Protocol for the collection
and dissemination of data
on children and adolescents
participating in studies





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Glossary

Assent: UNICEF (2015) defines this as "the willingness to participate in research, evaluations or data collection by persons who are by legal definition too young to give informed consent according to prevailing local law but who are old enough to understand the proposed research in general, its expected risks and possible benefits, and the activities expected of them as subjects". The World Health Organization (2019) states that: "Assent may be expressed (e.g. indicated verbally or in writing) or implied or tacit (unspoken or implied through the individual's actions, for example by not making eye contact with the researcher or by remaining unresponsive to the researcher's questions)"

Ethics committee: A group of individuals unrelated to the research to be reviewed. The committee is an advisory body tasked mainly with ensuring that research involving children and adolescents abides by a set of ethical standards. It must review the research designs and approve, reject or provide feedback. It must consist of at least three members who are free from conflicts of interest.

Confidentiality: According to the Ethical Research Involving Children (ERIC) project, the concept of confidentiality means that "The researcher and all staff involved in the research are ethically obliged to treat information acquired during the research process carefully, in confidence, and to not allow this to be revealed to others. Researchers must securely store, protect and dispose of information/data that has been collected. They must also be prepared to breach confidentiality if a child or others are at risk" (Graham and others, 2013).

Informed consent: According to the definition provided in ERIC, "Informed consent refers to the process of fully informing children and their parents/carers as to the purpose of the research and what their involvement will be, prior to their decision as to whether or not they participate in the research. Informed consent is an explicit agreement which requires participants to be informed about and have an understanding of the research. It must be given voluntarily and be renegotiable, so that children may withdraw at any stage of the research process" (Graham and others, 2013).

Caregivers: all persons who fulfil the role of father or mother and are responsible for the care of children and adolescents.

Harm: in the research setting, harm or damage refers to physical punishment or other sanctions inflicted by another person as a result of participation or non-participation in the research activities, in addition to physical harm, emotional suffering, anxiety or loss of self-esteem caused directly by the research study itself (Graham and others, 2013).

Participation rights: as enshrined in the Convention on the Rights of the Child, these rights underpin the obligation of researchers to consider, respect and protect children's participation. They require researchers to observe and assess children and their potential contribution to the research, while ensuring that children have a choice regarding their participation, including their right not to participate (Graham and others, 2013).

Protection rights: as stated in the Convention on the Rights of the Child, in the research setting these rights refer to the obligation of researchers to ensure the safety and protection of children (Graham and others, 2013).

Provision rights: The rights of provision or survival and development are included in the Convention on the Rights of the Child. In the research domain, they require researchers to ensure that children are adequately supported to participate in the research processes. (Graham and others, 2013).

Dissent: Refusal to participate in the research. Dissent may be expressed by refusing to sign a consent form; it may also be signalled verbally, or indicated by indirect verbal and nonverbal behaviour, such as saying "I'm tired", looking away, or moving away from the researcher (Graham and others, 2013).

Suitable or qualified respondent: a person who is capable of responding and providing the information needed to complete the particular requirements of a survey. The qualification status of the respondent may vary according to the characteristics of the survey, the topics addressed or the module to be surveyed. A person may be considered a qualified or suitable respondent to answer questions about the household and its members, but not about more specific questions that would require a respondent directly involved in the topic in question (for example, questions about fertility or mother and child health).

Children and adolescents: as defined in Article 1 of the Convention on the Rights of the Child, "For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier."

Non-maleficence: the principle of non-maleficence, or doing no harm, requires researchers to avoid any harm or injury to children, whether through action or through omission.

Chapter I

Background

The Working Group on Statistics on Childhood and Adolescence of the Statistical Conference of the Americas has been working since 2015 to improve the region's capacity to produce statistics on children and adolescents.

In this context, and having found that there are no ethical protocols for statistical research in the region, a decision was made to develop a standard protocol to facilitate the collection and dissemination of data on children and adolescents in statistical offices.

The instrument considers regional specifics and the effect of local cultural and gender norms; and it anticipates possible responses to sensitive situations (based on the identification of situations in which children and adolescents are at risk). It thus makes it possible to put measures in place to mitigate potential negative effects on children and adolescents in the fieldwork.

This proposal was designed on the basis of a qualitative and quantitative diagnostic assessment of research with children and adolescents in Latin America and the Caribbean.

Firstly, exploratory interviews were held with the supervisors of six local offices of the United Nations Children's Fund (UNICEF); and the bibliography on ethics in research with children and adolescents was reviewed and systemized.

Secondly, a questionnaire was sent to 25 national statistical offices in the region, 21 of which responded. Lastly, representatives of these offices were interviewed by videoconference in order to gain more in-depth and detailed information on certain issues that required greater precision.

As a result of this diagnostic assessment, it was concluded that the ethical considerations applied in the region, both in statistical research with children and adolescents and when producing data on them (collecting information through adults), need improvement to align with the standards of the Convention on the Rights of the Child.

Only 10 countries stated that they apply specific ethical research protocols for children and adolescents. In the other countries, the same protocols are used for both adults and minors under 18 years of age.

The most widely researched topics are employment, education, health and nutrition, gender-based violence and, to a lesser extent, migration.

It was found that the countries applied general ethical procedures (without distinguishing between adults and minors under 18) regarding informed consent, information to parents and caregivers, data protection and preparation of the field team for interviewing children and adolescents.

The diagnostic study revealed that some of the procedures described in the various international guidelines on ethical issues in research with children and adolescents were not being applied by the region's national statistical offices. The procedures that are applied least often by the countries include: analysis of the harms and benefits that the research may entail for the participating children and adolescents (which is usually done before starting the research process); a review of the research design by an external ethics committee; the lifting of confidentiality when rights violations are detected during the fieldwork (which require protective actions, without these actions necessarily being associated with a complaint); and, lastly, the containment or mitigation of risky or sensitive situations.

The assessment of harms and benefits is an extremely important procedure fore ensuring that a set of ethical standards are met in research involving children and adolescents. This analysis could be included in all studies with children and adolescents, even if they are not specific studies on childhood, or in studies on children and

adolescents in which adults are interviewed (as occurs in health and nutrition surveys that incorporate data on children under five years of age).

The lifting of confidentiality is a complex issue to address, especially because all statistical institutes in the region protect statistical secrecy in accordance with their respective legislation. It is important to launch discussion on how to preserve statistical secrecy when studies encounter serious violations of the rights of children and adolescents in the field, and provide adequate protection, while maintaining the balance between the best interests of the child and the privacy of the participants.

It is also important to note that many statistics on children and adolescents are compiled in other public institutions, albeit with support from the national statistical offices. This suggests that such offices could play an important role in disseminating good ethical practices through agreements with the institutions that comprise their respective national statistical systems.

As Lundy and McEvoy (2012) note, the Convention on the Rights of the Child provides a structural framework for establishing the ethical foundations for research involving children. Firstly, it recognizes the capacity and right of children and adolescents to participate and express their views freely on all matters that affect them, and thus establishes their right to participate in activities such as research. Secondly, it lays the groundwork for the precautions that need to be taken to protect children and adolescents involved in research.

This document seeks to strengthen the areas for improvement identified in the regional diagnostic assessment.

The first part of the document (chapter II) explains and develops all the elements identified in the protocol, thus justifying its incorporation and alignment with the Convention on the Rights of the Child.

The next two chapters correspond to the protocol itself and are structured as a practical guide. First, a flow chart is presented on the ethical aspects to be incorporated in research with children and adolescents (chapter III). This is followed by a questionnaire (chapter IV) that helps to verify whether or not the basic requirements for conducting ethical research with children and adolescents are met.

The diagram makes it possible to visualize in a sequential manner the different procedures that need to be addressed when involving children and adolescents in research.

The questionnaire displayed after the flowchart consists of two main parts: the first helps to verify whether or not it is advisable to carry out the research with children and adolescents. The second part of the questionnaire, which covers all stages of the research — design, fieldwork, analysis and dissemination — considers the following four main ethical domains:

- (i) Evaluation of harms and benefits
- (ii) Informed consent
- (iii) Confidentiality and privacy of the information
- (iv) Payments and compensations

Since these do not apply equally to all stages of the research, some domains are not developed for certain stages.

Before embarking on a research project, an external ethics committee should review all of these issues, as far as possible drawing on the advice of a child expert.

Chapter V of the document addresses a number of concerns raised by the countries in the diagnostic phase.

Chapter VI presents three examples of application in studies on childhood, considering the most sensitive and frequent issues in the region, namely studies on violence, studies on sexual and reproductive health, and studies on work and employment.

Lastly, chapter VII suggests a number of issues to be considered when conducting studies with children and adolescents via digital media.

Chapter II

Theoretical justification of the ethical aspects of research involving children and adolescents and the role of the ethics committee

In 2013, in an attempt to systemize the existing literature on ethical research involving children and adolescents, UNICEF published the compendium titled "Ethical Research Involving Children" (ERIC) to serve as a tool for critical reflection and foster internal dialogues in centres and institutions that undertake this type of research, and to guide their ethical decisions.

The compendium analyses the following four dimensions that should be taken into account when conducting research with children and adolescents: evaluation of the harms and benefits of the research; consent; privacy and confidentiality; and payment. It first describes the relevance of these four dimensions and then specifies the role to be played by ethics committees, which should make sure that these dimensions are addressed in the research design.

A. Harms and benefits assessment

Before embarking on research involving children and adolescents, the benefits and potential risks derived from their participation must be realistically assessed. As noted above, ethical research involving children and adolescents is based on the principles of justice, respect, beneficence and non-maleficence. Taken together, these principles emphasize that research participants should derive some benefit and no harm.

The decision to conduct the research involves appropriately weighing the relationship between the risks and benefits, whether direct or indirect, for the children and adolescents involved, and for their families or their community. These risks can be divided into four categories (drawn from health research): (a) no greater than minimal risk; (b) greater than minimal risk with the possibility of direct benefit to the children involved; (c) greater than minimal risk without the possibility of direct benefit to the children involved, but with the possibility of generating generalizable knowledge; (d) research that requires review beyond the ethics committee, because it does not satisfy the requirements of the previous categories, but presents a reasonable opportunity for improving understanding of a serious health or welfare problem for the children (Serrano, 2014, pp. 188 and 190).¹

Based on these categories, different levels of ethical dilemma can be observed, from which to advance in solving a problem that affects childhood in a given country or place, even if it causes harm. However, if the harm is greater, the decision transcends the competency of the ethics committee and will require the approval of one or more higher mechanisms and a panel of experts from different disciplines related to the issue in question. In this case, it will always be necessary to satisfy the conditions associated with the other risk categories; to anticipate and adopt appropriate measures to minimize the harm; to seek consent and assent; and to inform the interviewees adequately, so that they are aware of the risks involved in participating in the study.

¹ Serrano (2014) proposes four categories of risk and associated requirements, according to the level identified in the assessment to guide approval by the ethics committee.

Harms and benefits should be assessed in all research that involves participation by children and adolescents, even if it is not childhood-focused, and even when the interviewees are adults who provide information about children and adolescents (an example of data production in non-specialized research is an employment survey in which the sample incorporates 15–18 year-olds, in addition to the adult population).

Accordingly, at the initial stage of the research design, an assessment should be made of the direct or indirect benefit that the children and adolescents will receive as a result of their participation in the study, and the harm that could potentially be caused to them.

Risks of harm or damage as a result of participation in the research

The potential harms that need to be considered include the physical harm that children or adolescents might suffer as a direct consequence of their participation in the research; the reprisal, punishment or physical harm that others may inflict on them for their participation; and the suffering and negative emotional impact that this could entail.

All of the above raises a number of ethical issues that research with children and adolescents should actively reflect, such as:

- The possible emotional stress or feeling of re-victimization caused by interviews about cases of abuse and violence.
- The sanctions and punishments that the child could suffer as a result of disclosing compromising information.
- Possible abuse or mistreatment by the interviewer or survey staff.
- Biases in the analysis, and stigmatizing or discriminatory conclusions.
- The safety of children and adolescents in contexts of conflict or community violence, armed groups, violent gangs or the presence of organized crime.
- The coverage and capacity of social and child protection services to provide adequate care and to react in a timely manner if required during the fieldwork.
- Action protocols in the event of detecting situations such as rights violations.

