



## Intersex studies:

### A set of principles for ethical and human rights-based research practices

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This eBrief is part of the INIA: Intersex - New Interdisciplinary Approaches project and specifically, part of the research project “Ethics in intersex studies – Exploring ethical principles for a human rights-based research practice.” It is based on findings from a literature review and the project fieldwork which consisted in semistructured interviews with researchers, research participants, and experts in research ethics. These principles focus on qualitative research (for more information: <https://www.intersexnew.co.uk/>).

#### PARTICIPANTS

Principles focused on the participants’ well-being and protection of their rights.

- Acknowledging life experiences: It implies the centering of intersex people’s voices, giving power to their narratives and consequently their knowledge.
- Interview preparation: Understanding the background of the community and the participants’ preferred language could avoid stigmatization or pathologization. Also, it is advisable for the researchers to inform the participants regarding the general topics to be addressed in the interview.
- Informed consent: Understanding the informed consent as a constant process where the participants are active actors involved in all stages of the research project.

#### RESEARCHERS

Principles focused on the researchers’ well-being and preparation.

- Self-reflection: Understanding the personal motivation to develop the research. It implies analysis of the personal expectations, triggers, and beliefs that could impact in some way the research. It is considered a good practice to create personal strategies for taking care of the own mental health.
- Understanding the community: Understanding the internal dynamics that differentiate the intersex community from others can allow the researchers to avoid a misrepresentation of their identities and needs.

- Trauma-informed research practices: In case that during the research process, particularly during the interviews, the participants present some sort of discomfort, it is recommended for the researchers to have an action plan or set of tools to be used, such as the possibility of a psychotherapeutic session for the participants after the interview.
- Sharing findings: It could be helpful to share the data obtained and final results of the research with the community and particularly with the research participants. Thus, the relationship would not finish with the fieldwork. In addition, it is advisable to offer the participants the possibility to review the transcripts of their interviews and to indicate modifications.
- Appreciation: The effort and time that the participants employ sharing their life experiences should be acknowledged by the researchers.

- Previous training: Considering that many intersex people have endured violence to their bodies at some point of their lives, it is recommendable for the researchers to receive trauma-informed training and therefore be prepared to give support to the participants if needed.
- Consulting the community: The community could be of great support to determine the possible impact of the research project, and to review if it is aligned with the community priorities or if it could create any potential harm.
- Relationship of trust: An honest approach regarding the research aims, expectations of the researchers, the clarification of procedures in case of disagreements during the research project, and the respect of participants' rights can create an environment of trust throughout the research project.
- Language: Acknowledging the different existing terminologies within the community could be helpful to avoid possible discomfort for the participants or stigmatization.

**These principles are oriented toward the research of intersex-related topics. However, they can be implemented for any population group that has suffered at some point violations of their human rights during research.**

#### **About the INIA project:**

The INIA Innovative Training Network is supported by a grant from the European Commission's Marie Skłodowska -Curie Actions program project number 859869. This brief reflects only the views of the author, and the agency is not responsible for any use that may be made of the information it contains.

#### **To cite this eBrief:**

Mestre Martínez, Y. (2023). *eBrief "Intersex studies: A set of principles for ethical and human rights-based research practices"*. INIA: *Intersex – New Interdisciplinary Approaches*. Granada: Escuela Andaluza de Salud Pública.

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