Belong To LGBTQ+ Youth Ireland

Trinity College Dublin
The University of Dublin

Findings from Being LGBTQI+ in Ireland

Sub-report

Healthcare experiences, wellbeing and mental health of people who have variations in sex characteristics in Ireland

Being
LGBTQI+
in Ireland

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Foreward: Belong To – LGBTQ+ Youth Ireland

Being LGBTQI+ in Ireland (2024) covers many interconnected aspects of life as an LGBTQI+ person in Ireland, and with this sub-report we welcome the opportunity to focus on those respondents who identified as intersex or have an intersex variation. At Belong To, we have supported LGBTQ+ young people since 2003, and part of that work is to improve understanding of their experiences. The LGBTQ+ community faces a range of challenges, and thus far there has been limited understanding of the specific challenges faced by intersex people in Ireland.

This sub-report focuses on 31 participants who identified as intersex or as having an intersex variation. Much of this cohort reports negative physical and psychological wellbeing, and rates of self-harm, suicidal thoughts, and suicide attempts are high. Self-esteem and resilience are low in many participants, and body dissatisfaction is common. Among those who received medical intervention relating to being intersex, some reported that it was non-consensual or that they had not had the opportunity to make fully-informed decisions. Participants report that negative reactions from their family, healthcare providers, and wider society contribute to feelings of isolation and rejection as well as mental health difficulties.

Although it is a small sample, the findings of this sub-report show that much greater understanding of people with intersex variations is needed across society – from medical professionals to educators to friends and family. While there have been many positive developments for LGBTQ+ communities in Ireland in recent decades, there remain gaps in our collective knowledge and awareness. The experiences and needs of individuals with intersex variations are among those gaps and must be addressed in order to ensure inclusivity in LGBTQ+ healthcare and social supports.

On behalf of Belong To, I want to express our deep thanks to the research team at Trinity College Dublin led by Professor Agnes Higgins, the research advisory group members particularly Intersex Ireland, funders and each person who participated in this research. It is thanks to your responses that we can present this report and use it to inform more inclusive LGBTQ+ advocacy into the future.

Moninne Griffith (she/her)

CEO, Belong To – LGBTQ+ Youth Ireland

Foreward: Intersex Ireland

We in Intersex Ireland are grateful to Belong To and the team at Trinity College Dublin for this important report shedding light on issues faced by one of Ireland's most invisible and vulnerable communities. This report could not be timelier as anti-LGBTQIA+ rhetoric spreads seemingly unchecked with the rise of fascism, foretelling troubling times ahead for our communities. Recent research from the European Union[1] shows sharp increases in violence and discrimination against intersex people as well as transgender people. Intersex variations themselves are typically not visible; however, how intersex variations manifest affect even heterosexual, cisgender intersex people, leaving many with bodies and sometimes personalities that do not meet strict, binary hegemonic societal expectations.

Research shows even cisgender, heterosexual intersex children suffer high levels of bullying in schools, and discrimination in the workplace as adults[2]. Because of a paucity of intersex awareness in medical and mental health settings, intersex people in Ireland and elsewhere struggle to access adequate and appropriate care. Although we comprise as much as 1.7 percent of the population[3], we are rendered invisible through a combination of factors including stigma, shame, and a lack of cultural representation, as well as secretive medical practices, elements of which would be illegal under any other circumstances. Non-consensual intersex genital surgery was recognised in 2013 as torture by the UN Special rapporteur[4].

Since 2015, several countries have begun implementing bans on these medically unnecessary, irreversible, and harmful procedures but Ireland has yet to catch up[5]. In this age of rising intolerance, we increasingly fear for intersex children born into homes where parents might buy into right-wing unscientific narratives around sex and gender without the benefit of intersex awareness.

Thank you Belong To and TCD.

Adeline Berry, PhD
Intersex Ireland

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[1] European Union Agency for Fundamental Rights (FRA). (2024, May 14). *LGBTIQ equality at a crossroads: Progress and challenges*. FRA. fra.europa.eu/sites/default/files/fra_uploads/fra-2024-lgbtiq-equality_en.pdf

[2] Berry, A. (2024). Experiences and Needs of Older European Intersex People. *Unpublished PhD Thesis. Huddersfield: University of Huddersfield*.

[3] Office of the High Commissioner for Human Rights (OHCHR). (2017). Fact sheet: Intersex. United Nations Free and Equal. https://www.unfe.org/wpcontent/uploads/2017/05/UNFE-Intersex.pdf

[4] Méndez, J. E. (2013). *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment.* Human Rights Council. https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

[5] International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA). (2025). *Legal Frameworks | Restrictions on interventions on intersex minors.* ILGA. https://database.ilga.org/interventions-intersex-minors

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Glossary

Abrosexual describes the fluid nature of sexuality. It refers to individuals who experience fluctuations in their sexual orientation.

Androgynous is a term used to describe individuals whose outward gender expression cannot be distinguished as feminine or masculine, or combine traits that are considered masculine and feminine.

Asexual is a term used to describe someone who experiences limited or no sexual attraction.

AFAB is a term used to describe someone whose sex was assigned as female at birth, typically based on their anatomical and other biological characteristics.

AMAB is a term used to describe someone whose sex was assigned as male when born, typically based on their anatomical and other biological characteristics.

Bisexual or Bi is a term used to describe someone who is sexually and romantically attracted to multiple genders.

Cisgender or Cis is a term used to describe an individual's gender when their experiences of their gender correspond to the sex they were assigned at birth.

Demisexual is a term used to describe someone who feels sexual attraction only to people with whom they have an emotional bond.

Differences of Sex Development (DSD) is a term used to refer to a wide range of variations in sex characteristics within medical contexts. Many people with variations consider these terms to be stigmatizing and pathologizing.

Exploratory Laparotomy is surgery where the body is opened to examine the internal organs.

Gay is a term traditionally used to describe a man who is sexually and romantically attracted to other men. While the term 'lesbian' is typically used to describe women who are attracted to other women, many women with same-sex attractions self-identify as 'gay'.

Gender binary refers to the concept that there are only two genders, man and woman, and that everyone must be one or the other. The concept of the gender binary is often misused to claim that gender is biologically determined, e.g. that our bodies and biology define our genders. This concept reinforced the idea that men and women are opposites and have different roles in society.

Gender dysphoria refers to distress resulting from a difference between a person's gender identity and the person's assigned sex at birth, associated gender role, and/or primary and secondary sex characteristics.

Gender identity refers to how a person identifies with a gender category. For example, a person may identify as either a man or woman, or in some cases as neither, both or something else.

Gender incongruence is a term used to describe people whose gender identity does not align, to a greater or lesser extent, with the sex assigned at birth.

Heterosexual is a term used to describe someone who is sexually and romantically attracted to a person of the opposite sex.

Hypospadias Repair is surgery to correct a congenital defect in the opening of the penis.

Internalised intersexphobia is a term used to describe a negative attitude of intersex people to their body, to their intersex variation, to their gender identity and sexuality, to themselves.

Intersex is an umbrella term used to describe a variety of conditions in which a person is born with anatomy or physiology that does not fit societal definitions of female or male (e.g. sexual or reproductive anatomy, chromosomes, and/or hormone production).

Interphobia refers to negative cultural and personal beliefs, opinions, attitudes and behaviours based on prejudice, disgust, fear and/or hatred of intersex people or against variations of physical sex. Institutional interphobia manifests itself through the binary gender model and the pathologisation and medicalisation of intersex bodies. Social interphobia manifests itself in the forms of marginalisation, social exclusion and exoticisation of intersex people.

Lesbian is a term used to describe a woman who is sexually and romantically attracted to other women.

LGB is an acronym for 'lesbian, gay and bisexual'.

LGBT is an acronym for 'lesbian, gay, bisexual and transgender'.

LGBTI is an acronym for 'lesbian, gay, bisexual, transgender and intersex'.

LGBTQI is an acronym for 'lesbian, gay, bisexual, transgender queer/questioning and intersex'.

LGBTQI+ stands for 'lesbian, gay, bisexual, transgender, queer/questioning and intersex' with the '+' signifying inclusivity to all sexual and gender identities. This is the acronym used in the present study.

LGBTQIA+ is an acronym for lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual, and the + indicates expanding and new understandings of diverse gender and sexual identities.

Medical trauma is the experience of traumatic stress as a result of interactions with the medical system, which may include procedures (i.e., surgeries), new diagnoses (i.e., cancer), and professionals in healthcare settings.

Minority stress is based on the premise that LGBTQI+ people, like members of any minority group, are subject to chronic psychological stress due to their group's stigmatised and marginalised status. While LGBTQI+ people are not inherently any more prone to mental health problems than other groups in society, coping with the effects of minority stress can be detrimental to LGBTQI+ people's mental health.

Non-binary is a term used to describe someone whose gender identity is neither exclusively woman or man or is in between or beyond the gender binary.

Pansexual is sexual or romantic attraction toward people of any sex or gender identity.

Queer is an umbrella term used to describe people who are not heterosexual and/or are not cisgender. Queer was used as a slur against the LGBTQ+ community for many years and still can be. However, the word has been reclaimed by LGBTQ+ communities and many now embrace the term as one denoting any gender identity or sexuality that does not fit society's traditional ideas about gender or sexuality. Queer may also be used to indicate people's identification with a politically alternative perspective to what some might see as the more assimilationist perspectives of the LGBTQI+ communities.

Questioning is the process of examining one's sexual orientation and/or gender identity.

Polycystic ovary syndrome (PCOS) is a condition in which the ovaries produce an abnormal amount of androgens, male sex hormones that are usually present in women in small amounts.

Self-harm refers to the act of harming oneself in a way that is deliberate but not intended as a means to suicide. Examples of self-harm include cutting, scratching, hitting, or ingesting substances to harm oneself.

Sex Assigned at Birth refers to the designation of a person at birth as male or female based on their anatomy (genitalia and/or reproductive organs) or biology (chromosomes and/or hormones).

Sexual identity refers to how a person identifies in terms of sexual and emotional attraction to others. It includes a wide range of identities, with the most typical being gay, lesbian, bisexual and heterosexual. A person's sexual identity may be different than their sexual behaviours and practices.

Sexual and gender minority (SGM) is an umbrella term that encompasses populations included in the acronym "LGBTI" (lesbian, gay, bisexual, transgender and intersex), and those whose sexual orientation or gender identity varies.

Sexual orientation refers to an enduring pattern of emotional, romantic or sexual attraction to others. It includes a wide range of attractions and terms, the most common being gay, lesbian, bisexual and heterosexual.

Transgender is an umbrella term referring to people whose gender identity and/ or gender expression differs from conventional expectations based on the sex they were assigned at birth. This can include people who self-identify as trans men, trans women, transsexual, transvestite, cross-dressers, drag performers, genderqueer, and gender variant.

Transmasculine is someone assigned a female sex at birth and who identifies as masculine, but may not identify wholly as a man.

Trans misogyny is a term used to describe dislike of or strong prejudice against transgender women.

Transphobia is a dislike, fear or hatred of people who are transgender, transsexual, or people whose gender identity or gender expression differs from the traditional binary categories of ‘male’ and ‘female’.

Variations in Sex Characteristics (VSD) (also referred to as intersex variations) is an umbrella term used to describe physical sex development which differs from what is generally expected of ‘males’ or ‘females’. These variations are congenital and may be chromosomal, gonadal, anatomical or hormonal.

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Executive summary

An intersex variation is an umbrella term used to describe people who have differences in internal reproductive organs, external genitalia, chromosomal, genes or hormonal levels which do not fit or align with how society defines male or female. Intersex variations are congenital and when detected at a young age, the person can receive medical, surgical, or hormonal interventions to reinforce sex assignment or align the physical body to a gender. For some people, life-saving medical interventions are necessary, for example, if a baby is born without the capacity to urinate or if hormone treatment is required. However, some interventions are not necessary for physical functioning and are performed to align the physical body to a gender.

