Age Matters!

Comparative review of age-related policy & legislation affecting the rights of adolescents and youth in the ECARO region

Principles, Guidelines & Protocols

for ensuring subjects' safety, protection of human subjects' identities, and protection of data

RESEARCH INVOLVING CHILDREN

August 2017
Youth Policy Labs

Introduction

This document is intended to outline the overarching principles and guidelines regarding research with children (younger than 18 years) in the "Age Matters!" project. A consultation will be held with adolescents (ages 10-17 years) in the form of an online survey and focus groups in five ECARO countries (Armenia, Bulgaria, Kazakhstan, Ukraine, Romania) between September and November 2017. This project is commissioned by UNICEF Europe and Central Asia Regional Office (ECARO), and implemented by Youth Policy Labs in partnership with the UNICEF Country Offices (CO) in each participating country.

This document is based on child protection policies of prominent national and international organisations that conduct research with children, as well as the UNICEF Innocenti publication *Ethical Research Involving Children* (2013), to align the "Age Matters!" project with international best practice.

This document is targeted at Youth Policy Labs researchers, facilitators and other project staff who are conducting research with children and adolescents. They are required to read the document, demonstrate understanding, and adhere to its principles. Additionally, researchers and facilitators are required to attend the online webinar which covers the protocols covered here, as well as complete the 90-minute UNICEF online course, "Introduction to Ethics in Evidence Generation".

Additional project documents that should be read in conjunction with this guide:

- UNICEF "Age Matters!" Research Protocol
- UNICEF "Age Matters!" Adolescent Survey
- UNICEF "Age Matters!" Focus Group Questions and Facilitator's Guide

International Charter for Ethical Research Involving Children

From Graham, A., Powell, M., Taylor, N., Anderson, D. & Fitzgerald, R. (2013). Ethical Research Involving Children. Florence: UNICEF Office of Research – Innocenti.
http://childethics.com/

As a research community working with children, we are committed to undertaking and supporting high quality ethical research that is respectful of children's human dignity, rights and wellbeing. The following seven commitments guide our work:

Ethics in research involving children is everyone's responsibility

We, the research community, including all who participate in undertaking, commissioning, funding and reviewing research, are responsible for ensuring that the highest ethical standards are met in all research involving children, regardless of research approach, focus or context.

Respecting the dignity of children is core to ethical research

Ethical research is conducted with integrity and is respectful of children, their views and their cultures. Involving children respectfully requires that researchers recognise children's status and evolving capacities and value their diverse contributions.

Research involving children must be just and equitable

Children involved in research are entitled to justice. This requires that all children are treated equally, the benefits and burdens of participating are distributed fairly, children are not unfairly excluded and that barriers to involvement based on discrimination are challenged.

Ethical research benefits children

Researchers must ensure that research maximizes benefits to children, individually and/or as a social group. The researcher bears primary responsibility for considering whether the research should be undertaken and for assessing whether research will benefit children, during and as a consequence of the research process.

Children should never be harmed by their participation in research

Researchers must work to prevent any potential risks of harm and assess whether the need to involve the individual child is justified.

Research must always obtain children's informed and ongoing consent

Children's consent must always be sought, alongside parental consent and any other requirements that are necessary for the research to proceed ethically. Consent needs to be based on a balanced and fair understanding of what is involved throughout and after the research process. Indications of children's dissent or withdrawal must always be respected.

Ethical research requires ongoing reflection

Undertaking research involving children is important. Ethical research demands that researchers continually reflect on their practice, well beyond any formal ethical review requirements. It requires ongoing attention to the assumptions, values, beliefs and practices that influence the research process and impact on children.

Informed Consent

Informed consent is an ongoing process throughout the research. Young people should be reminded throughout that they are able to withdraw their participation at any point, as they wish.[1] When involving children in research, be sure to explain the following:

We respect your rights:

- *To take time to decide whether to help us;*
- *To refuse to take part without this affecting your care/education/ status;*
- *To refuse to answer some questions;*
- *To withdraw from this project at any time;*
- *We will keep notes and tapes from the groups in a safe lockable place;*
- *When we talk about the research or write reports, we won't use your names so that you remain anonymous.*

For participants in the **online survey**, parental consent will not be required but all reasonable steps are taken to inform parents about the survey so that they are aware that their child might be participating. Informed consent of the young person will be obtained on the first page of the survey.

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[1] Adapted from Howard League for Penal Reform (2013), *"Statement of Ethical Research Practice"*, http://www.howardleague.org/fileadmin/howard_league/user/pdf/Office_policies/Ethical_research_practice_paper_W_Oct_2007.pdf

For participants in the **focus groups**, obtaining parental consent prior to participation in a focus groups is *mandatory and legally required in countries where research is conducted,* in addition to obtaining the signed consent of the young person prior to the focus group session. Completed consent forms will be scanned and submitted to the "Age Matters!" project team, and paper consent forms will stay with UNICEF. Information sheets will remain for parents/adolescents.

