The evolving social science research landscape as part of AIDS vaccine R&D

Zuhayr Kafaar, Anthea Lesch, Leslie Swartz, Ashraf Kagee

Genesis

- In Feb 2003 the South African AIDS Vaccine Initiative (SAAVI) initiated the development of a Socio-behavioural (SB) research arm for the Cape Town HIV Vaccine Trials Consortium
- This led to the development of a national SB working group that was tasked with developing SB capacity at all SAAVI trial sites

Social Science: beyond informed consent [a]

- Developing an effective AIDS vaccine is essentially a biomedical concern
- However, the efficient implementation of vaccine trials requires an understanding of social and behavioural issues related to HIV vaccine trial participation

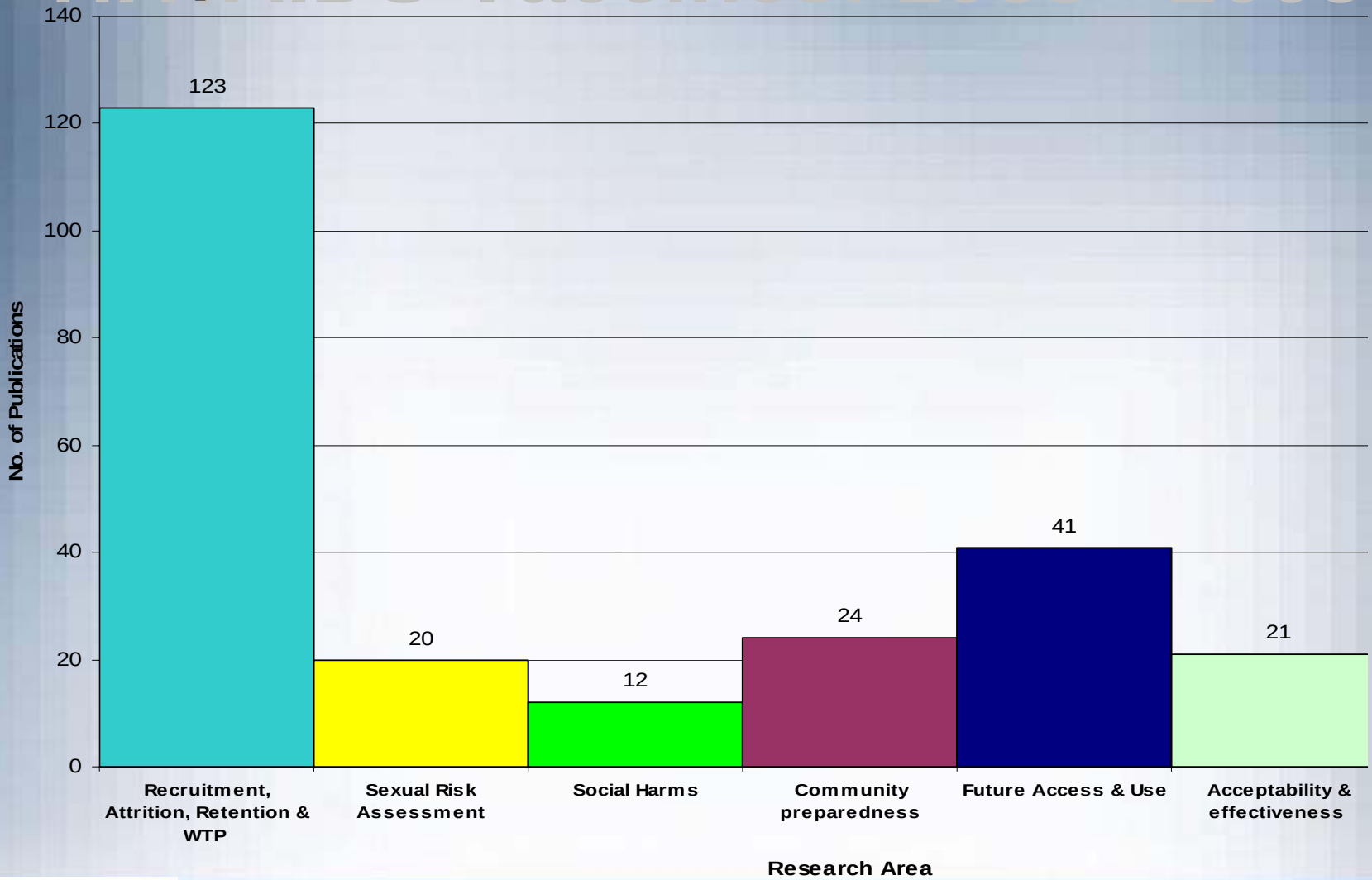
Social Science: beyond informed consent [b]