Given the invisibility of people with intersex variations within society and research, the *Being LGBTQI+ in Ireland* study included focussed questions relating to healthcare experiences and mental health wellbeing for this population, the findings of which are presented in this sub report. Findings from the main study can be found elsewhere (Higgins et al. 2024). The report objectives are as follows:

- Objective 1: To report on the manner intersex participants discovered they were intersex.
- Objective 2: To describe the intersex participants' experience of medical interventions for their intersex identity.
- Objective 3: To provide a descriptive analysis of the wellbeing and mental health of participants who identify as intersex.
- Objective 4: To report intersex participants' perspectives on the impact of being intersex on their mental health and wellbeing.
- Objective 5: To report on intersex participants' perspectives of belonging within the LGBTQI+ community.

Participants in the *Being LGBTQI+ in Ireland* study were asked if they identified as intersex or have an intersex variation, to which 31 participants answered 'yes'. In addition to focussed questions in relation to their experiences, the study included validated measures on indicators of wellbeing and mental health, including self-esteem, resilience, depression, anxiety and stress, alcohol use, drug use and eating disorders. Participants were asked questions relating to self-harm and suicidality as well as being asked to rate their happiness, comfort with their gender and sexual identity, general health and satisfaction with their body. Demographic questions, including gender identity, sexual orientation and disability status were asked as well as a range of open-ended questions inquiring on experiences relating to being LGBTQI+ in different areas of life. One of these questions related to one's sense of belonging to the LGBTQI+ community, the responses to which were analysed for this cohort.

Most participants discovered their intersex variation incidentally, through engaging with healthcare services regarding a health issue or realising themselves through, for example, noticing that their body was different to other people. Just less than half of participants (45%, n=14) had not experienced a medical intervention related to being intersex, with a further 16% (n=5) reporting that they did not know if they had experienced a medical intervention, reflecting the lack of disclosure/transparency that can exist around treatments for people with variations of sex characteristics. Of the remaining sample, 12 (39%) individuals had undergone a medical intervention related to being intersex, eight of whom stated it was non-consensual. However, of the four participants who reported that the medical intervention had been consensual, two of them qualified their responses in open-ended text saying that they hadn't made fully informed decisions due to a lack of information or misleading information being given around the consequences and outcomes of the treatment. Therefore, for the majority of those who had experienced a medical intervention, it appeared to be non-consensual. Words such as 'invasive' and 'coercive' were used by some participants to describe their experience of medical interventions while others highlighted a lack of information and explanation around the treatments they received. A desire to have known sooner about one's intersex variation(s) was expressed by some participants highlighting the need for openness and information to be made available to people with intersex variations.

The nature of the interventions included surgery as a child for hypospadias repair (n=3) and related to undescended testes (n=1); surgery as a baby with exact details unknown as hospital records not available (n=1); exploratory laparotomy (n=1); invasive examinations (n=1); breast augmentation surgery and other cosmetic procedures (n=1); and hormone treatment as teenagers (n=3). Participants reported that the interventions themselves caused a range of adverse physical and psychological effects on participants, some of which were long-term, including sexual and urinary difficulties, chronic pain, sleep disorders, an array of mental health difficulties, gender dysphoria and issues related to body image.

Further indications of the physical and psychological wellbeing of participants emerged from the quantitative data, wherein the majority of participants reported having a psychological or emotional condition or a mental health issue; difficulty with learning, remembering or concentrating; and difficulty with pain, breathing or any chronic illness or condition while just less than two-fifths rated their general health as either good or very good. Three in five reported symptoms of severe or extremely severe anxiety, two in five reported symptoms of severe or extremely severe depression and 3 in 10 reported symptoms of severe or extremely severe stress. Lifetime prevalence rates of self-harm, suicidal thoughts and suicide attempt were high at 60%, 74% and 50% respectively.

Nearly half of the sample had scores indicative of low self-esteem and two-fifths low resilience. Participants rated their happiness at 6.00 out of 10 on average. Mean scores for comfort with gender identity and sexual orientation were 7.00 and 7.64 respectively on a 0-10 scale with higher scores reflecting greater comfort. Almost half of participants expressed dissatisfaction with their body while 38% reached the risk threshold indicative of having a potential eating disorder.

Around one third abstained from alcohol consumption. Of those who did drink, 25% scored as being at moderate risk for problem drinking. Among those who had taken drugs, most had taken them in the past month (n=12/16), with over half of these scoring at a moderate or severe level of drug use, for which further investigation or intensive assessment would be required.

Participants reported that negative and stigmatising reactions to their intersex variation(s) from within their family, society and healthcare services contributed to feelings of isolation and rejection as well as mental health difficulties. The findings highlight how the pathologisation of bodily variations as abnormal has led to corrective genital surgeries and gender assignment for some participants, contributing to the stigma and shame which surrounds having variations in sex characteristics. In terms of sense of belonging to LGBQTI+ communities, while two-thirds reported feeling welcome, over half reported unequal recognition in the LGBTQI+ communities and over one third reported feeling excluded. Comments on sense of community belonging highlight how a lack of understanding and recognition of intersex within LGBTQI+ communities, prejudices within the community and pressure to conform to certain expectations as well as a lack of solidarity among intersex people may contribute to feeling unaffirmed and excluded.

In interpreting the findings several limitations need to be considered. Given that the questions relating to experiences of having intersex variations were located within a much larger survey focused on well-being and mental health in the LGBTQI+ communities, the researchers were unable to ask the breadth of questions that would have gleaned a more comprehensive picture of the experience of living with intersex variations in Ireland in all aspects of one's life beyond healthcare. Most of the sample was aged under 35, therefore the findings may not reflect the experiences of older cohorts. More than half of the intersex sample identified as transgender and most had a non-heterosexual orientation, therefore there is clearly an intersection of identities informing people's experiences and outcomes which may not have been fully captured within the scope of the survey and this report. The researchers relied on participants' self-identification of having an intersex variation/s. Based on this, there was quite a large number (n=268) who answered that they did not know if they had variations in sex characteristics. A different method of determining participants' intersex status may have yielded more participants. The small sample size prevented any analysis of the quantitative data beyond descriptive statistics.

Considering these limitations, the following recommendations are provided:

- More research is needed in Ireland into the needs and experiences of people who have variations in sex characteristics, including longitudinal studies to map health and wellbeing and research into the knowledge and competence of people working in paediatric settings on intersex variations.

- Given the dearth of information on people with intersex variations, in particular, the HSE should undertake or commission a review of the needs of the intersex community. Specific attention needs to be given to mental health, reproductive and gynaecological care, bone health, cancer care and gender-affirming healthcare.

- Given that positive attitudes towards diverse identities is improved with both knowledge about and exposure to them (Higgins et al. 2024), it is important that teaching on intersex variations is introduced into school curricula in order to combat prejudice and promote acceptance.

- In light of the qualitative comments there is a need for a programme of work that focuses on the education of health care professionals, general public as well as LGBTQI+ organisations on the needs and experiences of intersex people.

- In light of the healthcare experiences of participants, those who provide their healthcare must be cognisant of the needs of individuals with intersex variations. Thus, the delivery of LGBTQI+ inclusive and affirmative healthcare needs to ensure that the rights of individuals with intersex variations are respected and upheld when receiving care.

- In the spirit of co-production, there is a need for greater involvement of intersex people in shaping research agendas, curricula (school and health care) and policy to ensure that all these areas are informed by their experiences and needs.

- Organisations which provide peer support and education to people with intersex variations should receive adequate funding to do so.

- Greater collaboration between LGBTQI+ advocacy organisations and intersex community groups and individuals, including ‘Intersex Ireland’, is needed to explore how best to represent Intersex people’s voices. Additionally, health-based advocacy organisations and groups also need to work with intersex community groups and individuals to ensure this cohort’s needs are advocated for beyond LGBTQI+ contexts.

Chapter 1: Introduction

Introduction

Intersex is an umbrella term which describes variation/s linked to physical, biological and chromosomal sex characteristics that do not fit the typical binary ideas of male and female bodies. A person with an intersex variation can have different genetic or chromosomal genotypes other than XX female and XY male (Marimus and Cense 2024). These genetic variations include a mix of chromosomes (XXY, XYY), a mix of cells that are both XX and XY or may be just one X chromosome (XO). They may also have variations in internal reproductive organs, external genitalia or hormonal levels or secondary characteristics (like body hair) which do not align with how society defines male or female.

Presentations of intersex variation/s can be identified at any time antenatally, at birth or throughout the lifespan with some people never becoming aware of variations throughout their life (European Union Agency for Fundamental Rights (FRA), 2015; Rosenwohl-Mack et al. 2020; FRA, 2020). The broadly accepted prevalence of intersex conditions is 0.5 - 1.7% of the population (FRA, 2015; Hill et al. 2020). However, a lack of population studies that ask questions about intersex variation/s, disagreement among professionals as to what defines an intersex variance, combined with a reluctance among intersex people to disclose their intersex status, means that this percentage range is only estimated (Rosenwohl-Mack et al. 2020; Price et al. 2021). In some medical settings, the term 'disorders/differences of sexual development (DSD)'[6] is used to describe intersex variations. However, this term is rejected by intersex people as it is considered pathologising and stigmatising (FRA, 2015; Price et al. 2021; Monro et al. 2024), with a distinction being made between medically necessary interventions and 'cosmetic procedures' that are used to 'normalise' an intersex body (Haghighat et al. 2023). Hence, intersex advocacy groups are attempting to reframe intersex diversities as part of the natural variation of human bodies, as opposed to being medical problems requiring intervention in themselves, with some arguing that early interventions have resulted in people with intersex variations being hidden in society, stigmatised and shamed.

Given the invisibility of people with intersex variations within society and research, the *Being LGBTQI+ in Ireland* study included focussed questions relating to healthcare experiences and mental health wellbeing for this population (Higgins et al. 2024). Drawing on the data from the 31 participants who answered 'yes' to the question that asked if they identified as intersex or have an intersex variation, the focus of this report is on answering the following five objectives:

1. To report on the manner intersex participants discovered they were intersex.
2. To describe the intersex participants' experience of medical interventions for their intersex identity.

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[6] While intersex or variation/s in sex characteristic are preferred terms, some authors use the term DSD to describe the population of their study so DSD may be used in that context in this report.

3. To provide a descriptive analysis of the wellbeing and mental health of participants who identify as intersex.
4. To report intersex participants’ perspectives on the impact of being intersex on their mental health and wellbeing.
5. To report on intersex participants’ perspectives of belonging within the LGBTQI+ community.

Prior to discussing the methodology and findings and to help set the context, the following section briefly reviews the national and international literature.

Discovery and awareness of one’s intersex variation

How and when a person becomes aware of one’s intersex variation is addressed in a few studies. In an EU LGBTI study (FRA, 2020), 34% of intersex participants stated that they received a specific medical diagnosis from a medical practitioner while another 33% received some information, but did not get a specific diagnosis or clear information about this. Another 43% indicated that they found out themselves but do not say how, while 1 in 10 stated that other people told them about their intersex variation/s, but it was not stated who that was. In an Irish study, involving 25 participants, 58.3% (n=14) reported that someone told them about their intersex variation, with 41.7% (n=10) reporting that they discovered themselves (Ní Mhuirthile et al. 2022). Four participants (16%) reported that they always knew about their variation/s, twelve (48%) learned about it during adolescence and another eight (32%) learned during their twenties, with one person (4%) finding out in their sixties.

The binary two sex model, which assumes that sexual development is unambiguous and congruent in one sex only - male or female (Victorian Department of Health and Human Services, 2018), has guided the medical management of people with intersex variation/s, particularly since the 1950’s when surgery and hormone therapy have been used to assign gender, as a corrective measure for intersex variation/s (Munro et al. 2024). Within this model, treatments commence early in life to ‘normalise’ children and assign them a sex (Falhammer et al. 2018; Hill et al. 2020; Rosenwohl-Mack et al. 2020; Zeeman and Aranda, 2020; Amos et al. 2023; Monro et al. 2024) which raises the issue of informed consent for medical interventions. Indeed, a lack of information in terms of how intersex people are informed of their variation/s as described above, and a lack of information on the medical interventions performed, including the long-term consequences of treatments is a common thread in studies involving intersex people (Zeeman and Aranda, 2020; Haghighat et al. 2023). In Berger et al.’s (2024) international sample of intersex people, over half (51%, n=38) reported that they did not know how to describe their intersex variation/s due to a lack of information, with the majority of these being aware that they previously had some medical interventions. In Hill et al.’s (2020) Australian study (n=47), 54% (n=25) of participants had undergone medical treatment for an intersex variation, of which 68% (n=17) had the medical intervention as a child. Of the 25 who had undergone a medical intervention, less than one quarter (24%) reported that they were able to provide informed consent, while 27% (n=6/22) reported that their parents were able to provide full and informed consent.

