

# AMP Implementation Update: Addressing and Managing Stigma and Misconceptions in the AMP study



# What is Stigma?

## Group Dialogue/Discussion

# Stigma

- ❑ A mark of disgrace associated with a particular circumstance, quality, or person (Oxford Dictionary).
- ❑ It's a social process that marginalizes and labels those who are different from the rest of the community
- ❑ A mental or physical mark that is characteristic of a defect or disease (Dictionary.com)

# Stigma Exercise

- ☐ Think about a time when you felt like you were being discriminated against.
- ☐ What were you being discriminated against – i.e. what was the issue that provoked the discrimination?
- ☐ What are the reasons why people discriminated against you?
- ☐ How were people acting towards you?
- ☐ How did that make you feel?

# Stigma Exercise Report Back

Causes	Actions (External Stigma)	Effects (Internal Stigma)
<input type="checkbox"/> Lack of knowledge <input type="checkbox"/> Inaccurate information <input type="checkbox"/> Fear of the unknown <input type="checkbox"/> Societal norms <input type="checkbox"/> Religious beliefs <input type="checkbox"/> Morals and values <input type="checkbox"/> Cultural beliefs <input type="checkbox"/> Misperceptions and myths	<input type="checkbox"/> Avoidance <input type="checkbox"/> Excluded <input type="checkbox"/> Ridiculed <input type="checkbox"/> Laughed at <input type="checkbox"/> Singled out <input type="checkbox"/> Different <input type="checkbox"/> Resentful <input type="checkbox"/> Exaggerated kindness <input type="checkbox"/> Judgement	<input type="checkbox"/> Feeling lonely or alone <input type="checkbox"/> Anxiousness/Anxiety <input type="checkbox"/> Stress and Depression <input type="checkbox"/> Low self esteem <input type="checkbox"/> Failure to value oneself <input type="checkbox"/> Substance or alcohol abuse <input type="checkbox"/> loss of hope and feelings of worthlessness <input type="checkbox"/> Fear of losing friends and family <input type="checkbox"/> Psychological distress

# Difference between obvious and covert stigma

- ❑ Actions by other people will induce external stigma = Obvious or Overt Stigma. Overt means done or shown openly or plainly apparent. This can refer to all sorts of actions which are done in plain sight or with clear manifestations.
- ❑ Effects result in Internal stigma = Covert stigma. Covert stigma means the exact opposite of overt – not openly acknowledged or displayed.

# So what does this mean for the sites?

Implications of Overt Stigma	Implications of Covert Stigma
<ul style="list-style-type: none"><li>❑ May lead to social harm caused by psychological distress</li><li>❑ Failure to Disclose participation may result in losing family and friends</li><li>❑ Early withdrawal of participating from the study</li><li>❑ Low retention rates</li><li>❑ Compromise the integrity and quality of study data</li><li>❑ Perpetuate or increase existing rumours and misconceptions about the site and study</li></ul>	<ul style="list-style-type: none"><li>❑ Covert-stigma, or internalised stigma has an equally damaging effect on the mental wellbeing of people including potential and enrolled participants. This fear of discrimination breaks down confidence to seek help, medical care and participating in HIV prevention trials</li><li>❑ All these may result in one putting themselves more at risk of HIV infection or risky behaviour</li><li>❑ Failure of continue participating in the study</li></ul>

# Misconceptions

- Let's recap on some of the misconceptions that were discussed yesterday?



# GROUP ACTIVITY 1:

## Misconceptions resulting from participating in AMP

Misconceptions	Come up with key messages to address these misconceptions
Site is infecting participants with HIV	
Participants enrolled in AMP must be sick or HIV positive because the study product is administered through an IV (drip)	
The blood collected from enrolled participants is being used for satanic purposes, witchcraft or is being sold in the US	
AMP researchers are enrolling child-bearing aged women to make them infertile	
AMP researchers are deliberately not providing PrEP to African women because they want to use them as guinea pigs in their researches	

# Group Activity 2: Overt and Covert Stigma in Enrolled Participants

Overt Stigma in Enrolled Participants	Covert Stigma in Enrolled Participants	Possible Solutions to reduce the stigma

## Group Activity 3: Overt and Covert Stigma in Potential Participants in the AMP Study

Overt Stigma in potential participants	Covert Stigma in potential participants	Possible Solutions to reduce the stigma

# Conclusion

- It is important that research staff is *fully aware of obvious and covert stigma and comes up with innovative and strategic tools and ways of managing stigma and misconceptions!*
  - role plays*
  - pre-empt and discuss difficult scenarios*
  - consistent and accurate messaging*
  - work with relevant and appropriate stakeholders and structures in addressing stigma and dispelling misconception.*

# Thank you

**Tatenda**  
**Siyabulela**  
**Obrigado**  
**Zikomo**  
**Asante**  
**Re a leboga**