



## Article

# “These Researchers Think They Come From Heaven with Analytical Superpowers When They Don’t”: A Qualitative Analysis of Research Experiences in Intersex-Related Studies

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**Abstract:** This article explores diverse ethical considerations related to the study of vulnerable population groups to produce meaningful project outcomes that avoid harm to the involved communities. In the specific context of the intersex community, previous analyses have encountered various challenges, including the medicalization of intersex people’s bodies, the use of pathologizing language, and misrepresentation of the population’s needs. The article explores some of the beliefs, experiences, and tools that experts in research ethics, researchers, and intersex research participants consider most important regarding research ethics in intersex-related studies. The article is based on original empirical research; semi-structured interviews were conducted with 21 participants, recruited through email and snowball sampling methods, and the data were examined using thematic analysis. It moves from issues related to the research design (positionality, researcher preparation, framing intersex within the LGBT acronym) to experiences related to the research development (ethical approval, informed consent process, language use, relationship of trust). The article describes some of the major concerns and raises discussions that could be relevant for the development of future research under human rights-based perspectives. The findings are aimed to be useful beyond the field of intersex-related studies, as they can be relevant to research about other communities that have endured violations of their human rights during research.

**Keywords:** intersex; human rights-based approach; positionality; qualitative research



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## 1. Introduction<sup>1</sup>

Studies about vulnerable populations have led to the development of research projects to access these communities and understand their issues, raising complex ethical considerations regarding research practices (Hugman et al. 2011). In the pursuit of knowledge and the advancement of scientific understanding, researchers have the ethical responsibility to conduct studies that uphold the well-being of all participants involved (Beauchamp and Childress [1979] 2019). This ethical imperative is considered especially relevant in studies involving vulnerable communities, where cognitive, institutional, medical, social, or economic disparities can magnify the ethical challenges faced by researchers (Kipnis 2001). In this sense, “vulnerability, in the context of research, should be understood to be a condition, either intrinsic or situational, of some individuals that puts them at greater risk of being used in ethically inappropriate ways in research” (NBAC 2001, p. 85). From a broader perspective within social sciences, there is sometimes a disconnect between the “goals of science” and ethical considerations (Fisher 1999, p. 29). Researchers conducting studies with vulnerable populations often find themselves navigating these complex ethical challenges, drawing “upon their own moral compass, the advice of colleagues, and recommendations of institutional review boards (IRBs)” (Fisher 1999, p. 29). The decisions made in this regard “have immediate and possibly long-term impact on participants, their families, and the communities they represent” (Fisher 1999, p. 29).

Recognizing the potential ethical dilemmas inherent in such research dynamics, various ethical frameworks have been developed to offer guiding principles. Key among these are (i) the Nuremberg Code ([International Military Tribunal 1946](#)), (ii) the Declaration of Helsinki ([WMA \[1964\] 2013](#)), (iii) the Belmont Report ([The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979](#)), (iv) the Guidelines for Research Ethics in the Social Sciences and the Humanities ([NNREC 2021](#)), and (v) the Ethics in Social Sciences and Humanities ([EC 2021](#)).

These guidelines are essential as they provide a framework for protecting the rights of participants engaged in social science research. As such, several ethical principles outlined in this article, including obtaining fully informed consent and assent, utilizing appropriate language, and understanding the community's history, have been selected, considering the parameters established in these guidelines.

The first three regulations offer an ethical framework for the essentiality of informed consent, the management of risk, the necessity of the study, and the benefit that particularly vulnerable groups will obtain as a result of the research ([International Military Tribunal 1946](#); [The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979](#); [WMA \[1964\] 2013](#)). The latter two guidelines, specific to the social science field, underscore the importance of additional considerations in research involving vulnerable populations. Given the historical context of "abuses of power and unethical research" against vulnerable groups, there is a recognition that members of these groups "may wish not to be subjects of research, for instance, for fear of stigmatization or other negative consequences. At the same time, excessive protection of weak and vulnerable groups is inappropriate" ([NNREC 2021](#), p. 29). Thus, the [NNREC \(2021\)](#) considers it advisable to implement additional measures to make the research as respectful as possible, "gaining knowledge about and respect the local context and social relations" of the group involved (p. 30).

In alignment with this perspective, the European Commission recommends the researcher: "Make sure you do not exacerbate people's vulnerability through your research or research participation" ([EC 2021](#), p. 12). The EC guidelines also highlight various scenarios where research may pose greater risks, including "research involving sensitive topics and those which might cause psychological stress, anxiety or humiliation" ([EC 2021](#), p. 19).

[Fricker \(2007\)](#) introduces the concept of epistemic injustice, illustrating instances where individuals, especially from marginalized communities, are not acknowledged as credible sources of knowledge. [Fricker \(2007\)](#) highlights how societal power dynamics systematically undermine the credibility and recognition of certain voices. Other scholars, such as Kristie [Dotson \(2011\)](#) and José [Medina \(2013\)](#), have further expanded the understanding of how epistemic violence or epistemic injustice manifests and perpetuates misrepresentation. While their perspectives may not be explicitly focused on research, their work holds ethical dimensions that are inherently relevant to the study of issues related to vulnerable communities.

