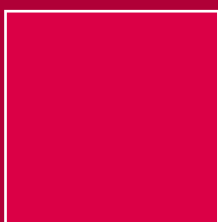


Perceived research priorities in sexual and reproductive health

for low- and middle-income countries:
results from a survey



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Perceived research priorities in

SEXUAL and REPRODUCTIVE HEALTH

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middle-income countries:
Results from a survey



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Contributors

Andres de Francisco contributed to developing the survey instrument, overseeing its administration and analysis, devising the paper, conducting discussions of inputs at two international workshops, and securing funding.

Catherine d’Arcangues contributed to the development, the weighted analysis, and devising the paper.

Karin Ringheim of the Population Reference Bureau, USA, further analyzed the qualitative data and contributed to writing the report.

Anna Liwander contributed to the survey’s administration, initial coding of the open-ended questions, basic analysis, and to writing the manuscript.

Alexander Peregoudov contributed to the questionnaire design, development of the software tool for automated data processing, and statistical analysis with SAS.

Hannah-Sarah Faich contributed to the analysis of some quantitative and qualitative results, organizing one of the international workshops, and to writing the manuscript.

Lakshmi Sundaram contributed to the development and administration of the survey, coding of the open-ended questions, and organizing one of the international workshops.

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Executive Summary

Universal access to reproductive health was agreed upon at the International Conference on Population and Development (ICPD) in Cairo in 1994. Although initially omitted, universal access to reproductive health by 2015 was added to the Millennium Development Goals (MDGs) framework in 2005. Though sexual and reproductive health (SRH) is now recognized as essential for achievement of all MDGs, the area remains highly neglected. Funding for sexual and reproductive health, exclusive of HIV/AIDS funding has not only failed to meet Cairo financial commitments; it has decreased in absolute terms. A greater understanding of research priorities, particularly in less developed countries where poor sexual and reproductive health appear intractable, is much needed. As a contribution to this effort, the Global Forum for Health Research and the UNDP/UNFPA/WHO/World Bank Special Programme of Research in Human Reproduction (HRP) collaborated in conducting a survey on research priorities as perceived by stakeholders working in the field in low- and middle-income countries.

The survey requested respondents to provide up to three questions that they perceived to be the most urgent and important questions needing to be addressed in the SRH field. More than 500 individuals from 99 countries submitted more than 1,400 research questions. Two-thirds of respondents were based in low- and middle-income countries (LMICs), providing input from a constituency that is often under-represented.

Respondents' questions cover a wide spectrum, from basic biomedical and clinical research to operations and health systems research. Their priorities reveal that many unanswered questions impede progress in the SRH field. Questions indicate the need for greater emphasis on social science research and programme development to better understand the determinants of SRH, particularly the influence of cultural norms, and how to use this information to design appropriate and accessible services and health programmes, especially to meet the needs of the poor and other vulnerable groups. Translation of evidence into practice, scaling up of effective interventions and establishing linkages between SRH and HIV services accounted for most strategy-related questions. Many questions concerned how best to provide sexuality education and services to protect the health of youth.

Results from this international consultative process suggest that answering such priority questions is critical to achieving the vision of Cairo and the MDGs. Respondents to this survey add new voices to the chorus of evidence showing that a critical shortage of resources for SRH activities, including research in low- and middle-income countries, must be addressed if universal access to sexual and reproductive health is to be achieved.

Introduction

“If donors – countries, banks, funders, and foundations – wish to see their investments flourish, they need to ensure that reproductive health is at the heart of their support”.¹

The year 2009 marks the 15th anniversary of the 1994 Fourth International Conference on Population and Development, (ICPD) held in Cairo. At this historic convocation, representatives of 179 countries agreed to a Programme of Action aimed to achieve sexual and reproductive health for all by 2015. As the first and most comprehensive international policy document to endorse reproductive rights and reproductive health,² the Programme of Action broke new ground in recognizing the fundamental role of women and young people in development. It provided a visionary 20-year blueprint of action for reducing poverty and inequity, promoting human rights, empowering women, protecting the health of adolescents and children, and constructively engaging men.

Cairo at 15: Where do we stand?

Cairo called for universal access to comprehensive reproductive health services by 2015, including family planning information, services and supplies, as well as safe abortion services (where abortion is legal), antenatal care, skilled attendance at birth, availability of emergency obstetric care and neonatal and postnatal care for mother and baby. The agreements reached at Cairo were affirmed in subsequent international agreements, and were incorporated into the Millennium Development Goals (MDGs). The Cairo consensus is relevant to all eight MDGs, but particularly to MDG 4 to reduce child mortality and to MDG 5 to improve maternal health.

In 2009, many governments are marking the 15th anniversary of the Cairo consensus by taking stock of their progress since Cairo. With just five years remaining until 2015, in regional Cairo plus 15 events throughout the world, representatives have acknowledged the urgent need to accelerate action if the Cairo vision is to become a reality.³

Status of the MDG 4 and 5 target indicators

As the year 2015 approaches, progress has been made, but it is uneven; much remains to be done if the promise of Cairo is to be realized. Each year, three million infants die in the first week of life, most of causes related to their mother’s health and to pregnancy and delivery. An additional one million infants die in the first month of life.⁴ In the developing world, health care during pregnancy is received by only two thirds of all pregnant women and only 60% of all deliveries are attended by trained staff. More than half a million women still die of causes related to pregnancy and childbirth each year, a negligible decline since 1990. Nearly all deaths occur in the developing world, where the maternal mortality ratio declined by only 30 points, (from 480 to 450 deaths per 100,000 live births) between 1990 and 2005.⁵ Women in sub-Saharan Africa face a one in 22 lifetime risk of dying of maternal causes, as compared to less than one in 6,000 in high-income countries.

Globally, the use of modern contraceptive methods has risen to 5%; at the same time, however, the numbers of women with an unmet need for contraception has risen dramatically: the percentage of women of reproductive age was 22% larger in 2005 than in 1990.⁶ More than 137 million women desire to stop having children or to space their births, but are not using any method of contraception to do so. The adolescent birth rate remains unacceptably high, even in some high-income countries. Sexually transmitted infections, excluding HIV/AIDS, represent the second most important cause of ill health among women of reproductive age, particularly young women, as well as a substantial cause of morbidity in men.⁷

Figure 1. MDG 4 and 5

| |
|---|
| MDG 4 Reduce child mortality |
| Target 4.2 Infant mortality rate |
| MDG 5 Improve maternal health |
| Target 5a: Reduce by three-quarters the maternal mortality ratio |
| Indicators: 5.1 Maternal mortality ratio (maternal deaths per 100,000 live births) 5.2 Proportion of births attended by skilled health personnel |
| Target 5b: Achieve universal access to reproductive health |
| Indicators: 5.3 Contraceptive prevalence rate 5.4 Adolescent birth rate 5.5 Antenatal care coverage 5.6 Unmet need for family planning. |

The vision of sexual and reproductive health for all people remains threatened by inequities: large health disparities between rich and poor countries, gender inequities between men and women, unjust restrictions in information and services for the young and unmarried as compared to married adults. Most deaths of infants and their mothers occur among the poor and often could have been prevented through simple and cost-effective strategies.⁸

Financial support for sexual and reproductive health has fallen far short of the targets set in Cairo.^{9,10} While funding commitments have been hampered by competing priorities (primarily the dramatic increase in resources needed to combat HIV/AIDS), funding for sexual and reproductive health has also suffered from a lack of effective “marketing”. The case for universal sexual and reproductive health has not been compelling enough, nor the solutions made clear enough to engender the level of support from policy makers that would make the achievement of universal coverage feasible. Advocating for sexual and reproductive health solely as a human right rather than also as a sound investment has not swayed donors and ministers of finance.¹¹ The human rights argument is not diminished by also building a convincing case for the economic dividends that investment in sexual and reproductive health will pay. Research to estimate the long-term savings to health systems and the social and economic benefits of improved sexual and reproductive health has been helpful in this regard,¹² and more such research is needed. Over the 15 years since the Cairo consensus was reached, research has helped to define what works and at what cost to improve sexual and reproductive. However, the remaining gaps in our knowledge and understanding are substantial, and impede greater progress and success.

Identifying gaps in research knowledge

“Research plays an essential role in identifying and overcoming social and economic inequalities and health-system deficiencies that stand in the way of achieving the highest attainable standard of sexual and reproductive health for all.”¹³

As a first step in an inclusive process to identify research gaps and priorities in the field, the Global Forum and HRP conducted expert consultations and a review of the literature. The above referenced report, outlining a rights-based conceptual framework centred on meeting the needs of individuals, and thematic and cross-cutting issues for sexual and reproductive health research, was published in 2007. In 2006 and 2007, the Global Forum and HRP also collaborated in conducting a survey to obtain input from stakeholders working in the field on their priorities for research in sexual and reproductive health. Preliminary results of the survey were shared during two stakeholders meetings which aimed to gain further input into priorities and gaps within the field.¹⁴

This paper describes the final results of the survey, and draws upon the 2007 report to provide background and context for the priority research questions identified in the survey. The priorities identified through this international consultative process provide further evidence of the gaps in sexual and reproductive health research in LMICs. They present a compelling argument for putting SRH back on the centre stage of public health.