- For participants completing the **online survey**, active and informed consent from the young person will be obtained on the first page of the survey (i.e. clicking a box that confirms that the understand the study and they choose to participate voluntarily). Young people will be informed that they can to stop the survey at any point.

Note on parental consent for online surveys: Given the nature of the internet itself, parents have little ability to control which websites are accessed by their children except for the most extreme or inappropriate (ex. by using parental controls or filters). As such, while parental consent was not actively sought, all reasonable steps were taken to inform parents/guardians about the survey, so that they are aware that their child might be participating in it in case there are objections. These steps included widely disseminating the survey on all public UNICEF communication channels, in local languages, with contact details clearly available if parents have any questions; and a statement on the front page of the survey that encourages adolescents to speak to their parents/guardians about the survey, and that they completed it.

- For participants of the **focus group**; All participants in the **focus groups** have to give their personal written consent prior to participation in a focus group discussion. Obtaining parental consent prior to participation in a focus group is *mandatory* for adolescents 10-13 years old.
- If possible under national law, prior consent from parents for older adolescents 14-17 years old, in addition to their own consent, may *not be mandatory*. This is because for adolescents 14-17 years of age, it will be assumed that when given sufficient information about the project and their participation, they will have the capacity to make their own decision about participation, in recognition of their evolving capacities. Moreover, the lack of autonomy of young people, combined with the authority of their parents in some families, can mean that parents may seek to obstruct the participation of young people with important things to say. This is especially relevant for young people from vulnerable groups (ex. LGBTQ). Exclusion of young people who do not wish to obtain parental consent, but still have a strong desire to participate in the research, is not defensible in terms of equity, justice and the potential benefit of the research findings. Even if parental consent is not sought, adolescents will be encouraged to discuss their participation with their parents, if they so wish.
- **However, in all five countries where this research is held, it is legally necessary to seek the consent of parents or guardians of individual young people under 18** using a completed parental consent form. Both parental and adolescent consent forms will be distributed prior to when the focus group is held, and parents will need to complete the form in order for their child to participate in a focus group. Active, written and informed consent from the young person will be obtained prior to the focus group as well. Young people will be reminded at the beginning and throughout of focus group discussion of their right to withdraw

their participation at any time. Additionally, participants will be provided an information sheet that describes the focus groups that they will be able to keep for themselves.

Confidentiality

- It is essential that the identities of respondents be protected. In particular, children with experience of violence are likely to be especially concerned about issues of confidentiality.
- Researchers need to take care never to write respondents' names on the same sheet as the data they give you, and to keep data in a secure place.
- It is also of course important to observe confidentiality in casual conversation with others around the research setting.[2]

For participants in the **online survey**, confidentiality is explained and ensured on the first page of the survey. No names or other identifying information will be collected other than basic demographic information (ex. age, sex, location, ethnicity).

For participants in the **focus groups**, confidentiality is explained and ensured before the session is started. The facilitator can ask the names of the participants while in the session for easier communication, but the names will not be recorded on paper. Names of participants recorded in the audio taping will be anonymised in the data transcription and translation, and subsequently properly stored and destroyed after the period of 7 years.

In selecting locations for the **focus groups:**

- Focus group facilitators to ask for a place where the focus group will be held (school, local NGO) where they and the respondents will not be in hearing distance of any other person.
- Focus group facilitators to explain to any persons present at the location that in order to do the focus group they must have privacy.
- If privacy not guaranteed, before questions relating to risks and behaviours, focus group facilitators to explain nature of questions and again ask for permission.
- If some adolescents need an accompanying adult, particularly, younger adolescents or those with disabilities, it will be important that those accompanying adults are not present in the focus group discussion and that they do not remain near the room where they could overhear the discussion.
- If third parties are interfering with focus group, focus group to be stopped if doing so will not create tensions, sensitive items to be skipped and absence of privacy noted on survey.

Limits to confidentiality

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[2] Adapted from Save the Children UK, (2004) "So You Want to Involve Children in Research? A toolkit supporting children's meaningful and ethical participation in research relating to violence against children", http://www.savethechildren.org.uk/sites/default/files/docs/So_you_want_to_involve_children_in_research_SC_2004_1.pdf

The limit to confidentiality is in a case when a child reveals information that requires immediate action by the Local Facilitator, such as when in an unlikely situation where researchers suspect child abuse or other unsafe or criminal activity, or have acquired information indicating this from child participants (intentionally or inadvertently shared on the child's part). This might include discovering that a child is being abused or neglected; is being harmed or threatening to harm her/himself or another person; or has a communicable or sexually transmitted infection which may place them and/or others at harm. The Local Facilitator will have to balance the needs, safety and protection of the child and to decide, together with the YPL Project Team and UNICEF, whether to share the information and with whom, for example, parents, the police or care and protection agencies.[3]

Further information on protocols when dealing with revelations of harm under "Safety" section.