[Dotson \(2011\)](#) discusses the idea of "[e]pistemic violence in testimony" (p. 238), which refers to situations where someone's words are not taken seriously or respected by others. This happens when people refuse to listen or respond to what someone is saying because they do not understand or do not wish to understand. [Dotson \(2011\)](#) calls this "pernicious ignorance," which means "any reliable ignorance that, in a given context, harms another person (or set of persons)" (p. 238). This concept highlights how not being heard or acknowledged can be damaging and unfair to the person trying to communicate ([Dotson 2011](#)). From here, she develops two important concepts: "testimonial quieting," which "occurs when an audience fails to identify a speaker as a knower" ([Dotson 2011](#), p. 242), and "testimonial smothering" ([Dotson 2011](#), p. 244). The author gives different meanings to this latter concept; one of them is "when an audience demonstrates testimonial incompetence with respect to the content of potential testimony" ([Dotson 2011](#), p. 245). In this case, the speaker is rendered silent, not necessarily through explicit censorship, but rather through a lack of social recognition and receptiveness to their testimony ([Dotson 2011](#)).

Similarly, Medina's (2013) elucidation of "hermeneutical gaps" (p. 75) contributes to a comprehensive interpretation of the multifaceted ways in which marginalized voices are suppressed and distorted in research contexts. He discusses a gap in the collective understanding or conceptual resources of a community, which may lead to the inability to articulate or include certain experiences (Medina 2013). Medina's (2013) emphasis on hermeneutical gaps highlights how certain groups, often those at the margins of society, face challenges in having their experiences intelligibly expressed and comprehended. When dominant cultural frameworks lack the conceptual tools to make sense of the experiences of marginalized groups, it creates a gap in understanding that contributes to their exclusion and misrepresentation (Medina 2013).

Applying the reviewed reflections on epistemic injustice (Fricker 2007; Medina 2013) or epistemic violence (Dotson 2011) to the field of research practices, acknowledging and rectifying epistemic injustices in research becomes an ethical imperative, particularly concerning vulnerable communities. Understanding these ethical and epistemological challenges, this article aims to present and give voice to the narratives and research experiences of one of the communities that have suffered violations of their human rights during research, the intersex population, as well as to researchers and experts in research ethics with experience in the field of intersex-related research.

Intersex babies, children, and adults continue to face a series of human rights violations (Ghattas 2015; UN 2019) because of their physical characteristics. These include "violations of their rights to be free from torture and ill-treatment, to health and physical integrity, and to equality and non-discrimination" (UN 2019, p. 4). This is highly problematic and is due to a lack of recognition of intersex people, as Ghattas (2015) explains:

In a world where the overwhelming majority of people and governments only know and accept two sexes ('male' and 'female'), the existence of intersex people and their bodies is not recognized. Instead, healthy intersex bodies are considered to be a 'medical problem' and a "psychosocial emergency" that needs to be fixed by surgical, hormonal, other medical, and sometimes psychological means. (Ghattas 2015, p. 9; reference removed)

According to a publication of the European Union Agency for Fundamental Rights (FRA 2015, quoted in Ghattas 2015, p. 9), within the European Union, surgeries aimed at 'normalizing' intersex children are performed in at least 21 Member States.

In the case of intersex-related studies, health professionals acquired a position of power under the name of science due to the ownership that medicine has taken of intersex bodies (Karkazis 2008). This sense of entitlement amongst medical practitioners implies decision-making processes about what is best for intersex people without them actively participating. It produces an atmosphere where only medical knowledge and experiences are taken into consideration; disregarding the experiences and knowledge that the community itself can propose for its own well-being which is a violation of their self-determination and constitution of the mentioned epistemic injustice within intersex-related studies (Bastien-Charlebois 2016).

Scholars from the field of intersex studies and activists have exemplified and contextualized the ways in which the experiences of intersex people have been disregarded and marginalized (Cabral Grinspan 2009; Carpenter [2014] 2019; Carpenter and IHRA 2018). This includes exposing instances where researchers wield privilege in the production and access of knowledge while emphasizing testimonial injustices and dehumanizing treatments endured by intersex individuals (Bastien-Charlebois 2017). The work of authors from the field of intersex studies underscores the need for a paradigm shift in knowledge creation, advocating for a more inclusive approach that considers the nuanced context surrounding intersex experiences (Bastien-Charlebois 2017; Carpenter and IHRA 2018).

From an activist perspective, members and organizations of the intersex community have raised their voices regarding the violation of human rights within research. For instance, Koyama (n.d.), ISNA (n.d.), and interACT (2023) have created different guidelines aiming to advise researchers to center the participants' voices, think critically, and avoid

creating harm or re-traumatization. From an academic standpoint, [Lundberg \(2021\)](#) and [Jones \(2022\)](#) have conducted analyses on reflexivity concerning the ethical and methodological aspects of studying intersex-related topics. [Jones \(2022\)](#) contends that conducting research with intersex individuals demands heightened ethical sensitivity given the history of institutional power abuses (especially in medical contexts) coupled with social stigma and marginalization. She emphasizes the importance of employing methodologies that empower participants and do not perpetuate existing power imbalances. Similar reflections have been developed from the perspective of trans studies ([Adams et al. 2017](#); [Vincent 2018](#)).

