

# Intersex in Russia

Research was done by Irene from July to September 2016, other members of Association Russian-Speaking Intersex helped her with it.

## Goal

To get information about life of Russian-speaking intersex people from Russia and other countries.

## Agenda

To find about lives of intersex people, their experiences with the medical community, experiences of discrimination, thoughts on being intersex and intersex activism.

Creation of an online survey, analysis of the received data and work on the final report.

## Object

Russian-speaking intersex people living in Russia and other countries, their life experiences of medical treatment, discrimination, their thoughts on intersex activism.

## Method

Anonymous online survey and data analysis.

## Hypothesis

We assume that problems that intersex people face are generally the same all around the world. But in Russia and Post-Soviet we have very strong gender norms, heteronormativity and homophobia.

We presume that there is almost no information available in Russian language about intersex, and there is no adequate intersex representation in our media.

We presume that very few intersex people in Russia are public about being intersex.

## Relevance of our research

Our research is the first of it's kind, nobody before made research of Russian-speaking intersex community. Russian academic community has no interest in the topic of intersex, and our Ministry of Health is not keeping any official statistics related to intersex.

The survey was not shared publicly on the internet, and since it's so hard to find Russians-speaking intersex people, the survey was sent personally to particular intersex people we knew personally, and also it was posted in several local forums and social media pages related to intersex.

2 social media pages about specific intersex variations didn't want to have our survey posted. People from one page just deleted the post with the survey without any explanation, and when they were contacted, they said that

“it's hard to be different here, a freak, but one thing is to be like that, and the other is to attract attention, to say that it should become the norm, to demand rights... because these are the signs of degradation of society... And when we will become the norm, at least in Europe, some people would want to be like us, at least because of originality, this will damage the health of society itself a lot. So no matter how shitty I feel, I would still choose to gravitate towards the norm”.

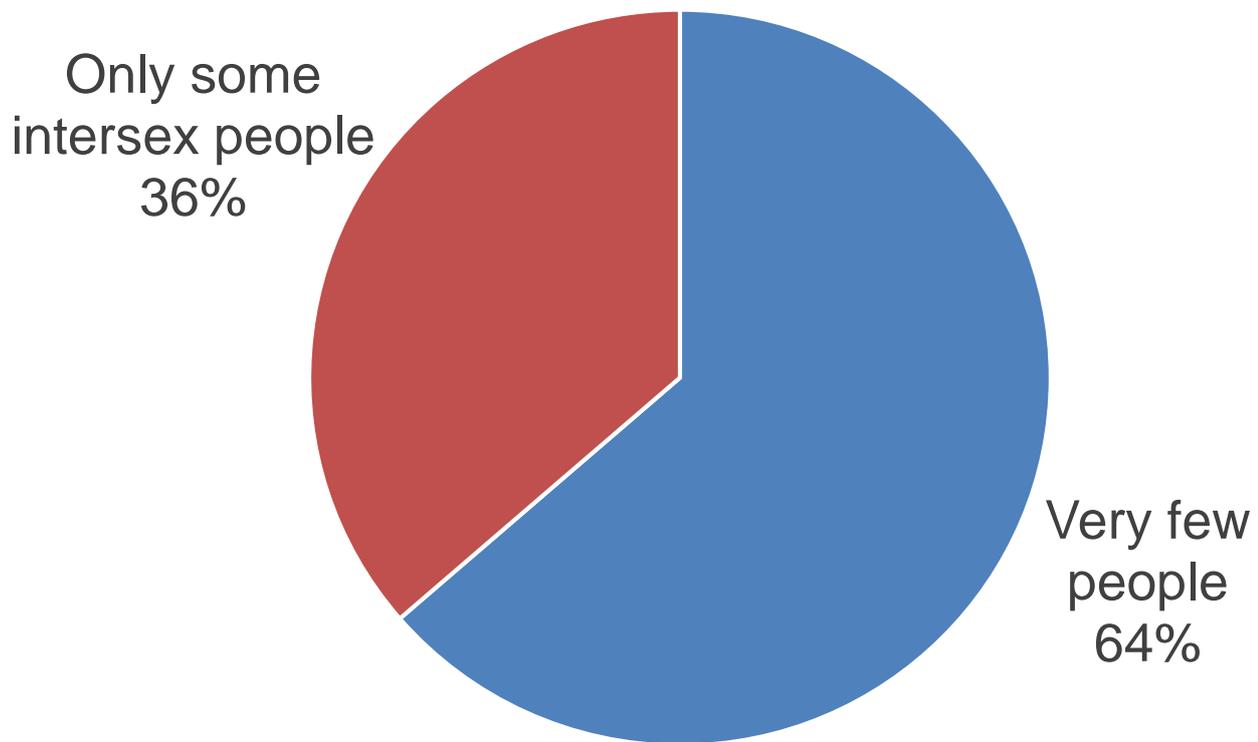
People from the second page said that they won't post our survey in their closed group, saying that

“our diagnosis has nothing to do with intersexuality, all girls with our syndrome have a female karyotype”.

This shows how some intersex people in Russia struggle with internal intersexphobia, that they don't want to think of themselves as intersex, and also how many people in Russia misunderstand the definition of intersex, thinking that an intersex person always has to have traits of both sexes at the same time, and not understanding that intersex is about having any sex characteristics, that are different from the “typical” male or female.

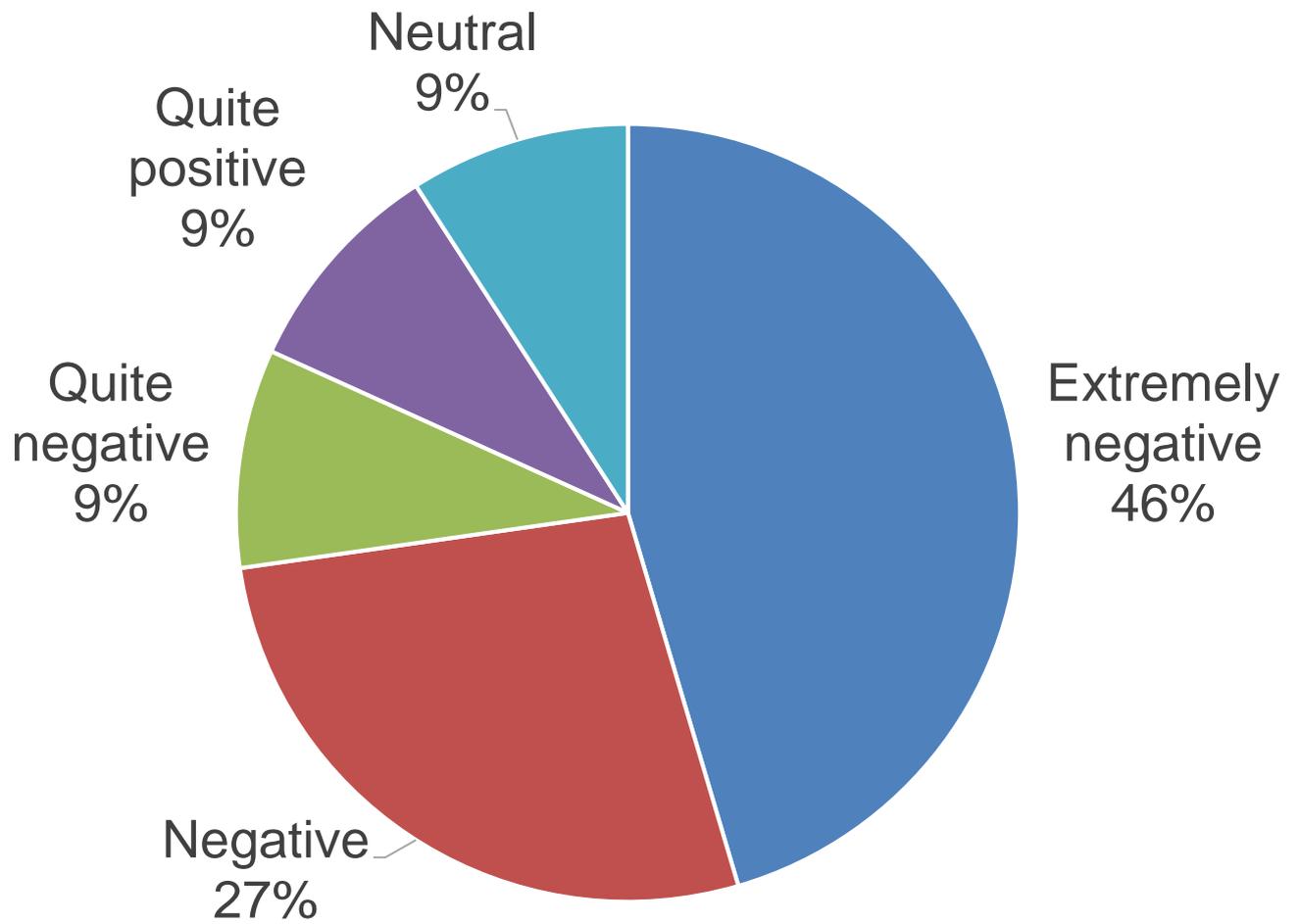
12 people total participated in our survey, 11 of them had intersex variations. Only answers from those 11 people were taken into consideration in the survey results.

## Who knows about Intersex in Russia and Post-Soviet countries?



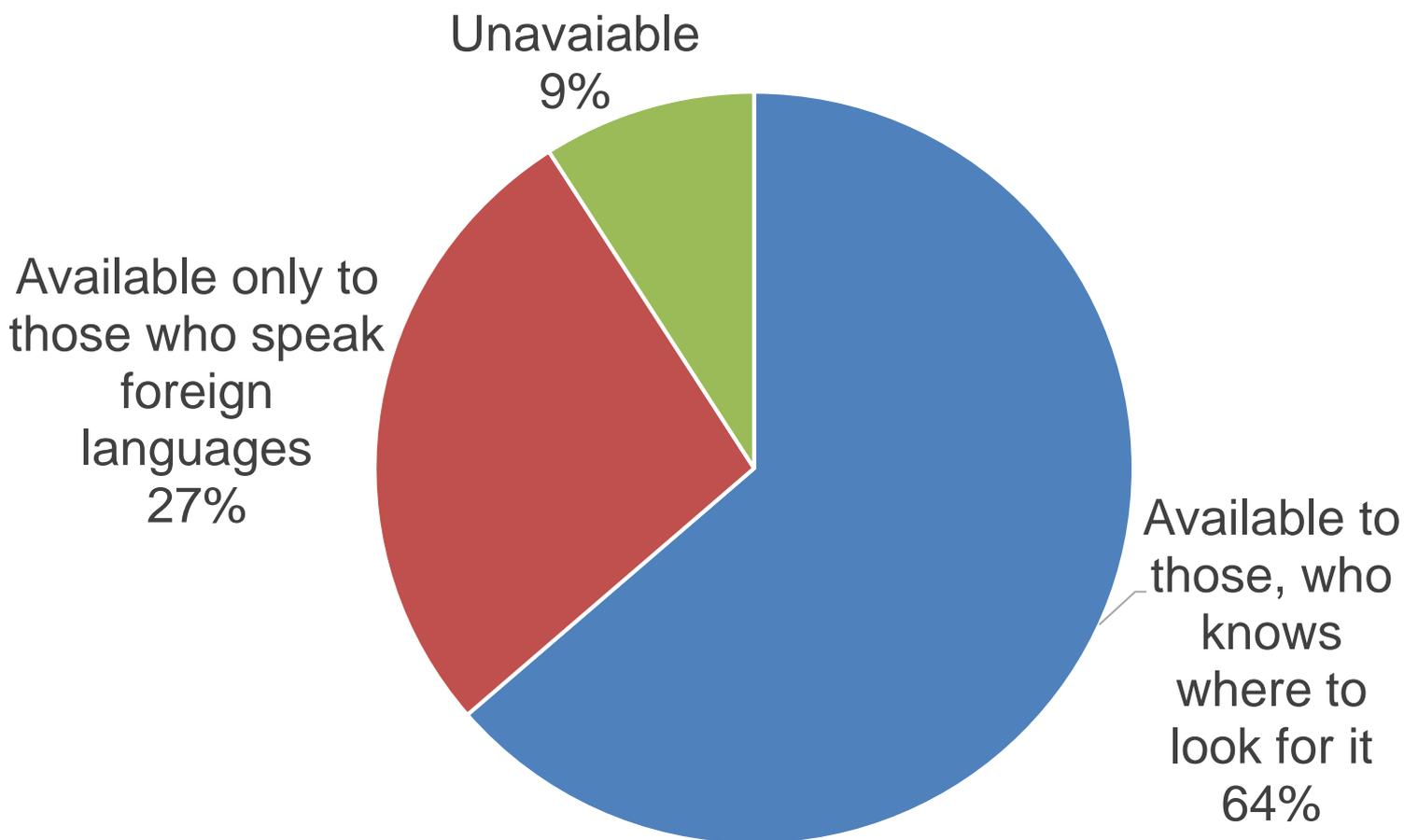
The participants were asked about who knows about intersex in Russia. All participants thought very few people or only some intersex people knew about intersex in Russia and Post-Soviet countries.

## Intersex representation in the media in Russian language



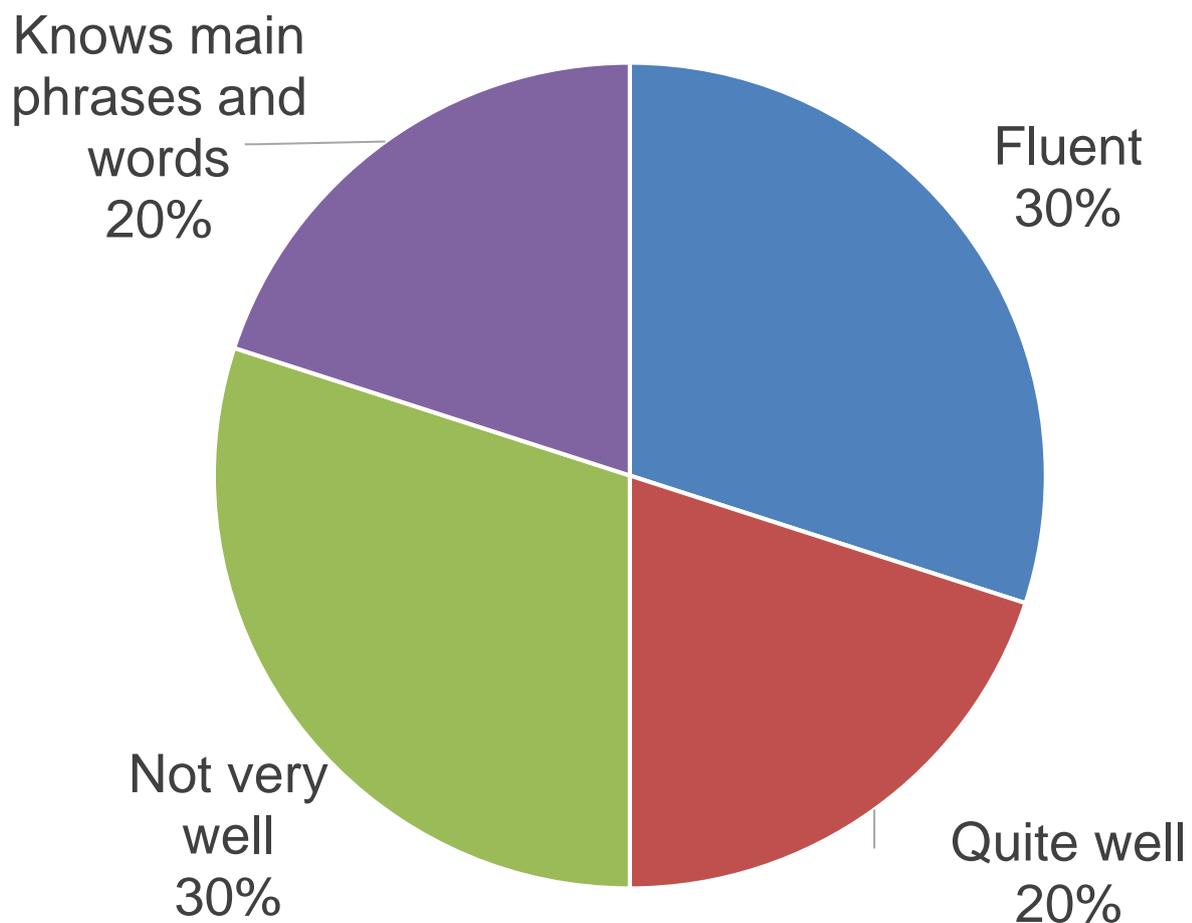
Most participants (82%) see intersex representation in the media in Russian language as negative.

## Availability of information about Intersex in Russian language



When asked about availability of information about intersex in Russian language, all participants answered that it is available only to very few people or is completely unavailable. 30% said that that information is only available to people who speak other languages.

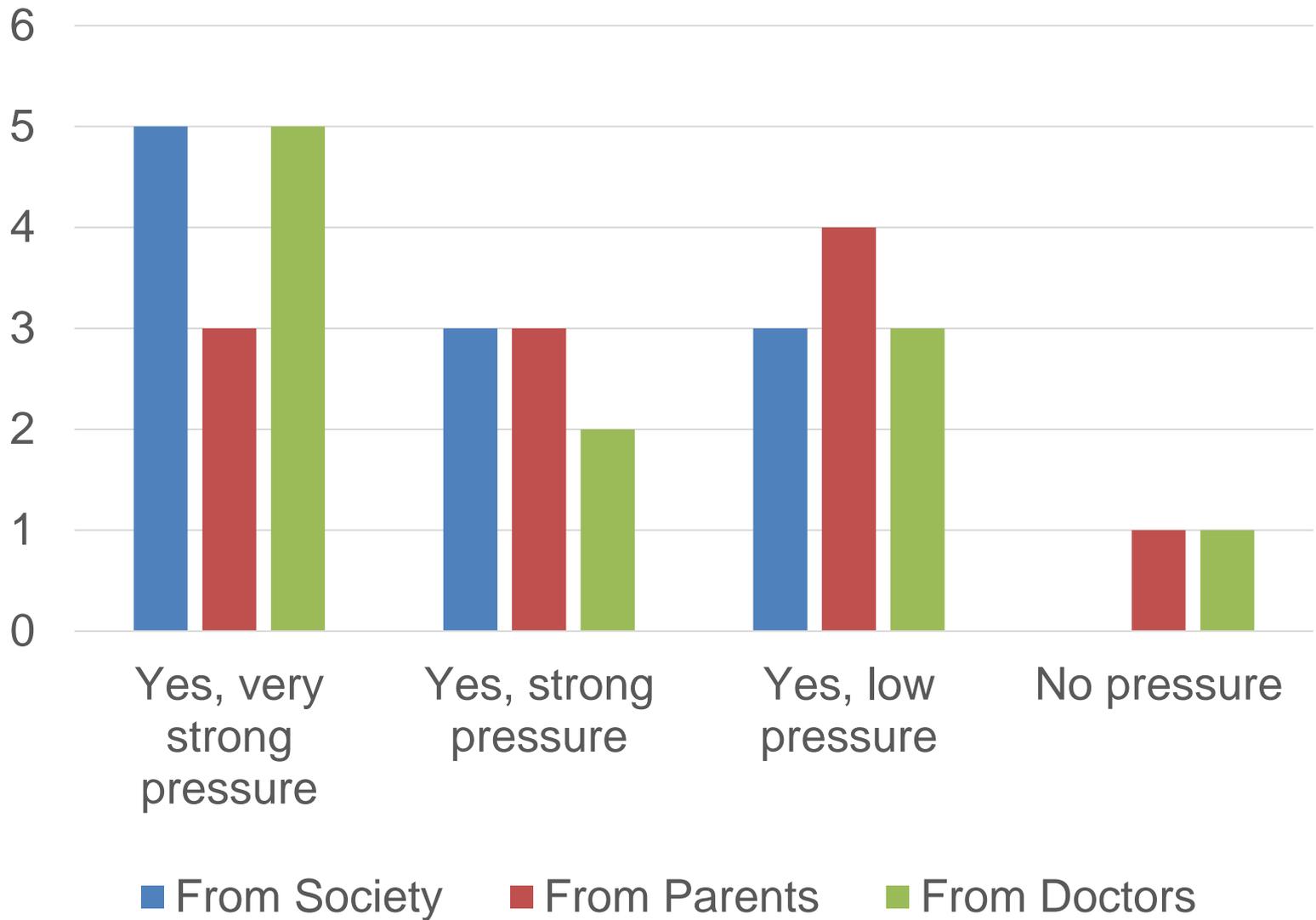
## How well do you speak English?



Continuing with the topic of the previous question, the participants were asked about how well they speak English. Only half of our participants spoke English well or fluent, the rest didn't speak English very well or knew only main phrases and words.

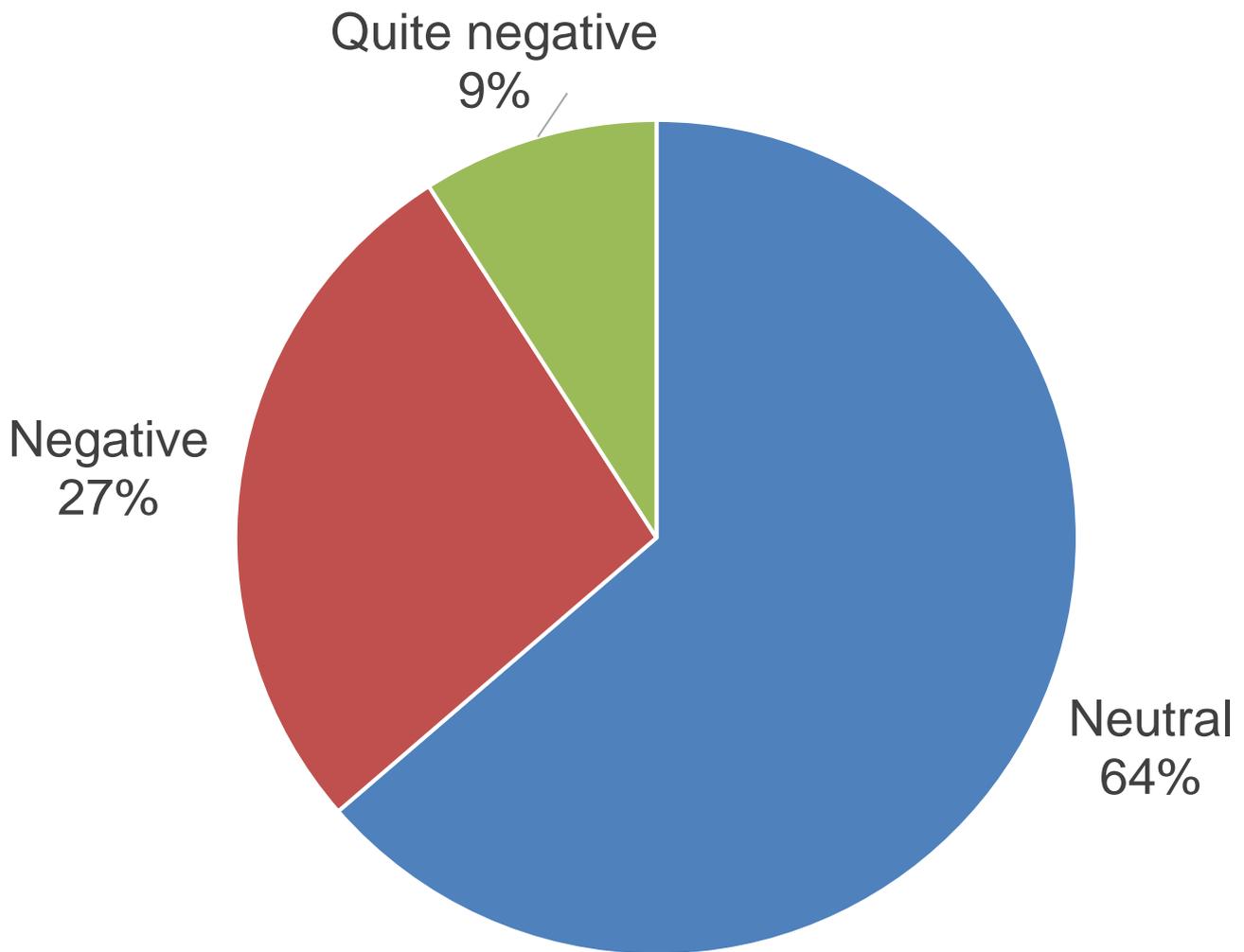
Easily accessible and accurate information about intersex in Russian language is very important, considering how most Russians don't speak English very well.

