D5.2.3 Report providing results of the review of existing ethical principles in intersex studies and related fields

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1. INTRODUCTION AND KEY FRAMEWORK

Within the last decades there has been an increasing interest from international organizations, governmental bodies, and academia to produce quality research, understanding this as research that is able to create an impact within the society and not only aims to knowledge production; the result has been the questioning of traditional techniques for developing research, and the desire to implement new methodologies and interpretations to obtain better outcomes.[i] Within the tools to promote change, the community participatory approaches in social research have been a guided framework especially for the research of populations who throughout their history have suffered marginalization, and violations of their human rights.[ii]

The study about and with vulnerable populations has led to the development of research projects to access these communities and understand their issues, which has raised complex ethical considerations regarding research practices.[iii] On many occasions, participants from vulnerable communities have stated that they have been victims of violence and re-traumatization performed by the researchers, feeling that they are being treated as objects of research instead of people with rights.[iv] From this point a range of ethical concerns appeared; such as the tendency to try to \`correct´ with the research a condition or way of living,[v] the disregard of people's knowledge on their personal experiences,[vi] the relationship of power between participant and researcher,[vii] the settlement of unrealistic expectations,[viii] the lack of true understanding of the informed consent,[ix] and the misuse of sensitive participant data.[x]

The lack of preparation for the researcher to avoid the above issues, and consequent violations of human rights can lead to the creation of more harm for the communities involved and lose of trust to research practices.[xi] With the idea of protecting the participants against harm and misrepresentation, institutional ethical guidelines have been created to align the research with the internal contexts of the studied groups, and their cultural, socioeconomical, and political system.[xii] Guidelines such as the Tri-Council Policy Statement - Ethical Conduct for Research Involving Humans in Canada,[xiii] the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research,[xiv] Guidelines for researchers and stakeholders in Australia,[xv] or the SAMHSA Concept of Trauma and Guidance for a Trauma-Informed Approach of the United States,[xvi] among others, have the purpose to build research practices with awareness, trusting relationships, prioritizing community members knowledge and the wellbeing of all the people involved in the research project.

This report is intended to briefly explain the current ethical frameworks implemented in three population groups who have suffered violations of their human rights during research; the first one will be intersex people, the second one indigenous people, and the third one victims of armed conflicts, victims of domestic violence, victims of forced displacement, victims of human trafficking and victims of sexual violence.

The report aims at describing the common key resources in terms of research practices within these three groups and highlight the recommended tools that can be implemented in all of them.

2. METHODOLOGY

The following report is based on a narrative literature review with the aim of analyzing existing ethical principles in intersex studies and related fields and review key resources regarding the practice of ethical research within three different population groups which have been exposed to human rights violations and social vulnerabilities.

The first selected group were intersex people since the protection of their human rights during research is the focus of my project, understanding intersex person as somebody "born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns."[xvii] In terms of research, the intersex community has suffered from a history of medicalization,[xviii] misrepresentation,[xix] and epistemic injustice,[xx] that have jointly created scenarios of harmful practices during research.

The second group were indigenous people. Acknowledging that there are different terminologies to denominate this population, such as 'aboriginals' and 'native', for this report, the term indigenous will be used, understanding the concept recognize and respect their pre-colonial history.[xxi] Due to the social vulnerabilities that indigenous people have historically passed and made a profound impact in their life experiences, considerable research have been done to understand their issues and respect their beliefs,[xxii] which makes pertinent the analysis of their research practices.

Regarding the third group, the initial idea was to focus on people who have suffered sexual violence, nevertheless, the literature review showed a tendency to frame the research practices and key resources for these people within a larger category of people who have gone through traumatizing life experiences of violence, and consequently the framework of trauma-informed[1] research will used to analyze this third part with guidelines from research. The group is composed of people who have gone through traumatizing life experiences of violence, this group gathered trauma-based research practices from victims of armed conflicts, victims of domestic violence, victims of forced displacement, victims of human trafficking and victims of sexual violence. This section of study was selected because of the severe human rights abuses these populations groups have suffered and the importance given to not aggravate the participants' pain, to promote their recovery and also to consider the researchers' wellbeing during the research project.