In 2023, I conducted a narrative literature review aimed at examining methodological research approaches and ethical considerations in studies related to intersex people ([Mestre Martínez 2023a](#)). While the majority of papers reviewed adhered to general ethical standards such as signed informed consent and data management information, some exhibited concerning practices ([Mestre Martínez 2023a](#)). That study formed a foundation for this article, as it revealed an absence of qualitative studies exploring the perspectives of experts in research ethics, researchers, and intersex research participants together. This article seeks to address this gap.

The results are categorized into two primary research stages: research design and research development. These stages were chosen due to the distinct ethical and epistemological considerations they entail. Participants contributed a variety of perspectives throughout both stages, unveiling their experiences with research and articulating concerns significant to them. This approach aims at establishing a platform for dialogue and improvement within the broader research community, and holding significance for the intersex population by giving voice to the human rights violations experienced by these individuals during research.

## 2. Materials and Methods

This research has a qualitative design involving a series of semi-structured interviews conducted in 2022 as part of the European research project 'INIA: Intersex—New Interdisciplinary Approaches.' Potential research participants were contacted by sending invitation emails to international and national intersex organizations, academic networks, and individual persons. In addition, a snowball technique was used. The research fulfils the parameters stated in the General Data Protection Regulation (Regulation (EU) 2016/679) (GDPR), and the Spanish legislation on data protection (Ley Orgánica 3/2018, de 5 de Diciembre, de Protección de Datos Personales y garantía de los derechos digitales).

The selection criteria for participants were having experience in the field of qualitative research on intersex issues as ethical experts, researchers, or intersex research participants, and residing in the European Continent, the American Continent, or Oceania. The study included 21 participants: 2 ethical experts, 17 researchers, and 2 research participants. However, within the ethical experts and the researchers' groups, a total of 9 people (who identified as intersex people) had also, at some point, had experience as research participants of intersex-related studies, which means they could offer a double perspective for the research purposes. Given the limited number of people involved in the field of intersex studies, demographic details about all three groups of participants, such as their region of residence, discipline, and career stage, will not be published to ensure confidentiality.

The semi-structured interviews allowed research participants to express their experiences regarding the development of research related to intersex issues and to engage in a reflexive exercise. The interview process tried to follow a human rights-based approach, which means research that prioritizes not only the study objectives but also how they are achieved, with a commitment to upholding human rights principles throughout the project ([Smith 2018](#)). Participants received an information sheet about the project, an informed consent form, and an explanation of their rights. They had the opportunity to review the information provided in the interview and the possibility to withdraw their interview at any time before the results were published. In order to avoid people feeling pressured to

participate, the interviewing process always offered alternatives, such as not answering questions that the person did not feel comfortable with. During the interviews, the use of a depathologizing language was important in order to provide the participants with a comfortable environment for them to express their thoughts and therefore minimize the risk of possible re-traumatization. The project offered two funded psychotherapeutic sessions for intersex participants and access to a support organization contact sheet upon request.

Each interview took place remotely, was recorded, and lasted approximately one hour. The interviews were carried out from April 2022 to October 2022. The interview information was transcribed and imported into secured digital spaces along with the audio files. A thematic analysis was conducted, following Braun and Clarke's (2006) methodology. The data were organized using five initial codes, according to the structure of the interview script: background of the participant, experiences before the interviews, experiences during the interviews, experiences after the interviews, ethical insights, and recommendations/feelings. Thereafter, relevant themes mentioned by various participants were identified, related mainly to experiences before and during the interviews.

This article primarily aims at delineating the themes underscored by participants, by means of a descriptive approach. These themes can serve as a catalyst for fostering new dialogues within the area of intersex research. Consequently, the results section is dedicated to amplifying the voices of the participants, elucidating their experiences and recommendations related to the research design (positionality, researcher preparation, framing intersex within LGBT), and the experiences related to the research development (ethical approval, informed consent process, language use, relationship of trust).

Following the reflections on research methodology contributed by other scholars (Garland and Travis 2023; Monro et al. 2021), this research does not intend to speak for the intersex communities and, therefore, refrains from interpreting the participants' experiences. Instead, it aims to engage in dialogue with them for the purpose of knowledge development (Garland and Travis 2023). This overview addresses the contentious areas articulated by participants earlier. It is imperative to note that the sources of knowledge underpinning this article extend beyond scientific and academic research, incorporating activist perspectives and non-governmental reports. These sources were included to engage and recognize the different ways of knowledge production and existing contributions to the development of intersex-related studies.

As a non-intersex (or endosex) individual, my interest in intersex studies has developed closely in the last seven years alongside my work in public policy with other communities that have also experienced human rights violations during research, such as the trans and Indigenous communities. Through my involvement in the INIA Project as a Marie Curie Researcher, I have been dedicated since 2021 to studying the history, struggles, injustices, oppression, and marginalization faced by the intersex community.

### 3. Results

#### 3.1. Experiences Related to Research Design

##### 3.1.1. Positionality

Throughout the semi-structured interviews, most participants raised concerns related to researcher positionality. They pointed out the challenges associated with the internal personal processes and self-reflection that researchers undergo when studying a population that has experienced human rights violations, such as intersex individuals. A particular concern was voiced regarding researchers who are not intersex persons. Participants noted that the legitimacy of their involvement is assessed by both themselves and the intersex community.

