

Building a Youth CAB – The MU-JHU Experience

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IMPAACT

International Maternal Pediatric Adolescent
AIDS Clinical Trials Network

ANNUAL MEETING
2024

Outline

MU-JHU Rationale for YCAB Formation

Importance of YCABs

Defining a Youth

What is a YCAB?

Roles of YCAB in Research

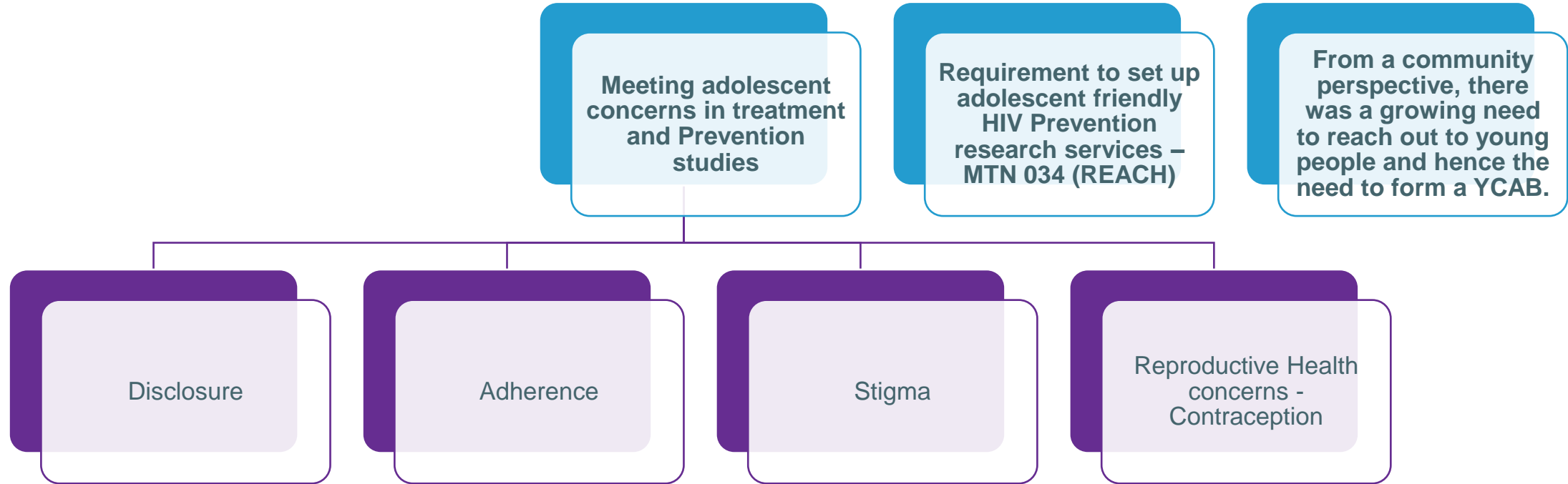
Formation of the MU-JHU YCAB

YCAB Suggestions – At start & During study

Achievements

Challenges

MU-JHU's Rationale for YCAB Formation



Therefore, YCABs are Important in Research for.....

Community
Engagement

Youth-Centric
Perspectives

Ethical
Considerations

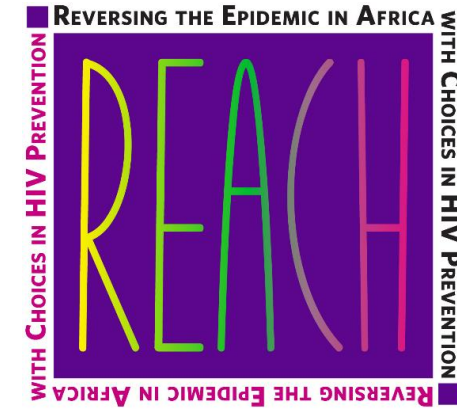
Enhanced
Communication

Innovation and
Creativity

Policy and
Advocacy

HIV Prevention Studies

- **HI-4-TU** (Health Improvements for Teen Ugandans)
- **IMPAACT 2009**: Pharmacokinetics, Feasibility, Acceptability and Safety oral PrEP for Primary HIV prevention during Pregnancy and Postpartum in Adolescents and Young women and their Infants.
- **INSIGHT Study** (A cohort for evaluation of open-label PrEP delivery and PrEP preference among African women).



HIV Treatment Studies

ODYSSEY Study: was a pragmatic strategy trial evaluating the efficacy and safety of a once daily dose of dolutegravir-based antiretroviral therapy compared with the current standard HIV treatment in children and adolescents with HIV.

IMPAACT 2017 (MOCHA Study): Aimed at confirming the dose and evaluation of the safety, tolerability, acceptability and PK of oral CAB and long – acting injectable RPV among children and adolescents aged 12 <18 yrs.

D3: looking to see if a new tablet whether a combination of two anti HIV medicines, DTG and 3TC, are as good as and effective in treating HIV in children and young people living with HIV in comparison to the current anti-HIV medicines available.

Implementation Science

- Using Implementation science to understand and design stakeholder informed innovative Interventions to improve Youth HIV prevention and Care continuums in Rural and Urban Uganda.
- HIV Prevention and Care Interventions for Youth in Uganda (HIP-CY)



Defining a Youth

The United Nations defines 'youth', as those persons between the ages of 15 and 24 Years and the commonwealth as persons between 15 and 29.

Community / CAB members defined a youth for research as:

- Those not in school
- Aged 13 – 30 years
- Youth could also be determined by their physical appearance and behavior
- They are people who need guidance

What is a YCAB?

- A YCAB is a group of young individuals with diverse backgrounds (out of school, emancipated minors, youth living with HIV, Professionals and advocates), selected from the community to advise and facilitate dialogue between the community and the research team.
- Members typically range in age from 14-24.