The narrative literature review established as selection criteria documents related to research practices, ethical principles, and human rights-based research within the three mentioned groups. In this sense, 47 documents were analyzed, which includes 33 academic papers, 21 activist documents and NGO reports, 9 book chapters, and 5 national laws. The paper is divided in two main parts, one dedicated to each population group mentioned and the research frameworks used in the reviewed bibliography, lastly the report has a discussion part where some common understandings of the frameworks are highlighted and concepts are mentioned that can potentially be complemented in research practices of other population groups.

3. REVIEWED RESEARCH FRAMEWORKS

Over the years, the development of general research practices have been useful for the development of knowledge in some aspects of people´s life.[xxiii] However, there are cases where the research benefits have been questioned, in this sense the establishment of ethical frameworks to lead the research processes and make them meaningful has become a

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[1] In the reviewed literature, the terms trauma-informed and trauma-based were used by different authors as synonyms. Thus, the terms will be used according to the preferences of each author.

responsibility for different national and international organizations with the aim of respecting the values and life experiences of the communities studied.[xxiv] In this sense, the following section will introduce three research frameworks and ethical understandings regarding intersex population, indigenous population, and people who have gone trough traumatizing life experiences of violence.

3.1 Intersex People

Throughout their history, the intersex community have suffered violations of their human rights during research.[xxv] The need to categorize the bodies in either female or male has brought pathologizing associations to what is good and bad with their bodies, and therefore some research has tried to stigmatize and misrepresent the community towards the need to be fixed, so the intersex person will adequate 'properly' to society.[xxvi] In this sense, the deconstruction of these ideas requires the implementation of different research approaches and techniques where the community can feel represented and their voices be centered. The following approaches are the recompilation of different research practices in the field of intersex studies that could improve the projects development and findings, respecting the intersex community voices.

- Study of the population: The reviewed authors highlight that before starting the research or present a proposal, it is pertinent to study the history of the intersex population and their current agenda.[xxvii] IHRA affirms that learning about the general context will not be sufficient to develop proper research, it is necessary to acknowledge the background, main actors, and different scenarios where intersex people have been subjected to discrimination and stigma.[xxviii] According to Karkasis, getting comfortable with the terminology that intersex people have, the correct language use, and particular circumstances that distinguish them from other population groups could help to remove false assumptions and biases from the researcher and avoid the misrepresentation of the intersex people's needs with other communities.[xxix]

- Positionality: Lundberg indicates that the reflexivity about the researcher's motivation is an important step within the research process. [xxx] Making an analysis as early as possible of personal expectations, struggles, biases, and beliefs could impact considerably the research development because it can create an awareness through the possible discomforts and emotions that the research may bring for the researcher and how to navigate through it.[xxxi]
- Personal training: As Berry and Monro state, many intersex people have endured violence to their bodies and violations of their sexual and reproductive rights throughout their life.[xxxii] According to the reviewed literature, it is recommendable for the researcher to be trauma-informed and prepared to give support to the participants after the interviews if needed.[xxxiii]
- Designing a research proposal: The Darlington Statement suggests different research priorities[xxxiv] which are beneficial for the researcher to know beforehand since it could help her/him/them to know the areas where the intersex community would rather have more research development. Once that the researcher has a defined project idea, it is suggested to consult the community regarding the pertinence of the research topic and their advice about the benefits and impact that the research could bring to the population.[xxxv] The reviewed authors mentioned that engaging with the community from the beginning will allow the researcher to start building a relationship of trust, diminishing the risk of harm and ensuring the research projects have meaningful grounds.[xxxvi]
- Preparation of fieldwork: RéFRI suggests that during the preparation of the interviews or survey, the researcher have in consideration how the participants identify, which means not to make assumptions regarding the gender identity or sexual orientation. [xxxvii] They also recommend that the questions are phrased in a consensual language to avoid any type of pathologizing, retraumatizing or stigmatizing terms.[xxxviii]
- Acknowledging life experiences: Understanding that intersex people are the experts of their narratives, Bastien Charlebois comments that intersex people's opinions should not be disregarded during the research, which means, giving them within the research the

