

Historical note: How bringing women's health advocacy groups to WHO helped change the research agenda

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Abstract: *The politics of population control and its sometimes coercive methods in developing countries documented during the 1960s, 70s and 80s, gave rise to strong opposition by women's groups, and put into question the safety of contraceptive methods that were being developed and introduced into countries. In 1991, the Special Programme on Human Reproduction at the World Health Organization, a research programme focused on development of new methods and safety assessments of existing fertility regulation methods, started a process of "dialogue" meetings between scientists and women's health advocacy groups which lasted for nearly a decade. This paper describes the process of these meetings and what they achieved in terms of bringing new or different research topics into the agenda, and some of the actions taken as a result.* © 2015 Reproductive Health Matters. Published by Elsevier BV. All rights reserved.

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Nearly 25 years ago, Mahmoud Fathalla, then Director of the UNDP/UNFPA/WHO/World Bank Special Programme of Research, Development and Research Training in Human Reproduction (HRP) based at WHO in Geneva, spearheaded an initiative in which women's health advocates were brought into the process of defining research priorities in contraceptive research. At the time, in 1990, this was a bold and innovative step. HRP had been set up in the early 1970s to conduct research into human reproduction with a large emphasis on the development and long-term safety and efficacy of fertility regulation methods. It worked with a pool of scientists and institutions in both developed and developing countries, aided by a series of technical advisory committees with membership of scientists from around the world. HRP was established in good part as one contribution to address the fears of a "population explosion" in the 1970s and 1980s, perceived by some as likely to lead to mass starvation, a problem that could only be addressed by urgent measures to control population growth.¹ It was thought then that, if more contraceptive methods existed and were available, more women would use them.

While HRP was being established, the international development community was already engaged in providing massive support for population control policies in developing countries,

often implemented through programmes euphemistically called "family planning". The approach, concerned primarily with reaching targets for population reduction, used techniques like incentive schemes which were frequently coercive, pressuring women into accepting long-acting methods such as the IUD, injectables and implants without adequate information or informed consent.

The new wave of feminism in North America and Western Europe was also growing in the early 1970s, with the demand for free contraception and abortion on demand becoming a cornerstone of the political agenda.² The widespread marketing of the first oral contraceptive pill at the end of the 1960s made this demand, in part, seem possible. This had a positive influence on the women's liberation movement, but towards the end of the 1970s, the quality and safety of contraception started to be questioned by women's health advocates. During the same period, and into the decade of the '80s, women in developing countries started to fiercely oppose the coercive nature of the population control policies being implemented in their countries. A statement, for example, made by 16 women's organizations and professional health groups in Cusco, Peru, in June 1989, in response to a USAID document entitled "Strategy for Population USAID/Peru" stated clearly that family planning can be

imposed in a discriminatory way, and that it was women in the poorer sectors of society that were the main target of population policies.³ Women in India had concerns about the safety of the injectable contraceptives being introduced: “Feminist groups are concerned about the inconclusive animal studies and undesirable side effects demonstrated by the clinical trials in India and the world over. Therefore a campaign committee against long-acting contraceptives has been formed to try and prevent the introduction of these drugs.”⁴

Responding, in part, to this growing opposition by women's health advocacy groups in different parts of the world, HRP's governing body recommended the Programme consult with women's groups about the research agenda. HRP's Biennial Report for the period 1988-1989 states:

“Women are at the heart of development. They are also the main victims of unregulated fertility and it is imperative, therefore, that any organization concerned with reproductive health issues involves women in all aspects of its operations from policy setting through planning and implementation of activities to disseminating information. In this last respect the Programme has taken an active role during the biennium in seeking to expand its links with women's groups, which are important sources of information to women in many parts of the world.”

The major expansion of these “links with women's groups” was realized in 1991 when HRP, in partnership with the International Women's Health Coalition (IWHC),* held the first of what was to become a series of “dialogue” meetings between scientists and women's health advocacy groups. These meetings came to be known as Creating Common Ground, and took place from 1991 to 1997.

As the rapporteur for that first meeting and coordinator of another six such meetings at both international and regional level, I feel that this current issue of RHM presents an opportunity to reflect on what these meetings achieved and how they contributed to modifying, if not radically changing, the research agenda of HRP and to some extent that of its collaborators. The meetings highlighted the

kinds of questions that representatives of contraceptive users found important in a way that most scientists (until then) had simply not thought about. I offer it as an informal review from a personal perspective rather than a full evaluation of the events and their impact. I do, however, ground my reflections in documented references.

The first Creating Common Ground dialogue

The first Creating Common Ground meeting took place in Geneva in February 1991. It aimed to establish a dialogue between the scientists and scientific collaborators of HRP on the one hand, and people involved in women's health advocacy on the other, and to identify means by which women can influence and be involved in both the choice and introduction of methods of fertility regulation. It was an attempt to “narrow the distance between institutions that formulate policy and the consumers affected by policy.”⁵ The participants included sixteen scientists from different regions of the world, collaborating with the Programme, selected for their expertise on contraceptive safety and efficacy, sexually transmitted diseases, provider-dependent methods such as injectables and intrauterine devices (IUDs) and the introduction of new methods, but also for their ability to listen to different points of view. To match them, sixteen women's health advocates from international, regional and national organizations around the world (Bangladesh, Brazil, Chile, India, Indonesia, Netherlands, Nigeria, Peru, Sudan, USA) were invited to participate. All were from organizations working with IWHC and were selected on the basis of their long experience in working with women's sexual and reproductive issues, and their known ability to represent a broad range of women's views. Care was taken to ensure that all regions of the world were represented. Because of the weight that science carries, especially within an international organization such as WHO, IWHC insisted that there be the same number of women's health advocates as scientists.

The discussion was broad-ranging and often complex, but highlighted here are just some of the key issues raised, as they are by no means irrelevant today. They are all drawn from the report of the meeting.⁵

Concept of safety

The first meeting immediately brought to the fore the use of terminology, definitions and meanings.

*IWHC was founded in 1984 to advance the sexual and reproductive health and rights of women and young people, particularly adolescent girls, in Africa, Asia, Latin America and the Middle East, and advocates for supportive international and USA policies, programmes and funding. <http://iwhc.org/about-us/>.

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