

WOMEN'S REFUGEE COMMISSION Ethical Guidelines for Working with Displaced Populations through Programs, Research, and Media

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The Women's Refugee Commission (WRC) improves the lives and protects the rights of women, children, and youth displaced by conflict and crisis. We research their needs, identify solutions, and advocate for programs and policies to strengthen their resilience and drive change in humanitarian practice.

The Women's Refugee Commission is a 501(c)(3) organization.

womensrefugeecommission.org

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OVERVIEW: EIGHT THINGS YOU NEED TO KNOW

- 1. **First, do no harm**. Ensure that the person will not be endangered physically, psychologically, culturally, economically, or in any other way by participating.
- 2. State the purpose of the project. Interviewers should be clear about the purpose of the project and should not give false hope. Communicate that the Women's Refugee Commission (WRC) is neither a grant-making organization nor an aid organization, but rather an organization focused on creating long-term global change to improve the lives and protect the rights of refugee women, children, and youth through research and advocacy. Use WRC's Community Pre- and Post-Travel Fact Sheets, when appropriate.
- 3. Inform the person of their rights, such as the right not to participate, the right to confidentiality, and the right to receive feedback. Inform subjects of the purpose of the project/audio/video/film/photograph and the scope of its use. Ensure that they have seen an example of the context, such as a report or web page, in which their interview/photograph, etc., will be used.
- 4. **Get verbal and/or written consent** from the person by having them sign, mark with an X, or agree on camera an <u>authorization and release form</u> with the above full understanding, before interviewing, taking photos, filming, or taping. Verbal or written consent is also required from your focus group after a thorough verbal explanation of the written consent form.
- 5. Include partners and communities throughout the project life cycle, including formulating the research question, design, data collection, analysis, and dissemination. Proactive and sustained engagement with the communities from which participants will be invited shows respect for their value add and the traditions and norms they share. Ensure all research has resources for sharing findings in an accessible manner with participants and stakeholders.
- 6. **The research must have social and scientific value**. WRC staff should avoid collecting primary data to answer questions for which information is already available. Research should have clearly defined uses and users built into the project cycle.
- 7. Follow WRC's policy on gifts and compensation. Reimbursing expenses for travel or offering refreshments during the focus group meeting is allowable, as is offering a small token of gratitude such as a beverage, tea, or pencils for their voluntary participation. WRC does not further compensate for voluntary participation. Be sure to engage your partners when making this determination. See Annex B for more details.
- 8. **Disguise the subject's identity in your notes** by using pseudonyms and keep information about who is present separate from discussion notes. Notes, if falling into the wrong hands, can have dire consequences. Confidentiality is paramount.

INTRODUCTION

There are no better advocates for forced displacement issues than refugees, internally displaced persons, and people seeking asylum themselves. At the same time, it is our duty to do everything we can to ensure their privacy and protection.

Purpose of the Women's Refugee Commission's Ethical Guidelines

The Women's Refugee Commission's (WRC's) *Ethical Guidelines for Working with Displaced Individuals through Programs, Research, and Media* explains ethical considerations that must be followed by WRC staff and their collaborators who undertake information-gathering activities in refugee, internally displaced, and other crisis-affected settings. This may include programs, research, and multi-media activities that we use in our advocacy to improve the lives of refugee and internally displaced women, children, and youth, and people seeking asylum. These *Guidelines* should be shared and reviewed by all staff upon hire and WRC collaborators. They should be used as a resource to guide the implementation of programs, research, and multi-media projects to ensure the safety and dignity of participants.

Organization of the Guidelines

These Guidelines are organized into three sections: 1) ethical guidelines for working with displaced individuals; 2) ethics for human subjects research; and 3) the use of multi-media in work with crisis-affected communities. The information presented in section one provides guidance for WRC staff and collaborators that will ensure ethical conduct before, during, and after research or programmatic activities that are carried out with crisis-affected populations. Section two provides more in-depth guidance for research-specific activities and compliance. Section three provides general guidance to ensure ethical conduct in multi-media.

Definitions

WRC staff conduct research, programs, and advocacy activities to improve the lives and protect the rights of crisis-affected women, children, and youth.

Displaced individuals - This document applies to programmatic, research, and multi-media activities with all people who have been displaced from their homes or affected by crisis—regardless of the reason—and therefore is not just focused on those who have refugee status. This document refers to *displaced individuals* as internally displaced persons, refugees (not only those who have refugee status), and those seeking asylum.

Interviewer - When the word *interviewer* is used, this can also mean photographer, cameraperson, researcher—essentially, you or a person representing WRC.

Interviewee - The words *person, subject,* and *participant* are used interchangeably to indicate the interviewee or person you are interviewing, photographing, or filming.

Research is a systematic investigation (including research development, testing, and evaluation) designed to develop or contribute to generalizable knowledge. Systematic investigation follows a

predetermined plan for looking at a particular issue, testing a hypothesis or research question, or developing a new theory that may include:

- Collection of data using surveys, testing or evaluation procedures, interviews, or focus groups
- Collection of data using experimental designs such as clinical trials
- Observation of individual or group behavior

In this guidance document, **research** can be defined as any activity that involves systematic data collection for, with, or by people in situations of displacement to develop or contribute to generalizable knowledge.

Generalizable knowledge is information expressed in theories, principles, and statements of relationships that can be widely applied.¹ *Contribute to generalizable knowledge* means that the purpose or intent of the project is to test or to develop scientific theories or hypotheses, or to draw conclusions that are intended to be applicable and/or shared beyond the populations or situations being studied. This may include one or more of the following:

- Presentation of the data at meetings, conferences, seminars, or poster presentations
- The knowledge contributes to an already established body of knowledge
- Other investigators, scholars, and practitioners may benefit from this knowledge
- Publications including journals, papers, dissertations, and master's theses

Human subjects research involves a living person about whom the investigator (i) obtains information or biospecimens through interaction/intervention with the individual, and uses, studies, or analyzes the information or biospecimens; or (ii) obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens.² Research involving existing data and other materials that are individually identifiable are considered as research involving human subjects and is subject to ethical review. Human subjects research requires more rigorous ethical considerations and practices compared to programmatic work and research not involving human subjects. Human subjects research requires approval from an Institutional Review Board prior to implementation of activities. For additional information regarding human subjects research and ethical review see section on Research Ethics and Annex D.

Programming consists of direct service provision to affected populations or fact-finding missions that aim to apply findings only to a program or activity, rather than provide generalizable knowledge through hypothesis testing. WRC generally classifies the following activities as programs:

- Case studies
- Rapid and/or needs assessments to inform program design/development
- Journalism/documentary activities
- Oral history
- Quality assurance and quality improvement activities
- Review of monitoring data to improve program functionality

¹ 45 CFR 46.102 <u>E-CFR.gov.</u>

² <u>45 CFR 46.102.</u>

WRC collaborators - *WRC collaborators* include a diverse range of partners, including consultants, subcontractors, translators, facilitators, local NGO or INGO implementors, research assistants, enumerators, research managers, and others. *WRC collaborators* are defined as individuals who work jointly with WRC on a research or programmatic project. All WRC research collaborators are required to review and abide by these guidelines and sign a release form confirming they understand the guidelines and agree to follow them (see Annex A). For projects involving human subjects research, additional documentation is required (see section on *Research Ethics*).

Guiding principles

WRC's work with human relationships, logistics, partners, and advocacy is complex. It is inevitable that misunderstandings, ambiguities, and the need to make choices among apparently incompatible values will arise. WRC staff and their collaborators are responsible for grappling with such difficulties and for resolving them in ways compatible with the principles described below.³ The following principles are gleaned from the codes of the ethics of the Declaration of Helsinki,⁴ the Nuremberg Code,⁵ the International Ethical Guidelines for Health-related Research Involving Humans,⁶ the International Federation of the Red Cross and Red Crescent Societies⁷, and the Universal Declaration of Human Rights.⁸

Beneficence and Nonmaleficence

"First do no harm." The overall dignity, rights, safety, and security, both psychological and physical, of the person being interviewed, photographed, or filmed must take priority over all else, including our advocacy and promotion of issues affecting those in crisis. When dilemmas emerge, WRC staff and their collaborators will attempt to resolve these dilemmas in the manner that produces the least harm possible to all involved. Particular attention should be paid to the ways in which our work – directly or indirectly – can (re)traumatize, as well as contribute to racism, xenophobia, and the criminalization of migration. WRC staff should think carefully about the messaging that will be disseminated through interactions with media and policymakers. WRC staff must also consider how their mere presence in a specific location might heighten risks for workers and those impacted by forced migration.^{9,10,11,12} It is

https://reliefweb.int/sites/reliefweb.int/files/resources/0513_002_Fundamental_Principles_low.pdf ⁸ https://www.un.org/en/udhrbook/pdf/udhr_booklet_en_web.pdf.

³ American Anthropological Association Code of Ethics.

⁴ World Medical Association, 1964. Declaration of Helsinki (As amended 2004). Ferney-Voltaire: WMA.

⁵ Nuremberg Code, 1949. The Trials of War Criminals Before the Nuremberg Military Tribunals Under Control Council Law No. 10, Nuremberg/Washington DC, US GPO.

⁶ International Ethical Guidelines for Health-related Research Involving Humans, Fourth Edition. Geneva. Council for International Organizations of Medical Sciences (CIOMS); 2016. <u>https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf</u>.

⁷ The Fundamental Principles of the International Red Cross and Red Crescent Movement: Ethics and Tools for Humanitarian Action, 2016.

⁹ IASFM 2018.

¹⁰ World Medical Association, 1964. Declaration of Helsinki (As amended 2004). Ferney-Voltaire: WMA.

¹¹ Nuremberg Code, 1949. The Trials of War Criminals Before the Nuremberg Military Tribunals Under Control Council Law No. 10, Nuremberg/Washington DC, US GPO.

¹² International Ethical Guidelines for Health-related Research Involving Humans, Fourth Edition. Geneva. Council for International Organizations of Medical Sciences (CIOMS); 2016. <u>https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf</u>.

essential that staff fully detail the potential risks of the research to ensure that the benefits outweigh the risks in each context – both in the short and long term.

Fidelity and Responsibility

Given that the welfare and rights of the person being interviewed, photographed, or filmed take precedence over all else, WRC staff and their collaborators must be aware of their responsibilities to the communities they serve.

Included in these responsibilities are:

- upholding professional standards of conduct
- understanding community standards of conduct
- clarifying professional roles and obligations
- accepting responsibility for appropriate behavior
- managing conflicts of interest that could lead to exploitation or harm

When working in cooperation with other professionals and institutions, WRC is also concerned about the ethical compliance of our partners' professional conduct. Building trusting relationships within communities requires WRC staff and collaborators to be trustworthy and act responsibly.

Integrity/Competence

WRC staff and their collaborators will seek to promote accuracy, honesty, and truthfulness in all work, including interviewing, photographing, filming, data analysis, and report writing. By applying methodological approaches that are adapted to the cultural contexts in which we work, WRC staff will strive to ensure appropriate capacity is strengthened in all collaborators to avoid unwise or unclear commitments. There should never be fraud, subterfuge, or intentional misrepresentation of fact. Deception is never justifiable.

Justice

WRC staff and their collaborators recognize that fairness and justice entitle all persons to access and benefit from their contributions to work undertaken. Staff and collaborators must exercise reasonable judgment and take precautions to ensure that their potential biases, the boundaries of their competence, and the limitations of their expertise do not lead to or condone unjust practices. WRC staff and collaborators should avoid overburdening populations when the benefits of such work are not known or inequitably distributed.

Respect for People's Rights and Dignity

WRC staff and their collaborators respect the dignity and worth of all people, and the rights of individuals to privacy, confidentiality, and self-determination. We are aware that special safeguards may be necessary to protect the rights and welfare of persons with diminished autonomy. It is essential to ensure that genuine voluntary, informed consent is obtained from all participants using clear language that is understood by the individual. Voluntary consent and appropriate safeguards should take into consideration and respect cultural, individual, and role differences, including those based on age, gender, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, language, power structures, and socioeconomic status. We consider these factors when working with

members of such groups. We will not knowingly participate in or condone activities of others based on prejudices.

No code or set of guidelines can anticipate unique circumstances or direct actions in specific situations. The individual staff person or collaborator must, at times, be willing to make carefully considered ethical choices and be prepared to make clear the assumptions, facts, and issues on which those choices are based. These guidelines therefore address general contexts, priorities, and relationships that should be considered in ethical decision-making in our work.

ETHICAL GUIDELINES FOR WORKING WITH DISPLACED INDIVIDUALS

Rationale for conducting research or programmatic activities

The research or activity must have social and scientific value.¹³ WRC staff should avoid collecting primary data to answer questions for which information is already available to avoid "assessment fatigue" among affected populations. Before developing any activities, design a strategy for the inquiry by determining the "what," "why," and "how" of collecting information. Consider the purpose for gathering the information or pursuing the project in the first place. Consider if the activity is absolutely necessary. Is there another way to gather the information without conducting a survey or interviewing human subjects?

Before implementing primary data collection with affected individuals, staff must start with a review of secondary sources to ensure primary data is only collected when absolutely necessary. Collecting primary data to answer questions for which information is already available is unethical because data collection puts an undue burden on affected communities to participate in activities that are not necessary. WRC staff and collaborators can also lessen overall assessment fatigue by sharing data with other agencies, improving knowledge management, and/or undertaking joint needs assessments and intersectoral analysis.¹⁴

The information presented in the following sections provides more detailed guidance for WRC staff and collaborators in ensuring ethical conduct before, during, and after research or programmatic activities with crisis-affected populations. Ethical conduct in media is covered in Section 3 of the guidelines.

