



CO-CONSTRUCTION OF CONSENT AND COUNSELLING DURING PROVIDER INITIATED COUNSELLING & TESTING (PITC) IN NAIROBI KENYA

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SIGMA THETA TAU 27TH INTERNATIONAL NURSING
RESEARCH CONGRESS CAPE TOWN

21ST - 25TH JULY 2016

Learning Objectives

- The learner will be able to evaluate how informed consent and counselling are constructed during PITC in this context
- The learner will be able to examine the challenges of translation and implementation of PITC policy recommendations in diverse cultural and clinical settings.

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- ***This research was funded by the Aga Khan University seed fund***

Background

- HIV policy focus is to reverse the spread of HIV/AIDS and provide care, treatment and support (WHO 2015)
- These depend on timely diagnosis (HIV testing) and uptake of treatment
- However....
- The numbers tested remain low
- Missed opportunities identified in clinical encounters (Gichangi et al, 2006; Nakanjako, et al., 2007)
- The HIV testing process distinguishes it from other routine medical tests -> HIV exceptionalism

Background

- Provider initiated counselling and testing (PITC) introduced to meet testing needs and gaps
- PITC means:
 - A 'dilution' of the previously lengthy and stringent testing process
 - Replaces opt-in [signed]informed consent with an opt-out approach to consent
 - Extensive pre-test counselling replaced with an information giving session with more emphasis on post-test counselling

Background

- **The big debate: Human rights versus public health rights debate**
- Early and timely HIV diagnosis is the gateway to prompt initiation of ART (WHO, 2015).
- Standard of care is providing opportunities for testing and access to treatment
- Apprehension about coercive testing practices and lack of counselling particularly in developing countries like Sub Saharan Africa

Background

- Complexities of implementing PITC guidelines in different cultural and healthcare contexts
- Normalcy is elusive in the context of HIV (McGrath et al., 2014; Moyer & Hardon, 2014)
- Lack of clarity about the PITC process in diverse contexts outside the antenatal clinics (Angotti 2011; Bell et al 2015 & 2016)
- Information giving and consent are difficult to apply in contexts characterized by healthcare worker dominance, lack of sufficient resources and time constraints

Background

- PITC policy presumes that stigma is low yet.....
 - Mixed and contradictory findings on the state of HIV stigma even within the same setting
- Expectation of a patient provider interaction that is symmetrical
- Despite these issues, there is a dearth of research on the actual implementation of counselling and consent
 - Heavy reliance on self-reports and quantitative methods (Evans & Ndirangu, 2009).
 - Patient's voice and perspective is missing (Evans & Ndirangu, 2009)
 - Evaluation of the actual process of consent and counselling

Methodology

- Epistemological position – interpretivism (knowledge is socially constructed e.g. cultural meanings of particular actions)
- Ontological position – constructionism (single phenomenon can have multiple realities which are fluid and likely to evolve depending on the situation at hand)
- Qualitative design using multiple data collection methods
- **Ethical approval**
 - Aga Khan University Ethics Committee
 - Kenya Medical Research Institute (KEMRI) ethics committee
 - National Commission for Science, Technology and Innovation (NACOSTI)

Objectives

Methods

Investigate how patients (and counsellors) co-construct informed consent and 'perform' counselling during the PITC consultations

Explore patients' perspectives and understanding of HIV and HIV testing

Pre-test interviews n= 30

Examine how patients' perceptions of HIV influence their communication and interaction with counsellors during PITC consultation

