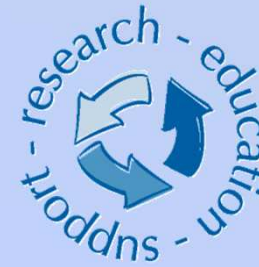


16th Annual Conference of the
National HIV Nurses Association (NHIVNA)



National HIV Nurses Association

Sylvia Nalubega

University of Nottingham

26-27 June 2014- City Hall, Cardiff



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The views and experiences of HIV research participants in sub-Saharan Africa: a qualitative systematic review

Sylvia Nalubega

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Presentation outline



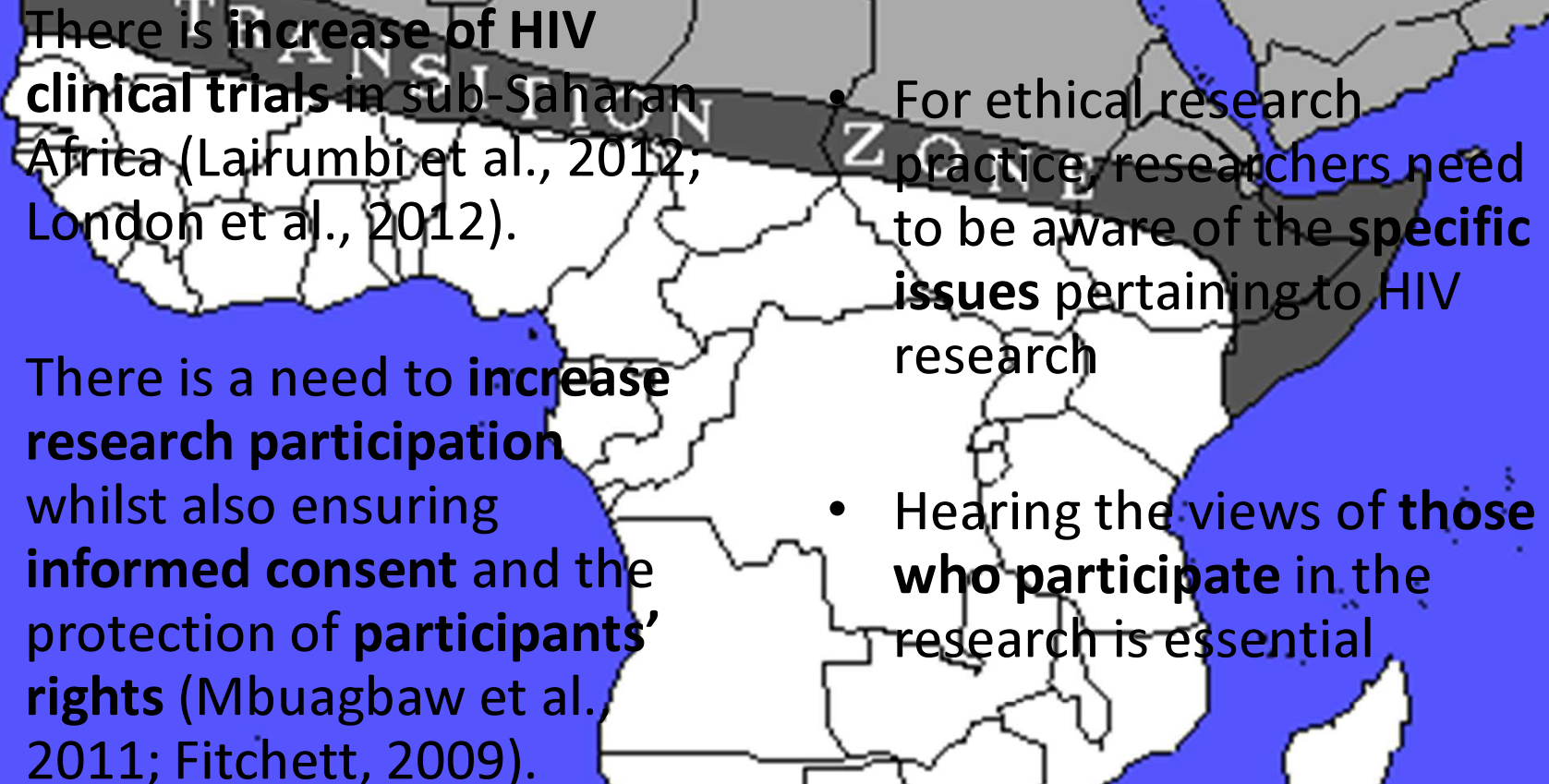
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Background