BEFORE THE SESSION

Preparation

Determine the "what," "why," and "how" of collecting information. Before developing any activities, it is important to design a strategy for the inquiry and detail this in a research or implementation plan.

Consider the purpose for gathering the information or pursuing the project in the first place. Every project needs an explicit purpose. Consider if the program or research is absolutely necessary. Is there another way to gather the information without conducting a survey or interviewing human subjects?

If the purpose is for research, develop a research plan that specifies the design and methodologies to be used in collaboration with communities and partners based on the appropriate research questions. If the purpose is for programmatic or advocacy activities, an implementation plan can be a helpful guide that supports reflection on ethics and determinations on how to identify the appropriate populations and any special considerations that need to be taken prior to the start of activities.

¹³ International Ethical Guidelines for Health-related Research Involving Humans, Fourth Edition. Geneva. Council for International Organizations of Medical Sciences (CIOMS); 2016. <u>https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf.</u>

¹⁴ Prisca Benelli and Tamara Low, "Ethical primary research by humanitarian actors," *Forced Migration Review* (June 2019), <u>https://www.fmreview.org/ethics/benelli-low</u>.

Engagement with communities should remain in the foreground of projects to ensure research and programming recognize their contributions and support transformative change. Consider developing a community engagement plan in advance of the commencement of any activities.

Carefully consider ethical issues that may be encountered in the project, keeping the design and methodology in mind. Informed consent procedures should be thought through and integrated into research plans. Consider the potential advantages and disadvantages of using photography, video, and audio equipment. If additional consent is required, be sure to make this documentation available in local dialects. If seeking institutional review board approval, ensure the submission is made with enough lead time to not delay implementation and cause undue burden on participants and partners.

Engagement with Communities and Stakeholders

WRC staff and collaborators should engage relevant partners, stakeholders, and community members throughout the project cycle. This may include informing or engagement on formulating the research question, design, data collection, analysis, and dissemination. Proactive and sustained engagement with the communities from which participants will be invited shows respect for them and the traditions and norms they share. Local community leaders, NGO/CBO partners, academics, rights monitors, and journalists may all be good sources to obtain up-to-date and accurate information about the project location, cultural values, and the current political situation. Obtain advice from knowledgeable locals or experts in the culture of the community regarding the suitability of methods and the most appropriate way to raise specific issues.¹⁵

Local community partners can support you on formulating culturally appropriate questions by exploring:

- the correct ways of beginning, carrying out, and ending a conversation between the person you are intending to interview and yourself (taking into account factors such as gender, age, class/caste, and other aspects of status) in the social and cultural group concerned;
- cultural ways of framing questions and answers;
- if the topic is one that can be discussed in conversation, if it can be discussed within that culture, or if it is of interest;
- the words and phrases normally used to discuss the topic, and what they mean; and
- the scope of the project/research and ensuring we are only asking questions within this and not those that are beyond our capacity or intention to address.

Community engagement helps ensure ethical and social value of proposed research,¹⁶ promotes collective implementation, and contributes to the community's capacity to understand the research process. Engaging the community strengthens local ownership and acceptance of the research and builds confidence in the ability of leaders to negotiate various aspects of the research, such as

¹⁵ Jason Hart and Bex Tyrer, "Research with Children Living in Situations of Armed Conflict: Concepts, Ethics and Methods," Refugee Studies Center, University of Oxford (May 2006): p. 18.

¹⁶ International Ethical Guidelines for Health-related Research Involving Humans, Fourth Edition. Geneva. Council for International Organizations of Medical Sciences (CIOMS); 2016. <u>https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf.</u>

recruitment strategies, care for the health needs of study participants, site selection, and data collection and sharing.¹⁷

Community Engagement Plan

Make a plan for community engagement, such as in the research protocol, and identify resources allocated for proposed activities.

- Documentation must specify what has been and will be done, when and by whom, to ensure that the community is clearly defined and can be proactively engaged throughout the research to ensure that it is relevant to the community and is accepted.
- The community should participate, when feasible, in the discussion and preparation of the research protocol and documents, and throughout the research life cycle.
- Engage the community at the earliest opportunity—before a study is initiated.
- Ensure resources are allocated to disseminate study findings to participants, local stakeholders, and communities through accessible media and language(s).

Identifying Appropriate Populations

WRC seeks to improve the lives and protect the rights of women, children, and youth displaced by conflict and crises.¹⁸ These groups, however, are not homogenous populations. Some subgroups of displaced women, children, and youth, such as those with disabilities, those who are sexual or gender minorities (e.g., LGBTQI+ individuals), those engaged in sex work, and unaccompanied or separated children,¹⁹ face different risks and have different perspectives or skills to contribute to solutions. In order to operationalize our core values of inclusion and equality,²⁰ as well as organizational commitments to understanding the vulnerabilities and capacities of different groups that we serve, WRC seeks to include a diversity of women, children, and youth in all our research and assessments conducted at community levels, and to safely gather more information on marginalized groups.

Special Considerations for Participant Engagement

Discrimination

When choosing participants to interview/photograph/film, do not discriminate based on sex, gender, gender identity, race, age, religion, status, educational background, or physical abilities.

¹⁷ International Ethical Guidelines for Health-related Research Involving Humans, Fourth Edition. Geneva. Council for International Organizations of Medical Sciences (CIOMS); 2016. <u>https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf.</u>

¹⁸ WRC Theory of Change, <u>https://www.womensrefugeecommission.org/research-resources/theory-of-change</u>.

¹⁹ Unaccompanied children are those children who are younger than 18 years old and who have been separated from their parents or legal guardian and are not being cared for by an adult who, by law or custom, has a responsibility to do so.

²⁰ Inclusion: We value and promote inclusion and diversity of identity, opinions, talents, and capacities, both within our organization and within the communities we serve. Inclusion is pivotal to the WRC's work and to our organizational culture. Equality: We believe in the universal and inalienable human rights of all individuals and strive to ensure that all persons should have equal access and opportunity to realize these rights without discrimination on any grounds.

Gender²¹

The gender dimensions of the intended research should be considered in advance; consider especially the ways in which the interview should be best conducted to ensure that women and girls are able to speak comfortably about their experiences.

- If the interviewer is male and intends to work with females, he should consider recruiting a female research assistant, especially when planning to work in a conservative culture where social interaction between the sexes may be highly constrained.
- Adolescent girls and boys may feel more comfortable talking about personal issues with someone of the same sex and similar age.
- In some societies, it may be difficult to gain access to girls and young women. Take particular care to ensure that girls are able to contribute their experiences, views, and aspirations in a manner that best suits their circumstances. A similar point can be made for people with disabilities and for those whose lives do not fit with local ideals (e.g., children who have dropped out of school, those living on the street, and those who are of especially low socio-economic standing).
- Conduct sex- and age-disaggregated focus groups with men, women, boys, and girls. It may also be appropriate to further separate groups of young people 10–24 years of age and by marital, LGBTQI+ and/or schooling status. Contact the WRC Research Team at research@wrcommission.org for more information on sampling techniques.

It is crucial to understand how consequences of conflict rarely affect males and females in the same manner. For example, in many settings girls are especially likely to be subject to sexual and gender-based violence. This should be considered when formulating questions and collecting resources for the subjects.

Disability

Set criteria that 20 percent of participants will be persons with disabilities. Include 1-2 persons with disabilities in each focus group discussion, appropriate to their age and gender (e.g., a group discussion with adolescent girls should include 1-2 girls with disabilities of the same age range). Partners and researchers can contact community committees, parents, children's and youth groups, and any disability groups or organizations that are working in the community, to ask for their assistance in sharing information with and identifying persons with disabilities who may be interested to participate. Persons with disabilities are not a homogenous group. Ensure representation of the many types of disabilities present within the target population—those with physical, cognitive, visual, hearing, and speaking disabilities, for example. This may require extra supports such as sign language interpretation, wheelchair access, and so on. These accommodations will support full meaningful and equitable participation regardless of differences.

²¹ Jason Hart and Bex Tyrer, "Research with Children Living in Situations of Armed Conflict: Concepts, Ethics and Methods," Refugee Studies Center, University of Oxford (May 2006): p. 23.

Working with Children

When trying to determine the best interests of a child, the child's right to have their views taken into account are to be given due weight in accordance with their age and maturity. Those closest to the child's situation and best able to assess it must be consulted about the political, social, and cultural ramifications of their participation and any reportage.

Keep in mind that:

- If the researcher is successful in developing a good relationship with children, the children may also feel encouraged to participate as an act of friendship even when they have doubts and concerns. To help ensure that this does not happen, researchers need to pay close attention to the participants' body language, silences, and other ways of communicating.
- The expression of interest in the lives, experiences, and well-being of refugees is often very welcome. This is especially likely in situations where children have been deprived of the warm concern and affection of adults—for example, those living in institutions such as orphanages or in child-headed households. As a result, some children can rapidly develop attachments to the researcher and, not having grasped that the interaction is likely to be short-lived, may feel let down or even abandoned once the research is complete. There is no simple means to avoid such a situation. Clarity about the extent and nature of the interviewer's role is vital. This clarity is necessary not only for adults and children but also for the interviewer herself or himself. Efforts to "rescue" children or to act as a surrogate parent are liable to create false hopes and increase the likelihood of sorrow upon parting.

Voluntary Informed Consent

The initial step in this process should include discussing the assessment or research with the community through key community leaders to seek their approval and support. It is also important to consult with local organizations on the best ways to approach the community.

Informed consent is a process, not a form. Informed consent is the term that describes the communication process that enables individuals to make an informed choice about participation in the project. Consent is ongoing, starting well before any forms are signed and continuing until the subject's participation is complete. The process includes the discussion that occurs between the interviewer and the participants as well as the written document that formalizes the agreement to participate and documents the process.

Genuine voluntary, informed consent can be challenging to obtain in displaced and crisis-affected contexts due to unequal power relations and dependence on service providers, who may also act as gatekeepers and/or researchers themselves. The psychosocial impacts of forced migration, as well as cultural and linguistic differences, may affect people's ability to understand the consent process in order to make an informed decision about their participation in the program or research project. WRC staff and collaborators need to think carefully about how consent applies when dealing with documents and data by professionals, volunteers, authorities, and others, which are based on information and stories

that are not their own.²² For consent to be informed, the participants must fully understand the project. Therefore, information must be conveyed in a manner that enhances understanding rather than just provides disclosure.²³

WRC is committed to making all efforts to ensure that WRC and collaborators comply with the <u>Child and</u> <u>Vulnerable Adult Safeguarding Policy</u> and <u>Code of Conduct</u>. For more information on informed consent, including informed consent process when interviewing children, see section on Research Ethics on pg. 25.

Finding a Translator or Interpreter

Finding a qualified translator or interpreter for activities is central to successful implementation of your research or implementation plan.

Helpful tips when engaging your translator or interpreter

- Work with a translator or local person to develop or review the questions in advance of the
 mission. You should have individual or focus group discussion questions reviewed by qualified
 translators and/or local partners in advance of the mission to make any adjustments. It is
 essential to pre-test translated research tools and translate them back to English to determine
 appropriateness and enhance validity²⁴ and reliability.²⁵
- Review protocols and ethical guidelines with the translator so they are familiar with how to maintain research/media integrity.
- With interviews and focus group discussions, there is a choice between translator facilitation and translated facilitation. The former would require more time for training the translator to ensure that they are appropriately trained to facilitate, including on WRC's ethical guidelines; however, if your team or other staff anticipate additional research activities in the geographic area, then it would be beneficial to train one or more translators. In many contexts, the investment in training a local research partner to facilitate interviews and/or focus group discussions is more culturally appropriate than translated facilitation. Participants may feel more comfortable speaking with a local research partner who shares their ethnicity, religion, and/or background. Social desirability bias may be less likely compared to translated facilitation because participants may be more likely to answer questions that they believe will be viewed more favorably by WRC staff who may be perceived to have more power, resources, and connections. Translated facilitation is more feasible in assessments with limited time, although each session would require time for translations, with interruptions to discussion. It is important to note that the quality of data may be affected with either translation method.²⁶

²² International Association for the Study of Forced Migration (IASFM), *Code of ethics: Critical reflections on research ethics in situations of forced migration,* (2018), iasfm.org/wp-content/uploads/2018/11/IASFM-Research-Code-of-Ethics-2018.pdf.

 ²³ University of Missouri-Kansas City Social Sciences Institutional Review Board, "The Consent Process," September 15, 2004: p.
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²⁴ Validity measures whether the item actually measures the intended concept.

²⁵ Reliability measures the extent to which a test yields the same results when repeated.

²⁶ For more information on translated focus group discussions, see Gisele Maynard-Tucker "Conducting Focus Groups in Developing Countries: Skill Training for Local Bilingual Facilitator" Qualitative Health Research, Vol. 10 No. 3, May 2000, 396-410.

- The translator should be objective. Nationality, ideology, ethnicity, and gender should be considered.
- Translators should undergo background checks and may be required to sign a contract with WRC prior to starting work. WRC's ethical guidelines and our <u>Code of Conduct</u> should be reviewed and signed prior to their start date.