Subsequent non-disclosure of treatments to intersex people also raises questions about rights, consent and autonomy (Hill et al. 2020; Price et al. 2021). Ní Mhuirthile et al. (2022) highlights the difficulty intersex people have in accessing medical records. Within this study, participants report receiving no files or receiving redacted files with information missing, and consequently having to seek anecdotal accounts from doctors or parents or, in one instance, seeking school records, to ascertain time absent from school to determine when surgery may have taken place (Ní Mhuirthile et al. 2022).

Physical health in people with intersex variation/s

Several studies have been conducted into the physical and mental health of intersex people (Falhammer et al. 2018; Rosenwohl- Mack et al. 2020), with some researchers focusing on quality of life or health related quality of life (Jurgensen et al. 2014; Bennecke et al. 2017; Thyen et al. 2018). While there are some differences among study findings, most people with intersex variation/s are considered physically healthy (FRA, 2015; Jones, 2016; Falhammer et al. 2018; Rosenwohl-Mack et al. 2020). Nearly eighty percent of participants in the Jones (2016) Australian intersex survey considered themselves 'moderately' to 'extremely' healthy. Of those who did not consider themselves healthy, their intersex status was not always the reason for their poor health. Participants in Ní Mhuirthile et al.'s (2022) study also rated their physical health positively (either good or excellent) (n=9/15), with no person rating their physical health as very poor. However, despite positive self-reports of physical health, US and Australian studies note that intersex people have poorer health in comparison to the general population (Rosenwohl-Mack et al. 2020; Amos et al. 2023). Health difficulties noted by Falhammer et al. (2018) include issues with bone density, weight, heart and joint problems, fertility, and risk of certain cancers. There is also an increased risk with some intersex variation/s for kidney and liver dysfunction, autoimmune conditions such as hypothyroidism/under-active thyroid, and hearing or vision problems (Falhammer et al. 2018). Medical procedures that take place to reinforce gender assignment or revise external genitalia, which are often irreversible, can have long lasting effects, including infertility, pain, urinary problems, loss of sexual function and loss of sexual sensation (FRA, 2015; Amos et al. 2023; Berger et al. 2024).

Mental health in people with intersex variation/s

Studies suggest that intersex people experience poor mental health outcomes in comparison to the general population (Jones, 2016; Bennecke et al. 2017; Falhammer et al. 2018; deVries et al. 2019; Hill et al. 2020; Rosenwohl- Mack et al. 2020; Bennecke et al. 2021; Price et al. 2021). In a study conducted in fourteen tertiary healthcare sites across Europe on the health status of people with disorders of sex development, of which mental health was one element, participants had an increase in self-reported long standing psychiatric health problems and an increase in self-reported suicide attempts in comparison to the general population, with men reporting worse mental health than women (Falhammer et al. 2018).

These findings are also supported by Rosenwohl-Mack et al. (2020) in their USA study, with the majority (53.6%, n = 104) of intersex adults reporting their mental health as fair/poor. Over

60% reported that they were previously diagnosed with a general anxiety or a depressive disorder, with 61.7% (n=119) screening positive for depression on the 4-item Center for Epidemiological Studies Depression (CES-D) symptoms index. Additionally, 41% (n=81) reported that they had a diagnosis of post-traumatic stress disorder (PTSD). Younger people (aged 18-39) in this study had higher rates of anxiety than those 40 years or older (71.2%, n=84 vs 51%, n=36) and slightly higher rates of PTSD compared to older participants (43%, n=51 vs. 38%, n=27) (Rosenwohl-Mack et al. 2020).

Additionally, Jones (2016) found that people aged 18 to 87 with intersex variance (n=272) were more likely to report having engaged in self-harm (26%, n=71), with 19% (n=52) attempting suicide and up to 60% (n=163) considering suicide in comparison to 3% of the general Australian population. More recently, Amos et al. (2023), also in Australia, found 87% (n=40) of people with intersex variation/s experienced suicide ideation, 53% (n=24) had attempted suicide and 82% (n=38) reported experiencing anxiety and depression. It should be noted that in the studies here, depression, anxiety, self-harm, and suicide are the mental health outcomes reported. No studies reported the rates of substance use or eating disorders in intersex people.

Risk factors for mental health problems

The risk factors that impact the mental health of LGBTQI+ people are well documented (Wallace et al. 2024), with minority stress theory being the overarching framework through which mental health inequalities are examined. Many of the studies on the mental health of LGBTQI+ people do not differentiate for intersex as the numbers of intersex participants are usually small. Therefore, as a minority within a LGBTQI+ minority, less information is available on the unique stressors that intersex people deal with in comparison to other members of the LGBTQI+ community. One of the few studies, if not the only study, to examine external and internal minority stress-related determinants on health in people with intersex variation(s) was conducted recently, and it identified a range of proximal and distal factors impacting negatively on health as well as resilience factors protective of health in this population (van de Grift et al. 2024).

Proximal/ internal stressors

Proximal stressors specific to people with intersex variations include body-related stress and interpersonal stress as well as stressors common to all gender and sexual minority groups, namely internalised stigma and negative expectations which manifested in this population in terms of being resentful of one's intersex status and having concerns regarding disclosure (van de Grift et al. 2024). These experiences stem from the shame and secrecy that surrounds the diagnosis, medical management and long-lasting effects of the variation/s itself and associated treatment on the person's physical appearance and fertility. Zeeman and Aranda's (2020), systematic review of health inequalities in people with intersex variation/s, reported higher rates of depression, anxiety and psychological distress in people with intersex variations/s than the general population. This was related to experiences of stigma and discrimination. Similarly, de Vries et al. (2019) from the dsd-LIFE study[7] found that poor self-esteem, dissatisfaction with care, body dissatisfaction and experiences of shame were associated with an increase in mental health problems. As the condition cannot be changed, developing a healthy self-esteem and positive body image can be challenging (de Vries et al. 2019). Van de Grift et al. (2018) studied self-esteem and body image as part of the dsd-LIFE study (n=1040) and found that individuals with DSD showed lower rates of satisfaction with body image and self-esteem linked to body embarrassment, a lack of openness and higher anxiety and depression scores.

Similarly, Jones (2016) and Ní Mhuirthile et al. (2022) describe internalised intersexphobia[8] and its associated implications for mental health. Societal expectations of being born with a body that fits with social constructions of male or female contributes to internalised intersexphobia This leads to an intersex person developing a negative attitude to their own body, sexuality, gender identity and their intersex variation/s which results in an inability for the person to accept themselves.

Early treatment on a child can mean a loss of body autonomy but can also convey a sense of shame on the person and their parents, that intersex variation/s should be hidden and not disclosed (FRA, 2015; Berger et al. 2024; Monro et al. 2024). The language used to describe intersex variance such as disorders, anomalies and abnormalities can further stigmatise leading to isolation and disconnection from others (Jones, 2016). Medical interventions and the resulting sense of shame felt from being different combined with treatment side effects can impact the physical and mental health of intersex people (Hill et al. 2020; Rosenwohl-Mack et al. 2020; Haghighat et al. 2023). Ní Mhuirthile et al. (2022) report that participants felt very strongly that not knowing what happened to them or fully understanding what medical interventions took place was harmful and traumatic. An expectation of secrecy that the intersex person would not disclose their intersex status, stemmed from medical professionals and parents hiding the variance from the intersex person leading to a sense of shame (Jones, 2016; Ní Mhuirthile et al. 2022).

Distal stressors

Distal stressors specific to people with intersex variations include stressful or stigmatizing health care experiences, medical stress and trauma, secrecy and erasure, as well as stressors common to all gender and sexual minority groups, namely discrimination, rejection, victimization, and non-affirmation (van de Grift et al. 2024). Difficulty accessing one's medical history, rejection within LGBT communities, rejection within intersex support communities, healthcare and sexual victimization, and non-affirmation of diverse gender presentation or sex characteristics contributed to these stressors (van de Grift et al. 2024).

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[7] Dsd-Life is a European multicentre cross-sectional study of intersex people across 14 recruitment sites in 6 countries that specialise in the management of disorders of sexual development which examined the quality of life, clinical care, long-term effects of hormone therapies, experiences with surgery, and psychological support in persons with intersex variation/s.

[8] Internalised intersexphobia describes a negative attitude of intersex people to their own body related to their intersex variation, to their gender identity, sexuality and themselves.

Differences have been found among groups within the LGBTI+ community in their experiences of discrimination and harassment. The European Union Agency for Fundamental Rights (FRA) in their third LGBTIQ survey of twenty-seven EU countries involving 1,920 people with intersex variation/s (FRA, 2024) found that intersex people (along with trans people) still report the highest levels of discrimination (56% compared to EU-27 average of 37%) and hate-motivated harassment (74% compared to EU average of 55%). Moreover, the results indicate that trans and intersex people are experiencing growing levels of hate-motivated violence and discrimination across the EU (FRA, 2024).

Discrimination of intersex people on the grounds of their sex in terms of access to healthcare, education, public services, employment, and sport has been found in studies (FRA, 2015; FRA, 2024). This may be because outside of the medical context there is a lack of recognition of intersex people (Monro et al. 2024). As such, intersex people face several challenges relating to registering their intersex status in public documents and accessing suitable supports in areas such as employment, healthcare, and education.

Discrimination when accessing health/medical services was reported by 70% (16/23) of participants in Ní Mhuirthile et al.'s study (2022) related to their intersex variation/s. Discrimination experiences described by participants included no referral to support groups, feeling excluded during discussions, a lack of continuation after leaving children services, hearing medical staff refer to intersex variation/s using negative language and medical staff making assumptions about their needs. Healthcare staff confusing intersex variance with transgender identity and being ignored or being offered inappropriate care were also reported. Participants' negative experiences with some individual healthcare professionals who lacked sufficient knowledge or experience in caring for intersex people were noted, with reports of participants traveling to other countries to access suitable healthcare (Ní Mhuirthile et al. 2022). In the aforementioned EU study, approximately one in five intersex participants reported having to change their medical practitioner due to their negative reaction, while one in four reported that inappropriate curiosity or comments presented the most frequent problem in accessing healthcare services (FRA, 2024).

Challenges in accessing knowledgeable and affirming healthcare are associated with poor mental health outcomes in LGBTQ people with intersex variation/s (Amos et al. 2023). Care can be fragmented with problems finding specialists to provide suitable care, with intersex people having to deal with many specialists who do not communicate with each other (Zeeman and Aranda, 2020). Specific problems related to having to educate healthcare practitioners and finding someone with the suitable expertise has been found to be stressful for intersex people resulting in them disengaging from healthcare services (Thyen et al. 2018; Zeeman and Aranda, 2020; Amos et al. 2023).

Parental and peer rejection can also be a stressor with family-based silencing a constant worry (Henningham and Jones, 2021). Personal rejection from people close to them is reported by intersex people, specifically those who do not align with the gender assigned to them at birth (Jones, 2016; Price et al. 2021). Peer rejection has also been noted in studies based on young people's experience of school (Jones, 2016; Hennigham and Jones, 2021). Stress in adolescents from the uncertainty, confusion, and insecurity of trying to fit into a peer group has been noted in some studies, with intersex young people not disclosing their intersex status to avoid bullying or rejection (Sanders and Carter, 2015; Jones, 2016; Henningham and Jones, 2021). However, Jones (2016) found that while 75% (n=77/106) of Australian intersex young people were bullied, bullying was based on physical appearance as intersex status had not been disclosed. Consistent bullying relating to name calling, discrimination and physical violence were also described among school experiences in a survey of intersex people (n=86) conducted by Hennigham and Jones (2021). Students found ways to try to 'fit in' by maintaining gender roles aligned to their assigned gender, seeking same gender or other gender friendships aligned to their assigned gender, or seeking support in other 'outcasts' or members of the LGBT community (Henningham and Jones, 2021). However, the majority stated that they had no or few friends in school and spent more time than normal on their own.

