"I'm always a little bit skeptical": Intersex young adults' recommendations for community-partnered health research

Aaron Samuel Breslow, PhD;[1,2,3] Ellora Vilkin, PhD;[1,3] Bria Brown-King;[4] Elizabeth Cavic, MA;[1] Ginette Sims, PhD;[1] Marla Renee Fisher, MD;[1,5] Kimberly Zieselman, JD;[6] Alesdair Ittelson, JD[4]

[1] PRIME Center for Health Equity, Psychiatry Research Institute at Montefiore Einstein, Department of Psychiatry and Behavioral Sciences, Albert Einstein College of Medicine, Bronx, NY

[2] Einstein-Rockefeller-City University of New York Center for AIDS Research, Albert Einstein College of Medicine, Bronx, NY

[3] Department of Psychiatry and Behavioral Sciences, Montefiore Medical Center, Bronx, NY

[4] interACT: Advocates for Intersex Youth, Sudbury, MA

[5] Mount Sinai Morningside/West, Icahn School of Medicine at Mount Sinai, New York, NY

[6] Outright International, New York, NY

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Corresponding author: Aaron Samuel Breslow, PhD, PRIME Center for Health Equity, Psychiatry Research Institute at Montefiore Einstein, Department of Psychiatry and Behavioral Sciences, Albert Einstein College of Medicine, 1300 Morris Park Ave, 4A-47, Bronx, NY 10461, USA. Email: aaron.breslow@einsteinmed.edu

Author Contribution list: Aaron S. Breslow: Conceptualization, Methodology, Software, Validation, Formal Analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review and editing, Supervision, Project administration, and Funding acquisition. Ellora Vilkin: Conceptualization, Methodology, Data Curation, Writing – Original Draft, Writing – Review and Editing. Bria Brown – King: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft. Elizabeth Cavic: Conceptualization, Methodology, Validation, Formal Analysis, Data Curation, Investigation, Writing – Original Draft, Visualization, and Project Administration. Ginette Sims: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data Curation, Writing-Original Draft, Writing-Review and Editing. Marla Renee Fisher: Conceptualization, Methodology, Formal analysis, Investigation, Writing – Original Draft. Kimberly Zieselman: Conceptualization, Validation, Resources, Writing – Review and Editing. Alesdair Ittelson: Conceptualization, Validation, Resources, Writing – Review and Editing.

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ABSTRACT

Background: An estimated 1.7% to 4% of people in the United States are born intersex, or with congenital variations that transcend binary sex. Historically, Western medical protocols have advocated for the 'correction' of intersex variations through early surgical intervention, a practice opposed by the majority of intersex-led organizations. Stakeholder voices remain underrepresented in research.

Objectives: This study aimed to explore the experiences of intersex young adults participating in health research, with the goal of gathering recommendations to improve intersex-affirming research practices.

Methods: In collaboration with interACT: Advocates for Intersex Youth (interACT), a leading intersex rights organization, we conducted four focus groups between January and May 2022 with 11 intersex young adults. Participants were recruited via convenience sampling through interACT's mail listservs and purposively sampled for diversity in age, geographic location, race and ethnicity, and gender identity. Thematic analysis was used to analyze focus group transcripts.

Results: Three central subthemes emerged regarding participants' problems with intersex health research: dehumanization and objectification; stigmatizing language; and underrepresentation in research. Four subthemes emerged in terms of recommendations for intersex-affirming research: using community-based research approaches; focusing on strengths rather than pathology; conducting translational research that improves healthcare services; and prioritizing respondent experiences in study design.

Conclusions: This study emphasizes the negative experiences of intersex individuals with non-affirming research practices and underscores the need for more ethical, participatory, and

humanizing research approaches. By centering intersex stakeholders, future research can better support the autonomy, wellbeing, and health equity of intersex communities.