The research team should visualize the harm that could potentially be caused at each of the stages of the research, and consider whether it is possible to eliminate each of the risks identified. If, despite the elimination or mitigation strategies that could be implemented, the risk of harm at any of these stages remains high, the best interests of the children or adolescents must prevail; and the research team must examine other sources to obtain the information they require.

Along these lines, and considering that all research with children involves some risk to the participants, the first question the research team should ask itself is whether it is necessary to conduct the research at all.

The team must be certain that the required information cannot be obtained without interviewing children and adolescents directly, or by collecting information about them through other primary sources, and that the information in question is absolutely necessary to achieve the objectives of the research.

As noted in Graham and others (2013), using secondary, already existing, data is a way to avoid the potential risks to children from participation in the research; and it is a very useful form of research in itself. If the information already exists then it is not necessary for children to take part.

The following is a description of a series of precautions and measures that need to be adopted at different stages of the research, since they would make it possible to anticipate and manage the harm caused by action or omission to children and adolescents, as well as to the participating families and communities, if detected in time. This serves as a guide for assessing risks, and also for adopting the consequent mitigation or control measures.

Design and definition of the sample to be studied. The research provides children and adolescents with an
opportunity to participate and exercise their right to express their opinion on all matters that affect them.
Accordingly, the arbitrary or unjustified exclusion of any collective or group of children from the sample
to be studied could be considered a violation of this right and a silencing of their voices.

Similarly, the presence of bias in the sample design could serve to distort the representation of the opinions and judgments of children and adolescents, or result in spurious analyses that encourage prejudice or the stigmatization of certain groups.

For this reason, the research design should clearly explain the reasons for including certain groups of children and adolescents in the sample, and for excluding others, in order to determine whether these decisions respond strictly to the research objectives rather than other motives, and thus avoid possible biases.

It is also important to properly assess and adjust for groups of children and adolescents who are in conditions of extreme vulnerability; have a disability; are unaccompanied migrants; are in street situations; or are serving custodial sentences.

- The harm that children and adolescents may suffer in the fieldwork as a result of their participation in a research project can vary according to the purposes of the research and context in which is carried out.
- The participation of children and adolescents who are victims of violence or abuse can cause suffering, stress and re-victimization. Participation by vulnerable children and adolescents in research on violence is a matter for concern, as it may cause them to relive painful moments and therefore be considered a form of revictimization. However, suffering or emotional impact may also affect children and adolescents who, even if they have not been victims of violence, could suffer emotional harm if they are unnecessarily exposed to painful topics that they would not otherwise have known about.

The few available studies show that about one-third of children and adolescents participating in studies on violence report feeling upset or violated by questions about violence, with this percentage being higher among girls and younger children (Ybarra and others, 2009; Langhinrichsen-Rohling and others, 2006).

The researchers must be prepared to detect and address these types of situation in the field, and build specific measures into the research design to ensure the protection and care of children and adolescents. These measures include:

- Ensuring that children and adolescents have the support of a significant adult.
- Using a methodological approach focused on children and adolescents that respects their rhythms and gives them control over the process (Mudaly and Goddard, 2009).
- Incorporating information processes that respect childhood and adolescence.

It is also important that the data collection team ensure that children and adolescents know and understand that they can withdraw from the research whenever they wish. The team must also be alert to all verbal and nonverbal signals (for instance, if the child does not respond to questions or does not pay attention) that indicate discomfort and distress. This implies that its members should be trained to recognize these signals and respond appropriately (UNICEF, 2012).

• Detection of rights violations or security risks. During the fieldwork, the researcher may suspect or be informed by the participant him/herself of situations of abuse, violations or safety risks that require protection. Such disclosures call for concrete and immediate responses from the research team.

From an ethical standpoint, based on the principles of justice, benefit and non-maleficence, upon learning of situations of abuse, the research team is obliged to activate the protection networks available for the child at risk, acting always in the child's best interest. This means that whatever measures are adopted, they must have the child's welfare as a priority, which includes not aggravating the child's situation.

Consequently, the measures adopted must be prudent and discreet; they should also respect the principle of confidentiality of information, particularly, but not only, in relation to the abuser.

In addition, the decision regarding the scope of possible measures or courses of action must be made in accordance with the regulations in force in the country, both with regard to the protection of personal data, legal norms governing national statistical offices, and the protection of children and adolescents.

- Handling and safeguarding of sensitive and personal information disclosed by the children or adolescents
 interviewed. The dissemination and disclosure of sensitive information, such as experiences of abuse
 and mistreatment, but also topics such as sexually transmitted diseases or gender identities, can lead
 to stigmatization or discrimination by the community against the child who revealed his or her situation
 to the researcher. Accordingly, such information should be handled as confidential and sensitive, with
 discretion and professionalism. This in no way implies inaction in terms of measures to be adopted to
 protect the child.
- Realistic safeguarding measures in situations of risk for the children and adolescents involved and based
 on their higher interest. The measures adopted should consider the effective protection resources available
 to the child, as well as the consequences of protection initiatives.

For example, in very poor communities, the protection network needed to ensure the safety the child whose rights have been violated may not exist. As a result, informing the local authorities of the child's situation may not have any real consequences in terms of protection; on the contrary, it may be a source of disappointment and suffering for the child who confided in them by disclosing his or her situation (Kotch, 2000).

The specific responses and measures adopted to protect children who are known or suspected to be at risk will always be tailored to each specific context. However, it is imperative for the research team to have clear procedures in place to deal with such situations. As noted in Graham and others (2013, p. 35), attending to potential well-being concerns and ensuring that children are safe, and that follow-up support is provided as necessary, is an integral component of high quality and ethical research planning.

Qualification of the data collection team and the research team. The responsibility that arises from
knowing of the risk situations faced by some of the research participants highlights the need for qualified
personnel; and it underscores the importance of working with child protection experts and experienced
researchers, in order to adopt a rigorous approach to the subject matter (Gorin and others, 2008; Graham
and others, 2013).

As noted in the ERIC document, researchers must consider the possibility that adults with abusive intentions may use research as a means of gaining access to children (Graham and others, p. 35). However, maltreatment by the data collectors may also be unintentional and originate from incompetent practices and lack of appropriate qualifications. These considerations mean that teams undertaking research with children should adopt measures, such as the following:

- Apply strict criteria and conditions when hiring the data collection team.
- Develop and enforce codes of conduct, specifying expected behaviour.
- Incorporate mechanisms for processing allegations of abuse by a member of the data collection or wider project team (or by someone else).
- Incorporate protocols aimed at providing protection both to the children and adolescents and to the work team itself during the data collection process and across the project lifespan.
- Provide training and support to those who interact with the participating children and adolescents.
- In training activities for the interviewer or survey staff, include the development of skills in non-verbal language and other techniques for the detection of stress, emotional alterations or post-traumatic behaviour patterns in the participating children.
- Importance of avoiding bias in the post-data-collection stages. The analysis may not be rigorous and may encourage prejudices or stigmatization of a population. The dissemination of results may also affect and be detrimental to the participants, their families or communities. Reducing such risks requires the results

always to be disseminated in a way that protects the identity of the participants, as well as any particular characteristics that would make it possible to identify them or their families and communities.

2. Benefits of participation in the research

The benefits of the research may be either direct or indirect. With the exception of clinical therapeutic studies and a few others, the intended benefit of research with children usually involves the implementation of intervention policies or programmes benefiting the population or group represented by the participant, rather than the participant individually. Another example is biomedical studies, where the participant is unlikely to benefit from the study, although other children may.

Moreover, in many studies and surveys that routinely include children and adolescents in their samples (for example, employment or general victimization surveys), the benefits in terms of targeted programmes or policies are diluted relative to the primary purpose of such studies, namely, to monitor specific indicators.

However, despite these difficulties in specifying the benefits and beneficiaries of participation in research, these should be clearly stated in the research design, in accordance with the principle of beneficence that governs the ethical aspects of research with children and adolescents.

It is useful to consider other possible benefits of participating in the study, such as:

- The knowledge acquired by being informed of the results of the study, which implies having strategies for returning the information.
- The formative experience of participating in a scientific research project.
- The gains in self-esteem and social validation when there are opportunities to participate in relevant stages and processes of the research.

B. Informed consent

The consent of parents or guardians, and of the participating children and adolescents themselves, is a fundamental requirement of ethical research with this age group, for two main reasons. First, the request for consent entails due respect for the dignity of the participants and their right to make decisions on matters affecting them, as enshrined in the Convention on the Rights of the Child.

Second, the request for consent recognizes that the participants are likely to be best placed to assess the risks of their participation. This latter consideration implies the right of the child or adolescent to desist from participation in the research, or to withdraw from it, irrespective of the wishes of their parents.

Some countries make it a legal requirement to request and obtain the consent of the parents or guardians for a child or adolescent to participate in research (this is not the case in Latin America and the Caribbean). In terms of research ethics, having the informed consent of parents or guardians is based on the fact that the vast majority of parents or guardians, as caregivers and educators of children and adolescents, play an important positive role in protecting children from possible harm.

Nonetheless, a dilemma often arises as to the appropriateness and desirability of seeking the consent of parents or responsible adults. For example, parents might not want to give such consent, for reasons motivated by their own interests, as in the case of an abusive father who does not want his child to participate in a study on abuse, fearing that the child's situation of violation will be revealed and the corresponding complaint will be lodged.

In some situations, passive consent (in which parents only have to inform researchers if they do not want their child to participate), or the designation of another trusted adult, has been used to encourage children and adolescents in situations of abuse or exploitation to participate in the research and thus incorporate their experiences and needs.

However, the literature indicates that the general rule should be to obtain the consent of parents or legal guardians. Except when the research is focused on the participation of children and adolescents at risk, in most cases the detection of this type of situation is an unforeseen consequence of including children or adolescents in the study sample and represents a minority of cases. Therefore, it does not seem reasonable to substitute what in many societies is a parental prerogative because of potential outcomes (given that the consent strategy is defined before the fieldwork begins) for a minority of participants.

The consent of responsible adults should be considered especially in the case of participants who are under protection measures, in which case consent should be sought from the child's custodians or guardians. When children and adolescents do not have parents or guardians, or they are not available, as in the case of research with children and adolescents who live on the street, an alternative is the aforementioned strategy of asking the child to designate a trusted adult to ensure his or her rights in the consent.

When seeking consent (and assent), conflicts may arise in countries where participation in certain studies (such as household surveys) is mandatory (a regulation that generally predates the normative standards of the Convention on the Rights of the Child). Although international guidelines recommend that consent should always be sought from mothers, fathers and guardians, and that, in addition, assent should be sought from children and adolescents themselves, in such cases the request for consent may become irrelevant.

However, the legislation of each country should be considered as the starting point on which to build an ethical framework governing research involving children and adolescents, and not as a limiting factor. The recommendation in these situations is that the research teams should progress from the current situation of obligation and incorporate the request for consent in their procedures.

1. Assent by children and adolescents

In many countries, children and adolescents under the age of majority are not legally empowered to give their consent to participate autonomously in research, since it is considered that they have not yet reached a sufficient level of development to exercise their capacity to make autonomous decisions responsibly. Hence, parents or legal guardians are responsible for authorizing or denying the participation of children and adolescents in research on childhood and adolescence.

However, even when children and adolescents cannot legally decide to participate in the research and studies, the research team must still have their assent when they are capable of providing it. As in the case of consent, assent must be an explicit act (either verbal or written). UNICEF (2015, p. 2) defines assent as the "willingness to participate in research, evaluations or data collection by persons who are by legal definition too young to give informed consent according to prevailing local law but who are old enough to understand the proposed research in general, its expected risks and possible benefits, and the activities expected of them as subjects."

Obtaining assent is important because it materializes the right of children and adolescents to be heard in any procedure that affects them (Convention on the Rights of the Child, article 12). Therefore, irrespective of the legal status of children in this regard, consideration of their wishes regarding participation in the research is an ethical mandate and allows the child to accept or refuse to participate, even if the parents have already given their consent.

The need for assent by children and adolescents participating in research is often dismissed because of cultural conceptions or because of the children's lack of cognitive competence.