place that their knowledge deserves.[xxxix] Handing to intersex people the same knowledge authority that has been given to the people who have studied them as experts, according to Koyama, will minimize considerably harmful discourses, and start centering intersex people's voices.[xl]

- Appropriate use of images: The reviewed authors highlight that due to the history of bodily integrity violations that the intersex people have endured, the use of images becomes a very sensible matter since it has been attached to the idea of pathologization, reconstruction of bodies[xli] and recreation of stigmatizing narratives,[xlii] which makes the respect of the people's privacy and their images is a key area within the research of intersex people's issues. Therefore, a relevant recommendation is that the researcher use images only when it is pertinent for the analyses, always with respect and having a critical view of the context of the images.[xliii]
- Informed Consent: According to the reviewed literature, the ethics of informed consent within the study of intersex people's research is a sensitive matter since the population has come with a history of lack of agency in their bodies, and consequently the performing of medical treatment without their free and informed consent.[xliv] In this sense, Henrickson et al. emphasize that the procedure of informed consent in research should be prioritized and presented in an age-appropriate way, particularly when researching intersex children so there will be totally understanding of the research aim.[xlv] IHRA recommends that the researcher seeks to provide and explain the information related to the research, including information of contacts for peer support, advocacy organizations and ethical norms.[xlvi]

3.2 Indigenous People

The indigenous population or first nation people come with a long history of values, and traditions that are not generally practiced in the world.[xlvii] The following ethical frameworks are a compilation of different documents, academic papers, reports and guidelines, whose purpose is to present an overview of recommendations for ethical research practices with indigenous communities.

- Analyze if the research topic will benefit the indigenous community: The reviewed authors highlight that every community has different priorities, therefore it is recommended that the research is aligned with those; this idea is based on the principle of indigenous-led research.[xlviii] If the researcher does not find enough public data to determine the community's main priorities, authors like Pirjo suggest advisory mechanisms to get more information from the local communities and identify the specific community needs and how the research idea can impact the community.[xlix]
- Cultural awareness: According to Hale, it is expected that the researcher possesses deep knowledge in the specific indigenous history, dynamics, and traditions that will be researched.[l] Recognizing indigenous narratives is considered as a way of decolonizing knowledge production and creating more ethical research which does not problematize the communities' lives under western values.[li] AIATSIS considers that this recognition is culturally based and values the ancestral wisdom by giving it the importance it deserves.[lii]
- Positionality and self-reflection: AIATSIS argues that unconsciously or not, every researcher has their own bias, reason why, before the research starts, there should be an internal reflection about the motivations for doing the research, the strengths and weaknesses the researcher may face when she/he/they get immersed in the cultural context of the community, and the researcher's capabilities to adapt the research according to the community needs.[liii]
- Consultation: The Māori ethical guidelines emphasizes that the details of the research project and development should involve the community.[liv] They imply that this participation can reduce risks of harm, give validity to the research proposal, and open the space for constructive advice regarding the possible outcomes and how that can benefit the community.[lv]