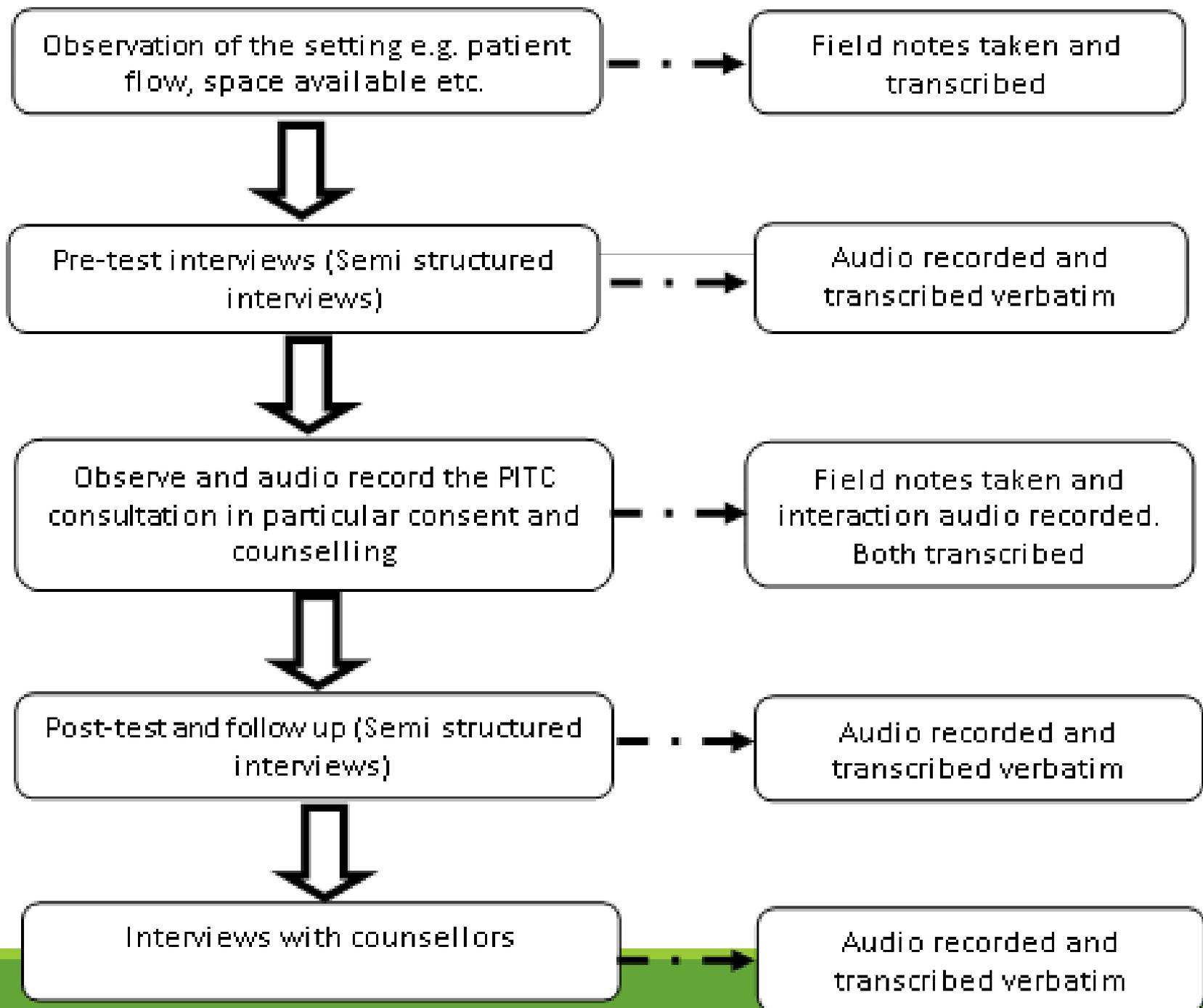
Observations and audio recording of consultations n= 29

Explore how the role of the counsellor is constructed by patients and health professionals, and how 'counselling' is performed during the PITC consultation

