Panel 7: Community, Provider, Operational, and Regulatory Perspectives on PrEP Implementation

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THIS ISN’T GOOD ENOUGH.

The only important thing to know and do is always wear a condom.

– Larry Kramer
March, 2012
• What is Mapping Pathways?
• Snapshot of community stakeholder perspectives on PrEP from India, South Africa, United States
• Focus on U.S.
  – Advocacy challenges, opportunities, activities
What is Mapping Pathways?

- Multinational project, began 2011
- Funding
  - Merck 2011
  - Merck and NIH (BTG Bridge) 2012
- Review potential social, economic and clinical impacts of ARV–based prevention
- South Africa, India, U.S.
- AIDS Foundation of Chicago, AIDS United, Desmond Tutu HIV Foundation, Naz India, RAND, Baird’s CMC
Stakeholder Interviews

- Conducted 43 semi-structured interviews with selected “grasstops”
- India=9, RSA=13, US=21* (19 individuals)
  - * two group discussions (6 individuals per) in U.S. – each group counted as 1 individual for coding purposes
Stakeholders and PrEP

Likely Programmatic and Policy Impacts of PrEP

United States (N = 20)
- Positive: 5%
- Skeptical: 65%
- Mixed: 30%

South Africa (N = 12)
- Positive: 8%
- Skeptical: 33%
- Mixed: 58%

India (N = 7)
- Positive: 14%
- Skeptical: 86%

Controlling the HIV Epidemic with Antiretrovirals
## Stakeholders and PrEP

### Likely Programmatic and Policy Impacts in Detail

<table>
<thead>
<tr>
<th>Positive Responses</th>
<th>India</th>
<th>South Africa</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ease of Use a Plus</td>
<td>0.0%</td>
<td>8.3%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Established Efficacy/Effectiveness</td>
<td>14.3%</td>
<td>25.0%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Empowerment</td>
<td>0.0%</td>
<td>0.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Useful for High-Risk Populations</td>
<td>0.0%</td>
<td>50.0%</td>
<td>25.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Skeptical Responses</th>
<th>India</th>
<th>South Africa</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concerns over Adherence Rates</td>
<td>0.0%</td>
<td>33.3%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Cost/Resource Concerns</td>
<td>42.9%</td>
<td>75.0%</td>
<td>95.0%</td>
</tr>
<tr>
<td>Uncertain Effectiveness/Efficacy</td>
<td>28.6%</td>
<td>83.3%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Will Increase Risk Behavior</td>
<td>42.9%</td>
<td>8.3%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Local Circumstances or Politics an Obstacle</td>
<td>57.1%</td>
<td>16.7%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Other Issues (Besides ARV) are Important</td>
<td>0.0%</td>
<td>0.0%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Difficulty Identifying High-Risk Groups</td>
<td>28.6%</td>
<td>25.0%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Long-Term Safety Issues</td>
<td>0.0%</td>
<td>16.7%</td>
<td>10.0%</td>
</tr>
</tbody>
</table>

**Note.** Columns can sum to greater or less than 100% as respondents could provide more than one detailed response or could not have responded directly to the first two survey questions.
Stakeholders and PrEP

Does the evidence support changing guidelines?

United States (N = 15)
- 13% Positive
- 87% Skeptical

South Africa (N = 9)
- 100% Skeptical

India (N = 2)
- 100% Skeptical
It will be hard for an individual to accept that he or she is “high-risk” and should take this treatment. [INDIA]

I am skeptical about how to use the PrEP results...the guidelines could be modified to include abused women, sex workers, couples wanting to conceive, MSM who self-identify as high risk, but how do you put that in ... at the discretion of the clinician? [RSA]

Cost effectiveness is important. Realistically there are way too many couples to put all negative partners on treatment. We need to reach the people who are so vulnerable they can’t negotiate condom usage regularly. [UNITED STATES]
Challenges, Opportunities and Activities

- FDA sNDA
- “Tea bag” science
- Cost
- Access
  - Most in need
- Implementation
  - Delivery, adherence, testing, monitoring,
- Community stigma

- Natl PrEP working group led by AVAC
  - www.prepwatch.org
- Demo projects
  - [SF, Miami]
- Policy papers
Instead of denigrating people on PrEP as willful, filthy whores, what if we respected them as people who were willing to venture into uncharted territory for their own health and the good of the world?

myprepexperience.blogspot.com
PrEP didn’t make me stop using condoms. Instead PrEP provided me with protection that I would use consistently, rather than protection that I was already rejecting.

What has angered me the most, is watching and listening to doctors, politicians, and experts decide what my choices and risks should be. For most of them, it is their job. But for me.... it is my life.

myprepexperience.blogspot.com
For consideration

- When deciding whether or not to implement PrEP or TasP (TLC+) or any other ARV-based strategy, how do we incorporate community stakeholder wisdom and perspectives into the evidence base, and not simply privilege P-values and confidence intervals?
- How do we ensure access to PrEP for the most vulnerable populations?
- How do we reframe “safer sex” to expand beyond condoms to include PrEP and Tx?
- What can/should we do about the stigmatizing conversation that has erupted around PrEP?