***Ever delayed going to the doctor for general healthcare (% Yes)***



Question: Have you ever delayed going to the doctor for general healthcare because of your gender identity?

Also, the respondents self-reported health status resulted in significant differences in delaying going to a GP, with respondents with a bad health status delaying going to the GP more often (77.4 %) than those with a good health status (51.4 %). The main reason for people delaying seeking healthcare is a fear of bad treatment (75 %).

23.2 % of the participants state having experienced discrimination because of their gender identity or -expression from a healthcare provider in the last 12 months. Those who have experienced this, reported higher levels of delaying going to a general healthcare practitioner (92.2 %) than those without discriminatory experiences (52.5 %).

The same effect of higher levels of delaying healthcare was found in those who had experienced gender affirming care (67 % versus 33 %) and for those belonging to a sexual minority group (63.8 % versus 36.2 %).

Comments on discriminatory treatment from healthcare staff included:

“I didn't get a morning after pill because they wanted to check what was between my legs before they gave it to me.”

“People that have deliberately called you by the wrong name or pronoun. Said that it's nasty that I'm trans, that I was sick. That there are only two genders and refused to use my pronoun when I've asked them to.”

“I called to make an appointment with a doctor and this happened: ‘What's your name?’ ‘My name is X’ ‘So your name is X, but you're a girl?’ Extremely unprofessional treatment from the phone operator at the hospital.”

“I called the local health clinic to ask if they had experience in hormone treatment for trans people. Was told the following: ‘But sweetheart, you know that testosterone is for men, you can't take it. Furthermore, our nurses would feel uncomfortable giving you your medication.’ Never went back there again.”

“My endocrinologist was way too curious, fascinated by me.”

“Been denied care/examinations numerous times. With arguments such as I'm not gluten intolerant, it's just because I'm trans. And ‘the lump in your breast doesn't need examining since according to the records you were born a man so you can't get breast cancer’.”

We asked about how open people are about their gender identity in different settings. This data has not been statistically analysed so differences between gender identity groups might not be statistically significant, however the data gives some insight into the differences in openness about one's gender identity in different parts of life. In healthcare settings 40.0 % state that they are fully open with their gender identity and 18.6 % say that they are never open to their healthcare provider. Non-binary people and trans men seem to be less open than trans women in this setting. This question is a bit ambiguous and it's hard to know if the respondents answer if they are open with their trans identity/background or if they are open with their current gender identity. It's not important to come out in all healthcare settings, in many cases this is irrelevant for the care.

Figure 12. **Openness in healthcare settings (%)**

	FULLY OPEN	PARTIALLY OPEN	NOT OPEN AT ALL	DOESN'T APPLY TO ME
TRANS WOMEN	68.2 %	27.3 %	4.5 %	0 %
TRANS MEN	41.1 %	47.0 %	11.9 %	0 %
NON-BINARY	19.8 %	41.3 %	34.3 %	4.7 %
OTHER	50.0 %	18.2 %	18.2 %	13.6 %
TOTAL	40.0 %	39.0 %	18.6 %	2.3 %

