

The Participant Adherence Discussions

Patrick Ndase, MBChB, MPH

Regional Physician,
Microbicide Trials Network

1. Enhancing ring adherence is a call to action

The true cost of inaction

- Local HIV statistics matter (*134,000 New HIV infections per year = 376 new infections per day in KZN alone in 2008*)
 - *40% of women in ANC HIV positive*
- In the next 3 years of ASPIRE ~ 402,000 new infections in KZN alone
 - Orphans
 - Lost income due to ill health
 - Losses in all sectors of production
- IS ALL THE ABOVE TRUE? There are ARVs, RIGHT?

2. We generally have imprecise objective measures of adherence

- Most non-adherent women will wear the ring hrs to possibly a few days prior to next scheduled visit
 - But sero-conversions do not only happen around time of scheduled visit
 - Having ring in for at least 8hrs prior to visit may not be differentiated from a ring in for a month (based on vaginal fluid & plasma levels)
- We cannot afford complacency leading to real eventual disappointment

3. Individualized messaging key.....



Not all women are the same, we need to speak to @ participant's concerns

Rachel:

- Personal experiences (Infected friends & relatives, worries about partner, HIV incidence/prevalence in population)

Kat:

- Motivation to use dependent on ease/comfort in using
- A little extra trade-off for comfort if she knew product protective

Participant adherence meetings; What are they?

- They are NOT:
 - Informational sessions
 - Educational sessions (but rather sharing sessions)
- They should be:
 - Highly emotionally charged, (not from a rehearsal session, but from the heart).
 - Participants too read beyond what you say
 - They should be REAL
 - Focused & person-centered (you elicit individual stories & messages)
 - It's the individualized stories a moderator uses to elicit true emotions & guide ppts on the bigger picture

Why this approach?

- Review of how successful past strategies were

| | Truvada Tablet | Tenofovir Tablet | Tenofovir Gel |
|---|----------------|------------------|---------------|
| Returned Pill or Applicator Counts | 92% | 87% | 86% |
| Self Report | 91% | 90% | 90% |
| Drug Detected in Blood | 29% | 28% | 23% |
| Percentage of women with <u>no drug detected in <i>any</i> sample</u> | 50% | 58% | 55% |

How do you structure them?

- The size of the group matters
 - Highly recommended to not exceed 15ppts at a time
- Constitution of the group is critical
 - Always best if you avoid dealing with groupings (better to have them into separate groups)
 - You need a good mix of good & bad
 - Critical to vary the age ranges too
- Whenever possible, should be structured to allow for uninterrupted discussions
 - As part of a scheduled visit not the most desirable
 - Curved out time, whenever feasible best

Focus of the Discussion

- Depends on stage of your discussions
 - Initial discussion
 - Follow on discussion

Initial discussion

- Discussions need to begin on an emotional high:
 - ✓ highlighting the extent of the local epidemic
(contextualizing the cost of inaction and/or # of new infections with each failed effort, based on the estimate of ~350 new infections in KZN alone each day),
 - ✓ where necessary, invoking some scriptural elements in regard to failed responsibilities, etc. etc.

Initial discussion

- Critical for moderator to keep emotions high by highlighting how he/she has been impacted by the epidemic
- The depth of your description of impact very essential in setting the tone
- You then ask participants to share their own stories of how HIV has impacted them
 - *Each participant's story gets expounded to reflect on how each one is benefiting from research efforts of the past*

If you want a story, you've got to tell one

- The way you share your story provides:
 - the detail you want in one told back to you
 - the emotions to be involved
 - you need to have an eye out for one likely to have a compelling as an initiator
- It shows you belong & you care beyond your job

Pick-up stories for discussion at Tongaat

- Relative infected for 14yrs, now on ART in the past year
- Neighbor infected. His CD4 now 7, but has new girl friend
- Many in family infected, many died & Dad infected currently
- Best friend lost to HIV
- Ppt with a brother who's currently on 3rd line (still not taking his medications regularly) & having sex

Brain teaser

- What be your message to a participant who during the sharing of HIV's impact on one's life, says she's never been impacted by the HIV epidemic in her family nor among her friends?

Initial discussion: About study product

- Be certain to notify participants about current efforts to determine rate of product use in the study
 - PK analysis for any dapivirine vs high concentration from blood & swabs
 - used ring appearance
 - Residual drug levels in used rings etc.&
 - how the trends we're noticing are the reason for meeting them
- Normalize ring removals
 - Its part of being human & the past is of less concern
 - *But, now, to whom much has been given, much will be expected*
- Discuss individual rings experiences (when removed & why, if & when partner feels it & consequent actions, ring & menses, etc.)

Initial discussion

- Elicit examples of negative influence experienced at the clinic
- Elicit knowledge of other participants not adhering to ring
- Be certain to let participants air-out their resolve at the end of the discussions
- End by putting the emphasis on the importance of using the ring so we can determine if it's efficacious

Who needs to moderate them? Celebs

- The messenger must be convinced of the message they carry
 - The message itself carries far less weight than the way it's delivered
 - Body language
 - Passion
 - Genuineness
 - Sensitivity to the complex human context in which our ppts live
- The moderation frame is not static

Skill sets engaged

- Eye contact is critical
- Your story must be compelling
 - The way it is told really matters a great deal
 - Your body language counts
 - Seemingly soft landing stories can be potentially misconstrued
- Read participants body language as you relay your story
 - Essential for determining a soft landing
 - You need a man to do a man's job & not a boy
- Evolve as your audiences concerns evolve

Monitoring impact

Critical to remember:

- Every CRS is different, approaches to same idea are bound to be different
- There is “no once size fit all”, but the guiding principles to efficiency improvements are the same:
 - Regular internal audits of your systems
 - Listen to your participants
 - Keep open to evaluating new ideas
 - Every step or process needs to add value

Monitoring impact

- Participant Adherence Discussions are just but one of the various strategies at site
 - Need to evaluate their impact to determine level of resource allocation
- Follow up meeting to determine extent of peer influence vital
- Critical attention to the appearance of ring at consequent visits
- Follow up on participants commitments post these discussions
- Ring appearance tracking log at Umkomaas