# Have you ever felt pressure from society/parents/doctors to conform to gender norms of male or female?



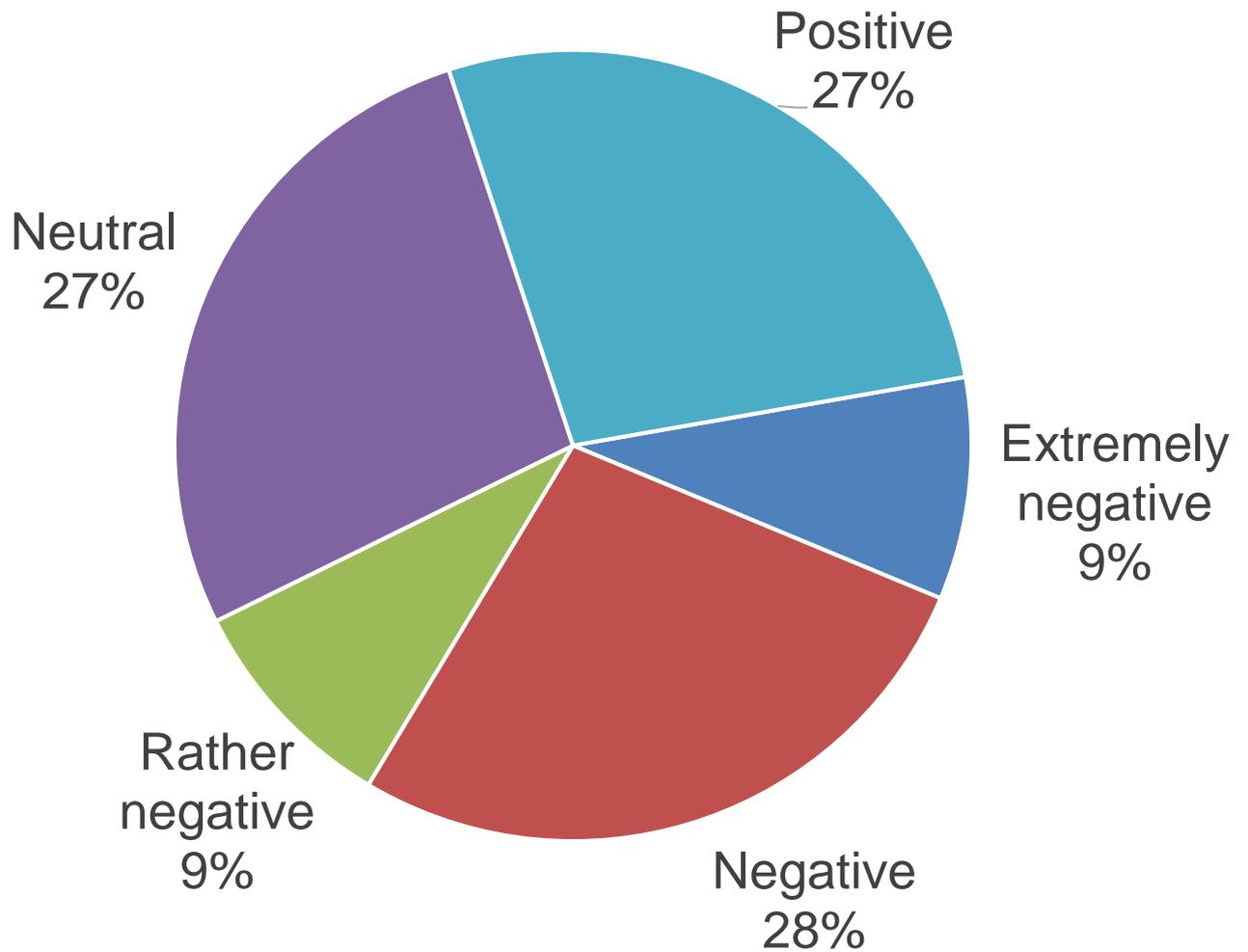
All our participants felt pressure to conform to social norms of male/female at some point of their lives. 100% of participants felt that pressure from society on some level.

## Your opinion on the term Disorder of Sex Development (DSD)?



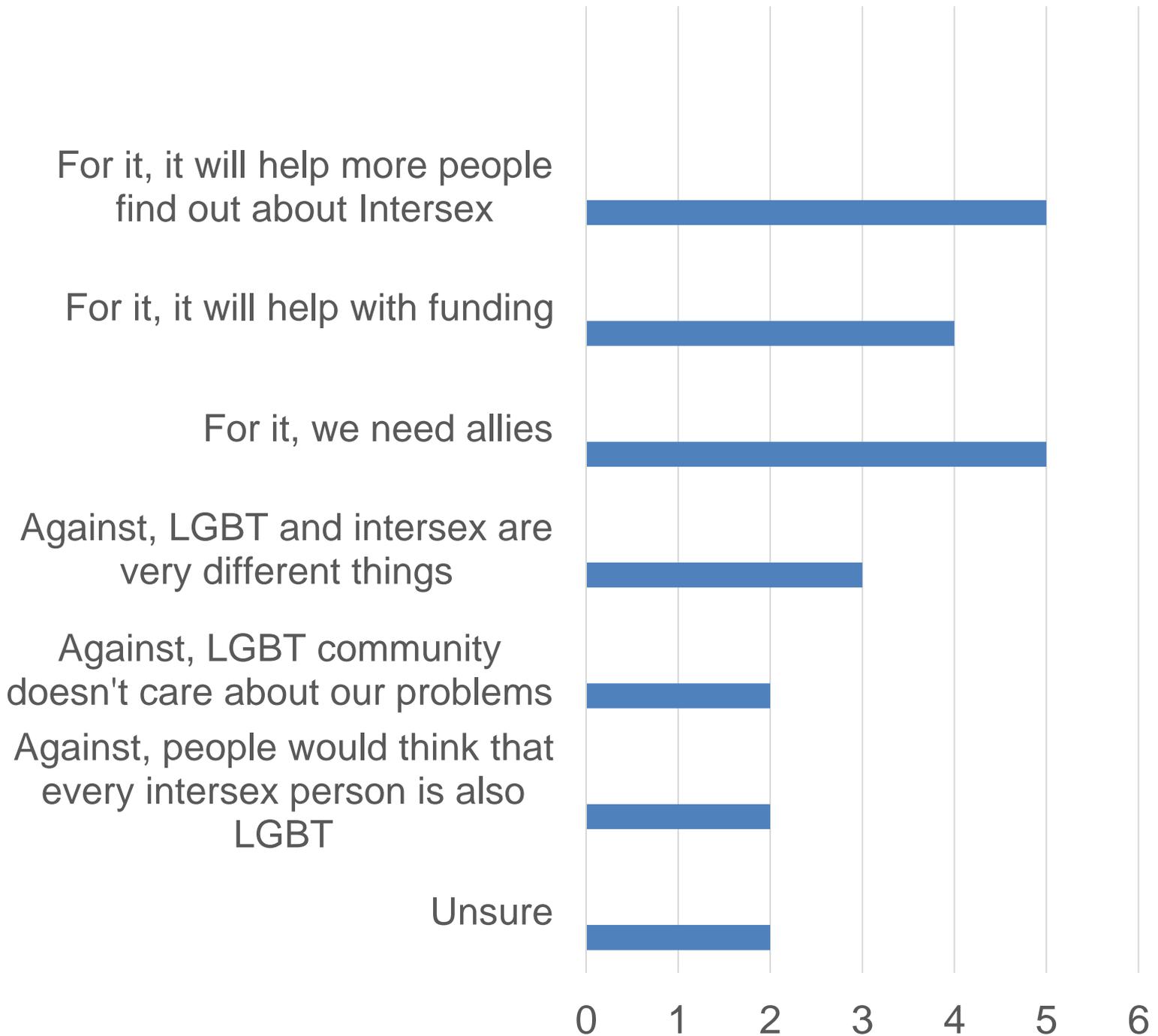
The majority of participants (64%) felt neutral about the term DSD, the rest (36%) felt negative about it.

## Your opinion on the word Hermaphrodite?



Participants had all kinds of opinions about the word hermaphrodite – almost half (46%) of participants felt negative about it, about a third (27%) felt positive about it, the same amount felt negative.

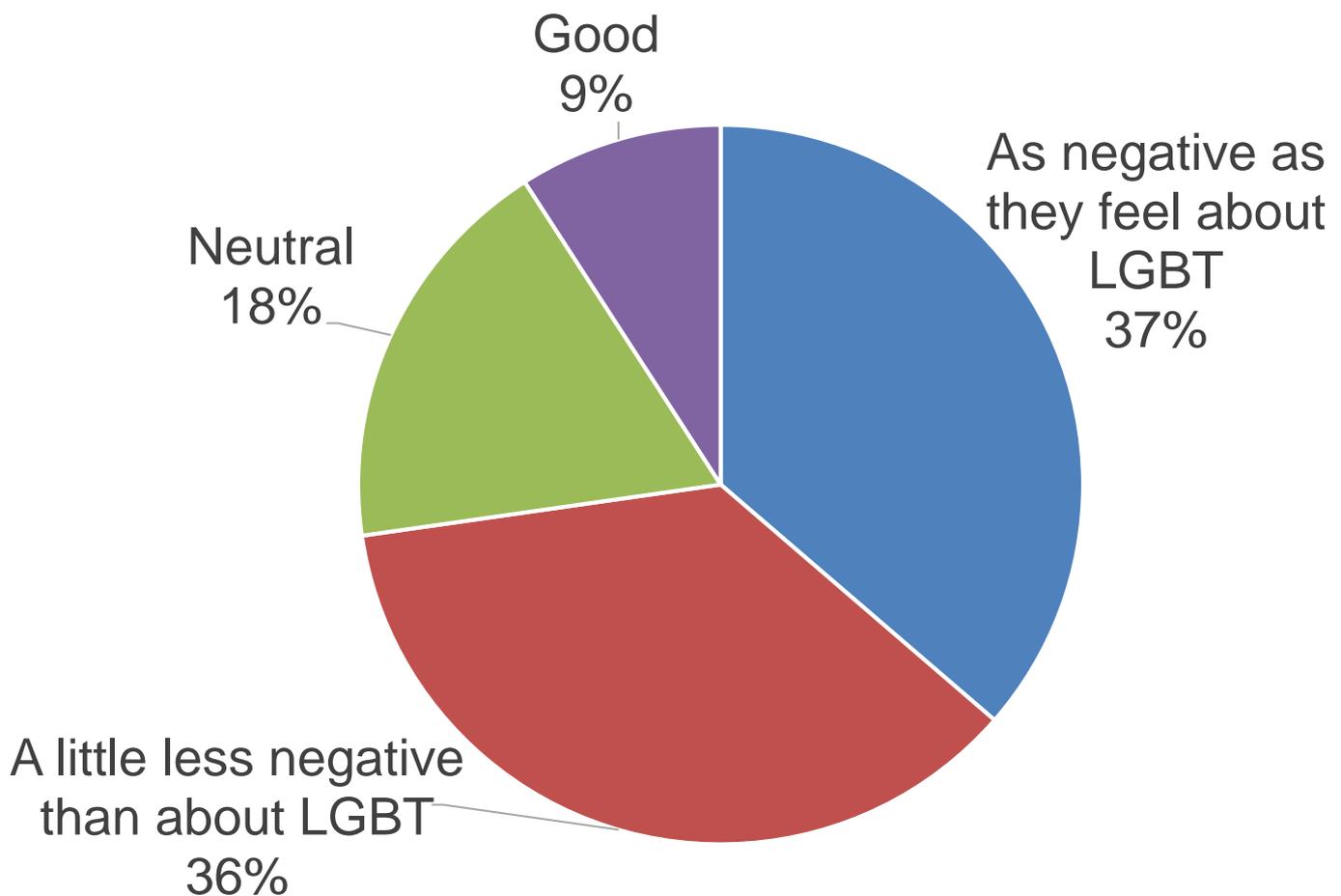
## Are you for including I in LGBTI (and joining the LGBT community in general) or against it?



Adding the I in LGBTI is a big topic of discussion in Russian intersex community, many people have very strong opinions about it. The majority of our participants are for adding the I, they think that it will help more people in our countries to find out about Intersex, it will help our community get more allies and it could help us with funding. The participants, who were against adding the I, thought that Intersex and LGBT are very different things, that LGBT community doesn't care about our problems, and that adding the I will do us more harm than good, because people wouldn't differentiate Intersex from LGBT, they'd think that every intersex person is

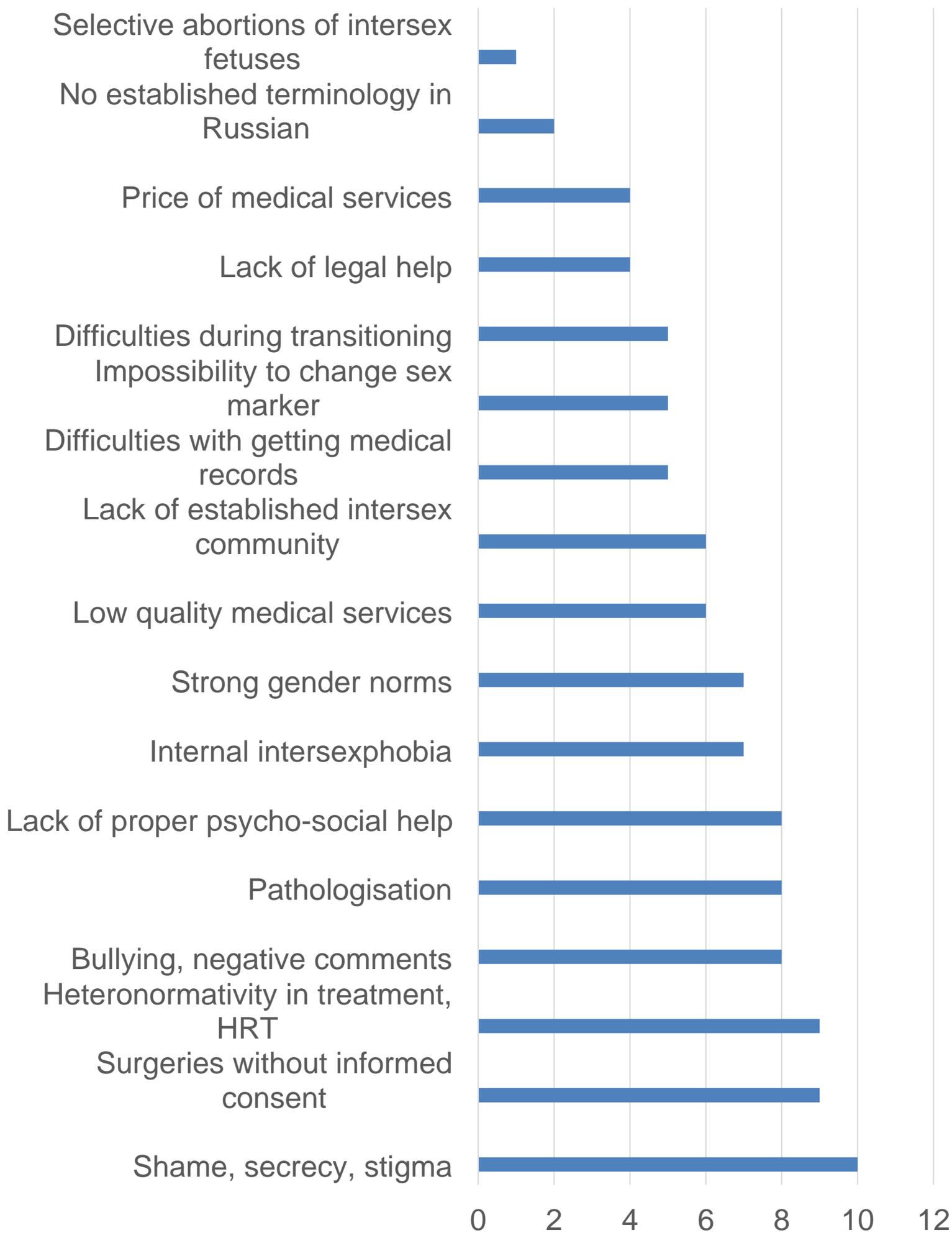
also LGBT, and their negative attitude towards LGBT would pass onto our community too.

**According to many studies, Russia is very homophobic. If most Russians knew about intersex community, how would they generally feel about it?**



Continuing with the topic from the previous question, the participants were asked how Russians would feel about Intersex community if they knew about it. About a third (36%) of our participants think that Russians will hate the intersex community just as much as they hate LGBT. The same amount thinks that Russians would feel a little less negative about Intersex than they feel about LGBT. The rest thinks that people in Russia would feel neutral or good about Intersex community.

## What are the main problems the intersex people face in Russia and Post-Soviet countries?



Participants were asked to name main problems in their opinion that Intersex people face in Russia and Post-Soviet countries. Problems named most often were shame, secrecy, stigma and of course, surgeries without medical need and full informed consent of the patient.

Heteronormativity in treatment of intersex people and in choice of HRT were also mentioned – doctors here never ask about how patient identifies and what kind of HRT they would prefer, they always go with the medical standards, like CAIS = female gender identity, Klinefelter = male gender identity, etc.

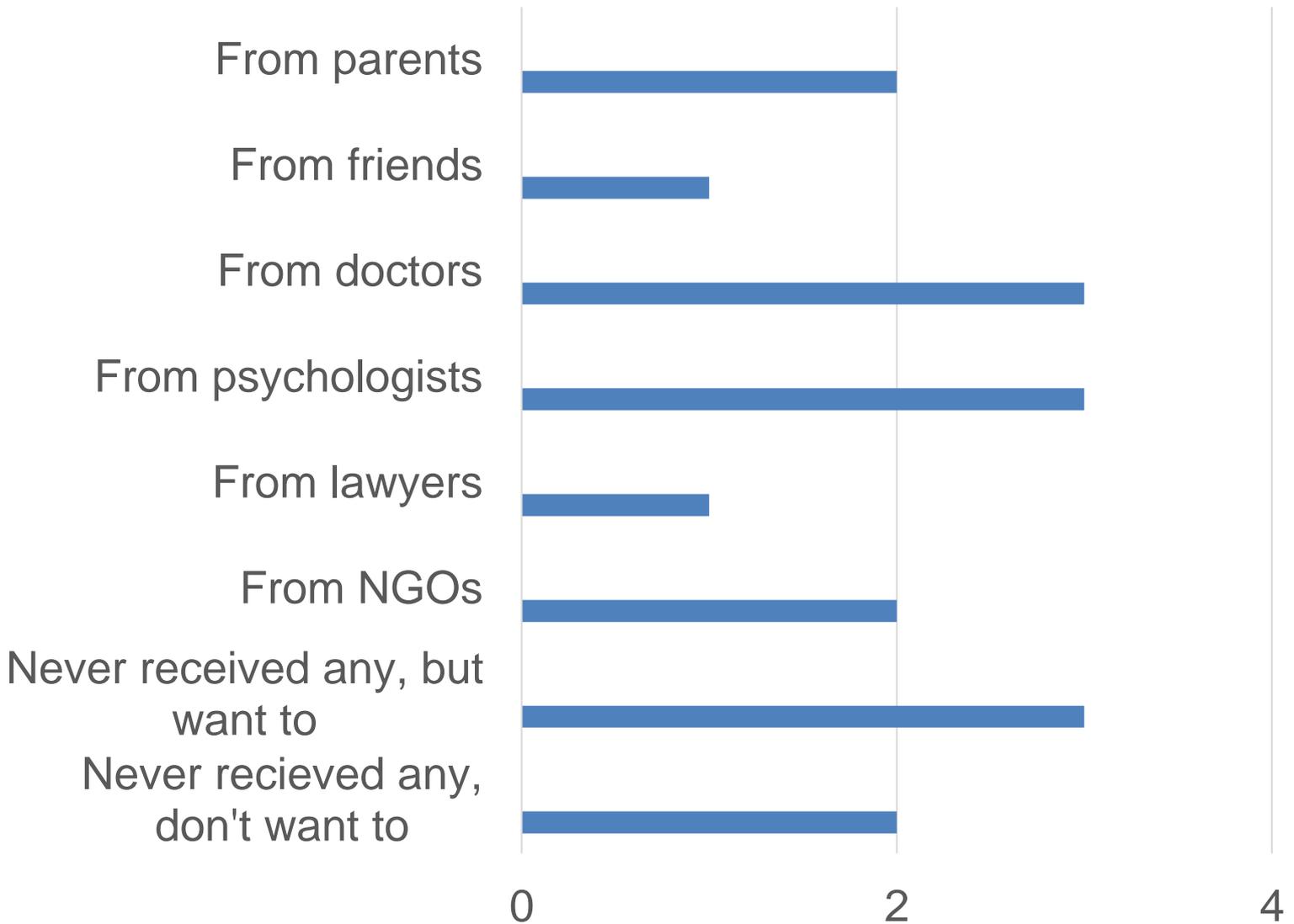
Strong gender norms, pathologization, negative comments, bullying and lack of psycho-social help were named too.

Problems during transition for transgender people also were mentioned – in Russia and Ukraine intersex variation are considered an obstacle in getting the official diagnosis and permission for transitioning. As an example, I can think of the words that the doctor said to a transgender patient with PAIS in one Ukrainian TV show, they said that he probably won't be allowed to transition and to change sex marker in his passport, because "Patients with testicular feminization usually are not allowed to do it. The nuances of a diagnosis, like yours, can interchange, those wishes, male and female...What if you'll be disappointed, and you may start wishing to be female again. You'll have more serious mental issues, depression, and even... And who would take responsibility for that? Doctors don't so they decline."

Impossibility to change the gender marker in their passport for intersex people also was mentioned as a problem, along with internal intersexphobia, problems with getting own medical records for intersex patients, low quality and high price of medical services and other problems.