Observations and audio recording of consultations

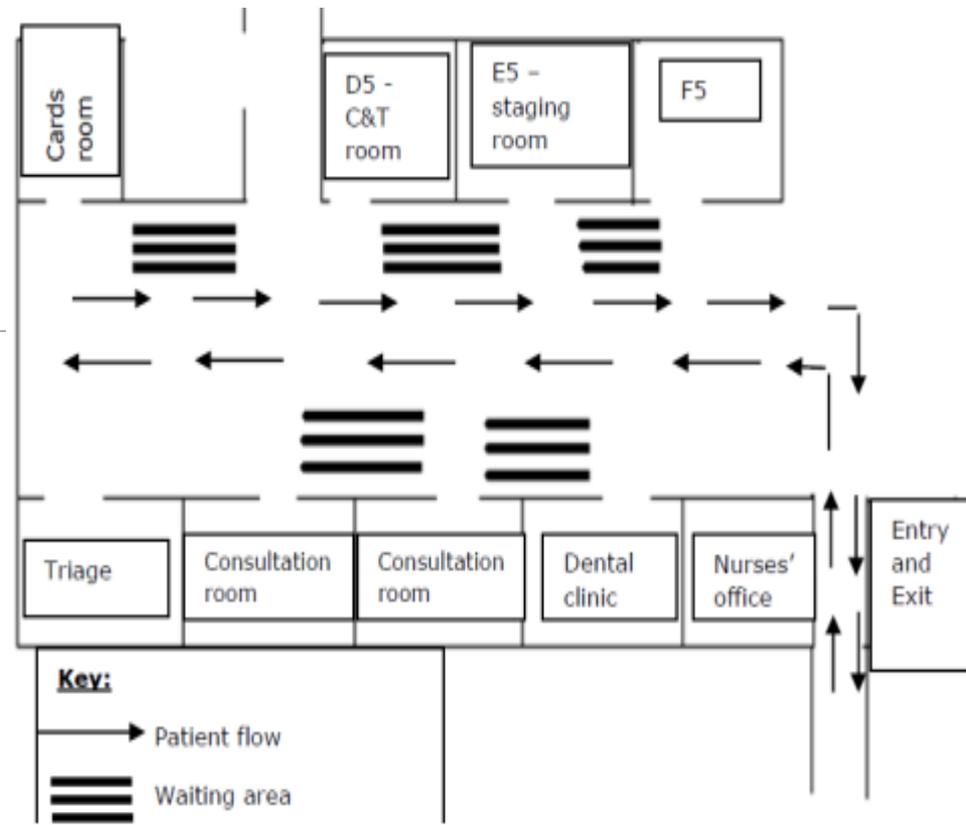
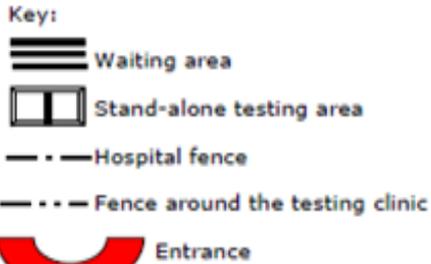
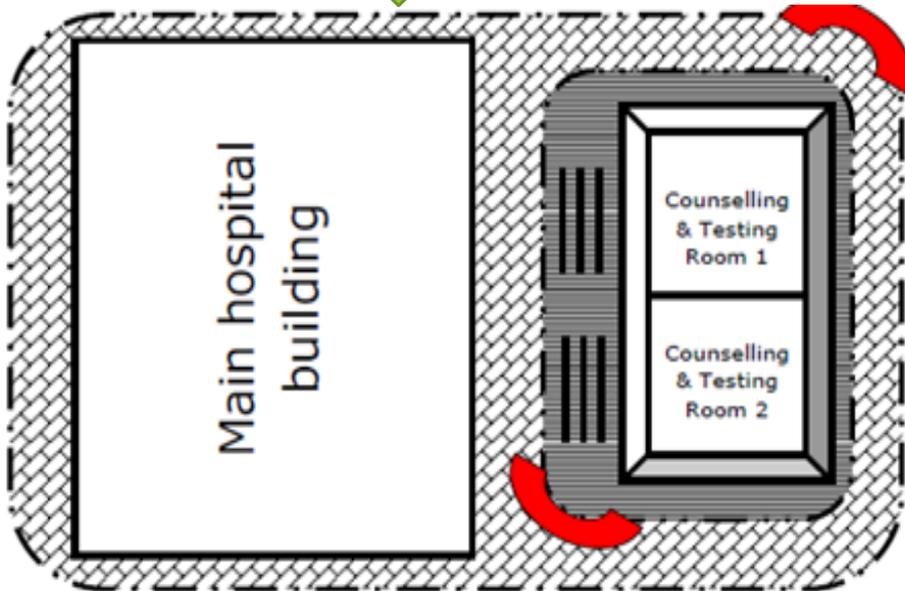
Explore how informed consent is understood by patients and counsellors, and how it is obtained during PITC

Post-test interviews with patients (n= 22) & counsellors (n= 5).