Referrals

Staff should understand their obligation to protect and support women, children, and youth who are abused or who are at risk of being abused. This includes being trained to talk to and behave sensitively and appropriately with these women, children, and youth, being aware of any legal obligations to act, and of what support services, if any, may be available. Always make a concerted effort to know what services are available for referrals and develop a response protocol when/if a subject reveals that he or she is in danger or in need of services. This is especially important if the topic is sensitive, for example, gender-based violence. **Research should only be conducted in locations where referral systems are available or where they can be established to prevent women and girls from being harmed simply for their participation in a study.**

Where participants reveal they are at risk of harm, the interviewers must take into account the person's views and wishes in deciding how to act. Where the project is with people who are by definition abused, such as sexually exploited children, it may be necessary to draw up special procedures, ensuring that those involved are clear about the limits of confidentiality.²⁷ Make sure there is a clear response strategy planned before implementation – and that it is updated, as needed, during the conduct of the research. In some contexts, there may be mandatory reporting laws, in which disclosures of risk or harm must by law be reported to authorities, such as government authorities or camp authorities. Any mandatory reporting laws must be identified during planning and shared with participants during the consent process.

Payments, Gifts, and Compensation

The form of compensation for interview participants should be discussed with the host organization in advance of the meeting or interview. Reimbursing expenses for travel or offering refreshments during the focus group meeting is allowable, as is offering a small token of gratitude such as a beverage, tea, or pencils for their voluntary participation. WRC does not further compensate for voluntary participation. Keep in mind that in situations where there is expectation or a clear responsibility to reward certain individuals, this should be done in a manner that avoids fueling tension within the community. Attempts to offer rewards secretly may backfire, fueling resentment. It may be safe to make transparent the criteria for participation and the reasons for payment or reimbursement of particular individuals.

Other Potential Costs to Participants

Even if there is no expectation of material reward, attention must be paid to the possible loss of income and other costs involved for participants.

- Transportation and other incidental costs can be reimbursed, and refreshments, snacks, or meals should be provided to participants.
- Rewards do not have to be clearly economic. In some settings, the provision of symbolic rewards—such as a certificate to acknowledge participation—may be appreciated and may

²⁷ "Research and Children and Young People," <u>http://www.chronicpoverty.org/CPToolbox/Children.htm</u>.

avoid tension, especially when the criteria for participant selection have been made clear in advance. $^{\rm 28}$

 It is imperative to avoid raising expectations of any lifestyle changes as an outcome of participating in the project.²⁹

Ethical Procurement in Project Settings

WRC staff must engage in ethical procurement practices to reduce any adverse social, ethical, or environmental impacts that may be caused from contracting related to our research activities. All donor procurement policies take precedent to the general guidance provided herein. As far as possible, procurement of goods and services should be obtained in the setting where the study is taking place through a competitive bidding process. Competitive bidding is a process whereby suppliers are asked to make bids in terms of pricing before the buyer chooses the best offer. In some humanitarian settings, formal bidding cannot be used; therefore, informal competition may be achieved through price quotations from several national suppliers provided that that price, quality, time of delivery, and other key features of the contract are competitive by national standards.³⁰ WRC staff must follow the following ethical principles as they relate to the procurement in research settings:

- Respect for rules and regulations
- Integrity
- Impartiality and fairness
- Transparency
- Confidentiality
- Avoidance of appearance of impropriety
- Due diligence³¹

DURING THE SESSION

All participants have the right to protection from any harm or retribution, including the potential for harm or retribution. WRC staff and collaborators should take care to "Do No Harm" and protect the physical and psychological safety of participants and themselves.

Physical Safety

Pay attention to where and how the person is interviewed and where group discussions are administered. Transparency about your methods and aims is essential. This must be balanced with confidentiality and protections put in place to preserve physical and auditory privacy. Participants should be fully consulted on how best to participate in a way that will minimize risks to themselves.

²⁸ Jason Hart and Bex Tyrer, "Research with Children Living in Situations of Armed Conflict: Concepts, Ethics and Methods," Refugee Studies Center, University of Oxford (May 2006): p. 22, <u>https://www.rsc.ox.ac.uk/publications/research-with-children-</u>

 $[\]underline{living-in-situations-of-armed-conflict-concepts-ethics-and-methods}.$

²⁹ Casper Edmonds, "Ethical Considerations When Conducting Research on Children in the Worst Forms of Child Labour in Nepal," International Labour Organization (Geneva, October 2003): p. 10,

https://www.ilo.org/ipec/Informationresources/WCMS IPEC PUB 1341/lang--en/index.htm.

 ³⁰ M.J. Maria, , W. Githii, and O.O. Thomas, "Ethics and Procurement Performance of Humanitarian Organizations in Kenya," *American Journal of Industrial and Business Management* (2018)8, 833-849. <u>https://doi.org/10.4236/ajibm.2018.84058</u>.
 ³¹ United Nations. UN Procurement Practitioner's Handbook. 2012. <u>https://www.ungm.org/Areas/Public/pph/ch04s04.html.</u>

- Ensure that participants are in a safe place and are comfortable so that they are able to tell their story or be photographed/filmed without outside interference.
- Ask participants whether they would like anyone else to be present during an interview, such as a friend, family member, or teacher; however, be aware of power dynamics and speak directly to the subject if possible, rather than to their companion.
- Limit the number of interviewers and photographers in the room. If the research partner is facilitating an interview or focus group discussion in a local language, the WRC staff member should leave the room once the discussion is underway, so participants do not feel uncomfortable.
- In film, video, and radio interviews, consider what the choice of visual or audio background might imply about the person and their life and story.
- Ensure that the person would not be endangered or adversely affected by showing their home, community, or general whereabouts. In many places, the prospect of people speaking up and voicing their issues may represent a threat. This could result in backlash against them. Work carefully to assuage local concerns and fears as these arise.

Psychological Safety

Staff and Interviewer Responsibility

Interviewers can inflict traumatization³² by the questions they ask or the answer they seek to elicit. It is paramount to abide by the following:

- WRC staff and collaborators should avoid questions, attitudes, or comments that:
 - o are insensitive to cultural values
 - o place a person in danger or expose a person to humiliation
 - reactivate a person's pain and grief from traumatic events.
- WRC staff and collaborators must avoid giving false hopes and should be clear about the purpose of the activity. Interviewers have a responsibility to interact with their subjects in a sensitive and supportive manner. It is important to allow them the chance to:
 - pause or to change the subject
 - express grief in the manner that best suits them
 - skip questions
 - withdraw from the activity altogether.

Affirm the positives that are said and offer sympathy and encouragement.

Not just anyone should partake in one-to-one interviews or interviews with participants of this nature. If you are not trained and/or experienced, avoid sensitive questions around gender-based violence or other culturally sensitive issues. If participants volunteer this information in the course of a more general conversation, seek assistance of more experienced staff members or collaborators to follow up.

Understanding Secondary Traumatization

Secondary trauma is defined as indirect exposure to trauma through a firsthand account or narrative of a traumatic event. Secondary traumatization is also referred to as "compassion fatigue" and "vicarious

³² Yandisa Sikweyiya et al, "Examining the Risks of Engaging in Population-based Surveys on Violence: Follow-up Study of the Individual Deprivation Measure in South Africa," *Journal of Empirical Research on Human Research Ethics* <u>https://journals.sagepub.com/eprint/JAWPXV4V2UNTWTN2RYTE/full</u>.

traumatization."³³ The vivid recounting of trauma by the survivor and the interviewer's subsequent cognitive or emotional representation of that event may result in a set of symptoms and reactions that parallel post-traumatic stress disorder (e.g., re-experiencing, avoidance, and hyperarousal). Where there is likelihood of such a situation arising, it is vital that the interviewer establish in advance a system for support and backup. Appropriately trained staff in a local NGO or community-based organization may be able to fulfill this role. However, in making such arrangements, the researcher must bear in mind the concern for confidentiality and the right of the participant to consent. When experiences of ongoing abuse are revealed, there is still a need to carefully assess the situation before attempting to involve outsiders.

Power Relations between the Interviewer and the Subject

The particular relations of power between the interviewer (as an adult and probably an outsider) and local subjects may lead some to feel that they have no choice but to participate.³⁴ As a result, the following measures should be taken to mitigate the power imbalance.

Minimizing the Power Imbalance

Power Relations between Interviewer and Participants

Considering your own feelings about the potential sharing of power with participants: To what extent will your questions be open to negotiation? How can you ensure that you do not impose a fixed agenda, timetable, and way of working? Effective planning ahead is critical so that the activities can be flexible to the participants. Effective project management strategies should be used, and may include:

- Have a workplan of activities and itinerary that is agreed upon, in advance, between WRC, host organization, and community members.
- Before starting any activities, hold a meeting with collaborators and community members to review and revise the questions/activities with WRC, prior to carrying out the activity.
- Budget for enough travel time so that there is sufficient time for negotiation and iterative processes.

Some strategies for minimizing power imbalance during the session may include:

- Sitting at the same level as subjects can help achieve a less hierarchical relationship. Never sit them behind desks or sit behind a desk or table yourself during an interview.
- Consider the consequences of people's participation in relation to their position within the family and community.
- Don't use a patronizing voice for participants or act and speak in an authoritarian manner.
- Be sensitive to the person's level of literacy and use of language, but don't talk down to them.

Power Relations among Participants

Consider the matter of access. Which people are involved in interviews/photo shoots/filming and on what basis? Who is excluded from such activities and is exclusion systematic (e.g., on basis of geography, gender, or class)? Such questions are vital from an ethical point of view.

³³ Rose Zimering, James Munroe, and Suzy Bird Gulliver, "Secondary Traumatization in Mental Health Care Providers," *Psychiatric Times*, April 2003, <u>http://psychiatrictimes.com/p030443.html</u>.

³⁴ Jason Hart and Bex Tyrer, "Research with Children Living in Situations of Armed Conflict: Concepts, Ethics and Methods," Refugee Studies Center, University of Oxford (May 2006): pp. 20, 22.

Especially with children, it is critical to understand how power relations³⁵ are shaped by attributes including but not limited to:

- Age
- Gender
- Birth order
- Education
- Caste/class
- Ethnicity
- Ability (skills)
- Disability
- Individual personality
- Physical stature
- Nationality
- Displacement
- Marital status
- Parental status
- Employment/Occupation
- Schooling status
- Socio-economic status
- Sexual orientation or gender identity

Be cautious that your work does not contribute to the creation or strengthening of hierarchies among people. Having the participants engage in icebreakers before the interviews, for example, may help reduce power imbalances within the group.

- Allow for participants in focus group discussions to ask questions to each other as well.
- Maximize youth participation as much as possible, particularly by setting up and carrying out interviews with young people.
- Involve adult community leaders in organizing interviews, unless this will discourage youth participation.

Note Taking and Audio Recording

- Be sure to fill out forms properly or label tapes and A/V files during or immediately after sessions to prevent confusion later. For video or audio recordings, it can be helpful (especially for multilingual activities) to orally state the description of the activity, at the beginning of the recording, to make it easier to label the file later.
- Divide questioning and note-taking responsibilities. Try to have two researchers conduct focus group discussions so these responsibilities can be shared. One can ask questions, one can take notes.
- Try to take notes word for word when possible. Your notes are evidence, so try to keep them as authentic as possible.
- Note your observations on who talks, who listens, body language of participants, nonverbal responses, and group dynamics.

³⁵ Jason Hart and Bex Tyrer, "Research with Children Living in Situations of Armed Conflict: Concepts, Ethics and Methods," Refugee Studies Center, University of Oxford (May 2006): p. 21.

- No staging. Do not ask participants to tell a story or take an action that is not part of their own history.³⁶
- Note the context and your interpretation of meaning.
- Have materials working and ready. Make sure you have enough pens, paper, charged batteries, etc.
- Disguise the participants' identity. Keep information about who is present separate from discussion notes. Do not note the names of those interviewed. Alternatively, number the people in the group by where they sit and take notes noting their numbers. That way, patterns can be identified when analyzing data, but no names will appear.
- Summarize and analyze findings as much as possible as you go along.
- Be sure to not make note-taking the central attraction of the conversation.

AFTER THE SESSION

Attachment

The expression of interest in the lives, experiences, and well-being of refugees is often very welcome. This is especially likely in situations where children have been deprived of the warm concern and affection of adults— for example, those living in institutions such as orphanages or in child-headed households. As a result, some children can rapidly develop attachments to the researcher and, not having grasped that the interaction is likely to be short-lived, may feel let down or even abandoned once the research is complete. There is no simple means to avoid such a situation.

Clarity about the extent and nature of the interviewer's role is vital. This clarity is necessary not only for adults and children, but also for the interviewer. Efforts to "rescue" children or to act as a surrogate parent—albeit well intentioned—are liable to create false hopes and increase the likelihood of sorrow upon parting.

Managing Information

Obscuring Identity

Unless evidently unnecessary, all identities—individual and communal—should be concealed through the use of pseudonyms. No individuals should be named unless they have given clear permission. In the case of children, such permission should also be secured from their adult caregivers.

When recording contact information, consider whether the individual is:

- a current or former child combatant, whether or not he or she is accused of violence or atrocities;
- a survivor of sexual assault, unless it is an adult who wants to tell their story publicly and has given permission;
- a perpetrator of physical or sexual abuse;
- HIV-positive or living with AIDS, and any other person with a socially stigmatized condition, unless the adult subject or a guardian of a child subject gives fully informed consent;
- charged or convicted of a crime; or
- asks not to be identified for personal reasons.

