

Is CAB effective in community
engagement?
Confession of an optimist

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NCAB

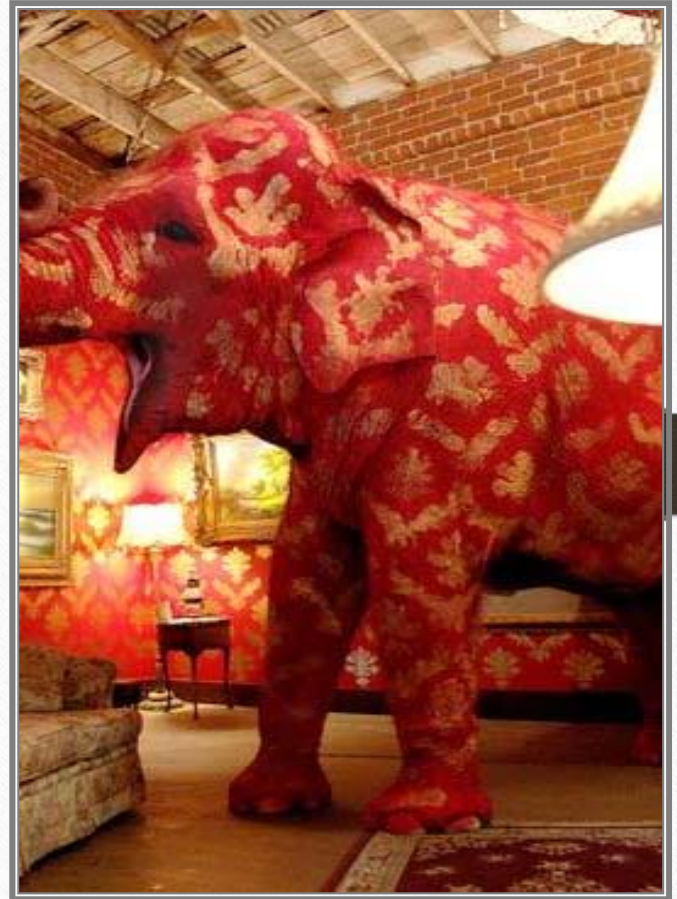
Disclosure, notification

- I am a consultant in community engagement and GPP (good participatory practice) to AVAC.
- I am a consultant in CAB development to a research center in Thailand.
- This is a very subjective reflection.
- There is no eureka moment, no wisdom or lessons learned, only food for thought.

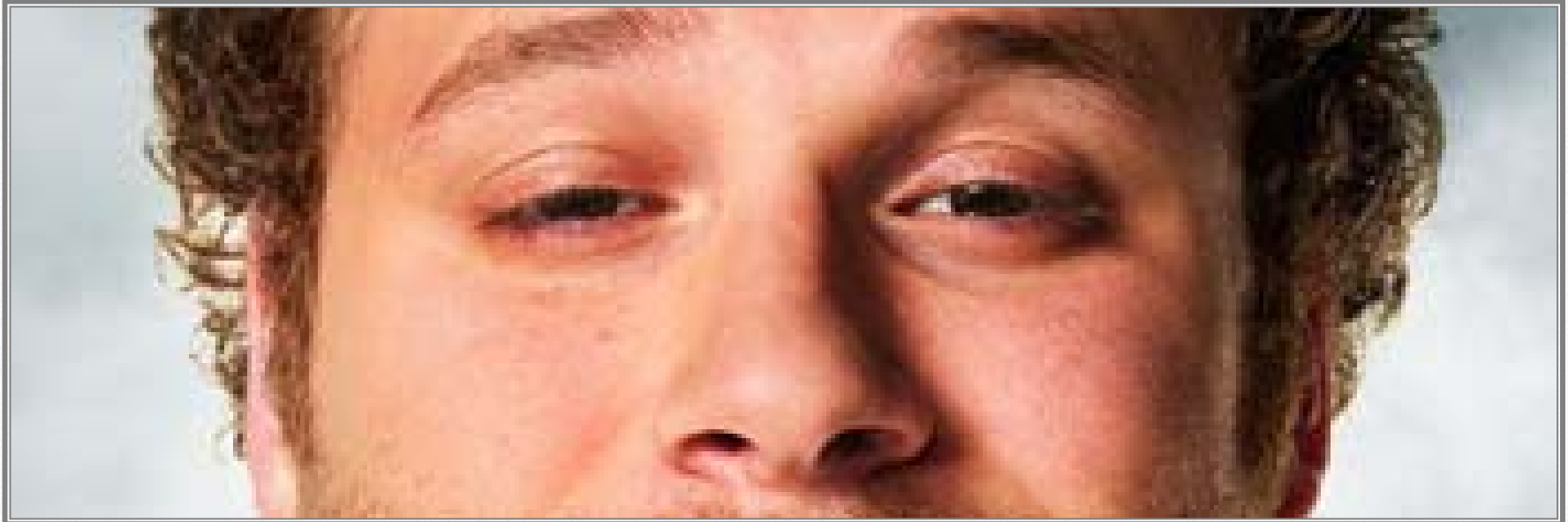
A personal retrospective on history of CABs in Thailand

An elephant in the room

- RV144 – big trial, big money, many volunteers, many years, limited engagement
- Lingering doubt and embroilment
- Compromised discussions, engagement
- Shot gun wedding: a tactical CAB was created
- Preemptive CAB was created in the north







**No more guinea pig. We have a CAB!
CAB or its look-alike was incorporated in many HIV clinical research
centers.**

Conceptual miscue

Thai NGOs were very active and involved in HIV programs and supportive to community involvement in HIV clinical research and the concept of CAB but.....