- Respectful engagement: It is recommended that the researcher is willing to demonstrate her/his/their interest to work for the wellbeing of the community.[lvi] Sometimes the research aspirations may not align with the development of the research, however, ethical guidelines of aboriginal communities highlight the researcher's responsibility to value the community knowledge and give priority to the experiences shared and the relationship of trust over the research aims.[lvii]
- Negotiation of the research relationship: Guidelines for the research of indigenous people manifest that from the beginning there should be a clarification of mutual expectations depending on the characteristics of the research and the community values, the scope of the research in topics such as intellectual property and data interpretation, the participants' right to dissent from the project, the procedures in case of disagreements, the establishment of possible mechanisms to guarantee the respect of the participants' rights such as the set-up of a research review board.[lviii]
- Flexibility in the research protocol: when the research is actively involving the community, using a participatory approach, according to Jamieson et al. there are occasions where the researcher could experience unexpected outcomes or feedbacks from the community during the course of the research, which means that there should be a preparation and further willingness to adjust the development of the research while maintaining scientific rigor.[lix]
- Ensure fully informed consent: the reviewed authors recommend that the communication of the research funding, aims, protocol and scope are as clear as possible and using a terminology that can be easily understood for all community members.[lx] Ensuring that participants fully comprehend the risks of the research is considered a measure for the protection of their rights.[lxi] To facilitate the correct understanding of the research, Fitzpatrick recommends to have a method to communicate the information during the consent process, this method can embrace cultural protocols and ancestral values through different ways like storytelling.[lxii] According to the author, the implementation of these

methods will reduce the risk of coercion and diminish the feeling of power imbalance between researcher and participant.[lxiii]

- Community control and ownership: according to Schnarch, the materialization of the effective community involvement and respect for their knowledge is given through control and ownership of the research.[lxiv] The research is being developed inside the community and the results will affect them in some way, therefore the author stresses that based on the right of self-determination and a human rights-based research approach, the community members are the ones who should have the control over the findings, data, and physical possession of the data to guarantee all the time the integrity of the research.[lxv]
- Sharing of data: Researchers recommend to share the obtained data for working with and within the community in an easy language and accesible material.[lxvi] Making the research as accessible as possible for the community is a way of honoring them; the data can be shared through informal reports, copies of the academic papers, co-authorship, in community events, and other opportunities where the research outputs can be shared.[lxvii]

3.3 Groups Who Have Gone Through Severe Traumatic Life Experiences

Although in this third part of the report there is not only one specific sector of the population as were the two previous population groups, it is also pertinent to analyze experiences of this third group from the perspective of massive human rights violations that a person has endured through a prolonged period, generating considerable traumas. For the purpose of the analysis, it is important to define trauma as the actual or perceived threat that a human being can experience over their psychological or physical integrity and that due to its impactful consequences, it can overwhelm the person´s responses to deal with it, and the result will be the presence of side effects in the person´s life and how she/he/they can perceive the world.[lxviii]

Even though the impact of an event and further trauma can vary depending on the person´s individual response, there are certain events that will considerably create long-term impact and require a previous training for the researcher who wants to be involved in these topics.[lxix] In this sense, the following recommendations come from a variety of sources created for population groups such as: victims of armed conflicts, victims of domestic violence, victims of forced displacement, victims of human trafficking and victims of sexual violence.

- Debriefing and support: According to Smith, the researcher should receive previous "training about countertransference and the importance of debriefing and seeking support to offset the vicarious trauma, secondary stress, and compassion fatigue."[lxx] During the research of population groups which are survivors of massive human rights violations, according to Barrington and Shakespeare-Finch there will be positive and negative effects that will have a considerable emotional impact on the researcher, in this sense it is recommended that the researcher seeks for support groups that help her/him/them to assimilate the emotional reactions of their work, and the implementation of effective coping strategies for soothing and taking care of the mental health.[lxxi]
- Study design: Due to the sensitive topics that most of these project developments have, Newman et al. recommend the research plan to consider meticulously every possible risk and solutions, also the different ways the data collection will be gathered throughout the research.[lxxii] The reviewed authors imply that the researcher should have an open mind regarding the ways of getting data, there are different methods to acquire knowledge; the authors suggest to perform interviews about sensitive matters when it is the only method to achieve the project aims.[lxxiii] In case of developing interviews, it is considered advisable that the study design is trauma-based and have a revision from review boards or ethical committees.[lxxiv]
- Relationship of trust: According to the reviewed literature, one important element within the building of a relationship of trust with a person who have gone through severe trauma