³⁶ MediaWise, Reporting Asylum and Refugee Issues, <u>http://www.mediawise.org.uk/display_page.php?id=657</u>.

Do not publish a story, image, or film that might put the person and/or their family or peers at risk even when identities are changed, obscured, or not used.

Revealing Identity

In certain cases, using the identity of a participant is in his or her best interest. Some examples are:

- When a participant initiates contact with a staff person or collaborator, wanting to exercise his or her right to freedom of expression.
- When a participant is part of a sustained program of activism or social mobilization and wants to be identified as such.

Accuracy

- Data should be analyzed with rigor and integrity.
- Prior to wider dissemination, WRC staff and collaborators should make every effort to review key findings with participants and the community.
- Take care when publishing images that may identify individuals. Make sure captions are accurate. If in doubt about the use of images, talk to the people being portrayed, or do not use them.
- Contact Information: Identify a contact person (community leader or designated lead participant) and obtain their contact information so findings and reports to contributors can be sent back to the participatory community.
- Offer them your information so they can contact you.
- If it is possible to share photos or findings at a later date, offer to do so and follow through.

Reporting Information

Determine the analysis and information dissemination plans in advance so that the data are not manipulated to draw or present false conclusions, which has ethical implications for the integrity of the research or assessment. Outline the activities to reach your target audiences, taking into account their attitudes, habits, and preferences.³⁷ Work with community partners to understand the appropriate means of communicating results to the community. If possible, include participants and community members in both the analysis and dissemination of findings. Traditional dissemination activities such as publication in scholarly journals are likely not always appropriate means to promote two-way dialogue. Face-to-face meetings or briefings are very effective ways to reach community members and decision-makers. Many times, in-person dissemination activities are not feasible; therefore, a brief report summarizing key findings tailored for the community and translated into the relevant local languages may suffice to communicate findings. <u>Community Pre- and Post-travel Fact Sheets</u> may be a useful resource to support the dissemination process.

Stigmatization

Do not further stigmatize any subject in reports. Language is fluid and acceptable descriptions may change over time. In principle, aim to avoid categorizations or descriptions in your work that expose the person to negative reprisals, such as:

- patronizing attitudes
- additional physical or psychological harm

³⁷ Canada Health Services Research Foundation, Communication Notes, <u>https://www.queensu.ca/urs/sites/webpublish.queensu.ca.urswww/files/files/dissemination_plan_CHSRF.pdf.</u>

- lifelong abuse
- discrimination
- rejection by their local communities

Stereotypes

Avoid reinforcing stereotypes. Material that relies upon stereotypes for its impact (for example, using images of masked or hooded young men to imply threat and illegality) can mislead and distort perceptions, especially where they do not relate to the facts of a story. Each person's story is different.³⁸

Context

Always provide accurate context for the subject's story or image. Do not inflate numbers, exaggerate the gravity of a situation, or over-dramatize. You should be able to back up your statements with accurately analyzed findings. If the data collected is for research purposes (versus a media interview), the methodology of the research and its specific limitations should be included in reports to inform the reader to potential biases. This will enhance credibility. Confirm the accuracy of what the person has to say either with the subject or with others.³⁹

Considerations and Consequences of Information

- People fleeing persecution leave families behind who may face retribution from repressive regimes if relatives are identified.
- Exiled political activists from other countries may risk death threats or attacks by agents of the regime they opposed, or by regime loyalists in the country where the work will be published.
- Women and girls might be abused by their husbands or intimate partners if they find out they participated in a survey about gender-based violence.
- Normal considerations of respect for personal privacy apply to people seeking asylum and refugees, particularly when identifying children.
- Giving prominence simply because of their asylum or refugee status could lead to unwarranted discrimination and hostility.⁴⁰

When in doubt about whether a person is at risk, report on the general situation for a group rather than on an individual person, no matter how newsworthy the story.

³⁸ MediaWise,

³⁹ Ibid

⁴⁰ Ibid.

RESEARCH ETHICS

Ethical conduct in research remains central to the mission of WRC. The following section provides more in-depth information on the guiding principles to be used in human subjects research and special considerations for research conducted in crisis-affected settings.

Guiding principles of human subject research⁴¹

Respect for People

Research should be guided by respect for the autonomy and self-determination of study participants and ensure protection for those who lack or have diminished autonomy. WRC staff and collaborators should thoughtfully secure informed consent, privacy, and confidentiality for any research conducted.

Informed Consent

WRC staff are responsible for ensuring all participants have given informed consent to take part in human subjects research. Informed consent is a process, not a form. Informed consent is the term that describes the communication process the enables individuals to make an informed choice about participation in the project. Consent is ongoing, starting well before any forms are signed and continuing until the subject's participation is complete.

The initial step in this process often includes discussing the research with the community through key community leaders to seek their input, support, and approval. It is also important to consult with local organizations on the best ways to approach research within communities. The following section describes the purpose and intent of the informed consent process, as well as guidance to support WRC staff to ensure informed consent is voluntary, the appropriate permissions are taken, participants' privacy and confidentiality are safeguarded, and ethical review and approval is obtained from an institutional review board before research activities commence.

Purpose and Intent

The process includes the discussion that occurs between the interviewer and the participants, as well as the written document that formalizes the agreement to participate and documents the process. For consent to be informed, the participants must be presented with all the information, fully understand the information, and voluntarily consent to participate. Therefore, information must be conveyed in a manner that enhances understanding rather than just provides disclosure.⁴²

Clearly explain the purpose and intention of the activity during the voluntary, informed consent process:

- Ensure that the subject knows the purpose of the interview/photo/film and its intended use. If possible, show samples of WRC documents where photos and materials are used.
- Clearly explain who is conducting the study and any research procedures (survey, interviews, focus group discussions (FGDs), etc.).
- Identify the risks and anticipated benefits from participation.
- Explain that the results of the study may be posted online and available to a global public audience, if applicable.

⁴¹ National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1979). The Belmont Report.

 ⁴² University of Missouri-Kansas City Social Sciences Institutional Review Board, "The Consent Process," September 15, 2004: p.
 1.

- Explain any possible misinterpretations some people might have when the results are shared with a broader public audience.
- Allow the subject to ask questions and explain the ways by which the participant can withdraw from the study at any time.
- Provide contact information, so they can reach you or another member of the research team to withdraw.

Comprehension

- Present information in a manner that is clear, organized, and culturally appropriate to enhance understanding of the research study.
- Make sure that the consent process is conducted in a language that the participant is fluent in.
- Ensure consent processes are adapted to the participant's maturity and language. For example, when working with low literacy populations and children, ensure consent language is simple, clear, and concise. If there is any doubt as to the participant's ability to comprehend the consent process or at any later stage of the research process, the researcher should take appropriate steps to further safeguard the participant from risks, including continuation with the research.

Voluntariness

- Ensure the consent is taken in a language and comprehension level appropriate for the participant.
- Ask the subject if their participation will conflict with other engagements or responsibilities.
- Time should always be allowed for the person to reflect on the consequences of their participation and/or to consult guardians, other adults, or friends.
- Ensure that the subject has enough time to understand that they have the right to refuse to answer any questions, withdraw from the session at any time, or pull the interview/image after completion of the project.
- Identify and provide real opportunities for the subject to pull out at each distinct stage of the research.

Written Consent Forms

Consent forms generally have the following information: purpose of study; procedures involved; withdrawal procedures; subject termination; risks/discomforts; benefits; cost/compensation; and alternatives. Language used in consent forms and/or information sheets must be understandable to the research participant.

- Use short sentences and non-technical terms.
- Do not use qualifying phrases such as "You understand that." Substitute wording such as "You have been told" or "It has been explained to you."
- Avoid language that may appear to waive any rights to which the participant is entitled.
- All scientific, medical, legal, and technical terms should be defined or explained.
- If people are involved who are unable to give informed consent, provide for consent from a legally authorized individual and provide a consent form to be read by or read to the research participant.
- All forms should be written in the language that is easily understood by participants.

- Clearly state the names and contact details of the interviewer, organization, and other stakeholders in the project so that children and parents can contact them.
- Provide contact channels that are usable to the participants. For instance, WhatsApp may be more usable in some contexts than email.

Permission

- Permission must be obtained to ensure that the subject is not coerced in any way and that he or she understands the implications of being part of a story that might be disseminated locally and globally.
- Secure permission from the subject for all interviews, surveys, videotaping, and photographs beforehand. Verbal consent following the guidance of the consent form is acceptable, but when possible and appropriate, this permission should be in writing. A written record of verbal consent should indicate clearly that such consent was obtained (ideally with time and place).
- For focus groups, it is recommended that written or oral permission be obtained from all participants. It is *required* that the facilitator of the focus group convey the contents of the consent form *before* the session. The facilitator must indicate on the consent form that this has been done, and the form filed in the WRC office.
- As photographs and video material make identification much easier, consent in the use of cameras must be negotiated with particular care, ensuring that participants have fully considered the possible ramifications and elevated risk profile associated with easily accessible media materials online.
- Understand that even if one participant in a group interview objects, photography, video, and audio may not be used.
- If any form of payment or compensation is involved, the terms of payment and conditions under which partial or no payment will be received must be described in the consent form and discussed before participation.

Working with Children

If children under 18 are involved, parental/guardian consent in addition to child assent to participate is required. The text should state that the project has been discussed with the parent and child and they agree to participate. WRC staff should follow the inter-agency guidelines for ethical research involving children when interviewing or engaging with children for research and assessment purposes.

Working with People with Disabilities

People with certain types of disabilities, such as speech or cognitive impairments, may also require consent from a guardian. WRC staff should follow the National Disability Authority's guidelines for conducting research with people with disabilities.^{43,44}

Working with Low Literacy Populations

The vast majority of people in the world are multilingual. Many people and communities use multiple languages to achieve communicative goals. For example, a community may use one language for trade

⁴³ Handicap International Ethiopia. 2012. *HIV and AIDS and sexual and reproductive health knowledge, attitudes, practices and services utilization of persons with disabilities in Addis Ababa, Ethiopia.*

⁴⁴ National Disability Authority, "Ethical guidance for research with people with disabilities," (2009), <u>https://nda.ie/publications/ethical-guidance-for-research-with-people-with-disabilities-report</u>.

in the market, another for talking at home, and another for learning to read and write in formal schooling. Some communities use "literacy brokers" and other strategies to achieve communication goals related to written language. It is possible, even likely, among the populations with which WRC works that individuals and research participants may not be able to read the language in which the consent form is written, although they may be able to understand it when read aloud. In these situations, it will be necessary to read the consent form out loud and ensure a waiver of verbal consent is authorized under your research protocol. Some communities may use fingerprinting in place of signature or be more familiar and accustomed to verbal consent for participation. The cultural context, in addition to the use of collected information, should be considered when determining the best course of action for the consent process. The consent form should be read slowly and in the language of fluency for the participant.

For group interviews or FGDs, the facilitator should inform the participants that they are free to leave at any time during the meeting, free to stay and remain silent, and to answer only when they want to. Then ask the participants to acknowledge they understand what you have said and that they agree. The group can decide if it would like to choose one person to sign the consent form on behalf of the group or for each person to sign the consent form to reflect this. It is important to remind participants that their responses should reflect their general views on the situation and not necessarily their own personal experiences. In addition, all information shared within the group is confidential to the group and should not be shared with others; however, participants in focus groups must also be made aware that there is risk that what they say in a group setting might not be kept confidential to the group.

Privacy and Confidentiality

Confidentiality and privacy are particularly important where the immigration status, liberty, or safety of participants and their friends, families, and associates can be jeopardized by findings generated from programmatic, research, and media outputs. WRC staff and their collaborators should pay attention to online methods of data collection, which may be subject to interception, as well as specific legal contexts which may require reporting of illegal or harmful activities (e.g., asking a healthcare provider about the provision of abortion care in their health facility where abortion is illegal in the country). Interpreters, research assistants, and community partners should be made aware of these confidentiality and privacy issues, and where appropriate, sign a confidentiality agreement.⁴⁵ WRC staff and their collaborators must implement appropriate information management and security procedures to safeguard the confidentiality and privacy of program and research participants, including aggregating and deidentifying participant data, protecting data with passwords, and safely securing the data on a protected server. For photographs and quotes, names will only be used if explicit consent is provided.

Beneficence

This guiding principle provides a duty to safeguard the welfare of individuals and communities involved in the research process—assuring that the benefits of participation outweigh the risks. "Risks" refers to any "psychological harm, physical harm, legal harm, social harm, and economic harm."⁴⁶ Ensuring that study benefits exceed risks in humanitarian settings means that the implementation and dissemination of research does not impose burdens on local organizations providing essential services and local social

⁴⁵ IASFM Code of Ethics. 2018. <u>https://www.fmreview.org/ethics/clarkkazak.</u>

⁴⁶ National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1979).

value is inherent in its intended conduct. WRC staff and collaborators have an ethical responsibility to "...make every effort, in cooperation with government and other relevant stakeholders, to make available as soon as possible any intervention or product developed, and knowledge generated, for the population or community in which the research is carried out, and to assist in building local research capacity."⁴⁷

Justice

This guiding principle provides a duty to distribute the benefits as well as the burdens of the study fairly. WRC staff and collaborators should thoughtfully review the selection of research participants so that no undue burdens are placed as a result of study participation.