CHAPTER 1

Material and Methods

1.1 Study population

The study was conducted between December 2006 and June 2007. Participants were identified through internal databases, internet searches, list serves, recommendations from senior staff and country representatives of WHO and its collaborating centres. To be eligible, individuals and organizations had to be working on, commissioning, or using research for SRH programme development. Organizations and individuals identified through the search were sent a questionnaire directly. A total number of 1,874 people based in research-oriented bodies/academia, nongovernmental/civil society organizations, government, intergovernmental organizations, and others, were contacted.

Respondents in this “primary group” received the questionnaire as an email attachment, and were asked to forward the questionnaire to interested colleagues active in the field of SRH. The survey was also advertised in the WHO HRP/RHR Newsletter, *Progress in sexual and reproductive health research*; distributed via several networks, including the Implementing Best Practices in Reproductive Health (IBP) Knowledge Gateway (with more than 6,800 members), and the International Council of Nurses (ICN) Research Network (with 680 members); and was available from HRP at the World Health Assembly in May 2007. The number of recipients in this “secondary group,” who received the questionnaires from colleagues or through networks or newsletters, is unknown.

1.2 Study methods

The questionnaire was first pilot-tested among 11 individuals (included among the primary group in Table 1). Respondents were asked to “describe the most urgent and important questions which ... need to be addressed in the field of sexual and reproductive health.” Up to three questions, ordered by priority, could be submitted by each individual. Secondly, respondents were asked to classify each question according to one or more of 10 classifications of research. These included: basic biomedical research; product development; clinical, epidemiological, social science, and operations research; research on health systems, on policies and on programme development; and “other” fields of research that did not correspond to any of the above areas.

Respondents were asked to identify the type of research they primarily focused on or used. Data on the type, size and geographical location of the organization, and the respondent’s personal function within the organization were also gathered.

Participation in the survey was anonymous, although respondents were given the opportunity to provide name and contact details if they wanted to be involved in further work in the area. The questionnaire was written in English but respondents could submit their research questions in another language.

During the study period, two reminders were sent to those who had not returned the questionnaire. An extra reminder was sent to 797 targeted recipients to encourage representation of different perspectives.

1.3 Coding of responses and priority research questions

The questionnaire was designed for automated data processing and extraction of all the responses directly into a database. Responses from open-ended research questions were analysed for content and coded into primary and secondary codes according to five core aspects of sexual and reproductive health as outlined in the conceptual framework described earlier, with the addition of policies and programs and cross-cutting issues.¹⁵

The primary coding categories were:

- Individual situations and interpersonal relations
- Sexuality, gender and sexual health
- Sexually transmitted infections, including HIV and reproductive tract disorders
- Fertility desires by women, men and couples
- Steps to successful pregnancy outcome for the mother and the newborn
- Development of policies and programmes¹⁶
- Other, cross-cutting issues including mental health, and marginalized groups.¹

The coding table was pre-tested and revised. Coding was performed independently by two people and compared for accuracy and consistency. Discrepancies were reconciled by a third party when necessary. Simple descriptive statistics were produced directly from the database. Further quantitative analysis was conducted using SAS. Finally, a qualitative content analysis of the open-ended research questions was conducted by hand, using both existing codes and new categories that emerged from an in-depth reading of the data. Questions were grouped according to major themes and ordered by frequency.

¹ An additional category “other” was added to the above categories after the pre-test.

CHAPTER 2

Results

2.1 Study population

Of the 1,874 original emails sent, 211 (11%) could not be delivered, resulting in a total of 1,663 primary recipients. Of these, 358 responded, representing a response rate of 21% among the primary group (Table 1). From the outreach via colleagues, networks and newsletters, an additional 144 responses were received (secondary group), bringing the total number of respondents to 502.

Table 1. Number of questionnaires sent and received

| Source | Valid sent | Replies |
|-----------------|----------------|------------|
| Primary group | 1663 | 358 |
| Secondary group | unknown- | 144 |
| Total | unknown | 502 |

Characteristics of the respondents

- **Area of work:** In all, about 70% of respondents indicated that they focused on more than one area of work, most often reporting two or three different areas. The largest groups of respondents described the focus of their SRH work as social science (49%), followed by epidemiology (35%), programme development (34%), operational research (33%), health systems (30%) and policy (30%).
- **Type and size of organization:** The majority of respondents represented nongovernmental/civil society organizations (37%), research-oriented bodies or academia (36%) and government (20%). Most of those who responded to the question on organizational size said they worked in relatively small organizations of fewer than 100 people.

Table 2. Respondents area of work, type of organization and personal function (%, n=502)

| | | |
|---------------------|-----------------------|----|
| Area of work | Social science | 49 |
| | Epidemiological | 35 |
| | Programme development | 34 |
| | Operational | 33 |
| | Health systems | 30 |
| | Policy | 30 |
| | Clinical | 28 |
| | Other | 11 |
| | Basic biomedical | 8 |
| | Product development | 8 |

| | | |
|-----------------------------|----------------------------------|----|
| Type of organization | NGO, national/international | 37 |
| | Research body/academia | 36 |
| | Government | 20 |
| | Other | 7 |
| | Development agency | 5 |
| | Intergovernmental agency | 4 |
| | Business | 2 |
| | Individual | 2 |
| | Media | 1 |
| Personal function | Researcher | 47 |
| | Programme manager | 30 |
| | Educator | 20 |
| | Other | 17 |
| | Clinician / health care provider | 15 |
| | Advocate | 11 |
| | Policy-maker | 6 |
| | Funder | 4 |

Note: Percentages add to more than 100% as multiple responses were permitted.

- Personal function:** Respondents were asked to choose one of eight categories to describe their personal function within their organization. About one-third of respondents indicated two or more areas in which they worked. Given these multiple responses, job categories total more than 100%. The two largest groups of respondents qualified themselves as researchers (47%) and programme managers (30%), followed by educators (20%) and health care providers (15%). In all, 83 individuals (17% of respondents) felt their function did not fit into any of the given categories and chose “Other”.
- Geographic location:** Respondents were based in 99 countries. The majority (66%) were based in low- and middle-income countries (LMICs)¹⁷, while 34% were based in high-income countries (HICs) (Table 3). The most frequently cited locations by country were USA (13%), Nigeria (8.2%), India (4.6%) and the United Kingdom (4%).

Table 3. Respondents’ geographic location

| Country economic status | % | Selected countries, ranked by number of respondents per region |
|-------------------------|----|---|
| Low- and middle-income | 66 | <i>Africa:</i> Nigeria, Kenya, Ethiopia; <i>Asia:</i> India, China, Pakistan; <i>LAC:</i> Brazil, Uruguay, Mexico; <i>Middle East/Central Asia:</i> Jordan, Turkey, Georgia. |
| High-income | 34 | USA, UK, Switzerland, Australia, Belgium. |

2.2. Research questions identified as priority by the respondents

Respondents could submit up to three questions, ranked in order of priority. Most respondents (84%) provided three questions. In total, 1,402 questions were submitted.

Research priorities grouped by major areas

As research questions were presented in order of priority by the respondents, the first research question (Q1) with the highest priority was analysed separately from the other two (Q2+Q3). The only statistically significant difference between the Q1 and Q2+Q3 distributions according to the primary category was the somewhat lower priority given to the development of policies and programmes by respondents in Q1 as compared with Q2 and Q3 (Table 4). The greatest frequency of first priority questions concerned sexually transmitted infections, including HIV/AIDS. (Table 4). When all three questions are considered jointly, the most frequent category is the development of policies and programmes (23%). Within these categories, a great diversity of questions was offered. These categories and questions are discussed in more detail later.