Roles of YCAB in Research

- YCABs represent the voices of youth in research
 - They want to be heard
 - They want to contribute/participate
 - They have rights
- YCABs help researchers to understand the social and cultural dynamics of the research community
- Facilitate adolescent understanding of the research.
- They can contribute to generation of adolescent research priorities
- Advise about suitable research processes that are respectful of, and acceptable to the adolescent community.

Involvement of YCAB in research = Successful Implementation

Formation of the MU-JHU YCAB

Youth were identified from (2017):

- Community youth groups,
- MU-JHU Young Generation Alive (YGA)
- PrEP centers.
- Reproductive Health Uganda

Composition

Five members (4 Females & 1 Male)

- Advocate for Care and Treatment
- Key Populations
- Gender and Equity
- Social Scientists
- Youth Friendly Communication

YCAB Selection Criteria

- Willingness to talk freely about HIV
- Willingness to participate in meetings
- Willingness to air out the voices of young people
- Had good knowledge of youth in research within their communities

MU-JHU YCAB with Adult CAB Members



YCAB Suggestions – At Start

- Youth friendly staff/Peers to support adolescents in research
- Train staff on engaging adolescents in research
- Designate a safe space for adolescents
- Attractive clinic spaces for adolescents
- Provide Wi-Fi, computers and TV screens and adolescent friendly information packages



Youth Friendly Study Team



Adolescent Friendly Staff

Training in offering adolescent Friendly Services



MEMORANDUM OF UNDERSTANDING

Between

MU-JHU CARE LTD /RESEARCH COLLABORTION

AND

NAGURU TEENAGE INFORMATION AND HEALTH CENTER

(NTIHC)

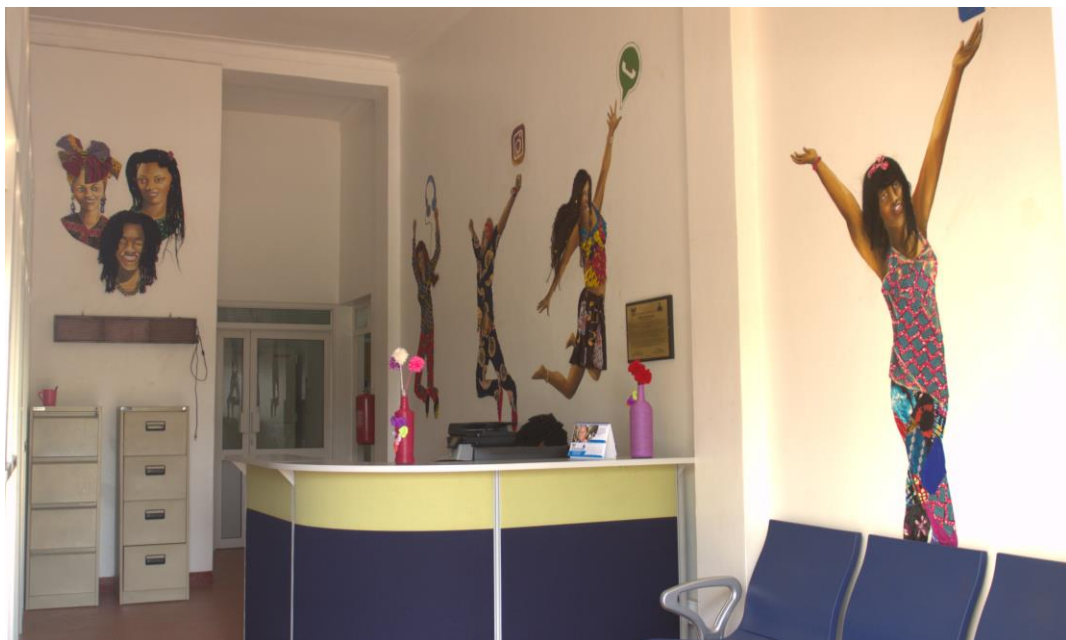
This Memorandum of Understanding (hereinafter referred to as the 'Memorandum') is entered into on this _____ day of _____, 2019

Between



Adolescent Safe Space





Youth Friendly Clinic Space

YCAB Suggestions – During Study

- Offer Peer Support : Invite ART and PrEP ambassadors for adherence support
- Consider Skilling activities for the adolescents
- This is like home to adolescents – celebrate milestones together
- COVID 19 outbreak: Support their adherence with provision of essential needs
- Include hygiene, Income generating, cooking, counselling and IT sessions within the component of research

Peer Support Ambassadors



Skilling Activities







Milestone Gifts



Hygiene Gift Sets



Body Splash



Shavers



Bathing Soap



Deodorant





Duvet
Covers

Bedsheets



Towels

Study Exit Appreciation Tokens

Achievements

- Designed the youth clinic space
- Advocated for the hire of adolescent/youth peers
- YCAB input for new research protocols (HPTN 084-01, INSIGHT & HIP-CY)
- YCAB supported the designing of study materials (HPTN 084-01 palm card and website development)
- They were able to recommend recruitment populations
- Aably represent at Network meetings (Microbicides Trials Network Regional Meeting, National Cross CAB Forum)
- Trained on Good Participatory Practice (GPP)



YCAB Reviewing Study Materials



YCAB/CAB GPP Training



Challenges

- Resource Constraints to provide adequate training and support
- Visa denials to attend conferences
- Limited time due to other commitments (Formal employment)
- Lack platforms to engage efficiently with global YCABs

Acknowledgements

- MU-JHU YCAB
- MU-JHU CAB
- All Research Participants
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- FHI 360 Community Team
- IMPAACT Leadership
- HPTN Leadership
- MTN Leadership
- NIH/DAIDS



Thank You!

