

# Research into female controlled HIV prevention in the region

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# Why we need more HIV prevention tools

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- Sex 'happens'
- Prevention tools that can be separated from sex are desirable
- Condoms can reduce male sensation, affecting willingness to use
- Conception may be desired
- Women may lack power to negotiate condom use
- Marriage is a risk for HIV acquisition for women (undisclosed partner activity)
- Prevention that does not require partner negotiation is required.

Condoms and lubricant and needle and syringe programs are effective primary prevention in many contexts. Condoms are very good for sexual and reproductive health.

# Biomedical HIV prevention context

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## ■ Proven:

- Mother-to-child transmission
- Post-exposure prophylaxis (PEP)
- antiretroviral coverage to reduce population viral load
- STI treatment
- Circumcision\*

## ■ Experimental

- Microbicides
- Pre-exposure prophylaxis (PrEP)
- Vaccines

Behavioural prevention too: condoms and lube, needle and syringe programs

## Key issues in biomedical prevention research

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- The vaccine goal is elusive; current generation likely only to ameliorate disease
- Microbicides are unlikely to be 100% effective in first generation products
- PrEP raises issues of toxicity, adherence, cost and unequal gender dynamics
- Biomedical prevention should be an adjunct to behavioural prevention

Imperfect but incremental advances, no magic bullets – if these are a substitute for behavioural prevention, sexual health outcomes may be impacted negatively.

# Issues in trial design

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- Communities should have some power to negotiate changes to research protocols
- Volunteers should have access to HIV treatment and care if they seroconvert, or are found to be positive when volunteering
- Trial participants should have access to best practice HIV prevention
- Will populations on whom the intervention is tested have access to a proven product?
- Decent healthcare is not an undue inducement

# Microbicides: topical protection

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- Safe? (non-oxynol 9 *increased* HIV transmission)
- Prevent HIV?
- Prevent STIs (which?)
- Contraceptive?
- Safe in pregnancy?
- Effective for anal sex?
- Acceptable (or undetectable) to partners?

Less likely to have systemic effects – safer for long term use. The contraceptive element may be a bonus or otherwise.

## PrEP: A pill a day HIV prevention?

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- Cost
- Toxicity
- Safe in pregnancy?
- Adherence
- Less than 100% effective?
- Long-term toxicity
- Who is expected to take it (women/men)?

Gender inequality is a significant issue here: women may be pressured to take PrEP (or participate in research) by partners, and thus disproportionately bear the burden of side effects.

## Community participation in research

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- Research should be conducted with people not on them
- Communities need to be involved before major decisions have been made
- Industry model of 'community advisory boards' is ineffective and tokenistic, lacking any clear power.

# Building capacity to participate

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- Strategies needed now
- Prevention studies are large, international and multicentred, held in lower-income countries with high HIV prevalence
- Factors like epidemiology and existing research links affect choice of trial populations
- Community capacity building around research should ideally be complementary to, but independent of, research

People need to be skilled to make decisions about how research should be framed for their communities and to make informed decisions about how or whether to participate. Potential for exploitation is enormous

# The task

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- Create a coalition of experts and advocates in SRH, HIV and community work for the primary purpose of facilitating effective community participation in research through:
  - Developing communication strategies between communities and researchers
  - Facilitating community input into setting research priorities
  - Involving communities in debate about research
  - Improving research literacy and developing skills
  - Promoting critical analysis and ethical practice in research

# Partnerships not tokenism

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- Lived experience
- Women's and men's sexual and reproductive health
- Family planning
- HIV community sector
- Primary care
- Education and communication

# Failure and success

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- PrEP trials in Africa and Cambodia have been failing largely due to community concerns.
- Meaningful community participation in research requires investment, support and the development of some infrastructure.
- Developing stronger partnerships between existing community and health sector organisations and civil society in the region is the way forward.