However, the available empirical data show that children and adolescents, even the youngest of them, are capable of making informed decisions when provided with the necessary information. Thus, the challenge rests with the researchers, who must be able to creatively tailor consent requests to the age, development, and context of children and adolescents, and also find ways to determine whether potential participants and their parents understand the information accompanying the consent request (aims, methods, purpose, risks, possibility to desist).

Both informed consent and assent must meet four requirements; they must:

- (i) Be an explicit act. Consent has been described as "the invisible act of evaluating information and making a decision, and the visible act of signifying the decision" (Alderson and Morrow, 2011, p. 101). Consent can be verbal or written, so it does not consist of filling out or signing a form or a legal document; above all, it is a communicative act between the researcher, the potential participants and, in the case of research involving children and adolescents, their mothers, fathers or guardians. Nonetheless, whether verbal or written, consent implies a conscious and manifest action.
- (ii) Be informed. It goes without saying that participating mothers, fathers, guardians, children and adolescents must be informed and understand the objectives of the research, its purposes, the methods to be used and the risks that it might entail for the participants. In addition, the confidentiality of the information, the possibility of desisting or withdrawing at any time, and the procedures for reporting any abusive behaviour on the part of the research team should be clearly explained. The information related to the research should be provided in a manner adapted to age, context and competencies, always seeking to be clear and easy for the participants to understand.
- (iii) Be voluntary. Both the consent and the assent of children and adolescents should be given freely and without coercion. This means analysing in detail the power relations that constrain free will, especially of minors. Relations between childhood and the adult world, as well as the relations between the children themselves and with teachers, can influence the free will of children and adolescents, so that they are conditioned to accept or reject participation in the study.
- (iv) Be renegotiable. Neither consent nor assent are limited to the initial stage of the research, but are continuous processes that must be updated at each of its stages. This means that participants have the right to desist from participation in the study at any stage. The possibility of desisting must be made explicit and clearly communicated to the participants.

Critical elements of informed consent

A critical element in relation to the assent of children and adolescents participating in the research is that it must be voluntary. As noted above, the power relations in play in the daily dynamics involving children and adolescents may constrain their free will to decide whether or not to participate in the study. A clear example of this is provided by studies and surveys carried out in school, where children and adolescents can project the pedagogical authority relations that characterize teacher-student relationships on to the researcher. In these contexts, children and adolescents may feel implicitly obliged to cooperate with the research, which is perceived as an extension of school activities.

In societies such as those in Latin America, where children and adolescents are culturally expected to obey their parents, freedom to participate in the study may also be restricted, depending on the willingness of adults to participate in the research. Researchers must therefore be alert and have the ability to identify verbal and nonverbal cues that may indicate children's desire not to participate in the research or to withdraw from it. This implies an active willingness on the part of the research team to detect such signals and to defend the children's and adolescents' right not to participate, or to desist.

The consent of mothers, fathers or guardians often gives rise to questioning, especially when the research engages sensitive topics such as sexuality, mistreatment, child abuse or exploitation, among others. In these situations, the researchers may be concerned about the appropriateness of informing adults and seeking their approval for children to participate in research on certain subjects that parents or guardians would prefer not to disclose.

Similarly, the consent of parents and guardians is a source of concern in studies on adolescent sexuality, fertility or sexually transmitted diseases, for example, in which children and adolescents are consulted on certain information that they would prefer to withhold from their parents or guardians.

A frequent solution in these cases is passive consent, whereby parents need only inform researchers that they do not wish their child to participate. However, this is an ethically contentious area that requires very well-founded justifications; and ethics committees usually recommend that active parental or guardian consent should be the general rule. One of the main problems with passive consent is that the absence of a refusal to allow children and adolescents to participate in the research, in some cases, may not imply consent, but may simply be due to not having received the notification informing them of the study, or not having understood it.

Another situation occurs when parental or guardian consent cannot be obtained because parents or guardians do not exist or cannot be identified or found—for example, in research involving orphaned, displaced, refugee or asylum-seeking children and adolescents. Children and adolescents are particularly vulnerable in such circumstances, so the research team must make a special effort to subordinate the research to the best higher interest of the child or adolescent.

The alternatives that have been deployed in these situations include participation in the consent process by:

- Teams of ombudspersons for the rights of children and adolescents.
- Guardians or persons legally responsible (including government officials when the State has assumed responsibility for the protection of the child. This usually occurs in protection centres, schools, custodial facilities or other similar institutions).
- Trusted adults designated by the child or adolescent (such as teachers, social workers or community leaders). This last alternative has also been used in cases where the children are themselves heads of household or are considered "emancipated minors".

Lastly, obtaining consent requires taking into account the social contexts in which the research takes place, especially in situations of conflict. Examples of the latter include territories controlled by guerrillas or drug trafficking, where parental consent may entail a risk of reprisals for the families, or other types of consequences that threaten the integrity of the children and adolescents and their families (and also the researchers). In such cases, risk-benefit assessment is essential to decide whether it is necessary and advisable to conduct the research, and under what conditions.

C. Confidentiality and privacy of information

When children and adolescents participate in a research project, their privacy and the confidentiality of the information gathered must be respected. As article 16 of the Convention on the Rights of the Child states, "no child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation."

This consideration implies the establishment of action protocols at the research design stage with regard to:

- The privacy of the interview or survey.
- The anonymity of the participants.
- The adoption of measures in the event of disclosure of rights violations.
- Data storage.
- Dissemination of the results of the study.

Participant privacy means, first and foremost, respecting the fact that children may not want to share certain information with the researcher, and they should not be pressured to do so.

This concept also implies that the place where the interview is conducted should be secure; and it should enable child and adolescent participants to confide information without being overheard by outsiders or, in the

case of written material, without their responses being seen by others. This is not easy to guarantee, since most studies with children and adolescents (at least in Latin America and the Caribbean) are conducted in their own homes or schools, and adults may often feel entitled to participate in the interview.

Given that it is very difficult for children and adolescents to refuse the presence of adults, it is the researchers' responsibility to request privacy from them. On the other hand, while the principles of privacy and confidentiality of information require that the children's answers not be heard or read by third parties, the place chosen for the interview must be in full view, in order to ensure the children's safety and guarantee their protection from possible abuse by the researchers.

The privacy and confidentiality of information must be safeguarded even with respect to the mothers, fathers or guardians who consent to the child's or adolescent's participation in the research. Parents or guardians should also not know, hear, or read the information provided by the child. This is especially relevant in research on sensitive topics, where children may feel pressured or inhibited by the presence of the responsible adult. This reinforces the need to explicitly underscore the confidential nature of the information at the time of requesting consent.

It is also important to guarantee the participants' anonymity. One commonly used measure is to mask the identity of the participant (or the data that make it possible to identify them) or to use pseudonyms in the databases and keep the record of their true identity in different folders with restricted access.

A recurrent ethical conflict in research involving children and adolescents arises when, during the course of the research, situations of abuse, mistreatment, neglect or other forms of violation of their rights become known or suspected, or when it is found that the child suffers from a contagious disease that needs to be reported. In these situations, the researcher must decide between maintaining the confidentiality of the information or informing the parents, police or relevant prevention and care agencies. This poses a dilemma between the principle of privacy and confidentiality of the information provided, and the principle of protection and benefit of the participating children.

The laws on this issue differ between countries; some require situations of rights violation to be reported. Others, such as most Latin American ones, have no legal frameworks or, on the contrary, have laws and regulations that oblige statistical and research institutes to safeguard the principle of confidentiality and "statistical secrecy." This implies a conflict between an ethical imperative on the one hand and a legal one on the other. The first recommendation in this regard is, therefore, to take account of the relevant legislation when designing strategies to deal with these situations.

However, as noted in section A.1 of this chapter, a decision on what to do if a violation of the rights of a child or adolescent research participant is identified should be guided ethically by the principle of the higher interests of the child. Research teams should not be indifferent to the disclosure of mistreatment, abuse or rights violation; and they should consider measures aimed at protecting children and adolescents at risk. This does not necessarily mean that situations of abuse must be reported; other alternatives can be considered, such as putting the child or adolescent in contact with support organizations or providing information on where the victim can turn for help.

The privacy and confidentiality of the information can also be extended to the stage of dissemination of the research findings, especially when the identification of respondents may entail risks or harm to them. The ethical principle of nonmaleficence implies that research participants, and their families or communities, should not be harmed by the dissemination of the research findings. Again, the use of pseudonyms and fictitious names in reports and in the findings presented is a useful strategy to protect the research participants.

Lastly, the practices applied to safeguard and store the information collected or produced should also be considered under the principle of privacy and confidentiality. In this regard, when designing the research, it is necessary to:

- Develop protocols for safeguarding information after data collection.
- Keep personal data or information that enables identification of the participants in a separate folder from information provided during the fieldwork.

- Prevent access to the names of children and adolescents interviewed during the information processing stage, especially when another work group (outside the data collection process) is checking for possible incongruencies in the interview.
- Restrict access to the data, to guarantee the security of the information against leakage or hacking of the databases.
- Encrypt the information when it is shared through e-mail.
- Designate a secure place to store the information, and specify how long it must be stored. A prudent time period is up to five years after the findings have been published.

D. Payments and compensation

In the specialized literature on the subject, there is no consensus on whether or not children and adolescents should charge a fee for participating in the research. While some researchers argue that this could induce responses or even be considered bribery, others believe that it is fair to compensate children for their participation, especially in cases where the time spent participating in the research is detrimental to work for which the participant or his or her family is remunerated.

The ERIC compendium distinguishes four possible types of payment to children and adolescents participating in research:

Payment as reimbursement, which compensates the children or their parents for any expenses incurred as a result of their participation (such as transportation, meals or lodging, among others). This type of payment does not generate ethical dilemmas, since it conforms to the principle of justice;

Payment as compensation to the children or their parents for their time, effort and any inconvenience caused such as loss of income. As in the previous case, this type of payment does not generate ethical dilemmas, since it conforms to the principle of justice;

Payment in recognition of the child's participation in the research. This is an expression of appreciation to the participants for their collaboration, and usually takes the form of small gifts given at the end of participation. Many researchers prefer that participants do not learn of the possibility of a payment of this type until the interview is concluded, so as not to condition the children's participation or responses. In this way, ethical issues associated with the use of incentives are avoided;

Payment as an incentive to participate. This form of payment raises the most ethical issues, since it can be seen as a form of persuasion that contravenes the norms of the Nuremberg Code, under which potential participants should not be persuaded in any way to participate in research. In contexts of economic deprivation, incentives can be a form of coercion or pressure on children and adolescents, or on their parents to accept the participation of their children in research, which compromises the latters' freedom to decide whether or not to participate.

E. Ethics committee

It is recommended that ethics committees be set up to provide feedback on the research design and strategies to address the ethical issues involved. This committee is advisory in nature and should consist of at least three individuals who are external to the research, avoiding conflicts of interest. The committee members, with different experiences and expertise, seek to ensure that research involving children and adolescents fulfils locally and globally agreed ethical standards. Their task, therefore, is to review research designs from an ethical standpoint and to approve or reject them, or provide feedback on them. Given the advisory nature of the committee, it will be the responsibility of the organization to which the researchers belong (or the requesting institution) to decide whether approval by the committee will be a requirement to proceed with the research.

Ethics committees should consist of at least three members and may be established at the national level or at the level of certain organizations, such as universities or research centres.

The ethics committee must avoid conflicts of interest when evaluating protocols, in order to ensure that its members act primarily to protect the rights of the research subjects and that their integrity and well-being are not affected by participation in the study.

The role of the ethics committee is to review the research designs, along with the other materials produced at that stage of the research, to determine whether the participants are exposed to any risk or are adequately protected.

The committee's decision to approve or reject the research is usually based on an analysis of the risks and benefits to the participants, and on whether or not they believe the benefits will far outweigh the potential harms, once strategies are in place to minimize risk and harm.

In reviewing a research proposal, the ethics committee should review the following elements:

- Justification of the research.
- Evaluation of risks and benefits.
- Research methods and instruments to be used.
- Description of the recruitment process.
- Protocols and models for obtaining consent and assent.
- Protocols for safeguarding the participants' privacy and confidentiality.
- Protocols for protecting and supporting children and adolescents in the event that violations are detected (including identification of public or private protection networks that can provide the support needed in each case).
- Protocols for supporting children and adolescents in the event of adverse reactions to questions or verbal or non-verbal signs of revictimization or suffering.
- The field team's qualification and skills to undertake research work with children.
- Evaluation of the study to verify whether it takes into account and respects gender differences when selecting and training fieldworkers, collecting and analysing data, and disseminating the information.