Thinking through Inclusion and Participation

WRC research, by mission, aims to shed light on the situation for women and girls most marginalized in crisis-affected contexts. Our community engagement approach emphasizes a participatory and empowerment methodology, involving underrepresented populations, including children, adolescent girls, women, people with disabilities, LGBTQI+ individuals, people engaged in sex work, and other marginalized people. WRC believes in "starting at the margin," involving people who are too often not found "at the table," and uses a variety of participatory research methods and sampling approaches to enable active participation of community members. Examples include developing research objectives and questions with partners and community members to make sure they are culturally relevant and appropriate, defining concepts based on indicators determined by the community, and training data collectors and consultants who share backgrounds similar to or the same as target populations. WRC works to acknowledge data collectors for their active role in the research process and provides recognition of participants and local support staff in reports. It provides opportunities for refugees to use the findings to advocate for their rights.

WRC aims to include community members in developing and implementing research activities to the greatest extent possible. See WRC's *Guidance on Inclusion in Research and Assessment Protocols* for support on actively including people with disabilities in all research, assessments, and consultations with affected populations, and to collect sex-, age-, and disability-disaggregated data that will help us to reflect on the diversity of women, children, and youth with whom we work. The guidance also includes strategies to engage partners in reaching more marginalized populations, including how to safely collect information about refugees engaged in sex work and LGBTQI+ refugees; because these populations have long been overlooked within humanitarian response and related research, even small amounts of data collected from communities can contribute meaningfully to the knowledge base globally. The selection of research participants needs to be carefully balanced with the broader social benefit and scientific merit of the proposed study that would enable programmatic and policy decisions.

Human Subjects Research Certification

All WRC staff and their collaborators should obtain human subjects research certification prior to collecting data from human subjects. Staff are responsible for maintaining up-to-date certifications and ensuring that their collaborators' certifications are also current. You may find additional information regarding the human subjects research certification process in Annex E.

⁴⁷ CIOMS (2016, p. 3)).)

Ethical Review

Ethical review is an important step in the research process to fully explore the ethical issues surrounding your proposed research. Through the ethical review process, you will consider the wider consequences of your research and engage with the interests of your participants.⁴⁸

What Is an Institutional Review Board?

An Institutional Review Board (IRB) is a committee that reviews, monitors, and approves research that involves human subjects. IRBs can be known by many names, such as Ethical Review Boards or Research Ethics Committees, and have differing functions based on their organization. In general, IRBs comprise at least five members of varying backgrounds who follow written procedures for initial and continuing review of human subjects research. They possess the authority to approve and/or require modifications to submitted research plans—and ultimately can terminate research due to serious harm on participants or non-compliance.⁴⁹

Various institutions can host IRBs, including universities, research organizations, agencies, and humanitarian organizations. IRBs are mandated to provide ethical and regulatory oversight of research that involves human subjects:

- Protecting the rights, welfare, and well-being of human research participants, recruited to participate in the research project.
- Ensuring compliance with relevant local, state, and federal laws and regulations.
- Employing the highest ethical standards for human research protections in all human subjects research.
- Giving guidance to ensure sound research design, scientific integrity, and determining if the research contributes to generalizable knowledge and is worth exposing subjects to risk.^{50, 51, 52, 53}

IRB approval is required before you start your research. The IRB must approve or determine the project to be exempt prior to the start of any research activities. The IRB cannot provide approval or determinations for research that has already been concluded.

⁴⁸ Consortium of European Social Science Data Archives, Ethical Review Process, <u>https://www.cessda.eu/Training/Training-Resources/Library/Data-Management-Expert-Guide/5.-Protect/Ethical-review-process.</u>

⁴⁹ Grady (2015).

⁵⁰ National Institute of Environmental Health Sciences, NIEHS Institutional Review Board, <u>https://www.niehs.nih.gov/about/boards/irb/index.cfm.</u>

⁵¹ Strauss RP, et al. The role of community advisory boards: involving communities in the informed consent process. Am J Public Health. 2001;91(12):1938–1943.

⁵² D.S. Buck, D. Rochon, H. Davidson, and S. McCurdy, Committee of Healthcare for the Homeless--Houston (HHH), "Involving homeless persons in the leadership of a health care organization," *Qual Health Res. 2004 Apr; 14(4):513-25.*

⁵³ J.O. Andrews, G. Bentley, S. Crawford, L. Pretlow, and M.S. Tingen, "Using community-based participatory research to develop a culturally sensitive smoking cessation intervention with public housing neighborhoods," *Ethn Dis.* 2007 Spring; 17(2):331-7.

When Is an IRB Necessary?

Determining when to seek out external ethical review from an IRB can be challenging and needs careful consideration, given the context in which the proposed research activities are to be conducted.

WRC staff and collaborators should first ask themselves, "Am I conducting human subject research?" The US Department of Health and Human Services Office of Research Integrity defines research as "a systematic investigation (i.e., the gathering and analysis of information) designed to develop or contribute to generalizable knowledge."⁵⁴ The following decision-making tree has been designed to support your thoughtful consideration of whether you should proceed with the IRB application process given your proposed project.



⁵⁴ Office of Research Integrity (2020). *What is Research?* U.S. Department of Health & Human Services. <u>https://ori.hhs.gov/content/module-1-introduction-what-research</u>.

Beyond understanding whether or not your study meets criteria of human subjects research, international, national, institutional, and other contexts must be considered fully prior to making a final determination. For example, it is important to think through whether there are any national policies that are in place in the country, camp, or settlement about health research and/or human subjects research. If so, do these policies require ethics review of all or some of your research protocols? Do they require approval through a national ethics committee, regardless of prior institutional approvals? Do your institutional approvals also register you through formal national or local registration systems? Careful contextual consideration with collaborators and communities can help inform these discussions and ultimately reach a shared decision on the best way to proceed. The WRC Research Team is also available for a consultation process that can provide further support.

Application Package

To obtain IRB approval or exemption for a new study, complete a protocol application form, which can usually be found on the website of the IRB you are submitting to or by request.

Protocol application forms for non-clinical trials usually consist of the following:

- Title page
- Summary of proposed research aims and objectives
- Background and rationale
- Study design
- Study procedures
 - o Method selection and instrument development process
 - Sample size
 - Participants and recruitment process
 - Study implementation
 - o Data custody, security, and confidentiality protections
 - Risk and benefits of study
 - o Compensation
 - Study management
 - Informed consent process
- Training and qualifications of personnel
- Annexes
 - o Informed consent documents
 - Local IRB approval
 - Study instruments (questionnaires, focus group guides, others)
 - Ethical training certificates
 - Certificates of translation
 - Letters of support (e.g., authorization to conduct study from government agency)

Any modification to the protocol requires an amendment from the IRB. For full board protocols, you must also submit a request for continuing approval each year, regardless of whether or not any of your study procedures or personnel have changed.

Levels of IRB Review

All protocols are categorized based on the level of risks introduced to human subjects and whether they meet the qualifications under specific categories established by the federal regulations at 45 CFR 46.

- Not Human Subjects Research
 - o Determination of Not Human Subject Research
 - Does not meet the definition of "research" and/or "human subject" as per regulations
- Exempt⁵⁵
 - Exempt determination
 - Generally low risk
 - o 6 exemption categories
- Expedited
 - Expedited review
 - o Minimal risk
 - 9 expedited categories
- "Full Board"
 - Convened review
 - o Greater than minimal risk research
 - o Minimal risk research that is not eligible for exempt or expedited

Other Types of Ethical Review Available for Research

It is not possible for one person or one team to adequately identify all the possible risks posed by a research study or other data collection activity. Therefore, a first step in undertaking data collection that directly involves people is to secure ethics review and approval from the appropriate body or bodies that have the expertise and knowledge to identify ethical issues or to approve the ethics of a research or data collection activity. Several types of ethical review bodies are available and worthy of consideration prior to submission.

WRC Research Team

The WRC Research Team is available to review all research and non-research proposals and protocols to ensure they uphold the highest ethical standards. The <u>Research Team</u> (<u>research@wrcommission.org</u>) can help determine what level of risk is involved and guide staff in what ethical review processes are called for.

Government Ethics Bodies (Local, State, National)

Research implemented in countries other than the United States may require IRB and local country approval if available. Local, state, or national IRB approval is important, given many members of IRBs in middle-to-high income countries have little (if any) experience in implementing research in low-income countries and do not understand local constraints. Local, state, or national IRBs may be helpful

⁵⁵ "Exemption" from IRB review is not the same thing as "not human participant research"; exempt research is still considered human participant research under federal regulations, though it can be reviewed and approved administratively by IRB staff, rather than the IRB committee.⁵⁵

especially with regard to the correct language of the consent form or for recommending procedures that are culturally suitable.⁵⁶

National Reference Group

For various reasons, some contexts or localities may not have a suitable ethics committee or research ethics board at the time of the study; and while you may have IRB from an out-of-country institution, you may wish to have an additional layer of ethical review from experts or stakeholders with specific knowledge of the local context. In those cases, an informal group of local researchers and protection experts can be convened to review the research protocol and tools, provide guidance on cultural and political issues, and generally advise on ethical concerns; this may be done in addition to review from an IRB.

Global Advisory Board

Similar to a national reference group, a global advisory board might be convened to enable ethical review of planned research or other projects related to content-specific recommendations or recommendations for multiple contexts. A global advisory board may be used when IRB approval has been obtained, but the IRB institution does not have content or context area expertise to cover all the possible ethical issues in the study.

Community advisory board

A community advisory board (CAB) is a type of advisory board made up of individuals who reflect the community of interest and who meet with researchers to voice concerns and priorities for the researchers' agenda. A CAB provides a platform for community members to advise researchers on suitable research processes that are respectful of and acceptable to the community.⁵⁷ CABs may advise research teams on the following:

- Study protocol design and implementation
- Facilitating community consent
- Evaluating education materials
- Disseminating information
- Using research findings to advocate for policy change⁵⁸

CAB approval of your research protocol is not required prior to the start of your research project; however, it is strongly encouraged and will likely improve the success of your research project by facilitating community trust and ownership of the research, improving your research methods, and supporting the translation of research findings into social changes within communities.

⁵⁶ **R.H.** Gilman and H.H. Garcia, "Ethics review procedures for research in developing countries: a basic presumption of guilt," *CMAJ*. 2004;171(3):248–249. doi:10.1503/cmaj.1031121.

⁵⁷ *R. Chené et al.,"* Mental health research in primary care: mandates from a community advisory board," *Ann Fam Med.* 2005 Jan-Feb; 3(1):70-2.

⁵⁸ S.C. Quinn, "Ethics in public health research: protecting human subjects: the role of community advisory boards," *Am J Public Health*, 2004 Jun; 94(6):918-22.

Youth Advisory Group

Young people do not usually participate in the above committees and groups and might not have a chance to assess protocols that involve or affect young people; or, even if youth are included in a CAB, they may not feel comfortable speaking in front of adults. A youth advisory group is a group of young people who are brought together to review the protocol and ethics of an activity involving young people in the community. This would most likely be used for participatory action research with adolescents. Some localities may already have active youth groups; these groups may be engaged to provide ethical review of a proposed activity. This may be used for both research and non-research data collection activities.

Public Accountability for Research

WRC staff and their collaborators have an obligation to share research results in an ethical manner to further achieve the full social and scientific value of research.⁵⁹ To do so requires that the results of research are published and disseminated, responsible data-sharing policies are adopted, and safeguards are put in place to protect the privacy and confidentiality of study participants. The following sections describe the *minimum* necessary actions that WRC staff and collaborators should take to ensure public accountability for research.

Publication and Dissemination of Research Findings

During the inception phase, WRC staff should develop a research uptake plan that outlines the value of the research in the short and longer term and how the research study team can take steps to enhance its influence on policy and practice.

Within this plan, the researcher should describe the ways in which research participants and communities will be engaged in the validation of study results and implementation of any uptake strategies.

- Make sure to identify a contact person (community leader or designated lead participant) at the
 onset of the project and obtain their contact information so research findings and participant
 reports can be sent back to the participatory community. Offer them your information so they
 can contact you. <u>Community Pre- and Post-travel Fact Sheets</u> are a useful template to guide
 your discussions with communities.
- Detail how and when you will communicate results to government officials, other stakeholders, and to communities. The method of dissemination is important to ensure its overall translation into social action.

Plans should also include whether there will be any local meetings to disseminate results and other possible forms of dissemination including conferences and written materials such as study briefs, reports, or peer-reviewed publications.

Be sure to consider whether you are elevating risks for participants or community by the way in which you are presenting and/or disseminating results. Also consider whether forms of dissemination (e.g., language, literacy, format) are accessible to diverse community members.

⁵⁹ CIOMS, 2016, International Ethical Guidelines for Health-Related Research Involving Humans.

Data Sharing

A data use agreement should be developed at the inception phase of the project to ensure all necessary privacy protections are observed. This agreement will guide the sharing of data, including datasets, codebooks, interview transcripts, and other materials generated during the conduct of the research.

WRC staff should review grant requirements related to data use and sharing prior to project start to ensure compliance. It is increasingly common that donors require a data sharing plan. Peer-reviewed journals similarly request that authors make their data available at the request of others seeking to analyze should you wish to publish.

WRC staff should consult with the WRC Research Team and legal during the development of their datasharing plans so that any data use agreements can be developed to observe all necessary privacy protection.

Data Storage and Security

WRC staff and their collaborators must implement appropriate information management and security procedures to safeguard the confidentiality and privacy of research participants. Research team members and their collaborators must develop a data management plan that outlines how confidentiality of the dataset will be maintained; where data will be stored; and who will have access to the data and any security measures in place.