KEYWORDS: intersex, healthcare, community-participatory research, focus groups

Introduction

An estimated 1.7% to 4% of people in the United States are born intersex, with congenital variations transcending binary medical criteria.[1] Historically, intersex health research and medical protocols have focused on 'normalization' of intersex variations through early surgical interventions, often violating bodily autonomy.[2] Intersex organizations and human rights groups advocate delaying nonessential interventions until individuals can participate in their care.[3–6] Despite this, early interventions persist, guided by non-affirming research.[7,8]

Reviews suggest most intersex health studies focus on surgical management and gender conformity,[9,10] with limited attention to well-being and experiences across the lifespan.[7,8,11] Comprehensive studies are needed, given high rates of adverse psychological outcomes among intersex people.[12,13] A recent study found 43% of intersex U.S. adults report 'fair/poor' physical health, 53% 'fair/poor' mental health, and a third struggle with everyday tasks.[13] These outcomes position intersex people as a gender minority group affected by minority stressors,[4] though intersex health remains underexplored in lesbian, gay, bisexual, transgender, queer, intersex, asexual, and other (LGBTQIA+) research.[2,3,5,10]

Emerging studies center intersex experiences in LGBTQIA+ research, with scholars in feminist, queer theory, disability, and critical intersex studies recognizing vital stakeholder perspectives.[14–18] Recent qualitative studies in North America have highlighted intersex stakeholders' experiences with healthcare and research, revealing common concerns of medical trauma, minority stressors, frustration with inadequate provider knowledge, and adverse reactions to stigmatizing language (e.g., hermaphrodite,' 'disorders of sex development') in scientific reports.[5,19] These findings underscore the need for research led by intersex stakeholders to improve methods, outcomes, and healthcare policy.

Community-based participatory research (CBPR) offers a promising framework for involving intersex communities in research that respects their insights and needs.[20] This iterative approach lets stakeholders co-create protocols and interpret findings in context.[5,21–23] Our study gathered intersex stakeholders' experiences and recommendations to improve intersex-affirming health research.[19]

Present Study

We partnered with interACT: Advocates for Intersex (interACT), a leading intersex rights organization, to conduct four focus groups with intersex young adults (n=11). The study aimed to understand their experiences with intersex health research and gather suggestions to make studies more affirming. To maximize community leadership, we adapted a a previously validated methodological framework for a process-oriented approach to transgender and nonbinary health research centralizing community needs and addressing power dynamics,[24] and followed guidelines for participatory research with interACT, our community partner.

Methods

Community Partnership

This study aimed to describe stakeholder experiences with intersex health research and to highlight examples of unethical practices reported by community members. We offer recommendations for more inclusive and ethical research practices with diverse intersex communities. Starting in 2022, we developed a partnership with interACT: Advocates for Intersex Youth, a leading intersex rights organization representing youth. Grounded in CBPR principles, intersex stakeholders led development, implementation, and dissemination of the focus group methods and results over a 12-month period. We followed the organization's Policy Statement on Participation in Research.[5,21–23,25] Authors include scholars and community

organizers from sexual and gender minority communities, including four who were affiliated with our community partner, interACT, at the time of study design and conceptualization. Three have since transitioned to different roles. The authorship team consists of individuals who are endosex, intersex, and transgender.

Design and Procedure

We conducted four 90-minute focus groups with intersex young adults, facilitated via a HIPAA-compliant Zoom platform between January and May 2022. Groups were co-led by an interACT liaison and a researcher. Recruitment occurred online through convenience sampling via interACT's Youth Program email listservs, seeking young adults (18-29 years old, fluent in English) who identified as intersex or who were born with intersex traits but may not identify as intersex. Interested individuals completed an online survey on Qualtrics.com, providing informed consent and demographic information (i.e., age, intersex identity, race and ethnicity, gender identity, and geographic location). Twenty-four individuals expressed interest in participating, and all met eligibility criteria. Our original protocol specified two small focus groups of four participants each (n=8). After completing the first group, we amended the protocol to allow up to 12 participants to increase thematic saturation. From the 24 eligible, we used purposive sampling[26,27] and selected 12 participants to maximize diversity in demographic characteristics. One participant did not attend, resulting in a final sample of 11 participants across four groups.

