The Participant Adherence Discussions

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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

It takes real skill, observation & precision
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

<table>
<thead>
<tr>
<th></th>
<th>Truvada Tablet</th>
<th>Tenofovir Tablet</th>
<th>Tenofovir Gel</th>
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</thead>
<tbody>
<tr>
<td>Returned Pill or Applicator Counts</td>
<td>92%</td>
<td>87%</td>
<td>86%</td>
</tr>
<tr>
<td>Self Report</td>
<td>91%</td>
<td>90%</td>
<td>90%</td>
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<tr>
<td>Drug Detected in Blood</td>
<td>29%</td>
<td>28%</td>
<td>23%</td>
</tr>
<tr>
<td>Percentage of women with no drug detected in any sample</td>
<td>50%</td>
<td>58%</td>
<td>55%</td>
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Marrazzo, CROI 2013
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 girlfriend
- Many in family infected, many died & Dad infected currently
- Best friend lost to HIV
- Ppt with a brother who’s currently on 3\textsuperscript{rd} 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