For instance, from a researcher's perspective, Participant No. 15 (Researcher)<sup>2</sup> mentioned the ethical dilemmas that she went through during the publication of findings as an endosex person. The legitimacy of the research was always a topic of consideration because it made her feel that she was occupying a place that did not correspond to her.

Other researchers agreed with this internal discussion of legitimacy and doubting of their research. Participant No. 13 illustrates:

[. . .] I think with time, it's been always a question of the legitimacy of me working on this issue, but that something, I mean, what helped me was going to meet intersex people that told me that, like, thank you for doing your research, and it's important that there are people doing it. So, it's kind of keeping in mind that if what I do can also serve their knowledge of intersex people and their rights [. . .] if you're not intersex, I think it's really complicated to do research with intersex people about their history and experience, but I guess you have to especially like try to do what your positionality in it, it's complex. So always remind, you know, yourself and the others what from what kind of point of view you're doing this research. (Researcher. P13)

Emphasizing the significance of scrutinizing internal motivations for conducting the research, participants underscored the importance of self-reflection in navigating these complexities. Particularly, researchers who are endosex showed more concern regarding their positionality and legitimacy in the research.

### 3.1.2. Researcher Preparation

According to the participants in this research, intersex individuals have endured experiences characterized by medicalization and human rights violations. Throughout the interviews, the interviewed endosex researchers highlighted the importance of educating themselves and taking part in training about research ethics previous to the research design. This emphasis aims to better comprehend the life experiences that individuals will share and, importantly, to prevent misconceptions.

Some of the researchers were aware of the problems; for example, Participant No. 6 (Researcher) stated that "[. . .] researchers will use intersex people to get information, but then they consider themselves as experts." This researcher mentioned how some researchers do not give the same value to the activist experience in comparison to the scientific experience.

Other participants who hold the position of researchers and have been participants of intersex-related research mentioned:

I feel like quite comfortable talking about these issues where I know the researcher understands the population and that's what they're talking about, but it's incredibly frustrating when they clearly don't, they confuse it with trans issues all the time. [. . .] I think it could be quite confronting if you're talking to researchers who don't quite understand the population and like your issues. (Researcher—Participant. P17)

[. . .] the researcher is coming from outside and you have to respect that this person understands their lived experience better than anybody else. These researchers think they come from heaven with analytical superpowers when they don't. (Researcher—Participant. P21)

The majority on the people interviewed commented at some point on the importance of researchers receiving previous training that creates an awareness of intersex people's experiences and makes them understand better the issues that they face and how future projects could help to solve them.

### 3.1.3. Framing Intersex within the LGBT Acronym

The research participants discussed approaches to research design, including framing intersex within the LGBT acronym, and emphasized the potential impact of this on the representation of the community's identity and priorities. Many participants expressed concerns about possible misrepresentations that could occur with the framing of intersex within LGBT, particularly when intersex issues are portrayed solely as gender or sex identification issues rather than acknowledging the violence they endure.

Participants mentioned possible reasons for this framing. Participant No. 9, who is a researcher, indicated that in some instances, it is easier to obtain ethical approval when the frame of the study is LGBT+ and therefore “[...] that creates a problem, because it means that it’s pushing researchers towards this LGBT framing of intersex and not a medicalized of intersex because it’s easier to get the data here.” Another researcher, participant No. 4, states that some academics write about intersex people having an LGBT background, which could limit their focus, mentioning that “[...] gay people are not mutilated, so mutilation is not on their radar and then they focus on what they know, like discrimination, hate, hate speech and stuff like this, [...].”

Other perspectives came from people who have been researchers and participants. Some of them explained how this LGBT framing could remove the attention from real concerns that are specific to intersex people. Some of them stated the following:

[...] if you had to draw one comparison, it would be more with victims of incest or victims of pedocriminality, like how you treat the people who are sharing the testimonies with you, how you can, I think often people would assume that is a question of identity or question of body, but it’s not, it is about the experience of violence since you are very young, [...]. (Researcher–Participant. P11)

[...] what is that doing to people who are cisgender heterosexual because I know they exist and they’re part of my community? They tend not to become part of many intersex groups who are very LGBT focused. And sadly, that kind of pushes them. I mean, the only spaces that some of those people feel comfortable in is medicalized spaces because at least those spaces are not trying to tell them they are something that they don’t feel they are, so it’s a difficult situation. (Researcher—Participant. P1)

The framing of intersex-related studies within LGBT is a topic that created different opinions among participants. However, some of them agreed on the idea that to avoid misleading of locating intersex people’s issues within LGBT research, it is necessary to consult the community in the research design so they can have a voice in what is important to them.

### 3.2. Experiences Related to Research Development

#### 3.2.1. Ethical Approval

The process of securing ethical approval for the research projects emerged as a recurrent issue mentioned by the participants. They expressed concerns regarding the necessity of ethics approval, the composition of ethics committees, and the overall utility of the approval process for the research. A prevalent and shared concern was the expertise of the board members concerning the challenges faced by the intersex population. The opinions of some participants were as follows:

The problem is that many of those boards are not familiar with the population. So many of much of the bad practice that I’ve talked about has been approved by an ethics review board that really has just not understood the population. (Researcher—Participant. P1)

[...] passing a research ethics committee guarantees that the research is ethical, no, for a very clear reason, because first, because ethics committees as they are organized today, there are people who brutally ignore the realities, so they are approving things they have no idea about. (Researcher. P15. Own Translation)

A common opinion among some of the participants was that beyond the formality, ethics committees may not understand the realities and struggles of the people involved in the research.