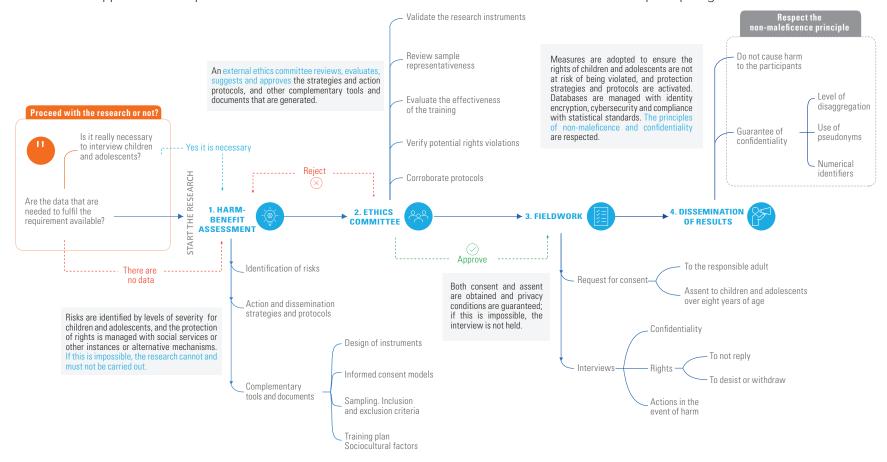
Chapter III

Flow chart for application of the ethics protocol in research with children and adolescents

Conducting research that involves the participation by children and adolescents requires a number of key ethical issues to be considered at each stage. This **consolidated outline** makes a sequential presentation of the ethical elements to be considered at each stage, which the literature on this aspect of research with children and adolescents has highlighted as the most important (see diagram III.1).

The details and specific procedures related to each stage of research are presented below (see diagrams III.2, III.3 and III.4).

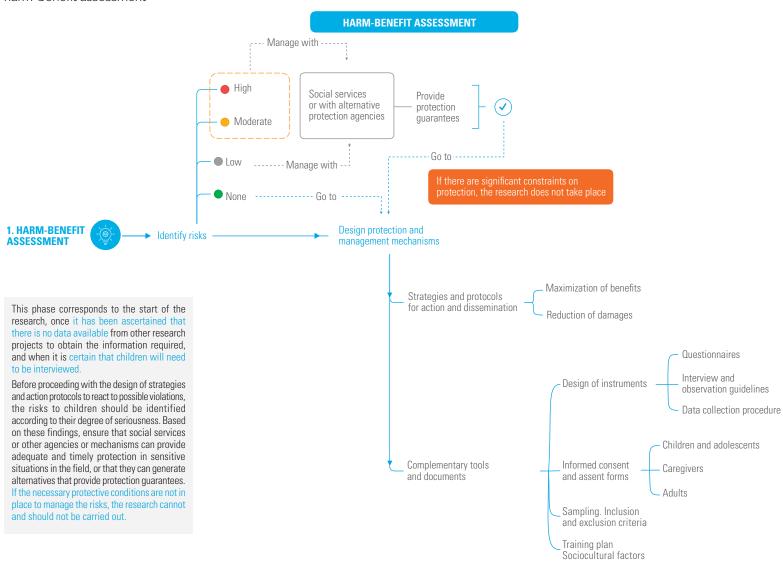
Diagram III.1
Flow chart for application of the protocol for the collection and dissemination of data on children and adolescents participating in studies



Source: Prepared by the author.

Diagram III.2

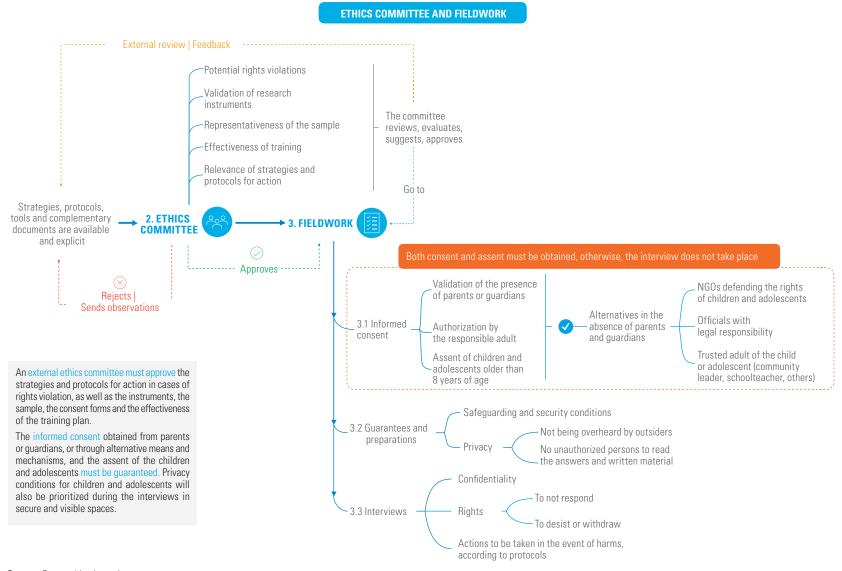
Flow chart for application of the protocol for the collection and dissemination of data on children and adolescents participating in studies: harm-benefit assessment



Source: Prepared by the authors.

Diagram III.3

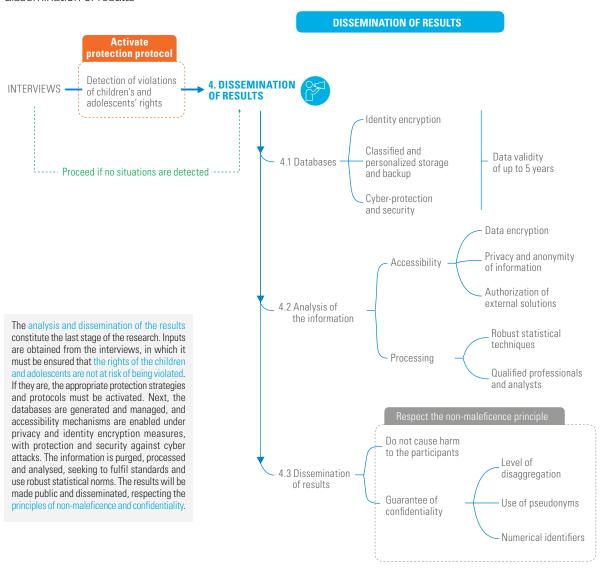
Flowchart for the application of the protocol for the collection and disclosure of data on children and adolescents participating in studies: ethics committee and fieldwork



Source: Prepared by the authors.

Diagram III.4

Flow chart for the application of the protocol for the collection and dissemination of data on children and adolescents participating in studies: dissemination of results



Source: Prepared by the authors.

Chapter IV

Protocol for ethical research with children and adolescents

Chapter II, titled "Theoretical justification of the ethical aspects of research with children and adolescents and the role of the ethics committee", sets out the theoretical justification for each of the points contained in the proposed protocol. For ease of reading, each point indicates the page number of the section in which it is defined, with a hyperlink to make it easy to consult.

This protocol is not intended to establish a rigid normative mandate; on the contrary, it aims to provide a framework and a set of elements that the research team should take into account and apply, depending on the specific context and purpose of each research project. This will enable the team to anticipate potential ethical dilemmas that may arise in the course of the research, and develop strategies to address them in a preventive manner.

Involving children and adolescents in the research can strengthen their right to participate and express their opinions, especially when conducted in a markedly adult-centred context, where their views as subjects, and their legally enshrined rights, are not respected. However, this can also put their integrity at risk. If appropriate measures are adopted, the risk is minimized and their voice can be amplified.

This has been highlighted particularly in research projects that inquire about traumatic experiences (such as physical or sexual violence in childhood), which stress the need to "involve children in these types of studies because information is significantly lost over time" (Pereda, 2019, p. 16).

Sometimes, a low degree of harm may be acceptable when set against the right to participate. In explaining precisely what this may imply, Noemí Pereda argues that temporary harm, discomfort, or some distress derived from participation in the study is acceptable under certain circumstances, [...] for which the researcher must be prepared and know how to respond, providing the resources required to ensure that the child or adolescent who needs support and assistance receives it (Pereda, 2019, p. 23). The level of well-being among the children and adolescents cannot be altered by their participation in the survey. What is important is that they and their caregivers have adequate information to make the decision for themselves (ECPAT International 2019). This should be made explicit through informed consent and assent, despite the rejection that this may generate and the resulting difficulties in completing the sample.

A. Procedures are verified in two steps

Firstly, it must be verified that the participation of children and adolescents in the research is relevant and necessary (step 1).

Secondly, it must be verified that certain ethical procedures have been incorporated in the design, fieldwork and data analysis and dissemination stages (step 2).

1. First step: evaluation of relevance and readiness

To formulate the research adequately, a first set of questions should considered.

A first step is to assess whether participation in the research by children and adolescents is justified. It is necessary to verify the balance between the children's right to be heard and the possibility that their participation could cause them physical or psychological harm, whether by action or by omission.

If your answer to any of the relevance and readiness questions is "No", then children and adolescents should not participate in the research.

Review the objectives and reformulate your research before moving on to the next stage, paying special attention to aspects identified as negative.

It is extremely important that the research team has the technical capacity to conduct research with children and adolescents, in order to avoid bias and to anticipate and adequately handle critical situations that may be encountered during fieldwork.

This is especially relevant when the target population is vulnerable, and institutional capacity to protect them adequately and in a timely manner is weak.

Table IV.1

Questions to evaluate the relevance and readiness of the research

		Yes/No
1	Have you made sure the required information is not available in other research?	
2	Does the research require the direct participation of children because data cannot be obtained in other ways (such as by using secondary data or interviewing individuals aged over 18 about their experience in childhood or adolescence)?	
3	Do you have the technical knowledge and interpersonal skills to involve children in the research?	
4	Following careful review, are you sure that the research will not impose excessive costs or negative effects on participants (such as missed classes, monetary costs, extra work)?	
5	Following careful review, are you sure that the research takes account of gender differences, specific situations and risks to which children and adolescents may be exposed through their participation in the study?	
6	Are there protection services, or public or private institutions, which can provide adequate and timely care to child participants in the event of serious physical or psychological risks or harm identified in the fieldwork, while also taking gender differences into account?	

Source: Prepared by the authors.

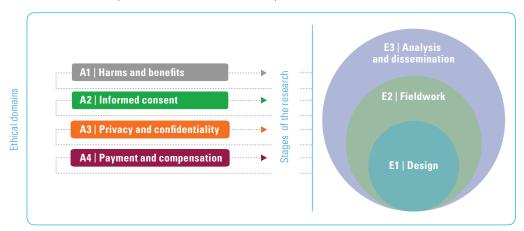
2. Second step: ethical aspects to be implemented at each stage

Next, you are asked to indicate whether or not your study incorporates each of the procedures indicated for the research stage in question.

The list of questions assigned to this step should be answered before starting the research. This will make it possible to detect, in time, whether or not certain aspects of the research design need to be adjusted. The questions to be considered in each of the three stages —design, fieldwork, and analysis and dissemination—are structured around four ethical domains: harms and benefits, informed consent, privacy and confidentiality, and payment and compensation.

Diagram IV.1

Second step in the verification of procedures: structure of the process



Source: Prepared by the authors.

If the domain for each step displays more than one "no", but the potential harms associated with non-compliance are insignificant, it is recommended that you justify your decision in the methodological report and proceed with the investigation.

Otherwise, if the potential harm is moderate or greater, consider whether you can make adjustments to your research to reduce and control the level of harm that may be caused.