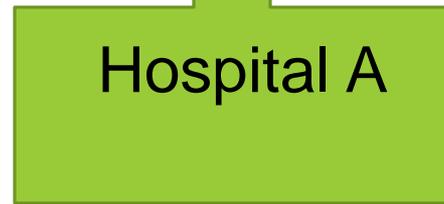


Study Settings

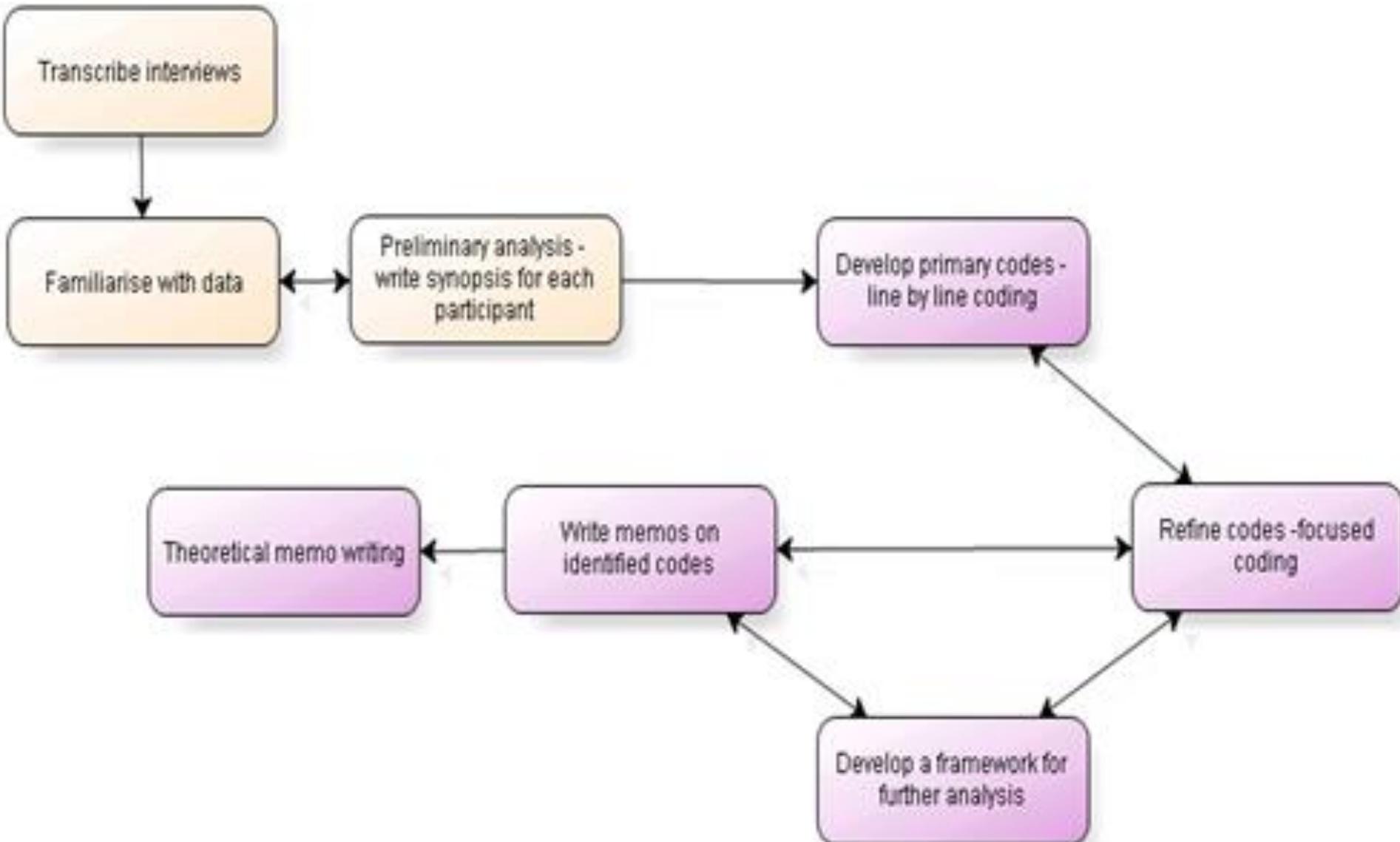
Hospital B



Hospital A



Data Analysis



Findings – Biodata

HIV test results at Hospital A

| Testing area | No. tested | Negative | Positive |
|-------------------|---------------------|-----------|-------------------|
| Outpatient | 6 (4 male) | 4 | 2 (Male) |
| Inpatient | 4 (3 male) | 3 | 1 (Female) |
| TB clinic | 4 (3 male) | 3 | 1 (Male) |
| Total | 14 (10 male) | 10 | 4 (3 male) |