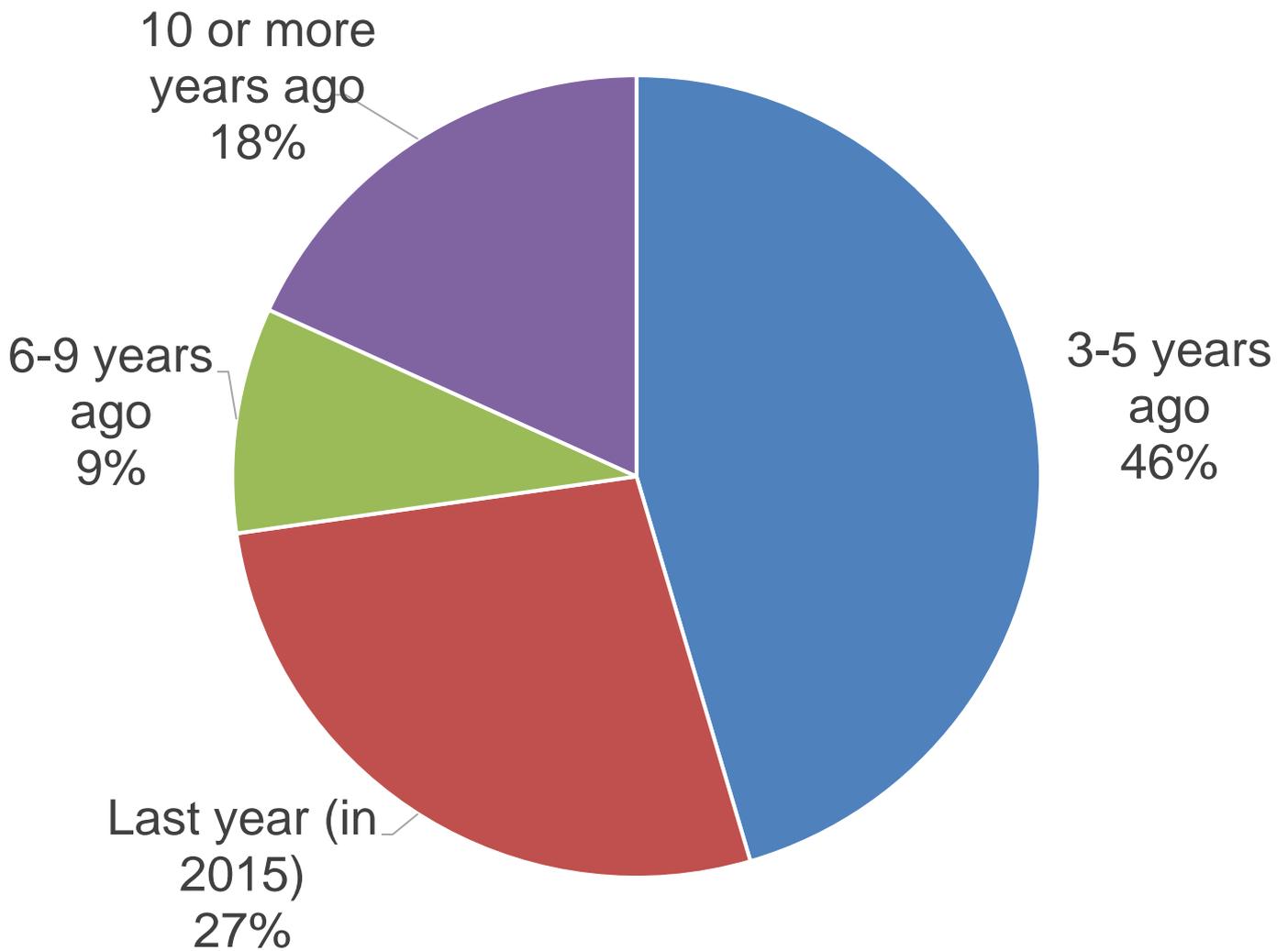
Lack of established Russian intersex community and terminology in Russian were mentioned too – for example, in Russia many people still use the word "intersexuality", which in Russian language is incorrect, because it's makes intersex sound as it's connected to sexuality, because in Russian language "sex" doesn't mean "biological sex", as it does in English.

# Have you ever received help regarding problems, related to your intersex variation?



Less than third of our participants received help from doctors and psychologists. Third never received any help but would like to.

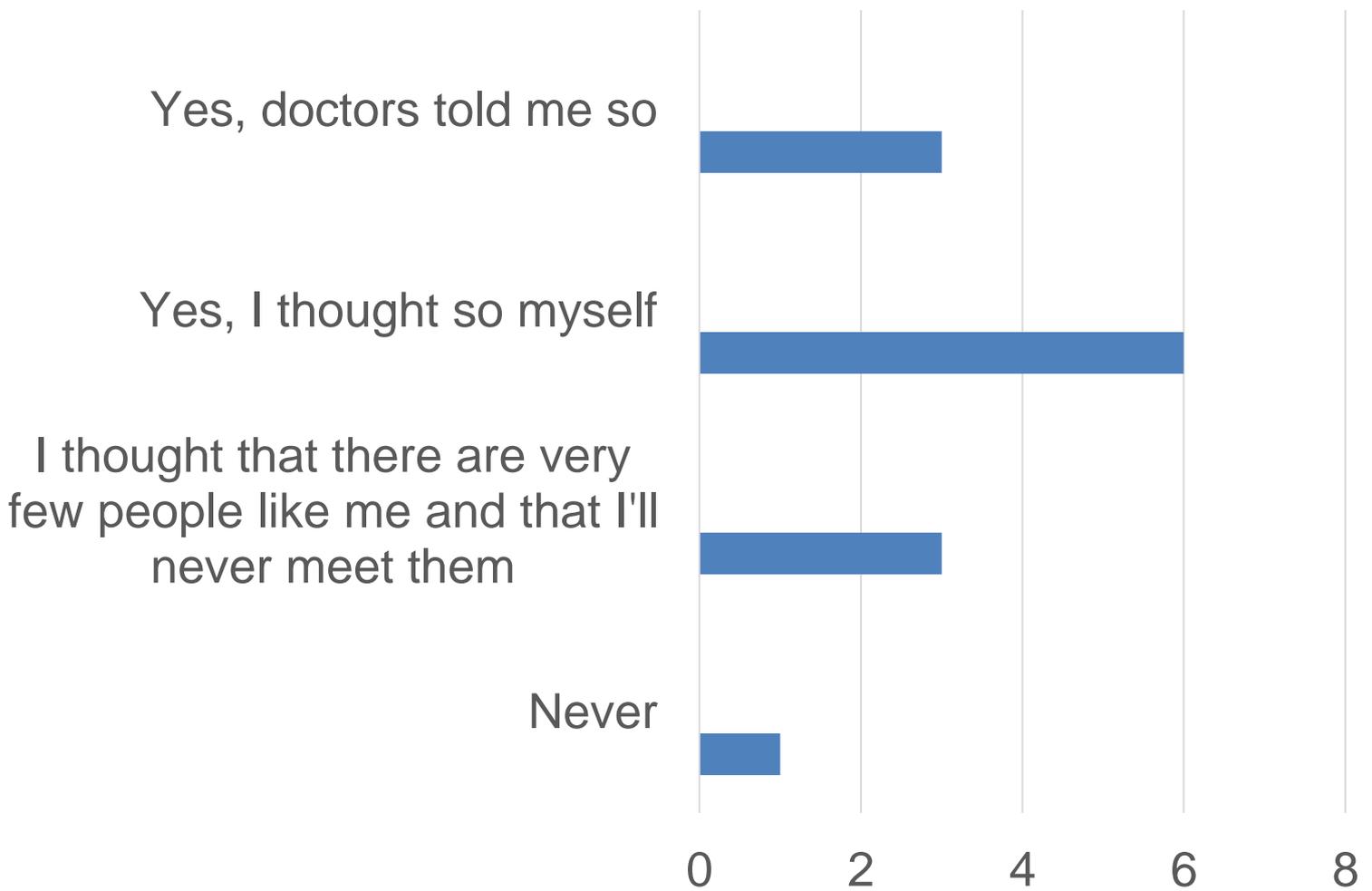
## When have you learned the term Intersex?



When asked about when they learned the word intersex and its meaning, almost half of participants (46%) learned that word 3-5 years ago, third (27%) learned it last year, in 2015. The rest learned that word 6 or more years ago.

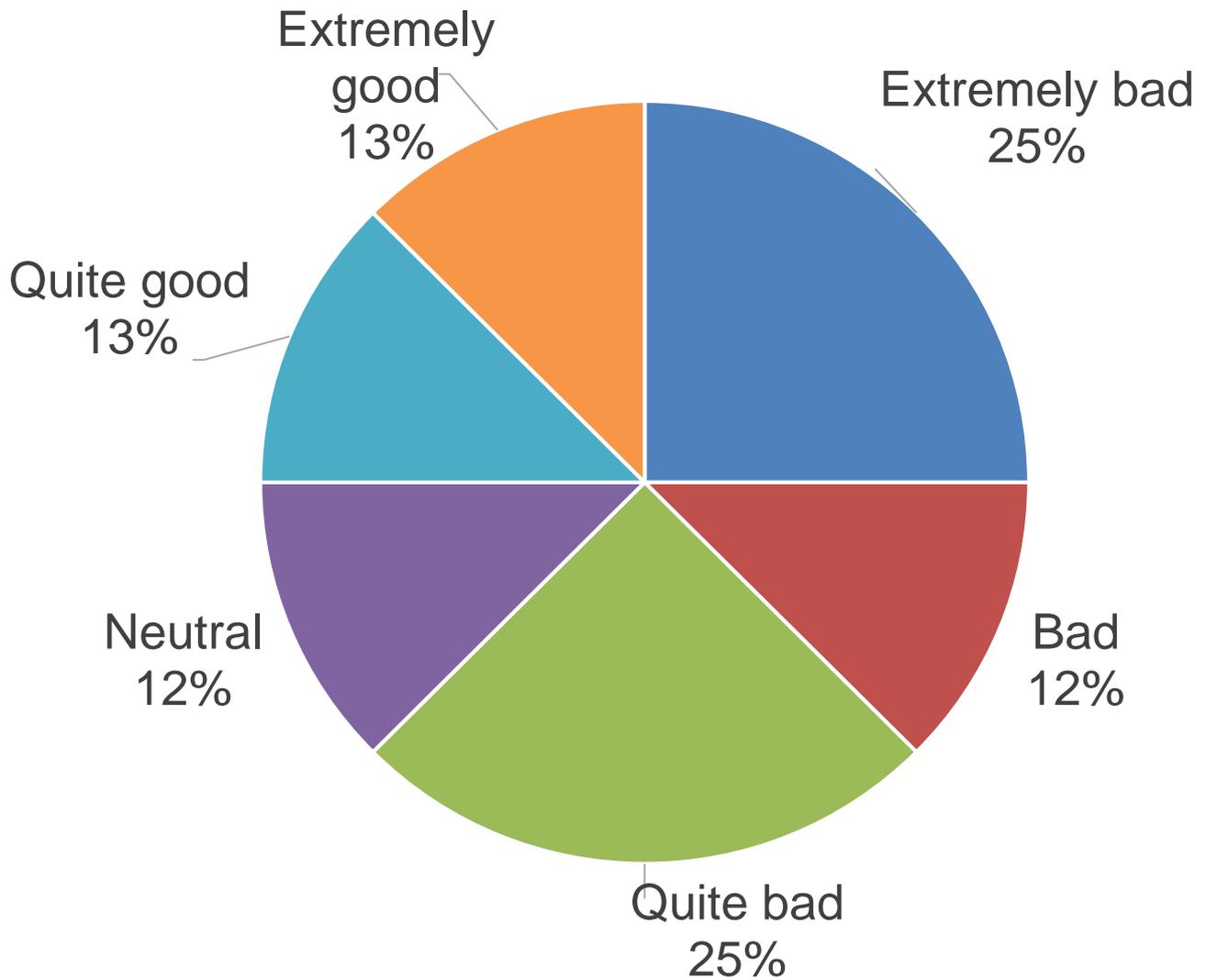
When asked about how they learned that word, 1 person learned it by accident during a research, 3 participants learned it from the internet, one person specifically - from the "What It's Like To Be Intersex" video made by InterACT and BuzzFeed.

## Have you ever thought that you're the only one like that?



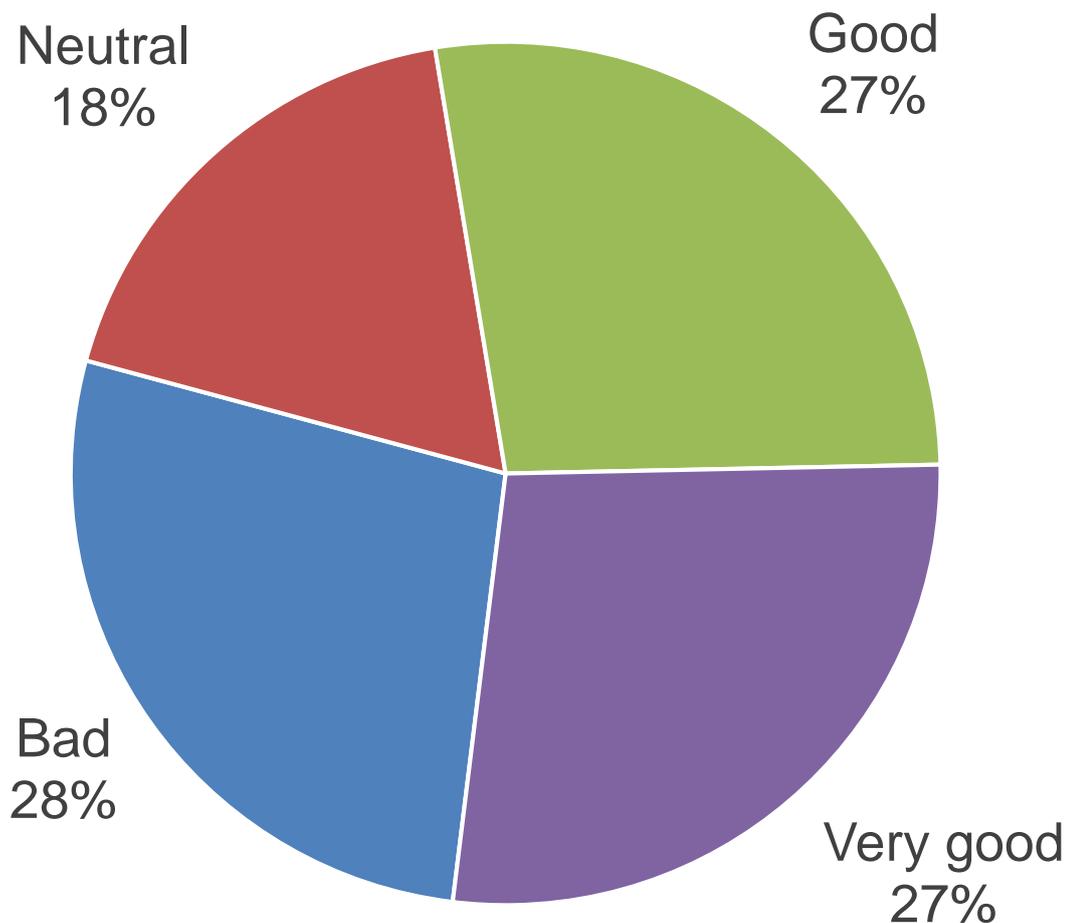
Participants were asked if they ever felt they were the only one like that. More than half participants felt that they're the only ones like that at some point in their life. Third were told so by doctors. And another third thought that there are very few people like them, and that they'll never meet them in the lives.

## How you felt about your intersex variation when you just found out about it?



When first learned about their variation, the majority (62%) of participants felt negative about it, about a third (26%) felt positive about it, the rest felt neutral.

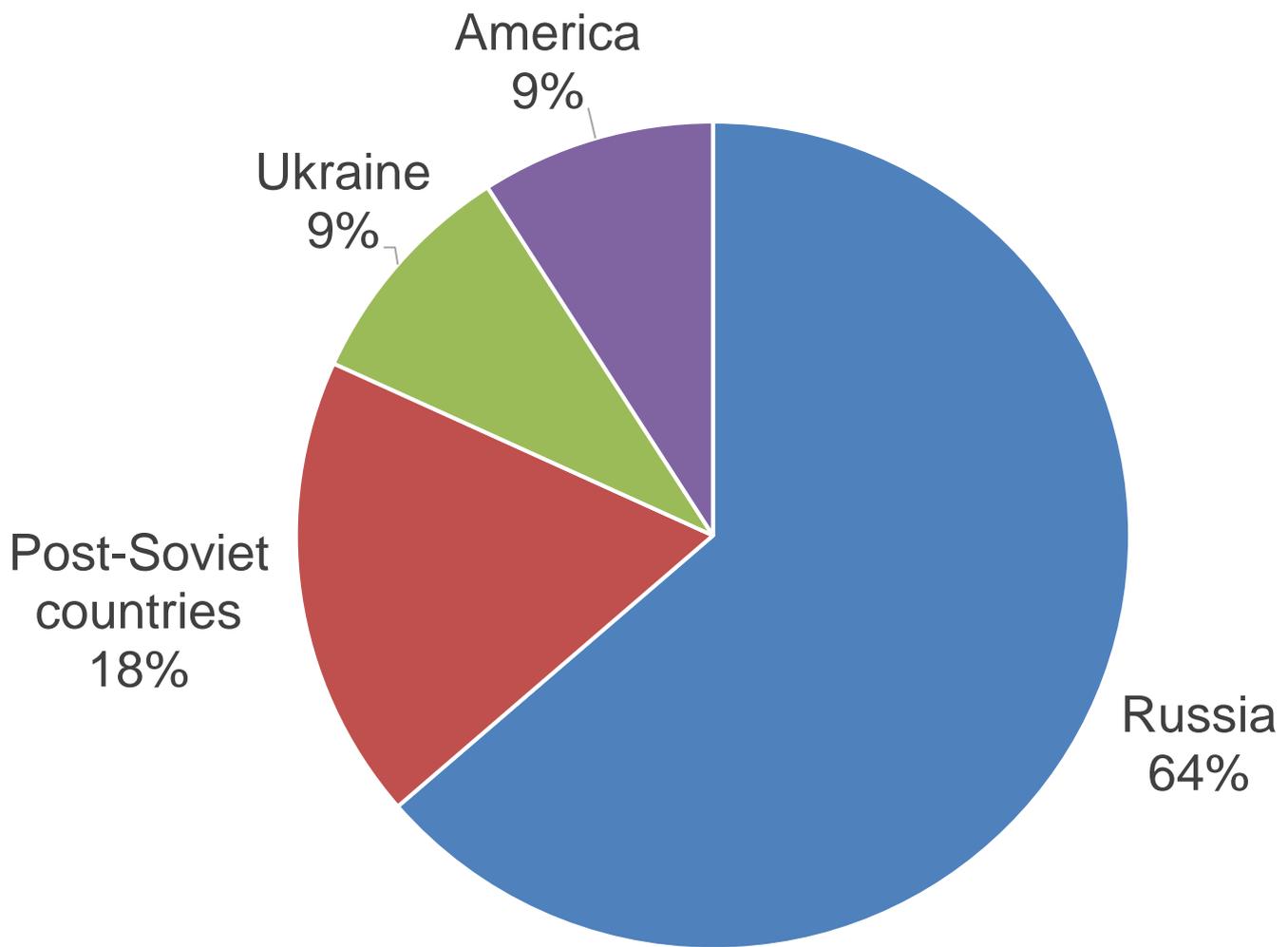
## How do you feel about your intersex variation now?



Then the participants were asked about their feelings about their variations now, and the results were the opposite from to the previous question. Now the majority (62%) feels positive about their variation, and about a third (28%) feel negative about it, the rest feel neutral. 2 participants feel differently about their variation depending on mood.

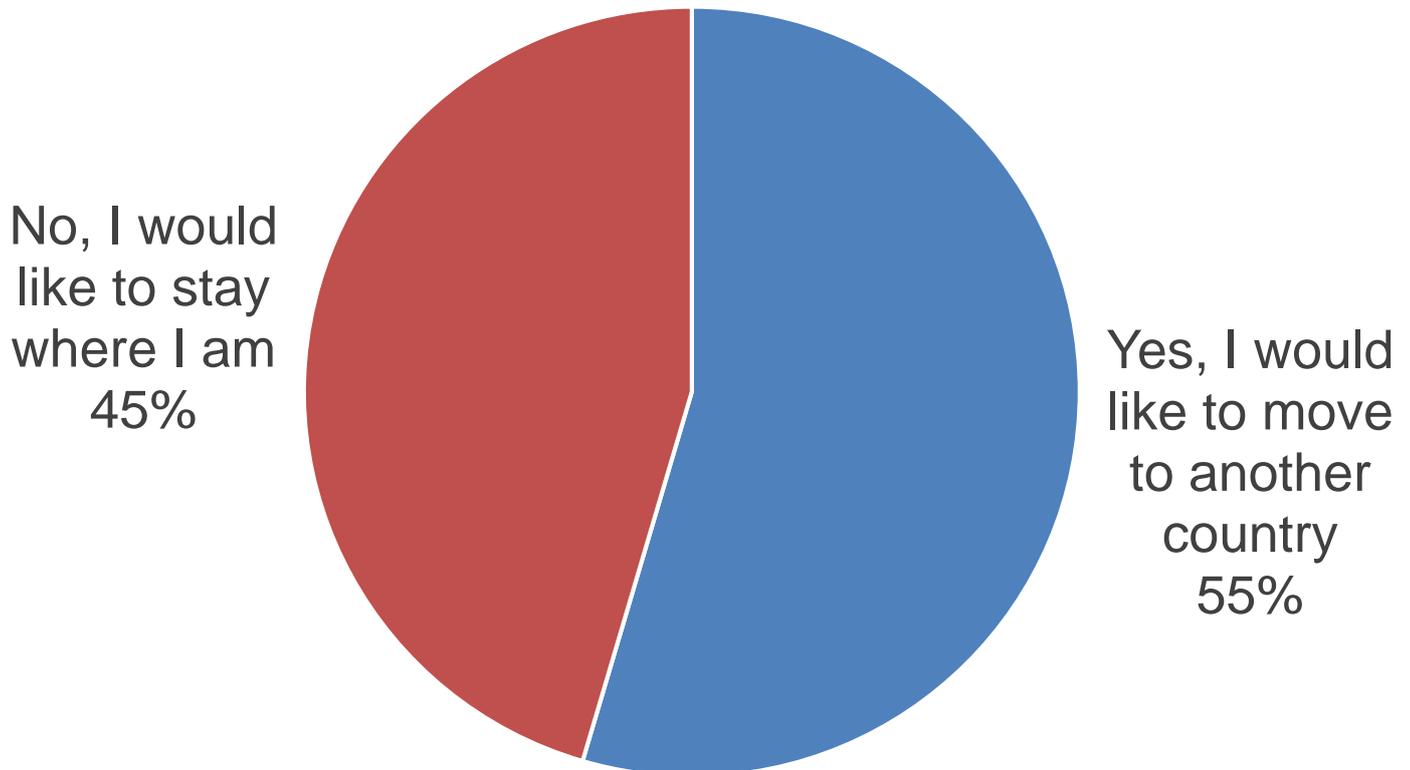
Such difference in the results compared to the results of the previous question is logical – with time, with meeting other intersex people and by learning more about intersex many people accept their variations over time. This is why it's so important to develop a community and put it out there, to make it easier for other intersex people to find us.

## Where do you live?



The majority of participants (64%) live in Russia, almost third (27%) lives in other Post-Soviet countries, and one person lives in USA.

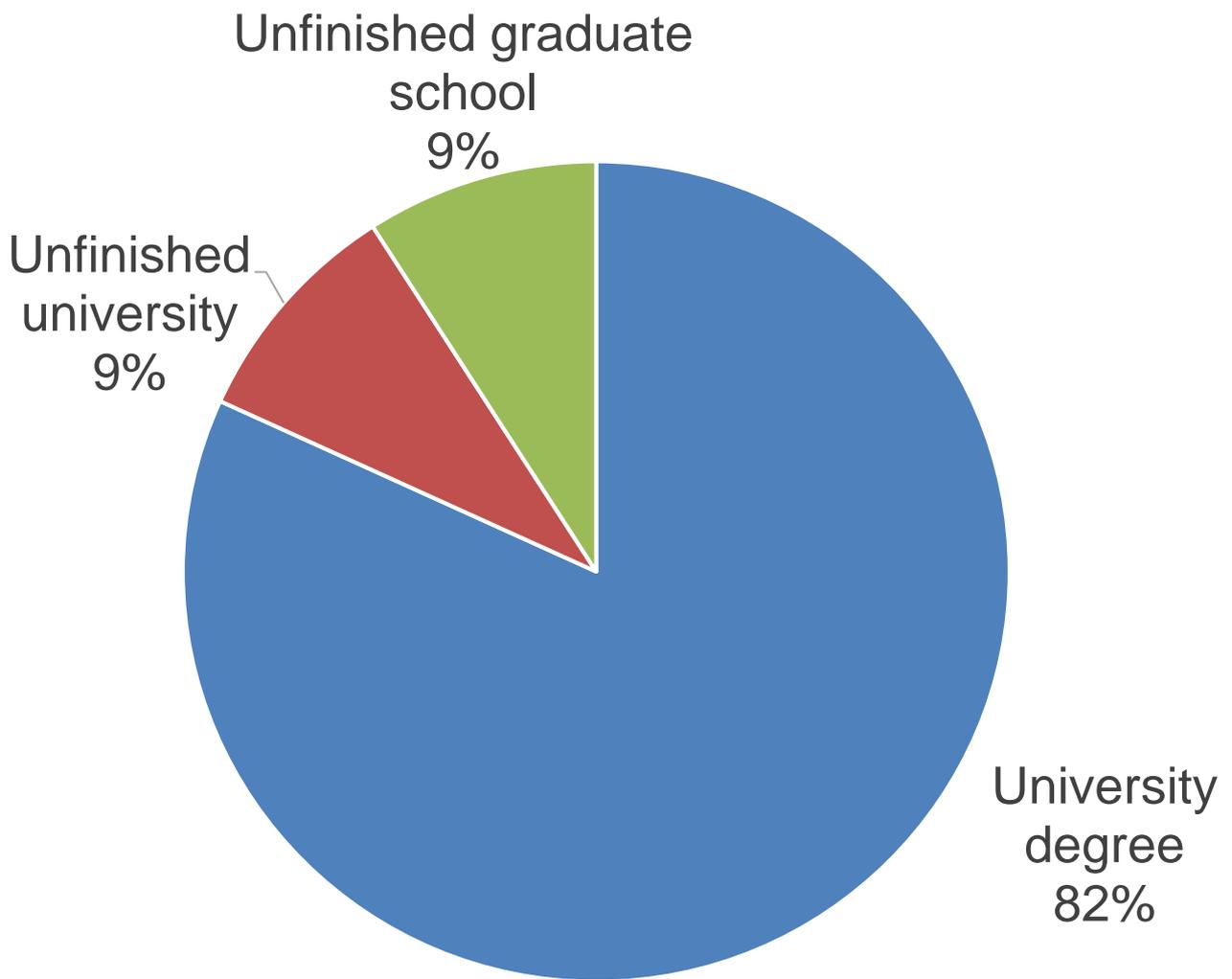
## Would you move to another country?