is confidentiality.[lxxv] The reviewed authors highlight that most of these people are victims of severe harm, some of them were involved in illegal activities, and don't want their identities to be recognized for these events, particularly if they are still under any type of risk, and that is why it is recommended that the researcher is careful with the disclosure of the information received during the project development because it may lead to re-traumatization or endanger the participants wellbeing.[lxxvi] Seedat et al. recommend researchers to seek for the creation of a relationship that does not finish with the fieldwork but involves a continuous dialogue during the whole project development, including asking the participants' opinion in the analysis of data, techniques used, and ideas for publication.[lxxvii]

- Transparency in the research aim: According to the reviewed authors, some of the participants from these different groups could be going through a delicate condition of vulnerability.[lxxviii] It is considered advisable that the researcher is clear about the project purposes and if it will improve in some way the wellbeing of the participants or not.[lxxix] The authors argued that the researcher should not take advantage of their positionality to mislead the participants' expectations with the research project.[lxxx]
- Informed Consent: Particularly with the groups that have going through severe trauma, the informed consent is considered more as a constant process rather than as a simple act.[lxxxi] The reviewed authors stress that many of the victims of severe trauma are still going through difficult emotional situations at the time that the research is being carried out, which makes the informed consent a very careful process where the participants should be reminded throughout the project process about their rights, research aims, researcher position, and possible risks to avoid further misunderstandings.[lxxxii] Mackenzie et al. recommend researchers to acknowledge the possible perception of power dynamics for the people being researched, and making sure that there is true "moral agency" and autonomy in the approval of consent and not only for the hope of assistance to the participants.[lxxxiii]

- Preparation of participants for the interviews: According to WHO it is up to each researcher the amount of information that is given to the participants regarding the questions of the interview, however, it is recommendable that the researcher prepares their participants informing them of possible violence-specific questions and how they could be uncomfortable and if that is the case, the interview can stop at any moment.[lxxxiv]
- Preparation of the researcher for the interviews: With the purpose to maximize as possible the participants´ wellbeing, the reviewed authors recommend the researcher to carefully prepare the interviews or survey.[lxxxv] It is considered advisable that the interview questions have a meticulous wording, in this sense, the authors said that there should be a preparation around the proper time and space to introduce the type of questions related with trauma exposure.[lxxxvi] Also, it is recommended for the researcher to acquire proper training skills to detect symptoms of distress in the participants and be able to identify when it is pertinent to suspend or terminate the interview without discouraging the participant.[lxxxvii]
- Referring to a mental health professional: Seedat et al. highlight that ideally, the research project should have the possibility to offer the participants a mental health assistance in the case that during the research any distress occurs.[lxxxviii] If there is no possibility to include an additional health care professional within the research team, it is suggested that the researcher have previously received trained to "gather traumatic or symptomatic material and to distinguish normative from pathologic responses to trauma"[lxxxix] to support the participants efficiently and avoid re-traumatization.
- Sharing the findings: According to Faulkener, research that at some extend involves the human suffering of other person requires an extensive accountability from the researcher in the way that the information will be presented to respect the people´s life experiences that have been shared, and safeguard their rights and wellbeing.[xc] It is expected that the findings of these type of research will also be used to improve or benefit in some way the different groups studied.[xci] Hence, Faulkener argues that the publication of findings should

be culturally sensitive and always from a respectful position, where the people are seen and perceived as participants and not as mere source of data.[xcii]

4. DISCUSSION AND CONCLUSIONS

During the review of the different population groups analyzed in the report, there was possible to observe a past trend of research being designed and developed to research on the community and not with the community, generating violations of participants' rights during the process. According to the three groups studied, there are common good practices that can be implemented to improve not only the research development, but also to take care of the wellbeing of the participants and researchers during and after the project.