- Seminal work had been done by the HIV/AIDS Vaccine Ethics Group (HAVEG) on issues relating to ethics in vaccine trials generally, and informed consent specifically
- There was, however, a dearth of social science research related to broader vaccine trial participation issues

Social science literature

- An initial review of the literature conducted in 2004 suggested that there were four main areas of concern:
  - Informed Consent and Social Harm monitoring
  - Retention and attrition
  - Sexual Risk Assessment and Monitoring
  - Willingness to participate (WTP)
- A more detailed review of the literature revealed the following data

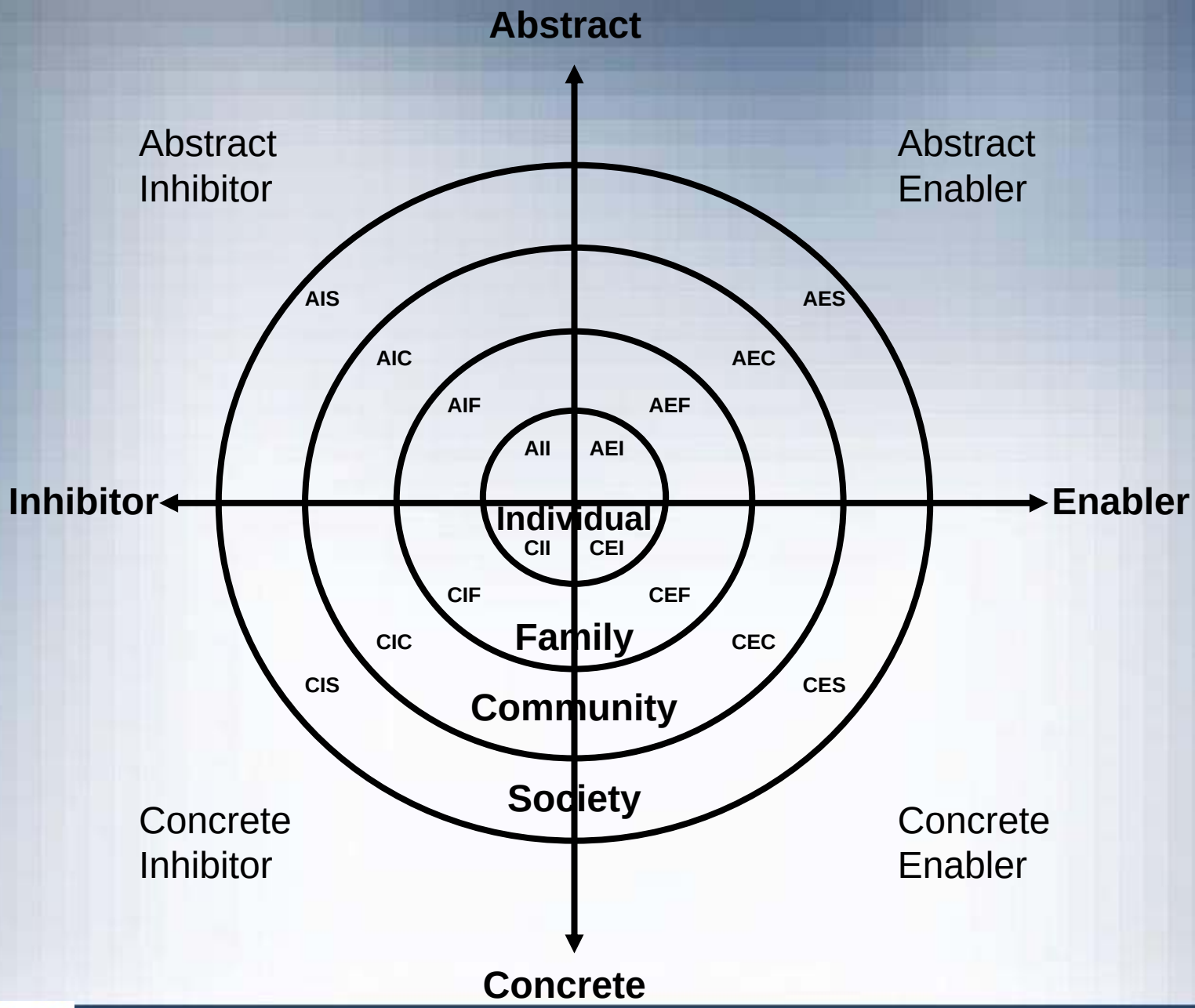
Social Science Research on HIV/AIDS Vaccines: 1983 - 2005



Enablers and Inhibitors to WTP

- In 2005 the SB group was commissioned by Masikhulisane, the Community Involvement group of SAAVI, to conduct a study into factors that may enhance or inhibit WTP in HIV vaccine trials
- This national qualitative study uncovered a number of factors that may enable and inhibit trial participation
- An explanatory quadrant model was developed out of the findings of this study in order to organize these factors.