Table IV.2

Questions to evaluate ethical issues at each stage of the research process

E1 | DESIGN STAGE

Stage	2 1 Domain 1 HARMS AND BENEFITS (p. 11)	Yes/No
1	The benefits, whether direct or indirect, that the participants will obtain from their participation in the study are clearly stated.	
2	The risks or possible harm that the research, in each of its stages, may cause to the study population or part of it, will be analysed.	
3	Specific measures have been considered to address the risks identified and to obviate or mitigate any harm or emotional impact that the research may cause to any participant. The measures in question consider the increased exposure of girls and adolescent women to sexual abuse and exploitation.	
4	If measures to prevent or reduce harm to a specific population or group cannot be guaranteed, consideration has been given to excluding the group or cases in question from the sample under study, or to cancelling or redesigning the study.	
5	Representative samples of the population are used, giving all groups an opportunity for representation, including those that are harder to reach. The criteria for inclusion in, and exclusion from, the sample are made explicit. Alternatively, their absence is justified, and a mitigation strategy is devised.	
6	Data collection will use methods that are appropriate to the age and stage of development of participating children and adolescents.	
7	Support is available for the children and adolescents during and after the research process, if necessary.	
8	There is a protocol for action when situations of child mistreatment, abuse or exploitation are detected. This will provide for support and referrals to specialized protection and support networks.	
9	The protocol of action to be applied when situations of child mistreatment, abuse or exploitation are detected considers the real chances that reporting such cases will activate a network of protection and support for the child in question, and that it will not cause him/her any harm.	
10	The data collection team will be trained in protocols for incorporating ethical aspects in research with children and adolescents, and will be sensitized to gender issues.	
11	If the research addresses issues such as gender violence, trafficking, sexual abuse or exploitation, the design prioritizes a female data collection team.	
12	The research design is reviewed by an ethics committee (academic or institutional), preferably external and independent. If this is not possible, a committee whose members are not directly involved in the study will be asked to review the design.	
13	If the research addresses issues such as gender violence, trafficking, sexual abuse or exploitation, the data collection team will be sensitized on these issues, taking account of the gender differences that exist between boys, girls and adolescents.	

Table IV.2 (continued)

Stage 1 Domain 2 | INFORMED CONSENT (p. 15)

- The request for consent is based on the laws of the country in question.
- The consent of mothers, fathers or guardians is considered.
- 16 The consent form provides information on:
 - the purposes and objectives of the research;
 - the potential benefits and risks to which the child will be exposed;
 - the methods and instruments to be used;
 - the confidentiality of the information provided by the child;
 - the privacy required for the interview;
 - the possibility of refusing the interview and of withdrawing at any time;
 - the procedures and channels for reporting possible abusive behaviour by the research team; and
 - focal points for asking questions about the research.
- The research design includes requesting assent from children and adolescents participating in the research. Assent should be requested from all children over 8 years of age.

Yes/No

- The children's assent request includes:
 - a clear and age-appropriate explanation of the research for each participant;
 the objectives of the research;

 - the existence of potential risks, if any, and benefits associated with both the population participating directly in the fieldwork and the extended population (national, regional, specific or other);
 - assurances of complete confidentiality; and
 - an explanation of the possibility of refusing to participate before or after the study process has begun.
- The explanations and information on the research given to participants have been pretested to ensure that they are intelligible
- 20 The research design has a clear protocol for how to proceed when children want to participate but their mothers or fathers do not,

Stage 1 Domain 3 | PRIVACY AND CONFIDENTIALITY (p.18)

- Privacy conditions have been defined for the place where the information is collected.
- The situations and conditions in which the privacy and confidentiality of the information could be waived have been made clear; for example, situations of abuse that require specialized intervention. Any lifting of the principle of confidentiality should always be justified in terms of the best interests of the child in question, and should be noted in the informed consent.
- The processes through which the information and data collected will be anonymized are made explicit.
- Security protocols are provided for the information collected and stored, and for the corresponding access authorizations.

Stage 1 Domain 4 | PAYMENT AND COMPENSATION (p. 20)

- Provision has been made for disseminating the research findings to the participants (for example, through a child-friendly version of the final report).
- If gifts are given by way of thanks or recognition, this has been discussed with local experts or leaders so as not to generate conflicts between participants and non-participants.
- 27 Monetary payments for children's participation are ruled out.
- Children and adolescents can participate in the research without incurring expenses or loss of important daily activities (such as school attendance).

E2 | FIELDWORK

Stage 2 Domain 1 | PAYMENT AND COMPENSATION (p. 11)

- The language used by the interviewer and in the data collection instruments will always be respectful, empathetic, inoffensive and non-disruptive with respect to the experiences and knowledge of participating children.
- The language used in the data collection instruments and the overall experience of participating in the study do not victimize, blame or affect the self-esteem or emotional integrity of children.
- The data collection team has been trained and has the necessary skills to work with the study population and has been sensitized
- Checks have been made to ensure that none of the members of the data collection team pose a threat to participating children (for example, by including individuals who are banned from working with children).
- The data collection team has been trained and has clear protocols and identified sources of support for taking care of children who suffer an emotional impact during the interview.
- 6 The data collection team has been trained and has clear protocols and sources of support identified for action, if abuse or violation of the rights of any of the participants is detected. This will take account of gender differences and the greater exposure of girls and female adolescents to sexual abuse and exploitation.

Table IV.2 (concluded)

Stage 2 Domain 2 | INFORMED CONSENT(p. 15)

Yes/No

- 7 The interviewing of children can only start once informed consent is obtained from their mothers, fathers or guardians, together with the assent of the participating child. The possibility of refusing to participate or withdrawing at any time, without any penalty, will be clearly stated.
- 8 The information provided for assent will be checked to ensure that it is understood, in terms of both the benefits and risks of the research, and the possibility of desisting or terminating the interview at any time.
- 9 The data collection team is trained to always ensure that the request for children's assent is made in a context that is free of pressures that could undermine or restrict the child's freedom to decide whether or not to participate. The voluntary nature of participation in the study must be emphasized.
- 10 Once the information has been provided and explained, if mothers, fathers or guardians do not give their consent, or if the children do not give their assent, the interviewer should accept the wishes of the mothers, fathers or guardians, or of the children themselves, without trying to convince or persuade them otherwise.

Step 2 Domain 3 | PRIVACY AND CONFIDENTIALITY (p.18)

- 11 The researcher or interviewer who interacts with the child shall ensure the privacy of the space in which the interview is held and the confidentiality of the information.
- 12 The confidential nature of the information provided by the child will be made explicit when requesting consent from mothers, fathers or guardians.
- 13 Younger participants —adolescents under the age of majority and younger children— will be offered the possibility of having an adult present during the collection and production of data.
- 14 The methods and instruments used in data collection and production safeguard the participants' privacy.

Stage 2 Domain 4 | PAYMENT AND COMPENSATION (p. 20)

15 If, in the research design and following consultation with local leaders, it is decided to offer a gift or make a donation of educational material, the field team will deliver it individually, without this influencing the decision to participate.

E3 | ANALYSIS AND DISSEMINATION STAGE

Stage 3 Domain 1 | HARMS AND BENEFITS (p. 11)

- 1 To avoid biases or misinterpretations of the data that could distort the participants' voice, and hence their right to express themselves, the analysis for the official publication of the research will be performed by qualified professionals.
- In no circumstances will the dissemination of research findings allow, or lead to, identification of the participants, their family or their community.
- 3 When presenting the findings and making the databases publicly available, steps will be taken to ensure that all indicators are presented with an age and gender breakdown.

Stage 3 Domain 3 | PRIVACY AND CONFIDENTIALITY (p. 18)

- 4 Databases of variables and transcripts should mask participant identification data; and the original identification data should be kept in separate folders.
- 5 The consents given for children and adolescents participating in the study should be kept in separate folders from the variable and transcript databases.
- 6 Databases containing participant identifying information as well as those containing variables and transcripts, should be adequately protected against hacking and cyber-attacks.
- 7 Databases will only be shared through insecure means, such as e-mail, USB devices or laptops, if personal data are encrypted and anonymized.
- 8 The information collected, especially data that makes it possible to individualize the participants, will be kept in folders of restricted access and clearly identified authorizations.
- 9 Data that individualizes the participants will be kept (stored) for a maximum period of five years following publication of the study.

Source: Prepared by the authors.

Note: In the analysis and dissemination stage, only two domains are considered.

Chapter V

Ethical dilemmas in research with children and adolescents in the region

A. From what age can children and adolescents be asked questions about contraceptive methods and fertility?

Research on contraceptive methods, fertility and the sexual activity of children and adolescents involves several ethical considerations that need to be taken into account to minimize the harm potentially caused. This may be more complex to address when dealing with girls and female adolescents, owing to cultural issues and the role traditionally assigned to women in highly patriarchal societies.

First, it is necessary to consider the cultural contexts in which the research will be undertaken. In many communities and societies, the sexual activity of children and adolescents may be a taboo or unaccepted subject; as a result, their sexual education may be non-existent or even designed to reject all types of sexual behaviour. This may have consequences, not only making it more difficult to obtain the consent of mothers, fathers or guardians for children and adolescents to participate in the research, but also in terms of the emotional and social impact that it could have on the participants, if a stranger asks them openly about subjects they do not know about or which are directly forbidden to them.

Moreover, even in societies that are more open about the sex lives of children and adolescents, the participants' responses about their sexual activity will depend on their level of maturity, which will naturally vary even when they are the same age. Accordingly, the data collection team should be prepared to respond to different reactions in the research environment, and should have the skills needed to assess the maturity level of the participants, and to detect verbal and nonverbal cues that indicate discomfort or irritation.

A second element to consider is the legal age of sexual consent, which may vary between countries or states. From an ethical standpoint, this means that the research team should be prepared to act if it becomes aware of cases of children and adolescents under the legal age of sexual consent who have become sexually active. Before starting the fieldwork, the research team should be clear about the measures to be adopted in such cases and what the consequences thereof may be.

Lastly, an important element that needs to be taken into account is the ability of the research team to ensure privacy when collecting information and to maintain the confidentiality of the responses. For many reasons (including retaliation, stigmatization, and shame), children may not want their mothers, fathers, guardians, or other community members to know about their sex lives. Therefore, from an ethical standpoint, the research should include such questions only if the team in charge is able to guarantee the confidentiality of the responses; and the parents or guardians should be informed of this when their consent is requested.

Consequently, there is no single answer as to the appropriate age to participate in research on contraceptive use and sexual activity, as this will depend on cultural and legal factors, and also on the maturity of the participants and the ability of the research team to anticipate and address the consequent ethical issues.

For international reference, the Demographic and Health Survey (DHS) and Multiple Indicator Cluster Surveys (MICS) interview women and men of reproductive age from the age of 15 years. The modules include questions on contraception, sexual behaviour, female genital mutilation, HIV/AIDS and attitudes towards domestic violence.

B. Dealing with the absence of support services for children who disclose abuse²

Researchers are often faced with the dilemma of striking the right balance between the risk of potential harm to the children and their right to participate and have a voice in matters that affect them. In this context, the ethical principles of research with children and adolescents state that, if abuse is revealed or detected, the research team should take steps to ensure that children are adequately supported. However, many communities do not have support services available.

In a research project involving children who were themselves heads of households, conducted in three regions of Namibia to generate inputs for designing policies and programmes to address their needs, the research team found that there were no support services for children and adolescents in the selected regions. There were no psychiatrists or psychologists, and the few social workers employed by the government were located in the capitals of each region.

To address this situation, before starting the fieldwork, the researchers identified and forged collaborative relationships with a number of local actors, who helped them select children and adolescents who were heads of household and provided assistance in the event of harm or rights violation being detected. These included religious, traditional authorities, churches and local volunteer organizations, who were available to offer assistance and support to study participants in case of need.

In another case, a participant with suicidal thoughts was referred, with his agreement, for follow-up by a local organization specialized in working with orphaned children.

Strategies such as these show that risk and potential harm can be greatly reduced if the potential local support networks are exhaustively analysed and alternative procedures are considered.

C. Conditions to be met for interviewing heads of households under 18 years of age

The request for consent from mothers, fathers, guardians or other adults is based on the fact that the vast majority of them, as responsible for, and educators of, children and adolescents, play an important and positive role in protecting them from possible harm.

However, in some cases, requesting consent from mothers, fathers or guardians is unfeasible or inappropriate, as in the case of minors who live alone or are heads of family. In these cases, the literature recommends that consent be obtained from a trusted adult designated by the minor in question. This adult may be a social worker, community leader, teacher, or any other adult trusted by the potential participant.