More than half (55%) of participants would like to move to another country. The country most participants wanted to move to was Canada.

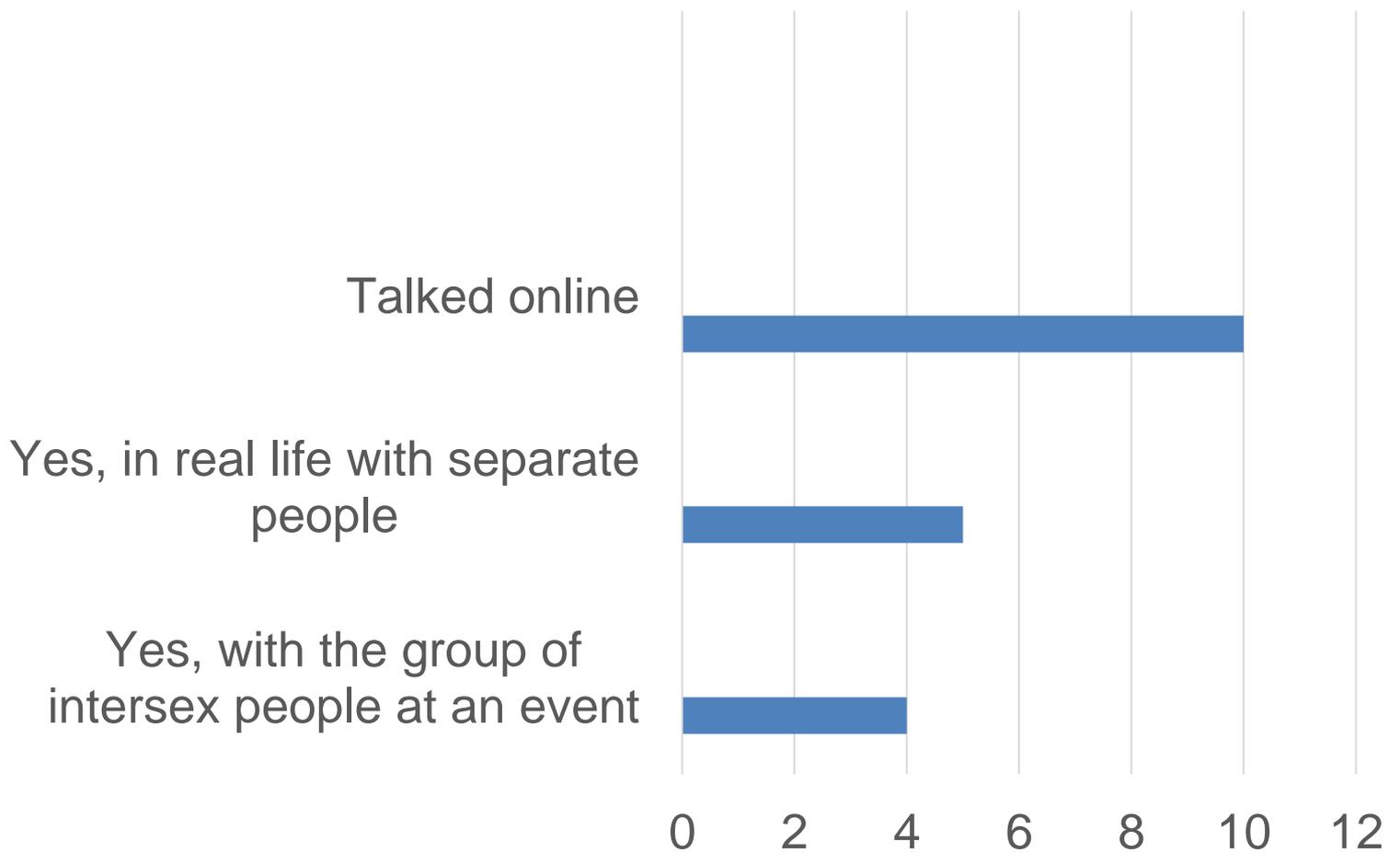
All participants who don't want to move to another country also don't speak English very well, and almost everyone who wants to move speaks English well.

## Education



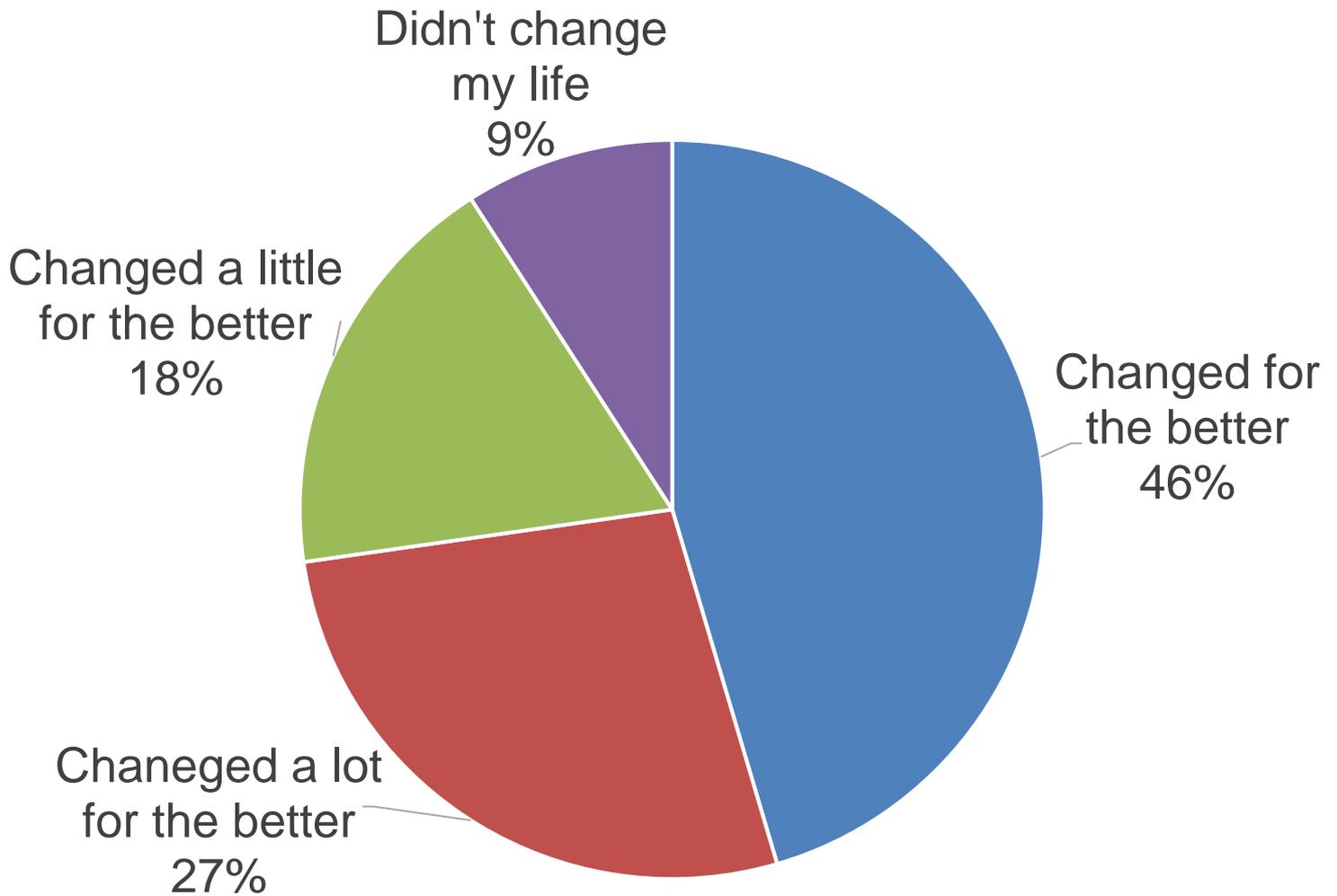
91% of the participants have graduated from university.

## Have you ever communicated with other intersex people?



All participants have communicated with other intersex people, most (91%) participants spoke to other intersex people online, a little less than half (45,5%) spoke to them in real life, and a third communicated with a group of other intersex people on specific conferences or events.

## How communicating with other intersex people changed your life?

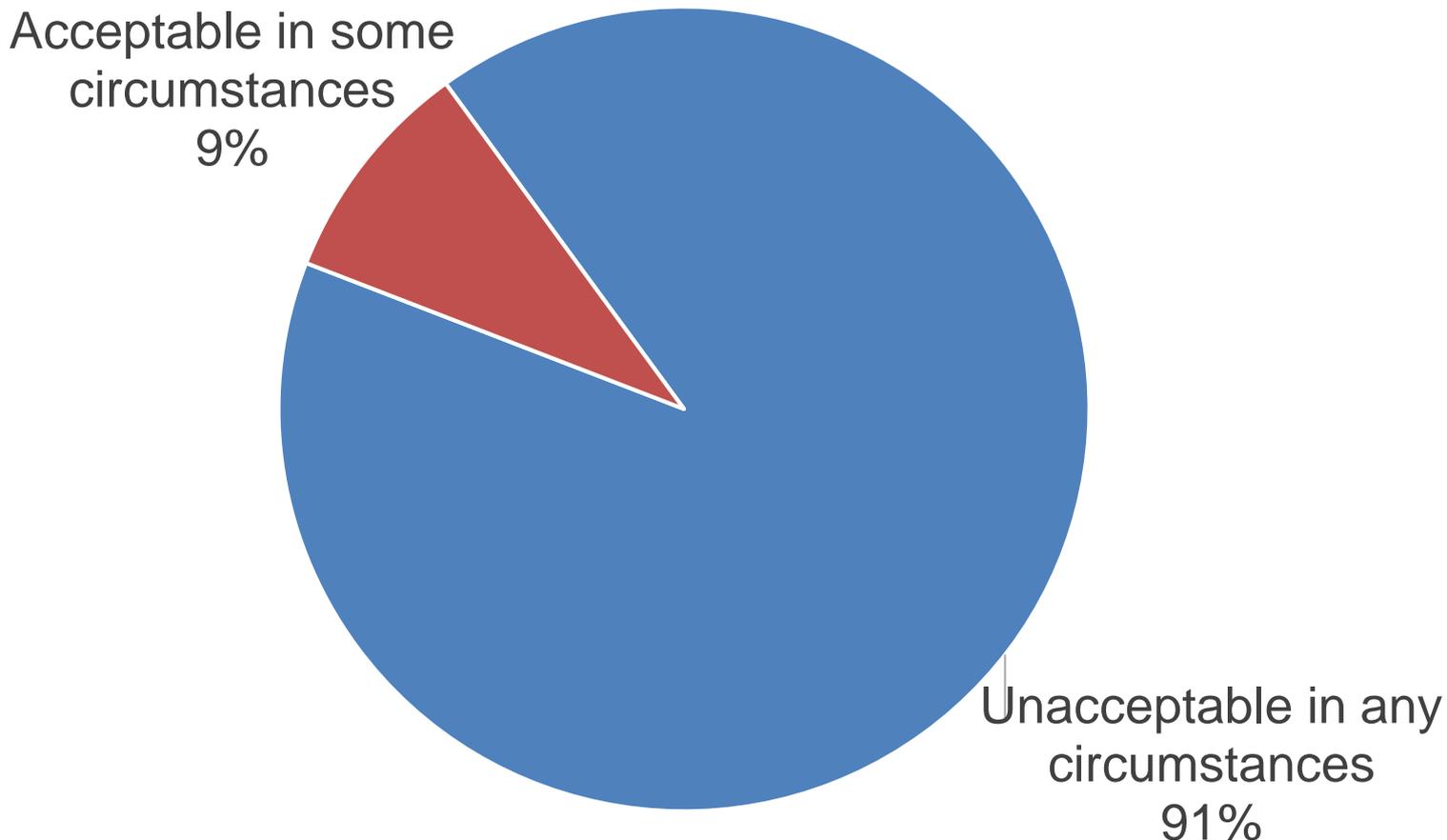


Almost all (91%) participants said that communicating with other intersex people changed their lives for the better on some level.

It gave a sense of community to one participant, another participant said it helped them with self-acceptance, and another participant doesn't feel alone anymore in most of their life experience anymore.

Do you think it's acceptable for a doctor to lie to a patient or keep something secret from a patient in general?

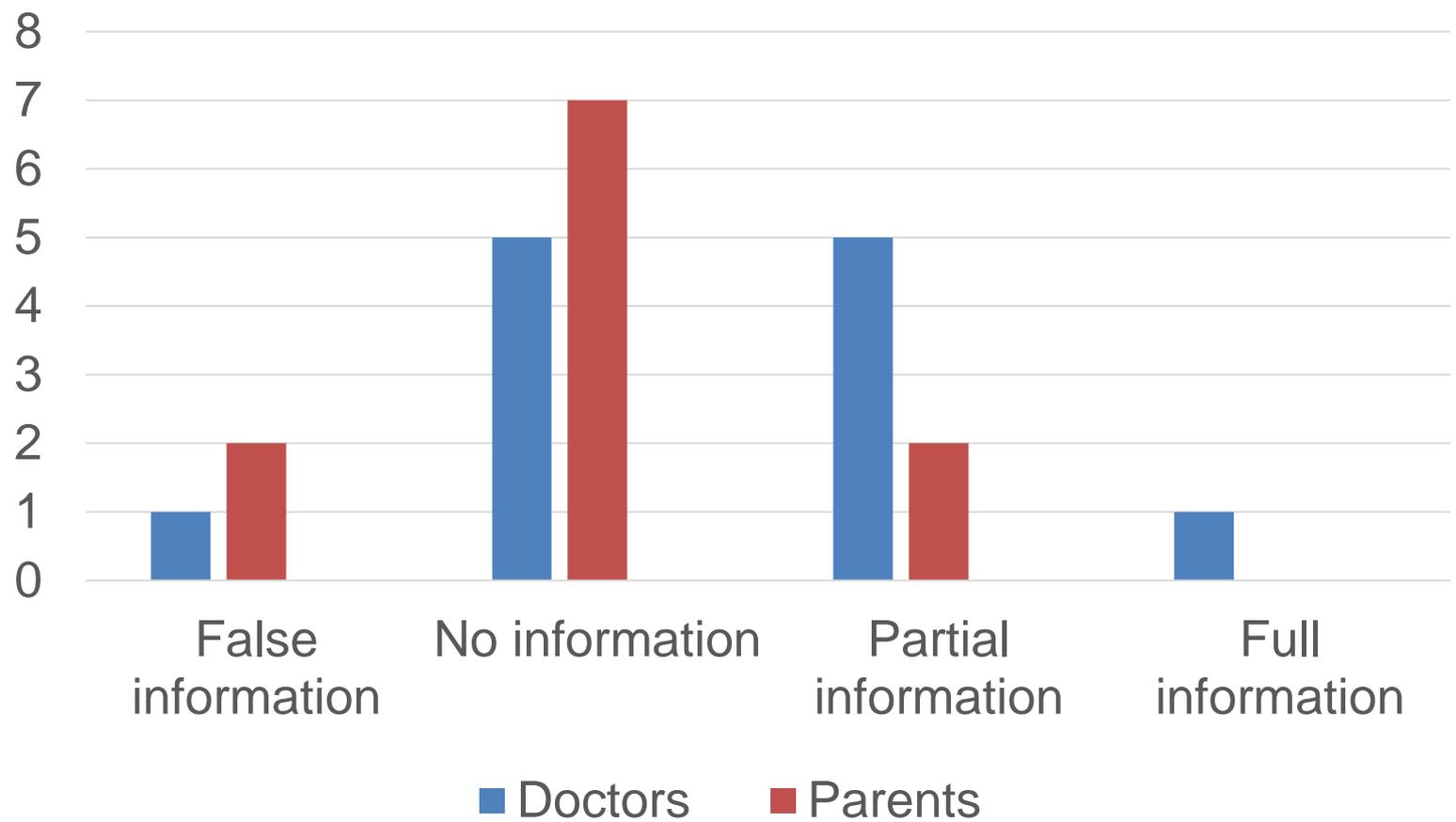
And when it's related to patient's intersex variation?



Almost all (91%) participants said that it's unacceptable in any circumstances for a doctor to keep something secret from a patient or lie to them.

Another question was asked, this time asking about the same actions but this time about the situation when it's related to a patient's intersex variation – and both times the results were the same, 91% of participants said that it's unacceptable in any circumstances for a doctor to lie to a patient or to keep something secret from them.

## What information have doctors and parents provided you with regarding your intersex variation?

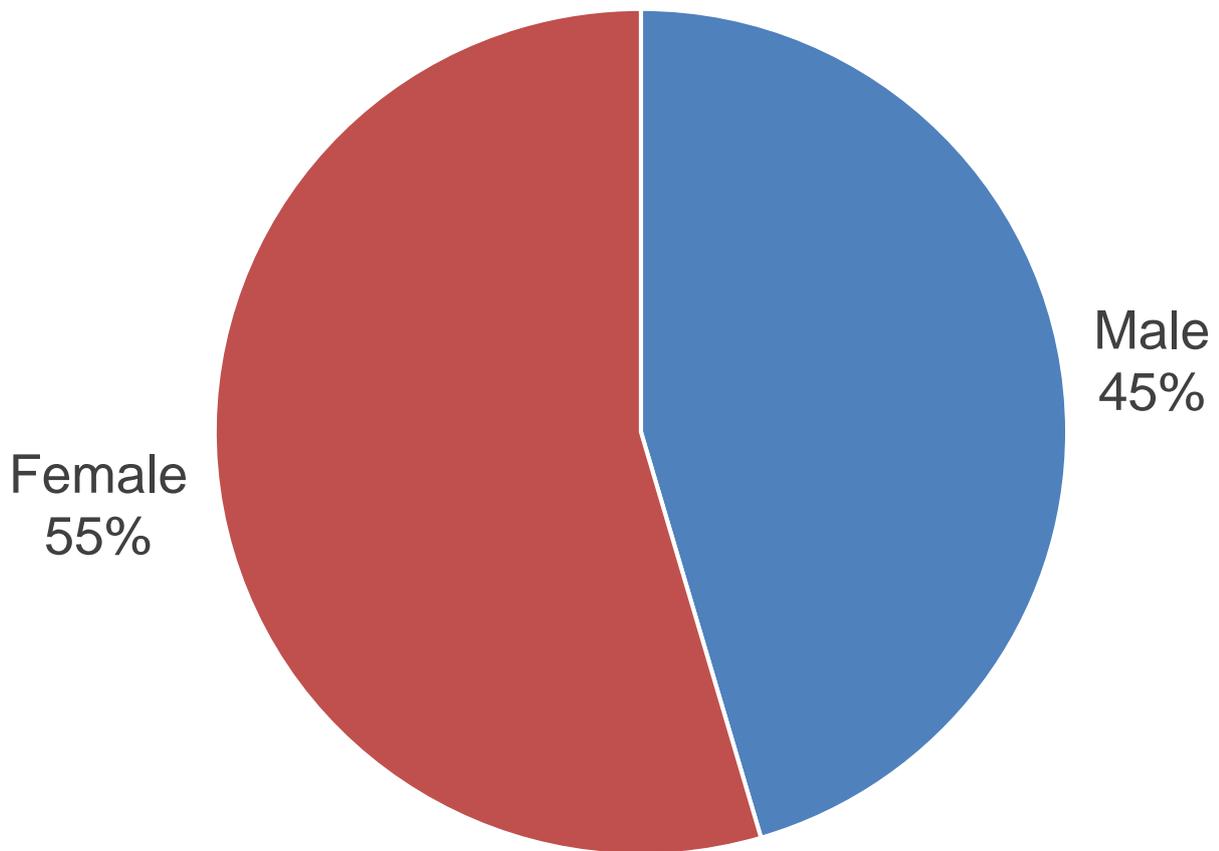


Participants were asked, which information they received about their intersex variation from their doctors and parents.

Almost half of participants (46%) received no information from doctors at all, the same amount of participants was provided with the partial information from the doctors.

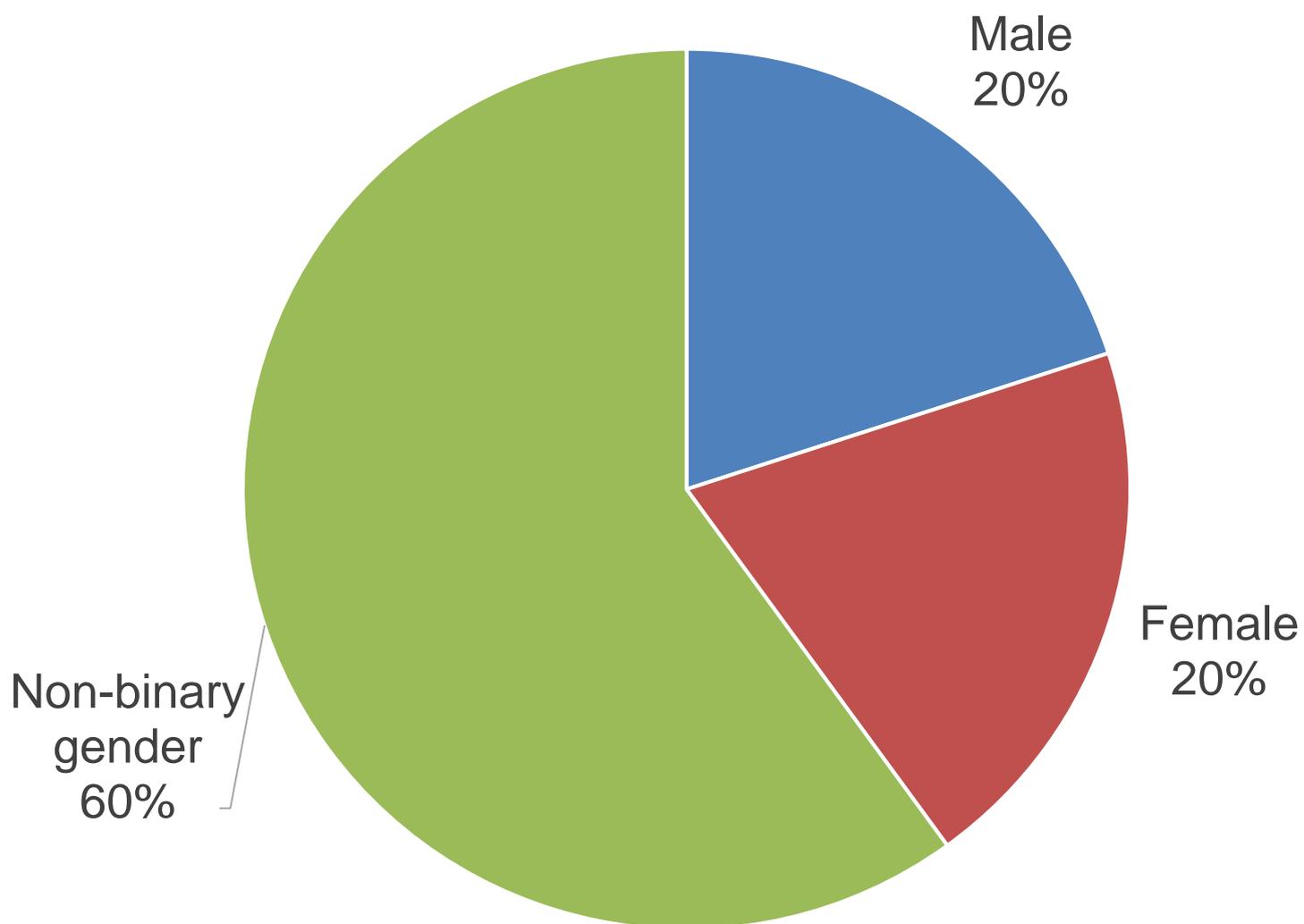
Majority (64%) of participants received no information from their parents, and to 18% of participants their parents lied about their intersex variation.