Participants received detailed study procedures, consented online, and received a $100 incentive. Participants were invited to continue contributing as member checkers; three participants engaged in member checking, two of whom also assisted with the coding process. See Table 1 for the full focus group guide. We analyzed responses to questions 2–5 for this

manuscript, which focuses on problems with and recommendations for intersex health research. Questions 6 and 7 were more exploratory, eliciting reflections on broader community needs and aspirations, and will be analyzed in a separate manuscript. See Table 1 for the full focus group guide. Study procedures were approved by the Albert Einstein College of Medicine Institutional Review Board, protocol #2021-13191.

Thematic Analysis

Our thematic analysis followed a systematic approach grounded in established methodologies for analyzing qualitative data from focus groups. We began with a deductive approach based on our two key a priori themes of interest: problems with intersex health research and suggestions for improving intersex-affirming research.[28,29] As data collection progressed, we transitioned to an inductive phase to capture emergent subthemes,[30,31] accommodating pre-defined and novel insights.[32]

Codebook development. To systematize the analysis, a codebook was developed to capture recurring patterns and subthemes. Preliminary codes were developed based on the first two transcripts. These codes were collaboratively refined by the research team; the finalized codebook was applied to all four transcripts using an iterative approach that allowed for adjustments. As new subthemes emerged in subsequent focus groups, we refined the codebook through collaborative discussions between six coauthors and three interested focus group participants. This approach ensured that multiple perspectives were considered, aligning with best practices in community-participatory research and focus group analysis.[33]

Member checking. Once a penultimate draft of the codebook was prepared, we engaged in member checking with participants to enhance the credibility and trustworthiness of analyses.[34] This participatory feedback loop ensured that the participants' voices were accurately

represented in the findings. Participants provided guidance on refining code definitions, particularly by offering contextual clarifications grounded in their lived experiences. They also gave feedback on the overall structure of the codebook, including how certain codes might be combined or repositioned under broader thematic categories. Specifically, they recommended merging two closely related concepts—dehumanization and objectification—into a single theme to reflect their phenomenological overlap. Participants offered a number of practical recommendations to improve survey research, and we asked for clarification on how best to group these thematically. Member checkers suggested describing these under a single theme: 'Design studies to prioritize respondent experience' (Theme 2d). These revisions were incorporated to improve analytic clarity and strengthen the development of subthemes.

After incorporating their input, three researchers applied the finalized codebook to code the remaining focus group transcripts. Discrepancies were resolved by consensus, and new subthemes were incorporated or set aside by agreement until interrater reliability was >70%.[35] This iterative coding process allowed for a thorough and transparent examination of the data, ensuring the findings were reflective of participants' experiences and methodologically sound.

Results

See Table 2 for participant characteristics. See Table 3 for themes, subthemes, definitions, inclusion/exclusion criteria, and exemplar quotes. Participants were 11 young adults (20–29 years old) who identified as intersex and/or as having intersex variations or traits. The majority were non-Latinx White (*n*=7), with others identifying as biracial, mixed, East Asian, and Arab (*n*=1 each). Gender identities were diverse, with members identifying as 'women' (*n*=3), 'agender' (*n*=2), 'cis male' (*n*=2), 'male' (*n*=1), 'Two-Spirit' (*n*=1), 'trans man' (*n*=1), and 'bigender, center of masc, genderfluid, two-hearted, middle being' (*n*=1). Participants lived

in the United States (*n*=9) and Canada (*n*=2).

Theme 1: Problems with Intersex Health Research

Subtheme 1a: Dehumanization and objectification. Participants consistently described research experiences as dehumanizing or denying them of their humanity. Often, participants described feeling 'used' without their consent for medical research and training. Andy (23) recalled being "used as a sort of pedagogical tool" during a pediatric urology visit, where residents were called in to observe what the physician described as "one of the most severe cases that I've ever had in my practice." Bo (21) recounted a visit where they were subjected to invasive examinations, stripped naked in front of residents, and told their case would be helpful for research and clinical training without prior consent: "I was not informed that this doctor essentially wanted to collect my data for research, but when I walked in I was...being talked about as if I was a kind of animal, or like a lab rat."