Anonymity

With qualitative data, it will be necessary to consider whether a person's story might identify them. Stories can sometimes be altered so as to disguise identifying details, in keeping with the integrity of the findings, but at times they may have to be omitted. Qualitative data should not be clearly attributable. This can be done by:

- Removing direct identifiers (e.g. personal information such as name, addresses);
- Aggregating or reducing the precision of variables that might be identifiable;
- Generalising text variables to reduce identifiability;
- Restricting continuous variables to reduce outliers;
- Draft reports are reviewed by third party (who was not involved in drafting) to ensure that reports do not provide any sort of identifying information.

Research with adolescents from marginalised or vulnerable backgrounds

Some focus groups (1-3 in total) will be comprised of adolescents only from specific marginalised or vulnerable backgrounds (ex. institutionalised children, those in conflict with the law, LGBT youth, low socio-economic status, special ethnic groups, youth with disabilities[4]). Their selection is to ensure the representation of their voices and experiences in the study, and to compare with other groups of mixed backgrounds. The specific marginalised or vulnerable groups will be selected by UNICEF Country Offices according to the local specificities of the country.

When working with youth from marginalised or vulnerable backgrounds, additional care needs to be taken, including:

- Greater concerns for confidentiality;
- Reluctance to share experiences in a group;
- Sensitivity or potentially negative reaction to some subjects discussed;
- Adaptable spaces and methods for differing abilities (ex. wheelchair access, hearing & seeing impairment).

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[3] Adjusted from Graham, A., Powell, M., Taylor, N., Anderson, D. & Fitzgerald, R. (2013). Ethical Research Involving Children. Florence: UNICEF Office of Research - Innocenti.

[4] www.unicef.org/disabilities/files/Take_Us_Seriously.pdf provides practical guidance on how to create disability friendly spaces.

Safety

The underlying principle to ensure safety of the participants is to “Do no harm”: avoid harm or injury to participants, families and their communities. While the primary purpose of research is to generate new evidence, this goal should never take precedence over the rights of individual participants or place them in harm’s way. The child’s well-being is primary. Participation should promote the best interests of each child within the particular cultural and environmental context. Where possible and reasonable, direct benefits should accrue to participants; if not, clear evidence should be provided as to benefits to the broader child population. All participants, their families and communities have the right to be protected from direct or indirect manipulation, coercion, violence, abuse or exploitation as a result of, or consequent to the research. In addition, everyone conducting the research should be aware of their role as a researcher along with potential power dynamics that could distort freely expressed voluntary participation, general feelings of safety, openness and sincere nature of discussions. The researchers should be self-aware of these issues and mitigate for them so there are minimum disparities in power and status between the researchers and the child research participants.

Guidance from the United Nations Convention on the Rights of the Child

No child should be discriminated against on the basis of their sex, race, religion, abilities, or any other social or political characteristics, in terms of their participation in research (Article 2).

Researchers, research organizations and governments have a responsibility to do what is best for children and make sure that all children are protected (Article 3).

Children have the right to protection from research that is exploitative, harms them or is bad for their health, education or development (Articles 6, 19, 32 and 36).

Researchers have a responsibility to ensure children have access to advice and support if they are adversely impacted by issues raised in the course of the research process (Article 39).

Research should honour children’s right to express their opinions, by talking, drawing, writing or in any other ways. Researchers have a responsibility to listen and take children’s views seriously (Articles 12 and 13).

Being involved in research has a formative value and therefore should help children use and develop their talents and abilities. (Articles 5, 6, 12 and 13).

All children have the right to be protected from being hurt and mistreated, in body or mind, throughout the research process (Article 19)

Children are not allowed to be punished in research (Article 37)

Protection protocols[5]

Regarding potential for concerns or complaints raised by participants or communities:

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[5] *Adapted from Gabrielle Berman, UNICEF Office of Research - Innocenti, (2016), “Method Guide 2: Ethical Consideration for research with children”, http://blogs.lse.ac.uk/gko/wp-content/uploads/2016/05/Guide-2-Ethical-considerations-Berman.pdf*

- A focal point for inquiries and complaints should be local focus group facilitator and designated UNICEF CO representative, and UNICEF ECARO representative.
- Participants and communities will be given contact details of a focal point for concerns or complaints as well as "Age Matters!" project team researchers.