### 3.2.2. Informed Consent Process

A crucial aspect and focal point of discussion during the interviews was the informed consent process—its formalities, scope, and utility post-interview. Participants employed various approaches related to the informed consent process and voiced concerns, particularly regarding the terminology used in the consent forms and the assurance of their rights throughout the research once they signed the forms.

Some of the participants who are researchers agreed on the idea that the importance of this lies in what happens after the informed consent has been signed, and the integrity that the researcher will have afterwards. Another point highlighted by one of the researchers was the way in which the consent forms were written. Participant No. 6 (Researcher) advised, “[. . .] you need consent forms that are accessible, they can explain in a very simple way, all the steps, and also provide an alternative in case that you don’t like your research, the research, you can withdraw, but also mentioned a complaint mechanism or something, or someone to contact an organization to contact, something.”

Other people emphasized the process that comes along with informed consent; one of them said the following:

Maybe say things like, ‘So would you like to know why I’m doing this research? What the objectives are? If you have any questions in that regard I would be happy to answer them’ and to present the objective and what participation consists of; if there are any questions at all regarding the components of the research, feel free to ask and what I think would still be important may be that they are knowledgeable of consent forms but not everyone is knowledgeable about research and what it consists of [. . .]. (Researcher–Participant. P10)

The majority of the participants, especially those involved in research roles, emphasized the importance of viewing informed consent as a dynamic process. This process involves a series of actions that demonstrate respect for participants’ rights and provide them with a safe space to express any concerns regarding the study.

### 3.2.3. Language Use

Several challenges disclosed by participants, especially within the researchers’ group, became apparent during the interviews, particularly regarding the creation and development of the interview process. Some researchers encountered difficulties with language use, and interview partners with experience as research participants recounted instances where the misuse of language could compromise the trust in the relationship. One of them advised the following:

[. . .] maybe use vocabulary at first that is as neutral as possible, interventions that you were subjected to, start with that and adjust regarding how the person describes them; I mean, I know I am using for myself human rights violations, at first I was using non-consensual interventions, I know that it is still considered a hot topic, it is shocking blurting out human rights violations and even for intersex people, they don’t want to use ‘genital mutilation,’ others will, or ‘sex mutilation’ or ‘sexual mutilation,’ not just concentrated on genitals, because there might be different reasons a person doesn’t want to hear ‘genital mutilation,’ and we can’t just push people, it’s a very sensitive thing [. . .]. (Researcher–Participant. P10)

A few individuals interviewed who are researchers and have been research participants commented on the mistrust that they have when somebody talks to them with a pathologizing language. Others emphasized the importance of using the preferred language of the person, even if it is medicalized. For instance, Participant No. 20 (Researcher–Participant) said, “[. . .] if you speak with a patient or organizer or whatever, and they only use their own variation and say syndrome, and don’t use intersex. Don’t say this intersex person, it’s not like correct, but if I say I’m intersex, don’t go and say, oh, this person with this syndrome because it’s not the way I want.” Overall, most of the people interviewed



came to the conclusion that the language used plays a fundamental role in the development of a relationship of trust between researcher and participant.

#### 3.2.4. Relationship of Trust

In the qualitative research process, participants underscored the significance of sustaining a relationship of trust with their research counterparts across all stages of the study, not solely limited to the interview process. Within this framework, some participants conveyed their discomfort, describing instances where they felt utilized solely as sources of data. This discomfort hindered their willingness to engage in subsequent research participation.

[. . .] it is a feeling I think Yessica, a growth feeling valued. If you don't feel valued, it doesn't work because being valued and having trust, I think, is paramount key. In any research. You don't trust someone, then you may as well say no. [. . .] I think, if you feel that the interviewer, researcher, give something of themselves, not seeing anything deep or really dramatic, I think it always gives permission for the person being interviewed to give something of themselves, it becomes reciprocal, if that makes sense. (Participant. P5)

Some of the researchers interviewed in the study agreed upon the idea that building a relationship of trust is something that cannot be pushed because it requires time for the people to trust in the researcher's intentions and the position that he/she/they have of certain intersex issues. Participant No. 9 (Researcher) commented: "[. . .] in a way you are as a researcher to try to explain how you stay in that field, and you're not taking people's data or doing something horrible or creating intersex as a third gender [. . .]."

Participants of each group gave different perspectives on the relationship of trust and how it can develop. Nevertheless, consistency in the researcher's actions and time to build a relationship were two positive factors present in some of the answers. One of the researchers highlighted the importance on human connection to allow the relationship to grow:

[. . .] for me, trust is something that arises from that relationship, and we can work on things beforehand to allow it to emerge, but it is, above all, something that will emerge if we are really capable of connecting humanly and if we are not capable of connecting humanly, it does not even emerge, it doesn't emerge, and it's possibly very good that it doesn't emerge because there's probably a protection from the other part and that is very appropriate. (Researcher. P14. Own Translation)

This study addressed results across a range of topics, including the significance of internal reflections such as positionality, the necessity of thorough researcher preparation, and the importance of consulting the community when framing topics under the LGBT umbrella. Additionally, the study highlighted the requirements for ethical approval and the process of informed consent, the correct use of language, and the value of fostering a trusting relationship between the researcher and the participants.