Participants felt objectified by portrayals in research literature. Tyler (20) noted that studies often "talk about us in dehumanizing ways." Imagery of exposed genitalia in textbooks and research papers exacerbated these feelings. Bo (21) described "case study after case study of...naked adolescents...piles of case studies...often about like a baby or a child...of bodies being dissected in these horrific ways." Ila (24) described the available health research as "very exploitative" and having a "medicalized focus in a way that doesn't feel at all affirming." Some participants also expressed concerns about inadequate informed consent protocols, exacerbating feelings of being dehumanized, with others feeling "misled" (Tyler, 20) by unclear study descriptions. Amelia (20) described her experiences with intersex health research as "invasive," stating, "I think it's interesting, being intersex–it is such an umbrella word that being intersex looks like so many different things, but at the same time you don't owe anyone an explanation of

what that looks like for you. So yeah, very intrusive, definitely."

Subtheme1b: Stigmatizing language. Another major concern was the use of outdated and offensive terminology in research, such as 'hermaphrodite' and 'disorders of sex development' (DSD). Participants noted that such language perpetuates the myth that intersex traits are rare, abnormal, and difficult to diagnose. Leo (23) shared, "I'm always a little bit skeptical of intersex research...I would not agree to participate in any survey that used DSD in place of intersex. I've seen a couple of things like that, but I would never... I don't do them." Stigmatizing language included descriptions of intersex traits as 'rare,' 'uncommon,' or 'difficult to diagnose.'

Maria (21) noted that while stigmatizing language is becoming less common, encountering it can be emotionally triggering. She advocated for studies to be updated with community-generated terms: "I found a lot of studies, like, from the 90s...where they use language like 'hermaphrodite'...I just think it needs to be updated." Ska (28) felt marginalized by language in more recent studies, stating, "The language was not appropriate at all. They make it sound like it's still a problem that needs to be fixed, immediately, at birth. They still talk about DSD, and they still refer to things from the 80s and 90s." Participants stressed language choices affect their willingness to engage with research.

Subtheme1c: Underrepresentation in research. Participants highlighted a critical shortage of literature on intersex health. Leo (23) captured this concern: "One thing that I've heard a lot...about intersex health research is that there isn't [any]." After asking a rheumatologist about potential connections between intersex traits and autoimmune conditions, Ash (29) shared: "There's nothing. He didn't find anything...I don't know if the research isn't there, or if people aren't asking intersex people." This may leave significant gaps in understanding and addressing intersex health needs.

Even within the limited intersex research that does exist, participants pointed out a lack of diversity and nuance, particularly concerning different types of intersex variations. Ska (28) expressed frustration over the overrepresentation of conditions like Klinefelter syndrome and Turner syndrome, which are often less stigmatized. Ska stated, "I'd like to see more research being done about other conditions...so that people don't have to feel left out anymore."

Participants also discussed the tokenization of intersex identities within broader LGBTQIA+ research. Andy (23) commented, "There are studies on the LGBT population...attempting to include intersex...it'll be just sort of like lumped in with gender." Ash (29) noted the problematic conflation of intersex and transgender identities in research, saying, "There's a lot of trans-intersex overlap and research...not all intersex people are trans, and not all trans people are intersex, but sometimes they are." This tokenization within broader research further exacerbates the underrepresentation and marginalization of intersex health issues.

Theme 2: Suggestions for Intersex-Affirming Health Research

Subtheme 2a: Community-based research. Participants recommended that researchers engage in community-based research by partnering with intersex individuals and advocacy organizations. Leo (23) emphasized the need for stakeholder involvement: "Have any of you people talked to the people – the actual people – who had the interventions? Because most of them don't. I'd like to hear more of that. Community-based research." Tyler (20) underscored the importance of intentional and ongoing community engagement: "I would really consider engaging in any intersex research if I feel like the team is actually...being intentional throughout to build...relationships with [the] intersex community all throughout." Across focus groups, participants reported many studies interview parents or doctors, rather than community members, and emphasized the need for more proactive collaboration with stakeholders.