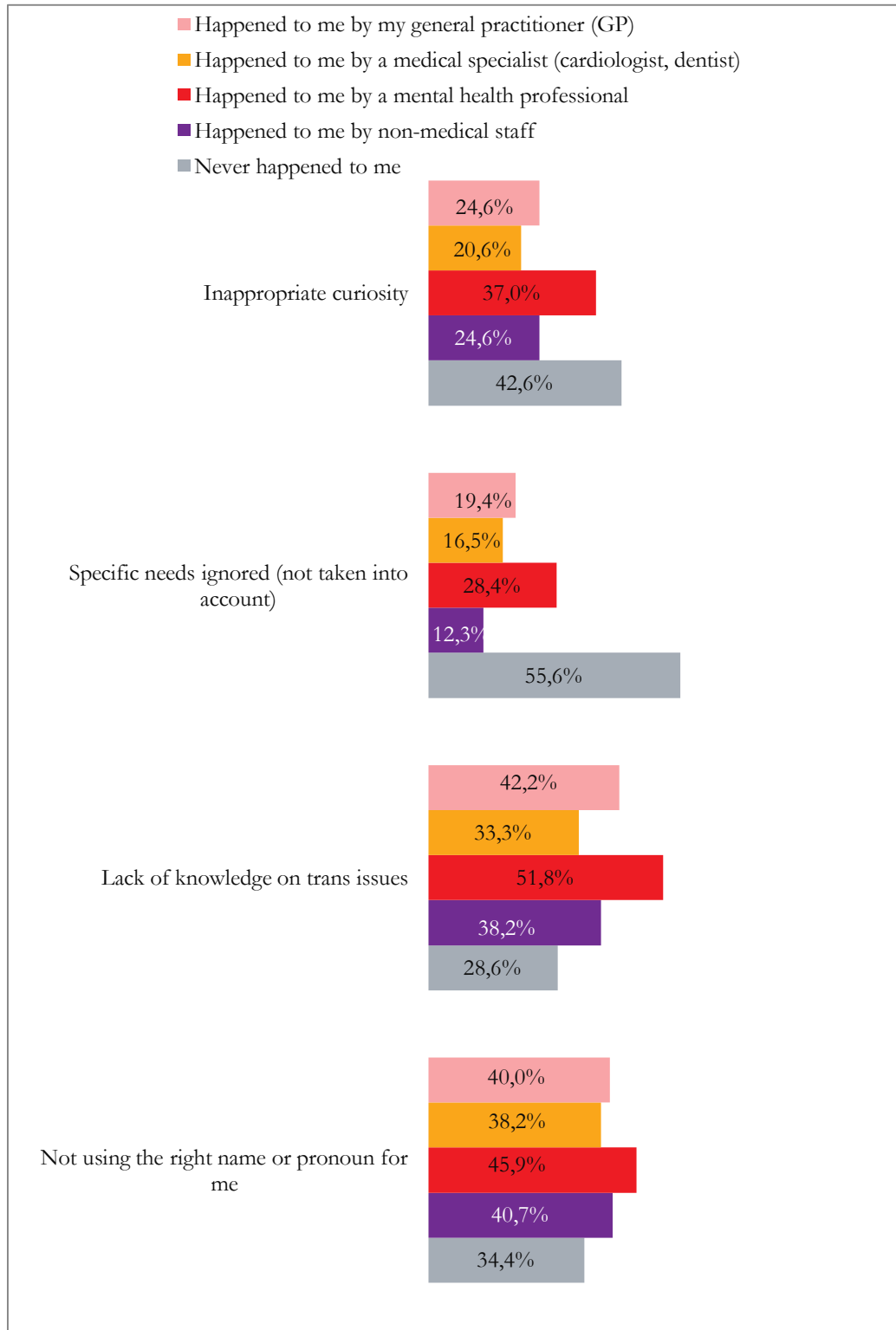
Question: At the present time, how open are you about your gender identity around the following people? In each case, please select the option that is most applicable to your life nowadays.

91.2 % of our respondents think it would improve access to general healthcare if all staff members underwent mandatory and regular education on trans issues. 82.6 % also think it would be good to have LGBTI- or trans-specific healthcare clinics. 89.6 % think a list of trans friendly doctors or clinics would also improve access to healthcare for trans people.

Only 27 % of the Swedish respondents know any trans-friendly healthcare providers. Compared to the other countries this is a very low number. In Spain 70 % of the respondents say they know of trans-friendly healthcare providers, and in Poland 48 % say this and in Serbia 40 %.

The participants were asked about their experiences when accessing healthcare settings, with different providers such as their general practitioner (GP), a medical specialist (cardiologist, dentist), a mental health professional, or non-medical staff. Of the Swedish respondents 57.4 % had experienced inappropriate curiosity from healthcare staff, 44.4 % had experience of their specific needs being ignored, 71.4 % had experienced staff having a lack of knowledge in trans issues and 65.6 % had experiences of healthcare staff not using the right name/pronoun. People seem to have experienced this somewhat more with mental health professionals than other healthcare staff.