This consistent bullying described in the study above contributed to participants feeling depressed and considering suicide (Henningham and Jones, 2021). These findings are also evident in Irish experiences described by Ní Mhuirthile et al. (2022), where 30% (n=7/23) of participants reported feeling discriminated against in school. Experiences of not being allowed to use the correct toilet or no access to gender neutral toilets, not being called by the correct name or pronoun, asked what gender they were, being shouted at, a lack of inclusion in the curriculum and hearing discriminatory comments were reported. Therefore, it is not surprising that the EU LGBTI study (FRA, 2020) reported that in the younger age group (15-17 years) only 5% reported being very open about their intersex status in school, with 18% avoiding certain places in comparison to lesbian (8%), gay (14%) and trans (12%) people (FRA, 2020).

People with intersex variation/s can also experience other vulnerabilities. Price et al. (2021) compared the experiences of LGBTQ young people who were intersex (N=1,132) and those who were not (N=34,759), and reported that 25% of LGBTQ people who were intersex experienced increased physical harm and dating violence in comparison to 19% of LGBTQ people who were not intersex. In addition, 64% of intersex youth had experienced discrimination or harassment based on sexual orientation or gender identity which increased to 68% for intersex youth aged 13-17 (68%) and to 73% for those who were transgender or non-binary, figures which were comparatively higher than those reported for intersex youth aged 18-24 (61%) and those who were cisgender (50%) (Price et al. 2021).

Protective factors for mental health outcomes

Familial and peer support, school safety, access to inclusive healthcare and gender affirming services as well as self-acceptance, and openness and disclosure in an accepting environment, are identified as protective factors in LGBTQ people's mental health (Thyen et al. 2014, Wallace et al. 2024). While less is known about the overall protective factors for mental health in intersex people, many of the factors appear similar. van de Grift et al. (2024) report on a number of resilience factors in their study with youth with intersex variations, which included activism, social support and acceptance, psychosocial/medical support, self-acceptance, openness and agency, and posttraumatic growth. Similarly, Price et al. (2021) report that acceptance of sexual orientation and/ or gender identity, particularly parental and peer acceptance, is a powerful protective factor for intersex young people (aged 13-24) who are also LGBTQ. Intersex participants who had supportive relationships, particularly from one or both parents, reported half the rate of suicide attempts in the year prior to study completion (9%) compared to those who did not have parental support (20%). Similarly, those with supportive friends reported lower rates of attempting suicide (15%) compared to those who had less support from friends (24%) (Price et al. 2021). Another protective factor identified within that study was having access to LGBTQ affirming spaces (Price et al. 2021), with 70% of people finding this online, 50% reporting access to this in school, while another 35% reported having this at home. People having respect for pronouns was also considered an important indicator of support, which was particularly important for intersex people who identified as transgender or non-binary. Those who had their pronouns respected by all or some of the people they lived with were less likely to report attempting suicide in the past year in comparison to those who did not (Price et al. 2021).

Chapter 2: Methodology

Objectives

The objectives of the study are as follows:

- Objective 1: To report on the manner intersex participants discovered they were intersex.
- Objective 2: To describe the intersex participants' experience of medical interventions for their intersex identity.
- Objective 3: To provide a descriptive analysis of the wellbeing and mental health of participants who identify as intersex.
- Objective 4: To report intersex participants' perspectives on the impact of being intersex on their mental health and wellbeing.
- Objective 5: To report on intersex participants' perspectives of belonging within the LGBTQI+ community.

Research design

This report is based on data from *the Being LGBTQI+ in Ireland* study (n=2,806). The *Being LGBTQI+ in Ireland* study as a whole examines the mental health and well-being of the LGBTQI+ community in Ireland. It collected data using an anonymous online survey from individuals who identified as LGBTQI+, were 14 years of age or over and living in the Republic of Ireland. This study received ethical approval from the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin. A more detailed methodology of this study is published in a full report (Higgins et al. 2024). The results related to people who identified as intersex or as having variations in sex characteristics (VSC) are outlined in this report.

Survey questions

Participants were asked a number of socio-demographic questions, including their age, gender identity and sexual orientation. Additionally, they were asked whether they identify as intersex or have an intersex variation. Participants who responded 'yes' were then asked a series of questions around their experience of being intersex particularly in relation to their healthcare experiences as well as their mental health. The questions were as follows:

1) How did you discover you are intersex/have variations in your sex characteristics? (i.e. did someone tell you?/ did you realise yourself?) (Open-ended question)
2) Has your experience of being intersex impacted your mental health? Please tell us. (Open-ended question)
3) Have you experienced any medical interventions for your intersex identity? (Four response options: Yes, non-consensual; Yes, consensual; No; Don't know)
4) If you are willing, please tell us about your experiences of the medical interventions/medical care you received? (Open-ended question)

The survey also contained questions related to general health, body image, disability, and community belonging.

Participants were asked to rate their general health with five response options given: very good, good, fair, bad and very bad.

With regard to body image, participants were asked to rate their satisfaction with their body on a 1-5 point scale, with 1 being ‘very dissatisfied’ and 5 being ‘very satisfied’.

Questions regarding disability were taken from the most recent census in the Republic of Ireland (CSO, 2022). Participants were asked to indicate the presence of any of seven long-lasting conditions or difficulties and the extent of a difficulty by choosing from three response categories: ‘no’, ‘yes, to some extent’ or ‘yes, to a great extent’.

To get participants’ perspectives on their sense of connection to LGBTQI+ communities participants were asked to rate (strongly agree to strongly disagree) six statements regarding belonging, inclusion and representation. These were:

- I feel welcome in the LGBTQI+ communities
- I don't feel included in the LGBTQI+ communities
- I feel the LGBTQI+ organisations do a good job advocating for my rights & needs
- I don't feel that my identity is given equal recognition in the LGBTQI+ communities
- I feel my identity is visible in the LGBTQI+ communities
- I feel isolated and separate from other people who share my identity

The survey also contained several validated tools which measured indicators of wellbeing and mental health. The following measures have been included in the analysis.

Happiness

Participants were asked, ‘Taking all things together, how happy would you say you are?’ on a scale of 0 meaning ‘extremely unhappy’ to 10 meaning ‘extremely happy’.

Comfort/Consonance around gender identity and sexual orientation

To measure comfort (consonance) or discomfort (dissonance) around gender identity and sexual orientation, an eight-question measure was generated, in the absence of an accepted validated measure for dissonance/consonance (Vaidis & Bran, 2019). The Comfort (Consonance)/Discomfort (Dissonance) Scale was constructed based on the comfort measure used in the *LGBTIreland* study (Higgins et al. 2016) and supplemented with themes based on the literature on the experiences of LGBTQI+ communities. Four questions focused on dissonance/consonance around gender identity (GI) and four were focused on sexual orientation (SO). Participants were asked to rate each item on an 11-point Likert scale ranging from 0 to 10. Total scores were computed for the GI scale and the SO scale, with higher scores on these scales indicating greater comfort/consonance with sexual orientation/gender identity.

Self-esteem

Rosenberg’s Self-Esteem Scale (RSES) was used to measure self-esteem. Participants were asked how much they agreed or disagreed with a series of 10 statements which comprise the Rosenberg Self-Esteem Scale (Rosenberg, 1965). Responses were scored from one to four, with higher scores indicating greater self-esteem. Participants were then given a total score based on their responses.

Resilience

The Brief Resilience Scale (BRS) (Smith et al. 2008) is a reliable and valid six item scale that assesses self-perceived ability to bounce back or recover quickly from stress. Each item is scored on a 5-point Likert scale ranging from 1 (low resilience) to 5 (high resilience).

Depression, anxiety and stress

The Depression Anxiety and Stress Scales (DASS-21; Lovibond & Lovibond, 1995) were developed to provide self-report measures of anxiety, depression and stress by assessing negative emotional symptoms experienced in the previous week. The scale has three subscales comprised of seven items for each dimension: depression, anxiety, and stress. Responses for each item were scored from zero to three and ranged from 'did not apply to me at all' to 'applied to me very much, or most of the time'. The items for each subscale were added and participants were given a total score. Because the DASS-21 is a short form version of the DASS (the Long Form has 42 items), the final score of each subscale (Depression, Anxiety and Stress) was multiplied by two (x2) in line with Lovibond and Lovibond's (1995) recommendation to allow comparisons to be made with the DASS-42. Scores on each of the sub-scales range from 0 to 42, with higher scores reflecting higher levels of distress. Scores are categorised into five groups: normal, mild, moderate, severe, and extremely severe. While not a diagnostic tool, this categorisation provides an indicator of the severity of the negative emotions of depression, anxiety, and stress. Interpretation of severity is based on cut-off points, with higher scores indicating greater levels of distress; for example, 'mild' means that the person is above the population mean, but still well below the typical severity of people seeking help (Table 2.1 for cut-off points).

Table 2.1: Scoring of the DASS-42

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28+	20+	34+

Self-harm and suicidality

Self-harm and suicidality questions were derived from the Lifestyle and Coping Survey (Madge et al. 2008). For self-harm, participants were asked whether they had ever deliberately harmed themselves in a way that was not intended as a means to take their own life. For suicidal thoughts, participants were asked whether they had ever seriously thought about taking their own life? For suicide attempt, participants were asked if they had ever made an attempt to take their own life.

Alcohol use

Participants were asked 10 questions to ascertain their alcohol use based on the Alcohol Use Disorders Identification Test (AUDIT) (Babor et al. 2001). Responses were scored from zero to four. Scores were totalled and fell into four categories: low risk level of alcohol consumption (7 or lower), moderate risk level of alcohol consumption (8-15), high risk level of alcohol consumption (16-19), and a very high risk level of alcohol consumption (20+).

Drug use

The Drug Abuse Screening Test (DAST-10) is a brief, self-report instrument for drug abuse screening and clinical case finding. It consists of 10 items, with a total sum score ranging from 0 to 10. A score of zero indicates that no evidence of drug related problems was reported. As the DAST score increases there is a corresponding rise in the level of drug problems reported. The level of drug problems may be categorised as follows: Low (1-2); Moderate (3-5); Substantial (6-8) and Severe (9-10) (Skinner, 1982).

Possible eating disorders

The SCOFF Questionnaire is a valid and reliable screening tool for detecting the possible existence of an eating disorder. The instrument was designed for use by both professionals and non-professionals. It has shown excellent validity in a clinical population and reliability in a student population. It is a brief 5-item measure where an answer of ‘yes’ to two or more items indicates the possibility of an eating disorder and warrants further questioning and more comprehensive assessment by a healthcare professional (Morgan et al. 1999, Luck et al. 2002). A further two questions have been found to have a high sensitivity and specificity for bulimia: i) Are you satisfied with your eating patterns? (‘no’); ii) Do you ever eat in secret? (‘yes’). These questions are not diagnostic but would indicate that further questioning and discussion is required (Hay, 2013).

Data analysis

Quantitative data

The quantitative data were analysed in SPSS Statistics Version 27 (IBM Corporation, 2020). Data analysis consisted of descriptive statistics (frequencies, percentages, means, standard deviations and cross tabulations). The valid percentage is reported for each question i.e. the percent when missing data are excluded from the calculations. Internal reliability analysis was conducted to assess the reliability of scales used in the survey. Most scale measures achieved high Cronbach’s Alpha values (>.70) indicating that they are reliable. SCOFF’s Cronbach’s Alpha was slightly lower at 0.58 (Table 2.2).

Table 2.2: Internal consistency analysis

Measure	Cronbach's Alpha
Rosenberg Self-Esteem Scale	0.93
Brief Resilience Scale	0.89
DASS 42 - Depression subscale	0.93
DASS 42 - Anxiety subscale	0.89
DASS 42 - Stress subscale	0.87
AUDIT	0.83
DAST-10	0.73
SCOFF	0.58
Comfort/Discomfort Scale	GI = 0.84; SO = 0.85

Qualitative data

The three open-ended questions relating to people's experiences of healthcare and the impact of being intersex on mental health were analysed. In addition, an open-ended question which asked participants to comment on their sense of connection or belonging to the LGBTQI+ communities, and how it might be improved was also analysed. All of the open-ended questions were examined for references relating to having an intersex identity. Thus, there are four themes presented: 1) Discovery of variations in sex characteristics; 2) Healthcare experiences; 3) Impact of being intersex on mental health; and 4) Community belonging. Participant quotes are used to illustrate these themes and these are accompanied by the participant's age, gender identity, sexual orientation and their unique study identification number.