Another, more complicated, case involves minors who are "emancipated". This is a situation that varies greatly from one country to another and for which it is difficult to define a precise age a priori. Nonetheless, informed consent should always be sought from a person under the age of 18 who is considered legally or culturally emancipated; and it is not necessary to seek consent from their mother or father. The minimum age for a person to be considered emancipated may vary from one country to another. Criteria that can be used to determine emancipation include their capacity to earn and manage their own income, being criminally responsible, being of minimum legal age to give sexual consent, having been declared emancipated by a judge, or having no economic dependency.

Adapted from Graham and others, 2013, p. 132.

D. Ethicality and justifiability of collecting data in relation to children and adolescents under false premises³

Sometimes, the research team may feel that disclosing all information about the purpose of the research may limit the number of people willing to participate; and, consequently, it may decide to conceal or disguise part of the research. An example would be to present the study as health research when the real objective is to collect information on violence against women.

From an ethical point of view, however, such strategies contravene the principle of informed consent and conceal information that is relevant to participants' assessment of the risk of participating in the study. Ultimately, they may endanger the children and adolescents who participate in them. For this reason, the use of such ethically questionable strategies is not recommended.

Nonetheless, some researchers point out that the use of deception or artifice can sometimes be justified. For example, in natural or ethnographic observations, the fact that participants are aware of the specific conducts being recorded may alter their behaviour and thus detract from the validity of the study's conclusions.

However, even in these cases, the tension between the strategy adopted and the principle of informed consent needs to be carefully weighed, in addition to minimizing harm and balancing the achievement of valid results with possible beneficial effects for the participants.

E. Permissibility of interviewing children and adolescents without the presence of mothers, fathers or other adults, and age considerations in this regard

The privacy of the participants and the confidentiality of the information is one of the principles that ethical research with children and adolescents must respect. Other people, such as mothers and fathers, may be interested in the information collected; but the researcher is ethically obliged to respect the confidentiality of what is disclosed and to ensure that, regardless of the age of the child, it can be communicated without being heard or read by third parties (including mothers, fathers or guardians).

Safeguarding confidentiality and privacy may conflict with the cultural customs or practices of the participants' community or family. However, respect for the child's privacy requires that the researcher maintain the confidentiality of the information and secure a private, yet visible, location for the interview. Mothers, fathers, or guardians, therefore, should be informed of this condition of the child's participation when their consent is requested. If parents are reluctant, or refuse, to accept this condition, the researcher should adapt his or her expectations regarding data collection. Respect for children's privacy regarding how much information they wish to share, which may be affected by who is present, should be prioritized over the researcher's wish to elicit more information" (Graham and others, 2013, p. 79).

In conclusion, irrespective of age, the data collection team should ensure that children are able to communicate the information without their answers to the questionnaire being heard, checked, viewed or read by third parties (whether on a paper questionnaire or tablet), unless they request the presence of their or her mother, father or another person. In such cases their wishes should be respected, in accordance with respect for the wishes and autonomy of children.

³ For example, presenting the study as health research when the real objective is to collect information on violence against women.

Chapter VI

Examples of application of the protocol in the main areas of research with children and adolescents in Latin America and the Caribbean

The consultation carried out with national statistical offices identified some of the most sensitive areas linked to research with children in Latin America and the Caribbean. These areas focused on three areas of study: employment surveys, health surveys (sexual activity), and surveys of violence.

The following presents a summary of the application of the protocol in the studies that most frequently require participation by children and adolescents in the statistical offices of Latin America and the Caribbean.

The first column shows the main risks and sensitive issues detected by the national statistical offices in the diagnostic survey conducted in the first phase of the consultancy. The risks are listed in order from the pre-assessment stage through to the dissemination of results.

The second column indicates the points of the protocol that cover these dilemmas, and how application of the protocol would have facilitated their detection.

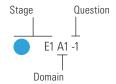
The third column briefly outlines possible strategies and how to respond to the risks identified, to be able to proceed with the research.

The table shows that the incorporation of a series of measures in the research process makes it possible to cover all aspects considered in the protocol.

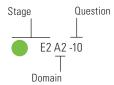
The requirements of the protocol are arranged in the second column of the tables above the examples of application; and each one has been assigned a distinctive code consisting of a coloured circle and an alphanumeric series that refers to the list of questions indicated in the second step of the protocol: ethical aspects to be implemented in each stage (see section A.2 of chapter IV).

Instructions for interpreting the identifier code in the second column (coverage of requirements):

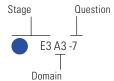
The combination of the letter "E" and a number (1, 2, 3) refers to the three stages; this is followed by the combination of the letter "A" and a number (1, 2, 3, 4), which indicates the four ethical domains, and ends with a dash "-" and then a number, referring to the question or requirement included in the protocol list. Example of code reading:



Interpretation: this refers to the "Design stage", in the domain of "Harms and benefits", and requirement or question No. 1, namely: "The benefits, direct or indirect, are clearly explained, ..."



Interpretation: this refers to the "Fieldwork stage", in the domain of "Informed consent", and requirement or question No. 10, namely: "If, once the information has been provided and explained, mothers, fathers or guardians do not ..."

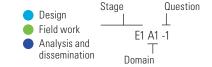


Interpretation: refers to the "Analysis and dissemination stage", in the domain of "Privacy and confidentiality", and requirement or question No. 7: "Databases shall only be shared through insecure means, such as...".

The purpose of this exercise is to show that many of the conflicts and ethical dilemmas faced by national statistical offices in studies with children and adolescents can be anticipated, thanks to the reflection and discussions generated by this protocol.

A. Studies on violence

Table VI.1
Application of the protocol in studies on violence



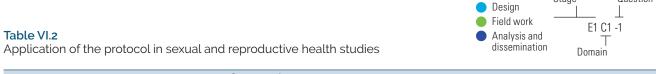
Risk	Coverage of requirements	Strategy
The research does not involve benefits for the participants, or the potential harm is greater. - Addresses sensitive issues that may cause suffering or re-victimization. - Possibility of harm or reprisals for disclosing situations of violence. - Increased risk of girls and adolescent women suffering some types of violence, especially abuse and sexual exploitation.	E1A1-1 E1A1-2 E1A1-3 E1A1-4 E1A1-5	 Briefly describe the context of the research, its objectives and methodology. Explain the age and demographic group that constitutes the study population and its justification. Indicate if any group will be excluded and why. Describe the relevance of the research and the direct or indirect benefits that participants will receive. Identify the main risks that participation in the research may involve for children and adolescents in terms of re-victimization, suffering, reprisals or negative consequences of any kind. Consider possible risks for the data collection team. Design possible actions to eliminate any risk of harm detected. Assess whether measures and courses of action, in coordination with protective services, will aggravate the harm identified. Analyse the potential harms and benefits together with experts outside the research, and indicate the reasons why the benefits outweigh the risks.
The instruments or methods are not age-appropriate and cause distress or re-victimization. - The research team should consider the risk that the instruments and the wording of the questions may cause distress or re-victimization among the children participating in the study. - Incorporation of inclusive language when formulating instruments and questions.	E1A1-6 E2A1-1 E2A1-2	 Justify the data collection methodology and its suitability for the age group examined. Indicate the bibliography and scientific evidence supporting its use. In a controlled environment, test the collection instruments on a group of children and adolescents with similar characteristics to those who will make up the sample Ensure that they do not generate harm or re-victimization. Submit the instruments for review by experts.

Table VI.1 (concluded)

Risk	Coverage of requirements	Strategy
Violations of a participant's rights are detected. – During the fieldwork, the researcher may suspect or be informed by the participant of situations of abuse, violations or security risks that require protection. These types of disclosures require specific responses and immediate actions by the research team	E1A1-7 E1A1-8 E1A1-9 E1A3-22	 Refer to the corresponding legislation. If there is no legislation on the subject: Make explicit the network of public, private and third sector organizations available to receive complaints and provide support to children whose rights are violated. Identify which organization to turn to in each case. Analyse, together with experts from outside the research and representatives of the referral organizations, possible courses of action in the event of becoming aware of situations of violence perpetrated against children. Present the conclusions and the names of the experts. Clearly and precisely instruct data collection personnel on the type of situations they should report and to whom; as well as the information they should provide to children whose rights have been violated. Include this in the manual and training provided to survey staff and moderators. Instruct data collectors, interviewers and moderators to explicitly state in the request for assent and consent that all information on violence or abuse against children will be forwarded to the competent authorities. Include this in the manual and in the training provided to interviewer and moderator staff. In the case of research conducted in the school environment, confirm that the best way to address these situations has been discussed with the school's management and teaching staff.
The data collection team is not appropriate for working on issues related to violence with children. - The data collection team acts in an abusive or negligent manner with the children participating in the research. - The data collection team is not trained to detect signs of emotional disturbance or post-traumatic behaviour in children.	E1A1-10 E1A1-11 E2A1-3 E2A1-4 E2A1-5	 Provide the data collection team with the skills required to conduct interviews or group activities on violence with children and adolescents. Demonstrate that these skills are in place. Provide the data collection team with the skills required to support and comfort children in situations of stress or suffering caused by the interview or workshop. Ensure that interviews and workshops with female children and adolescents are always conducted by female interviewers or moderators. Consider a clear and accessible system for receiving and handling complaints and allegations.
The participation of children and adolescents in the research is not voluntary. In studies on violence, it is essential to request the assent of the participants because, ultimately, they are best placed to judge whether their participation in the research entails any risk. The request for assent should make clear the voluntary nature of participation, as well as the possibility of not answering a question or stopping the interview. In studies conducted in school environments, it is particularly important to emphasize the voluntary nature of participation, since the presence of the researcher could reproduce the relationship of authority between teachers and students and, as a result, the child may perceive a certain cultural pressure to participate.	E1A2-14 E1A2-15 E1A2-16 E1A2-17 E1A2-18 E1A2-19 E1A2-20 E2A2-7 E2A2-9 E2A2-10	 Always consider the assent of the participants and the active consent of the parents or responsible adults. Provide sample consent and assent forms, outlining the information to be provided. Test consent and assent forms with a group of similar characteristics, to ensure clarity and understanding. In addition, in the case of research conducted in school or institutional settings, consider the consent of the principal or administrator. In the case of situations where a responsible adult does not exist or cannot be located, consider the option of requesting consent from an adult trusted by the child or adolescent. In the training and manual provided to interviewers and moderators, clearly state that the session cannot begin without the consent of the responsible adult and the assent of the participants.
The child's or adolescent's participation in the research exposes him/her to negative consequences or retaliation. - For example, retaliation by the abuser in case of disclosing situations of violence at home, school or elsewhere.	E1A3-21 E2A3-11 E2A3-12 E2A3-13 E2A3-14	 In the training and manual provided to interviewers, clearly state that interviews or focus groups should be conducted in full view, but protected from being heard or read by third parties. Provide clear instructions in the training and manual provided to interviewers and moderators on what to do in situations of limited or no privacy: Reiterate the request for privacy, also to consenting adults. If privacy is impossible, suggest rescheduling the interview. In the event of interruptions or the presence of third parties during the interview or focus group, skip questions on topics that may involve reprisals or have negative consequences for the participants. If possible, use technology to conduct computer-assisted interviews.
Data confidentiality is at risk. – Third parties have access to the records.	E1A3-23 E1A3-24 E3A3-4 E3A3-5 E3A3-6 E3A3-7 E3A3-8 E3A3-9	Present data handling protocols indicating the following: - Procedures for data masking. - Procedures for data storage and consent. - Security measures to protect databases and folders. - Identification of personnel with access to stored information. - Procedures for data transportation and transmission. - Duration of data storage.
Dissemination of the research findings causes harm to participants.	E3A1-2	 Present the draft of the final report to experts outside the research to verify that no group is stigmatized. Confirm, through the external experts, that the report does not identify the participants.