- CAB became an end (instead of a means to an end)
 - Selection of CAB members: arbitrary, noninclusive and NGO-laden
 - CAB operation: casual, fuzzy by-law and responsibility (and role), led by researchers
 - CAB support: minimal; last in, first out; study-centric not well institutionalized
 - CAB capacity building: afterthought, occasional, no long-term plan
 - Linkage between CAB and institute: top-down, lack of authority and ill-prepared
- CAB and community: unaccountable and very limited or selective interaction and communication

Expectations

What Researchers wanted

- Advise on informed consent form and related documents (brochures, banners, IE&C)
- Advise on recruitment and enrollment, and community activities
- Being informed about on-going trials or planned trials and later on a few more trials and a few more
 - Regular meeting for trials updates
- Inputs for social and community issues
- Wholistic – everyone in but NGO heavy
- Limited engagement

What CAB members understood

- Advise and approve a trial or trials
- Assist research team in what....recruitment, solving conflict, as needed?
- Voluntary: minimum effort and expectation
 - No real commitment, meeting room responsibility
- One-way engagement
- Privilege and gratitude
- NGO-led
- Advise on social and community issues, allergic to science

CAB meeting

- Meet every two months, except one CAB
- Meet for half a day (2.5 to 3 hours), except one CAB
- A little more than half attend the meeting regularly
- Agenda are routine, most are trial updates
- Discussion is limited in time and among a few key persons
- Most go through the motions

CAB Inputs

On community engagement,

“We are not community advisory board (CAB). We are advisory board from the community.”

On informed consent,

“Signing the consent form means that you won’t sue the researchers if anything goes wrong.”

On HIV acute infection study,

“Why do you call it acute HIV infection? Why don’t you call it early HIV infection?”

On ART treatment of HIV infection in infants,

“Eh... we didn’t read the documents sent to us. We didn’t have time.”

Deconstruct CAB

- Linkage between CAB and researchers: CAB coordinator with minimal authority
- Capacity building for CAB: occasional or never, light on content
- Lopsided capacity and power relation plus the Thai concept of *Kreng Jai* (a desire to avoid conflict, disagreement, disrupting someone's pleasure or intention, and trying to please others)
 - Humble, deferential to researchers and research team, and ask no or few questions
 - As requested advise, passive
 - One-way engagement , unclear of role and responsibility
- Representation – who represents whom or as a free agent?
- Recruitment – mostly selected by researchers and arbitrary, not selected or elected by peers
- Concept of CAB independence and neutrality

Promising CABs (1)

An institutional CAB

- Consultations with AIDS NGOs before CAB establishment
- CAB capacity building activity is integrated in bi-monthly meeting
- Involvement of CAB members in developing by-law and capacity building plan
- Annual participatory CAB evaluation and annual capacity building training
- Involvement of leadership and supported by a dedicated engagement team
- Sensitivity training of research team in relevant topics by CAB members
- Review and comment on protocol drafts and other documents

Promising CABs (2)

Population-based CAB

- Involvement of affected community
- Initiated and led by community members
- Leadership buy-in and support
- Regular training in relevant topics (clinical research, research ethics, GPP)
- On-going engagement with community members and researchers

A Chimera CAB?

- Diverse: members with different skills, backgrounds, representations, experiences, interests or passions
- Mission: clearly defined role and responsibility and links to higher goal/s
- Members character: accountable, dedicated, goal-oriented
 - Inquisitive and preferably autodidact (or bibliophile)
 - Having spare time or flexible working arrangements
 - Not timid, not too assertive, and mindful of group dynamic
- Actively engage with community and researchers
- Accountable to science (and research ethics) and community

Effective CAB: things to consider

- Capable and willing members particularly CAB chair and co-chairs
- Empowering process to increase research literacy: orientation, systematic CAB training, tutoring, coaching, opportunity to become involved and to improve, and capable CAB liaison officer
- Institutionalized supporting system: genuine commitment & leadership, resources, supporting personnel and policy, and translation services
- Go beyond CAB and trials: community forum, meeting, exhibition, special event, multi-pronged engagement strategies, sufficient resources and staffs and time

It's both art and science. It's a hand-on and iterative process.

Is CAB an effective engagement mechanism?
Could it escape from tokenism, paternalism?

Not without genuine commitment, hard work, concerted efforts, and a hefty dose of soul searching from trial sponsors and researchers, CAB members and community member.

Thank you for your attention