## 4. Discussion

These qualitative findings show a range of concerns and contribute to an open discussion about research on intersex issues. This discussion section addresses issues of legitimacy, epistemological violence, intersex-specific research methodology concerns and guidelines, the construction of an intersex identity, language use, and general issues concerning research with marginalized populations.

Although some of the topics mentioned during the interviews were not explicitly formulated as questions, the participants consistently and prominently introduced them into the conversation. An unexpected revelation emerged during the researchers' self-reflection process, particularly among those who do not identify as intersex. Initially, this theme was not identified as a separate category. However, researchers consistently

referenced this topic, discussing their struggles in their positionality throughout their research project, especially those who are not intersex individuals themselves.

Many of the researchers involved in the qualitative study found themselves questioning their legitimacy within research projects and pondering the extent of responsibility associated with speaking and writing about a community that has long grappled for recognition. This self-reflection is understandable considering the history of epistemic injustice that the population has faced, mainly within medical research, including pathologizing classifications of their bodies (Merrick 2019).

Through the analysis of the interviews, most of the interviewed researchers were keen to constantly think of measures to avoid subjecting their studies to a framework of epistemic injustice concerning the intersex community. As mentioned above, the epistemic injustice frames a determined group in a defenseless stereotype (Fricker 2007), and the discreditation of their voices with the presence of “[e]pistemic violence in testimony” (Dotson 2011, p. 238) could occur in different contexts, among them research.

This study contributes to existing scholarship on intersex-related research. From a perspective of intersex studies, Janik Bastien-Charlebois (2017) explains extensively how epistemic injustice develops within the field of intersex-related research and the negative consequences it has brought for intersex people. She states that “the combined effect of hermeneutical marginalization and testimonial injustice can create credibility deflation. [...] It is impossible to produce comprehensive empirical investigations into the effects of non-consensual body modification when the medical profession has exclusive access to the records [...]” (Bastien-Charlebois 2017, n.p.; own translation). Following Medina’s (2013) framework of hermeneutical gaps, Ziemińska (2020) highlights that for intersex people, “[i]t is not only a problem that intersex voices have a deflated level of credibility, but it is also a structural problem that is easy to miss: their voices cannot be understood in the public arena, as the public binary notion of two sexes makes too little space for these voices. The intersex experience is closed behind hospital doors” (p. 54).

Within the participants’ responses during the interviews, several comments were directed toward the researchers’ attitudes. It was emphasized that researchers should value the activist knowledge and experiences of the participants and not diminish them in comparison to scientific knowledge. These comments align with the report published in 2014 by the organization GATE—Global Action for Trans Equality; the report addressed intersex issues in the International Classification of Diseases, including an epistemological analysis (GATE 2014). While this epistemological analysis is primarily centered on clinical research, its insights are crucial for comprehending the broader epistemological context in intersex-related research. It highlights the detrimental outcomes that arise when a researcher relies on their “own judgment as intrinsically better than the judgments of persons with intersex variations” (GATE 2014, p. 14). In this context, GATE (2014) has made observations such as: “Power-dynamics influence data-collection” and “[r]esearchers interpret their own results, often in their own hospitals, assessing the outcomes of their own treatment paradigms; there is selection and sampling bias” (p. 15; references removed).

The findings of this research revealed a consensus among some researchers regarding the historical challenges intersex individuals have faced due to objectification in research. They emphasized that current research on intersex-related topics should prioritize the voices and experiences of intersex individuals throughout the study’s development. In this sense, Bartolo Tabone et al. (2024) suggest that “[t]o remedy the divide between human rights and medical narratives, medical professionals must reflect on their own epistemic primacy and the privileging that their views are granted. In order to combat both hermeneutic and testimonial epistemic injustice, priority must be given to the voices and testimony of intersex people” (p. 15).

To avoid the discussed objectivization, Koyama (n.d.) has elaborated guidelines for non-intersex researchers who decide to write about intersex issues, including the following suggestions: “Recognize that you are not the experts about intersex people, intersexuality, or what it means to be intersexed; intersex people are. When writing a paper about

intersexuality, make sure to center voices of intersex people” and “[d]o not write about intersex existence or the concept of intersexuality without talking about the lives and experiences of intersex people as well as issues they face. Do not use intersex people merely to illustrate the social construction of binary sexes” (n.p., bold removed). These principles appeal to a human rights-based research framework that centers on voices and experiences and tries to produce research that recognizes the community’s struggles.

Following along with the trajectory of these research dynamics, in the context of intersex-related studies, the findings of this study showed that the three interviewed groups emphasized the necessity for researchers to possess profound insights into the historical and present concerns of intersex individuals. Similar assertions have been made previously. For example, participants in an Amnesty International study emphasized the significance of researchers acknowledging the community’s research context, which has historically been marked by severe human rights violations ([Amnesty International 2017](#)). These violations stem from the perception of intersex people’s bodies as bodies that need to be ‘normalized’ in their sex characteristics to fit the gender binary categories, leading to a pathologizing experience for them and the perception of a need for their bodies to be corrected ([Amnesty International 2017](#)).

