

# Community Issues Related to Prevention Research in Developing Countries

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**AIDS**  
**VACCINE 2008**  
**CAPE TOWN 13-16 OCTOBER**

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*“...most of the gay population is willing to participate [in HIV research]...[we] are the population that contributes the most [on finding] a solution to HIV...”*

Formative research: Feasibility of  
a Male Circumcision Trial for HIV Prevention  
Focus group, Gays 18-30 y.o.  
Lima, 2008



# Andean HIV Prevention Research Sites



# Andean HIV Prevention Research Sites (cont.)

STUDY	Phase	Sample size	Initial accrual date	Final accrual date	Number of screenees	Screening/ Enrollment ratio
HTPN 036	Obs.	254	Apr. 2002	Aug. 2002	350	1.37
HVTN 903	Obs.	200	April 2003	Sep. 2003	210	1.05
HVTN 026	I-II	40	May 2002	Feb. 2003	72	1.8
HPTN 039	III	1400	Dec. 2003	Sep. 2006	~7000	5
HVTN 050	I-II	30	Oct. 2003	Oct. 2004	45	1.5
HVTN 502	IIB	500	Jul. 2005	Ago. 0206	512	1.64
HVTN 069	I	n.a.	n.a.	n.a.	-	-
iPrEx	III	1400	Jun. 2007	On-going	2425	2.1
Total: 8 studies		2352	6 years		10614	

# Andean HIV Prevention Research Sites (cont.)

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- HIV prevention clinical research infrastructure: 2000
- Concentrated HIV epidemic in MSM mostly in urban areas
- Naïve population in HIV prevention clinical research
- Legacy of a strong prevention program for vulnerable populations at the Peruvian MoH

# Andean HIV Prevention Research Sites (cont.)

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- Little access to ARV medications for PLWHA
- HIV research capacity
- Willingness to expand HIV research infrastructure

# Andean HIV Prevention Research Sites (cont.)

- Community participation in HIV research was a new concept at the time
- The CCG model was difficult to adapt to the prevention arena
- A Community Advisory Board (CAB)



# Andean HIV Prevention Research Sites (cont.)

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- Gaining community trust:
  - Formative research
  - Needs assessment
  - Community consultation
  - Quality of care monitoring system
  - Social marketing techniques
    - Community education through enter-education (entertainment education)
    - Community mobilization activities
  - Coordination with stakeholders

# Why do people join the trials?

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- To be proactive with regards to the epidemic
- To access high quality health care and constant health monitoring
- To benefit from the intervention
- For the reimbursement
- For the additional benefits

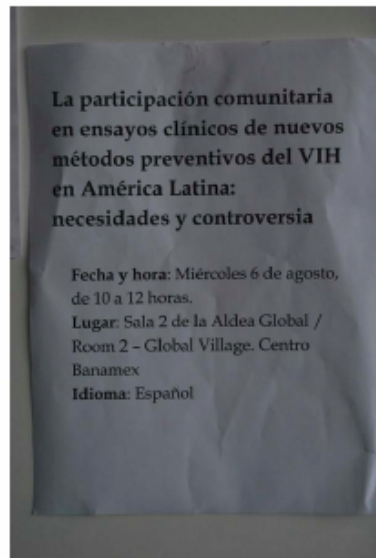
# Surrounding Community Raises Concerns



## Sesión de debate

**“La participación comunitaria en ensayos clínicos de nuevos métodos preventivos del VIH en América Latina: necesidades y controversias”**

## Memoria resumen



- *Community Participation in New HIV Prevention Methods Clinical Trials in Latin America: Needs and Controversies*

IAC, August 2008



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# Surrounding Community Raises Concerns (cont.)

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- Mechanisms for CAB members in the South to be in the protocol design process
- HIV prevention research should empower their target communities
- In scarce resource settings research funds should be allocated to reduce the gap of impoverish public systems on HIV prevention
- Researchers and institutions should support political initiatives leading at improving the conditions of the affected populations

# Surrounding Community Raises Concerns (cont.)

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- Researchers should be willing to work with CBOs, listen to them, pay attention and gain their trust
- A clinical trial should finish the research process by improving the conditions of the community that was the target of the intervention

# Surrounding Community Raises Concerns (cont.)



**ENSAYOS CLINICOS  
EN GAYS Y TRANS:  
¿NOS BENEFICIAN O NOS PERJUDICAN?**

¿Se respetan nuestros derechos en estos ensayos?  
¿Deben realizarse los ensayos en los países en desarrollo?