## What sex you were assigned at birth?



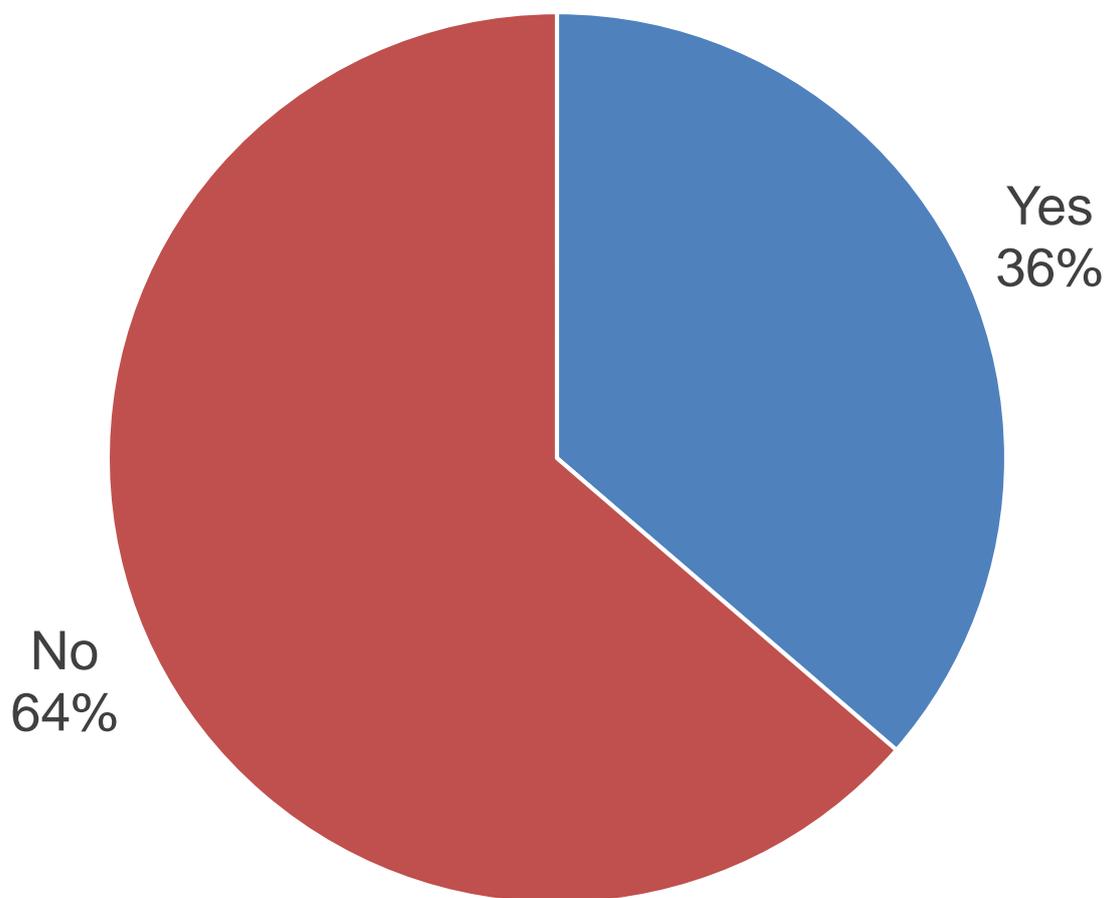
Little more than half (55%) of participants were assigned female at birth, the rest were assigned male.

## With what gender/genders do you identify with now?



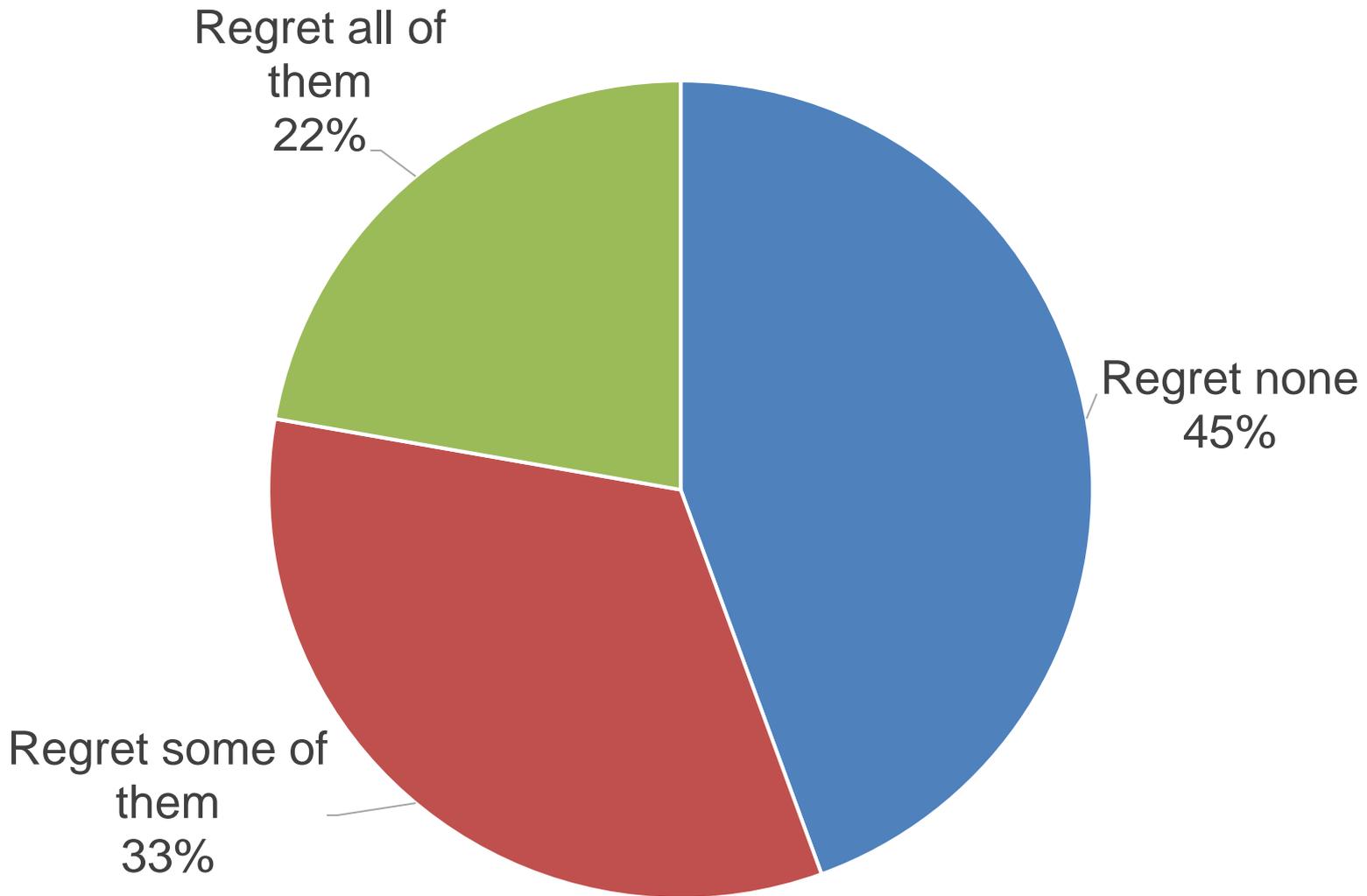
Now, on the other hand, the majority of participants (60%) constantly or sometimes identifies with a non-binary gender, the rest identified as male or female.

Have you ever had surgery without your full informed consent?



36% of participants had surgery without their full informed consent.

## Do you regret any of the surgeries you've had?



More than half (55%) of participants who received surgeries regret some or all of these surgeries.

The reasons for regret the participants named were:

“Because I don’t know what exactly was made to me”

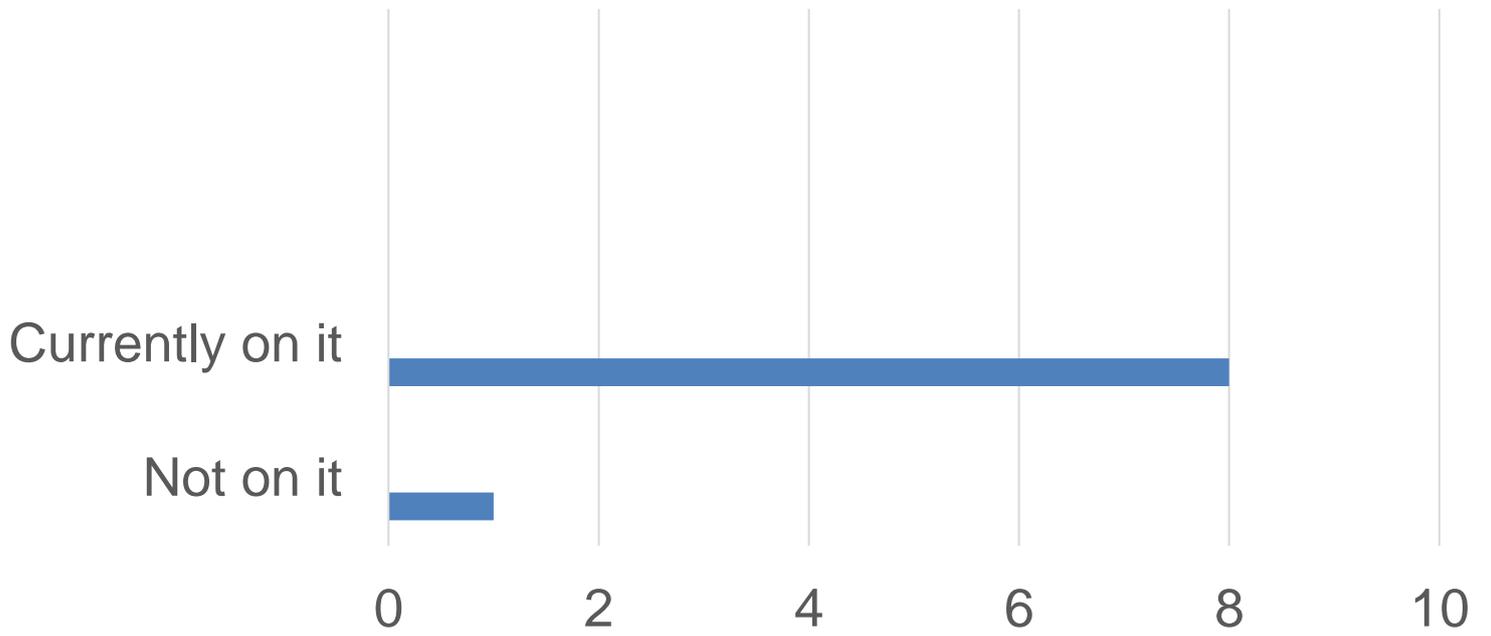
“Because the direction of the surgery doesn’t match the sex I identify with”

“Removal of the testis, it impacted the deterioration of my health”

“The put me in danger without necessity, and without my consent”

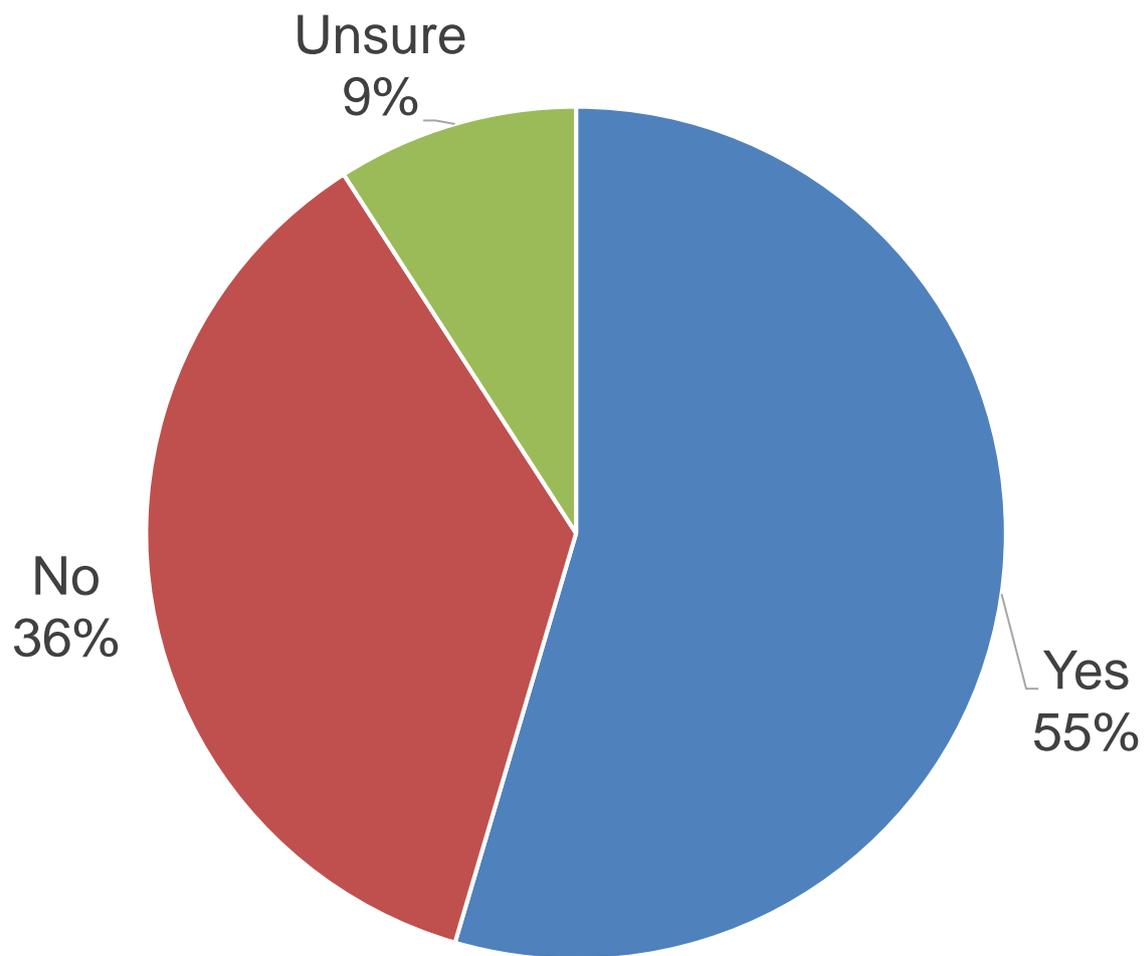
One person doesn’t regret the surgery they had, even though it was done without their consent - the surgery helped them not to experience masculinization they didn’t want.

## Hormonal replacement therapy



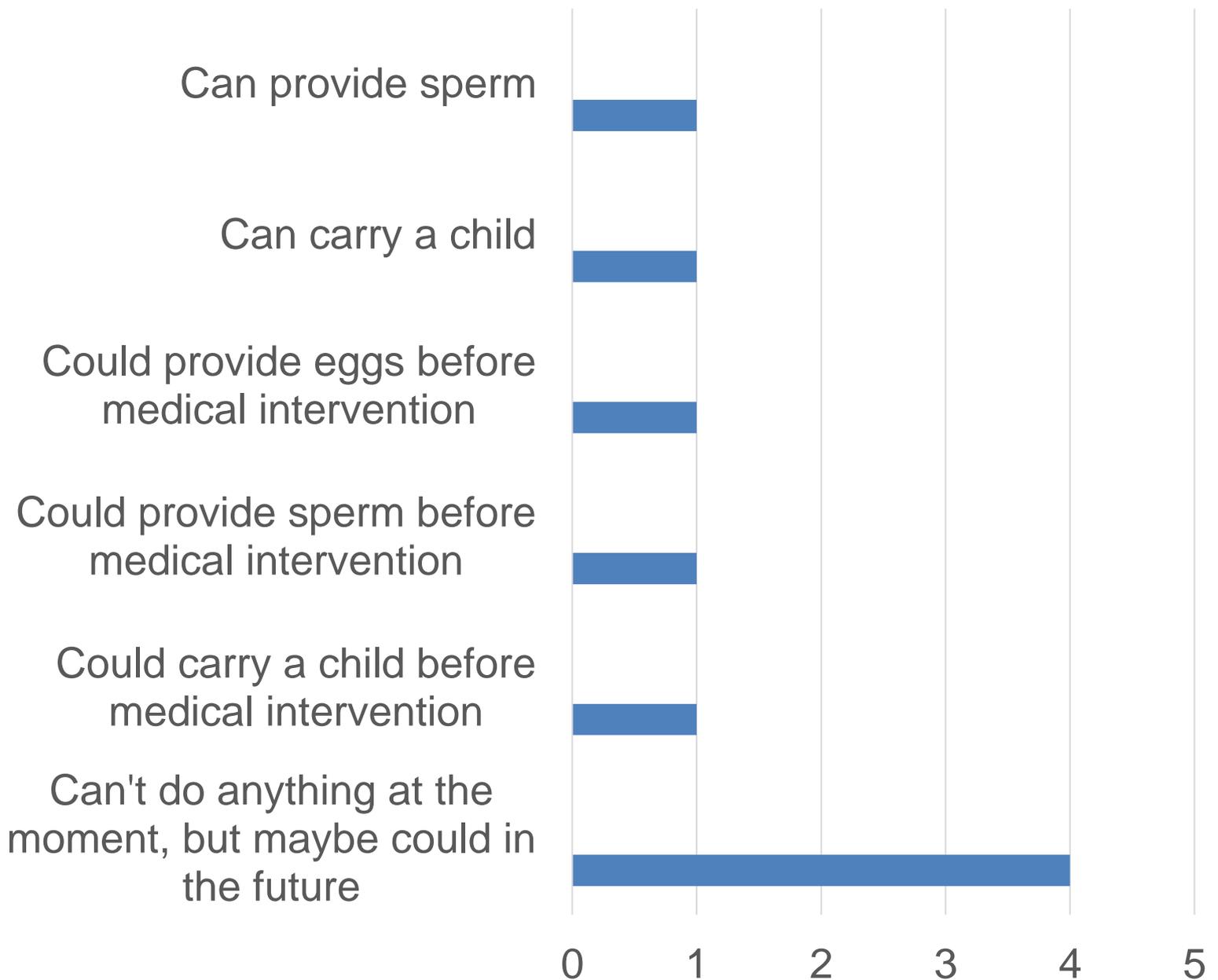
Most (72%) participants are currently taking hormonal replacement therapy.

## Do you want to have kids?



A little more than half (55%) of participants want to have kids.

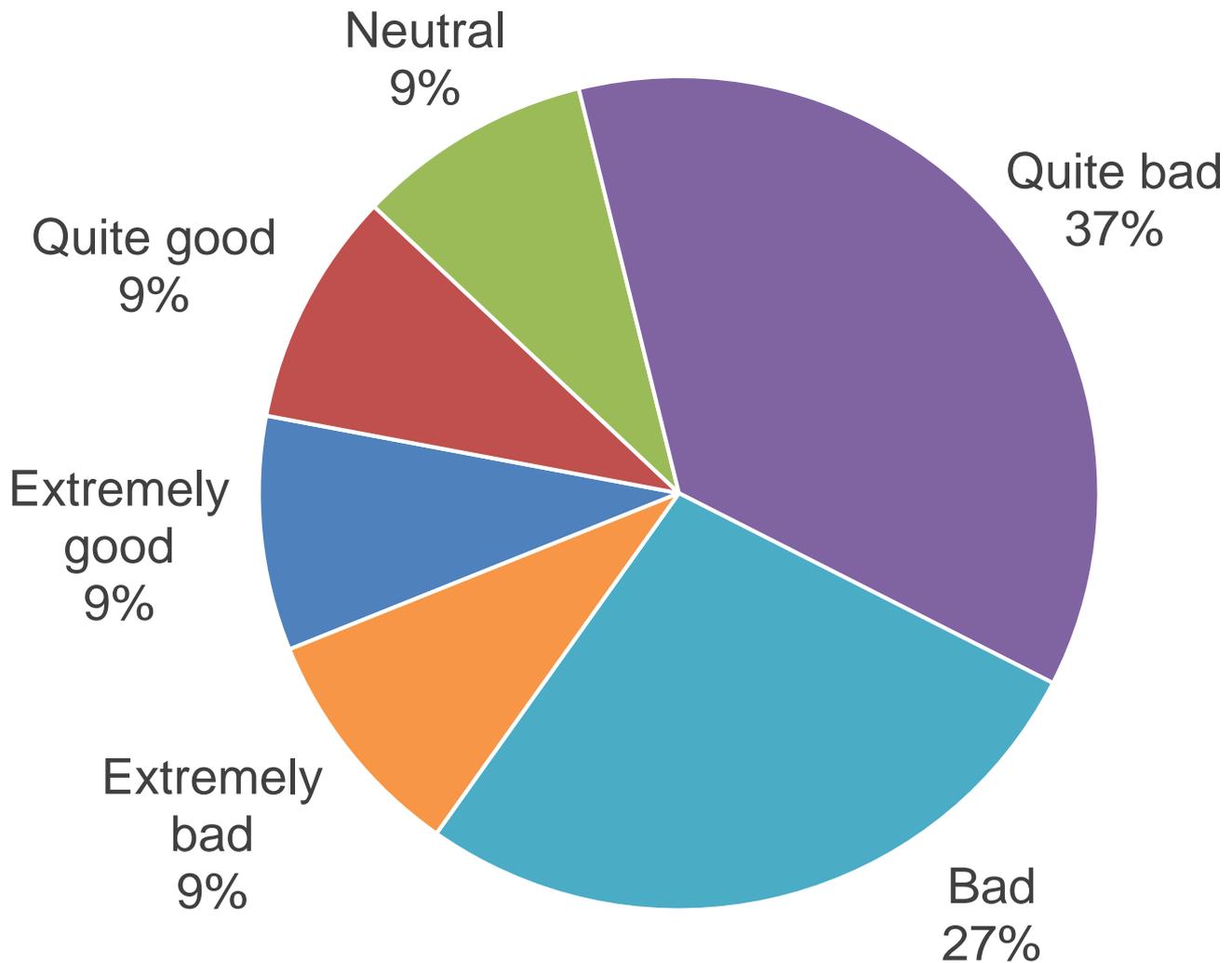
## Having biological children



Two participants can have biological children, another two participants lost their ability to have children after medical treatment that was performed on them.