Chapter 3: Findings

Demographics

Out of the Being LGBTQI+ in Ireland total sample of 2,806, 31 (1.1%) participants identified as intersex or as having variations in sex characteristics. There were 12 (0.4%) people who preferred not to answer and nearly one tenth (9.6%, n=268) who indicated that they didn't know. Of the 31 who identified as intersex or as having variations in sex characteristics, 19 reported that their gender did not match the sex they were assigned at birth. Participants' gender identity is displayed in Table 3.1. Five identified as a trans woman, four identified as a trans man, and ten as non-binary or gender non-conforming. A further eight identified as a man and three a woman.

Table 3.1: Gender identity

Category	n
Man	8
Woman	3
Trans woman	5
Trans man	4
Non-binary/gender non-conforming	10

The average age of the sample was 31 years (Range 16-61, SD=14.5). Most of the participants were aged under 35 (N=23/31) (Figure 3.1).

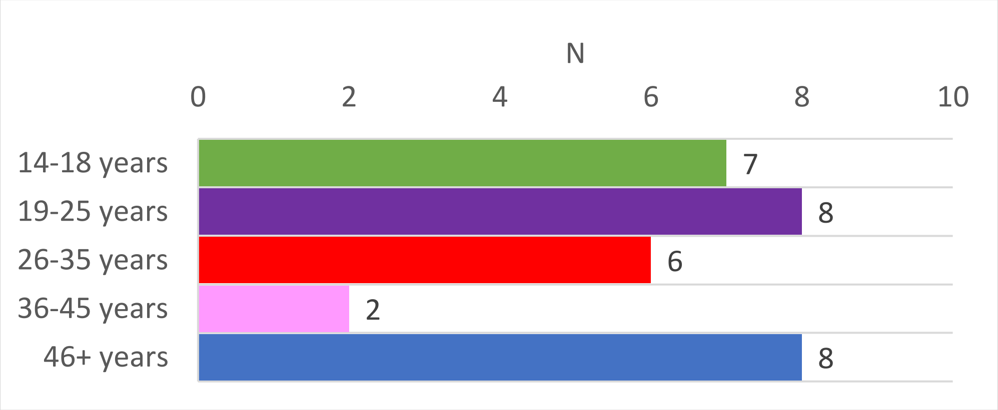

Figure 3.1: Age group

12/31 identified with LGB sexual orientations, six as queer, four as heterosexual and smaller numbers identified with minority sexual identities such as asexual, pansexual, and other non-listed identities while two were unsure or questioning their sexual orientation (Figure 3.2).

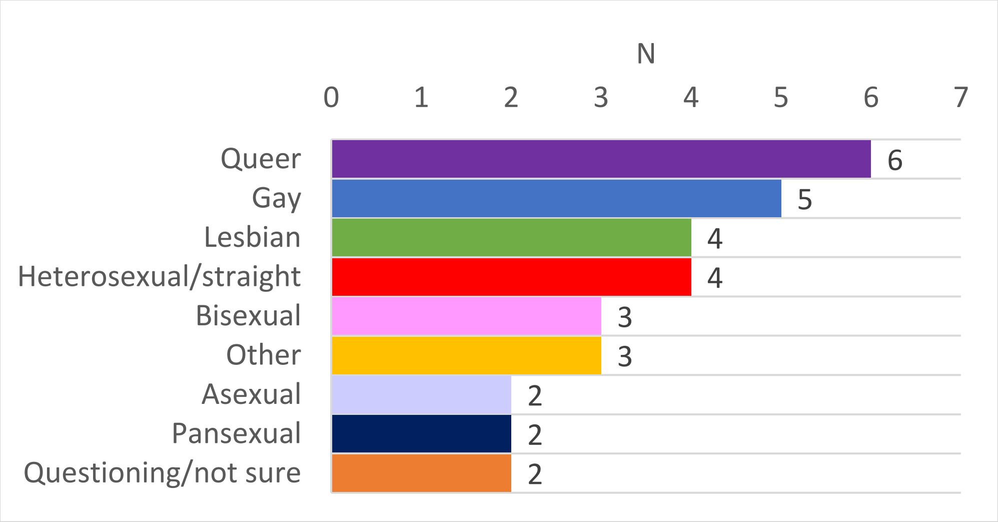

Figure 3.2: Sexual orientation

Objective 1: To report on the manner participants discovered they were intersex

Discovery of variations in sex characteristics

Participants who identified as intersex were asked how they discovered they were intersex or had variations in sex characteristics. Thirty (n=30) provided comments to this free text question. Eleven (n=11; 36%) stated that they found out from medical professionals or from having medical tests. The main reason given for attending for medical tests was Polycystic Ovary Syndrome (n=5) with others reporting a lack of secondary sex characteristics or excessive facial hair for which they were referred for blood tests and discovered a hormonal imbalance.

> *"I have PCOS (Polycystic Ovary Syndrome) and since puberty had somewhat abnormal development regarding body hair and fat distribution which is related to hormonal imbalance." (23, non-binary, lesbian, ID667)*

> *"My periods are irregular, and I have facial hair, so at 18, I was tested for PCOS (Polycystic Ovary Syndrome) and found that I have it". (18, non-binary, queer, ID2260)*

Twelve participants (n=12, 40%) stated that they realised themselves after noticing differences, and/or with help/information provided by TikTok, college literature, an LGBT organisation and reviewing medical notes.

> *"Realised myself, and got confirmation from looking at my medical notes". (50, man, heterosexual, ID1341)*

> *"I realised I had a lower voice and a broader stature than others when I was 9, and others started mistaking me as a boy, or that they couldn't tell. My mother told me to be comfortable as who I am, so I became androgynous". (16, non-binary, abrosexual, ID2233)*

> *"I was taking a course on Gender and Culture 2 years ago there I found out that I had an intersex condition from an academic paper that we were required to read. Then, I*

> *connected the dots and realised the "circumcision" surgery I had when I was 6, was actually an intersex operation". (24, man, queer, ID1087)*

Another three participants (n=3) stated that they found out from parents.

> *"I was told by my father that I needed surgery because I wasn't "even born with a proper penis". I have had many difficulties since as a result of these surgeries". (51, non-binary, queer, ID2345)*

> *"I was told by my parent that before I was born doctors were unsure of my sex, and that after I was born that I had mixed qualities of both sexes. I had to receive a large amount of tests after I was born due to different conditions I had, at which point the doctors had assigned me a gender based on the hormonal level of my body and other results, as according to my parent". (17, non-binary, asexual, ID1505)*

> *"Mother told me after I came out as transgender". (21, woman, trans woman, heterosexual, ID544)*

Objective 2: To describe the participants' experience of medical interventions for their intersex identity

Healthcare experiences of medical interventions for participants with an intersex variation/s

Participants were asked if they had experienced any medical interventions for their intersex identity. In total thirty-one participants responded to this question, eight (25.8%) indicating they experienced a non-consensual intervention and four (12.9%) reporting that they had experienced a consensual intervention (Figure 3.3). However, two of these qualified their response in open-ended text saying that they hadn't made fully informed decisions due to a lack of information or misleading information being given around the consequences and outcomes of the treatment. Both briefly described the circumstances around hormone treatment which they commenced in their teens.

> *"I was put on birth control from age 13-14. I consented at the time, though looking back I wish I'd understood the changes it would make to my body a bit better." (29, transmasculine, pansexual, ID 686)*

> *"Testosterone injections as a teen. I was assured that this would bring me into line with being a typical male. I was lied to." (50, man, heterosexual, ID 1341).*

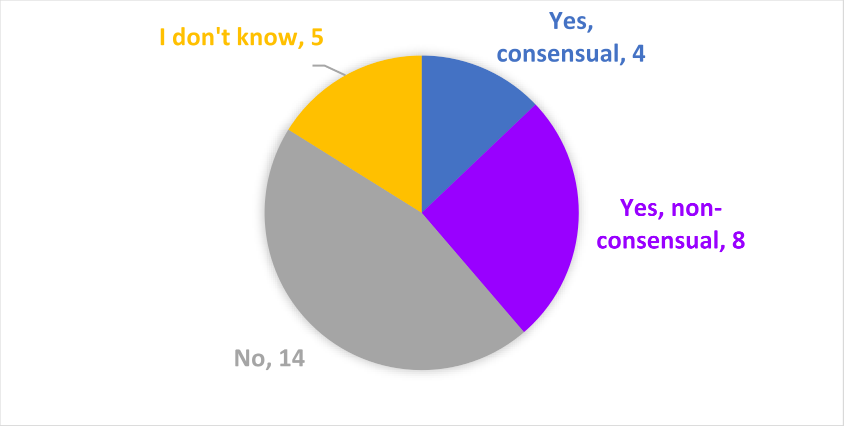

Figure 3.3: Experience of medical interventions related to being intersex

Fourteen participants (n=14; 45.2%) reported that they hadn't experienced a medical intervention, while five individuals (16%) reported that they did not know reflecting the lack of disclosure/transparency that can exist around variations of sex characteristics and treatments (Figure 3.3). The age breakdown in terms of whether participants experienced any medical interventions for their intersex identity and whether these treatments were consensual or not is provided in Table 3.2. None of the participants in the youngest age group (who were aged between 16 and 18 years old) experienced any medical intervention that they knew of.

Table 3.2: Experience of medical intervention for intersex identity by age group

	14-18 years	19-25 years	26-35 years	36-45 years	46+ years	Total
Yes, consensual	0	1	1	0	2	4
Yes, non-consensual	0	3	2	0	3	8
No	5	2	3	1	3	14
I don't know	2	2	0	1	0	5
Total	7	8	6	2	8	31

Eleven participants provided additional information on the medical interventions received. Three (n=3) reported having surgery for hypospadias repair (surgery to correct a defect in the opening of the penis that is present at birth), and one participant (n=1) reported having surgery on their foreskin and undescended testes when they were a child, all of which were reported to be non-consensual. Three participants (n=3) reported receiving hormone treatment in their teens, with two of these receiving testosterone injections, and another prescribed the oral contraceptive pill. One of these participants also reported experiencing physical examinations as a child which were non-consensual. Non-consensual and '*coercive*' examinations were also reported by another participant as well as having undergone an exploratory laparotomy (n=1). '*Invasive examinations*' was also reported by one other participant who indicated that this was consensual (n=1) while one participant reported having breast augmentation surgery and other cosmetic procedures which they consented to (n=1). One participant reported having surgery as a baby but were unsure about the details as hospital records were not available (n=1) (non-consensual).

Overall, there was a general dissatisfaction reported with the medical interventions experienced especially around the issue of consent, information provided and outcomes. Two participants used double quotation marks around the word ‘repair’ in relation to the surgery they had for hypospadias, clearly implying that they felt that it didn’t have this affect and in fact one participant described the problems that had emerged as a direct result of this surgery. Another participant also described undesirable outcomes related to their prescribed course of treatment.

> *“Hypospadias “repair” that left me unable to urinate and without feeling in my phallus. Hormonal interventions that gave me sleep disorders and worsened my gender dysphoria.” (51, non-binary, transgender woman, queer, ID 201).*
>
> *“It (birth control) caused terrible migraines, and it led to premature development of a large chest, which I absolutely despised.” (29, transmasculine, pansexual, ID 686)*

As previously mentioned, some participants used words such as *‘invasive’* and ‘*coercive*’ to describe their experience of medical interventions and several comments underlined the lack of information and explanation around the non-consensual treatments they experienced.