Subtheme 2b: Strengths-focused. Participants emphasized research that highlights resilience and coping strategies, rather than focusing solely on medical 'disorders' and trauma. Ila (24) expressed the importance of capturing these strengths: "A lot of the focus is always on the stigma, the suffering, the silence...I think there's nothing more that we have in common that we want to just be at peace, be happy, be accepted, and be loved." Stella (29) echoed this sentiment, reflecting on her own journey: "You know, I've done a lot of healing from things that I've experienced."

Such experiences of strength and recovery are often overlooked in intersex health research but represent a crucial direction for future studies. Tyler (20) added, "I want research to explore...trauma, medical violence, all that stuff, but also in a way that still gives intersex people agency and autonomy, and...our own healing." Participants agreed that a strengths-based approach is far more affirming than one focused primarily on pathology.

Subtheme 2c: Translational research. Participants emphasized the need for more translational research—studies that generate data with direct applicability to improving healthcare services for intersex people. Ska (28) highlighted a key issue: "That's a problem with any kind of research...there's the research, and then either it doesn't translate to real life, or it takes a really long time for it to translate to real life."

Participants advocated for research that equips providers to deliver affirming care and empowers patient-provider interactions. Leo expressed, "I am totally looking for research that enables therapists to do their job better, and doctors to do their job better, and patients to know how to communicate with everybody else."

Subtheme 2d: Design studies to prioritize respondent experience. Participants gave concrete suggestions for research protocols improving intersex people's experiences as

participants. A key suggestion was the use of inclusive, participant-centered language to describe intersex traits. Andy (23) advised, "Using inclusive language when it comes to intersex people with intersex characteristics, or DSD, or whatever like that people want to use." It was clear from the focus groups that not all participants agreed which terms, specifically, were acceptable within the community versus stigmatizing. Some recommended using 'differences in sex development (DSD),' whereas others found 'DSD' too stigmatizing as an abbreviation for 'disorders of sex development.' Participants recommended allowing individuals to type in their preferred terms when completing online surveys, with those terms auto-populating throughout the survey. Teddy (20) echoing the importance of centering participants' experience, stated "Questions that you would ask would be best to be entirely optional... They [should] make it clear this is the safe space and some things just generally not need to be shared publicly, so that...we can make intersex people more comfortable, and get them the health care that they need."

Another suggestion was to include multiple response options to reflect diverse identities. Ila (24) highlighted the need for "making sure that, like, a multiple-choice answer can have multiple selection." Participants also advocated for open-ended questions that allow for qualitative responses, as Stella (29) noted: "For some questions, it was just, like, an open text box...I found those ones some of the most valuable things." Participants also recommended providing options to skip questions that may be irrelevant or triggering, with Ila (24) advising, "Always [give] people the option to not, like, answer a question...if they don't want to."

Discussion

This community-engaged focus group study offers critical insights into the lived experiences of intersex individuals and their perspectives on improving intersex health research.

By partnering with an intersex-led advocacy organization, we align with emerging literature advocating for more participatory approaches[36] in intersex and LGBTQIA+ health research.[5,21] These parallel calls for respect, patient autonomy, and informed consent within intersex healthcare.[36,37] Qualitative findings from the current study revealed three subthemes describing problems with intersex health research alongside four subthemes describing recommendations for intersex-affirming health research.

A key finding was the profound dehumanization participants experienced, reflecting structural issues wherein intersex bodies are pathologized.[19,38] Participants' accounts mirror those in recent qualitative studies, which documented widespread disempowerment and violations of informed consent in healthcare settings.[19,23,39] These experiences may foster mistrust of healthcare systems and alienate intersex people from research.[21,39] The persistence of these issues highlights the need for more ethical, patient-centered practices.[14,40] To ensure more ethical and affirming research practices, we recommend Institutional Review Boards include members or consultants with specific expertise in intersex community priorities. Stigmatizing language was also core to participants' experiences, reinforcing harmful stereotypes and perpetuating mistrust and alienation from health research. That said, not all participants agreed which language was stigmatizing. The power of language shapes both self-perception and social narratives around marginalized communities.[19] As participants in this study noted, the continued use of terms like 'hermaphrodite' and 'disorders of sex development' signals a lack of respect, discouraging participation.[19,41] While some strides have been made toward adopting affirming language, the persistence of pathologizing terminology creates barriers to trust. This aligns with the position that intersex variations are not 'disorders,' and that such framing causes harm.[42] Using person-centered language may be a crucial step in fostering accuracy and utility of

findings.[43]