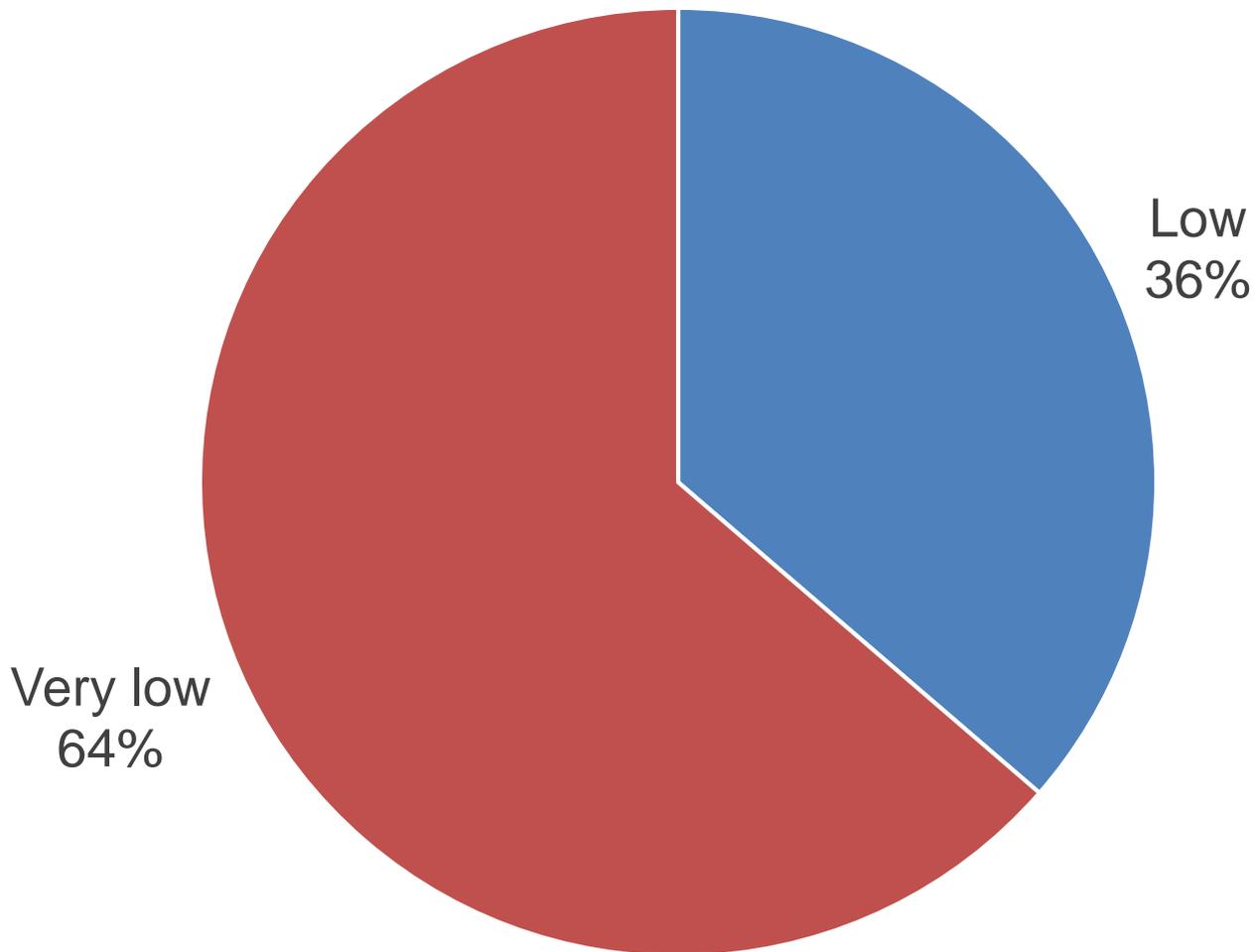
4 participants can't have biological children now, but maybe they could with some medical help in the future.

In general, how would you describe your experience with medical community related to your intersex variation?



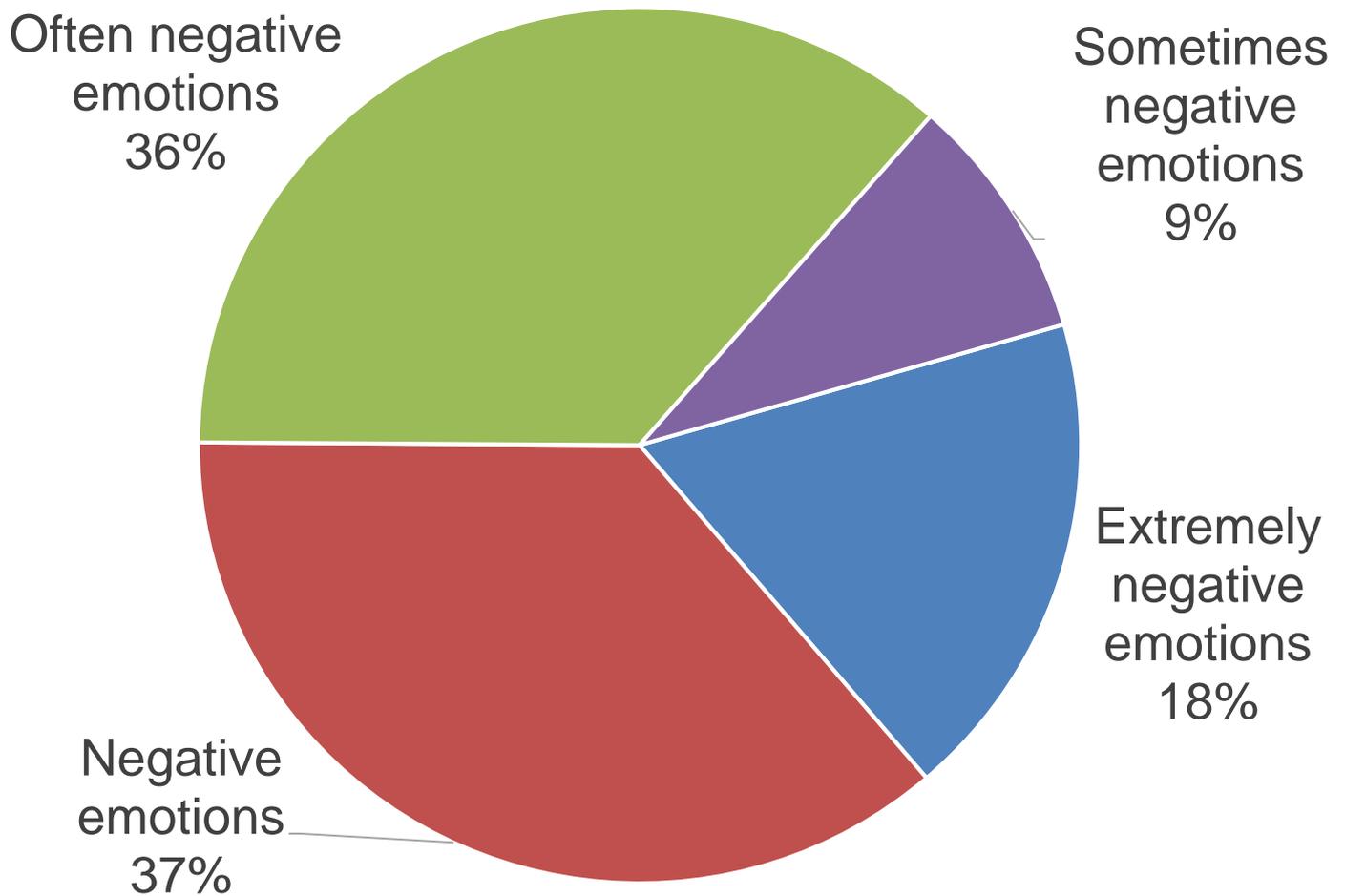
The majority (73%) of participants defined their experience with the medical community related to their intersex variation as negative.

## Level of awareness doctors have about Intersex in Russia and Post-Soviet countries



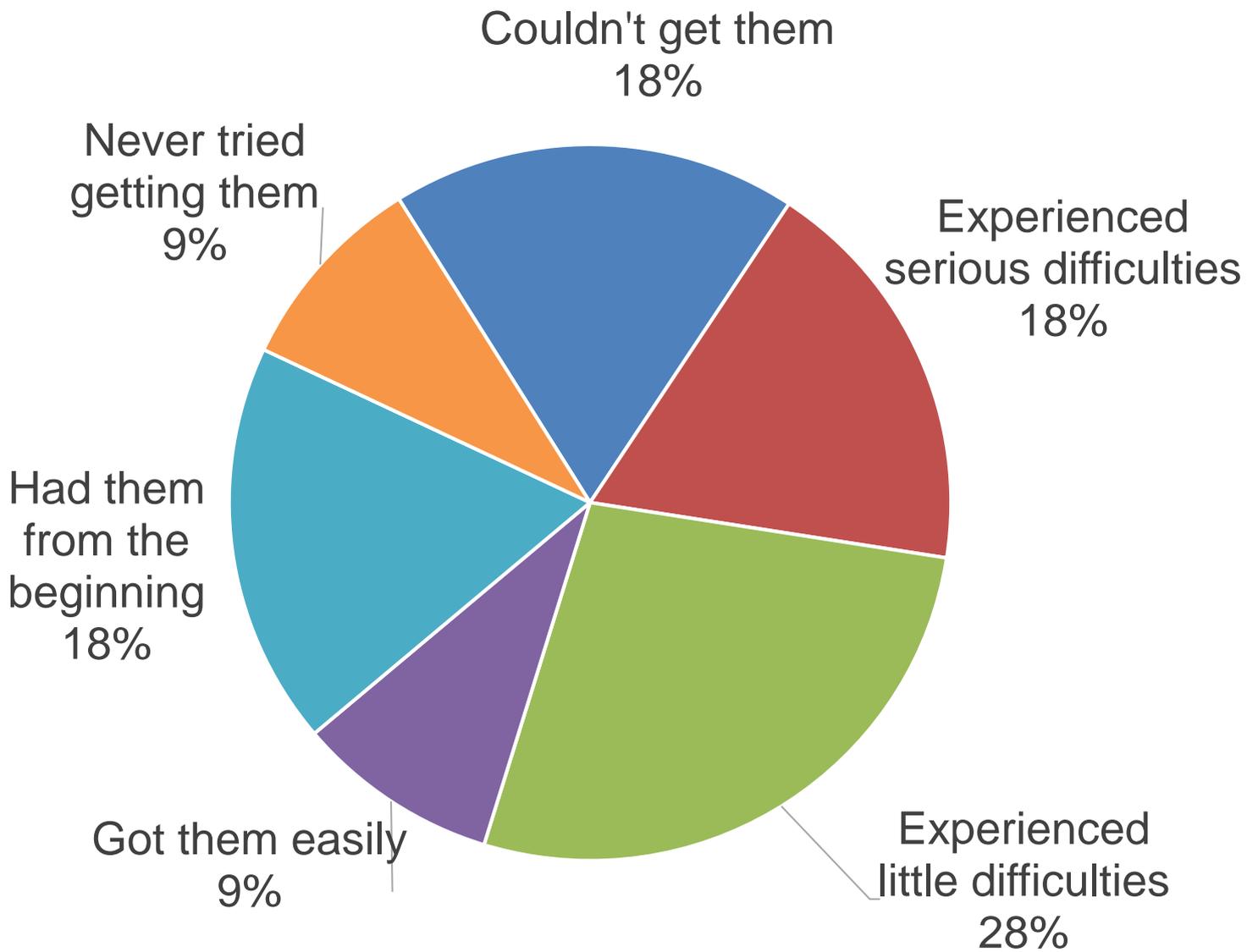
All participants see the level of knowledge doctors in our countries have about intersex as low or very low.

## Which emotions you're feeling when visiting a doctor on behalf of your intersex variation?



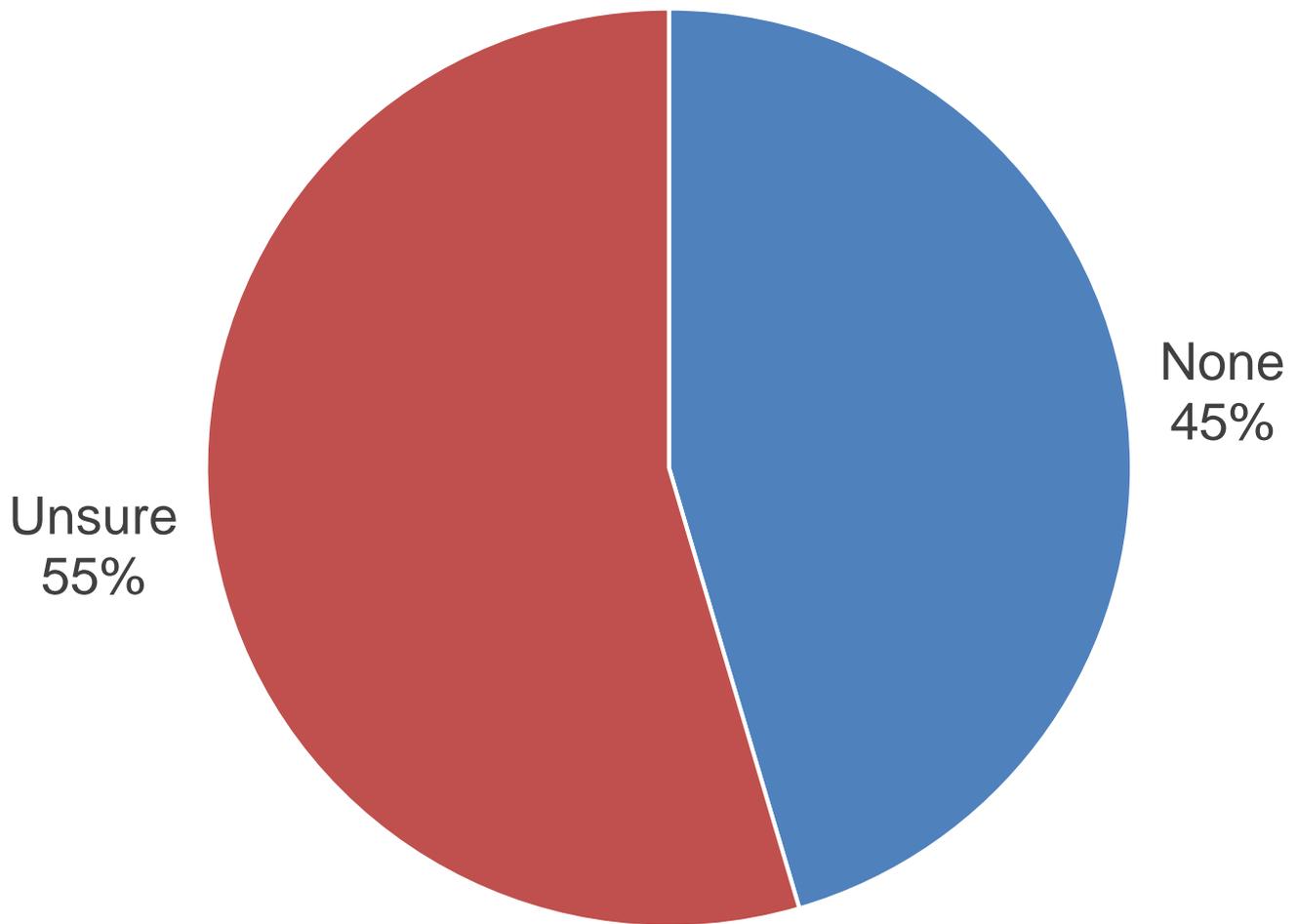
All participants still experience negative emotions when visiting a doctor on behalf of their intersex variation.

## Getting your medical records



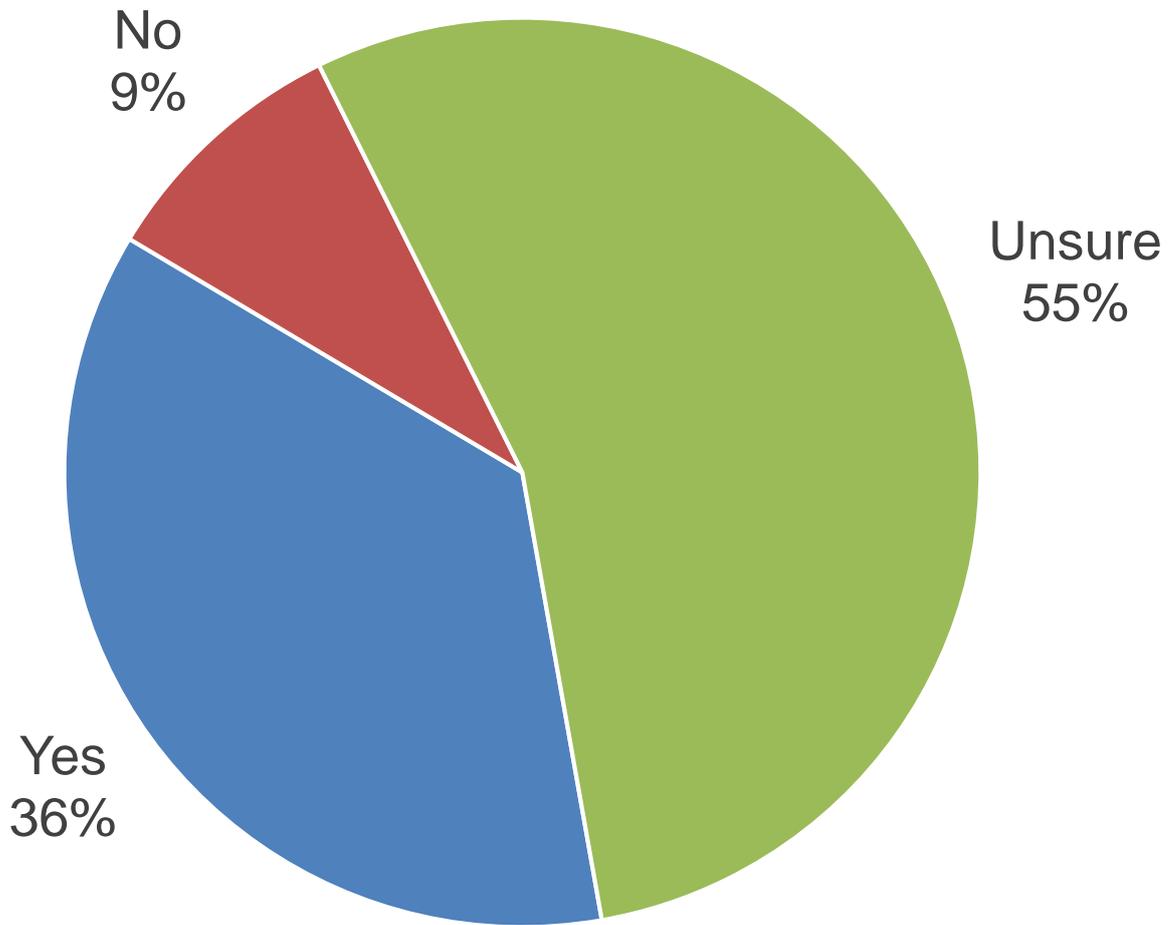
The majority of participants (64%) had problems with getting their medical records, two of those people never got medical records in the end.

Are there any other intersex people in your family?



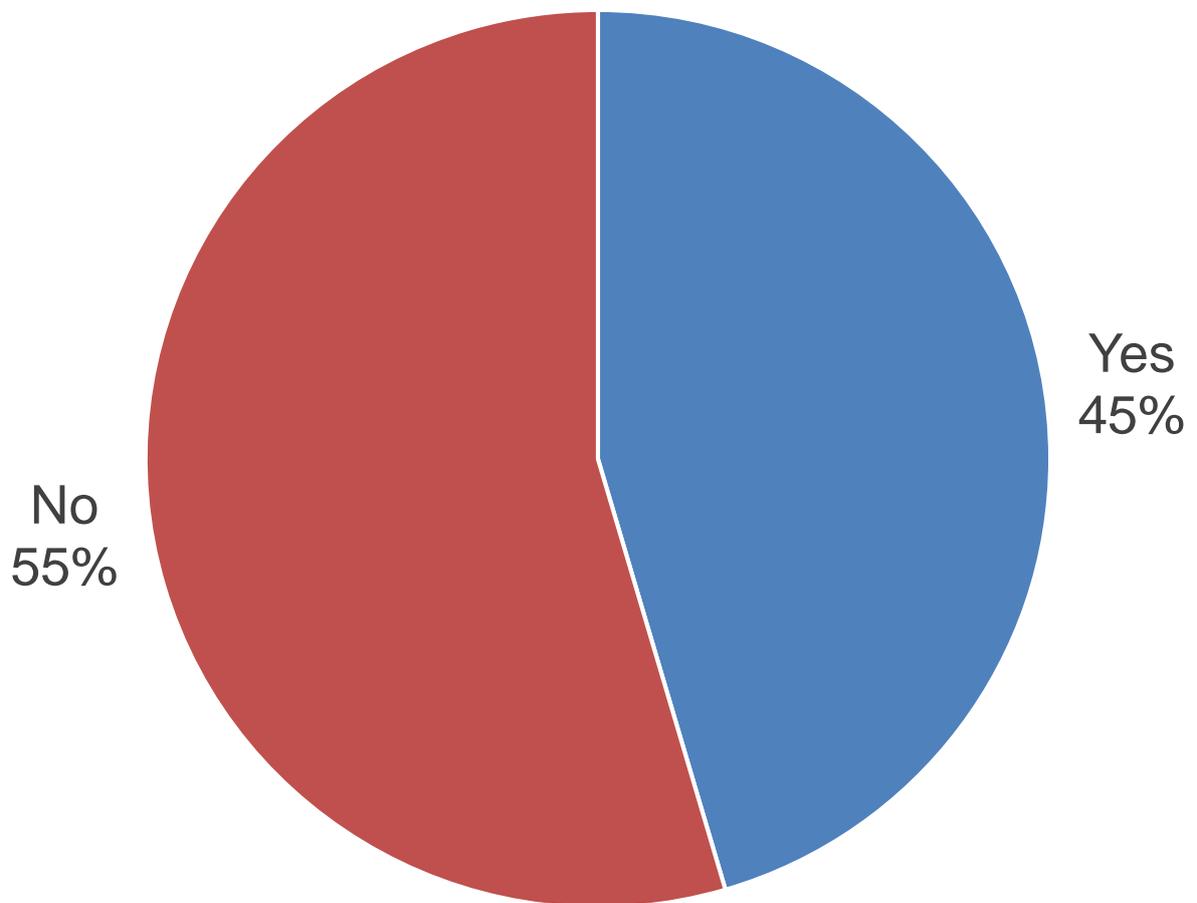
Nobody had intersex relatives or they didn't know about them.

## Do you identify as LGB or queer?



About third (36%) of participants identified as LGB or Queer, and about half (55%) were unsure.