Figure 13. *Experiences when using or trying to access general healthcare (% of cases)*³

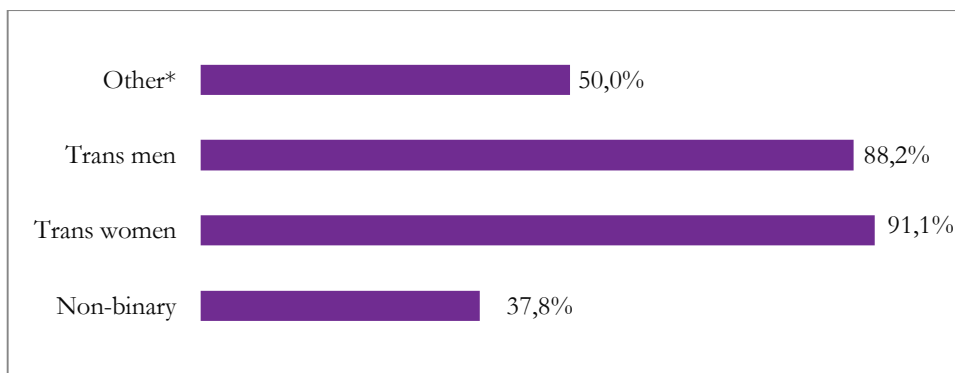


³ Question: Have you ever experienced any of the following situations when using or trying to access general healthcare services as a trans person? Please check all answers that apply to you.

Experiences of gender affirming healthcare

Of all Swedish respondents 69.1 % have ever sought psychological or medical help related to being trans, with the group of trans men and trans women reporting the highest levels of seeking trans specific help.

Figure 14. ***Ever sought psychological or medical related to being trans, by identity group (% yes)***



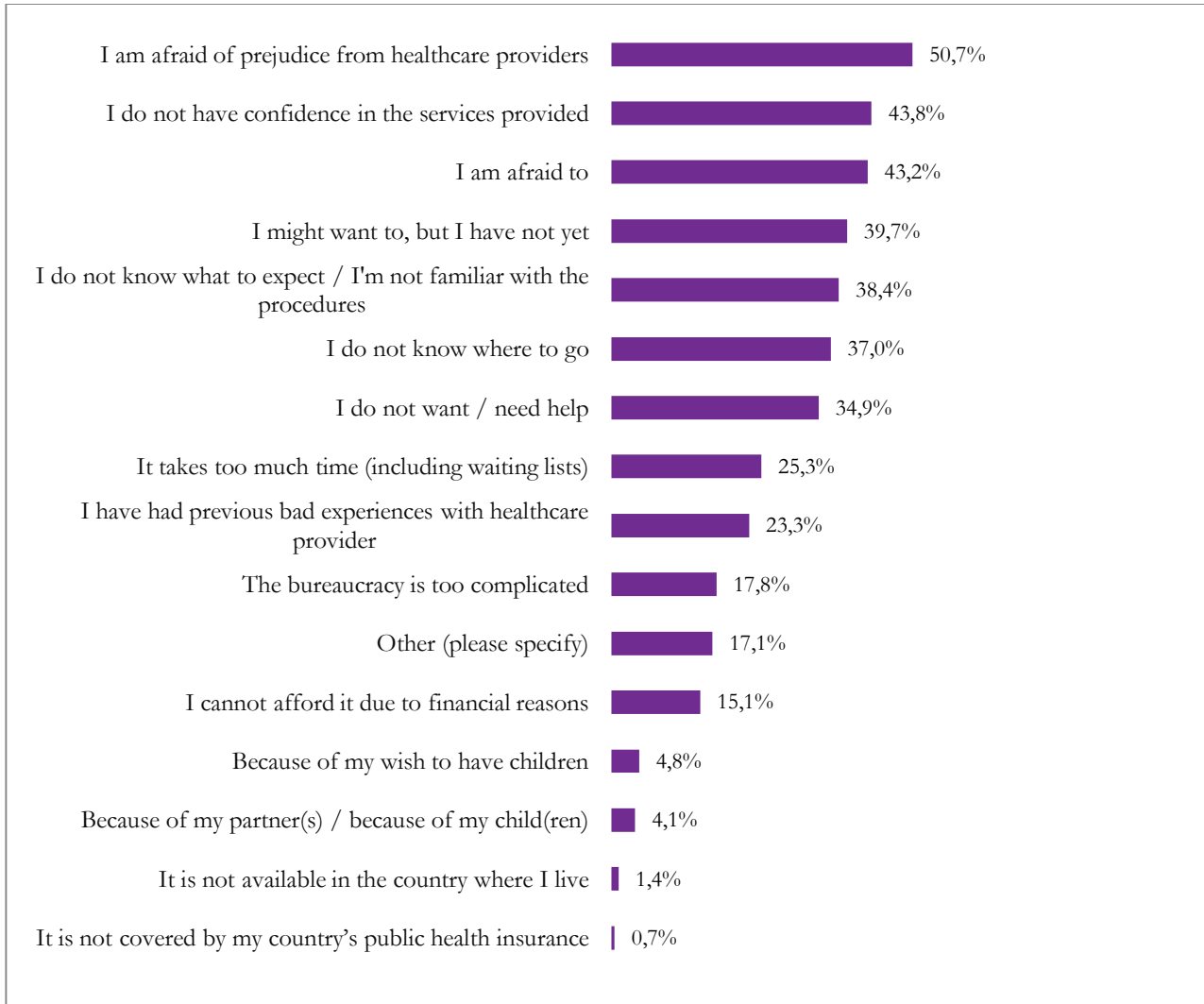
Question: Have you ever sought psychological or medical help for being trans?