- 
- There is **increase of HIV clinical trials** in sub-Saharan Africa (Lairumbi et al., 2012; London et al., 2012).
 - There is a need to **increase research participation** whilst also ensuring **informed consent** and the protection of **participants' rights** (Mbuagbaw et al., 2011; Fitchett, 2009).
 - For ethical research practice, researchers need to be aware of the **specific issues** pertaining to HIV research
 - Hearing the views of **those who participate** in the research is essential

Review aims and objectives

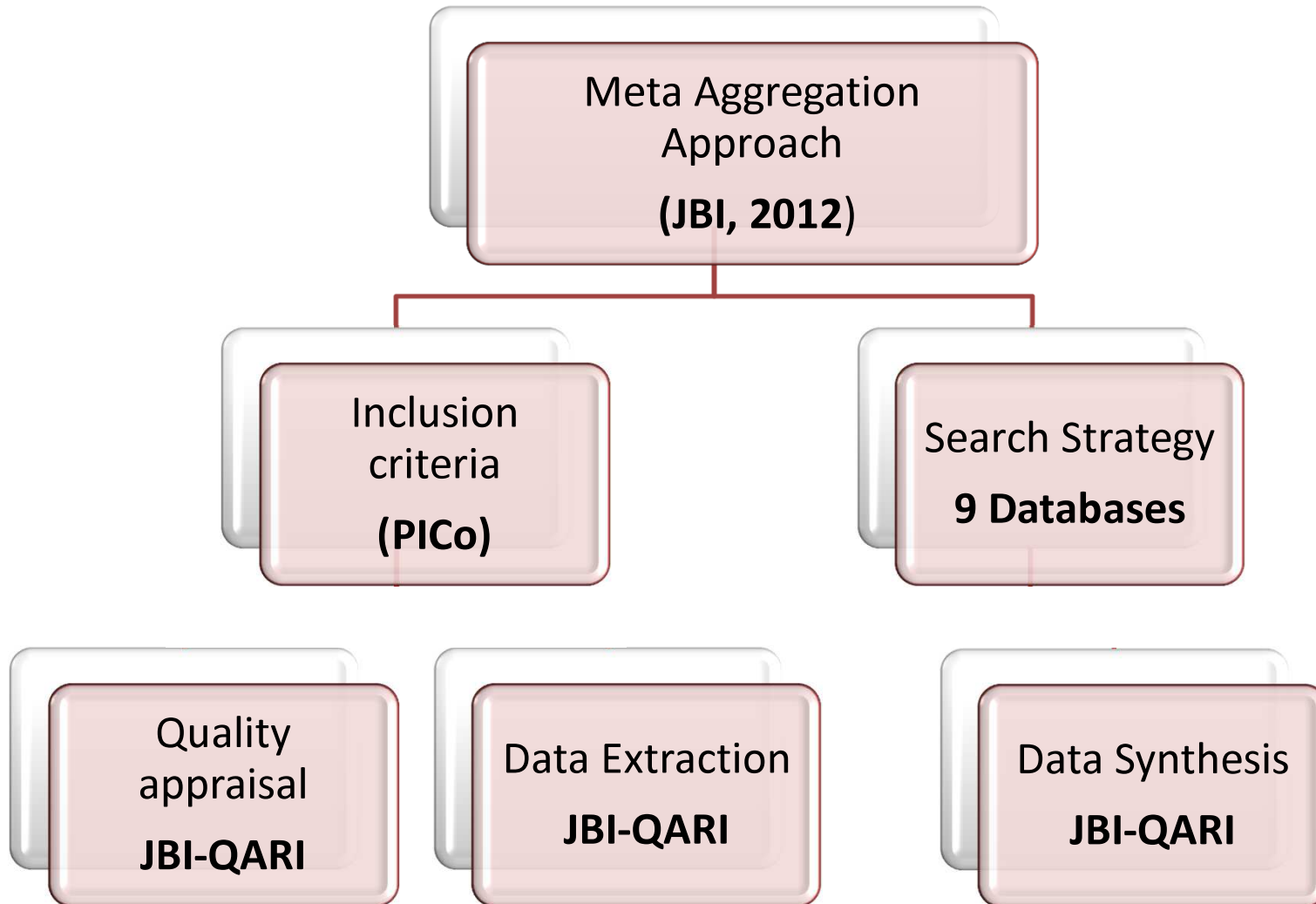


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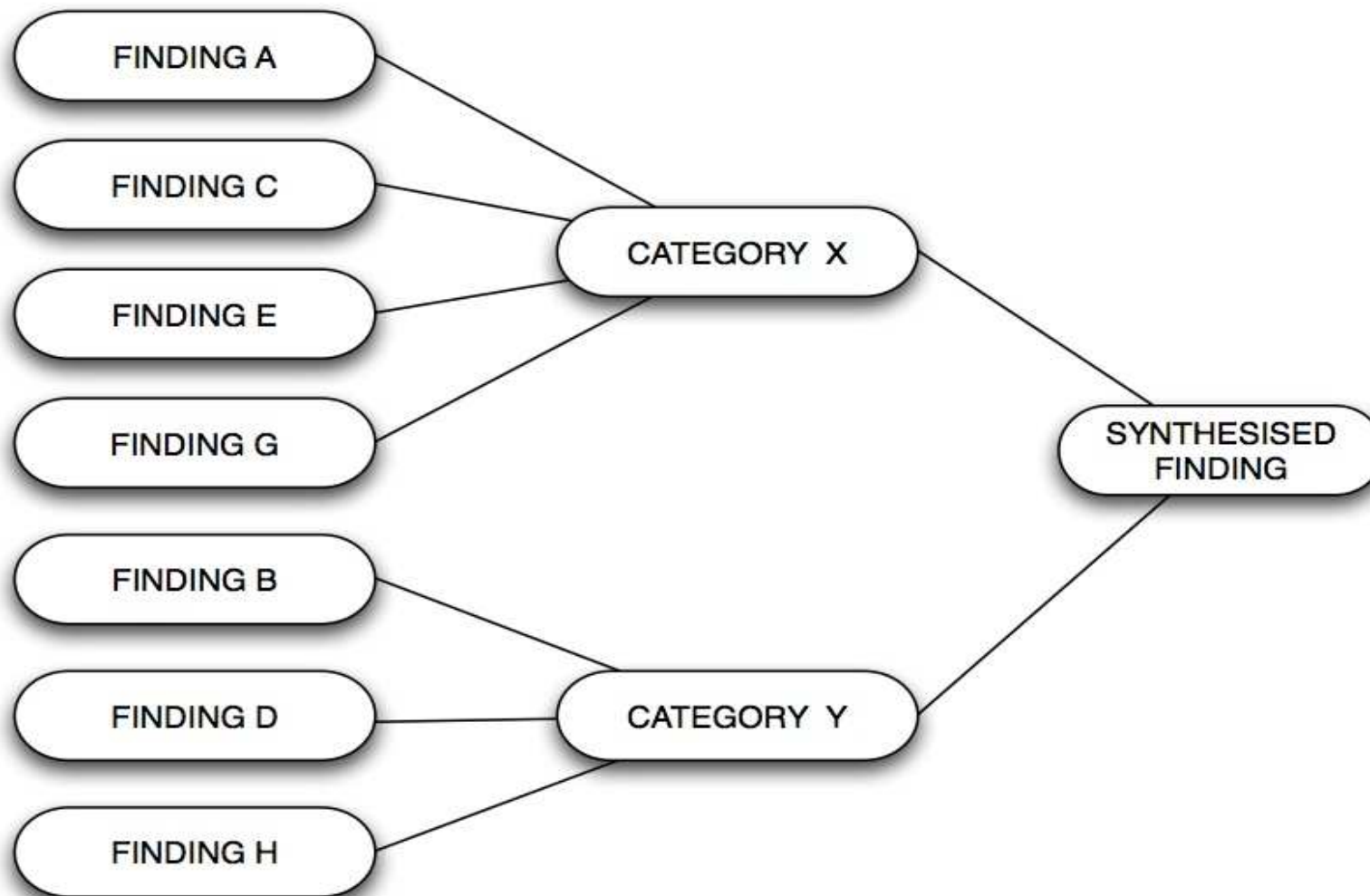
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- Aim
 - To establish the views and experiences of HIV research participants in sub-Saharan Africa

