

# ETHICAL CONSIDERATIONS IN RESEARCH ON FEMALE GENITAL MUTILATION

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# ACRONYMS AND ABBREVIATIONS

<b>ARP</b>	alternative rites of passage
<b>CBO</b>	community-based organization
<b>CBPR</b>	community-based participatory research
<b>CIOMS</b>	Council for International Organizations of Medical Sciences
<b>DHS</b>	Demographic and Health Surveys
<b>FGM</b>	female genital mutilation
<b>FGM/C</b>	female genital mutilation/cutting
<b>MICS</b>	Multiple Indicator Cluster Surveys
<b>NGO</b>	nongovernmental organization
<b>SDG</b>	Sustainable Development Goal
<b>UNESCO</b>	United Nations Educational, Scientific and Cultural Organization
<b>UNICEF</b>	United Nations Children's Fund
<b>WHO</b>	World Health Organization

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## PREFACE

Female genital mutilation (FGM) is a harmful traditional practice that involves the partial or total removal of external female genitalia or other injury to female genital organs for non-medical reasons (WHO, 2020). Over 200 million girls and women alive today have undergone FGM, with approximately 3 million girls at risk each year (UNICEF, 2016). FGM is widely condemned from a human rights and public health perspective. The abandonment of FGM is a target in the Sustainable Development Goals (SDG target 5.3) (UN, 2015).

High-quality, ethical research on FGM is an essential component of international, national and local efforts to end the practice to enable investors, policy-makers and programmers to make evidence-based choices to maximize the impact of interventions, while ensuring that the rights of research participants are respected. Research on FGM has been conducted for many decades with no specific ethical guidance available as a resource for researchers, despite it involving a complex range of potential risks and harms that require careful consideration to maximize the value and impact of the research while minimizing the risks.

Research on FGM uses a range of study designs and methodologies. This guidance document has been developed to strengthen the ethical conduct of all research on FGM by highlighting the key ethical considerations faced by researchers developing protocols and conducting research and by research ethics committees reviewing protocols. The document is grounded in concepts from existing ethical guidance for research involving human subjects (CIOMS, 2016) as applied to research on FGM.

Due to the sensitive nature of FGM and the potential risks individuals may face when conducting or participating in research on FGM, specific guidance is needed on how to ensure that safety measures and ethical principles are addressed in all stages of research on FGM, from study design and implementation to the interpretation and dissemination of the results.

In communities where FGM is practised, questions of identity and power are closely linked to the FGM status of a girl or woman. The very nature of information that might be shared during research on FGM, and on other sensitive topics, is often personal and linked to individual and cultural identity. It is also linked with the overlapping layers of risk and vulnerability due to age.

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