Respondents who had sought psychological or medical help also reported higher levels of family support (70.4 %) in comparison with those who did not seek psychological or medical help (52.4 %). However, they also delayed more frequently (67 %) going to the doctor in general healthcare because of their gender identity when compared to those who did not seek trans specific help (51.1 %).

39.7 % state that they would want to seek help but haven't done so yet. Looking at respondents from all countries, non-binary people state more often than others that they might want to seek help in the future (Transgender Europe, 2017), we did however not do these calculations for the Swedish results. The international data also showed that people who are younger, belonging to an ethnic or sexual minority group or had no difficulty to make ends meet seek help to a lesser extent than others (Transgender Europe, 2017).

The reasons for not seeking help are varied, with the most common reasons being afraid of prejudice from healthcare providers (50.7 %), not having confidence in the services provided (43.8 %) and being too afraid to seek help (43.2 %).

Figure 15. **Reasons for not seeking help (% of cases)**



Question: Can you tell us why not (for you personally)? Please select all answers that apply to you.

We asked an open question about experiences in gender affirming healthcare, and got all in all 190 answers from our respondents.

Many of the people responding were in the process of waiting for a first visit to a gender clinic after referral, or in the process of trying to get a referral to a gender clinic.

“The psychiatrist and doctor in my home county were very helpful and interested, but stalled the referral for months. It felt like the psychiatrist wanted to do their own little investigation before they sent a referral to the assessment team.”

“Primary care refused to refer me. I had to fight very hard in order for them to make a referral.”

“The waiting times have been very bad, it took over a year after the referral was sent out until my first meeting, but the team has been nice.”

There is a lot of frustration about waiting times and the extent of time the assessment takes among the respondents.

“The waiting times were horrible. It took 2 years to get a diagnosis and about 80 % of that time was just waiting. Have now waited 7 months to start hormone treatment and surgery but haven't gotten any appointments yet.”

“Had very little contact with the team and the sessions were far apart. Between the first and second meeting with the psychiatrist more than a year passed and then the psychiatrist had forgotten that we'd met and I had to tell them everything all over again. Felt that I had to call repeatedly to get an appointment, they said I would be called, but I never was.”

Some respondents are satisfied with the treatment and care they got from their team.

“Partly I felt strengthened by the contact with my team, but I felt that it was really difficult to be dependent on them. It's hard to build a relationship of trust when they try and support and control/judge you at the same time.”

“They have all been helpful and supportive. I've gotten a good reception and had support and encouragement to explore what help I need. For me and my loved ones the counselling they got was very good and useful for our communication.”

“I got the diagnosis and access to testosterone two months after the first meeting (for non-binary within the structure CASM/ENID⁴).”

“I have started a gender assessment, and so far, I have only met a doctor and a psychologist. The treatment I've gotten so far is good. I have felt that I can be open with that I'm not completely sure of if I identify as trans masculine or non-binary and I have, especially in

⁴ The old name for the gender clinic for adults in Stockholm, the new name is ANOVA.

the meetings with the psychologist, had the opportunity to talk about my feelings about this in a worthwhile way.”

Other respondents are very critical of their providers and have found the process humiliating, stereotypical or in other ways bad.

