INDUSTRY LIAISON FORUM
INTERNATIONAL AIDS SOCIETY

ILF CONSULTATION MEETING
EVALUATION REPORT

OCTOBER 2010
Executive Summary

One of the strategic priorities of the International AIDS Society’s Industry Liaison Forum (IAS-ILF) is to strengthen HIV clinical and operations research projects in resource-limited settings that address the needs of women and children. A major initiative was established to address this priority: Mapping and Building Consensus on HIV Research Priorities for Women and Children.

The initiative was guided by an IAS-ILF Expert Reference Group that included experts in research on paediatrics and women from major research-granting agencies and foundations, independent investigators and clinicians and multilateral organizations (UNICEF, WHO and UNAIDS).

Part of the process was a multi-stakeholder consultation held on 19 July 2009 in conjunction with the 5th IAS Conference on HIV Pathogenesis, Treatment and Prevention in Cape Town, South Africa. Following the consultation, the participants were asked to fill in an online evaluation survey. Results showed that:

- Overall, 72% of the participants were quite satisfied with the importance of the initiative and relevance to the current work of their organizations. In addition, 62% of the survey respondents found it “very successful” and “successful” in identifying priority research questions related to the treatment needs of women and children affected by HIV and AIDS.
- 92% of the respondents rated the consultation as “very successful” and “successful” in prioritizing the top five research priorities within each research area, and all the respondents found the “Draft Environmental Scan Summary and Draft Recommendations” “excellent” and “good”.
- The clarity, the relevance and the format of the Consensus Statement have been well received by the majority (between 88% and 92%) of the respondents.
- 25% of the respondents planned to take any action, for instance, support specific research studies, implement additional operations research activities, review existing data for potential application of research priorities, seek additional research funding sources, and conduct clinical studies.
- Half of the respondents expect the IAS to: track progress on accomplishing the goals; advocate for increased research around priority topics; report periodically on achievements and findings; disseminate these documents to the wider community; and follow up on recommendations at upcoming conferences.

About ILF

The Industry Liaison Forum (ILF) is an initiative of the International AIDS Society (IAS) with a mission to accelerate scientifically promising, ethical HIV research in resource-limited countries, with a particular focus on the role and responsibilities of industry as sponsors and supporters of research.

During 2008-2011, the ILF is committed to focusing on scientific, ethical and policy issues related to HIV research for women and children by identifying research gaps in this area. The ILF is committed to:

- Creating opportunities for researchers from within and outside industry to coordinate with partner agencies to advance HIV research in resource-limited settings
- Building consensus on best-practice models and guidance for the conduct of HIV research in resource-limited settings that safeguard the rights of research participants on contentious issues related to such areas as post-trial treatment and care, prevention technologies and the involvement of local communities in trial design and conduct.
Feedback from Participants

Importance of the initiative
Of 108 participants, 29 completed the consultation meeting survey online. With regards to the importance of the initiative and relevance to the current work of their organizations, the survey respondents were quite satisfied, with 72% (n=21) responding that it was “very important” and “important”, whereas 14% (n=4) said that it was “somewhat important” and 14% (n=4) rated it as “not very important”.

A majority of the survey respondents found the initiative to be “very successful” or “successful” in identifying priority research questions to close some of the most important knowledge gaps related to the treatment needs of women and children affected by HIV and AIDS today; 35% (n=10) rated it as “somewhat successful” and only one respondent found it (3%) “not very successful”.

Quality of the initiative
Of the respondents (n=13) who attended the multi-stakeholder consultation held at the 5th IAS Conference on HIV Pathogenesis, Treatment and Prevention in Cape Town, South Africa, from 19 to 22 July 2009, all believed that the relevant experts and organizations were represented.

In addition, 92% (n=11) of the respondents who attended the consultation rated the meeting as “very successful” and “successful” in prioritizing the top five research priorities within each research area, while only one rated it as “somewhat successful”.

Again, 100% of the respondents attending the consultation rated the quality of the “Draft Environmental Scan Summary and Draft Recommendations” as “excellent” and “good”.

Multi-stakeholder consultation
With regards to future consultative processes, 81% (n=22) of the respondents would not change anything, while 19% (n=5) provided suggestions for improvement. Suggestions include:

- Invite a wider pool of participants.
• Explore some research gaps for women and children in countries where the epidemic is driven by drug use and sexual behaviour.
• Limit the meeting to areas that do not currently have much focus by other partners to avoid duplication of efforts.
• Harmonize across partners or serve as a coordinating secretariat, rather than conducting the consultation.
• Ensure participation of relevant stakeholders through advance discussions and clarification of meeting objectives.
• Add more time to go through topics and apply stricter criteria for participation as experts.

Some of the respondents suggested some improvements regarding this initiative:
• Make sure that the activities are sectored into implementation research and basic mechanistic type research questions.
• Know the impact in terms of communication and support on the matter by experts and teams.
• Make sure that these priority areas are indeed covered by agencies, researchers and implementers in the foreseeable future.
• Survey industries on their priorities.

Consensus Statement
In total, 36% (n=9) of the respondents’ organizations were signatories of the Consensus Statement, “Asking the Right Questions: Advancing an HIV Research Agenda for Women and Children”; this was not the case for 40% (n=10) of respondents, and 24% (n=6) were not sure.

The clarity, the relevance and the format of the statement have been well received, with 88% (n=22) of the respondents rating the clarity of the content as “excellent” and “good”, and 92% (n=23) rating the relevance to the main objective of the initiative and the format as “excellent” and “good”.

![Figure 2. Ratings on aspects of the Consensus Statement](image)

Participants were also asked about the utility of the report for their current work or the current work of their organizations. The majority of the respondents found it very helpful, with 64% (n=16) rating it as “very useful” and “useful”, 16% (n=4) as “somewhat useful”, and 12% (n=3) as “not very useful”; 8% (n=2) did not read it.

Future plans
Participants were asked if their organizations planned to take any (other) action as a result of this initiative: 67% (n=16) of the respondents were not sure; 8% (n=2) of their organizations would not; and 25% (n=6) of the respondents planned to take any action, for instance, support specific research studies, implement additional operations research activities, review existing data for potential application of research priorities, seek additional research funding sources, and conduct clinical studies.

In addition, 46% (n=11) of the respondents expect the IAS to:
- Track progress on accomplishing the goals.
- Advocate for increased research around priority topics.
- Report periodically on achievements and findings.
- Disseminate these documents to the wider community.
- Follow up on recommendations at upcoming conferences.

**Survey respondents’ profile**

**Country of work.** The majority of survey respondents worked in North America and Canada (43%), followed by Europe (26%), Africa (23%), Asia and the Pacific (4%) and Latin America (4%).

**Profession.** One-quarter of the respondents identified themselves with an academic profession; 22% worked for non-governmental organizations; 13% worked both for the government and for intergovernmental organizations; 9% worked for the private sector (other than pharmaceutical companies); 4% worked for grassroots community-based organizations; 4% worked for media organizations; and 4% worked for a group or network of people living with HIV/AIDS. The remaining selected the category “other organization/affiliation”.

![Figure 3. Overview of the type of organization/profession of the respondents](chart)
**Gender.** Male participants were better represented than females (52% vs. 48%).

![Figure 4. Respondents' gender percentage](image)

**Age.** More than half of survey respondents were older than 50 years, while 39% were between 41 and 50 years, and the remaining 4% were younger than 40 years.