Table 4. Priority research questions by primary category

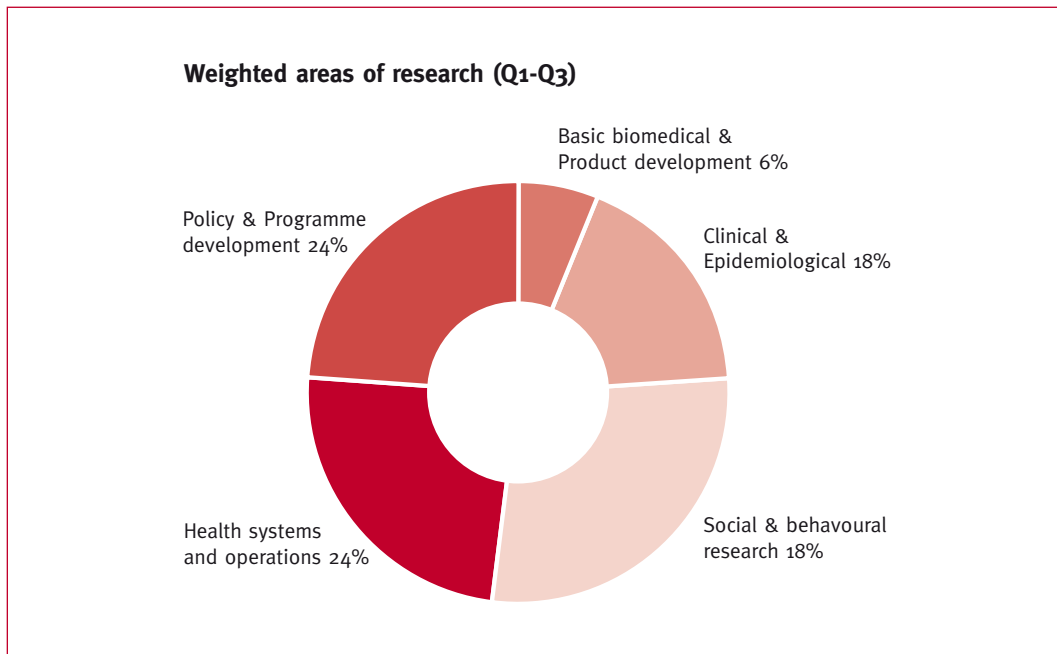
| Research question area | Q1 only (n=501) | | Q2+Q3 only (n=901) | | Q1+Q2+Q3 (n=1402) | |
|---|-----------------|-------|--------------------|-------|-------------------|-------|
| | n | % | n | % | n | % |
| Development of policies and programmes | 95 | 18.96 | 234 | 25.97 | 329 | 23.47 |
| STIs, incl. HIV, and reproductive tract disorders | 104 | 20.76 | 183 | 20.31 | 287 | 20.47 |
| Fertility desire by women, men and couples | 73 | 14.57 | 115 | 12.76 | 188 | 13.41 |
| Individual situations, interpersonal relationships and life-course events | 74 | 14.77 | 102 | 11.32 | 176 | 12.55 |
| Sexuality, gender and sexual health | 60 | 11.98 | 93 | 10.32 | 153 | 10.91 |
| Other | 57 | 11.38 | 96 | 10.65 | 153 | 10.91 |
| Steps to successful pregnancy outcome for the mother and the newborn | 38 | 7.58 | 78 | 8.66 | 116 | 8.27 |

Research classification: Weighted analysis

To identify which types of research would be needed to answer their own priority questions, respondents were asked to classify each of their questions into one or more pre-defined research categories. In all, respondents chose one research classification for 42% of the 1,402 questions, and 38% of the questions were assigned three or more research classifications (which was presumed to be related to the multidisciplinary nature of many questions). To determine the relative frequency of the research classifications, given that the majority of

questions were assigned to more than one, a weighted analysis was conducted whereby any question contributed a maximum of 1 point, divided by the number (n) of research classifications assigned to that question. Social science research was by far the most common classification for the first priority questions, and, as can be seen in Figure 2, was also the most frequently cited classification of research when all three questions were combined.

Figure 2. Weighted categories of research for all questions combined



Respondent's research focus according to whether institutions are based in high-income or low-income countries

There were statistically significant differences in respondents' areas of expertise according to whether they were based in a high-income or low- to medium-income country. Respondents reporting expertise in clinical research and product development were more likely to be based in a high-income country. Those reporting expertise in operational and health systems research were more commonly based in low- and middle-income countries. Although other areas of expertise were about equally distributed for both economic settings, a stratified analysis was conducted to determine whether the respondent's perceived research priorities reflected the economic status of the country in which he/she was based.

A weighted analysis of both strata showed that, despite the differences in area of expertise according to location, there were no statistical differences in the top five overall (Q1+Q2+Q3) classifications for research on priority questions. Respondents based in both HICs and LMICs prioritized SRH research in social science, operational research, programme development, policy and health systems research (Table 5).

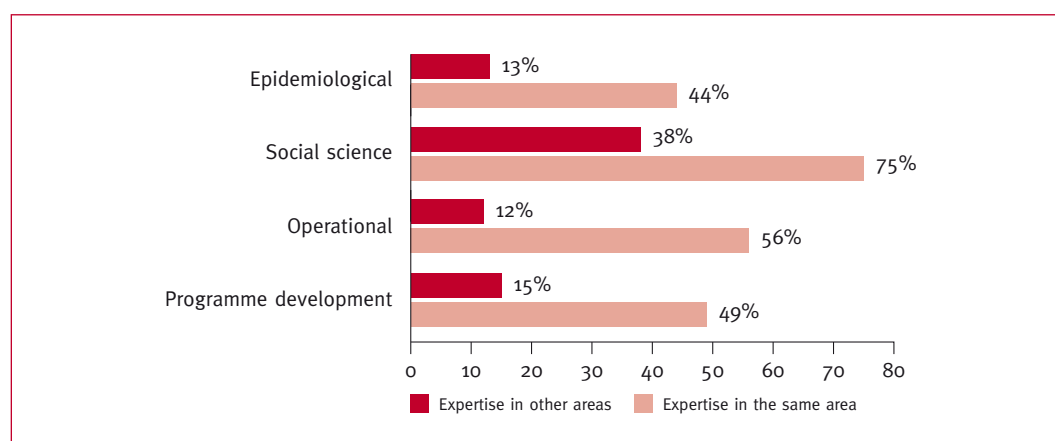
Table 5. Top five research classifications by country economic status

| Priority research areas (top five) | HICs (% , n=169) | | LMICs (% , n=333) | |
|---------------------------------------|------------------|----------|-------------------|----------|
| | Q1 | Q1+Q2+Q3 | Q1 | Q1+Q2+Q3 |
| Social science | 27.4 | 25.9 | 31.5 | 28.1 |
| Operational | 9.9 | 12.4 | 12.7 | 12.4 |
| Programme development | 10.6 | 11.4 | 10.1 | 12.8 |
| Policy | 10.1 | 10.6 | 12.2 | 11.8 |
| Health systems | 8.5 | 10.0 | 10.1 | 11.3 |

Did respondents give preference to their own area of work?

As shown above, social science (26%), operational research (12%), and programme development (12%) ranked highest in the weighted analysis of proposed research. Given the dominance of social science (49%), epidemiological research (35%) and programme development (34%) in the respondents' professional profiles, we considered to what extent selection of a research classification was influenced by respondents' own areas of expertise. There was congruence between respondents' area of expertise and selected research priorities (Figure 2).

Figure 3. Selection of research categories by selected area of expertise (% , primary question only)



For example, questions requiring epidemiological research came from 44% of respondents with expertise in epidemiology and an additional 13% from those not reporting epidemiological expertise. For social science research, 75% of those with a social science background identified social sciences for key research as well as 38% of respondents who did not report social science as a primary focus of their work.

Frequently occurring themes within categories

Within each of the seven primary categories of research described above, the most frequently recurring research themes across all three questions are shown in Table 6. The most common themes include access to services and products and health-seeking decisions. Cross-cutting, recurrent issues overlap to some extent with these themes (e.g., health-seeking decisions among adolescents). These cross-cutting issues and the extent to which they overlap with Table 6 are shown in Table 7.