According to the literature review, taking awareness of the own positionality becomes a first step before starting to dig into research ideas. Determining the personal why and what for starting that research is key to understand what drives the self-motivation during the project development, and if those interests will align with the research aims or community priorities. Bastien Charlebois highlights that selecting emotionally demanding research only for career development purposes can be very damaging for the participants because the establishment of a relationship of trust will not have strong basis, and situations such as dismissal of knowledge, dominant power dynamics, and dehumanization can bring serious long-term consequences for the participants.[xciii]

Regardless of the positionality, deciding to work with a community requires a deeper understanding of their context. The different population groups mentioned the need to study their history, values, beliefs, current struggles, and population goals. For the case of the third group (people who have gone through severe life experiences), the priority is on the understanding of the participants' culture, and the context in which their traumatic experiences were created. Accepting that no matter the previous studies done about the community and their experiences, the researcher will not achieve the level of knowing better/more the narratives than the participants is a way of showing respect for their life experiences and stopping the cycle of epistemic injustice[xciv] through which the three groups have passed in previous research.

Once that the researcher has conducted the internal (personal) and external (community) preparation, it may be easier that the creation of a study design helps to conduct a more respectful and ethical research. The documents analyzed[xcv] from the intersex and indigenous population suggest that the study design should always be consulted by members of the community to avoid or diminish any possible harm for the participants, in the same line of action, the third group with a trauma-based approach goes towards finding the best research methodology which does not necessarily has to imply interviewing the community. The authors reviewed[xcvi] advise to analyze if effectively it is necessary to perform interviews to accomplish the project aims, the researcher should acquire special training to cope with the emotional impact that this process can trigger in the participant and in herself/himself/themselves. Through the literature review it was possible to observe that the documents related to trauma-informed research methodology aims to center the wellbeing of the participants but also to consider the researchers' emotional welfare during the process, which may be left out sometimes.[xcvii]

Regarding qualitative interviews, trauma-informed research approaches propose different frameworks oriented to minimize any possible risk of re-traumatization of the participants.[xcviii] Among these frameworks, the informed consent takes a protagonist role because the participants should be totally aware of the risks, rights, and project aims. The documents from the three populations[xcix] agree on the fact that the informed consent should be taken as a continuous process and not as a singular act, which means that participants should be reminded all the time about the research process and what it implies. This is very important especially if the group studied has gone or is still going through traumatic experiences, the existence of these experiences can deeply distress the participant during the interview, and it is under this scenario that the supporting groups from participants and researchers can be a fundamental help to provide assistance if needed.

Lastly, the three population groups highlight the importance of sharing findings in a respectful way to the community's knowledge and life experiences, having in mind that the findings should help them in some ways with their struggles.[c] For the particular case of intersex people, the lack of data control has been a considerable source of human rights violations within the research of intersex people,[ci] which brings a responsibility for the researcher to comply with strict standards of data management to acknowledge the expertise of intersex people´s life experiences, considering them as the only ones entitled to share their narratives, same as with the other two groups. It is recommendable by the reviewed authors to co-conduct data collection with intersex scholars and organizations, and that their expertise is remunerated.[cii]

Also, it is considered advisable to share the findings with the community in the most accessible formats for them.[ciii] In this sense, the literature review recognizes that the creation, execution, and culmination of a research project implies many different frameworks which may vary depending on the population, but in general terms, research with communities that have suffered from marginalization and trauma requires an in-depth analysis and training to prevent any of the parties from getting hurt in the process.[civ] There are several tools available such as the guidelines and recommendations previously quoted in this report, however, it depends on the researcher and her/his/their level of commitment to carry out an investigation that protects the participants and herself/himself/themselves in the best possible way.

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