> *“Exploratory laparotomy was performed with little - no explanation given, lacking this information means I could not have consented to the procedure. Several manual examinations performed with coercive consent.” (26, transgender man, queer, ID 1427)*
>
> *“Receiving testosterone as an adolescent, checks to my genitals and their "progress" as a child without knowing why.” (21, woman, trans woman, heterosexual, ID544)*

Objective 3: To provide a descriptive analysis of the wellbeing and mental health of people who identify as intersex

General health

Approximately one quarter of participants rated their general health as bad (25.8%, n=8/31), just over one third rated it as fair (35.5%, n=11/31), around one quarter as good (25.8%, n=8/31) while four participants rated it as very good (12.9%). In total, 21/28 indicated that they had at least one long-standing condition or difficulty. The most prevalent forms were a psychological or emotional condition or a mental health issue (66.6%, n=18/27), difficulty with learning, remembering or concentrating (57%, n=16/28) and difficulty with pain, breathing or any chronic illness or condition (57%, n=16/28).

Wellbeing

Participants were asked, ‘Taking all things together, how happy would you say you are?’ on a scale of 0 meaning ‘extremely unhappy’ to 10 meaning ‘extremely happy’. The mean happiness rating given for the sample was 6.00 (SD=2.9, N=30, Median & Mode=7.0), roughly one point above the midpoint of 5 on the scale (Figure 3.4).

Participants were asked to rate their comfort (consonance) or discomfort (dissonance) around gender identity (GI) and sexual orientation (SO) on an 11-point Likert scale ranging from 0 to 10. Total scores were computed for the GI scale and the SO scale, with higher scores on these scales indicating greater comfort/consonance with sexual orientation/gender identity. The mean scores for GI consonance and SO consonance were 7.00 (N=30, SD=2.91) and 7.64 (N=31, SD=2.57) respectively (Figure 3.4).

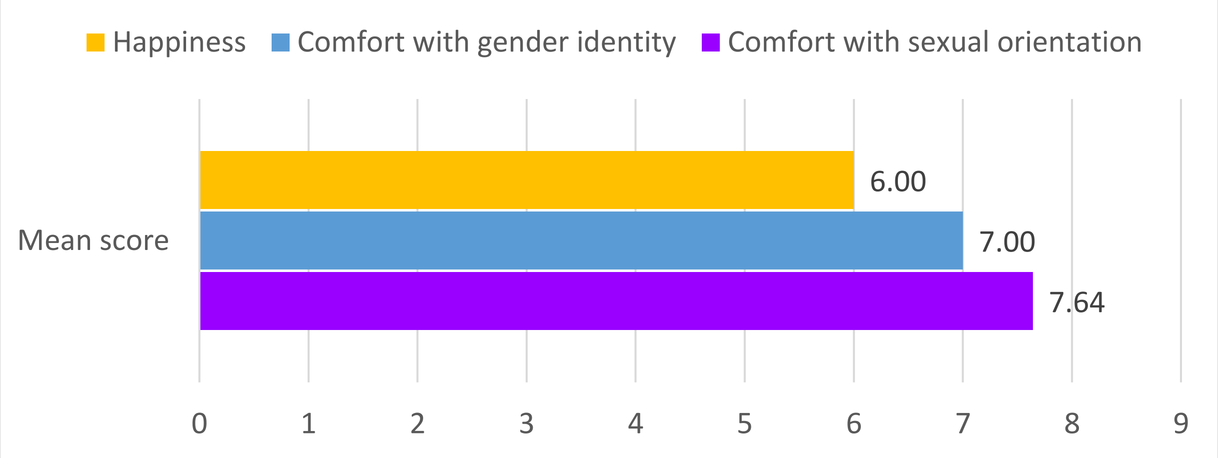

Figure 3.4: Happiness among sample and consonance with gender identity and sexual orientation

The mean score for self-esteem for the sample was 26.83 (N=31, SD=7.2, Range= 12-40), nearly two points above the mid-point of 25 on the scale. Norms for the Rosenberg Self Esteem Scale scores suggest the following ranges: 10-25 (low); 26-35 (normal), 36-40 (high) (Rosenberg et al. 1989). Accordingly, just over two fifths reported low self-esteem (41.9%, n=13), nearly half reported a normal level of self-esteem (48.4%, n=15), and nearly one tenth scored as having high self-esteem (9.7%, n=3) (Figure 3.5).

The mean Brief Resilience Scale (BRS) (Smith et al. 2013) score was 3.02 (N=31, SD=1.15, Range=1.33-5.00), at the mid-point of 3 on the scale. According to the norms for the BRS, (1-2.99 = Low; 3-4.30 = normal; 4.31 – 5.00 = high) (Smith et al. 2013), 48.4% (n=15), 35.5% (n=11) and 16.1% (n=5) were in the low, normal and high resilience categories respectively (Figure 3.5).

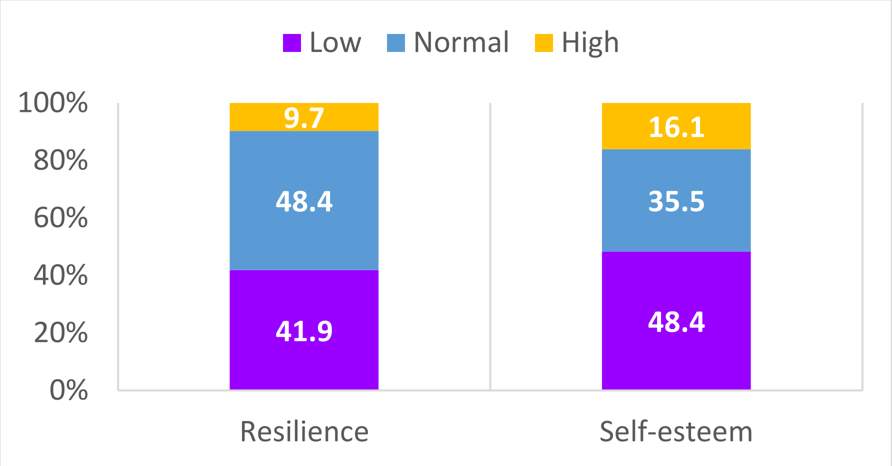

Figure 3.5: Level of resilience and self-esteem among sample

Mental health

The majority reported that they had sought help for a mental health problem in the last five years (n=21/30, 70%).

The mean scores for depression, anxiety and stress were 17.71 (N=28, SD=12.9, Range=0-42), 17.64 (N=28, SD=12.68, Range=0-42), and 18.29 (N=28, SD=10.21, Range=0-34) respectively. Figure 3.6 shows the distributions according to category. On depression, approximately one fifth (n=6) reported symptoms indicative of a moderate level of depression and two-fifths reported symptoms of severe/extremely severe depression (n=11). On anxiety, nearly two-thirds reported symptoms of severe/extremely severe anxiety (n=17) and less than one tenth (n=2) reported symptoms indicate of a moderate level of anxiety. On stress, half (n=14) had levels which fell within the normal-mild range of scores, while of the remaining half, one fifth (n=6) reported symptoms indicative of a moderate level of stress while nearly 30% (n=8) reported symptoms of severe/extremely severe stress.

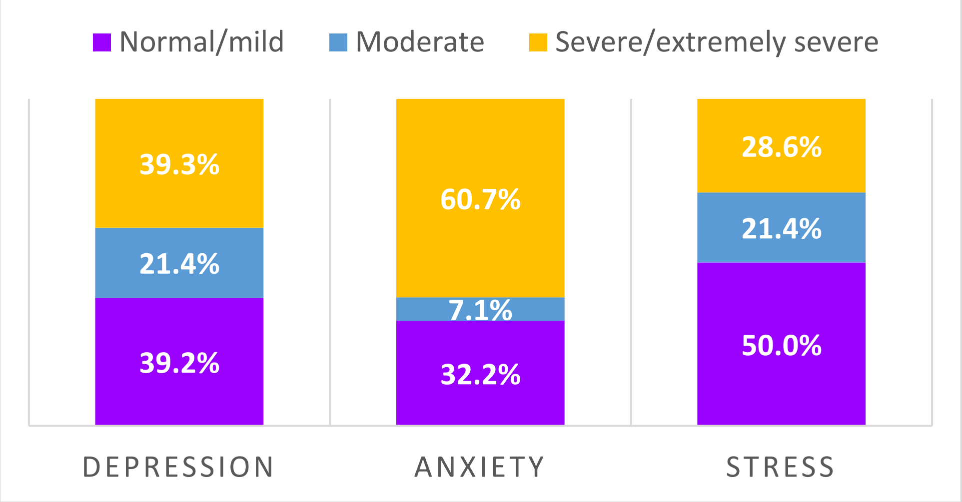

Figure 3.6: DASS-42 categories

Figure 3.7 shows the rates of self-harm and suicidality among participants identifying as intersex or as having variations in sex characteristics. Nearly 60% (n=16) reported that they had deliberately harmed themselves in a way that was not intended as a means to take their own life. The average age of first self-harm was 13 years (SD=9.3). Nearly 70% (n=11) reported that they had self-harmed within the last year. Half reported that no one know they had self-harmed (50%, n=8) while the majority (87.5%, n=14) had not received medical care from a GP, nurse or at the emergency department for treatment. The majority (13/16, 87.5%) reported that their self-harm was somewhat/very/very much related to their LGBTQI+ identity.

Three quarters (n=20/27, 74.1%) reported having seriously thought of ending their own life, with half (n=10/20) having last had thoughts within the last year. The average age at which participants first thought of ending their own life was 15 years (SD=8.3). In total, 15/20 (75%) reported that their suicidal thoughts were somewhat/very/very much related to their LGBTQI+ identity.

Half of participants (n=13/26) reported that they had made a suicide attempt, with most (n=8/13, 61.5%) having done so more than one year ago. The average age of (first) suicide attempt was 14 years (SD=4.1). Eight out of thirteen (8/13; 61.5%) reported that their suicidal attempt was somewhat/very/very much related to their LGBTQI+ identity. The majority reported that someone knew they had attempted suicide (76.9%, n=10/13) and that they did not receive medical care from a GP, nurse or at the emergency department for treatment (76.9%, n=10/13).

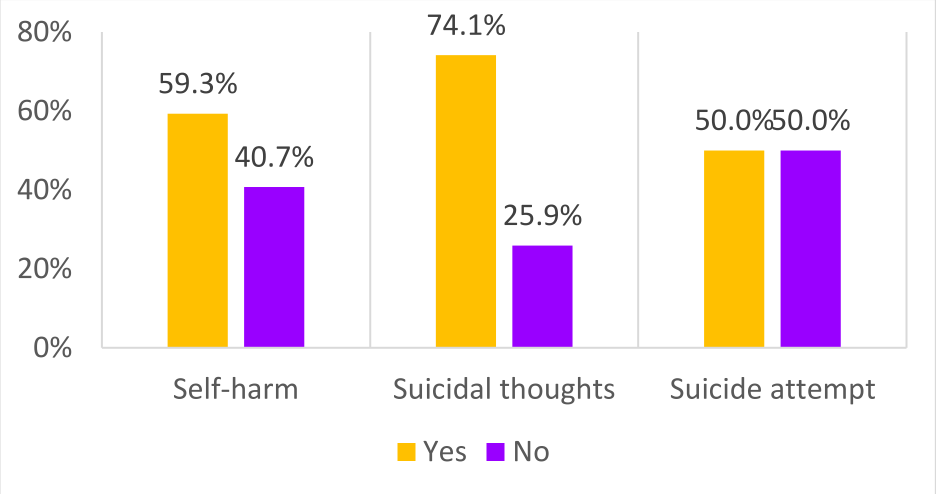

Figure 3.7: Self-harm and suicidality

Substance use

Alcohol use

Approximately one third never drank alcohol (32.3%, n=10). Around one quarter (25.8%, n=8) reported drinking monthly or less, while a slightly lower proportion reported drinking between 2-4 times a month (22.6%, n=7). Just over one tenth (12.9%, n=4) reported drinking a few times a week and 6.5% (n=2) reported drinking more than 4 times a week.

The average AUDIT score was 6.7, with a range of 1-18 (N=20, SD=5.48). In terms of AUDIT categories, 65% (n=13) of those who drank alcohol scored as low risk. Approximately one quarter scored within the moderate category (n=5, 25%), with AUDIT guidelines recommending that, at this level, the best course of treatment by healthcare professionals is to provide advice and information to reduce hazardous drinking behaviour. Two participants had scores indicative of a high-risk level of alcohol consumption, with recommended treatment at this level being brief counselling and continued assessment. None of the participants scored within the very high-risk level category.