B. Studies on sexual and reproductive health

Table VI.2



Stage

Question

Risk	Coverage of requirements	Strategy
The research has no benefits for the participants, or the potential harms are greater. - Exposure of girls' sexual acitivity can lead to family or social sanctions. - Parents do not allow questions about sex life and silence girls' voices on the subject. - Cases of sexual abuse are detected.	E1A1-1 E1A1-2 E1A1-3 E1A1-4 E1A1-5	 Briefly describe the context of the research, its objectives and methodology. Explain the age and demographic group that constitutes the study population and its justification. Indicate the strategy to be used to reach the most difficult-to-reach groups. Indicate if any group will be excluded and why. Describe the relevance of the research and the direct or indirect benefits that participants will receive as a result of the research (support programmes, sex or health education programmes, among others). Explain how the main risks that participation in the research could pose to participants, especially girls, will be addressed: embarrassment or discomfort with the questions, fear of possible disclosure of information that they would prefer their parents or their environment not to know (for example, about their sexual activity), possible retaliation for such information, and re-victimization or suffering in the case of victims of sexual abuse. Indicate the courses of action to be taken by the investigation team in the event of disclosures of sexual abuse. Discuss with experts outside the investigation whether the strategies to eliminate or reduce the risk of harm are appropriate, and explain why the benefits outweigh the risks.
The instruments or methods used are not age-appropriate and cause suffering or revictimization. Ouestions about sexuality intimidate, threaten or embarrass girls or adolescent women.	E1A1-6 E2A1-1 E2A1-2	 Justify the data collection methodology and its suitability for the age group being studied. Indicate the bibliography and scientific evidence supporting its use. Discuss the topics and the wording of the questions with community representatives (children, adolescents, mothers, fathers, teachers, paediatricians, etc.). In a controlled environment, test the collection instruments on a group of children and adolescents with similar characteristics to those who will make up the sample. Subject the instruments to a review by experts.
Violations of a participant's rights are detected. – During fieldwork, the researcher may suspect or be informed by the participant of situations of abuse, rights violations or security risks that require protection. These types of disclosures require concrete and immediate responses from the research team.	E1A1-7 E1A1-8 E1A1-9 E1A3-22 E2A1-6	 Refer to the corresponding legislation. If there is no legislation on the subject: Make explicit the network of public, private and third-sector organizations available to receive complaints and provide support to children whose rights are violated. Identify which organization to turn to in each case. Analyse, together with experts from outside the investigation and representatives of the referral organizations, possible courses of action in the event of becoming aware of situations of violence perpetrated against children. Present the conclusions and the names of the experts. Clearly and precisely instruct data collection personnel on the type of situations they should report and to whom; as well as the information they should provide to children whose rights have been violated. Include this into the manual and training provided to survey staff and moderators. Instruct data collectors, interviewers and moderators to explicitly state in the request for assent and consent that all information on violence or abuse against children will be forwarded to the competent authorities. Include this in the manual and in the training provided to interviewer and moderator staff. In the case of research conducted in the school environment, confirm that the best way to address these situations has been discussed with the school's management and teaching staff.
The data collection team is not suitable for working on sexual health issues with children and adolescents.	E1A1-10 E1A1-11 E2A1-3 E2A1-4 E2A1-5	 Check the background of the members of the data collection team and exclude all those with a history of child abuse or mistreatment. Provide the data collection team with the skills needed to conduct interviews or group activities on sexual health issues with children and adolescents. Demonstrate that these skills are in place. Provide the data collection team with the skills needed to support and comfort children and adolescents in situations of stress or suffering caused by the interview or workshop. Ensure that interviews and workshops with female children and adolescents are always conducted by female interviewers or moderators. Consider a clear and accessible system for receiving and handling complaints and allegations.

Table VI.2 (concluded)

Risk	Coverage of requirements	Strategy
Participation in the research by children and adolescents in exposes them to negative consequences or retaliation. — In studies on sexuality, it is essential to request the assent of the participants since, ultimately, they are best placed to judge whether their participation in the research entails any risk. — The request for assent should make clear the voluntary nature of participation, as well as the possibility of not answering a question or stopping the interview.	E1A2-14 E1A2-15 E1A2-16 E1A2-17 E1A2-18 E1A2-19 E1A2-20 E2A2-7 E2A2-9 E2A2-10	 Always consider the assent of the participants and the active consent of the mothers, fathers or responsible adults. Provide sample consent and assent forms, outlining the information to be provided. Test the consent and assent forms with a group of similar characteristics to ensure clarity and understanding. In addition, in the case of research conducted in school or institutional settings, consider the consent of the principal or administrator. In the case of situations where a responsible adult does not exist or cannot be located, consider requesting consent from an adult trusted by the child or adolescent. In the training and manual provided to interviewers and moderators, clearly state that the session cannot begin without the consent of the responsible adult and the assent of the participants.
Parents or the environment find out about girls' sexual activity.	E1A3-21 E2A3-11 E2A3-12 E2A3-13 E2A3-14	 In the request for consent to the mothers, fathers or guardians, clearly state the requirement for privacy to conduct the interview or focus groups, as well as the confidentiality of the responses. Reaffirm with the participants the confidentiality of responses and the voluntary nature of participation. In the training and manual provided to interviewers, clearly state that interviews or focus groups should be conducted in open view, but should be protected from being heard or read by third parties. In the training and manual provided to interviewers and moderators, give clear instructions on what to do in situations of limited or no privacy; (i) Reiterate the request for privacy, also to the adults that give consent. (ii) If privacy is impossible, suggest rescheduling the interview. (iii) In case of interruptions or the presence of third parties during the interview or focus group, skip questions on topics that may involve reprisals or have negative consequences for the participants. As far as possible, use computer-assisted interviewing technologies.
Data confidentiality is at risk. – Third parties have access to the records.	E1A3-23 E1A3-24 E3A3-4 E3A3-5 E3A3-6 E3A3-7 E3A3-8 E3A3-9	Present data handling protocols indicating the following: - Procedures for data and record masking. - Procedures for data storage and consent. - Security measures to protect databases and folders. - Identification of personnel with access to stored information. - Procedures for data transportation and transmission. - Duration of data storage.
Dissemination of the research findings causes harm to participants.	E3A1-2	 Submit the draft final report to experts outside the research to verify that no group is stigmatized. Confirm, through the external experts, that the report does not identify the participants.

C. Studies on work and employment

Table VI.3
Application of the protocol in work and employment studies

Design	Staye 	
Field work	F1 C	⊥ 1 ₋ 1
 Analysis and dissemination 	Domain	<u>-</u> ·
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Risk	Coverage of requirements	Strategy
The research does not involve benefits for the participants, or the potential harms are greater. - The research does not involve benefits for the participants. - The specific situation of working children and adolescents is rendered invisible in the presentation of general results. - Cases of child exploitation or worse forms of labour are detected.	E1A1-1 E1A1-2 E1A1-3 E1A1-4 E1A1-5	 Briefly describe the context of the research, its objectives and methodology. Explain the age and demographic group that constitutes the study population and its justification. Indicate the strategy to be used to reach the most difficult-to-reach groups. Indicate if any group will be excluded and why. Describe the relevance of the research and the direct or indirect benefits that participants will receive as a result of the research. In the case of general studies in which part of the sample includes children and adolescents, explain the specific analyses and strategies that will be used to give visibility to their specific situation. Indicate the courses of action to be taken by the research team if cases of child exploitation are detected. Discuss with experts outside the research whether strategies to eliminate or reduce the risk of harm are appropriate, and explain why the benefits outweigh the risks.
The instruments or methods used are not age-appropriate and cause suffering or revictimization	E1A1-6 E2A1-1 E2A1-2	 Justify the data collection methodology and its suitability for the age group being studied. Indicate the bibliography and scientific evidence supporting its use. In a controlled environment, test the collection instruments on a group of children and adolescents with similar characteristics to those who will make up the sample. Submit the instruments for review by experts.
Violations of a participant's rights are detected. - During the fieldwork, the researcher may detect that some of the participating children are victims of abuse or exploitation. These types of revelation require concrete and immediate responses from the research team.	E1A1-7 E1A1-8 E1A1-9 E1A3-22 E2A1-6	 Refer to the corresponding legislation. If there is no legislation on the subject: Make explicit the network of public, private and third-sector organizations available to receive complaints and provide support to children whose rights are violated. Identify which organization to turn to in each case. Analyse, together with experts from outside the investigation and representatives of the referral organizations, possible courses of action in the event of becoming aware of situations of violence perpetrated against children. Present the conclusions and the names of the experts. Clearly and precisely instruct data collection personnel on the type of situations they should report and to whom; as well as the information they should provide to children whose rights have been violated. Include this into the manual and training provided to survey staff and moderators. Instruct data collectors, interviewers and moderators to explicitly state in the request for assent and consent that all information on violence or abuse against children will be forwarded to the competent authorities. Include this in the manual and in the training provided to interviewer and moderator staff. In the case of research conducted in the school environment, confirm that the best way to address these situations has been discussed with the school's management and teaching staff.
The data collection team is not suitable for working on sexual health issues with children and adolescents.	E1A1-10 E1A1-11 E2A1-3 E2A1-4 E2A1-5	 Check the background of the members of the data collection team and exclude all those with a history of child abuse or mistreatment. Provide the data collection team with the skills needed to conduct interviews or group activities on sexual health issues with children and adolescents. Demonstrate that these skills are in place. Provide the data collection team with the skills needed to support and comfort children and adolescents in situations of stress or suffering caused by the interview or workshop. Ensure that interviews and workshops with female children and adolescents are always conducted by female interviewers or moderators. Consider a clear and accessible system for receiving and handling complaints and allegations.

Table VI.3 (concluded)

Risk	Coverage of requirements	Strategy
Consent and assent - The child's request for assent must be free from pressure or attempts at persuasion, so interviewers should be alert to any verbal or non-verbal signs that they may be being coerced. - Since it is very likely that in an employment survey the child's mother, father or employers will be present when assent is requested, the request needs to be repeated once the interviewer and participant meet in a space where their responses cannot be heard or read by anyone (principle of privacy and confidentiality). - The request for assent should make clear the voluntary nature of participation, as well as the option of not answering a question or stopping the interview.	E1A2-14 E1A2-15 E1A2-16 E1A2-17 E1A2-18 E1A2-19 E1A2-20 E2A2-7 E2A2-9 E2A2-10	 Always consider the assent of the participants and the active consent of the mothers, fathers or responsible adults. Provide sample consent and assent forms, outlining the information to be provided. Test the consent and assent forms with a group of similar characteristics to ensure clarity and understanding. In addition, in the case of research conducted in school or institutional settings, consider the consent of the principal or administrator. In situations where a responsible adult does not exist or cannot be located, consider requesting consent from an adult trusted by the child or adolescent. In the training and manual provided to interviewers and moderators, clearly state that the session cannot begin without the consent of the responsible adult and the assent of the participants.
Privacy Often, the mothers and fathers of children and adolescents tend to answer for them, leaving them "voiceless" in the study. This may occur either as a result of "social desirability" (in contexts where child labour is frowned upon) or to conceal information about abuse or other rights violations. The confidentiality of information is often tested by the fact that parents, even those who have been respectful of the privacy of the interview, often want to know some of the answers the child gave. Interviewers should respectfully reiterate the principle of confidentiality that the parent was made aware of when he or she consented to the interview.	E1A3-21 E2A3-11 E2A3-12 E2A3-13 E2A3-14	 In the request for consent from the mothers, fathers or guardians, clearly indicate the privacy required to conduct the interview or focus groups, as well as the confidentiality of the responses. Reaffirm with participants the confidentiality of the responses and the voluntary nature of participation. In the training and manual provided to interviewers, clearly state that interviews or focus groups should be conducted in open view, but should not be overheard or read by third parties. In the training and manual provided to interviewers and moderators, give clear instructions on what to do in situations of limited or no privacy: (i) Reiterate the request for privacy, including to adults who gave consent. (ii) If privacy is impossible, suggest rescheduling the interview. (iii) In case of interruptions or presence of third parties during the interview or focus group, skip questions on topics that may involve retaliation or have negative consequences for participants. Use computer-assisted interviewing technologies where possible.
Data confidentiality is at risk. – Third parties have access to the records	E1A3-23 E1A3-24 E3A3-4 E3A3-5 E3A3-6 E3A3-7 E3A3-8 E3A3-9	Present data handling protocols that indicate the following: - Procedures for data and record masking. - Procedures for data storage and consent. - Security measures to protect databases and folders. - Identification of personnel with access to stored information. - Procedures for data transportation and transmission. - Duration of data storage.
Dissemination of the research findings causes harm to the participants	E3A1-2	 Submit the draft final report to experts outside the research, to verify that no group is stigmatized. Confirm, through the external experts, that the report does not identify the participants.

