
ARE WE SO DIFFERENT? SAME SAME BUT DIFFERENT

Udom Likhitwonnawut
Thailand NCAB
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Disclosure

- I am a member of three Community Advisory Boards (CAB).
 - I am a consultant in community engagement and GPP for AVAC.
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We are not so different

- NGO and community members want HIV research.
 - We want HIV research that are scientifically sound and ethical.
 - We want HIV research that are useful and relevant to the needs of people living with HIV/AIDS, HIV vulnerable people and community members.
 - We want HIV research that are accessible, scalable and sustainable.
 - And we want to be engaged, involved in HIV research to ensure all of the above.
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Same same but different

We share similar values with researchers, trial sponsors and supporters, and ethicists. But

- Our experiences and perceptions are not always similar to researchers'.
 - Our interpretations and priorities may be different.
 - Participation in a study:
 - Ethics boards = voluntary acts
 - Participants = income-generating opportunity, enhanced access to health service, special services
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Echo from the past

- Different standard of care and use of placebo: PMTC trials
 - Standard of HIV prevention for injecting drug users: tenofovir PrEP study
 - Planned PrEP trials in Cambodia and Cameroon
 - Lack of afterthought or tokenistic community engagement in HIV vaccine trials
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Effects

- Distrust of researchers, scientists
 - Perception of disrespectful from both sides
 - Perception of being exploited
 - Lingering tension between researchers and NGOs
 - Apprehensive relationship between researcher, NGOs, CAB, and community members
 - Paternalistic attitude towards CAB and community members
 - Asymmetry relationship (researcher-community)
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Values in research ethics

(from “Ethical considerations of HIV cure research”, CUREiculum, AVAC)

- Scientific validity
 - Social value
 - Scalability
 - Fair participant selection
 - Favorable risk/benefit ratio
 - Informed consent, confidentiality, privacy
 - Community engagement
 - Independent review
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Selected values

- Social value
 - Is the research likely to advance research capability of the institute and its local partners, lead to health system improvement and long-term research collaboration?
 - Can the research provide an important benefit to the society?
 - Scalability
 - Can the end products of the research be implemented on a large scale to those who need it?
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Selected values

- Informed consent
 - Are potential participants empowered to freely decide whether to participate in the research based on their comprehension of the research?
 - Are researchers responsible for translating research into accessible layman terms?
 - Are there initiatives to improve research literacy of affected community and potential trial participants?
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Selected values

- Community engagement
 - Are communities impacted by the research meaningfully involved at all stages of the research?
 - Does the research take into consideration the health-related needs of the affected community and response to the needs accordingly?
 - Independent review
 - Is the research accountable for scientific and ethical evaluation by independent third parties including NGOs?
 - Will the research team disseminate results of the research and relevant data to the public in timely manner?
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Parting note: participation in research

- Beware of romanticization voluntariness
 - Altruism is fleeting and difficult to validate.
- Sensitive to people's motivation, intrinsic or extrinsic, for participating in the research
 - Participation in the research is an income-generating opportunity.
 - "For some participants, research participation was based on whatever studies were recruiting rather than the research topic."*
 - For some, it is better health service that a trial provides.
- For some, it is a strategy to counter stigma; for some, it is a strategy to improve their social capital; and for other, it is identity affirmation.

**From "We're giving you something so we get something in return": Perspectives on research participation and compensation among people living with HIV who use drugs. Alexandra B. Collins and co.*

REVISED DECLARATION OF GENEVA

- Move respect the patient autonomy to the beginning of the pledge to emphasis its importance

WMA DECLARATION OF GENEVA (October 2017)

The Physician's Pledge

*Adopted by the 2nd General Assembly of the World Medical Association, Geneva, Switzerland, September 1948
and amended by the 22nd World Medical Assembly, Sydney, Australia, August 1968
and the 35th World Medical Assembly, Venice, Italy, October 1983
and the 46th WMA General Assembly, Stockholm, Sweden, September 1994
and editorially revised by the 170th WMA Council Session, Divonne-les-Bains, France, May 2005
and the 173rd WMA Council Session, Divonne-les-Bains, France, May 2006
and the WMA General Assembly, Chicago, United States, October 2017*

AS A MEMBER OF THE MEDICAL PROFESSION:

I SOLEMNLY PLEDGE to dedicate my life to the service of humanity;

THE HEALTH AND WELL-BEING OF MY PATIENT will be my first consideration;

I WILL RESPECT the autonomy and dignity of my patient;

I WILL MAINTAIN the utmost respect for human life;

I WILL NOT PERMIT considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing, or any other factor to intervene between my duty and my patient;

I WILL RESPECT the secrets that are confided in me, even after the patient has died;

I WILL PRACTISE my profession with conscience and dignity and in accordance with good medical practice;

I WILL FOSTER the honour and noble traditions of the medical profession;

I WILL GIVE to my teachers, colleagues, and students the respect and gratitude that is their due;

I WILL SHARE my medical knowledge for the benefit of the patient and the advancement of healthcare;

I WILL ATTEND TO my own health, well-being, and abilities in order to provide care of the highest standard;

I WILL NOT USE my medical knowledge to violate human rights and civil liberties, even under threat;

I MAKE THESE PROMISES solemnly, freely, and upon my honour.

Thank you for the
opportunity