Drug use

Approximately half of the sample (51.6%, n=16) had taken drugs (other than those required for medical reasons) in their lifetime. Three quarters (n=12, 75%) of those had taken drugs within the last month. Two participants had taken drugs within the last year and two more than one year ago.

DAST-10 was administered to those who had taken drugs within the previous year. Of these, nearly half scored as being at low risk (46.2%, n=6), with the suggested action being to monitor and re-assess at a later date. Nearly one quarter (23.1%, n=3) scored at a moderate level, with further investigation recommended at this level. Just under one third (30.8%, n=4) scored at a severe level, with intensive assessment being the recommended course of action at this level. The mean score on the DAST-10 was 4.15 (N=13, SD=3.67).

Body satisfaction and possible eating disorder

Almost half reported that they were dissatisfied/very dissatisfied with their body (48.3%, n=14/29), just over one quarter reported that they were satisfied/very satisfied with their body (27.6%, n=8/29), while approximately one quarter were neither satisfied nor dissatisfied (24.1%, n=7/29).

The SCOFF Questionnaire is a 5-item measure used to raise awareness of the possible existence of an eating disorder (Morgan et al. 1999). A ‘yes’ to two or more items (Q1-Q5) (Table 3.3) indicates the possibility of an eating disorder and warrants further questioning and more comprehensive assessment by a healthcare professional. A further two questions (Q6 & Q7) (Table 3.3) have been shown to indicate a high sensitivity and specificity for bulimia nervosa and would indicate further questioning and discussion is required. In total, 37.9% (n=11/29) of participants reached the risk threshold indicative of having a potential eating disorder. In relation to the two additional questions, 39.3% (n=11/28) of the sample indicated that they were dissatisfied with their eating patterns and ate in secret, which would indicate a need for further assessment.

Table 3.3: SCOFF items (Q1-Q5) and additional questions (Q6-Q7)

Questions	**No**		**Yes**	
	n	**%**	**n**	**%**
Q1. Do you make yourself sick because you feel uncomfortably full?	24	82.8	5	17.2
Q2. Do you worry you have lost control over how much you eat?	18	62.1	11	37.9
Q3. Have you recently lost more than one stone in a 3 month period?	23	79.3	6	20.7
Q4. Do you believe yourself to be fat when others say you are too thin?	21	72.4	8	27.6
Q5. Would you say that food dominates your life?	20	69.0	9	31.0
Q6. Are you satisfied with your eating patterns?	19	67.9	9	32.1

Q7. Do you ever eat in secret?	16	55.2	13	44.8

Objective 4: To report intersex people's perspectives on the impact of being intersex on their mental health and wellbeing

Impact of being intersex on mental health

Participants were asked whether their experience of being intersex/having variations in sex characteristics impacted their mental health. Twenty-eight (n=28) participants provided comments. Seven participants provided a simple yes (n=2) and no (n=5) answer with no detail provided. The other twenty-one comments were coded into two themes which were 'Stigma and Shame' and 'Body Integrity'.

Stigma and shame

Participants felt that there was stigma attached to having an intersex variation and that this increased the mental health problems that they had. How others reacted to their disclosure impacted this more than living with the intersex variation. This was linked to non-acceptance and isolation as participants felt poorly understood or acknowledged by others, as well as society's binary view of gender.

> *"Yes, not feeling accepted-properly acknowledged by society and the medical system". (26, non-binary, queer, ID219)*
>
> *"It was a shock, but it explained a lot. My mental health was impacted more by others when I told them than the fact itself". (62, woman, trans woman, bisexual, ID2647)*
>
> *"It's impacted how people see me, and how to live my life continuing to be intersex". (16, non-binary, abrosexual, ID2233)*
>
> *"Of course it has we live in a patriarchy. Every instance I exhibited gender incongruence was met with resistance". (39, woman, trans woman, bisexual, ID570)*

Body integrity

The comments related to body integrity were linked to gender confusion, child abuse and sexual abuse as well as the effects of medical treatment and how people viewed their body image overall. A good example of this is encompassed in the comment below which shows just how complex living with an intersex variation is:

> *"Yes, drastically. I was considered a curse on the family, lots of shame, child abuse. I don't relate to the sex I was assigned. I have many issues related to child abuse and sexual and urinary difficulties from surgery. Lots of depression, anxiety, self-harm. Everything is a struggle". (51, trans woman, queer, ID201)*

For others, having an intersex variation caused some discomfort and changes in body image, however, it did not alter things in a big way.

> *"It shifted my body image for a while, but 'I am who I am' and nothing has changed, it was just a new information". (24, man, queer, ID1087)*

While others stated they had some regrets, these regrets centred around not knowing sooner about their intersex variation and not being able to exercise choice in terms of their sex and gender.

> *"Not particularly, I wish I knew sooner though but it didn't really change anything for me, I was still "assigned male at birth" and grew up being raised as male. I wish that hadn't been the case and the choice would've been left to me, but I have no regrets and don't think there's much point dwelling on that". (21, woman, trans woman, heterosexual, ID544)*

> *"I believe it has, however more so simply as an added factor of how much could have been avoided from such an early age and a how much help I could have had sooner on in life. It would certainly have helped when I began puberty". (17, non-binary, asexual, ID1505)*

Poorer mental health was also attributed to the adverse effects of medical treatment and issues related to body image overall.

> *"Experience of high degree of medical trauma due to the experiences associated with my intersex status - currently undergoing therapy to combat PTSD stemming from specific instances of medical trauma from early adulthood and adolescence". (26, trans man, queer, ID1427)*

> *"PCOS [polycystic ovary syndrome] itself could be responsible for some of my mental health issues like depression and poor body image. It has also impacted my weight, which certainly impacted my mental health growing up (I'm working on unlearning this weight stigma as much as I can). The label makes me feel proud and helps me feel included". (29 transmasculine, pansexual, ID686)*

> *"I am living with chronic pain that wears me down a considerable amount". (18, trans man, asexual, ID2387)*

Access to health care

The various impacts of being intersex and the intersectional nature of people's lives were also evident within responses made to other open-ended questions; these included challenges included accessing other aspects of health care and a lack of knowledgeable practitioners.

> *"I constantly have to jump through hoops to access basic medical care as a Transgender/Intersex woman and my self-harm is related to the constant disregard of the fact that these sort of waiting times exacerbate the feelings of dysphoria and mental anguish". (24, woman, transwoman, heterosexual, ID2713)*

> *"As an AFAB (Assigned Female At Birth) with a beard because of PCOS (Polycystic Ovary Syndrome) who isn't openly transgender, my endocrinologist was surprised that I didn't want to shave it, to such a degree that she included her feelings of surprise in a letter to another doctor". (18, non-binary, queer, ID2260)*

> *"We need trans and intersex therapists. Current options are not adequate. The situation in Ireland is very bad". (51, non-binary, queer, ID2345)*

Objective 5: To report on intersex people's perspectives of belonging within the LGBTQI+ community

Community belonging

Approximately two-thirds of the intersex sample reported that they felt welcome in the LGBTQI+ communities (67%). However, more than half reported that their identity wasn't given equal recognition in the LGBTQI+ communities (57%) and that they felt separate and isolated from other people who share their identity (53%). Just under half reported that their identity is visible within LGBTQI+ communities (47%) and that LGBTQI+ organisations did a good job advocating for their rights and needs. The other half either disagreed (approx. one quarter) or were undecided on these issues (27% - 30%). Just over a third of the sample reported that they didn't feel included in LGBTQI+ communities (37%) (Figure 3.8).

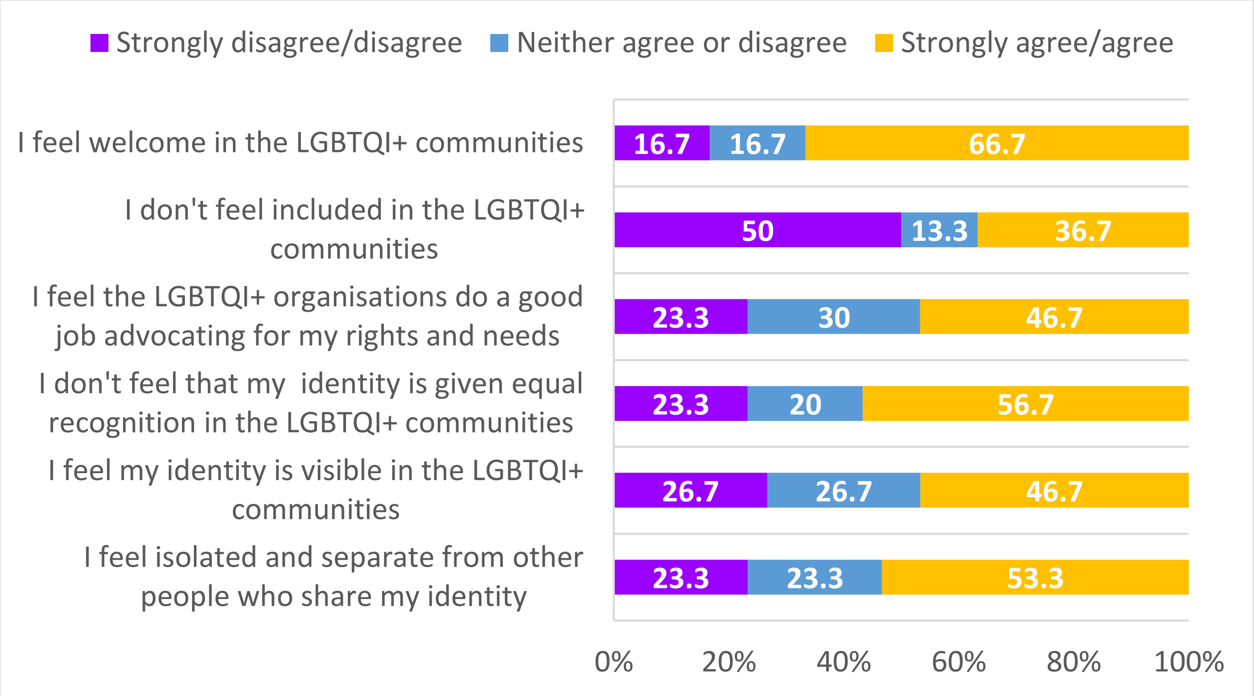

Figure 3.8: Community belonging

An open-ended question which invited participants to comment on their sense of belonging to LGBTQI+ communities elicited 15 responses, most of which highlighted challenges with community belonging. The responses underline that the intersex sample's experiences are informed by multiple intersectional identities, with many referencing gender identity and/or sexual orientation and indeed other facets of identity as impacting on sense of community belonging.

A few of the responses highlighted challenges for intersex people within LGBTQI+ communities: a lack of knowledge within LGB communities of what intersex is, it's erasure and a lack of solidarity for intersex people within a hierarchal LGBTQI+ community were cited.

> *“Most LGB people don't know what intersex is, and many trans people appropriate intersex for political reasons without understanding what it is”. (50, man, heterosexual, ID1341)*
>
> *“It’s complicated. Intersex erasure, LGBTQI+ hierarchy, etc. it’s not a big, happy family like on TV”. (51, non-binary, queer, ID2345)*

Some participants commented on prejudice and bigotry within LGBTQI+ communities towards particular sexual and gender minorities, namely trans and non-binary people as well as people with sexual identities which could be described as emerging, namely pansexuality, asexuality and demisexuality. Prejudices were also cited in relation to religion and age.

> *“I feel as though there's still a large amount of prejudice against asexuality and pansexuality in our communities at the moment, as well as non-binary people and demisexual individuals (demiboy, demigirl) between older and younger members of the community”. (17, non-binary, asexual, ID1505)*
>
> *“There is still a disconnect in some parts of the LGBTQI community between trans people and everyone else. People need to realise we have been part of the gay community forever, and it’s about time we were supported by our own”. (62, woman, trans woman, bisexual, ID2647)*
>
> *“Less religious bigotry and less trans misogyny.” (45, woman, questioning, ID2398)*

Others highlighted how, within LGBTQI+ communities, there is an expectation to conform to certain assumptions when someone identifies with a particular identity or behaves in a certain way. Participants described how variations from these expectations can be met with negative reactions and they can be made to feel invalidated and isolated because of it.