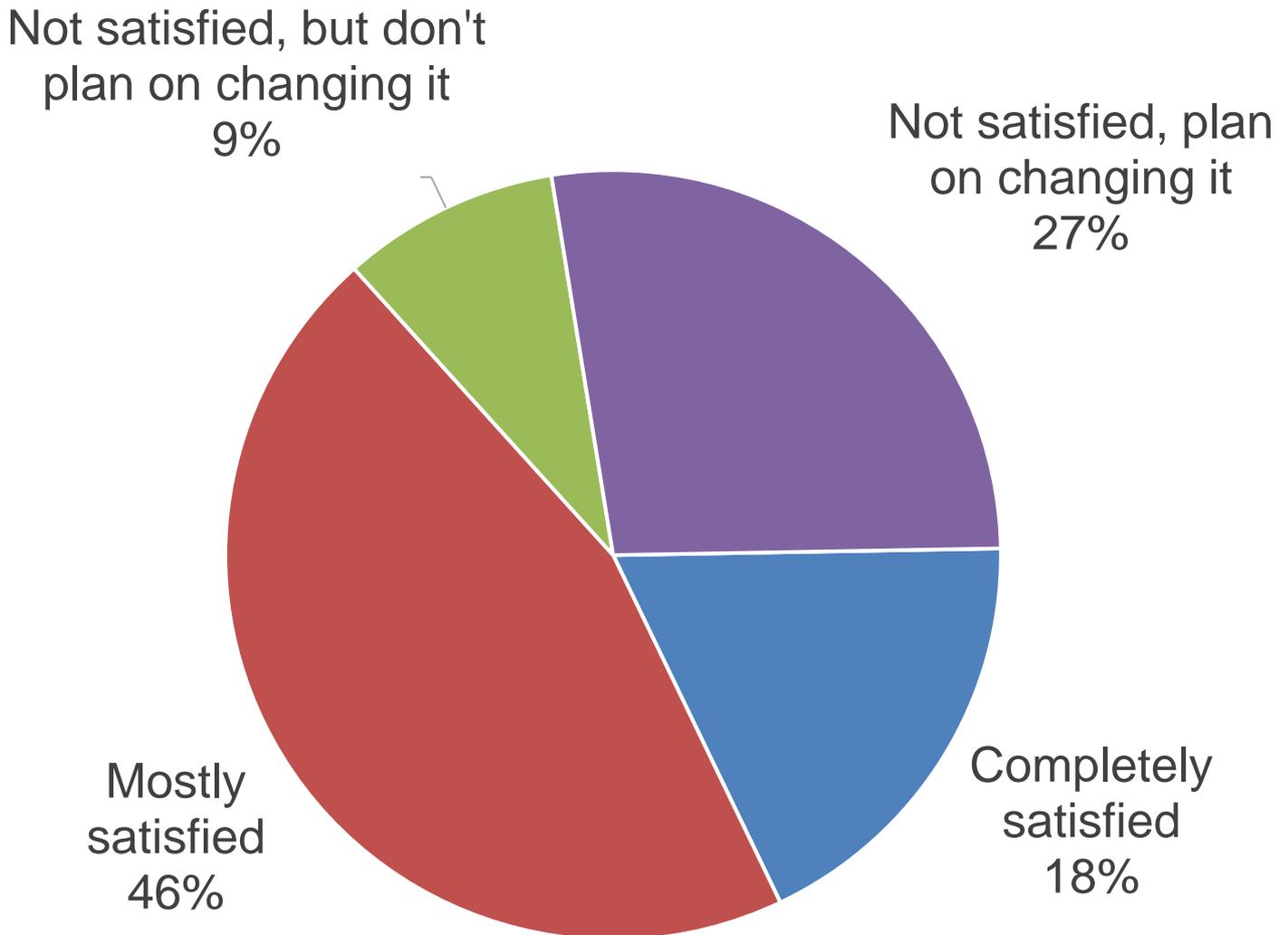
## Do you identify as transgender?



Almost half (45%) of participants identified as transgender.

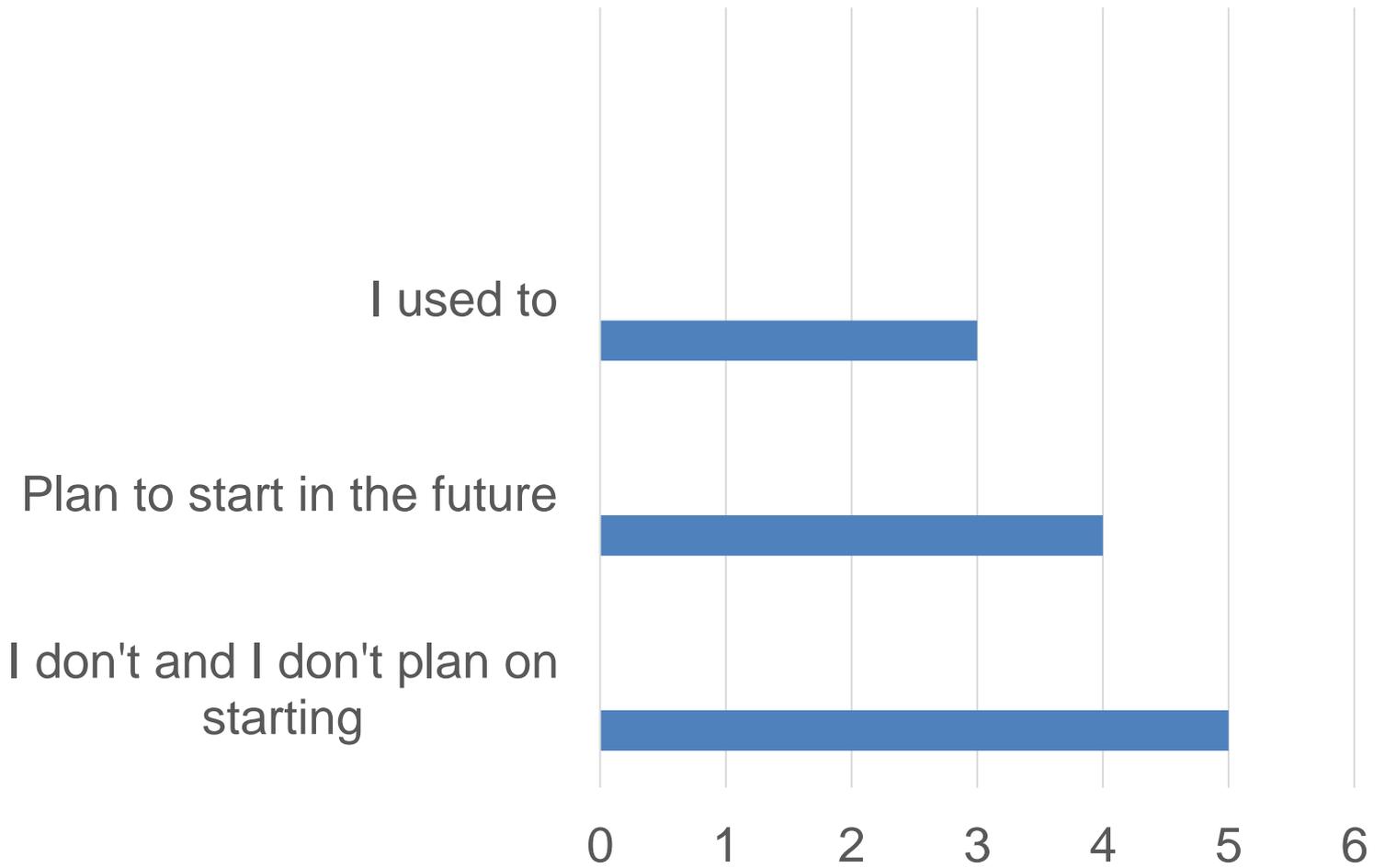
Maybe we can assume that in Russia it's easier to get a hold on information about intersex if you're already a part of the LGBT community?

## Are you satisfied with the gender marker in your passport?



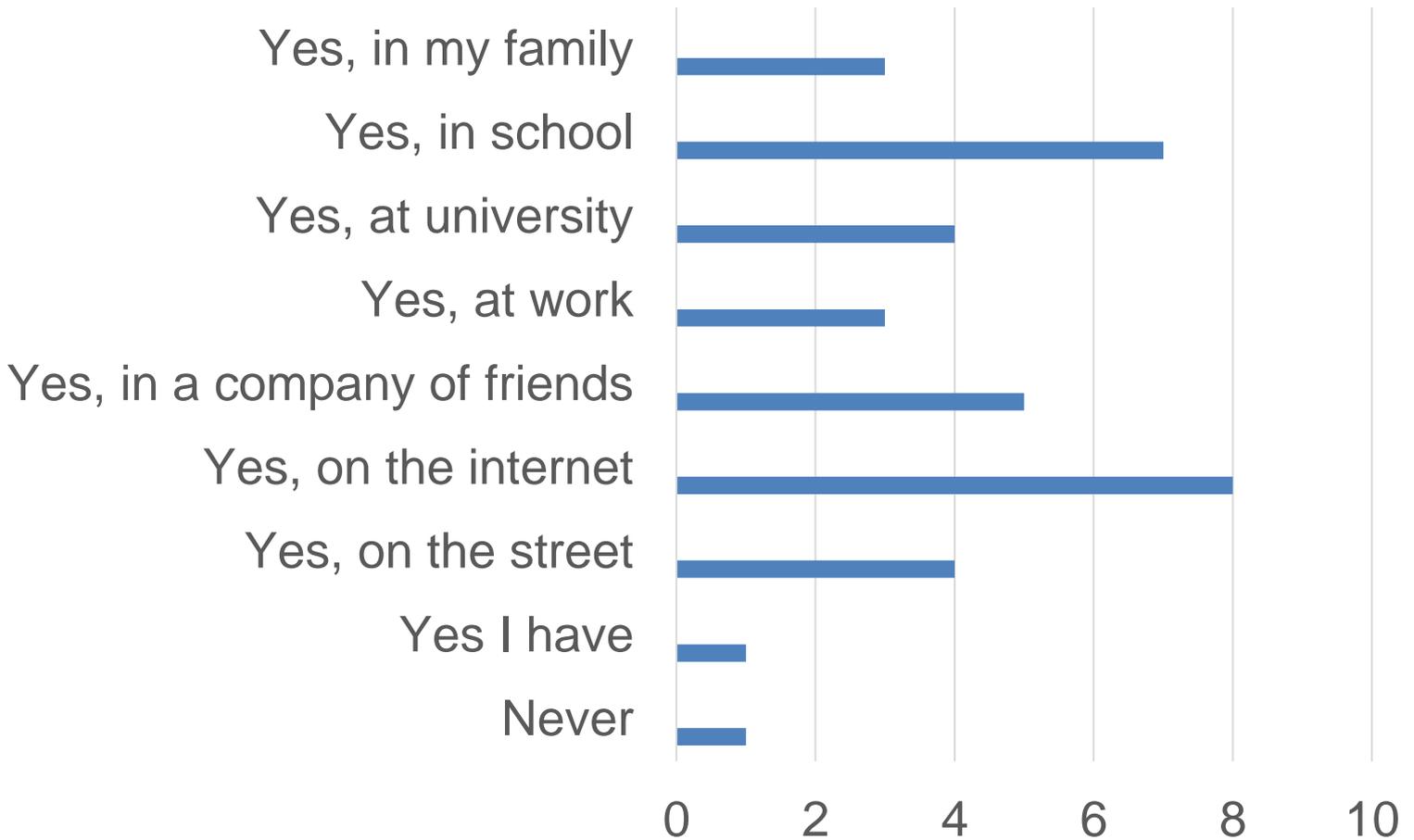
The majority (64%) of participants were more or less happy with gender marker they had in their documents, 4 participants were unhappy with their gender marker, 3 of these people plan on changing it.

## Do you get a disability pension?



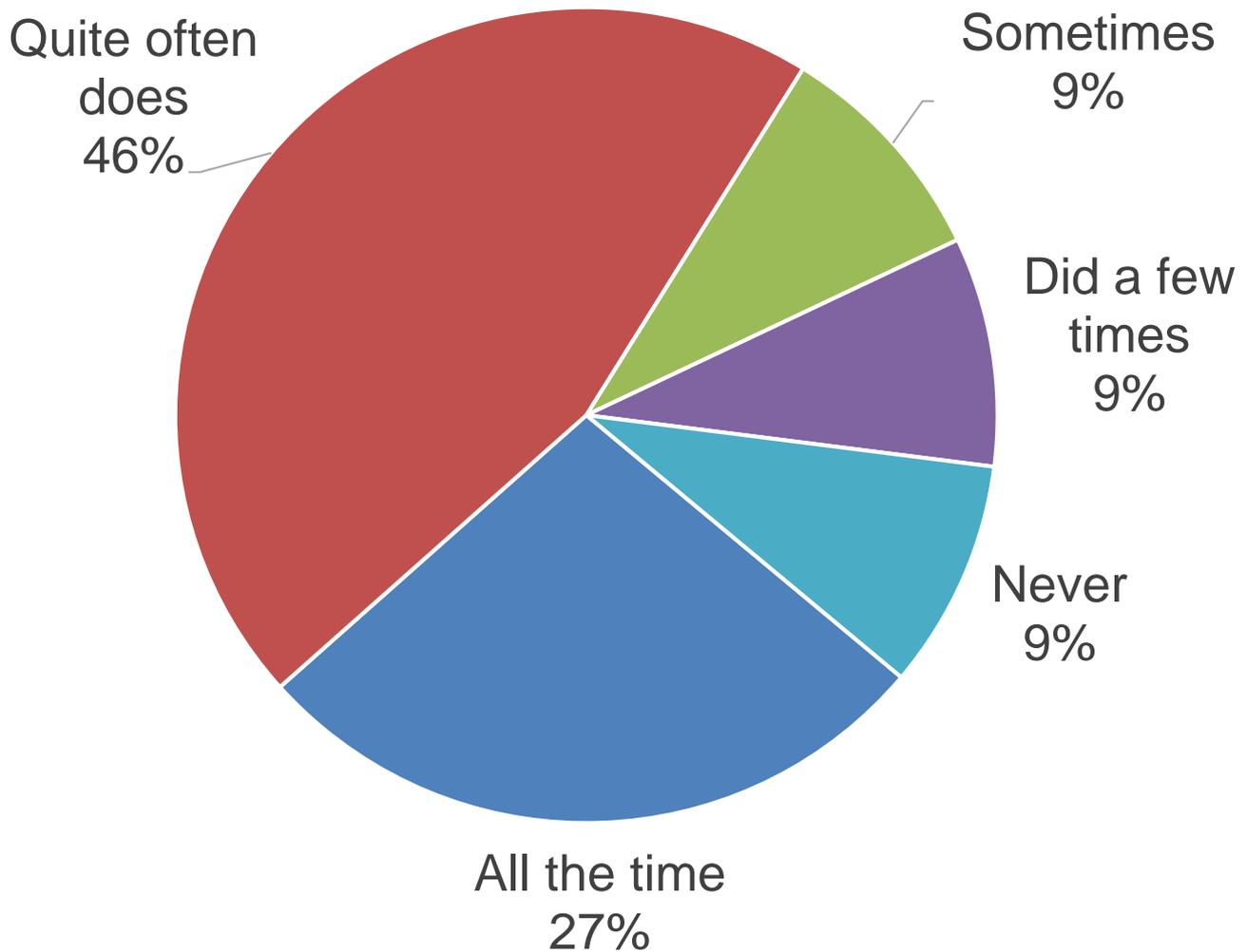
No participants receive disability pension at the moment.  
In Russia intersex variations are officially considered a disability.

## Have you ever experienced bullying related to your intersex variation?



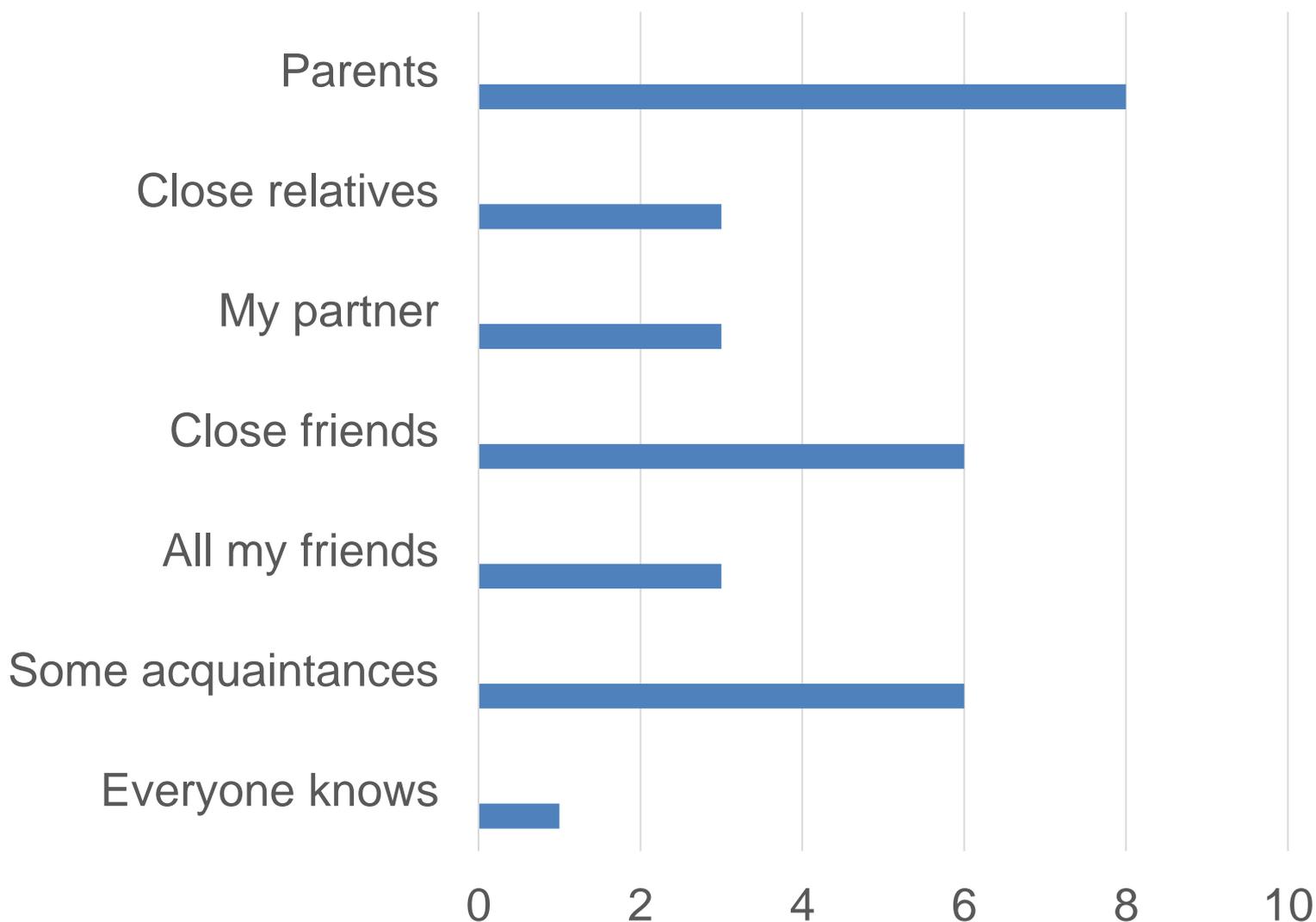
Almost all (91%) participants experienced bullying related to their intersex variation at some point in their lives. Most often the bullying happened on the internet (73%), in school (64%) and in the company of friends (46%).

## Your intersex variation ever causes you any problems in your love life?



To almost all participants (91%) their intersex variation created problems in their love life, the majority (73%) experience those problems constantly or quite often.

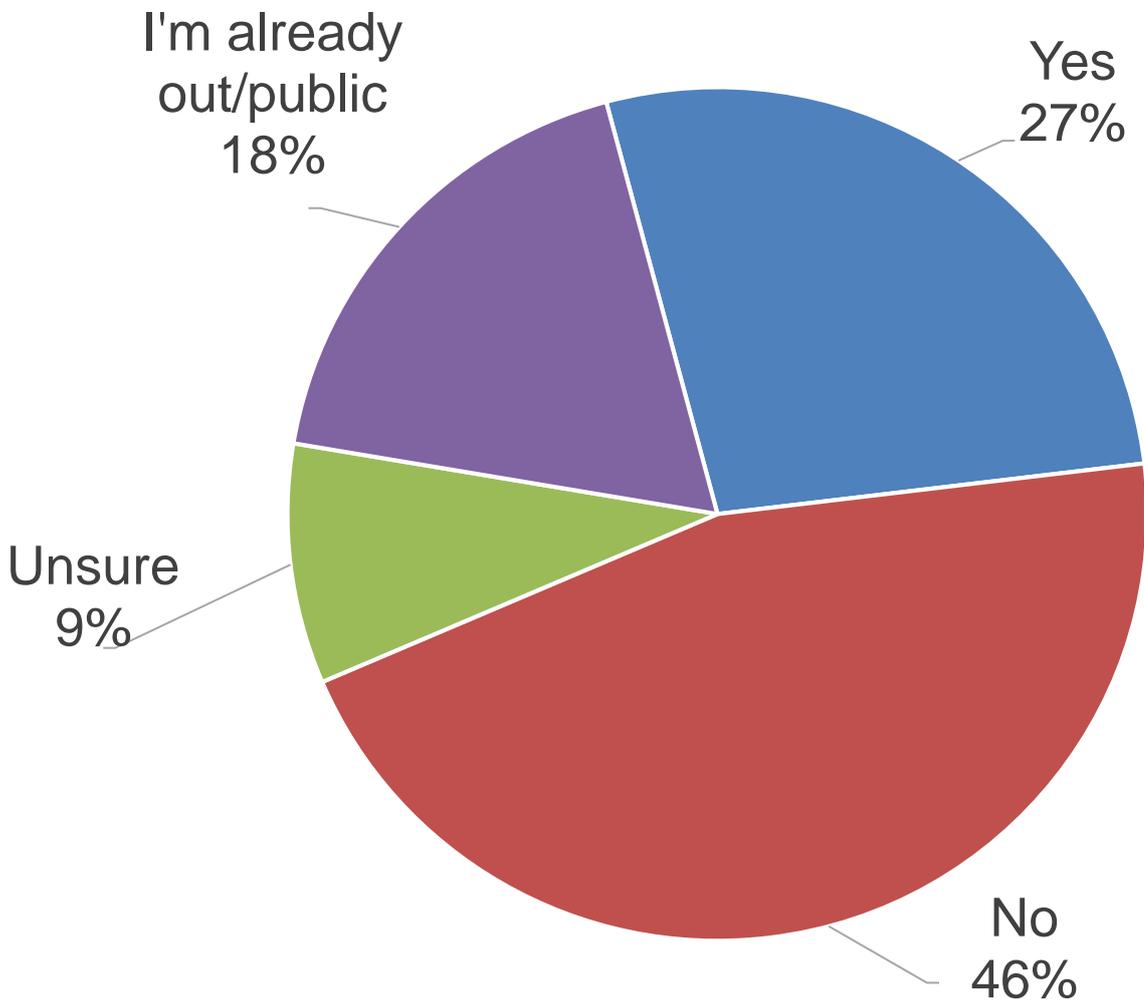
## Who knows about your intersex variation?



When asked about who knows about their intersex variation, most often the people who knew about it were parents (73%) and close friends and some acquaintances (55%).

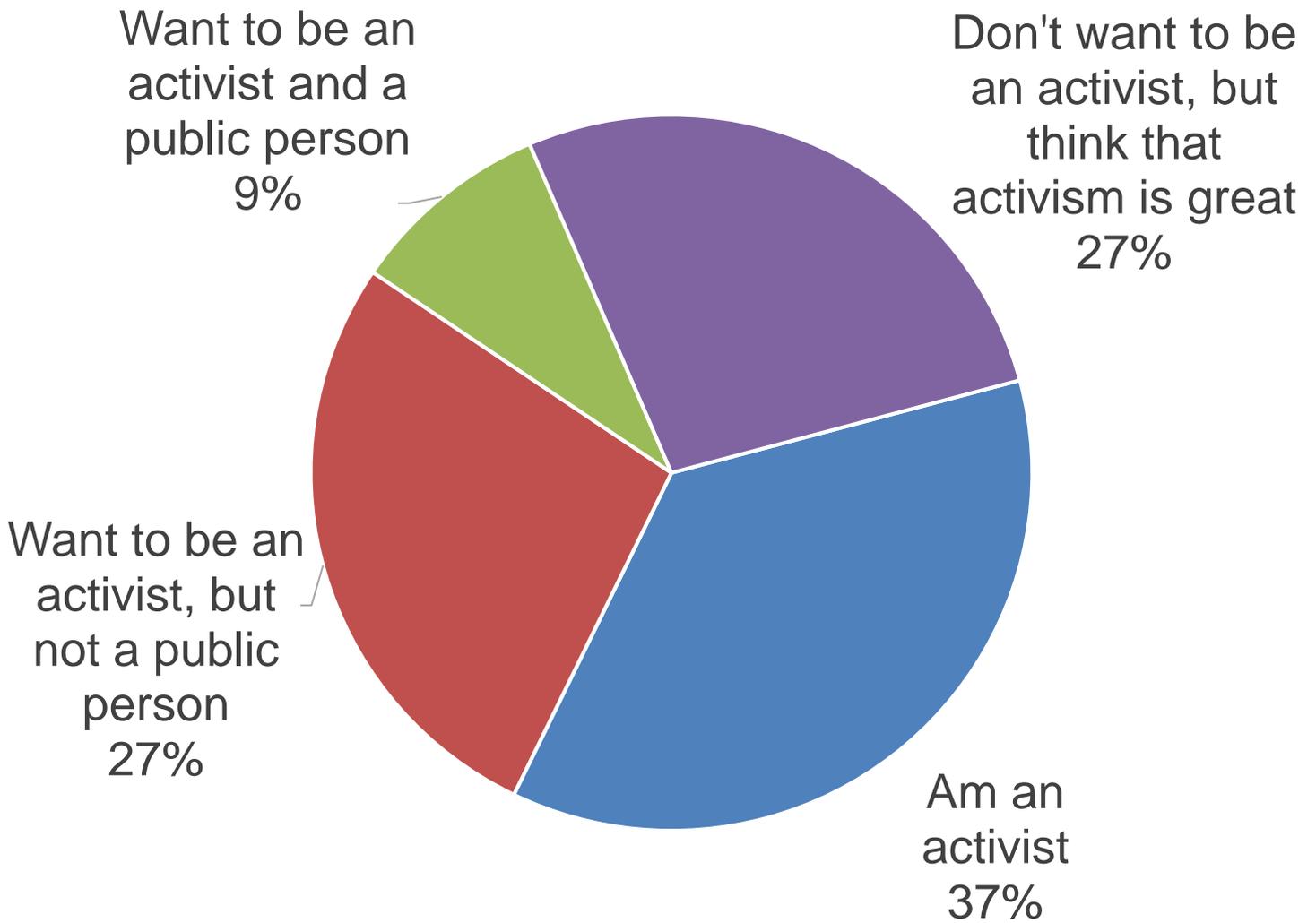
Only one person chose the answer «Everybody knows» about their intersex variation.