Table 6. Total responses by main themes

| Main themes of received responses (top ten) | Percentage of total questions | Number of questions (n=1249) | Sample research topics |
|--|--------------------------------------|-------------------------------------|--|
| Access to services & products | 8.8 | 110 | Improving SRH service provision at district and sub-district levels. |
| Health-seeking decisions | 8.0 | 100 | Basic factors that underpin the uptake of SRH services. |
| STIs- HIV- Diagnosis & therapy | 7.1 | 88 | Roles of rapid tests for control programmes; HIV vaccine development. |
| Sex education | 6.4 | 80 | When and how to introduce SRH in school curricula. |
| Financing & scaling up | 6.0 | 75 | Effect on RH services and supplies of new funding mechanisms; competition for funding among different SRH areas; optimizing human resources. |
| STIs, HIV- Care seeking | 5.7 | 72 | Factors which contribute to acceptability of SRH services; adolescent sexual practices. |
| Development of policies & programmes | 5.4 | 68 | Developing reproductive health policies in poor countries; SRH in global health initiatives. |
| Integration of HIV programmes | 4.9 | 62 | Effectively integrating SRH and HIV programs and services. |
| Managing consequences of unintended conceptions | 4.8 | 61 | Decreasing deaths and complications due to unsafe abortions. |
| Strategies to reduce maternal mortality | 3.9 | 49 | Factors contributing to high prevalence of maternal and infant deaths. |

Table 7. Cross-cutting themes extracted from responses

| Cross-cutting themes | As a primary code (n=145) | As a secondary code (n=245) | Percentage overlap with Table 6 | Sample research topics |
|---------------------------------------|----------------------------------|------------------------------------|--|--|
| Adolescents | 42 | 114 | 9.1 | Factors leading to adolescent pregnancy; early marriage. |
| Gender (including involvement of men) | 48 | 79 | 6.3 | Understanding processes of identity construction; effect of gender inequalities on SRH; male involvement in family planning. |
| Marginalized groups | 14 | 42 | 3.3 | SRH needs of sex workers, refugees and migrants, those with disability, isolated populations, the elderly, etc. |
| Mental Health | 4 | 8 | 0.6 | Postpartum depression; coping with HIV status; psychosocial effects on orphans; health provider burn-out. |
| Other | 37 | 2 | 0.2 | Unique issues, e.g., monitoring drug manufacturing practices; SRH decisions among sickle-cell carriers. |

CHAPTER 3

IN-DEPTH QUALITATIVE ANALYSIS OF THE PRIORITY RESEARCH QUESTIONS

To delve more deeply into the priority issues identified in Tables 6 and 7, the priority research questions were analyzed according to a number of different criteria, including the primary beneficiary or principle topic of concern to the respondent. The overarching research focus of the majority of questions related to understanding “*what*” are the social, cultural, religious and economic constraints or determinants that explain “*why*” the sexual and reproductive behaviours of various population groups, such as youth, are not optimal, and “*how*” access to and quality of information, education and services can be improved to better the health of particular groups, or mitigate particular health problems, such as HIV, maternal health, or violence. This includes use of preventive technologies such as contraception, and often in accordance with certain principles, such as gender equity.²

Although the range of questions is broad, seven subjects (the health of youth; contraception; HIV/AIDS/STIs; maternal mortality; unsafe abortion; violence against women; gender and rights) comprise the focus of nearly four out of five first priority questions and two-thirds of total questions. The following analysis is divided into six sections: the five core aspects of sexual and reproductive health and the role of research in the development of policies and programs.¹⁸ Cross-cutting issues are incorporated into these six sections. The predominant topics of interest are correspondingly given more attention in the descriptive analysis of each category of responses that follows. Quotes are provided verbatim, but are representative of others that are similar in wording or content.

3.1 Individual situations, interpersonal relationships and life-course events

“Reproductive rights embrace certain human rights that are already recognized in national laws, international human rights documents and other consensus documents. These rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health and includes their right to make decisions concerning reproduction free of discrimination, coercion and violence.”

ICPD Programme of Action, Paragraph 7.3.

The Cairo Consensus placed individuals at the core of development, and affirmed the rights of individuals to basic integrated health services, including reproductive health. Having genuine choices about the timing and number of their children would enable women and men to break the cycle of poverty that has for too long hindered human development. Access to education, gender equity and reproductive choice would also provide girls and women more equitable opportunities in the labour market and enable them to make greater contributions to their families, communities and societies.

This section describes priority questions concerning the individual situations, interpersonal relationships and life course events related to human rights to health, the causes and consequences of sexual and reproductive health problems, the individual’s health-seeking behaviour in response to the problem, as well as the type of service sought, and the response of the formal health sector to the needs of individuals.

a) Youth: the top research priority

A clear priority for respondents based in LMICs as well as in HICs was the sexual health and well-being of youth.³ With one quarter of the world’s population between the ages of 10 and 24, the focus on the futures of 1.8 billion youth is not misplaced. Two thirds of these young

² For further background and description of each of these categories, the reader is referred to *Research Issues in Sexual and Reproductive Health for Low and Middle-income Countries*.

³ It is interesting to note that, whether the question was ranked by the respondent as priority one, two or three, the most frequently cited subject was youth. About 20% of all respondents’ questions focused on youth.

people live in the less developed countries in the world, and they hold the key to their countries' development.¹⁹

Most countries in the developing world have very youthful age structures, with between 30-45% of their populations under the age of 15, in contrast to the high-income countries, which have an average of 17% under the age of 15. As the World Bank recognized in its 2007 World Development Report, early investments must be made in the education and health of youth if they are to become productive and stabilizing forces within their societies.²⁰

As youth become sexually active and vulnerable to unintended pregnancies, HIV and other sexually transmitted infections (STIs), the sexuality and reproductive health education and youth-friendly services called for in the Cairo consensus become a necessity. The consensus asserts adolescents' right to information and services to protect and enhance their health, and to foster gender equity and mutual responsibility:

“The reproductive health needs of adolescents as a group have been largely ignored by existing reproductive health services..... information and services should be made available to adolescents to help them understand their sexuality and protect them from unwanted pregnancies, sexually transmitted diseases and subsequent risk of infertility. This should be combined with the education of young men to respect women’s self-determination and to share responsibility with women in matters of sexuality and reproduction.”

ICPD Programme of Action, Paragraph 7.41

WHO defines “youth” as those between ages 10-24. For the 66% of respondents who were based in low- or middle-income countries, the largest percentage of first priority questions (23%) centred on youth. The concern with research related to young people was nearly as great among respondents based in high-income countries, among whom 16% of first priority questions concerned youth. This pattern held true for second and third priority questions as well. These were truly cross-cutting questions concerned not only with the interpersonal relationships and life-course events of youth, but spanning all core aspects of sexual and reproductive health. Respondents were most concerned with how to empower youth to avoid early pregnancy and prevent sexually transmitted infections, in understanding the factors that motivate risk taking or more healthful behaviours, and the effectiveness of sex education, behaviour change communication, parental interventions, youth-friendly services and government policies in bringing about better health and less risky behaviour. Respondents recognized that attitudes and beliefs were shaped by parents, gender norms and constraints, peers, schools and teachers, socio-household economic status, societies, religion and the media, and wanted to know the extent of these influences as well as how to modify or overcome them:

“What are the attitudes, beliefs and contextual factors which promote unsafe sexual practices among young people?”

“What are the most effective ways to promote the adoption of healthy sexual behaviours among young people?”

Respondents also recognized the diversity of the life challenges experienced by youth. For many adolescent girls, sex takes place within marriage, and while marriage does not necessarily reduce the risk of unintended pregnancy or acquiring HIV, it does change the ability of a young woman to exercise her rights. One in seven girls in developing countries is married before age 15; in many developing countries, as many as half of all adolescents girls are married.²¹ Once girls have married and are no longer in school, the opportunities to educate them about sexual and reproductive health and their rights to information and services become more limited. Respondents raised questions about the differences in decision-making autonomy and ability to access services between married and unmarried girls, as well as how best to reach very young adolescents.

“What is the difference in level of empowerment among married and unmarried girls of the age group below 18 years?”

“How can we best work with young adolescents (under 15) in order to provide them with the knowledge and skills needed to assure safe sexual behaviours?”

Early marriage is too often soon followed by early pregnancy, with up to half of adolescent girls in low-income countries having had at least one pregnancy.²² Complications related to pregnancy and childbirth are the leading cause of death among girls aged 15 to 19,²³ and preventing early pregnancy and maternal morbidities are a major concern among survey respondents. Some questions came from a psychological perspective:

“Why do young people in our public schools equate sex with love?”

Respondents also acknowledged that many youth, especially girls, are already living with HIV, and research questions concerned the sexual health needs of HIV positive youth.

b) Youth's rightful access to services

Respondents recognized that adolescents face barriers in their access to information and services. Some adolescents avoid services that are not youth-friendly, (e.g., providing private and confidential consultations in a respectful manner); others, particularly rural youth, may lack access to services altogether. The adolescent's right to privacy and confidentiality in seeking and obtaining information and services has been repeatedly affirmed in international agreements. Research has demonstrated that the ability to exercise the right to privacy (whether or not the young person is aware that he/she has such rights) is a critical factor in whether or not youth will seek health information or services. Without confidence that their personal information will remain private, their conversations not overheard, their parents not consulted, adolescents fail to seek health information and forgo health services and treatment that they need, whether to prevent pregnancy or treat an STI.²⁴

Survey respondents sought answers on how to improve the health-seeking behaviours of youth and how to empower adolescents to exercise their rights to information and services:

“What are the effective empowering approaches (that go beyond information provision, education and health service provision) that could enable adolescent girls to avoid too-early pregnancy and HIV infection?”