Gaining a comprehensive understanding of intersex issues extends beyond studying their history; it involves an examination of the sources contributing to this knowledge and the manner in which researchers articulate it. The Intersex Society of North America ([ISNA n.d.](#)) advises researchers to “[t]hink critically about all texts that deal with intersex” (n.p.). This involves asking pertinent questions about authors’ or speakers’ affiliations and the origins of their knowledge. Additionally, this organization suggests that when writing about intersex, researchers should strive to demonstrate a nuanced understanding and sensitivity towards the experiences and challenges faced by intersex individuals ([ISNA n.d.](#)).

Moving on with the theme of acquiring knowledge about the community’s experiences and diversity previous to the development of a project (research design stage), the analysis of my research findings revealed another significant theme—the fundamental role of constructing an intersex identity. As an illustrative example, participants mentioned the inclusion of intersex-related studies into LGBT studies, initiating a dialogue that underscores the complexity of the relationship and its potential impact. This inclusion, for instance, plays a significant role in shaping or misrepresenting the identity of the intersex community.

[Carpenter \(2022\)](#) expressed similar concerns regarding the possible dismissal that it can create of intersex people’s voices, indicating that “other reports suggest that people with innate variations of sex characteristics do not feel connected to an LGBTQ+ community [. . .]. It is vital to acknowledge the impact of misconceptions about intersex in LGBTQ+ and policy spaces, and a widespread ignorance of distinctly different community characteristics and demands” (p. 5). Similarly, [Garland and Travis’s \(2023\)](#) research discusses the meaning of LGBT embodiment for the intersex community. They present diverse perspectives on this contentious topic, including: “Such alliances are an integral strategy for many intersex activists to ensure that intersex falls inside rather than outside law’s protective sphere. They help politicize intersex, giving visibility” ([Garland and Travis 2023](#), p. 83). Additionally, they highlight that sometimes LGBT organizations could have totally different priorities than intersex people’s issues, creating consequences such as “misrepresent intersex-specific issues as relating to identity rather than bodily autonomy” ([Garland and Travis 2020](#), p. 176, quoted in [Garland and Travis 2023](#), p. 83). The authors also mentioned that within their qualitative study, some of their participants “felt that this was a product of organizations only including the ‘I’ to increase their chances of funding” ([Garland and Travis 2023](#), p. 86).

Lastly, within the LGBT sphere, some participants in the qualitative research considered that situating intersex-related studies within LGBT research could enhance the likelihood of obtaining ethical approval. This perspective prompts an exploration into the impact and relevance of research ethics committees. While I could not identify a dedicated line of inquiry on this topic within intersex studies, the outcomes and functioning

of research ethics committees as reviewing entities that look for the production of ethical research seem to be an open discussion in a broader academic context (Coleman and Bouësseau 2008). Critics are concerned about the tendency to focus more on the formalities rather than on the substance, the knowledge, diversity, and training that the committee members have of the research topic, the possible conflict of interests, and the enforceability of their decisions generate the question of their real impact (Coleman and Bouësseau 2008).

Transitioning to the domain of project development, according to the results of the interviews, informed consent plays a central role in intersex-related research, linked to the history of human rights violations, as well as the importance of agency and bodily autonomy for intersex people. The interview participants expressed the opinion that informed consent should be considered as a process rather than as a formal requirement. General ethical recommendations have been created to support the crafting of research protocols that adhere to minimal ethical standards (International Military Tribunal 1946; The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979; WMA [1964] 2013). Among these standards, the informed consent form is regarded as a critical component for participants involved in research projects, particularly within social sciences (EC 2021; NNREC 2021). Individuals interviewed in this study expressed discomfort when the informed consent process is reduced to a mere formality; some mentioned feeling objectified in previous projects. For intersex-related studies, the sensitive nature of the ethics surrounding informed consent stems from historical circumstances wherein intersex individuals have lacked agency over their bodies, leading to medical interventions being conducted without their voluntary and well-informed consent (FRA 2015).

Illustrating the various historical instances where intersex individuals have been deprived of adequate informed consent processes, Bastien-Charlebois (2016) asserts that “[i]ntersex people are a textbook case of what comprises being treated as ‘mere sources of information’ [. . .] we were very far from being considered as beings that should be asked for their thoughts and judgments” (n.p.). Regarding intersex-related research, interACT (2023) highlights that “studies must meet the highest standards of informed consent (and informed assent for children); respect the autonomy, dignity, and privacy of intersex participants and (where applicable) their families; avoid subjecting participants to unnecessary risks; and responsibly address questions relevant to the well-being of individuals with variations in their sex characteristics” (n.p.).

The considerations concerning informed consent go beyond the act of signing an informed consent agreement; they also touch on how information is presented. For instance, in the previously mentioned narrative literature review of qualitative and quantitative research on intersex issues I conducted in 2023, the inclusion of images in research publications emerged as a contentious issue (Mestre Martínez 2023a). In the review, I noted that “although it is not possible to recognize the participant, it may evoke a sensation of discomfort and pain to view these pictures, prompting the question: How does the participant feel about the public nature of these images and their right to privacy? Was it explicitly outlined in the informed consent form what types of pictures would be published?” (Mestre Martínez 2023a, p. 53).