Lesch, Kafaar, Kagee, & Swartz (2006). Community members' perceptions of enablers and inhibitors to participation in HIV vaccine trials. South African Journal of Psychology, 36(4), 734-761.


Abstract
Abstract Inhibitor
Abstract Enabler
AIS
AES
AIC
AEC
AIF
AEF
AII
AEI
Inhibitor
Enabler
Individual
CII
CEI
CIF
CEF
Family
CIC
CEC
CIS
CES
Community
Society
Concrete Inhibitor
Concrete Enabler
Concrete

Social and behavioural research issues related to AIDS vaccines

- Given this background, the SAAVI Socio-behavioural group convened an international meeting in June 2005 to consider social and behavioural research issues related to AIDS vaccines
- Conforming to the literature at the time, the issues raised at this meeting were:
  - Recruitment, Retention and WTP
  - Social Harms
  - Sexual Risk
  - Community Preparedness/Involvement
  - Future Access and Use

The changing landscape [a]

- Increasing recognition of the importance of SB issues
- Request for proposals from SAAVI for research into, particularly, community preparedness.
- Increasing visibility of social and behavioural research related to HIV vaccine trial participation in journals, at conferences etc.
- Indicative of a need for more SB research related to HIV vaccines e.g. community based participatory research

The changing landscape [b]

- Culminated in collaboration between SAAVI and IAVI to host a meeting to identify how best to facilitate meaningful community participation in HIV vaccine research
- Meeting was held with a range of role players from HIV vaccine trial sites and the communities in which they are located.
- Participants identified:
  - Strategic challenges
  - Gaps in current research
  - Research priorities to address the gaps identified.

The changing landscape [c]

- Four key areas were identified

1. Language, translation, literacy and understanding of scientific information.
2. Moving from community involvement to community engagement.
3. Integrating and linking HIV vaccine research with broader HIV prevention strategies.
4. Involving adolescents in HIV vaccine research.

Swartz, Singh, Giocos, Martin, Louw, Kagee, Evangeli, Kafaar & Lesch (2007). Facilitating meaningful community participation in HIV vaccine research. Poster presentation, AIDS Vaccine Conference, Seattle

Conclusion

- Initial SB work concerned mainly recruitment (informed consent, community preparedness, etc.), WTP and future access and use
- There has been a steady move from conducting research from the trial site investigators' perspectives and needs to research that engages with and involves the communities we aim to conduct research with.
- An integral component of such a perspective is participant-generated research agendas e.g. UNAID and AVAC (2007). Good Participatory Practice guidelines for Bio-Medical HIV Prevention Trials

Where to from here?

- Can Health Psychology theories such as TPB/TRA help in understanding WTP?

  Kafaar, Kagee, Lesch, & Swartz. Is participation in HIV vaccine trials a health promoting behaviour? *AIDS Care*, in press.

  Giocos, Kagee & Swartz (2007). Predicting hypothetical WTP in a future phase III HIV vaccine trial among high risk adolescents. Poster presentation, AIDS Vaccine Conference, Seattle

- Moving away from the checklist approach in assessing understanding of HIV vaccine trial information

  Lindegger, Milford, Slack, Quayle, Xaba & Vardas (2006). Beyond the Checklist: Assessing Understanding for HIV Vaccine Trial Participation in South Africa. *JAIDS, 43*(5), 560-566

- Adolescent inclusion in trials?

  Kafaar, Swartz, Kagee, Lesch & Jaspan (2007). Adolescent inclusion in HIV vaccine trials: cognitive developmental considerations. *South African Journal of Psychology, 37*(3), 576-594

- From community preparedness to community involvement

  Swartz, Singh, Giocos, Martin, Louw, Kagee, Evangeli, Kafaar & Lesch (2007). Facilitating meaningful community participation in HIV vaccine research. Poster presentation, AIDS Vaccine Conference, Seattle

- More nuanced understanding of factors influencing trial participation

  Arreola (2007). Enrolling Important Target Populations Into HIV Vaccine Trials. Presentation at HVTN Conference, Washington DC