HIV test results at Hospital B

| Number tested | Negative | Positive |
|---------------|-------------|----------|
| 16 | 16 (9 male) | 0 |

Key Themes

Lay constructs about HIV

- HIV as a killer disease
- Fear of moral and social contagion

Constructing notions of acceptable social norms of interactions

- Tensions of managing competing agendas
- Professionals writing their own scripts

Construction of informed consent

- Framing of the HIV test
- 'An offer you cannot refuse'

Lay Constructs About HIV

- **HIV as a killer disease**

“I have heard that HIV is a very dangerous disease, it kills people...” (Khamisi 24 year old male – Pre-test interview – Hospital B)

- **Fear of moral and social contagion**

“Eeh (Yes) you know people say those who have HIV move here and there. You find this girl whose status you do not know, you leave that one, you get another one again, you don’t know her status, you go with her. Now things like those bring HIV.” (Gakere 29 year old male – Pre-test interview – Hospital A)

- **Culpability & blame -> Need to maintain ‘moral’ face**

Constructing notions of acceptable social norms of interactions

- ‘HIV talk’: Taboo subjects were either glossed over vaguely or avoided all together

“..... so that when you are walking around without shoes you will know where you are headed” (Bosco – Counselling session Hospital A)

- Indigenous versus foreign language

*“...tunaona asilimia themanini ni **through unprotected sex.** **Whichever the sex.** Unajua kuna watu pia, hujidanganya ukifanya **homosexual sex** hio hautapata...” {“We see that 80% [of HIV transmission] is through unprotected sex. Whichever the sex. There are people who lie to themselves that by engaging in homosexual sex they will not get infected”} (Opiyo male, counsellor Hospital B)*

Constructing notions of acceptable social norms of interactions

- **Professionals writing their own script**
- Information control
- Strict structure was followed
- Very generic and none specific
- The structure followed was similar across the counsellors and the different settings
- But..... divergent from the policy guidelines
- No counsellor did a specific post counselling session

Structure of observed consultations

Pre-test session
- lengthy

HIV test carried
out

'Pre-disclosure'
counselling

Disclosure of
results

Termination of
session

PITC guidelines
recommended
structure of
consultations

Pre-test session
- brief

HIV test carried
out

Pre-test
counselling

Disclosure of
results

Post-test
counselling

Termination of
session

Constructing informed consent

■ Framing of the HIV test

“You were feeling unwell and you went to the doctor and told him that maybe you have a chest pain or whatever and he has written a prescription for you but he wanted to know your HIV status. That is why you are here. I will test you and there is a place I will indicate your status. You explained to the doctor that you are coughing and you have chest pains does not mean that you have the virus. We test to confirm so that even when you buy the medication and you return to the doctor he will know how to treat you” (Abdul counselling session with Ekirapa – Hospital B)

Constructing informed consent

- **An offer you cannot refuse – no direct HIV test offer**

Ihuoma: I will just take your blood, and as the test is running we shall talk. Ok?

Idowu: Will you tell me my status immediately or I will go.

Ihuoma: Your results will be ready before you leave.