“I met the team the first time in 2004 already, was badly treated, rejected and insulted. Now it's 2016 and I'm waiting for a new appointment after many years of mental ill-health. The waiting time is 14 months, which is way too long. I feel very bad and get little or no support.”

“I would also appreciate if the care was only about your gender identity and that you didn't get questions about how you for example have sex or masturbate. It's highly inappropriate and something that has nothing to do with your gender identity. It's what I call offensive treatment.”

“I have done an assessment but didn't want to have to do it and felt badly treated. I thought they were arrogant, messy, gender stereotypical and sometimes violating. Among other things they questioned that I was in a relationship with a man and wondered if he really wanted to be gay. And my assessment was prolonged so that it lasted for one and a half years, which was very frustrating. Felt no support during that time and felt I had to lie, for example about what type of sex I liked because I knew they wouldn't ‘approve of’ what I really felt and thought.”

“I am right now under assessment and unfortunately don't have much good to say about them. The endocrinologist left me in tears and the rest of the team isn't very accommodating either, very binary and you feel pressured to ‘answer correctly’ even though they emphasize that there is no right or wrong.”

“They (the gender clinic) have also asked me transphobic questions and made statements about me not being a real woman.”

“Long waiting times without any help, many appointments that feel unnecessary, lack of information, you feel powerless when all that happens is that other people fill out forms about you and then you get to wait to see if you even get the help you ask for.”

We asked about what our respondents' opinions are about trans-specific healthcare. 38.3 % say they would rate the trans care in general in Sweden as bad. 46.3 % think that it's fair and 18.1 % think that it is good. Trans women

seem somewhat happier with the gender affirming care than the other groups, with 27.6 % stating that it is good.

96.6 % thought it is common that people feel they have to prove that they are “trans enough” to receive treatment, and 95 % say it is widespread in trans-specific healthcare that people feel forced into presenting as gender binary during the assessment period.

Figure 16. *Occurrences in trans-specific healthcare (%)*

OCCURENCES IN TRANS-SPECIFIC HEALTHCARE	RARE	WIDE-SPREAD
People feel they must prove they are ”trans enough” to receive treatment	3.4 %	96.6 %
People feel forced into the gender binary (the concept that there are two genders, male and female)	5.0 %	95.0 %
People feel that healthcare professionals do not respect their gender identity or expression (for example being misgendered intentionally)	20.6 %	79.4 %
People experiencing transphobia or hatred in healthcare settings	31.3 %	68.7 %
People are afraid or anxious to access healthcare	6.8 %	93.2 %

Question: In your opinion, how widespread are the following in trans-specific healthcare in the country in which you live.

90.8 % of our respondents think that it is necessary to increase the numbers of healthcare providers in gender affirming healthcare, and 94.6 % think it is necessary to decrease waiting times for trans specific healthcare.

Strengths and limitations

There are a few limitations that are important to consider when interpreting the results. This is a self-selected sample, reached by social media and contacts, mostly, due to a lack of funding for dissemination of the survey. Hence the population reached are more likely to have contacts with the LGBTQ-community, and we have to a lesser extent reached trans people who are not in contact with a larger community. We also reached a fairly young group of trans people. This might be explained by the mode of dissemination, but also by that more and more young people identify as trans, possibly due to the increased knowledge about trans issues in society and the increased ability for young people to find words and identities that match their feelings. There are of course limitations to comparing data between countries since the differences between countries are substantial when it comes to the situation for trans people. People in different countries may have different expectations of health or healthcare, leading to different interpretations of the questions. However, the same

methodology has been used elsewhere (European Union Agency for Fundamental Rights, 2014), comparing countries and weighing the results according to population sizes. We have also to a high extent used the same questions as in the European Quality of Life Survey (Sándor, E; Ahrendt, D; Kuenzi, 2012), to be able to compare with the general population. A major strength of the study was that the questionnaire was constructed and disseminated by activists within trans- and/or LGBTI-organizations from all countries in the survey with knowledge about local situations, resulting in a relevant and culturally aware survey for people regardless of country.

Conclusions

Non-binary people's health

In this study, we reached reasonably many non-binary respondents, 172 persons in total. Hence it is possible to look at this group separately, which hasn't been done in a Swedish context before. It is clear from our results that non-binary people have worse self-reported health, more self-reported disabilities and are less happy with how society perceives them than do the men and women in the study.