Another issue that emerged from the research findings concerned how the information is presented. Participants interviewed in this research emphasized the significance and challenges of employing inclusive language in research and how language becomes one of the pillars for the establishment of a relationship of trust. The use of inclusive language is crucial for intersex-related studies, given the violations of bodily integrity experienced by intersex individuals (Carpenter and IHRA 2018). Lundberg et al. (2018) underscore the importance of language in shaping intersex individuals’ identities, emphasizing that the lack of precise terminology can contribute to dehumanization and further marginalization. Given the influence of language on the medicalization of intersex individuals, Davis (2011) contends that the use of pathologizing language has reinforced the authority of medicine over intersex people’s bodies.

Various intersex scholars, activists, and allies aim to generate awareness by stressing the existence of these pathologizing practices (Battaglini 2019; Cabral Grinspan 2009; Holmes 2008; Suess Schwend 2014, 2022). Similar reflections have been developed in research with other communities that have suffered marginalization. For instance, Vincent (2018), from a perspective of trans studies, mentions the connection between language and history, highlighting the importance of implementing a research methodology that is language-appropriate to avoid pathologization. Also, Adams et al. (2017) frame different issues related to research with trans individuals, which intersex people have also experienced. This highlights the importance of the researcher's linguistic choices during the interviews and dissemination of data (Adams et al. 2017).

To be consistent with the use of appropriate language and respect for trans people's rights within research, the European Professional Association for Transgender Health—EPATH and the World Professional Association for Transgender Health—WPATH have created Language Guidelines to advise researchers in the presentation and publication of results (Bouman et al. [2016] 2017). Furthermore, EPATH (2019) has launched a Research Policy to provide recommendations for research on trans issues.

It is noteworthy that the campaign 'Depath Intersex,' launched by OII Europe (2023), seeks to give visibility to pathologizing behaviors that can significantly impact the lives of intersex individuals by "creating and legitimizing stigma" (n.p.). The OII Europe initiative proposes recommendations, such as incorporating non-pathologizing information about intersex in educational materials and implementing human rights-based information and training for professionals, especially within the health care system (OII Europe 2023). Amets Suess Schwend (2022) has delved into an "ethics of depathologization," understanding the approach as "a research practice based on the depathologization and human rights perspective" (p. 111). Among other principles, Suess Schwend (2022) advocates for "[r]efraining from pathologizing language, using and promoting respectful, affirmative, and non-pathologizing conceptualizations and terminologies," and "[a]bstaining from a use of pathologizing images in publications or presentations" (p. 111).

The final aspect of research ethics that the participants emphasized is the importance of a relationship of trust during the execution of the project. One of them made a deep reflection on the importance of creating a human connection to establish a genuine relationship with intersex people. Costas Batlle and Carr (2021) noted this point, commenting that creating a genuine human connection is especially vital at this stage to truly capture the viewpoints of the participants, understanding this as a sharing relationship as valuable for the research as the other stages of the project. Therefore, following the line of thoughts of Costas Batlle and Carr (2021), it would be important to consider the creation of this relationship as an essential moment of the research process, particularly if the research topic involves the sharing of vulnerable aspects of the participants' lives.

## 5. Conclusions

The analysis of the fieldwork has opened avenues for new discussions and brought attention to existing gaps in intersex-related studies. Throughout the interview process, I encountered a variety of issues that were previously unseen (such as the important reflections around legitimacy, particularly for endosex people), and their identification was made possible through the experiences shared by the participants. One recurring issue that resonated closely with both the research participants and myself was the exploration of positionality. Internal struggles and self-reflection were consistently present, particularly among non-intersex researchers. A set of questions revolving around legitimacy, knowledge control, respect for intersex people's voices, and the establishment of trust were crucial for them (and for me) in determining the scope and relevance of research projects.

The engagement of research with a community that has faced human rights violations in certain aspects of their lives implies a commitment to studying their concerns comprehensively. This commitment is crucial to avoid overlooking essential elements that could contribute to defining the project's significance and coherence.

The interview quotes underscored the significance of establishing an authentic human connection between the researchers and the participants. This connection is vital not only for the advancement of intersex-related studies but also for research involving any population group that has experienced human rights violations. There is a historical wound of distrust, and a genuine human connection could aid in the healing process, ultimately enhancing the production of research results.

This study includes several limitations. Throughout the fieldwork, a recurring limitation was the challenge of accessing individuals with variations in sex characteristics who do not identify as intersex. The research project and informed consent documents were crafted using intersex terminology, posing difficulties in engaging with individuals who identify differently. For instance, someone identifying as having a Disorder of Sex Development (DSD) may choose not to associate with an intersex project. This challenge also extended to researchers; efforts were made to connect with those who had conducted qualitative research within the medical field involving DSD participants. However, upon sharing information, some researchers hesitated to participate in research framed under the intersex spectrum.

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**Informed Consent Statement:** Informed consent was obtained from all subjects involved in the study.

**Data Availability Statement:** The data presented in this study are available on request from the corresponding author due to privacy reasons.

**Conflicts of Interest:** The author declares no conflicts of interest.

## Notes

- <sup>1</sup> Some lines of the introduction have been previously published in two reports. See: [Mestre Martínez \(2023a, 2023b\)](#).
- <sup>2</sup> “Researcher,” “Participant”, or “Researcher—Participant” refers to the experiences and roles of the interview partner. “P15”, etc., refer to the participation in the current research project. This academic article does not include quotes from experts on research ethics.

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