WRC staff should consult with the WRC Research Team during the development of their data management plan and ensure data is stored within a WRC approved location for the appropriate amount of time required by the project and funding entity.

A few helpful tips are highlighted below related to confidentiality and data storage and security.

Confidentiality

- Unless unnecessary, all identities—individual and communal—should be concealed through the use of pseudonyms or study identifiers. No individuals should be named unless they have given clear permission.
- Participant data should be aggregated and deidentified.
- In the case of children, such permission should also be secured from their adult parents or caregivers.
- Take down contact information, with this is mind. If sensitive material is to be shared, the researcher must make sure that its source cannot be traced.

Data Storage and Security

- All notes and records are to be stored securely where they cannot be accessed by unauthorized individuals. This includes access by other WRC staff that are not assigned to the project and authorized under the current IRB protocol.
- Electronic data should be protected by passwords and safely secured on a protected server. Check with the WRC Research Team to ensure you are on an approved server.
- Notes are encrypted to conceal identities where such security is not possible.
USE OF MULTIMEDIA IN RESEARCH WITH CRISIS-AFFECTED POPULATIONS

Photographs and other audiovisual materials are an essential asset for WRC. They can convey our work in reports, on the website, in social media, and for fundraising, advocacy, event collateral, etc. However, each situation must be assessed to determine whether it is appropriate to take photos, videos, or audio recordings.

Consider the potential advantages and disadvantages of using photography, video, and audio equipment. While different media may be helpful, it may also change the results of your research or programmatic work. Individuals interviewed may be more or less willing to reveal information if it is recorded, and it may also be distracting.

If it's not appropriate to capture audiovisual media during the research sessions, consider whether it's possible to do so in a more general sense (camp scenes, informal settings, etc.).

It is often challenging for research staff to take photographs while they are conducting research. The communications team budgets a small amount each year to hire local photographers from affected communities. Consider this option either during your research trip or to get general photos of a project if you are not present.

Photography Protocol and Informed Consent Process

WRC's photography protocol and informed consent process is outlined and available for review by staff on SharePoint (<u>here</u>). WRC staff and their collaborators should familiarize themselves with the protocol and process on informed consent during proposal development and the design phase of research.

The Use of Multimedia within Human Subjects Research

The use of multimedia as a method to systematically collect information from human subjects to generate generalizable knowledge qualifies as human subjects research. WRC staff must evaluate whether the research project requires ethics review. If you need support in making a determination, contact the WRC Research Team (Research@wrcommission.org).

CONTACT INFORMATION

If you wish to report a violation of these guidelines, please contact our anonymous reporting service, Ethics Point. All anonymized reports will be directed to our ethics focal point, who will take appropriate next steps.

Contact:

<u>https://secure.ethicspoint.com/domain/en/report_custom.asp?clientid=74731</u>, via a <u>mobile app at</u> <u>https://wrcommission.navexone.com/</u>, or by calling a domestic toll-free hotline at 1-844-927-2279.

ANNEX A: WRC ETHICAL GUIDELINES AGREEMENT OF USE

I, the undersigned, hereby declare that I have read and understand WRC's *Ethical Guidelines for Working with Displaced Individuals through Programs, Research, and Media* that explains ethical considerations that must be followed by WRC staff and their collaborators who undertake information-gathering activities in refugee, internally displaced, and other crisis-affected settings. I commit myself to exercise my duties as a representative of the WRC in accordance with these Guidelines and understand that it is my responsibility to use these guidelines and seek out appropriate guidance during the discourse of my responsibilities under projects.

Employee's name and signature:	 Date:
Supervisor's name and signature:	Date:

ANNEX B: WRC'S POLICY ON PAYMENT, GIFTS AND COMPENSATION

The form of compensation should be discussed with the hosting partner organization in advance of the meeting or interview. Once determined, it is very important to be upfront and explicit with participants whether they should or should not expect any form of compensation. Respect local norms and coordinate with existing policies to avoid upsetting the balance in the area.

a. Consent

• If subjects will be compensated for participation, the consent form must describe the terms of payment and the conditions under which partial or no payment would be received, as previously explained under Informed Consent.⁶⁰

b. Avoid possible group tension

 Keep in mind that in situations where there is expectation or a clear responsibility to reward certain individuals, this should be done in a manner that avoids fueling tension within the community. Attempts to offer rewards secretly may backfire, badly confirming suspicions and fueling resentment. It may be safer to make transparent the criteria for participation and the reasons for payment/reimbursement of particular individuals.

c. Other potential costs to the participants

Even if there is no expectation of material reward, attention must be paid to the possible loss of income and the costs involved for participants.

- At the very least, transportation and other incidental costs should be reimbursed, and refreshments or meals provided to participants.
- Rewards do not have to be clearly economic. In some settings the provision of symbolic rewards—such as a certificate to acknowledge participation—may be appreciated and may avoid tension, especially when the criteria for participant selection have been made clear in advance.⁶¹
- It is imperative to avoid raising expectations of dramatic lifestyle changes as an outcome of participating in the project.⁶²

⁶⁰ University of Missouri-Kansas City Social Sciences Institutional Review Board, "The Consent Process," September 15, 2004: p. 1.

⁶¹ Jason Hart and Bex Tyrer, "Research with Children Living in Situations of Armed Conflict: Concepts, Ethics and Methods," Refugee Studies Center, University of Oxford (May 2006): p. 22.

⁶² Casper Edmonds, "Ethical Considerations When Conducting Research on Children in the Worst Forms of Child Labour in Nepal," International Labour Organization (Geneva, October 2003): p. 10.

ANNEX C: IRB GO – NO-GO DECISION TREE

IRB Decision Tree Is the activity a systematic investigation designed to develop or contribute to No generalizable knowledge? Yes Activity is research. Does the research involve obtaining information about living human subjects? Yes Is the research Will you or a member Will you, a member receiving U.S. federal of your research of your research funding* as the team be accessing or team or a primary recipient? analyzing identifiable collaborator No data or specimens? observe, interact OR OR with, or intervene Even if data are *This may also apply with living coded, data may be if receiving other individuals to considered funding sources, gather information identifiable if the including UN that will be used for study team has funding, so be sure research? access to the codes to check. Yes Project is likely not human Project is research with human subjects research. Further subjects. An IRB application, contextual assessment review, and approval are should be undertaken to required before the study can determine whether IRB application should be begin. submitted.

¹ Adapted from <u>HHS.gov</u>.

² Even if IRB application is not required for this data collection activity, it may still be useful for academic publication; and/or other kinds of ethical review may still be called for; see <u>WRC Guidance on Types of</u> <u>Ethical Review</u> and consult with Research Team.

IRB Go/No Go Guidelines WRC Research

DIRECTIONS: If you answer "yes" to the following two questions, you need to submit an IRB application for IRB review.

(1) Is it research?

Research is a systematic investigation (including research development, testing, and evaluation) designed to develop or contribute to generalizable knowledge (45 CFR 46.102 <u>E-CFR.gov</u>).

Systematic investigation is an activity designed to test a hypothesis and to draw conclusions as described in a formal protocol that sets forth an objective and procedures to reach that objective. Activities such as the practice of public health, medicine, counseling, or social work are not research.

Generalizable knowledge is information expressed in theories, principles, and statements of relationships that can be widely applied (e.g., by publishing findings or presenting findings at a professional meeting). Studies for internal management purposes (e.g., program evaluation, quality assurance, or quality improvement) are not research because the intent is not to provide generalizable knowledge but to apply findings only to the program or activity.

(2) Does the research involve human subjects?

Human subjects research is a project that involves a living individual about whom the investigator (i) obtains information or biospecimens through interaction/intervention with the individual, and uses, studies, or analyzes the information or biospecimens; or (ii) obtains, uses studies, analyzes, or generates identifiable private information or identifiable biospecimens (<u>45 CFR 46.102</u>).

Submission to the IRB may not automatically be required for the following activities; however, IRB submission for these activities may be called for depending on the possible risks and the intended channels and audiences for dissemination. Consult with the Research Team to determine.

- > Case studies [Consult with Research Team]
- > Implementation studies [Consult with Research Team]
- > Studies drawing on programmatic monitoring or evaluation data [Consult with Research Team]
- > Journalism/documentary activities
- > Oral history
- > Quality assurance and quality improvement activities
- > Research on organizations
- > Research using deidentified data or biospecimens
- > Research using publicly available data sets

ANNEX D: GUIDE TO TYPES OF ETHICAL REVIEW

BACKGROUND: It is not possible for one person or one team to adequately identify all the possible risks posed by a research study or other data collection activity. Therefore, a first step in undertaking data collection that directly involves people is to secure ethics review and approval from the appropriate body or bodies that have the expertise and knowledge to identify ethical issues or to approve the ethics of a research or data collection activity.

Ethical review from a research ethics board (REB) or other group requires resources in terms of funds (\$) to cover costs of application fees, ongoing study monitoring, per diems, etc. Ethical review also requires resources in terms of time (■) required to prepare applications; await application processing; to convene committee meetings; etc.

Below is a Quick Reference to the types of ethical review covered, and a Detailed Guide to the types of ethical review. The Research Team can help you to identify which types of ethical review below are suitable for your project.

Quick Reference: Types of Ethical Review

	Cost	Time	Required?	Rigor
WRC Research Team	\$		Ideally!	***
Institutional Review Board (IRB)	\$\$\$\$\$		Yes, for research	****
Government research ethics committee	\$\$\$\$		Sometimes	****
National reference group	\$\$		No	***
Global advisory board	\$\$		No	***
Community advisory board	\$	•	No	***
Youth advisory group	\$	•	No	***
Peer researcher	\$	•	No	**

Description of ethical review type	When to use	Costs
WRC Research Team ethics review \$		
The WRC Research Team is available to review the ethics of all proposals and protocols, both research and non-research. The Research Team can help determine what level of risk is involved and therefore which ethical review processes are called for. See: <u>WRC Proposal Consultation Checklist</u>	 Piloting tools and guidance Operational assessments Routine monitoring data Needs assessments for internal use 	None; schedule a meeting with the Research Team
Institutional Review Board (IRB), global <mark>\$\$\$</mark>	\$\$ ====	
An Institutional Review Board (IRB) is a formal research ethics committee responsible for reviewing, monitoring, and approving research involving humans in order to safeguard the rights and welfare of research participants. Various institutions can host IRBs, including universities, research organizations, agencies, government ministries, and humanitarian organizations. If a study is deemed to be research and involve human subjects, then it <u>must</u> be reviewed by an IRB; other data collection involving human subjects, such as evaluations and assessments, may or may not call for IRB review.	 All research studies Evaluations with minors (children), people with disabilities, or other vulnerable populations Any data collection that will be published in academic journal See <u>WRC IRB Go No-Go</u> <u>Guide</u> 	 Application fee Annual reapplication fee Monitoring costs a percentage of total budget Salary for consultant or principal investigato (PI) from the institution Can amount to anywhere from USD\$2,000 - \$30,000 depending on the study
Institutional Review Board (IRB), national o	r regional <mark>\$\$\$\$</mark>	
When a research study or evaluation takes place in a humanitarian setting, there is the choice of seeking IRB from an out-of-country institution or an in-country institution with a research ethics board (REB). In settings where there are functioning IRBs or REBs, it is preferable to obtain ethical review from that institution. National governments may have a list of approved REBs (e.g., the NHREC in Nigeria) from which you can identify an REB or IRB for your study.	 All research studies Evaluations with minors (children), people with disabilities, or other vulnerable populations Any data collection that will be published in academic journal See <u>WRC IRB Go No-Go</u> <u>Guide</u> 	 Application fee Annual reapplication fee (possible) Monitoring costs as percentage of total budget (possible) Salary for consultant or principal investigato (PI) from the institution

Description of ethical review type	When to ι	ISE	Costs
			Can amount to anywhere from USD\$2,000 - \$30,000 depending on the study
Government research ethics committee \$\$	\$\$ ====		
Governments often require that researchers doing studies secure approval from the appropriate ministry or agency of government (e.g., the Ministry of Health) or potentially from multiple ministries depending on the topic of the research. There may be different ethics committees depending on the level of government (e.g., local, state/provincial, federal) and depending on the context of the research (refugee camp, host community, etc.)	 Research st humanitariar Certain kinc evaluations in settings (e.g., camps) migh government 	a settings ls of n humanitarian refugee t require	 Application fee Annual reapplication fee (possible) Monitoring costs as percentage of budget Per diems for monitoring visits Salary for a dedicated focal
Although some government research ethics committees might be rigorous enough to serve as an IRB, for many of our research studies, application and review from a government ethics committee is done <i>in addition</i> to IRB review.			person Can amount to anywhere from USD\$2,000 - \$30,000 depending on the study
National reference group \$\$			
For various reasons, some contexts or localities ethics committee or research ethics board at the you may have IRB from an out-of-country institu additional layer of ethical review from experts o knowledge of the local context.	e time of the st ition, you may	udy; and while wish to have	 Meeting convening costs, venue, food, etc. Per diems for participants
In those cases, an informal group of local researchers and protection experts can be convened to review the research protocol and tools, provide guidance on cultural and political issues, and generally advise on ethical concerns; this may be done in addition to review from an IRB.			
Global advisory board \$\$			
Similar to a national reference group, a global ad might be convened to bring in additional levels of review to a research or other project, including specific recommendations and recommendation contexts.	of ethical content- ns for multiple	food, etc. - Per diems for - Possible data	
A global advisory board may be used when IRB a been obtained, but the IRB institution does not	• •	- Possible trave	l costs for some attend (if in person)

issues in the study.	
Community advisory board \$ =	
A community advisory board (CAB) refers to a group of community members that is convened to reflect the population being studied and is tasked to review the study protocol and ethics from the point of view of the population. A CAB might include community members; local community leaders and stakeholders; local government members.	 Meeting convening costs, venue, food, etc. Travel costs for participants Per diems for
Convening a CAB can be expedient both for research and non-research activities as the CAB can support recruitment of participants prior to the activity. The CAB can also support uptake of the findings after the activity.	participants
Youth advisory group \$ =	
Young people do not usually participate in the above committees and groups and might not have a chance to assess protocols that involve or affect young people; or, even if youth are included in a CAB, they may not feel comfortable speaking in front of adults. A youth advisory group is a group of young people who are brought together to review the protocol and ethics of an activity involving young people in the community. This would most likely be used for participatory action research with adolescents. Some localities may already have active youth groups; these groups may be engaged to provide ethical review of a proposed activity. This may be used for both research and non- research data collection activities.	 Meeting convening costs, venue, food, etc. Travel costs for participants Per diems for participants
Peer researcher \$	
A peer researcher is a technique ⁶³ that involves engaging a member of the affected community or the studied population as a "peer researcher" and point of contact throughout the duration of the research activity. This peer researcher could serve to provide ongoing review of the protocol and ethics of an activity, as well as to ensure certain aspects of research ethics, such as ongoing consent processes (e.g., contact channels for participants to withdraw from study) and participant feedback.	Per diems and/or ongoing stipend to the peer researcher

Costs

Description of ethical review type When to use

or context area expertise to cover all the possible ethical

Have you used other types of ethical review, that you would like us to know about? Please email <u>research@wrcommission.org</u>.