An empowering approach might take the form of life-skills education, including negotiation skills to delay sex or demand condom use for safe sexual. It may involve gender awareness raising and educating youth, especially girls, about their human rights (e.g. to bodily integrity), and about the legal system and how to use it (where it is, in fact, intended to protect them from customary law or harmful cultural practices such as child marriage and female genital mutilation (FGM)).

c) Meeting the needs of vulnerable groups

Numerous respondents singled out particular vulnerable groups, including immigrants, the elderly, the disabled and mentally ill, men who have sex with men, refugees, displaced persons, mobile populations, girls who have undergone FGM, unmarried women in Islamic societies, and the “poorest of the poor” for attention. The questions below are representative of the concern expressed for meeting the needs of these harder to reach populations.

“What are the sexual and reproductive health needs of the elderly and the physically challenged, and how best can their SRH needs be met?”

“How can the sexual and reproductive health of migrants be improved?”

d) Health-seeking behaviour

Many questions dealt with wanting to understand why people in need of health services do not seek health care or rely on traditional healers or unskilled providers:

“What are the factors that prevent most women from having a hospital delivery, even when the decision has been made to do so?”

Overcoming the constraints of poverty and economic downturn were also concerns:

“What different behaviour change communication initiatives need to be undertaken to develop early health-seeking behaviour among vulnerable poor groups like women and adolescents as the current system is not working?”

e) Formal Sector Responses: Integration

Universal access to sexual and reproductive health information and services by 2015 was the central goal of the Cairo consensus but, in many countries facing the challenge of HIV/AIDS, political commitment has been distracted from reaching SRH for all. The influx of new resources to fight HIV/AIDS enabled the creation of separate health services and the bureaucracies to manage them.²⁵ There is now a strong international consensus on the benefits of integrating SRH and HIV services.²⁶ Effectively integrating these services will broaden the reach of both programs, essential at a time when both must confront unsettling realities: neither a reduction in new HIV infections nor a reduction in the number of women with unmet need for contraception has been achieved.

More than 80% of new HIV infections are sexually transmitted, and women who are vulnerable to HIV infections are also at risk of unintended pregnancies. Integrating FP and HIV prevention efforts addresses both health issues in a manner that will benefit the client as well as the health system. Yet, despite the numerous policy proclamations to move forward, implementation of integrated services, regardless of the services being paired, has been slow to progress.

Research on integration issues is understandably of considerable interest to survey respondents. The priority research questions concerned the “how-to” of integration. Respondents were interested in information on models or best practices:

“What different configurations of integrating SHR and HIV services have been shown to be effective for reaching different populations?”

Women with HIV are known to have high levels of unmet need for contraception and many births to HIV positive women were unintended. Yet, services to prevent mother to child transmission rarely offer contraceptive counselling or referral:

“What model of integration of SRH and HIV-related services can effectively assist to prevent unwanted and unplanned pregnancies among women with HIV?”

f) Integration reduces stigma

The “one-stop-shop” approach to integration and provider-initiated testing and counselling (PITC) as part of routine care also help reduce the stigma associated with free-standing

HIV and STI clinics²⁷, and provide a partial answer to this respondent's question, one of addressing stigma:

“What are the causes and consequences of stigma and discrimination vis a vis HIV/AIDS?”

Research questions regarding the evidence on integration of maternal health and family planning or primary health care with sexual and reproductive health services were also posed.

3.2 Sexuality, gender, and sexual health

“Reproductive health includes ... sexual health, the purpose of which is the enhancement of life and personal relations and not merely counselling and care related to reproduction and sexually transmitted diseases”

ICPD Programme of Action, paragraph 7.2

This section describes questions concerned with sexuality information, education and services, particularly the needs and rights of adolescents for sexuality education. It also includes questions addressing gender, male involvement and gender-based violence.

a) Sexuality education

As a subset of questions related to youth, many respondents were interested in researching the role of sexuality education: what is the relevant content?; what are the obstacles and how can they be addressed?; what is the appropriate age to initiate?; is sexuality education effective?; and what influence does such education have on health and behavioural outcomes?. Whether respondents were from a developing country such as Malawi, where 35% of girls are pregnant or have a child by age 18, and HIV prevalence among young women aged 15-24 (8.%) is more than three times higher than for young men of the same age (2.4), or from the United States, where HIV among adolescent women is low (0.3%) but which has the highest rate of teen pregnancy rate among developed countries, (42 per 1000 population), respondents placed a high priority on understanding sexual vulnerability among youth and what can be done through education to mitigate it.²⁸

“What is the long term impact of sex education programs in preventing pregnancies and STIs among adolescents?”

While the critical importance of comprehensive and gender/rights-based sexuality education in schools (beginning in the primary grades and continuing into secondary school) has been established, respondents' questions note that policy makers demand a strong evidence base to convince them to invest in this strategy, especially since its impact on health may not become apparent for up to a decade. The emphasis respondents placed on sexuality education suggests that they find the implementation of such programs at the national or local level to be inadequate, and want more evidence that educational interventions are effective. The need to overcome societal, religious and cultural barriers motivated the questions of some respondents:

“How can education on family planning, sexual life and knowledge of STIs be introduced in the primary and secondary school curriculum in countries where religious and other leaders oppose such educational activities?”

“What are the possibilities for a consensus in the field of sexuality education in countries with strong religious (e.g. Catholic) background – how to bring health and human rights above ideological values?”

Understanding that youth become vulnerable to sexually-related health threats at a young age, respondents were concerned with how to engage with youth before they become sexually active:

“How can SRH be introduced in school curricula to raise awareness early?”

Respondents wanted to know the relative effectiveness of a curriculum emphasizing gender equity and rights, as is implemented in several Scandinavian countries:

“What are the effects of a sexuality/HIV education curriculum that is founded on critical thinking and places a central emphasis on gender and rights, rather than primarily focusing on anatomy, physiology, etc.”

b) Gender

Gender inequity remains one of the greatest contributors to poor health. Women too often lack power in decision-making, whether at the household level or within parliaments. Women comprise 60% of the world's poor, leaving them disproportionately vulnerable to all of the inequities that poor people face in accessing health services. As a recent WHO High Level Commission on Social Determinants of Health concluded:

“Gender relations of power constitute the root causes of gender inequity and are among the most influential of the social determinants of health...Taking action to improve gender equity in health and to address women’s rights to health is one of the most direct and potent ways to reduce health inequities overall and ensure effective use of health resources.”²⁹

Respondents were concerned about gender: how gender identities are formed, how malleable they are, what interventions have been shown to be effective in promoting gender equity, and in changing harmful traditional masculine norms. They also raised questions about how gender inequities affect health, and the implications of gender roles for sexual debut, risk of unintended pregnancy and HIV.

“How are the constructs of masculinity and femininity formed and sustained during the pre-adolescent ages and what are the sexual and reproductive health implications of these constructs in later years for young girls and boys?”

Respondents to this survey placed considerable emphasis on research questions related to overcoming gender biases and helping women and girls recognize and demand their rights to health information and services:

“How do systems of gender intertwine with sexual and reproductive health needs and with the other determinants of women’s health?”

Respondents also sought evidence that implementing such strategies would make a difference:

“What is the impact of introducing gender and rights perspectives in health policies and programs?”

Questions often alluded to the need for training to meet the new standards set by Cairo:

“How do health workers create gender sensitive care for people in a specific culture?”

c) Engaging men

A greater understanding of the importance of constructive men's engagement in reproductive health has begun to take hold around the world. Former sceptics, including women's health advocates, have largely been converted by the preponderance of evidence: unless men's roles in reproductive health decision-making are supportive of efforts to empower women, progress will remain slow, women will remain vulnerable to reproductive health threats and gender-based violence, and men themselves will remain trapped in the confining space of traditional masculine norms. These norms, including rigid control of decision-making, risk-taking, lack of health-seeking behaviour and self-care, and emotional distance from women and children, are harmful to men as well as to women and children.³⁰

Numbers of questions concerned how to constructively engage men and boys for the betterment of women and girls as well as to meet sexual and reproductive health needs of boys and men themselves:

“How can programmes take a more relational perspective in efforts to empower women and girls? That is, how can they more effectively involve men and boys?”

“How can our current reproductive health systems be developed to accommodate male participants?”

“What are the factors that inhibit male partner's involvement in antenatal care and childbirth?”