## Do you plan on coming out/being public about being intersex in the future?



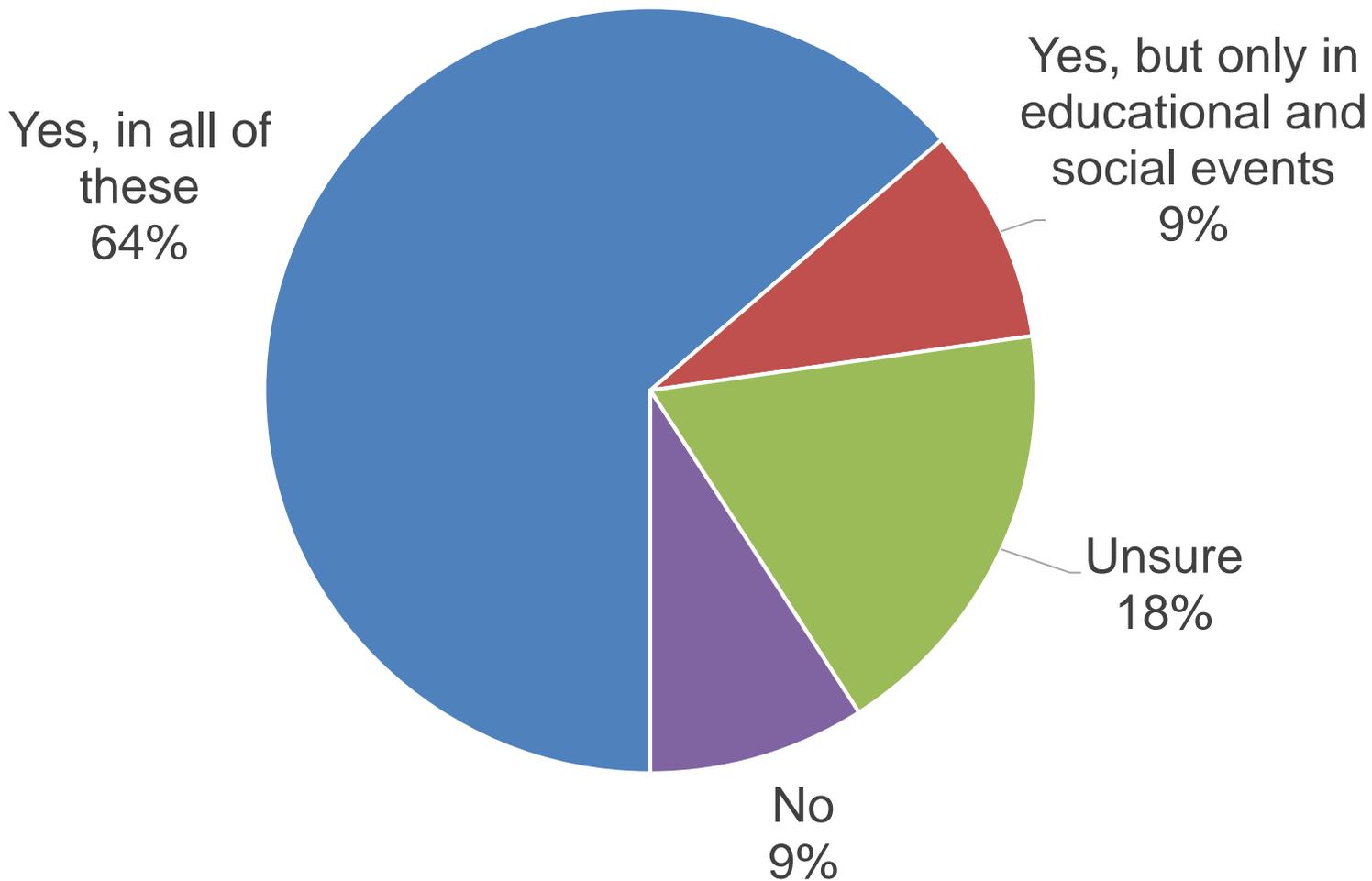
Almost third (27%) plan on coming out publicly as intersex in the future, two people (18%) are already out, and almost half (46%) does not plan on coming out.

## Your opinion on intersex activism



One third (37%) of participants said that they are intersex activists, the same amount wants to become activists in the future, the rest doesn't want to be activists, but they think that activism is great.

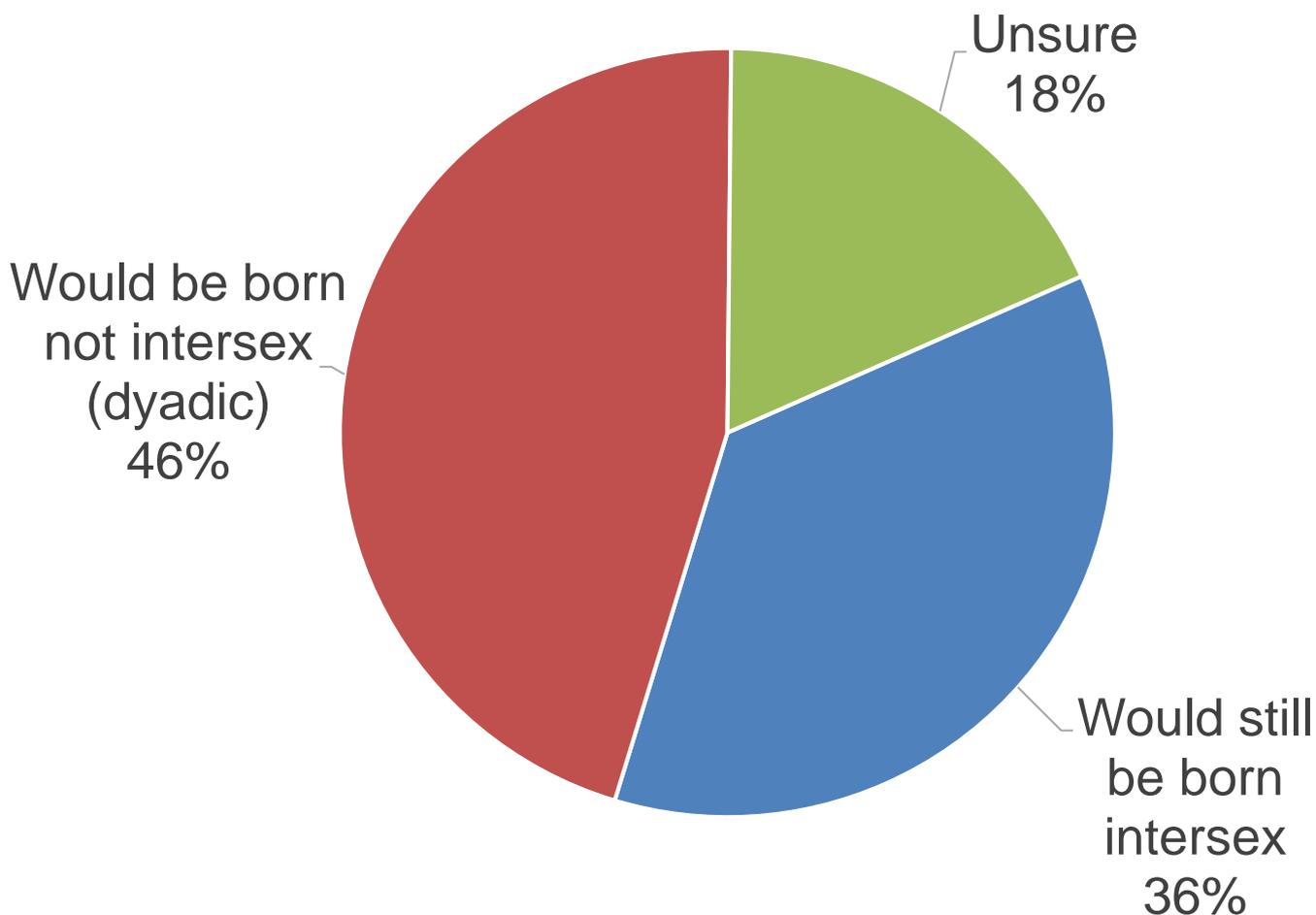
Would you participate in support groups, psychological trainings, educational and social events with other intersex people?



The majority (64%) of participants said that they would take part in support groups, psychological trainings and other events with other intersex people.

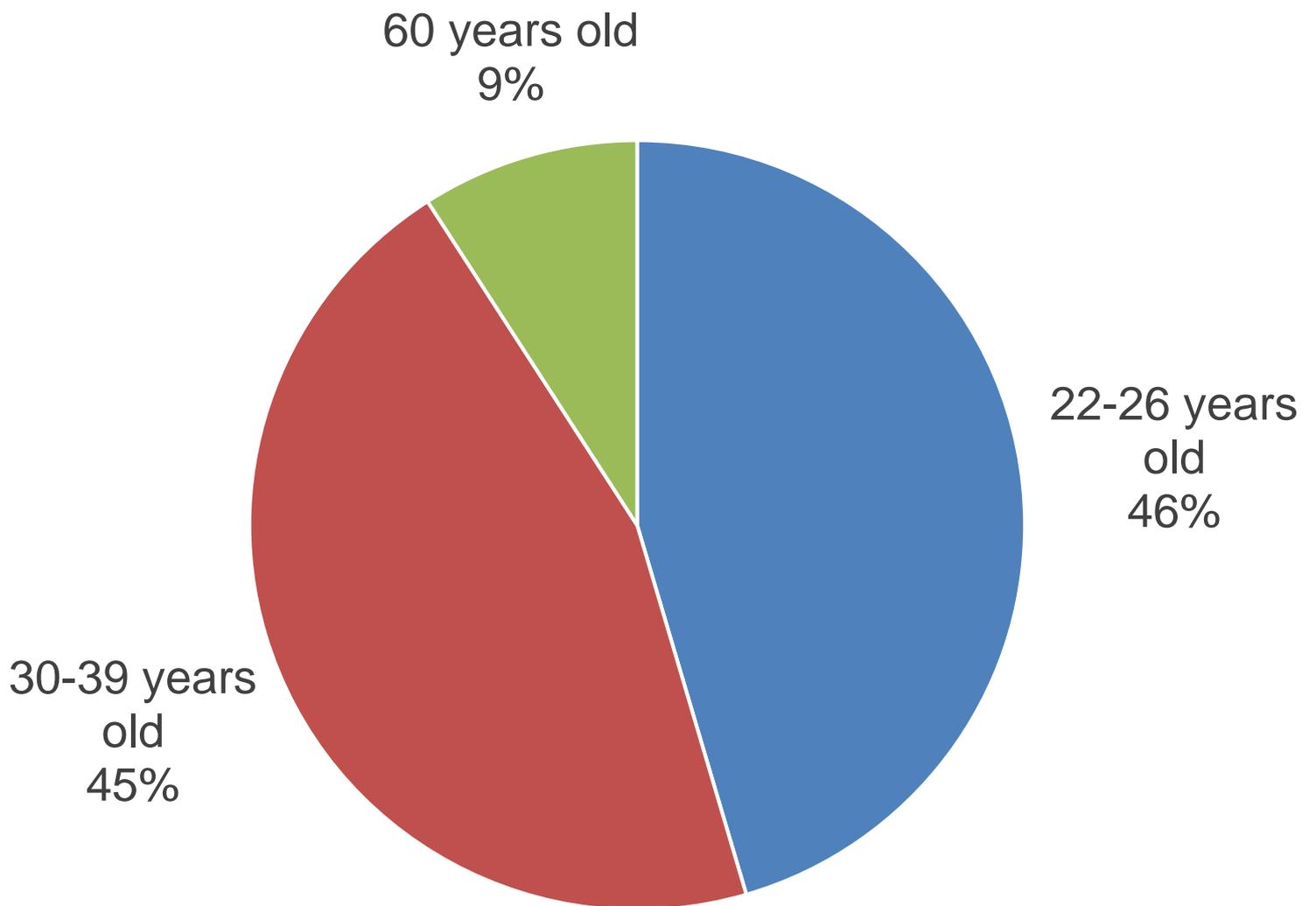
Participants saw goals of intersex activism as «sharing information, so no one would go through what I went through in my life» and «helping others accept themselves and to evolve in their life».

If you could choose to be born non-intersex, what would you choose?



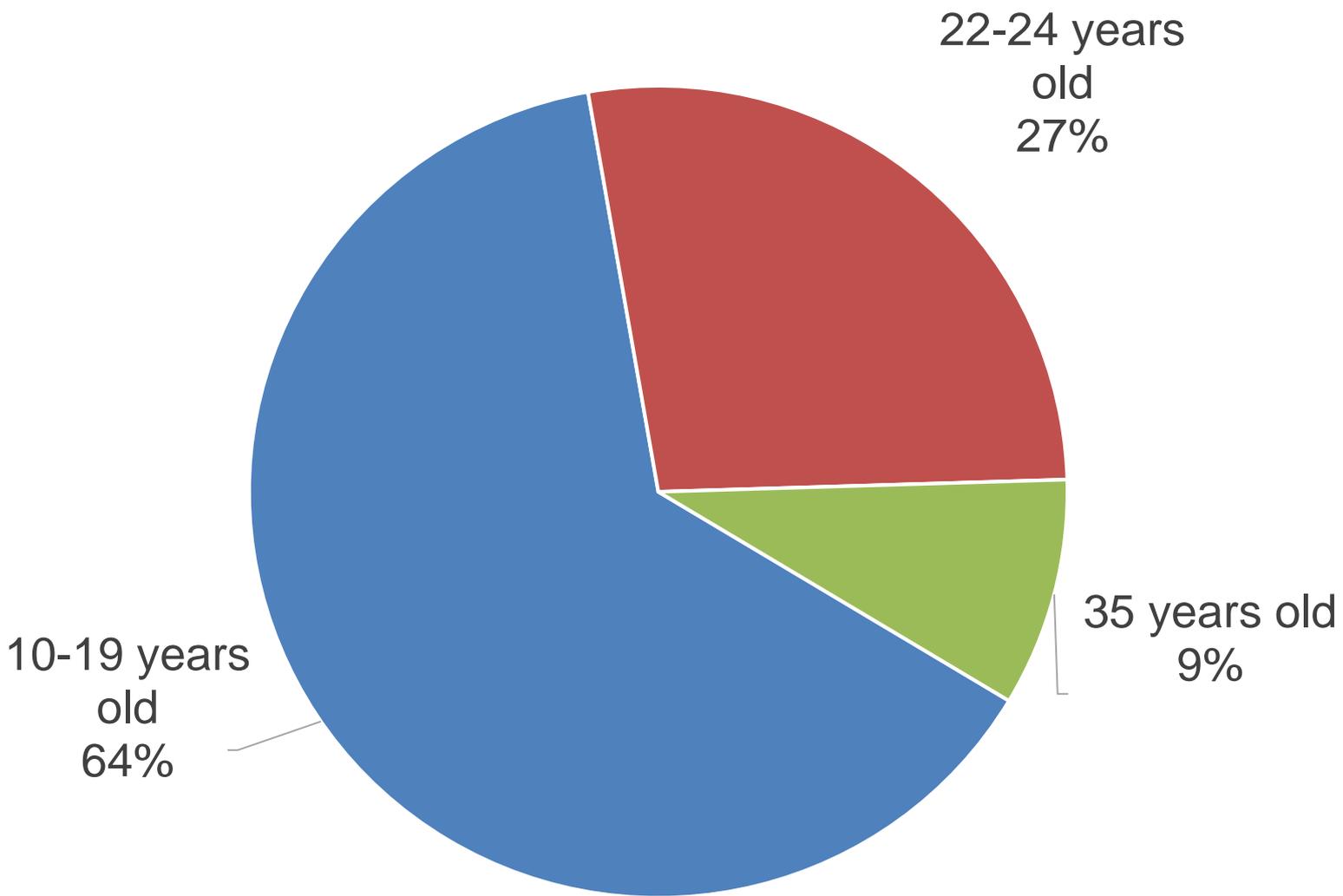
Almost half (46%) of participants would like to be born non-intersex (dyadic) if they could, third (36%) would still choose to be born intersex, the rest were unsure.

## How old are you?



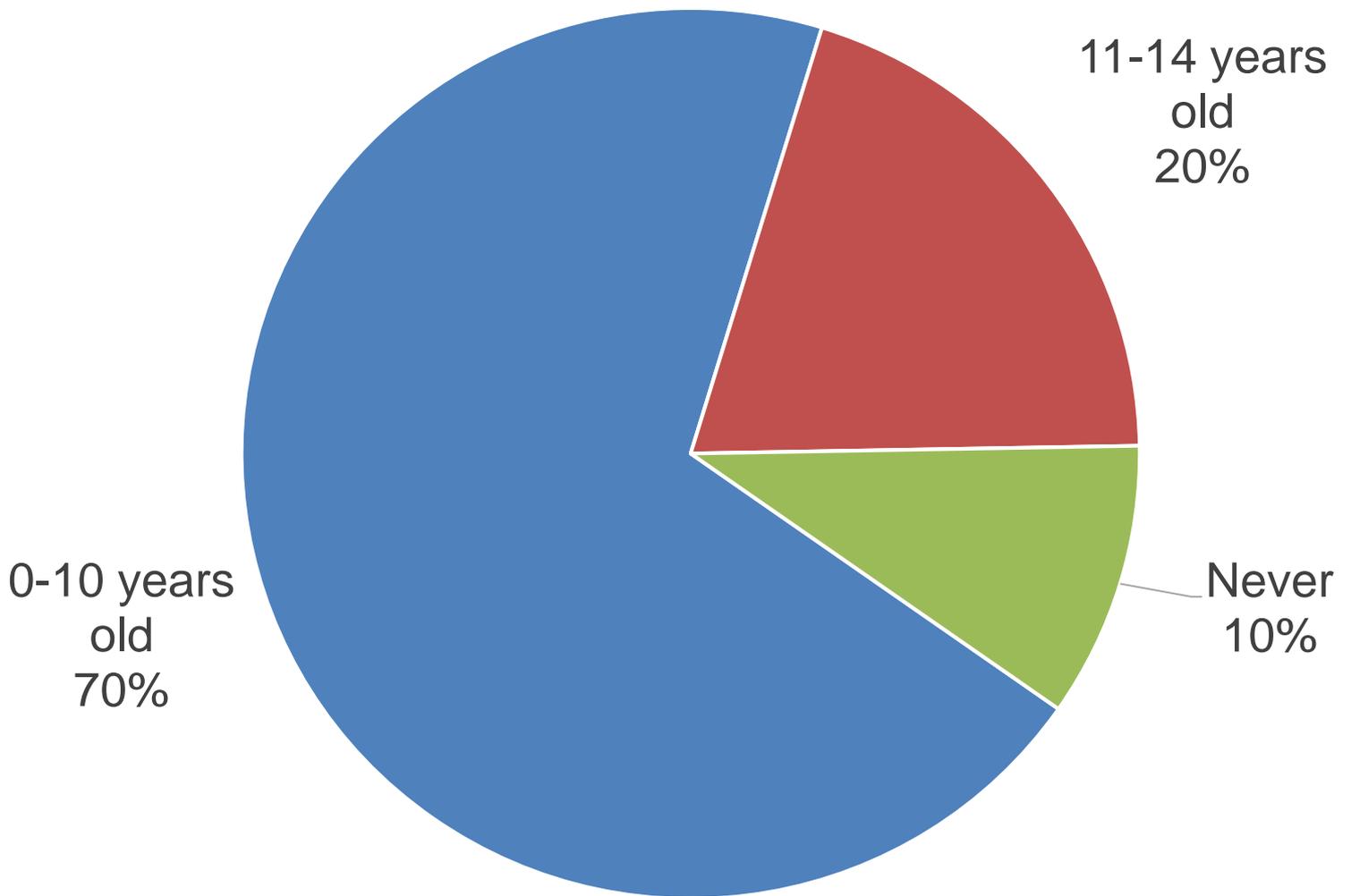
Most (91%) participants were aged from 22 to 39 years old.

## How old were you when you found out that you're intersex?



The majority (64%) of participants found out that they're intersex at the age of 10-19 years old, third (27%) found out in their early 20s, and one person at 35 years old.

## At what age you wish you learned that you're intersex?



When asked about when they ideally wanted to find out they're intersex, the majority (70%) of participants wanted to find out in their early childhood - from birth to 10 years old, 20% wanted to find out at 11-15 years old, and one person wanted to never learn that information.

So, the majority of participants wanted to find out that they're intersex much earlier than they actually did.

73% of participants told **which intersex variation they had**, most often participants had Klinefelter variation or AIS.

## Conclusions

In the end we had unexpected results, which showed that almost half of participants plans on coming out in the future or are already out; big percent of participants are intersex activists or want to become one in the future, and many participants agreed on taking part in intersex-related events. Our intersex community is quite young and not very well-developed, right now we have only 2 intersex organizations in the Post-Soviet region, Association Russia-Speaking Intersex and Egalite Intersex Ukraine.

Problems we face in our countries are mostly the same as everywhere else. Most participants agreed that almost nobody in our countries knows about intersex, there's almost no positive intersex representation in the media, that we have strong gender norms, pressure to conform to which all of our participants experienced at some point in their lives.

Participants who don't want to move to another country all don't speak English very well, and on the other hand, participants who speak English well almost all want to move to another country, they also all feel negative about the word "hermaphrodite" and almost all are for adding the "I" in "LGBTI".

Adding the "I" in LGBTI is quite a big topic in our community, some people are against it for various reasons (for example, the risk of people not understanding the difference between intersex and LGBT and their negative attitude towards LGBT passing onto intersex community as well), but the majority are for adding the "I".

Almost half of participants were transgender.

Many participants received no information or false information about their intersex variation from their doctors and parents, and the majority of participants wanted to find out that they're intersex much earlier in live than they actually did. Almost all participants have experienced bullying related to their intersex variation at some point in their lives.

Medical actions towards intersex people in our countries still leave a lot to be desired, and all our participants to this day experience negative emotions when visiting a doctor on behalf of their intersex variation.

Overtime the amount of people who feel positive about their intersex variation doubled, and almost all participants have noted that communicating with other intersex people changed their live for the better – this only proves how essential is a well-developed intersex community, that would provide support and information to other intersex people, especially to those who just found out that they're intersex.

Overall we can hope that Russia is potentially a little less intersexphobic than it is homophobic. And even though our Russian-speaking community is very young and small, every person in our community is interested in the bright future for us. But we're still on the very beginning of our path of recognition of intersex rights in Russia and Post-Soviet countries.

[www.arsintersex.org](http://www.arsintersex.org)