⁶³ Bakunzi, "Working with peer researchers in refugee communities," *Forced Migration Review 59* (2018).

ANNEX E: HUMAN SUBJECTS RESEARCH COURSES

The Research Team recommends that WRC staff update their human subjects research (HSR) certification every 12 months (annually). Below are some recommended online certification courses in ethics of HSR. If you would like, please send your HSR certification document to the Research Team for filing: research@wrcommission.org.

Name, Certify Link	ring institution,	Costs	Attributes	Certification
The science of Mirkound Lives	FHI360 Research Ethics Training Curriculum (RETC) > <u>Link</u>	Free of cost 3 – 4 hours (length)	 > Can be done individually or in a group > Very reflective of realities conducting research in developing contexts or low-resource settings; relevant case studies > Less tailored to social science research > Contains required components related to biomedical trials or clinical 	Post-course examination; personalized certificate
TRREE	Training and Resources in Research Ethics Evaluation (TRREE) > Link	Free of cost 3 – 4 hours (length)	research Developed to be tailored to the specific aspects of doing research in sub-Saharan Africa, including optional modules specific to several African national contexts Covers ethics of social-behavioral research Optional module on clinical research 	Each module has a post- test; 70% passing score gets certificate for that module
	Collaborative Institutional Training Initiative (CITI) Program > <u>Link</u>	Paid (\$129) 3 – 4 hours (length)	 > Has a separate course specific to social-behavioral-educational research, which is suited to types of research WRC does > Used mainly by US universities, institutions that have institutional subscriptions to CITI 	Post-tests with personalized certificate given
POLICIÓN PHRP Protecting Human References Original Canada	Protecting Human Research Participants (PHRP) > <u>Link</u>	Paid (\$40) 3 hours (length)	 > Developed to align with US NIH and DHHS guidelines and aligned with US government policies and legal framework (i.e., because the NIH no longer maintains its HSR course) > Has separate modules for biomedical research; behavioral research; and basic research 	7 modules with quiz; personalized certificate

Name, Certifying institution, Link		Costs	Attributes	Certification
	National Institutes of Health (NIH) Ethics Program > <u>Link</u>	Free of cost 3+ hours (length)	 Very rigorous and tailored to biomedical and clinical research Specific to US context, US government policies and legal framework As of 2018, this course is no longer maintained or updated by NIH; the course materials are archived in PDF form on NIH website 	No tests or certificate offered

ANNEX F: RESEARCH SUPPORT CONSIDERATIONS FOR PROJECT PLANNING

This document provides information on the level of support available from research staff. For additional information and budgeting requirements for each, contact <u>research@wrcommission.org</u>.

Item	Description
Proposal Developmer	nt
Initial consultation	A consultation session is available during the proposal development process to support staff in thinking through the design and budgetary implications of conducting research. The Proposal Consultation Checklist and Budgeting Considerations guide are available to support staff as they develop their research proposal (here).
Review of research design and methods sections	Based on the initial consultation, it may be useful for a member of the Research Team to review the design and methods sections of the proposal prior to submission. This support is available upon request and subject to availability of unit members.
Development of research design and methods sections	Based on the initial consultation, the Research Team may be able to develop the research design and methods section for proposals that engage unit staff in the conduct of the research. This support is available after consultation and is a collaborative process with program staff to determine the research design/methods most appropriate for the project.
Conducting Robust Re	eviews to Inform Program Design or Advocacy Initiatives
Desk reviews	Support is available to develop a desk review for your project (subject to availability). Desk reviews can be helpful in designing a study or evaluation, learning about the context of a program and how it has been implemented, and to document lessons learned, challenges, good practice, and recommendations.
Literature reviews	Support is available to develop a literature review for your project (subject to staff availability). Literature reviews are more time-consuming than desk reviews. Literature reviews can help identify key information, themes, trends, gaps, and new interpretations in existing data in a systematic way. This may be helpful in the identification of areas of future research and research methods, or to inform the design or evaluation of policies, programs, and services. Support for systematic reviews is not available at this time.
Institutional Review E	Boards
Consultation at project inception on whether IRBs are required	Human subjects research requires IRB approval prior to its implementation. If you are not sure whether IRB approval is required, a consultation with the Research Team can be arranged to determine the best course of action.
Support for linkages to IRBs	There are several types of ethical review boards – IRBs, local advisory committees, government stakeholder reviews. The Research Team can provide information on the best linkage to make for your project and in some cases, directly link you to the appropriate review board.

Item	Description
Oversight for ethical	The Research Team is available to oversee the entire IRB submission process –
review process	from the technical review of the research protocol through to the successful approval required to start research activities. This includes support for any
	modification or renewals that may be required over the duration of your project.
Research Design and	
Design and methodology consultation at project inception	A consultation session is available during the project inception phase to support staff in thinking through the design and methodologies to be employed within their projects. This is a brief, one-hour session to discuss the project aims and troubleshoot the staff member's research approach.
Co-creation of design and methodologies for project	If support is written into the proposal, a member of the Research Team is available to co-create the research design and methods used in your project. This level of dedicated support provides technical assistance as well as any staff refresher training on methods to ensure they can successfully carry out the methods independently.
Development and oversight over design and methodologies	If support is written into the proposal, a member of the Research Team is available to fully develop the research design and methods and serve as principal investigator for the research study. All technical oversight for the research will be managed by a member of the Research Team.
Research Implementa	ition
Consultation on research protocol at project inception	A consultation session is available during the project inception phase based on a review of the research protocol in order to provide input into its revision and a determination of its scientific integrity. This consultation is a one-hour session led by Research Team members to support the development of research protocols for IRB submission.
Development of research protocol and accompanying tools	 This includes: Development of guides for in-depth or key informant interviews, focus group discussions Development of surveys, questionnaires, monitoring systems Translation and transcription Basic Magpi, Kobo, or ODK software programming for surveys Piloting, preliminary analysis of results, and any augmentation of the tool accordingly.
Implementation of research protocol	 This includes: Consultation and development of research protocol and tools (see above) Coordination with partners for successful implementation of research plan Development of enumerator job descriptions Enumerator training and supervision Data analysis (see section below)
Statistical and/or Qua	alitative Data Analysis
Consultation at project inception	A consultation session is available during the project inception phase to review the data analysis section of your research protocol and provide input into its further development.

Item	Description
Development of analytic plan	In consultation with a member of the Research Team during the proposal development phase, the analytic plan will be developed for the proposal and adjusted, as needed, during the project inception phase.
Implementation of analytic plan	 After consultation during the proposal development and inception phases of the project, a member of Research Team is available to carry out the proposed analytic plan. This includes: Data entry and cleaning Coding and analysis Leading co-analysis workshops with partners Current software packages in use: STATA, SPSS, NVivo, Dedoose
Staff refresher training on analysis	For staff already proficient in qualitative or quantitative analysis, this option may provide additional one-on-one support for the staff member to ask questions about the software and/or different techniques that can be used to analyze the data.
Publication	
Consultation at project inception	If you are considering publishing and/or presenting research results externally, a consultation is offered at the proposal development and project inception phases. Note that most peer-reviewed journals require IRB approval for submission. Open-access journal fees vary widely. It is helpful to review a few journals that you intend to target during this phase to ensure you have properly budgeted for the fees.
Manuscript development	After consultation during the proposal development and inception phases of the project, a member of Research Team is available to lead and/or contribute to the development of manuscripts for peer-reviewed journals.

ANNEX G: RESEARCH PROPOSAL CONSULTATION CHECKLIST

Proposal development is an exciting time, and the Research Team is here to support you. We provide consultation sessions for program technical leads to ensure the most robust research design is incorporated, innovative methodologies are explored, and appropriate research staffing is considered in your proposal.

The **Proposal Consultation Checklist** (see next page) helps you to guide the proposal development process. Based on the input from the Checklist and Consultation, the Research Team will be able to advise you on:

- which parts of the **Research Protocol template** need to be filled out (See Annex J);
- whether a **formal ethical review process** is necessary, and if so, what kind of ethical review (See Annex C); and
- what <u>budget needs</u> to expect in order to best carry out the research or evaluation activities (See Annex H).

Please let us know if you have any questions: <u>research@wrcommission.org</u>.

Rese	earch Team Proposal Consultation Checklist			
STEP 1	 Is the project being proposed likely to include any of the following activities? assessments program monitoring (M&E toolkits) evaluations (pre-post with comparison group, randomized controlled trials RCTs, implementation studies, etc.) research (population-based survey, qualitative, participatory, etc.) Yes → Go to STEP 2 No 			
STEP 2	 Schedule a PROPOSAL CONSULTATION SESSION with the Research Team by reaching out to research@wrcommission.org If possible: Before the Consultation Session, consider questions in STEP 3, which will inform the most effective design, ethical review, and budgeting. 			
	Purpose; Uptake; and Dissemination			
	 What is the overall purpose of this project? What is the planned audience for the findings? What will the findings of this project inform? What kinds of outputs/products will be created from this project? 			
	Preparation			
	 What is the projected timeline for the project? Do you anticipate the project requiring a desk, structured, or systematic review? 			
ь В	Data Collection			
STEP	 What data are you collecting? From whom are you collecting the data? Do you anticipate new tools to be developed and/or adapted? Where are you collecting the data? Do you plan for a member of the Research Team or yourself (/project partners, consultants, etc.) to carry out the data collector training and data collection? 			
	Analysis			
	How do you plan to analyze the data?			
	Do you plan for a member of the Research Team or yourself (/project partners, consultants, etc.) to carry out the analysis?			

ANNEX H: RESEARCH PROPOSAL BUDGET CONSIDERATIONS

This document is a refresher to highlight budget items and direct costs to consider when carrying out research or evaluation projects or activities. For additional budgeting guidance, refer to the <u>Qualitative</u> <u>Data Collection Budget Estimator</u>.

Budget item	Considerations
Personnel	
Personnel: Population- based surveys	 For large household surveys, you should plan to recruit and train several teams of data collectors. Generally, one individual should not be expected to do more than 4-6 household interviews in a day (taking into consideration length of data collection tool and time needed to travel to respondents). You should plan out your team based on the time you have for data collection and the number of interviews you plan to complete. Each team should have a supervisor to manage problems and check completed questionnaires. This may be you, but likely you will need someone (a colleague or someone you hire and work <i>very</i> closely with) who fully understands the study and can make decisions. If you train people and feel good about their skills, you get the most for that investment, if they can work on data collection for a couple of weeks. This is not always feasible, but it's a better investment, as quality improves through the period of data collection.
Personnel: Qualitative data collection	 With in-depth or key informant interviews or focus group discussions (IDIs, KIIs, or FGDs), you must decide if you will facilitate the interview or sessions with a translator, or if you will train a team to implement the interviews/discussions in the local language. If you plan on the latter, there must be a <i>significant</i> investment in training. You may want to consider getting interviewers/facilitators who have experience in qualitative research, or NGO staff who have experience in data collection, in addition to those with prior background knowledge in the content area.
WRC Research Team time, program staff time	Consider time needed for desk or literature reviews, tool development, piloting and testing of tools, primary data collection, data entry and cleaning, coding and analysis, and reporting. Consider what elements you would like the WRC Research Team to do, and what you would like to do.
Data collectors: interviewers, FGD facilitators, enumerators	 Always plan to recruit and train a few more data collectors than you need, but make this clear to everyone. Check with context on how best to do this. For those who you aren't as interested in hiring, see if there are other ways for them to be part of the team. When providing a stipend, it is easiest to include meals, incidentals, local travel, and accommodation within one stipend, so that they can manage their own expenses.