Some respondents also considered that men may have need for reproductive health services:

“What are the sexual and reproductive challenges of the male?”

d) Violence against women and girls

Gender-based violence has been an historically invisible problem that has received greater and much needed attention in the last decade. The WHO-supported study on women's health and domestic violence, conducted in ten countries, has raised the profile by revealing the extent of physical, sexual and psychological violence against women and girls in varied socio-economic settings. Younger women were at greater risk of physical or sexual violence by a partner in nearly all the countries studied. Up to half of girls aged 15 to 19 in this study reported they were currently experiencing physical or sexual violence or both from an intimate partner.³¹ Research has also documented sexual violence and rape, as well as the extent to which first sexual experiences for girls are often coerced.³² Research in Nicaragua and elsewhere has begun to illuminate the reproductive and child health consequences for victims of violence.³³

Survey respondents recognized that gender-based violence against girls and women is a contributing factor to the risk of HIV and other reproductive health problems. They wanted to better understand the causes and health consequences of violence, including for the children of victims of violence or rape. Their questions revealed the extent to which domestic violence remains clandestine within families, a taboo that is underreported and seemingly impervious to outside intervention:

“What programme approaches and policies successfully convince people that physical, sexual and psychological violence are criminal acts that must be prosecuted?”

Reproductive and maternal health services are often the only health services that women make use of. The International Planned Parenthood Federation-Western Hemisphere Region (IPPF-WHR), saw the need to screen women for domestic abuse in the RH clinic setting, and to refer them for appropriate counselling and services. IPPF-WHR developed provider screening and training materials and conducted research in Latin America.³⁴ While violence screening in reproductive health settings has not been widely implemented outside of experimental programs in Latin America, respondents wanted answers to how reproductive health services should respond to violence, especially where violence remained invisible to the public eye:

“How can violence against women and children be addressed and integrated in the health systems and health facilities in a resource-poor setting where the problem is not even well recognized?”

Respondents wanted to know more about the effects of violence on reproductive health, and how to best support women who have been raped or sexually abused. They also raised questions about how to protect girls in school from sexual exploitation by teachers.

A few questions were devoted to sexual preference, some related to men who have sex with men, and to issues of sexual fulfilment. Respondents were concerned with practical research questions such as:

“How best can sexuality be discussed and communicated in SRH service sessions?”

3.3 Preventing and managing sexually transmitted infections, including HIV and reproductive tract disorders

HIV/AIDS is the most prominent and expensive health issue of our time. Other sexually transmitted infections (STIs) are given far less attention, even though they affect far more people, and treating them is a cost-effective strategy to reduce risk of acquiring HIV.³⁵ This category includes questions relating to recognizing risks, negotiating protection, perceiving symptoms, seeking (or not seeking) solutions, particularly in relation to HIV, STIs and to cancers and other disorders of the reproductive tract, including technologies to diagnose and prevent these conditions.

a) HIV/AIDS and STIs

Women now make up nearly half of all those infected with HIV globally, and girls make up 75% of 15-24 year olds infected with HIV.³⁶ HIV and AIDS prevention was the focus of many questions: about 13% of respondents focused their first, second and third priority question specifically on HIV and other STIs. Despite the massive influx of resources, new HIV infections have not declined. One of the most cost effective preventive strategies available is antiretroviral treatment to prevent mother to child transmission of HIV during pregnancy or childbirth.³⁷ Priority questions showed that this and other prevention strategies did not have the reach needed to lower the incidence of new infections. Many other questions dealing with

sexual and reproductive health alluded to HIV/AIDS. A few of these questions overlap with questions related to adolescence or to contraception, specifically condom use:

“Why do people still make a choice not to use condoms while they have the knowledge?”

HIV-related questions covered a wide range from the “*underlying epidemiological configurations that foster transmission*” to fertility desires and demand for contraception among women attending for services to prevent transmission of HIV from mother to child. Many of these questions appear to reflect a frustration with efforts to encourage or help individuals to change risky behaviours, a problem that has confounded health education efforts for generations, but one that is particularly critical when the health outcome is fatal without treatment.

The most common question is well stated by this respondent:

“What are the societal and behavioural factors that prevent male and female individuals from protecting themselves from HIV, given that they know how it is spread and, in principle, the physical means are at their disposal (the KAP gap)?”⁴

Respondents were concerned with the root causes of stigma and discrimination, and the best means to overcome stigma against persons living with HIV/AIDS, including in “*conservative Muslim cultures.*”

b) Factors related to HIV testing and uptake of antiretroviral therapy (ART)

Testing for a sexually transmitted disease can create an intersection between health-seeking behaviour and gender-based violence:

“Within a PPTCT program what strategies can be put in place to enhance the ability of a woman to safely disclose her (possibly) positive status to her intimate/cohabitating partner and gain his involvement and support without gender-based violence?”

Respondent questions concerned access to best practices for managing ART programs, as well as the health effects of such programs.

“What is the impact of anti-retroviral therapy on the sexual and reproductive health of persons living with HIV/AIDS?”

Numbers of respondents had questions about the fertility desires of HIV positive women and how their needs were being addressed.

c) Other sexually transmitted infections and reproductive morbidities

A far greater number of men, women and youth are affected by sexually transmitted infections other than HIV. Some 333 million cases of the four most common STIs occur each year; the majority are among youth under age 25. Perhaps because they are treatable, other STIs do not receive the attention that HIV does, but left untreated, they can cause life-long morbidity, including infertility and even death. That fact may have prompted this question:

“Why are sexually transmitted diseases perceived as a low health priority in most countries?”

⁴ The KAP (knowledge, attitudes & practices) gap refers to the discrepancy between awareness and behavior.

Numerous questions concerned the incidence and prevalence of these often undetected infections, suggesting the need for greater surveillance and population based surveys which include biomarkers. Questions about the efficacy of treatment included this concern:

“Is there increased resistance of gonorrhoea to antibiotics?”

The HPV virus causes almost all cervical cancers, and the HPV vaccine could prevent up to 70% of such cases.³⁸ Respondents were concerned with increasing access for screening and diagnosis for reproductive cancers as well as STIs:

“How do we make cervical screening tests widely available in the community?”

Respondents expressed the need for prevention technologies, including female-controlled barrier methods, such as the diaphragm and the female condom. There was considerable interest in microbicides currently under development.

“Is there an effective microbicide that can be soon developed and accessible at low cost?”

Some respondents also devoted their highest priority question to the prevalence of reproductive morbidities, including menstrual problems, and male circumcision as an HIV prevention strategy.

3.4 Helping women, men and couples to achieve their desired fertility

Meeting the Cairo goal of universal access to family planning has been hampered by diminished funding and growing demand. This section describes questions concerning preventing unwanted pregnancies, methods of contraception, unsafe abortion and infertility.

a) Meeting unmet need for contraception

Globally, more than 137 million women want to space their next birth by two years or more or stop having children altogether, but are not using any method of contraception.³⁹ The stark reality of unmet need for contraception, and the 75 million unintended pregnancies that occur every year largely as a result of unmet need, prompted the second most frequent category of questions: those related to contraceptive use. Overall, 19% of respondents' first priority questions were concerned with why women chose particular methods, the barriers to use, how these can be overcome, how better methods, including methods for men, can be developed, how condoms can be made more appealing and more widely used, and vasectomy more acceptable. The primary concerns are reflected in these questions:

“Why doesn't the population access family planning?” and “What can be done to bridge the gap between contraceptive knowledge and use?”

Some questions reflect that clients do not have access to a variety of methods from which to choose, or that their options are limited by provider biases:

“Which are the main factors limiting access to contraception and to free, informed choice of methods in public sector services in developing countries, and which would be the best strategies to improve the situation?”

A number of questions concerned a particular method: Intra-Uterine Devices (IUDs), Standard Days Method and other natural family planning methods, combined oral pills, long-acting progestins, permanent methods, vasectomy, emergency contraception, diaphragms and female condoms. Most of these questions concerned how use could be promoted and access improved, e.g., by offering methods over the counter. Some questions were from the client's perspective:

“What product and program factors enable women to successfully use female condoms for dual protection?”

Others were from the perspective of providers:

“What is the most efficient way (faster and larger scale) to educate and train providers on the IUD?”

How to better serve the unmet contraceptive needs of youth, as well as the needs of other vulnerable, disabled and marginalized populations was of importance to respondents. Respondents were aware that contraceptive discontinuation requires constant programmatic vigilance. They wanted greater understanding of factors affecting use and non-use:

“How can the myths and fears about side effects of contraception be dispelled, and the use of effective contraceptives be encouraged in order to prevent unwanted pregnancies?”

Interest was expressed in the non-contraceptive health benefits, as well as whether there was potential for hormonal contraceptives to affect vulnerability to STIs. Respondents were also concerned with contraceptive security and the impact that withdrawal of donor support might have on unmet need. A partially philosophic question was raised about research and development:

“Why is there so little interest in supporting research and development of new methods of contraception, especially those already well-advanced along the pipeline?”

b) The role of men in contraceptive practice

Respondents were interested in how to increase male involvement in sexual and reproductive health. They were particularly keen to understand what would improve men's roles and responsibility in contraceptive practice.

“What factors promote the introduction and utilization of male contraception?”