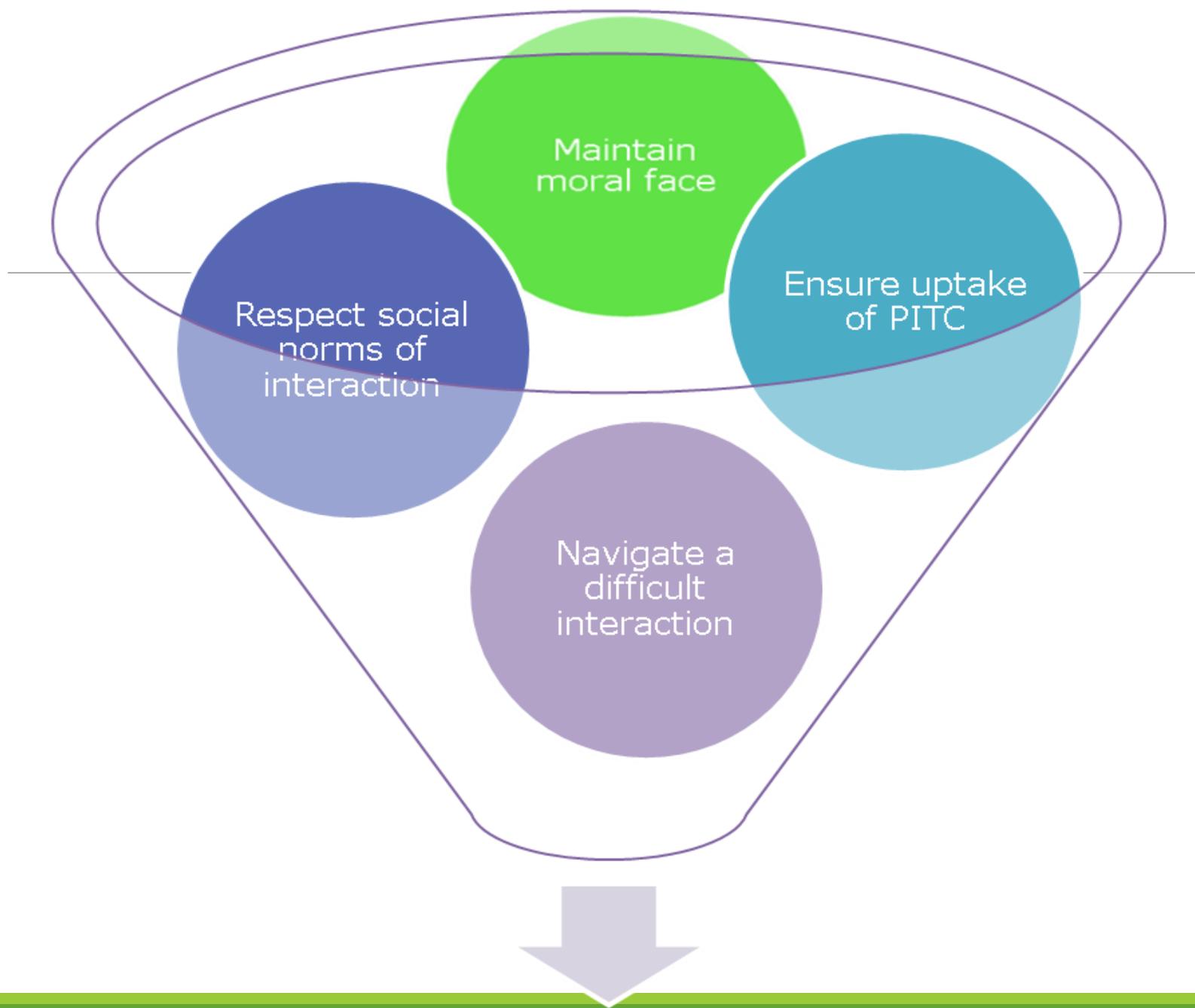
Idowu: Ok ok ok (Ihuoma counselling session with Idowu – Hospital B)

- Silent refusals – comparable to extensive research in the Kenyan coast about informed consent

Constructing informed consent

- **Counsellors were aware of the lack of choice**

“So PITC is an approach that is actually working. Cos you know when the doctor is like superior, if it’s a doctor-patient situation, the doctor is superior and when the doctor says, ‘utaenda kwa VCT’ (you will go to the VCT) they will not argue with that.” (Ihuoma, counsellor interviews – Hospital B)



PITC consultation

Discussion

- Counsellors are tasked with implementing policies and translating them to local contexts
- Dualism in participants constructs about HIV i.e. accepting attitudes towards HIV versus morality undertones
- Diversity and none universality in the expression of stigma (Gausset et al 2012; Jurgensen et al 2013; Knight et al 2014)
- Counsellors have to ensure a functional task of getting through the PITC consultation whilst dealing with lay constructs about HIV and respecting norms of communication
- Challenges of adhering to consent and counselling guidelines (Angotti 2010)

Discussion

- Norms of interaction were visible in the process of obtaining consent
- The consent process in Kenya is largely driven by the need to respect and maintain social relationships (Kimunya et al 2015)
- Yet policy documents focus on a stringent [value free] informed consent process
- There is little evidence for comparison with other non-HIV interactions in this setting
- Perhaps the recommendations about HIV testing consultations contain expectations that run outside the real of what is the norm in this context