Budget item	Considerations
Supervisors	 Any time there is a team of data collectors, it is advisable to have a supervisor. The supervisor does quality assurance and troubleshoots issues that arise during data collection. If it is one team, and you will be there during most of the data collection exercise, then the supervisor can be you. If there are multiple teams, or you won't be present at data collection, then you should consider assigning a supervisor. One option is to select the highest-performing data collector and make them the supervisor; however, the tradeoff is that this high performer does not directly collect data. A supervisor requires specific guidance/training on how to supervise (e.g., how to manage selection of respondents; how to observe data collection; how to spot check and ensure quality collection; how to give feedback to data collectors).
Travel	
Flights	[Based on the context]
Accommodation	 Accommodation for WRC staff. Depending on locations, include per diem and accommodation for local data collectors as well. Include 1-3 days upon arrival to the project site for last-minute planning and coordination.
Meals and Incidentals	[Based on the context]
Local transport	[Based on the context]
Vehicle hire for study team	[Based on the context]
Fuel for vehicle hire	[Based on the context]
Meetings and Conferences	
Data collector training	 Qualitative training should be planned for a minimum of 5 days unless you have very experienced colleagues. For inexperienced/less experienced data collectors for qualitative or participatory work, such trainings can be up to 2 weeks long. Make a decision on the direction you will go based on budget available, anticipated experience level of data collectors, and type of information needed. Include tea breaks, lunch, room rental, drinking water, etc.
Reimbursements/ incentives for study participants	 Transport arrangements or reimbursements for research participants may be necessary. Check the local context to see whether providing refreshments to participants is appropriate. If so, beverages like water or soft drinks and snacks for study participants (biscuits, fruit, etc.) are often appreciated (e.g., women/girls may bring their children to a data collection activity) Rarely do we provide gifts or incentives to participants for ethical reasons; however, benefits from the research should typically come back to the community researched.

Budget item	Considerations
Coding/Analysis workshop	For qualitative research, there will be a coding meeting to develop codes and apply first-cycle coding. This will most likely involve a training/workshop, since most data collectors will not be familiar with coding. This is especially true if you are using a CAQDAS software like NVivo.
Stakeholder meeting	Venue; food if needed.
Feedback to communities	Venue; beverages; transport, etc., if needed.
Contractual	
Transcribers/Transcription	 Qualitative data that is recorded will have to be transcribed and, perhaps, also translated. Transcription takes substantial time; you can count on at least 2x the time of audio; longer if the material must be translated. Interviews ideally need to first be fully transcribed in the language they were conducted in, and then translated into English. FGDs take longer to transcribe than one-on-one interviews. Most data collectors do not have transcription experience and will have to be trained in it. Regardless, all transcribers (even experienced ones) must be oriented to the study's particular transcription style guide and transcription software. It is worth knowing the analysis and reporting plan before beginning transcription; many features of spoken language may or may not need to be reflected in the transcription, depending on the detail of analysis.
Translators/Translation	 Many decisions need to be made around translation that will have cost implications. <i>Translation of study flyers</i>—May be needed for recruitment of participants <i>Translation of tools</i>—Translation is typically needed for the research tools (consider the number that are being developed) <i>Translation of transcripts</i>—If transcripts are recorded in local language- the translation of these transcripts can be expensive (e.g., \$2,000-\$6,000 would not be abnormal per site/ \$20 per page is another estimate that has been routinely cited) <i>Translation of participants' reports</i>—All research proposals should budget \$200-\$400 for translating both the one-pager about the WRC and the proposed work and 1–2-page participants' reports into the local language(s) There is still a lot of discussion regarding the best way to feed information back to communities. Ensure that you have budgeted for either feedback meetings, or a written report, or both, and accounted for interpretation or translation of these in the budget.

Budget item	Considerations
Data entry	Surveys carried out on paper forms have to be collected and entered into a database. This can take significant data collector or research assistant time depending on the length of the form and sample size.
Survey programming	 Questionnaires might be carried out in an online or tablet-based form. Unless the form is very basic, it will have to be programmed using more advanced software, such as Magpi or Kobo Toolbox. The WRC Research Team can program basic Magpi and Kobo forms, but if you have a complicated survey tool, you may choose to budget for a consultant to program Kobo. Please consult a Research Team member as there may also be other associated fees with mobile data collection.
Public Information	
Printing	Participants' fact sheets and reports can be printed in-house; summaries and technical reports are best printed externally. Ex., a 4- page report @250 copies or 10-page report @500 copies.
Photocopying	If implementing a household survey, producing copies of surveys can be a significant cost, especially in support offices where paper and toner supplies are limited.
Publications	Open-access journal fees vary widely. It is helpful to review a few journals that you intend to target during this phase to ensure you have properly budgeted for the fees. If you are partnering with an academic institution, check to see if they have member privileges with certain journals that will reduce the fee amount. Payment is only required if the article is accepted.
Analysis Software	STATA, SPSS, SAS, NVivo, Dedoose. Be sure to check with the Research Team to ensure the software package is available and up to date.
Equipment and Supplies	
Supplies for training and activities	Pens, notebooks, flipcharts + markers, printing, computer + projector, etc.
IT equipment	 Mobile phones and/or tablets if doing a mobile survey data collection. Digital voice recorders if recording interviews/FGDs; along with power banks if working in a place without a power source. Mobile credit for phone calls may be needed for data collection team. Credit for data for internet access or a portable hotspot may be needed for data collection team. If data collectors are transcribing interview audio, they will require laptops or computers; we can't count on data collectors to own personal computers, so computer access may either need to be provided by WRC or by a local partner. Transcribers may require over-ear headphones in order to best hear audio.
Other Direct Costs	

Budget item	Considerations		
Staff/professional development	Include analysis training if necessary or include funds for staff development (research trainings, workshops, meetings)		
Approval procedures (IRB)	 Human subjects research should involve ethical review. Institutional Review Board (IRB)—Review provided by a university IRB can be an expensive endeavor. Many universities would require that one of their staff be a principal investigator (PI) on any protocols that go through their system (this may involve a sub-grant to the institution). Other times, a simple consultancy agreement is sufficient. IRB ethics review typically costs \$200-\$3,000 depending on complexity of the study, and some IRBs request funds for monitoring or audits as a percentage of research costs. Some research sites also require ethical review from a local research or academic institution. This process may also have associated fees that should be determined at the planning phase, if possible. Local Advisory Committee—Not every assessment or evaluation requires review from an IRB. Where university institutional review is not incorporated, local advisory committees can be convened to improve the ethics of work. This may involve costs for transportation to bring committee members to a central location to meet. Government stakeholder review—Relevant government agencies or governmental bodies (e.g., ministries of health) may have dedicated committees or focal persons who are tasked with reviewing and approving research and evaluation in a given locality; formal review by government agencies may also involve a fee. 		
Contingency			
10% contingency of total dir	10% contingency of total direct costs would be helpful to add.		

ANNEX I: GUIDANCE ON PROCESSES OF PUBLICATION

The Women's Refugee Commission sees publication as a major route to enhancing the evidence-base for health and protection of crisis-affected populations and also of strengthening capacity for health research in these settings.

In enabling publication to meet these goals, this guidance is based upon balancing the following principles:

- (a) **Due recognition of contributions** made in conception, design, implementation, analysis, and write-up of research studies.
- (b) **Promotion of authorship** among junior researchers and those based in low- and middle-income settings.
- (c) **Ensuring quality assurance** of papers by those accountable for them through the [insert grant] award.

This annex provides an introduction to publication, including aspects related to the identification of your writing team and the development of journal articles. It should be used in consultation with a member of the Research Team to ensure it is tailored appropriately to the grant requirements and project circumstances.

Identification of the initial writing team

- All research papers will be associated with a work plan agreed upon by all partners.
- The nominated lead for the work listed in the spreadsheet should identify an initial writing team for each potential paper early in the conceptualization of the work package.
- Where the writing team does not include the principal/co-investigators [insert principal investigator (PI) and co-investigator (co-I) names] the approval of the initial writing team should be sought from the named PI lead on the project.
- Responsibilities of individual members of the initial writing team (e.g., first draft author, literature review, data analysis, technical inputs, manuscript review and editing) should—where possible—be identified at this time.

Monitoring progress of development of the paper

• The nominated lead for the work strand and/or proposed first author should take responsibility for monitoring progress of the paper against agreed timelines (reporting significant delays to the strand lead, who can report this to the donor as/if necessary).

Drafting of paper and circulation for review

- WRC encourages the circulation of early drafts of outlines of papers ("zero drafts") early in the paper preparation process to secure formative feedback and avoid significant investment of time in analysis or text unlikely to find its way into the final paper.
- Drafts should be circulated for review to the full writing team and—where this does not include the principal/co-investigators [insert PI and co-I names] —to the named strand lead.

Determining criteria for authorship

- WRC endorses the International Committee of Medical Journal Editors (ICMJE) criteria for authorship:
 - Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work;
 - Drafting the work or revising it critically for important intellectual content;
 - Final approval of the version to be published;
 - Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.
- Interpretation of these criteria should reflect the principles (a), (b) and (c) noted above. Specifically:
 - Coordination of data collection in fragile settings is a complex task and will normally be seen to represent a substantive contribution.
 - Tasks completed under direction from a listed author (e.g., completion of a background literature search, completion of a specific statistical analysis, preparation of graphics and tables) will normally appropriately be <u>acknowledged</u> but not constitute a basis for authorship; however, completion of a systematic literature review (or similar) or completion and interpretation of a series of statistical analyses will normally be an appropriate basis for authorship.
 - The 'agreement to be accountable' clause does not require all authors to be competent in all aspects of the study methodology and analysis but rather to assume responsibility for accuracy and integrity of the work described.
 - Named principal/co-investigators (insert PI and co-I names) have <u>no</u> automatic right to authorship on paper on the basis of their role in project funding or governance; however, in most cases one or more of these investigators will likely meet the 'substantive contribution' criteria for authorship on the basis of conception of the project and/or facilitation of acquisition of data (they will additionally, be required to meet the other three criteria if they are to be listed as an author).
- Application of these criteria may mean that authorship is different from membership of the initial writing team. Specifically, those identified as members of the initial writing team may—on the basis of their contribution—not meet criteria for authorship (but may be appropriately acknowledged). Also, those not identified as members of the writing team may now meet the criteria for authorship. Anyone unhappy with allocations of authorship following such adjustments may lodge their concerns using the process outlines in the *Managing disputes* section below.

Determining order of authorship

- At the stage of developing a first (or 'zero') draft of the publication the writing team should be consulted on the potential ordering of authors.
- The first author of the paper will normally be the person taking responsibility for coordinating inputs across the writing team and producing the initial draft of the paper.
- WRC—reflecting principle (b) above—actively encourages researchers from low- and middle-income countries and junior researchers to take on this role.

- Where there are a series of papers in development in relation to a work package, there is the expectation that the opportunity to take on the role of first author be shared across those able to take on this coordinating role.
- Subsequent ordering of authorship will generally reflect levels of contribution to the paper.
- Where the person leading in the conceptualization of the study does not take on the responsibilities of the first author, they may be considered to be listed as corresponding author.
- The last listed author may normally be a senior researcher who takes responsibility for quality assurance of the work and its fit within the overall research portfolio of WRC (in addition to meeting the general criteria for authorship listed above).

Actions in advance of submission

- <u>All</u> listed authors must approve the text of a manuscript before submission to a journal.
- Where one of the named principal/co-investigators [insert PI and co-I names] is <u>not</u> a listed author, the approval of one of these named principal/co-investigators should be gained before submission.
- The first author must ensure that relevant text required by WRC is included in any submission to a journal.

Making presentations based on a paper

• All co-authors can give presentations of a paper after publication, using material in the paper and dataset, providing they reference the paper and their co-authors.

Managing disputes

- If anyone considers that they have been unfairly treated on a matter related to publication and authorship covered by this guidance they should—in the first instance—raise the matter within the designated writing team noting the guidance provided here.
- If that does not result in resolution of the conflict, the matter should be raised with one of the named principal/co-investigators [insert PI and co-I names], who will seek to resolve the issue by discussing with all relevant parties.

ANNEX J: RESEARCH PROTOCOL TEMPLATE

Research Protocol Template

WRC Research

1. Project Summary
Title:
Funded by: Drinsinks Investigator on Draiget London
Principle Investigator or Project Leader: Location:
Study site(s):
2. Background
2.1. Introduction
2.2. Literature review
2.3. Problem statement and study justification
3. Research Question and Objectives
3.1 Research question
3.2 Study objectives
4. Design
4.1 Study design
4.2 Study setting and population
4.3 Inclusion and exclusion criteria
5. Sampling
5.1 Frame and sampling plan
5.2 Sample size determination
5.3 Participation recruitment
6. Methods

- 6.1 Data collection
- 6.2 Tools

- 6.3 Data management
- 6.4 Data analysis
- 6.5 Limitations

7. Ethical Considerations

7.1 Ethical review

- 7.2 Informed consent forms
- 7.3 Privacy and confidentiality
- 7.4 Mitigating risks
- 7.5 Describe benefits
- 7.6 Study monitoring
- 7.7 Researcher bias

8. Dissemination and Utilization of Results

- 8.1 Audiences
- 8.2 Products
- 8.3 Timeframe

9. Workplan

- 9.1 Timeline
- 9.2 Estimated/projected budget