Condoms and the need for dual protection

The unique role of the condom as the only method that provides dual protection against pregnancy and sexually transmitted diseases was important to respondents, and the male condom was the single contraceptive method which generated the most attention: why do people at risk and married couples not use them?; what are the social and cultural factors that impede use?; how can they be made more sensitive and pleasurable?

Reversible non-barrier methods for men

A significant number of questions concerned reversible methods for men currently under development: why is there no modern reversible method for men?; how can such a method be developed?; what sort of product would be most acceptable to men; what is the most

effective approach to regulating male fertility; what are the behavioural factors leading men to use male contraceptives?

“What are the most promising leads in the development of an effective hormonal male contraceptive?”

“What sort of product would be most acceptable as a reversible male contraceptive, e.g., hormonal vs. non-hormonal, pill, injection, implant, patch, gel, nasal spray?”

c) Infertility

The inability to conceive a child can have disastrous consequences for women in many societies, where demonstrating fertility within marriage is considered a necessity. In low resource settings where testing is not available, a woman is typically blamed for this failure, even though her husband is as likely to be the infertile partner. Infertility affects about 10% of the population in many low- and middle-income countries, but from 20 to 40% in parts of sub-Saharan Africa where endemic levels of STIs have led to secondary infertility.⁴⁰ Because of its importance in traditional societies, numbers of respondents were interested in exploring what types of diagnosis and treatment might be offered:

“What would be a basic infertility package to offer in primary care, and is it possible to implement this in relatively poor settings?”

d) Abortion

An estimated 19.2 million unsafe abortions take place each year, with 97% occurring in developing countries. 68,000 women die annually as a result of unsafe abortions, contributing about 13% of maternal deaths. Many millions more suffer short and long term consequences requiring hospitalisation.⁴¹

While the use of modern contraception to prevent unintended pregnancies can greatly reduce reliance on abortion, it cannot fully eliminate the need for safe abortion. As a medical procedure, legal abortion is one of the safest available, but more than 40% (19 million) of the 46 million abortions that occur annually are done under unsafe conditions and/or by untrained personnel. In countries where abortion is safe and available upon demand, deaths due to abortion are less than one per 100,000 live births; in countries where abortion is legally restricted, deaths increase to an average of 34 times that amount.⁴²

In sub-Saharan Africa, where unsafe abortion is responsible for a 30-40 per cent of maternal deaths, complications of unsafe abortion account for the largest share of hospital gynaecological admissions. These admissions do not include the millions of women who need medical attention for complications but do not receive it.⁴³ Health system resources that could improve maternal health must instead be expended to treat the unfortunate complications of these unsafe procedures.⁴⁴

About 5 % of all first, second and third priority questions concerned abortion. The majority of these concerned how to prevent (primarily unsafe) abortion.

Abortion among adolescents

Adolescents 15 to 19 account for 25% of all unsafe abortions.⁴⁵ Even where abortion is safe and legal, the stigma of abortion drives many young women to seek a clandestine abortion. Respondents were interested in learning how to lessen reliance on unsafe abortion, particularly among adolescents, and in countries where safe, legal abortion is available.

“In countries where abortion is legal but high numbers are provided unsafely, what societal factors could be influenced at the village level, e.g., specific education of women/TBA's? Would income replacement be required?”

Respondents were interested in the impact of liberalization of abortion laws on women and adolescents in several countries.

“Will liberalization of abortion laws influence sexual habits of adolescents in low-resource settings?”

In countries where abortion laws have been liberalized, an increase in the abortion rate has not been seen, although liberalization of restrictive abortion laws has led to rapid improvement in women's health indicators.⁴⁶ Yet, the political will to reduce unsafe abortion and maternal morbidity and mortality is often lacking, as suggested by this respondent's question:

“What kind of evidence is needed to convince policy makers to decriminalize abortion and make it safe and accessible?”

Reliance on abortion to regulate fertility in some countries remains a concern:

“What are the individual/societal factors that make abortion still so widely used as a contraceptive method in most of the countries in transition of the European region? How should they be effectively addressed?”

Respondents wanted to learn from legal and policy reforms that had been achieved elsewhere:

“What are the most effective strategies for reforming abortion laws and policies that are linked to maternal mortality and morbidity in developing countries?”

Respondents also formulated research questions regarding medication-induced termination of pregnancy outside the clinic and the potential for this practice to de-medicalize and decriminalize abortion.

3.5 Ensuring a successful pregnancy outcome for the mother and the newborn

Maternal mortality is considered by many the most neglected of health problems. Each year, 529,000 women die of largely preventable causes related to pregnancy and childbirth, about the same number as died of maternal causes in 1990. MDG5, to improve maternal health, is the least on track of the MDG health goals. This section describes questions related to the steps that are needed to achieve MDG5, including raising the profile of maternal mortality, essential care during pregnancy and delivery, and postpartum care and support for the newborn.

a) Reducing maternal and neonatal mortality

The low profile of maternal mortality and how to raise it was the concern of about 10% of respondents from the developed as well as low- and middle-income countries who devoted their priority question to maternal health and to a greater understanding of factors that would reduce maternal mortality and morbidity.

Government response

The lack of progress in reducing maternal deaths, and the reasons for it was reflected in numerous questions:

“Why is maternal mortality so high in low resource settings?” and “How can maternal mortality in underdeveloped countries be decreased?”

Numerous questions were concerned with a perceived lack of political will to improve women’s health:

“What more do policy-makers, health managers and ministries of health in low- and middle-income countries need to develop effective intervention strategies to prevent maternal mortality?”

Although the percentage of all women who are attended at birth by trained staff has risen to 6%, this hides great inequities according to wealth: in Asia, wealthier women (top 20% of income) are five times more likely to deliver their babies in a health facility than are poor women (lowest 20%).⁴⁷ How to improve access, especially for poor women, was a common concern. Respondents questioned the barriers to institutional deliveries in the developing world. Reliance on the traditional birth attendant was viewed as both a cause for concern as well as a missed opportunity:

“What are the societal factors promoting the continued use of Traditional Birth Attendants to attend to pregnant women during delivery?”

On the other hand, another asked: “*Is the Traditional Birth Attendant ignored?*”

b) Adolescent pregnancy

Adolescents 15-19 account for 11% of all births, but 23% of all disabilities related to pregnancy and childbirth. Giving birth at a young age also endangers the infant’s survival. Girls who give birth before age 20 have a 50% greater risk of having a stillbirth or death of the newborn within the first than women aged 20-19.⁴⁸

Many respondent questions related to adolescent pregnancy and how to prevent it or delay it. Simply put:

“How can we prevent adolescent pregnancy?”

Respondents also posed questions about the social, cultural and economic barriers to maternal care, institutional delivery and care of the newborn.

3.6 The development of policies and programmes and the role of research

The Cairo consensus placed many demands on reproductive and sexual health services and systems, which were subsequently confronted with a far greater HIV/AIDS epidemic than was foreseen at the time. This section concerns questions related to the development of programs and policies, to population-based research intended to measure inequalities in the distribution of sexual and reproductive health, and to policy- and programme-based research on the quality of care and accessibility of information and services, and scaling up

of interventions and services. It includes methodological questions to improve the collection of reliable and valid information, particularly on sensitive subjects dealing with sexuality, violence or unsafe abortion.

Numerous questions related to how to improve access to information and services, as well as to improve the quality of care. Some respondents recognized that challenge that these increased demands placed on providers.

a) Provider Training to meet the standards of Cairo

Not long after the Cairo and Beijing consensus agreements were reached, gender specialists from WHO and elsewhere recognized the need for practical training to enable program managers to implement gender and rights-based health programmes. A participatory training course, *Transforming Health Systems: Gender and Rights in Reproductive Health*, was jointly developed;⁴⁹ by 2009, the course had been offered for 12 years to health programme managers in the developing world

A continued need for such training to help providers understand and implement a gender and rights perspective in their services is implied in the questions posed by numbers of respondents:

“What are the problems experienced by health providers in seeking to meet the issues of sexual and reproductive health in low- and middle-income countries?”

“What would be the best strategies to ensure that sexual and reproductive rights are effectively respected in sexual and reproductive health service provision?”

b) Human resources and quality of care

Numbers of questions concerned the best strategies to train and retain providers, and to assure that their services met quality of care standards. Health worker shortages, particularly in rural and remote areas, are a staggering problem for many countries faced with enormous burdens of disease. Numbers of questions addressed health worker incentives:

“What are the most important non-financial incentives that could attract and maintain well-trained mid-level health staff in rural areas, to offer the full range of interventions to address sexual and reproductive health?”

c) Research methodologies

A number of questions addressed methodological issues and the continued need to improve them. How can we better measure empowerment?; gender equity?; what are the processes and indicators to measure the benefits that accrue to those who have attained rights to sexual and reproductive health?.

“How can the impact of sexual and reproductive rights be assessed?”