A majority seem to have supportive families. However, as many as 18.0 % of the non-binary respondents state that they don't know yet if their close family will be supportive or not when they come out to them. Since lacking family support seems to affect health negatively this is an important factor.

Misgendering is a big problem for non-binary people, where 84.9 % state that this happen all the time or most of the time. And even the 2.3 % who say that they are never read as someone of the gender they were assigned at birth might still be misgendered, but in the other direction. It is also clear from comments by our respondents that a great deal of the negative healthcare experiences are attributable to misgendering or healthcare staff not understanding, or wanting to understand, non-binary identities.

Only 3.5 % of the non-binary respondents think they can always live according to their gender identity, which is not strange in a society still very caught up in the binary. 42 % say that they can always or almost always live according to their gender identity, which is significantly lower than the number of trans women (71 %) and trans men (76 %) who can do so.

Since presumably most of the general population don't even know that non-binary people exist it is not strange that people get misgendered almost always. Non-binary people are often completely invisible, since there are no clear ways to signal that your gender identity is neither male nor female with your clothes, hair or other ways of expressing gender. Lack of knowledge, visibility and

affirmation is a huge problem in society for all trans people, and non-binary people in particular.

The current Swedish law makes it impossible for non-binary people to have their legal gender recognised, since there are only two legal genders, male and female. According to the sustainable development goals, that Sweden has ratified, one target is to provide legal identity for all (United Nations, 2015). This target will not be met without a change of the law on legal gender in Sweden.

It is impossible to know for sure that the frequent misgendering and inability to live according to one's gender identity leads directly to bad health. The theory and research about minority stress (Meyer, 2003) does however imply that the environment is the main cause of ill-health among sexual- and gender minorities and our research indicates that these factors do play an important role also in trans people's health. Previous research has also shown that non-binary people in Sweden have worse self-reported health than other trans people (Zeluf et al., 2016), hence the body of evidence of this is growing. The international report also shows that among respondents from all countries, non-binary people have lower scores than other trans people on mental health and well-being (Transgender Europe, 2017). It is apparent that actions are needed to improve non-binary people's health both physically and psychologically.

There are no significant differences between people of different gender identities when it comes to suicide ideation and attempts. Non-binary people think about ending their lives and attempt suicide as often as do other trans people. It is clear that this group needs specific attention and to be highlighted in suicide prevention interventions for trans people.

Suicide ideation and attempts

9.7 % of all respondents in this study had attempted suicide within the last year, so for many people this problem is very acute. In the general population of Sweden this number is 0.1-0.3 % (Folkhälsomyndigheten, 2016). This report therefore provides the second body of evidence indicating that the same issue is impacting Sweden; that a significant proportion of trans people have had serious thoughts of ending their own lives during the past year (37 % in a previous study (Zeluf et al., 2017), 54.0 % of all respondents in this study). In addition, both studies show that young trans people are struggling more than older trans people. The fact that almost 60 % of people who have had suicidal thoughts did not seek any help is discouraging, and shows the general lack of access to mental healthcare for trans people who need it. Research done in Sweden on mortality among people who have had legal gender recognition between 1973-2003 shows that suicide was a major cause of death in these individuals, indicating that suicidal thoughts and attempts might, for some, remain even after gender affirming healthcare and legal gender recognition (Dhejne et al., 2011). Hence, psychological support might be important in the long term, even for people who are not in contact with gender affirming healthcare anymore.

It is somewhat surprising that the level of suicide ideation and attempts among trans people does not correlate with gender identity, family support, possibility to live according to one's gender identity or levels of misgendering in society. All trans people hence seem to have the same, very high, risk for suicide ideation and attempts.

In this study we did not ask about alcohol or drug use. In another study, this factor has previously been shown to correlate with suicide ideation and attempts among trans people in Sweden. That study also showed that being subject to offensive treatment during the past three months and lifetime exposure to trans-related violence were highly associated with suicidality, and that older age was significantly associated with decreased risk of suicide ideation (Zeluf et al., 2017).