To complicate things, there was no myopic understanding of which language in particular was person-centered, even in our small group of intersex young adults. Some participants described affirming language as language that reflects how they identify and avoids medicalized or pathologizing terms. Others who were very emotionally connected with their diagnosis recommended referring to specific intersex variations (e.g., Congenital Adrenal Hyperplasia [CAH] or Partial Androgen Insensitivity Syndrome [PAIS]) rather than using umbrella terms. There was disagreement about use of the 'DSD' acronym. While some participants found the term 'differences in sex development' acceptable, others preferred terms like 'intersex traits' or 'intersex variations.' Several emphasized the importance of allowing participants to self-identify using their own language, which may differ from researcher-provided categories. Beyond terminology, participants recommended customizable response fields, opportunities to skip triggering questions, and survey designs that clearly communicate respect for intersex autonomy and lived experience.

Third, intersex people remain underrepresented, even within broader LGBTQIA+ health studies. Participants noted intersex people are often tokenized within transgender research, limiting focus on intersex health needs.[37] There is evidence of similar assimilative erasure among transgender, nonbinary, and agender people in sex and gender research[39] as well as calls to disaggregate gender minority subsamples. Moreover, the overrepresentation of certain less-stigmatized intersex variations, such as Turner and Klinefelter syndrome, may further marginalize individuals with more stigmatized conditions.[44,45] Disclosure of intersex traits or identity is a difficult process, and further inclusion of myriad variations may lead to increased openness.[45]

Directions for Future Research

Our findings align with a growing emphasis on community participation and strengths-focused research in intersex health studies, as well as a call that participant experiences are prioritized in the design and dissemination of research. Historically, research involving intersex people has often centered on pathologizing frameworks and deficit-based outcomes.[8,19,46] Our participants expressed a desire for research that actively affirms intersex resilience, wisdom, and community. Strengths-based research is particularly aligned with community-partnered approaches and may be better supported by funders who prioritize health equity and justice. The field of LGBTQIA+ minority stress research has shifted to a focus on resilience and minority strengths,[47–49] and we hope to see this replicated more fully with intersex communities.[38]

Participants emphasized the importance of CBPR methods that involve intersex individuals as active leaders throughout the research process.[24] In addition to these participatory approaches, future research should draw from the emerging interdisciplinary field of intersex studies, which offers critical reflections on intersex-related clinical practices, legal frameworks, and social inequities.[42] Specifically, the field prioritizes collaboration with academics with lived experiences, calling for an intersex epistemology that is co-constituted by scholars, stakeholders, and those who are both.[42]

This study was an aspirational example of this interdisciplinary, collaborative approach. Our partnership between the medical school and interACT fostered co-learning that strengthened mutual understanding, improved communication, and deepened commitment to affirming intersex rights and dignity. These shifts emerged through feedback loops during recruitment, codebook development, and member checking. Community partners provided recommendations that reshaped coding language, reframed study framing to center intersex autonomy, and

influenced the contextualization of findings. Participants emphasized the value of co-facilitation by an academic and an advocate who identified as intersex, which strengthened trust and supported a sense of safety. Overall, the project illustrated how long-term, reciprocal partnerships can enhance analytic rigor and promote a reparative research process. Future work should continue centering intersex voices to challenge existing power structures in knowledge production, foster more equitable healthcare practices, highlight positive aspects of intersex resilience,[38,47] and offer actionable strategies to support intersex strength, survival, and wellness.[20,50]