Priority questions also concerned ethical issues such as the challenges faced in biomedical research on HIV prevention technologies.

d) Knowledge translation of policies and practices

Considering the volume of training materials and protocols that have been developed to promote safe motherhood and improve care of the newborn, a number of priority questions

focused on why the development of these tools has not contributed to a more evident decline in mortality. In few other areas were respondents so likely to ask how to better implement *known* interventions and how best to transmit available information to practitioners in an effective way:

“What are the knowledge translation strategies that result in substantial reductions in maternal mortality and serious maternal morbidity?”

Given the substantial number of priority questions devoted to specific topics for which research has already provided answers, the above question might be considered a high priority. Among the survey questions submitted, a few suggested that the respondent did not have access to known information. Several respondents chose knowledge translation and research dissemination as their top priorities.

e) Global policy and macroeconomic Issues

Respondent questions sought strategies to raise the profile of sexual and reproductive health within particular countries, particularly in Islamic societies, or on the international agenda; to promote equitable access to services; and to motivate governments to act decisively to allocate resources and support known interventions:

“What are the factors that prevent governments in low resource settings to scale up know, effective strategies to improve maternal and newborn health?”

Cost-effectiveness of interventions and programs and the societal costs of non-intervention were recurrent themes:

“What are the economic consequences of maternal mortality?”

Other questions concerned the impact of decentralization on sexual and reproductive health services, finance mechanisms, and the development of policies to promote rights of individuals to SRH services.

CHAPTER 4

Discussion

Four particular areas of research received much attention in the open-ended response questions; the results highlight a broad range of potential research topics:

- (a) The area of social and behavioural research brought about questions pertaining to the determinants of sexual and reproductive health, particularly socio-economic factors and the influence of cultural norms, as well as questions regarding health promotion, access to information, and methodological questions.
- (b) In the area of health systems and operational research, research topics related to provider training and quality of care at different levels, and programme strategies (e.g. facilitating the transfer of evidence into practice, scaling-up effective interventions, retaining health workers in rural areas, etc.)
- (c) Issues in policy and programme development inspired questions addressing issues such as the role of local government, the impact of labour market changes on SRH, cost-effectiveness of interventions and equitable financing mechanisms.
- (d) Finally, potential research topics within basic biomedical and product development research included the development of new contraceptive methods for men and women, and the safety and efficacy of existing contraceptive-related technologies, vaccines, or anti-retroviral treatment.

To tackle sexual and reproductive ill health requires a wide array of approaches,⁵⁰ and this is reflected in the wide range of thematic issues prioritized by respondents. Collectively, respondents indicated that there is a need to undertake research which spans biomedical, clinical, social and behavioural research, as well as health systems and operations research. Multidisciplinary approaches are called for in many of the areas respondents deemed to be under-researched.

This survey of perceived research gaps has shown that there is a demand for research in the field of sexual and reproductive health. Such demand is evident not only among researchers, but also among policy makers, in the private sector and civil society. Much of this demand is related to better understanding the determinants of SRH, particularly the influence of cultural norms, and how to use this information to design services and health programmes that respond more closely to the needs of the individuals. How to scale up to meet the growing demands for services among women of reproductive age and the largest population of youth ever known was a commonly expressed concern.

With regard to programme strategies, the challenges that triggered the most research questions were on the best integrative models for SRH. Integrated programmes, such as the Integrated Management of Childhood Illnesses (IMCI) or the integration of Maternal, Neonatal and Child Health programmes have been essential vehicles to improve health coverage and effectiveness. Today's research on integration of SRH service delivery and management may deliver the 'know how' of the future.

4.1 Taking gender into account in research priority setting

An important consideration when developing a health research agenda is to pay heed to the findings of the WHO Commission on the Social Determinants of Health:

“Gender discrimination and bias not only affect differentials in health needs, health seeking behaviour, treatment, and outcomes, but also permeate the content and the process of health research. Gender imbalances in research content ... slow recognition of health problems that particularly affect women. ... Mechanisms and policies need to be developed to ensure that gender imbalances in both the content and processes of health research are avoided and corrected.”⁵¹

Although the gender of respondents to this survey is not known, we do know that respondents largely addressed their priority questions to research of importance to women's health. Their perspectives would therefore lend some balance to an often imbalanced assessment of

priorities. Furthermore, the majority were based in LMICs; an under-representation of these perspectives is most often the norm.

4.2 Policy Implications

Investments in global health research have produced remarkable results in the past 20 years. Yet, while the risk factors for disease in developed and developing countries are converging, that shift has not occurred in the burden of disease related to sexual and reproductive health, the vast majority of which still affects developing countries. For that reason, experts engaged in the 2006 Disease Control Priority Project highlight “*reproductive and sexual health research*” among “*promising research topics that are not yet priorities, but should be pursued.*”⁵²

In 1996, a committee convened by WHO identified the following “best buys” among key research and development investments:

- Develop, evaluate and refine the mother-baby package for pregnancy, delivery and neonatal care;
- Evaluate the implementation of a range of family planning packages offering a wide choice of methods;
- Develop new contraceptive methods to widen the choice of long-term but reversible methods, post-coital methods and for regular and emergency use, and methods for men; and
- Develop improved methods for the diagnosis, prevention and treatment of sexually transmitted diseases, including vaginal microbicides.⁵³

The consistencies between these “best buys” and the research priorities for low- and middle-income countries identified in this survey are at once both reassuring and disheartening. After more than a decade, these high payoff research needs remain under-addressed, providing further evidence that funding, even for high priority research, presents a great challenge. Building the research capacity in low resource settings also requires more resources.⁵⁴

4.3 Funding the vision of Cairo and the MDGs

At the Cairo conference, financial resources needed to achieve the goal of universal sexual and reproductive health were estimated and commitments made; one-third was to come from donors and two-thirds from governments and health service clients. These estimates have since been revised and updated to reflect current realities and more accurate accounting procedures. The UNFPA estimates that the annual cost of providing family planning, maternal and newborn care in 2009 will be \$23.5 billion, rising to \$33 billion by 2015. Maternal and newborn care requires the major share of this amount (72%), while contraceptive services account for 28%. Revised cost estimates for HIV/AIDS and STIs rise from \$24 billion in 2009 to \$36 billion in 2015.⁵⁵ Requirements for basic data, research and training, and policy analysis related to population and development average about \$2 billion per year over the 2009-2015 period.

Actual resource allocations have fallen far short of these goals: family planning is the least well funded among the SRH components, receiving just 11% of revised need in 2009; HIV/AIDS/STI receives about 35% of estimated need and the research component receives about 14%.

Cost recovery and long term benefits

Greater awareness is needed among policymakers of the substantial payback delivered by such investments. For example, if all women at risk of unintended pregnancy used an effective modern method of contraception, the accumulated savings in maternal health would be 2.3 times as great as the additional cumulative expenditure on family planning over a ten year

period. These are direct savings and do not include savings that can be expected in other areas such as education and health.⁵⁶ More importantly, scaling up health resources to meet MDGs requirements would avert 322,000 maternal deaths, save the lives of 4 million infants and children under age five, and prevent a massive amount of morbidity.⁵⁷

The approach used in this survey, targeting institutions and individuals from various disciplines and constituencies, particularly in LMICs, cannot generate a research agenda by itself. Interpretation of the survey's results are limited by the use a convenience sample, the unclear degree to which respondents are representative, the open-ended nature of the questions, and a suboptimal response rate. It is likely that research priorities may vary in different parts of the world. Similar types of surveys may be required at the regional level to capture the cultural and social diversity of regions. The disjuncture between priority research on SRH described in this study and funding availability can however be a powerful wake-up call to advocate for SRH research and funding.

Conclusion

“To ensure that the outcome of the research can be applied, the research community should ensure that their investigations are responsive to real needs, and that they are communicated to where the action is, and where they can have the most effect. (emphasis added)”⁵⁸

The Global Forum for Health Research has been at the forefront of efforts to focus more research on the needs of developing countries and to increase understanding of the role of health research in economic and social development.⁵⁹ Priority research questions identified through this international consultative process contribute toward understanding these real needs. Most are pragmatic questions, responding to legitimate concerns that must be addressed if low- and middle-income countries are to progress toward achieving MDG targets – preserving the health of the next generation, making pregnancy and delivery as safe as possible, promoting equality among men and women, and assuring access to comparable disease prevention and treatment as residents of high-income countries enjoy.

The second clause of the above quote is equally important: getting the substantive findings of research to where they are most needed and can do the most good.

Respondents based in LMICs are an often underrepresented constituency. Their perspectives add new voices to the chorus of evidence demonstrating that the critical shortage of resources for SRH activities, including research in low- and middle-income countries, must be addressed if universal access to sexual and reproductive health is to be achieved.

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