Formulating Guidelines for Community Advisory Boards

Nusara Thaitawat
Senior Expert, Community Engagement
Department of Retrovirology,
United States Army Medical Component –
Armed Forces Research Institute of Medical Sciences
Bangkok, Thailand

Suchada Chinaworapong
Thai NGO Coalition on AIDS
Bangkok, Thailand

Annual Meeting
Forum for Ethical Review Committees in the Asian and Western Pacific Region
Bangkok, 23-26 November 2008
Outline of presentation

• State of Community Advisory Boards (CAB) in Asia & Western Pacific
• Why a Community Advisory Board?
  – Ethical, scientific, practical rationales
• Thailand’s experience
• The way forward – formulating guidelines for constituting and functioning of CAB – challenges and opportunities
What is a CAB?

- CABs trace their origin in the early AIDS advocacy movement in the early 1980s in the US calling for more research to find medication and treatment for increasing number of people infected with HIV, as fast as possible.
- Their composition underlined the importance of non-medical perspectives into bio-medical research, the value of varied backgrounds, and equal male and female representation.
- Their mandate was to review protocols, monitor trials, and help educate and inform the rest of the community.
New and elusive concept in many parts of Asia and Western Pacific

- **New** – CAB as a Western invention of the 1980s to push for research in AIDS drugs

- **Elusive** – 5-Ws 1-H within the socio-economic context of each country
Why CAB?

Ethical rationale

- Need to protect communities in research
  - Individual harm addressed by existing international ethical guidelines
  - What about the **possibility of collective harm** to communities?
  - And the **possibility of collective benefit** – ie: community engagement in conduct of research and preparation for post-trial

- Need to focus research on communities health priorities

- Community consultation – as a key **benchmark of ethical research** esp. in context of research funded by developed countries conducted in developing countries
  - Number of guidelines
Why CAB?

Scientific rationale

– **Study design** and protocol development
– Standard of care for research participants
– Information disclosure and informed consent
– **Community engagement**
– **Post-trial planning** – access to product & technology, future use of samples
– Dissemination and publication of results
Why CAB?

Practical rationale

– Ties within the community – can help with designing of community engagement strategy and implementation

– Local wisdom to address community issues during and after trial

– Advise on set up of research infrastructure – location of clinic, business hours, etc.
Thailand’s experience

- First CAB was formed in 1999 as condition for US government funding
- Since then, 19 more were formed – all HIV/AIDS
- Evolving mechanism
  - Institution CAB, trial CAB, interest group CAB
  - Terms of Reference
    - Biggest challenges: relationship with the research team, science, English proficiency, availability, funding, and commitment/social responsibility
- Proposals made for National CAB Network and National CAB
The way forward

Operational guidelines for CABs?

• The role of a CAB
• Constituting a CAB
• Charter and operations of a CAB
  – Membership, terms of appointment, conditions of appointment, offices, independent consultants, conflict of interest, education for CAB members, staff, quorum requirements, meeting requirements, meeting procedures, format of meetings, decision-making, follow up, documentation and archiving
Some key challenges

• Can one size fit all (for Asia and Western Pacific)?
  – Diverse socio-cultural context with complex relationships
• Trust building – researchers & community
• Capacity building and empowerment
• Funding
• A CAB for every trial?
  – Big or small
  – Drug, vaccine; test kits, medical equipment and technology
  – Observational studies, cohort studies with no intervention
• How to define “community,” how to identify true community representatives?
## Defining Communities

### CHARACTERISTICS OF TYPES OF COMMUNITIES

<table>
<thead>
<tr>
<th>Community characteristic</th>
<th>Aboriginal</th>
<th>Geographic/Political</th>
<th>Religious</th>
<th>Disease</th>
<th>Ethnic/Racial</th>
<th>Occupational</th>
<th>Virtual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common culture and traditions, cannon of knowledge, and shared history</td>
<td>++</td>
<td>+</td>
<td>++</td>
<td>+/-</td>
<td>+</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Comprehensiveness of culture</td>
<td>++</td>
<td>+/-</td>
<td>++</td>
<td>-</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
</tr>
<tr>
<td>Health-related common culture</td>
<td>++</td>
<td>+</td>
<td>++</td>
<td>++</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
</tr>
<tr>
<td>Legitimate political authority</td>
<td>++</td>
<td>++</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>+/-</td>
<td>-</td>
</tr>
<tr>
<td>Representative group/individuals</td>
<td>++</td>
<td>++</td>
<td>++</td>
<td>+</td>
<td>+</td>
<td>+/-</td>
<td>+/-</td>
</tr>
<tr>
<td>Mechanism for priority setting in health care</td>
<td>+</td>
<td>+</td>
<td>+/-</td>
<td>+</td>
<td>+/-</td>
<td>+/-</td>
<td>-</td>
</tr>
<tr>
<td>Geographic localization</td>
<td>+</td>
<td>++</td>
<td>+/-</td>
<td>+/-</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Common economy/shared resources</td>
<td>++</td>
<td>++</td>
<td>+/-</td>
<td>+/-</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Communication network</td>
<td>++</td>
<td>+</td>
<td>+</td>
<td>+/-</td>
<td>+/-</td>
<td>+</td>
<td>++</td>
</tr>
<tr>
<td>Self-identification as community</td>
<td>++</td>
<td>++</td>
<td>++</td>
<td>+/-</td>
<td>+/-</td>
<td>+</td>
<td>+</td>
</tr>
</tbody>
</table>

++ The community nearly always or always possesses the characteristic. + The community often possesses the characteristic. +/- The community occasionally or rarely possesses the characteristic. – The community very rarely or never possesses the characteristic.

Source: C. Weijer and E.J. Emanuel
Science; Aug 18, 2000; 289. 5482, Pages 1142-44

Armed Forces Research Institute of Medical Sciences

www.afrims.org
Some key opportunities

• The ultimate aim of biomedical research
  – Strengthened community regardless of research outcome, esp. developing countries
  – Addressing community’s health priorities vs. doing research for research

• From “rubber stamp” to partnership
  – Trust, ownership
CAB but one mechanism of community engagement in biomedical research

Operational guidelines for constituting and functioning of CAB can benefit all stakeholders in the complex matrix (stakeholders, interests, politics) of biomedical research by formally

– Institutionalizing a role for the community
– Defining roles and responsibilities
– Requiring systematic capacity building and empowerment

Addressing the “how’s” of community participation in biomedical research
Thank you

Prime-Boost Trial CAB

Attempting a National CAB Network

Pre-CAB meeting Pattaya Municipality