Zeluf et al. also showed that a third of the trans people had attempted suicide (Zeluf et al., 2017) at some point in their life and that number in this study is 25 %, giving us a more solid indication that this problem is enormous, and that trans youth are especially affected.

Health and access to general healthcare

39 % of our respondents stated that their general health is bad. In the Swedish general population this number is 5 % (Folkhälsomyndigheten, 2016). Non-binary people have poorer health than respondents with other gender identities. People experiencing misgendering and people not being able to live according to their gender identity have worse self-reported health than other trans people, indicating that societal treatment is impacting health.

People with a lack of support from their families also report worse health than others. Previous research among young LGBT-people in Sweden has shown that youth who experience family support have better self-esteem than youth without family support, and that trans youth had less support from their families than did cisgender LGB-youth (Ahlin & Gäredal, 2009). 50 % of the respondents in this study who cannot live according to their gender identity report that it's because of reactions from their parents. Considering that the respondents of this study are fairly young (mean age 27) it is not strange that parental reactions are very important for the respondents. In their comments, many of the respondents state that negative reactions from their families prevent them from being open, to access gender recognition and to access healthcare. Family support and being able to live according to one's gender identity seem to be important factors for health among the people in this study. This survey did not reach children younger than 15 years of age, however, we know that the number of children seeking care at the youth gender clinics is increasing, hence it is clear that trans children and youth need increased support and attention.

Since as many as 65 % of the respondents report having chronic physical or mental health problems, illnesses and disabilities it also clear that trans people is a group that needs access to general healthcare, probably to a far higher degree than people in general. Considering this, the number of trans people

experiencing discrimination in healthcare settings or delaying healthcare due to fear of discrimination is very problematic. Many of our respondents delay seeking healthcare if they need it, with 62 % stating that they have done so in the past 12 months because of their gender identity. People with bad health hesitate more and so do trans men compared to other gender identity groups. From the comments on this question it's clear that fear of misgendering and bad treatment, and having to explain one's gender identity to the staff, are major causes for this. Some also state that they hesitate going to "gendered" health check-ups such as gynaecological examinations or pap smears more often than with other forms of healthcare. Delaying healthcare is connected to previous actual experience of bad treatment, which many of our respondents have had in the past year (23.2 %). Hence the reason for delaying healthcare is not only fear of bad treatment, but actually previously having experienced bad treatment within healthcare settings. It is clear that practitioners in general healthcare need more knowledge about trans to be able to treat trans people properly, both when it comes to interpersonal relations and actual medical treatment.

It is noticeable that the Swedish participants have poorer health than participants from Serbia, Spain and Poland. It is also interesting that fewer people in Sweden know of trans friendly healthcare, compared to the other countries (Transgender Europe, 2017). In Sweden it tends to be a common notion that we are far ahead of other, more conservative, countries when it comes to LGBTQ people's rights and health. However, this survey clearly shows that there is a lot to do in all the countries and that Sweden is not the best country when it comes to trans health. Other research has shown that the increased rights of LGB-people in Sweden the past 10 years have had a positive impact on preventable diseases (Bränström, Hatzenbuehler, Pachankis, & Link, 2016) and mental health (Hatzenbuehler, Bränström, & Pachankis, 2016), so one would assume that in a country with anti-discrimination legislation and access to trans healthcare, trans people would have better health than in countries without these important rights. However, it could also be that Swedish people have higher expectations for their own health and about treatment within healthcare than do other European trans people, but we have not assessed this within the frame of this study. Sweden also reached a higher number of non-binary trans people with this study than the other countries did, and since non-binary people have worse health it could be one explanation for the poor health results for Sweden.

Gender affirming healthcare

Many of our respondents have been in contact with the trans related healthcare services of the gender clinics or want to in the future. Many report problems with getting a referral to a gender assessment team and very long waiting times for a first visit to a team after getting the referral, indicating that the gender assessment teams need more funding and more staff to be able to help everyone who needs it.

The Swedish protocols for gender affirming care (Socialstyrelsen, 2015a, 2015b) state that the assessment time should be personalized to reflect how much time every individual needs. It is clear that the time the assessment presently takes impacts trans people's health negatively and many of the comments indicate that the processes of the gender clinics need revision to better meet the needs of their clients. The gender clinics need to ensure the professionalism and trans competence of all their staff members to ensure good interpersonal treatment and care. The requirement from the LAB on long assessment times also impacts the time one has to wait for gender recognition and gender affirming surgeries.