Chapter VII

Considerations in relation to on-line research with children and adolescents

The universalization of the Internet has made this medium an important source of public information, as well as a quick and inexpensive tool for conducting research, either through online questionnaires or through telematic interviews.

Some researchers argue that the use of the Internet in research is nothing more than "old wine in new bottles" (Ess, 2002), and that traditional principles of ethical research are sufficient in the context of this new research technology. However, the use of the Internet in research raises new ethical challenges, especially with regard to consent, privacy, and anonymity.

A. Evaluation of harms and benefits

Online research must address the same challenges, in terms of risks and harms, as any other research involving children and adolescents. However, the digital setting makes it difficult to support the participant in the event of distress or suffering, or to deploy effective support protocols if rights violations or abuses are detected.

Moreover, the practical difficulty for the researcher to control the participant's privacy —that is, the absence of a third party who can hear or read the information provided— arises from the impossibility of knowing for sure that there is no one else in the room from which the interview is answered, or of totally preventing interference (hacking) with the information transmitted.

For these reasons, the recommendation is to avoid using the Internet to conduct research with children and adolescents on sensitive topics, since it is impossible to meet fundamental ethical standards in respect of possible harm and participant protection protocols.

B. Confidentiality and privacy of information

Online research involves several additional confidentiality concerns, such as the security of data storage and transmission, and protection of the participants' identities.

The transmission of information over the Internet is always at risk of being intercepted by third parties. Strategies to make it secure may include encryption, the use of meaningless identification tags for persons outside the research team, or the separate transmission of individualization and variable data or transcripts.

The anonymity of the participants also cannot be fully guaranteed in studies conducted over the Internet.

Privacy. The distinction between public and private has implications for informed consent. Traditionally, consent is not required to obtain information that is already in the public domain. However, is information contained in chat rooms, or on Facebook or Twitter, among other platforms, public or private? A number of research studies have shown that, for many chat room participants, chat rooms are private spaces, even when they are publicly accessible or unrestricted.

Bruckman (2002) suggests that researchers can use online information provided that it meets the following criteria:

- (i) Officially, it is a public file.
- (ii) No passwords are required to access the information.
- (iii) The website does not have policies that prevent the use of the information.
- (iv) The topic is not a sensitive one.

Any information that does not meet any of these criteria requires consent for use.

C. Informed consent

It is more difficult to obtain informed consent in research conducted online than in traditional formats. This is explained by the lack of interactivity and, specifically, the absence of visual cues that enable the researcher to confirm who is answering and whether they understand the information being provided (NESH, 2019).

For this reason, in online research with children and adolescents, it is recommended that the consent of mothers, fathers or guardians be obtained in writing (on paper or by email) or by telephone, if the research is low risk; and face-to-face with the mother, father or guardian, if the research involves some risk (Bruckman, 2002).

Bibliography

- Alderson, P. and V. Morrow (2011), The Ethics of Research with Children and Young People: A Practical Handbook, London, SAGE Publishing.
- Berman, G. (2016), Method Guide 2: Ethical Considerations for Research with Children, London, Global Kids Online.
- Bruckman, A. (2002), "Ethical guidelines for research online", Atlanta, Georgia Institute of Technology [online] https://cc.gatech.edu/~asb/ethics/.
- ECPAT International (2019), Guidelines for Ethical Research on Sexual Exploitation Involving Children, Bangkok.
- Ess, C. (2002), "Ethical decision-making and Internet research: recommendations from the AoIR Ethics Working Committee," Chicago, Association of Internet Researchers (AoIR) [online] https://aoir.org/reports/ethics.pdf.
- Gorin, S. and others (2008), "Ethical challenges in conducting research with hard to reach families", *Child Abuse Review*, vol. 17, No. 4, Hoboken, Wiley.
- Graham, A. and others (2013), Ethical Research Involving Children, Florence, United Nations Children's Fund (UNICEF).
- Kotch, J. (2000), "Ethical issues in longitudinal child maltreatment research", *Journal of Interpersonal Violence*, vol. 15, No. 7, Thousand Oaks, SAGE Publishing.
- Langhinrichsen-Rohling, J. and others (2006), "Sensitive research with adolescents: Just how upsetting are self-report surveys anyway?", Violence and Victims, vol. 21, No. 4, Berlin, Springer.
- Lundy, L. and L. McEvoy (2012), "Children's rights and research processes: assisting children to (in)formed views", *Childhood*, vol. 19, No. 1, Thousand Oaks, SAGE Publishing.
- Markham, A. and E. Buchanan (2012), "Ethical decision-making and internet research: recommendations from the AoIR Ethics Committee (version 2.0)", Chicago, Association of Internet Researchers (AoIR) [online] https://aoir.org/reports/ethics2.pdf.
- Mudaly, N. and C. Goddard (2009), "The ethics of involving children who have been abused in child abuse research", *The International Journal of Children's Rights*, vol. 17, No. 2, Leiden, Brill.
- NESH (National Committee for Research Ethics in the Social Sciences and the Humanities) (2019), A Guide to Internet Research Ethics, Oslo.
- OHCHR (Office of the United Nations High Commissioner for Human Rights) (1989), Office of the United Nations High Commissioner for Human Rights, Geneva.
- Pereda, N. and others (2019), *Guía práctica para la investigación ética en violencia contra la infancia y adolescencia*, Madrid, Federation of Associations for the Prevention of Child Mistreatment (FAPMI).
- Salmons, J. (2014), Qualitative Online Interviews: Strategies, Design, and Skills, Thousand Oaks, SAGE Publishing.
- Serrano, M. (2014), "Aspectos éticos de la investigación en salud en niños", Revista Colombiana de Bioética, vol. 9, No. 1, Bogotá, El Bosque University.
- Stanford University (2021), "Internet research ethics", Stanford Encyclopedia of Philosophy, Stanford [online] https://plato.stanford.edu/entries/ethics-internet-research/.
- UNECE (Economic Commission for Europe) (2019), "Generic Statistical Business Process Model GSBPM (Version 5.1, January 2019)", Geneva.
- UNICEF (United Nations Children's Fund) (2015), "UNICEF procedure for ethical standards in research, evaluation, data collection and analysis", New York.
- ___(2012), Ethical Principles, Dilemmas, and Risks in Collecting Data on Violence against Children: A Review of Available Literature, New York.
- WHO (World Health Organization) (2019), Guidance on ethical considerations in planning and reviewing research studies on sexual and reproductive health in adolescents, Geneva.
- ____(2007), "WHO Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies," Geneva.
- Ybarra, M. and others (2009), "Impact of asking sensitive questions about violence to children and adolescents", *Journal of Adolescent Health*, vol. 45, No. 5, Amsterdam, Elsevier.

Annex A1

Table of correspondences between the Protocol and the Generic Statistical Business Process Model (GSBPM)

The Generic Statistical Business Process Model (GSBPM) is a complementary model for the production and management of statistical information, which defines and describes the set of processes needed to produce official statistics. This model should be applied and interpreted in a flexible manner, and not as a rigid framework. According to the specifications set out in the handbook, an organization may either implement the GSBPM directly, or else use it as a basis for developing a specific adaptation.

The model consists of three levels:

Level 0, the statistical process.

Level 1, the eight phases of the statistical process.

Level 2, the subprocesses within each phase.

As GSBPM is already being implemented progressively in national statistical offices across the region, the following table of correspondences is proposed for the individual procedures considered in the various stages of the protocol for the collection and dissemination of data on children and adolescents participating in studies.

Each column shows the phase, process and subprocess associated with GSBPM, followed by the requirements defined in the protocol according to its coding. This makes it possible to identify these requirements in the different phases of the statistical production and management process.

The columns headed "GSBPM Phase 1", "GSBPM Phase 2", "GSBPM Phase 3", "GSBPM Phase 4", "GSBPM Phase 5", "GSBPM Phase 6", "GSBPM Phase 7" and "GSBPM Phase 8" show the processes and subprocesses included in the model.

The columns headed "Protocol for children and adolescents" correspond to the ethical protocol for the participation of children and adolescents in research studies. These columns indicate the stage of the protocol that should be applied according to the GSBPM process or subprocess listed in the previous column. First, the corresponding step is indicated, for example: Step 1. Then, after a semicolon, the procedure number corresponding to that step is indicated (if there are several procedures, they are separated by commas).

As an example, for GSBPM phase 1, "Specification of requirements", subprocess 1.6, "Preparation and presentation of a business case", corresponds to step 1; while the numbers that come after the semicolon identify the procedures corresponding to that step (2, 3, 4, 5, 6). In the case of step 2, the corresponding stage is defined after the semicolon (E1A1); then, after the semicolon, the numbers identifying the procedures corresponding to the stage (1, 2, 3, 4, 7) of the ethical protocol for the participation of children and adolescents in studies are defined.

The tables below are based on the definitions set out in UNECE (2019).

Table A1.1

Phases (level 1) and subprocesses (level 2) of the Generic Model of Institutional Statistical Processes (GSBPM) and their correspondence with the protocol for the collection and dissemination of data on children and adolescents participating in studies

GSBPM phase 1	Protocol for childhood and adolescence Step 1 and step 2	GSBPM phase 2	Protocol for childhood and adolescence Step 2
Specify needs		Design	
1.1 Identify needs	Step 1; 2	2.1 Design outputs	E1A1; 6. E1A2 14, 15, 16, 17, 18, 19, 20. E1A3; 21, 22, 23, 24
1.2 Consult and confirm needs	Step 1; 2	2.2 Design variable descriptions	E2A1;
1.3 Establish output	Step 1; 2, 4	2.3 Design collection	E2A1; 1, 2, 3, 4, 5, 6
1.4 Identify concepts	Step 1; 5	2.4 Design frame and sample	E1A1; 5
1.5 Check data availability	Step 1; 1, 2	2.5 Design processing and analysis	E3A1
1.6 Prepare and submit business case	Step 1; 2, 3, 4, 5, 6 and step 2; E1A1; 1, 2, 3, 4, 7	2.6 Design production systems and workflow	E1A3; E2A2

GSBPM phase 3	Protocol for childhood and adolescence	GSBPM phase 4	Protocol for childhood and adolescence
Construction		Collect	
3.1 Reuse or build collection instruments	E2A1	4.1 Create frame and select sample	E1A1; 5
3.2 Reuse or build processing and analysis components	E3A1; E3A3	4.2 Set up collection	E1A1; E1C4
3.3 Reuse or build dissemination components	E3A1; 2, 3; E3A3; 6, 7, 8, 9	4.3 Run collection	E1A1; 6, 7, 8, 9, 13; E2A1; E2A2; E2A3; E1C4; E2C4
3.4 Configure workflows	E1A3; E1C4; E2A1; E2A2; E2A3; E2C4	4.4 Finalize collection	
3.5 Test production systems	E2A1; E2A2; E2A3		
3.6 Test statistical business process	E2A1; E2A2; E2A3		
3.7 Finalize production systems			

GSBPM phase 5	Protocol for childhood and adolescence	GSBPM phase 6	Protocol for childhood and adolescence
Process		Analyse	
5.1 Integrate data	E3A3	6.1 Prepare draft outputs	E3A1
5.2 Classify and code	E3A3	6.2 Validate outputs	E3A1
5.3 Review and validate	E3A3	6.3 Interpret and explain outputs	E3A1
5.4 Edit and impute	E3A3	6.4 Apply disclosure control	E3A1
5.5 Derive new variables and units		6.5 Finalize outputs	E3A1
5.6 Calculate weights			
5.7 Calculate aggregates			
5.8 Finalize data files			

GSBPM phase 7	Protocol for childhood and adolescence	GSBPM phase 8	Protocol for childhood and adolescence
Disseminate		Evaluate	
7.1 Update output systems	E3A1	8.1 Evaluation inputs	
7.2 Produce dissemination products	E3A1	8.2 Conduct evaluation	E1A1: 3, 4, 5, 6, 7, 8, 9, 13
7.3 Manage release of dissemination products	E3A1	8.3 Agree an action plan	
7.4 Promote dissemination products	E3A1		
7.5 Manage user support	E3A1		