Limitations

This study has important limitations. First, although purposive sampling aimed to support demographic diversity, the final sample was predominantly White, U.S.-based, and highly educated. Second, because the study relied on virtual data collection, individuals without stable internet access or private space to participate may have been excluded. Third, the use of a group format may have influenced participants' comfort with disclosing sensitive or stigmatizing information. Future studies should include more intersex people of color and older individuals.[19]

Most importantly, although the study includes participants with a range of intersex variations, the sample does not capture the full spectrum of intersex diversity. Recruitment for an 'intersex sample' is inherently challenging due to the heterogeneity of variations, terminology, and medical histories.[18] Future research should prioritize greater inclusion of individuals with intersex variations more often subjected to stigma to ensure a more comprehensive understanding of intersex health. While rarity may contribute to stigma, other factors often play a more central role in shaping how intersex variations are perceived and

treated. Variations involving visible anatomical traits—such as CAH or PAIS—are often subject to heightened stigma, particularly when they lead to early surgical intervention or are treated as medical emergencies in pediatric care. These responses can pathologize the body and increase shame or medical trauma for intersex individuals. In contrast, conditions such as Klinefelter syndrome (47,XXY) or Turner syndrome (45,X), which may be less visually apparent and are more familiar to clinicians, may be less stigmatized in both clinical and research contexts. Additionally, social invisibility and misclassification—such as being incorrectly grouped within transgender research or overlooked entirely—can further marginalize those with certain intersex variations. These distinctions highlight the need for research centering a broader range of intersex lived experiences.

Conclusions

This study highlights the negative experiences of intersex young adults with current health research practices, including feelings of dehumanization, exposure to stigmatizing language, and underrepresentation. Participants provided actionable recommendations to improve future research, emphasizing the importance of community-based approaches, strengths-focused perspectives, and the need for research that translates into practice. Implementing these recommendations can help create ethical, affirming research practices that respect autonomy, improve healthcare experiences, and ultimately advance health equity for this marginalized group.

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Tables

Table 1. Semi-Structured Focus Group Guide

Introduction and Rapport Building
1. Tell us about you: (a) Name or nickname; (b) Pronouns (if you'd like); (c) Do you identify as intersex? As a person with intersex traits? What language do you use to describe yourself?; (d) What brings you here today?
Theme 1: Problems with Intersex Health Research
2. What has your experience with intersex health research been like (if any)?
3. What have you heard from friends or other folks about intersex health research? What do you think it's like?
Theme 2: Suggestions to Improve Intersex-Affirming Health Research
4. What do you wish intersex health research would look into? Stop looking into?
5. What would make you want to be part of intersex health research?
6. What would be materially beneficial to come out of this project? For you? For other intersex people? For the community?*
7. What questions do you have about other intersex young people's lives?*
*Question not included in analysis for this manuscript.

Table 2. Participant Pseudonyms and Demographics

Pseudonym	Pronouns	Age	Race/Ethnicity	Gender Identity	Location
Ila	Any pronouns	24	Non-Hispanic/Latinx, Biracial (Indigenous Lenape and White)	Two-Spirit	California
Maria	She/her	21	Non-Hispanic/Latinx, Arab	Woman	British Columbia
Stella	She/her	29	Non-Hispanic/Latinx, White	Woman	New Jersey
Ska	Any pronouns	28	Non-Hispanic/Latinx, Mixed	Bigender, center of masc, genderfluid	Saskatchewan
Ash	They/them	29	Non-Hispanic/Latinx, White	Agender	Michigan
Leo	He/him	23	Non-Hispanic/Latinx, White	Male	Ohio
Amelia	She/her	25	Hispanic/Latinx, White	Woman	Connecticut
Teddy	They/them	20	Non-Hispanic/Latinx, White	Agender	Ohio
Andy	He/him	23	Non-Hispanic/Latinx, White	Cis Male	Washington, DC
Tyler	He/him	20	Non-Hispanic/Latinx, White	Trans Man	Washington, DC
Bo	He/him	21	Non-Hispanic/Latinx, East Asian	Cis Male	California