> *“I am asexual but everyone expects me to be ace [asexual] in a certain way, i.e. hating any jokes or displays of sexuality. Ironically the people who say this to me are often not asexual, mainly from the aromantic spectrum instead”. (18, trans man, asexual, ID2387)*
>
> *“Trans fem spaces almost always feel largely lesbian orientated and focused, as a straight trans fem (WLM) who spent most of my life out as a gay man, sometimes I feel more seen/validated in my sexuality with straight cis women or gay men, more so than in trans spaces (hearing things like "ew straight", being told "you'll start liking girls on HRT", being told my sexual preferences are "more MLM" etc.)”. (21, woman, trans woman, heterosexual, ID544)*
>
> *“LGBT community conversations have almost entirely shifted to gender / gender identity. The majority of people I know in my age range 30+ do not belie we all have an innate gender identity. It is frustrating too that a lot of non-conformity with sex stereotypes are considered non-binary or trans and I find myself defending myself I’m sometimes told I am non-binary or another gender. I’m very comfortable being a man*

> *and I do not subscribe to the idea that man equals masculine, rather we all have a range of interests and traits that could be classified as masculine or feminine. It feels regressive to be so strict about gender roles now. It's become an obsession by many people in their 20s. I know of many gay men and lesbians who are quietly frustrated by it, especially lesbians, but they dare not speak it. I see how many people can feel isolated from LGBT communities because of the assumption we all have the same views with little variation or that "community leaders" speak for all of us". (34, man, gay, ID986)*

For two participants, their sense of belonging to LGBTQI+ communities was impacted negatively for reasons of living rurally and being autistic.

> *"My issues with connecting with the queer community come not because of the communities themselves, but because I live in a rural place with few people and I cannot drive. This physical distance between me and my peers is the biggest barrier I face" (18, non-binary, queer, ID2260)*
>
> *"Being very shy, introverted and quiet as a very mildly autistic person always made me feel out of place in the loud LGBT+ spaces and groups". (27, man, gay, ID844)*

Chapter 4: Discussion

This sub report, focussing particularly on the healthcare experiences of people who have variations in sex characteristics in Ireland, adds to the knowledge on lived experiences for what is a largely hidden and invisible group within society and research. A seminal study on the lived experiences of people with variations of sex characteristics in Ireland conducted previous to this one didn't capture any participants under the age of 40 (Ní Mhuirthile et al. 2022). Participants in this study were mostly under the age of 40 (71%); having this younger demographic therefore adds a new dimension to the knowledge on experiences of having variations in sex characteristics in Ireland. Additionally, the study provides insight into their well-being and mental health status using validated tools and direct open-ended questions on mental health impact, which is valuable given the little research that has been conducted on this population in Ireland to date.

A lot of the participants described discovering that they were intersex incidentally, through engaging with healthcare services regarding a health issue or realising themselves through, for example, noticing body differences compared to peers. It is common for people not to become aware of their intersex identity until adolescence or adulthood as some intersex variations may not be apparent at birth (Ní Mhuirthile et al. 2022). However, the system of care for people with intersex variations in Ireland is set up for children, resulting in a huge gap in healthcare for those who transition out of the system or for those who only become aware of their intersex status in later life (Ní Mhuirthile et al. 2022). It is not a problem that is unique to Ireland; the literature documents that, despite the need for psychological support and healthcare arising from childhood medical interventions, there is inadequate and inappropriate service provision for adults (Jones et al. 2018; Crocetti et al. 2024).

Interestingly, none of the youngest participants in this study (those aged 16-18 years of age) had experienced any medical interventions that they knew of. By contrast, medical interventions were experienced by at least some of the participants in all of the older age groups with the exception of those aged 36-45 which contained only two participants in total. This may signal a shift away from approaches centred around 'normalising' bodily variations to ensure alignment with 'typical' male and female bodies towards an approach of not performing unnecessary interventions until the person can make a fully informed decision about their care. Indeed, the current practice as described by healthcare professionals caring for those with VSC in Ireland at a national level (an informal forum of expertise) suggest that they are in favour of postponing interventions until the intersex person can participate in the decision-making process. However, there are no formal treatment guidelines in place and approaches and practices make vary at a local level (Ní Mhuirthile et al. 2022).

Eight out of thirty one (8/31) participants in this study had experienced a non-consensual medical intervention and a further two participants had experienced treatment, which although they had consented to, with the benefit of hindsight, they realised that they had not made fully informed decisions regarding treatment, with one of these individuals feeling that they had been deceived. This corresponds to a non-consensual intervention for 10/12 participants (83%) who underwent a medical intervention for their intersex identity. Similar experiences of a lack of information and deception, as well as information gatekeeping by clinicians and pressure being applied in decision-making are reported elsewhere (Haghighat et al. 2023; Berger et al. 2023). A lack of fully informed consent to medical intervention stems from structural power inequalities within healthcare wherein people who are intersex and their families are not presented with “alternative treatment pathways or social frameworks to understand being intersex” (Hart & Shakespeare Finch, 2022, p925). A lack of fully informed consent contravenes human rights to bodily integrity and autonomy and can compound negative experiences and outcomes related to medical interventions (Carpenter, 2016; Crocetti et al. 2024). Furthermore, there is a lack of evidence of the long-term efficacy of some clinical interventions and an abundance of evidence on the harm and trauma caused by unnecessary and non-consensual treatment (Hart & Shakespeare-Finch, 2022; Haghighat et al. 2023; Amos et al. 2023; Crocetti et al. 2024).

Participants in this study reported various physical and psychological impacts from the medical interventions, including sexual and urinary difficulties, chronic pain, sleep disorders, an array of mental health difficulties, gender dysphoria and issues related to body image. Further evidence of physical and mental health challenges emerged from the quantitative data, wherein the majority of participants reported having a psychological or emotional condition or a mental health issue, difficulty with learning, remembering or concentrating and difficulty with pain, breathing or any chronic illness or condition. Just less than two-fifths rated their general health as either good or very good, which is comparably lower compared to more positive ratings of physical and general health given by intersex participants in other studies from Australia, Europe and Ireland (Jones, 2016; Rosenwohl-Mack et al. 2020; Ní Mhuirthile et al. 2022). Three in five reported symptoms of severe or extremely severe anxiety, two in five reported symptoms of severe or extremely severe depression and 29% reported symptoms of severe or extremely severe stress. Lifetime prevalence rates of self-harm, suicidal thoughts and suicide attempt were 60%, 74% and 50% respectively. Nearly half of the sample reported low self-esteem and two-fifths low resilience. Almost half of participants expressed dissatisfaction with their body while 38% reached the risk threshold indicative of having a potential eating disorder. Around one third abstained from alcohol consumption. Of those who did drink, 25% scored as being at moderate risk for alcohol abuse. Among those who had taken drugs, most had taken them in the past month (n=12/16), with over half of these scoring at a moderate or severe level of drug use, for which further investigation or intensive assessment would be required.

Large scale studies of intersex people have found high levels of mental distress among adults (Crocetti et al. 2024). Poor mental health outcomes (suicidality, depression and anxiety) have been linked to negative healthcare experiences, including a lack of autonomy, consent and access to psychological support as well as experiences of stigma and discrimination (Sanders et al. 2021; Amos et al. 2023), all of which emerged from participants’ qualitative responses on the mental health impact of being intersex. Participants described experiencing discrimination, mistreatment and stigma at all levels, including family, the medical system and society at large. One of the older participants recounted the shame and abuse they endured as a child within their family due to their intersex status. Others described the discrimination and stigma they experienced within medical settings. Binary ideas of sex and gender and the perception that those with intersex variations need to conform led to corrective genital surgeries and gender assignment for some participants after they were born. Not having a "*proper penis*", exhibiting "*gender incongruence*" and being an AFAB (Assigned Female at Birth) person with a beard that they did not shave were not considered acceptable variations. How people reacted to disclosure and the lack of acceptance, acknowledgement, and understanding within the medical system and within society at large led participants to feel isolated and stigmatised, and negatively impacted on their mental health, themes which are mirrored throughout the literature (Sanders et al. 2021; Hart & Shakespeare Finch, 2022; Haghighat et al. 2023). The pathologisation of bodily variations internalises negative feelings around oneself and affects one's sense of social connectedness leading to isolation and withdrawal (Hart & Shakespeare Finch, 2022).

Contributing to the stigma around variations in sex characteristics is the lack of understanding of them as cited by some participants in this study. Results from the *Being LGBTQI+ in Ireland* study showed that public knowledge of intersex identities and interactions with people with intersex variations in Ireland is extremely limited and there is disagreement and uncertainty as to whether intersex variations should be included in school curricula (Higgins et al. 2024). At present, as in many other countries, there is no information provided on variations in sex characteristics in school curricula which researchers argue contributes to a lack of awareness and understanding among the public (Ní Mhuirthile et al. 2022; Hunter et al. 2023). In a recent study on public attitudes towards minoritised groups in Ireland, intersex people were given less favourable ratings compared to a range of sexual and gender minority groups (Noone et al. 2021). Similarly, within the domain of public policy in Ireland, intersex issues are not included in any meaningful way (Monroe et al. 2024). Omissions of this nature exacerbate erasure of identity and inequalities for intersex people in Ireland (Monroe et al. 2024).

The findings also highlighted challenges with belonging within LGBTQI+ communities, with just over half of participants reporting unequal recognition in the LGBTQI+ communities and over one third feeling excluded. A lack of understanding and recognition of intersex within LGBTQI+ communities, prejudices within the community and pressure to conform to certain expectations as well as a lack of solidarity among intersex people were cited. Research suggests that more social and medical support and more affirmative communities can develop better self-esteem and resilience in people with intersex variations (van de Grift et al. 2024).

Limitations

Given that the questions relating to experiences of having intersex variations were located within a much larger survey focused on well-being and mental health in the LGBTQI+ communities, the researchers were unable to ask the breadth of questions that would have gleaned a more comprehensive picture of the experience of living with intersex variations in Ireland in all aspects of one's life beyond healthcare. Most of the sample was aged under 35, therefore the findings may not reflect the experiences of older cohorts. More than half of the intersex sample identified as transgender and most had a non-heterosexual orientation, therefore there is clearly an intersection of identities informing people's experiences and outcomes which may not have been fully captured within the scope of this report. The researchers relied on participants' self-identification of having an intersex variation/s. Based on this, there was quite a large number who answered that they did not know if they had variations in sex characteristics. A different method of determining participants' intersex status may have yielded more participants. The small sample size prevented any analysis of the quantitative data beyond descriptive statistics.

Recommendations

- More research is needed in Ireland into the needs and experiences of people who have variations in sex characteristics, including longitudinal studies to map health and wellbeing and research into the knowledge and competence of people working in paediatric settings on intersex variations.
- Given the dearth of information on people with intersex variations, in particular, the HSE should undertake or commission a review of the needs of the intersex community. Specific attention needs to be given to mental health, reproductive and gynaecological care, bone health, cancer care and gender-affirming healthcare.
- Given that positive attitudes towards diverse identities is improved with both knowledge about and exposure to them (Higgins et al. 2024), it is important that teaching on intersex variations is introduced into school curricula in order to combat prejudice and promote acceptance.
- In light of the qualitative comments there is a need for a programme of work that focuses on the education of health care professionals, general public as well as LGBTQI+ organisations on the needs and experiences of intersex people.
- In light of the healthcare experiences of participants, those who provide their healthcare must be cognisant of the needs of individuals with intersex variations. Thus, the delivery of LGBTQI+ inclusive and affirmative healthcare needs to ensure that the rights of individuals with intersex variations are respected and upheld when receiving care.
- In the spirit of co-production there is a need for greater involvement of intersex people in shaping research agendas, curricula (school and health care) and policy to ensure that all these areas are informed by their experiences and needs.
- Organisations which provide peer support and education to people with intersex variations should receive adequate funding to do so.
- Greater collaboration between LGBTQI+ advocacy organisations and intersex community groups and individuals, including 'Intersex Ireland', is needed to explore how best to represent Intersex people's voices. Additionally, health-based advocacy organisations and groups also need to work with intersex community groups and individuals to ensure this cohort's needs are advocated for beyond LGBTQI+ contexts.

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