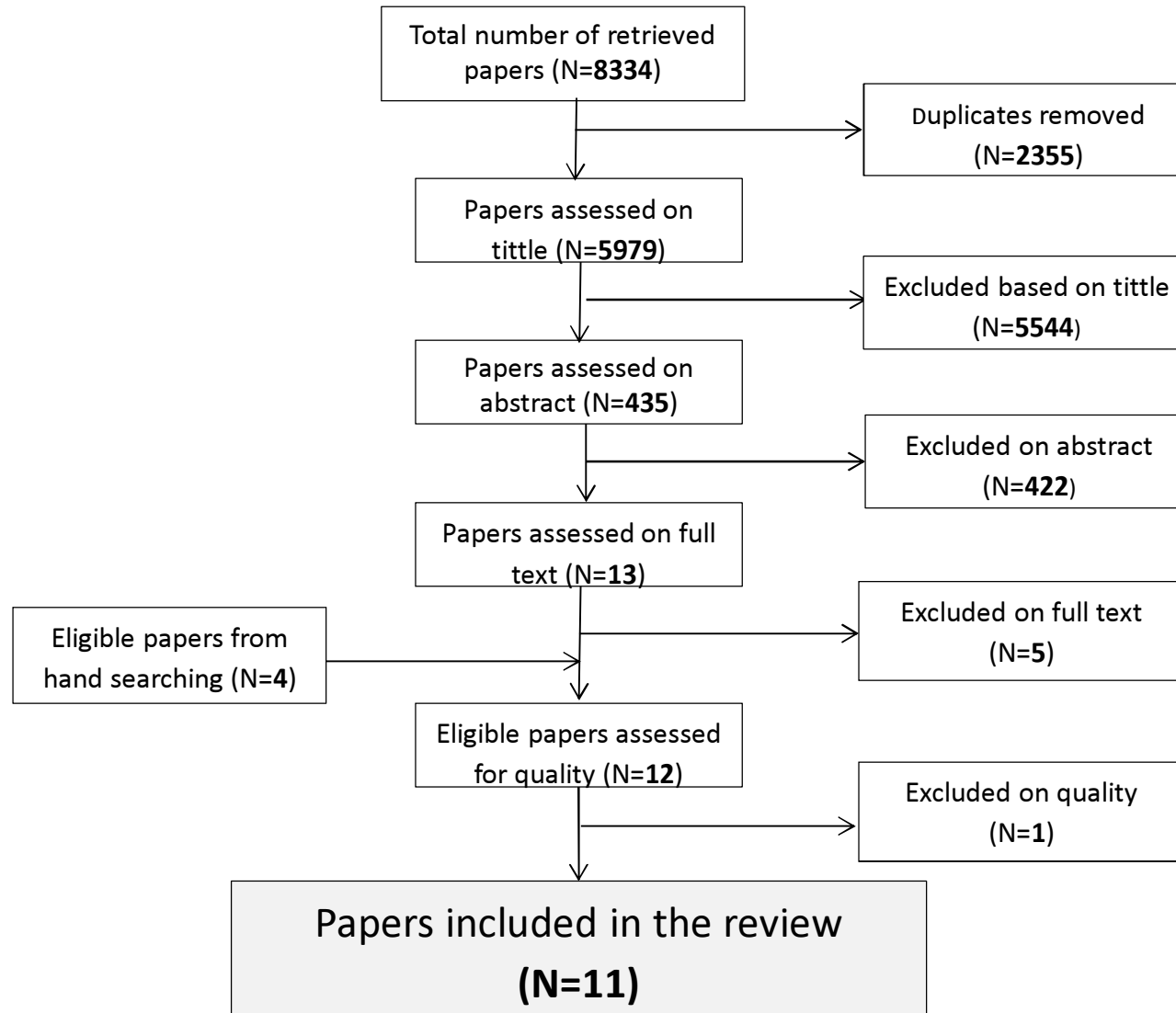


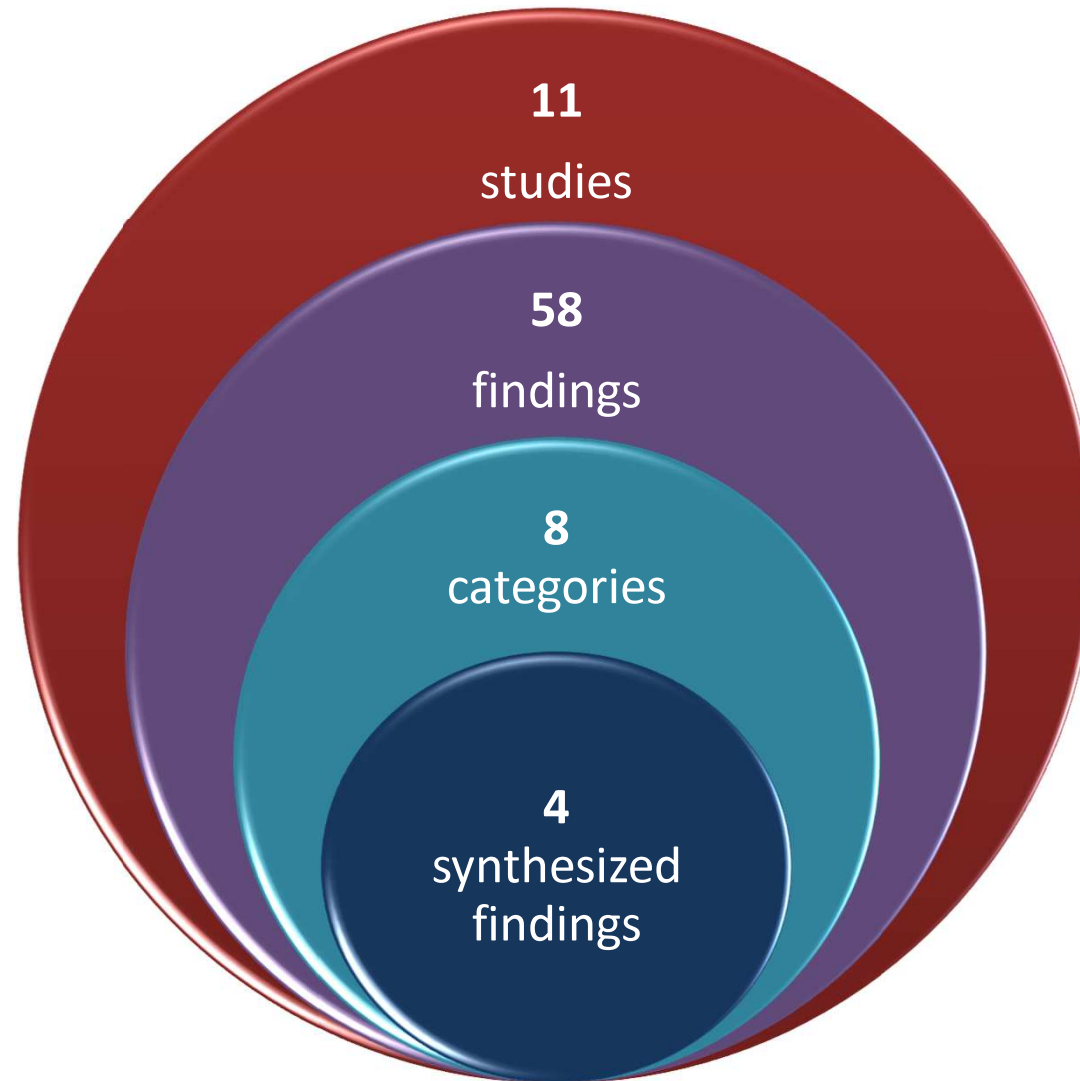


The metasynthesis process



Results





Characteristics of included studies



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Findings of the review



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BENEFITS

Individuals are motivated to

participate

a range of personal and social

benefits and also **benefits to wider society**

Benefits to wider society

*Others were pressing me until I decided to tell them, 'I have decided to sacrifice myself [...]' If it is a vaccine, then it will **help other people...***



*"I mean you are not supposed to give birth in that period. So, we perceived that when they are giving this to us and stay in our body for a long time it will **cause harm**"...*

Fears related to potential harm can be associated with **anxiety**, mainly due to **HIV stigma** and worries about **potential harm** from research interventions.

Findings cont....



"This research was about the product... like the gel that you put into the vagina if it can prevent STDs."; "She said they decided to give her AZT because she had had a miscarriage."



Misconceptions about research and **mixed/poor** understandings of concepts are still common

Mixed understandings of the research



Participation in HIV research is strongly influenced by **social relationships, economic and domestic factors, and the interactive nature of research.**

Economic and domestic factors

SOCIAL CONSTRUCTS

“I am not afraid of anyone, my husband is unemployed so I am always busy either looking after the children or something else to find money”;



