Integrating Social Research Into the HIV Cure Agenda

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- Patient and clinical researcher preferences, beliefs and hopes
- Social and contextual factors that influence biomarkers
- Patient willingness to participate

What is the role of social science in early basic research?

What are the social and ethical considerations in early clinical research?

What is needed to ensure the strategies be scalable and effective in the real world?

What are the critical aspects of community and stakeholder involvement?

- Cost-effectiveness research
- Implementation science
- Policy research

- Ethical and social analysis of therapeutic and curative misconception and informed consent
- Analysis using a shared-decision making framework

- Community perceptions
- Public understanding of Science
Key Areas of Social Research

• Stakeholder Perspectives
• Participation in Cure Clinical Trials and Related Studies
  – Recruitment, engagement, ethics, stigma
• Public Understanding of Science
• Access and Equity
• HIV Identities
Stakeholder Perspectives

• Patient/Participant
• Clinician/Researcher
  – Attitudes about “appropriate” participants
• Patient-Clinician Relationships
  – Patient-centered, shared decision-making approaches
  – Values frameworks
• Policy-makers & Funders
  – Cost effectiveness, systems readiness
• General Public
  – Public Understanding of Science
Participation in HIV Cure Research: Psycho-social Issues

- Barriers and motivators to participation in clinical trials
- Perceptions of and knowledge about clinical trials
  - Understanding the specific methodology
- Concerns about side effects
- Perceived risk-benefit ratio
- Fears of exploitation – by scientists or pharmaceutical industry
- Role of HIV stigma
HIV Stigma: Barrier or Motivator?

Stigma as a barrier:
- What is the degree of risk that others (family, friends, employers, etc.) might discover that a person is participating in a study? Do frequent study visits or particular study sites associated with cure research increase this risk?
- Do enhanced contraceptive mandates for women for many experimental therapies place them at risk for unintended disclosure to a sex partner?

Stigma as motivator:
- Does the experience of stigma increase motivation for altruistic participation in research?
- Can experiences of stigma lead to increased willingness to undergo greater risks in studies?

How might a cure strategy affect a person’s experience of stigma?
- Will it offer decreases in transmission potential over and above ART?
- Will it lead to a person losing antibody response? (e.g. “I’m HIV-negative now”)
- What is the risk that virus will return and how will a person know?
Public Understanding of and Engagement in HIV Cure Science

• How individuals and communities understand the notion of “cure” itself, as well as the science behind it:
  • Beginning with terminology/lexicon, especially when there is lack of consensus in the field.
• Impact of “cures” previously promulgated, but generally discredited:
  – Authority of those who make the claims
  – Invocation of “evidence”
  – Challenge to hegemonic “Western” science
• Therapeutic misconception
Ethical Considerations

• The word “cure” raises many ethical dilemmas with recruitment and informed consent, but what about other concepts or words that imply cure? How to minimize therapeutic misconception while remaining transparency about the ultimate aim of a line of research?
• Should we go beyond informing to ensuring comprehension with cure studies?
• How do we assess and value altruistic intent and evaluate its role in a prospective study participant’s decision-making?
• When ART is interrupted indefinitely, what is the need to reevaluate comprehension and consent?
• How may we best use social and psychological research and good participatory practices to ensure ethical design and conduct of studies?
Access, Equity, & Cost

- Who will have access to cure technologies, and how will that be determined?
- Who will cover the costs of cure strategies?
  - Will cure technologies be equitably distributed and available—locally, nationally and globally?
  - Lessons from Hepatitis C (Sovaldi)?
HIV-Positive Identity

- Denver Principles: 1983
- Greater Involvement of People Living with AIDS (GIPA): 1994
Key Social Science & HIV Cure Research Questions

- How do individuals and communities (i.e., publics including but not limited to HIV+ persons) comprehend notions of cure, attach meaning to it, and incorporate it (or don’t) into their everyday lives?
  - How do they weigh and balance competing notions of “cure” coming from different kinds of “experts’’?
- How does the relationship between patients and providers affect cure research participation?
- Is cure a cost-effective approach? Under what scenarios?
- How will HIV-related health disparities (inequalities) be affected by a cure?
  - Will such inequities be exacerbated or mitigated by a cure?
  - How will the cost of cure affect this?
- How are the identities of HIV+ individuals and communities affected by the search for a cure?