A Matter of Principle:
A Family Planning NGO Experience Setting Up an Independent Ethics Research Committee

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Problem Statement
Marie Stopes International (MSI) is one of the largest global providers of family planning (FP), delivering services in 39 countries. MSI conducts a wide range of research activities, including population-based surveys, clinical trials, marketing studies, service evaluations, client satisfaction assessments and retrospective analyses of routine client service data. As MSI expands its services worldwide, strengthening the quality and quantity of research contributes to improving services and sharing findings with the broader medical, scientific and NGO communities.

Given the absence of ethics committees in some countries, and the need for review in both ‘host’ and ‘sponsor’ countries, MSI explored options for independent reviews. MSI protocols were ineligible for review by existing UK committees (e.g. universities or hospitals) or other reviewing organisations’ ethics committees did not focus on FP and reproductive health.

Program Description
By establishing its own independent ERC, MSI aimed to ensure research meets standardised ethics requirements. The following activities were completed:

• Consultation among Ethics Committees, Research Institutions & NGOs
  Consultations with numerous ethics committees and other NGOs sponsoring research in developing countries was undertaken to develop a Terms of Reference. The TOR draws upon the Declaration of Helsinki and guidelines by the Council for International Organizations of Medical Sciences Nuffield Council’s report on ‘Ethics of research related to healthcare in developing countries’.

• Established MSI Ethics Working Group
  An internal Ethics Working Group brings together MSI representatives from a number of key sectors: program implementation, clinical quality and external relations to provide insights into the ethical issues related to research on reproductive health service delivery.

• Established MSI Ethics Review Committee
  MSI appointed a Chair who recruited 11 committee members with developing country experience across a variety of disciplines including: demography, epidemiology, clinical obstetrics and gynaecology, HIV & AIDS, qualitative and quantitative research, law and human rights.

• Reviewed Other Organisations’ Ethics Review Procedures
  FHI360, Johns Hopkins University, London School of Hygiene & Tropical Medicine, Population Council, Medecins Sans Frontieres reviewed

• Secured OHRP Registration of MSI Ethics Review Committee & MSI Federal-Wide Assurance

Reflections
To our knowledge, the MSI ERC is the first independent review committee established by a United Kingdom NGO. We are developing procedures to ensure MSI research meets the highest scientific and ethical standards, given the many sensitive issues unique to FP research.

From a gap in existing structures for ethical review of FP research arose a unique opportunity for MSI to develop a new process of ethics review, tailored to the needs of FP research.

MSI’s experiences revealed the inadequacy of existing structures to meet the growing need among FP service delivery organisations for support to conduct ethically sound research. While NGO research proliferates, not all NGOs can establish an independent ethics committee. Alternatives like shared or international ethics review bodies may be needed.

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