1

- Individuals seem **willing to participate** in HIV research

2

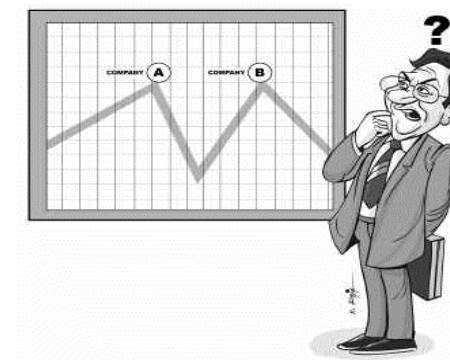
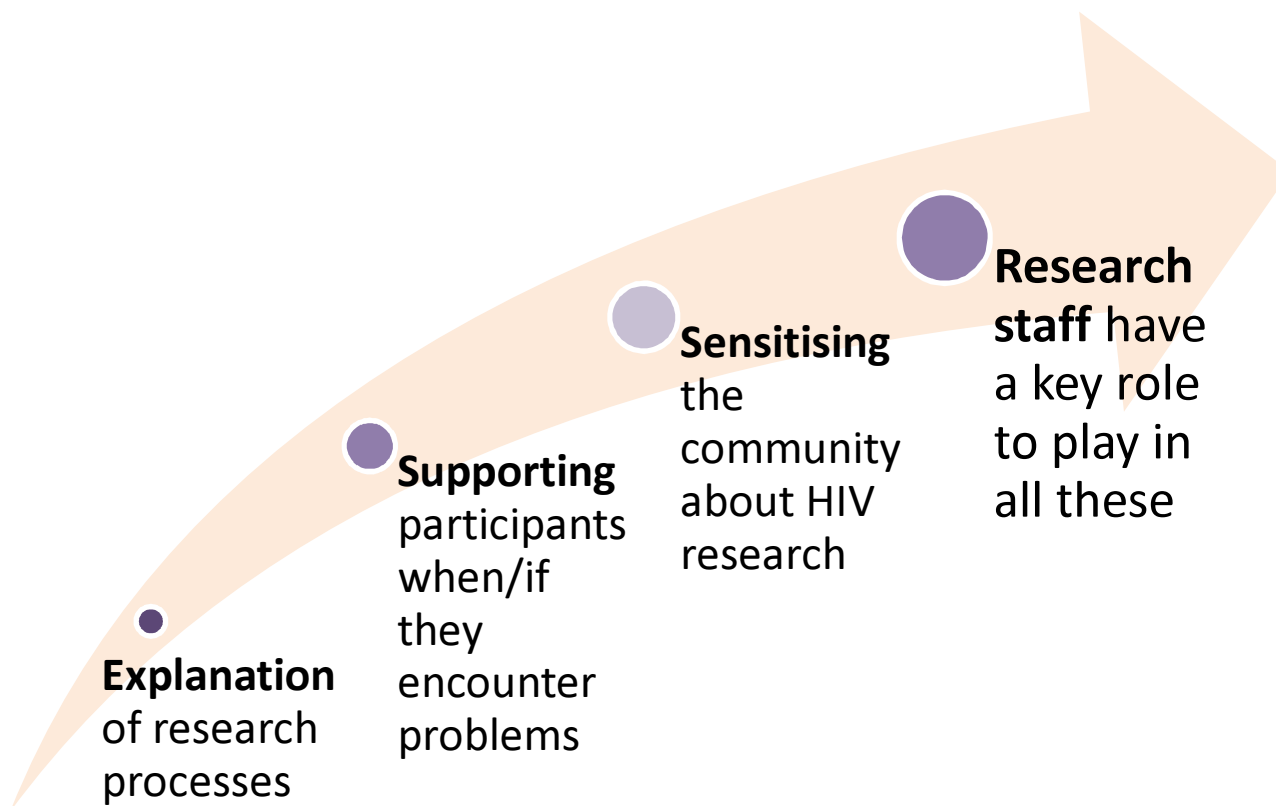
- There can be **limited understanding** of the process

3

- HIV research participation may **cause anxiety** or have **negative consequences**

4

- Sustained participation may become problematic due to **social-economic pressure**



Research on participants' experiences of HIV trial closure is lacking



Fitchett, J. R. (2009) Ethical considerations of clinical trials in the developing world. **Transactions of the Royal Society of Tropical Medicine and Hygiene** 103 (8): 756-760.

Joanna Briggs Institute (JBI) (2012). CS RTP study guide: the systematic review of evidence generated through Narrative and text. *Comprehensive Systematic Review Training program*. Adelaide, South Australia, Australia.: The Joanna Briggs Institute.

Lairumbi, G. M., Parker, M., Fitzpatrick, R. and English, M. C. (2012) Forms of benefit sharing in global health research undertaken in resource poor settings: a qualitative study of stakeholders' views in Kenya. **Philosophy, Ethics, & Humanities In Medicine** 7 7

London, L., Kagee, A., Moodley, K. and Swartz, L. (2012) Ethics, human rights and HIV vaccine trials in low-income settings. **Journal of Medical Ethics** 38 (5): 286-293.

Mbuagbaw, L., Thabane, L., Ongolo-Zogo, P. and Lang, T. (2011) The challenges and opportunities of conducting a clinical trial in a low resource setting: the case of the Cameroon mobile phone SMS (CAMPS) trial, an investigator initiated trial. **Trials [Electronic Resource]** 12 145