The satisfaction with the Swedish trans care is generally low, with approximately 40 % of our respondents rating the care as bad. The respondents report problems in gender affirming healthcare feeling that they have to prove that they are trans enough, or that they are being forced into one of the two binary genders. This happens despite the fact that the Swedish protocol for trans care states clearly that non-binary people should have access to gender confirming healthcare (Socialstyrelsen, 2015a, 2015b). Hopefully this will subside with time, since the protocols are still fairly new and many of our respondents might have come into contact with gender affirming healthcare before these came into place.

Improvement of gender affirming healthcare is needed on many levels. A recent doctoral thesis on the subject concludes that “[...] one way to reduce the risk that the healthcare *per se* induces stress is by working together with the transgender population and their organizations to improve care” (Dhejne, 2017).

Political demands

To improve the lives of trans people in Sweden some key steps need to be taken by decision makers at all levels of society. There is a lot to do, listed here are only a few of the actions needed to improve trans people's health and well-being.

Legal gender recognition

The Swedish Government must take action to make the process around legal gender recognition easier, separating it from the medical procedures and letting young people, less than 18 years old, have their gender recognised. These are key legal changes needed to improve the living conditions for trans people in Sweden. RFSL also recommends that the Swedish Government make the Swedish personal identity numbers gender neutral to simplify legal gender recognition. For non-binary people, legal gender recognition is presently impossible, since Sweden does not recognise more than the two binary genders. According to the sustainable development goals, that Sweden has ratified, one target is to provide legal identity for all (United Nations, 2015). This target will not be met without a change of the law on legal gender in Sweden. The Government should consider introducing a third legal gender or completely abolishing legal gender to make legal gender recognition available for everyone.

Training of general healthcare staff

Experiences of discriminatory treatment in healthcare settings prevents trans people from seeking care and having their right to healthcare met. All employers within the healthcare sector should make sure all staff in general healthcare get compulsory training on trans awareness and trans healthcare as a continuous professional development training. The universities need to ensure that all healthcare students get this training already at university level.

Improvement of, and access to, gender identity clinics

Many of the gender identity clinics need to improve their interpersonal treatment towards their clients and adapt more to the Swedish protocols for trans healthcare. The county councils (local governments for healthcare) need to make sure the gender clinics get increased funding in order to see more clients, and to reduce waiting times. The quality of the care must be high and equal, regardless of in what region you live. All existing clinics must be open to all people with gender dysphoria, including non-binary people. Every clinic should have a team for children connected to it.

Access to mental health services

Trans people who have mental health problems or suicidal thoughts need help. They need to know that there is trans-inclusive healthcare available, so that they don't have to explain or defend their gender identity when seeking help for life threatening mental health conditions. It is their right to get this help from

mental health services. The county councils need to make sure this improves, because a lot of improvement is needed. Suicide prevention interventions, that reach trans people of all genders, are also desperately needed. The Public Health Agency and the Swedish Government are responsible for improving the suicide preventative measures taken in Sweden.

Improved support systems

A support system for families with trans kids is desperately needed, social services locally need to gain knowledge about the lives of trans youth to be able to support families through difficult times and adjustments.

Trans youth who have non-supportive families or violent families need to know that they can get trans competent help from the social services, the police or any other authority they might turn to for help. Trans people who are victims of violence within the family need to know that they can get help if they turn to shelters for victims of domestic violence.

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Trans people's health and experiences of healthcare in Sweden

This report is based on a survey involving 472 Swedish trans people, conducted by RFSL in cooperation with Transgender Europe and four other European trans- and LGBTI organizations.

The report gives new insight into the health situation and well-being of trans people with different identities and experiences. It is the first comprehensive body of data on the well-being of non-binary people in Sweden. This group is very vulnerable when it comes to health and well-being, and special focus on health promoting interventions is needed.

Many measures need to be taken in order to improve trans people's health in Sweden. These measures include improving the quality and access to gender affirming healthcare, changing the law on legal gender recognition, improving access to and quality of mental health services for trans people, improving the support systems for trans people and families who need it and improving the knowledge on gender identity and gender expression in general healthcare.