Recommendations – Education

- **Education**
- Strategies to identify the complex stigma situation and deal with it
- Communication of bad news
- Rethink about how we teach assessment of and communication about sexuality

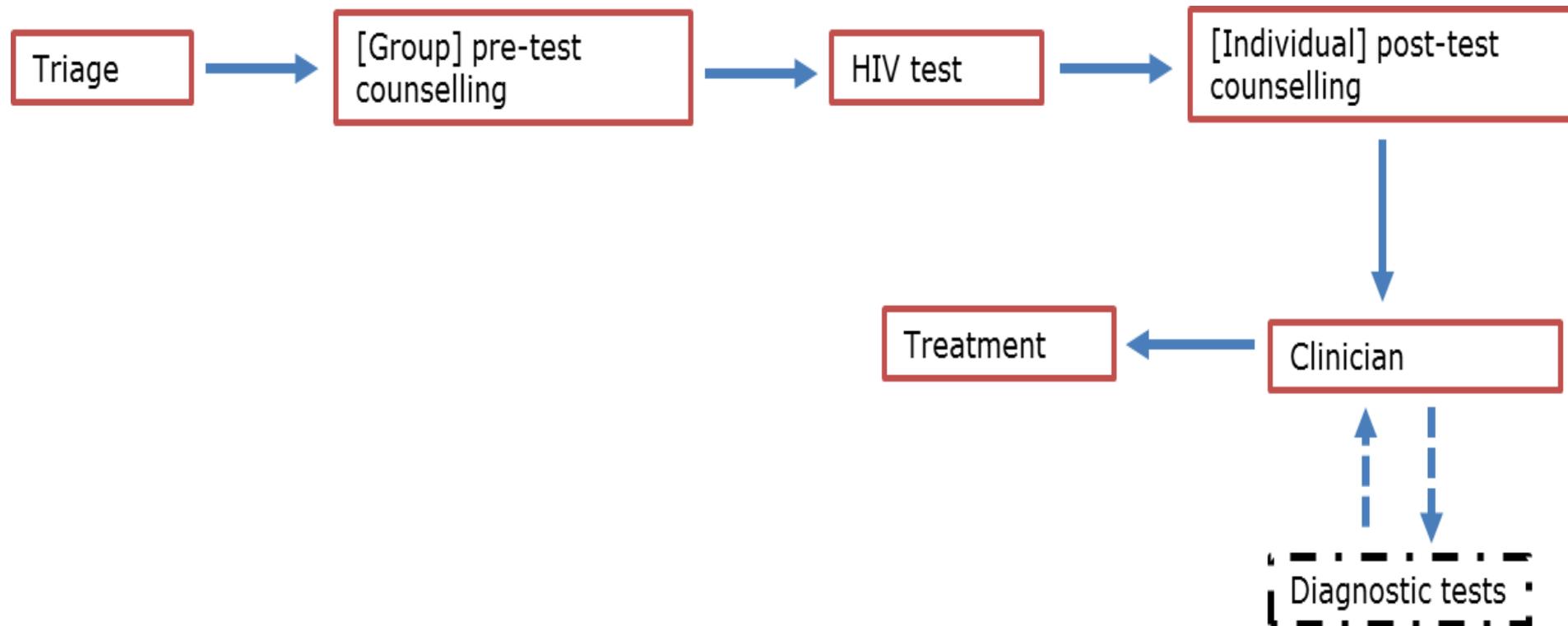
Recommendations – Research

- **Research**
- Extensive sociological and anthropological research to understand the complex terrain of HIV stigma and HIV exceptionalism
- Comparative studies on the operationalization of the use of ultra rapid test kits versus conventional rapid tests
- Patient – provider communication in situations outside HIV testing (culturally and socially contextualized)

Recommendations – Policy

- Continue expansion of PITC: it helps identify people who, due to continued HIV exceptionalism, will not seek HTC
- Group pre-test counselling to save time and resources
- Implementation of ultra rapid test kits: reduce the pre-test duration and save time for post-test counselling
- Policy should be drawn from and responsive to the practice setting realities of counselling and consent
- Quality assurance measures that are reflective of realities of the practice setting

Recommendations – Patient flow



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Thank you

QUESTIONS

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