Regarding potential for focus group facilitators or field researchers to cause distress to participants:

- Focus groups facilitators will provide referrals for support (ex. support organisations or helplines) in the local context should young people in focus group become distressed.
- Political and cultural sensitivities of participants and broader community determined through consultation with key local stakeholders in the UNICEF CO to ascertain recruitment needs for focus group facilitators.
- Focus group facilitators and field researchers are not to be allocated to clusters in which they are strongly tied or familiar with the residents.
- Focus group facilitators and field researchers with clearly identifiable religious or political affiliations are not to be allocated to clusters where there is a clear majority of residents holding opposing religious or political affiliations.
- Focus group facilitators and field researchers are trained not to provide any information regarding their religious or political affiliations
- Youth Policy Labs, UNICEF CO, and UNICEF ECARO will facilitate, follow up and manage complaints and provide relevant supports. Contact details are provided beforehand so adequate addressee is known to the participants.

Regarding potential for dissemination of findings stigmatising communities or groups:

- Consultation with advisory/community group/s regarding potential sensitive issues. Analysis of data at various levels of aggregation considered reflecting on potential stigmatisation of groups.
- Draft reports are reviewed by third parties (individuals/advisory/community groups) with sufficient technical knowledge and appreciation of ethical issues to ensure that reports do not stigmatise particular communities or groups.

All allegations of abuse must be reported. The "Age Matters!" project team will discuss and decide with each researcher individually the processes for reporting abuse relative to each country's context.

What to do if an allegation of abuse is brought to the researcher's attention:

1. Record all allegations of abuse. Be careful to record all details accurately and in the child's own words. Do not put words into the child's mouth. Allegations may be based on what the child tells you or your own observations (e.g. bruising, physical marks, child's state of mind).
2. Inform the "Age Matters!" project team of the allegation or incident immediately.

What to do if a child threatens suicide or self-injury:

1. Inform the child that you are seriously worried about their safety

2. Tell the child that you may need to tell someone (ex. relevant institution, parent, teacher) as you have a duty to look after his or her safety.
3. Try to encourage the child to talk to someone they feel comfortable with.
4. Ask if there is someone that they would like you to contact. This could be an officer, teacher, advocate etc. If the child agrees, you could contact this person directly.
5. If the child does not want you to talk to anyone else, discuss the issue with the "Age Matters!" project team. The decision may be made to contact a relevant institution if you have serious concerns, despite the child's reluctance.

Data protection

The data to be protected from unauthorised access and use include, but it is not limited to:

- Copies of the filled survey
- Focus group recordings
- Focus group transcripts
- Focus groups notes
- Names of the focus group participants
- Information consent forms
- Assent forms
- Data used in SPSS and MAXQDA or any other software for analysis
- Any other data that contains personal information about the participants of the research and their opinions, perceptions and experiences
- The data could be stored in physical form (paper, notes, pictures), electronic (on computer, email, USB, cloud, etc) or any other format

The above listed data should always be under good control:

- Do not leave transcripts, pictures, videotapes, or whatever you are working with lying about in public
- Do not make unnecessary copies, and keep a good track of the location of all copies (in both electronic and other formats)
- Do not hand your material to anyone without going over the handling procedures
- If the data is collected electronically, it needs to be encrypted prior to sending data electronically and access to the encryption key should be limited to the key researchers only.
- Encrypt or password-protect files (including computer files) that contain personal or identifiable data (such as names) and only allow access by agreed members of the team.
- If this data is to be transported physically (e.g. on USB or other hard drives), ensure these are password-protected, including when data is taken to other locations (including homes) for cleaning or analysis
- Attach passwords to any hardware that may be used to transport data (hard drives, USB sticks).
- Get prior consent from participants if you plan to archive data for use by other researchers.
- If data is to be uploaded to a cloud, the security of these virtual storage facilities must be appropriate to the risk context (encryption software)
- Securely lock away hard copies such as interview notes, audio-tapes so that they can only be accessed by agreed members of the research team.
- Keep all data locked in a safe place until the research is completed

- Archive all data after the research is completed
- The recordings, transcriptions and translations done by external or outsourced team members will be destroyed once it has been stored and archived by the central research team of Youth Policy Labs. This will be a contractual provision signed by all project associates.
- The raw data collected for this research study is intended for analysis in the context of this research and shall not be used for any other project or research, except in the form of the final project report and produced research paper.
- Destroy all data after the period of 7 years.

UNICEF “Age Matters!”

Declaration of Adhering to the Ethical Principles in Conducting Research with Children and Adolescents

I, a Local Facilitator for the UNICEF “Age Matters!” project, declare that:

- I have never been investigated or prosecuted for inappropriate conduct with, or abuse of, a child or adolescent.
- I will try, to the best of my abilities, to protect and safeguard children and adolescents.
- I will adhere to and comply with the principles laid out in the “Principles, Guidelines & Protocols for ensuring subjects’ safety, protection of human subjects’ identities, and protection of data”, created by the Youth Policy Labs for the purposes of conducting “Age Matters!” project.
- I have read and understood these principles.

NAME

DATE