Table 3. Qualitative themes, subthemes, criteria, and exemplar quotes from focus groups on intersex health research

Subtheme	Definition	Inclusion Criteria	Exclusion Criteria	Example Quote
Theme 1: Problems with Intersex Research				
1a. Dehumanization and Objectification	Treating people with intersex variations as research specimens without regard for their preferences, autonomy, and right to consent or consent to research procedures	Mentions of being observed, described, or handled in research or clinical settings in ways that feel dehumanizing.	Comments about clinical care experiences not tied to research or data collection.	"Being talked about as if I was a kind of animal, or like a lab rat, and being referred to as if I wasn't even there and the entire experience was deeply humiliating." (Bo, 21 years old)
1b. Stigmatizing Language	Use of outdated or offensive terminology in descriptions of intersex persons, intersex variations, or differences in sexual development (i.e. hermaphrodite, implying rarity in possessing intersex traits, etc.)	Critiques of terms like 'DSD', 'hermaphrodite', or references to medicalized framing.	General discussion of identity language not linked to research context.	"The language was not appropriate at all. [The researchers] make it sound like [intersex variations are] still a problem that needs to be fixed, immediately, at birth. They still talk about DSD, and they still refer to things from the 80s and 90s." (Ska, 28 years old)
1c. Underrepresentation in Research	Insufficient inclusion and representation of intersex people and/or diverse groups of intersex people in intersex health studies, which may lead to a lack of data and understanding	Mentions of invisibility, exclusion, or inadequate response options in research settings.	References to exclusion in clinical or legal settings without relation to research.	"There are studies on the LGBTIQQ* population as a whole, and they are attempting to include intersex in some capacity, it'll be just sort of like lumped in with gender [...] Or the only option will be: Are you intersex or not? And there's no reference to other language people might

	about their specific health needs.			use." (Andy, 23 years old)
Theme 2: Suggestions for Intersex-Affirming Research				
2a. Community-Based Research	Partnership approach to intersex-related research that meaningfully involves intersex community members and advocacy organizations in all steps of the research process.	References to working with intersex-led organizations, shared leadership, or participatory design.	Mentions of external expert consultation without community involvement.	"I would really consider engaging in any intersex research if I feel like the team is actually like not just rushing into it, not just sort of wanting to like get approval from like an intersex organization, just because they like, think it will make it look good at the end. But really like just being intentional throughout to build like relationships with intersex community all throughout." (Tyler, 20)
2b. Strengths-Focused Research	Focusing on the resiliencies and effective coping strategies that the intersex community already exemplify instead of centralizing oppression, marginalization, trauma, and pain.	Mentions of thriving, joy, identity pride, or the need to shift focus from harm to affirmation.	Critiques of pathology language without affirmative alternatives.	"A lot of the focus is always on the stigma, the suffering, the silence and, you know, as you know, communities who have this in common, I think there's nothing more that we have in common that we want to just be at peace, (...) be happy, (...) be accepted, and (...) be loved." (Ila, 24 years old)
2c. Translational Research	Creating research that is directly applicable to improving the healthcare services that intersex people receive and includes multifaceted data sources (e.g.,	Calls for research that directly supports providers, therapists, or patients.	Mentions of theoretical or cultural studies with no reference to practical application.	"So, I am totally looking for research that enables therapists to do their job better, and doctors to do their job better, and patients to know how to communicate with everybody else and that sort of thing." (Leo, 23)

	basic science, clinical, practice, population, and policy-based research).			
2d. Prioritize Respondent Experience	Prioritizing the comfort, safety, and well-being of intersex respondents in health research studies, by ensuring the research process is respectful, inclusive, and minimizes any potential harm or discomfort	Mentions of survey design, skip logic, open-ended response options, or being treated with care.	General critiques of past research not tied to design improvements.	"For some questions, it was just, like, an open text box and, to be honest, I found those ones some of the most valuable things." (Stella, 29)

* LGBTIQQ = lesbian, gay, bisexual, transgender, queer, questioning