¿Qué normas garantizan el bienestar de los y las  
participantes y cuál es el rol del Estado?

¿Qué intereses tienen quienes están a favor  
o en contra de las formas cómo se realizan  
los ensayos clínicos en el Perú?

La Red Peruana TLGB te invita a debatir e informarte  
sobre éste interesante tema con instituciones  
y personas que participan en estos ensayos.

Fecha: Martes 30 de setiembre del 2008  
Hora: 6:00 p.m.  
Lugar: Colegio Regional de Obstetras Lima Callao  
Av. Sucre 1351 Pueblo Libre, Lima, Perú

 TLGB  
redperuanatlgb@yahoo.com

- *Clinical trials involving gays and trans: Do they benefit or harm us?*

Peruvian TLGB  
Network

September 30th, 2008



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# Surrounding Community Raises Concerns (cont.)

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- Who benefits from clinical trials?
- Delivery of research results back to the community
- Clinical research protocols should allocate funds for community oversight
- How do we re-orient the priorities of the research agenda according to the host countries needs?

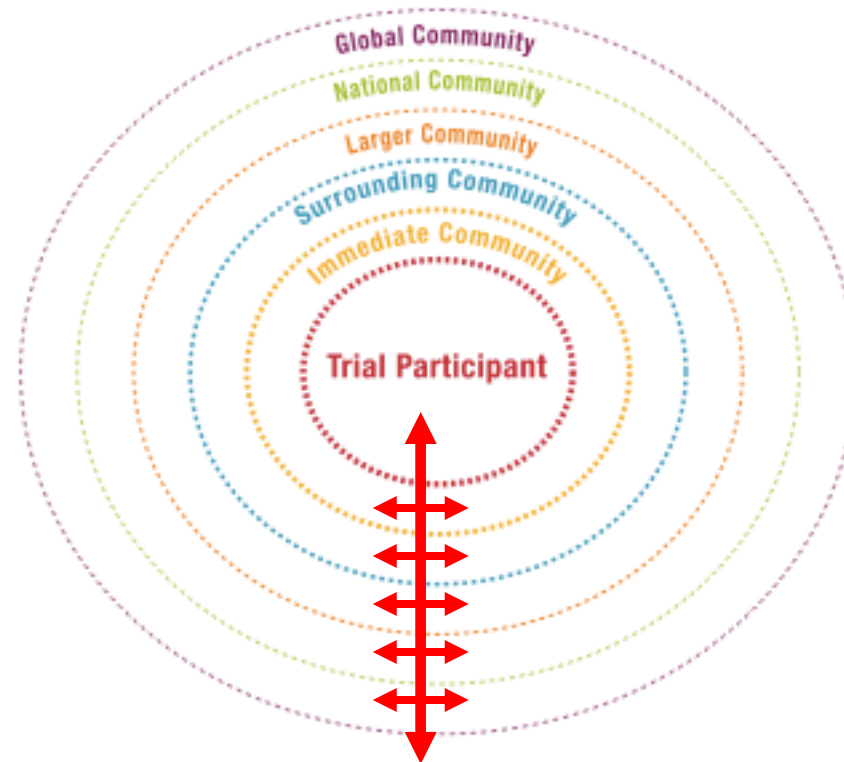
# Surrounding Community Raises Concerns (cont.)

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- The community should have a more proactive attitude towards research
- How could the relationship between researchers and community be improved?
- How do researches and community anticipate to research results for mutual benefit?

# Conclusions

Figure 7 ALL IN THIS TOGETHER: LAYERS OF THE AIDS VACCINE COMMUNITY



## Conclusions (cont.)

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- Communities are still interested in volunteering in HIV prevention trials in the Andean region
- Community leaders have legitimate concerns about how research may affect their constituencies, this should be clarified with research investigators
- There is a need to incorporate the gender perspective in protocol design and wording. Trans population is considered as male

## Conclusions (cont.)

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- The Investigator - Community relationship should be reconstructed so both are in egalitarian conditions
- Design, implementation and application of results should be a coordinated activity among the investigators, the sponsors and the community
- Research should facilitated the conditions for community empowerment

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*“...The services I got in this clinic have been very good, the environment is very pleasant, warm and you feel at home, thus, it made me feel very good. Well I want to thank iPrEx for this. I will put all of my effort to collaborate and make something very big for the history of humankind that is to find an alternative to prevent HIV/AIDS. Well, no much else to say, thanks for your attention to this...”*

Screened participant at iPrEx  
in one of the Andean Sites, 2007 - 2008  
Computer Assisted Self Applied Interview



