The challenges of child and adolescent engagement in SRH research
OUTLINE

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Why research adolescents?

- Growing realization of the need to invest more on 2\textsuperscript{nd} decade of life
- Sustain the gains of investments in 1\textsuperscript{st} decade
- Adolescence an age of opportunity
- The world is increasingly “adolescent”, ? adolescent bulge
- Understand better how their potentials can be released/harnessed for world economics, global peace, technology and innovation etc “making impatience a virtue” Therefore:
- Urgent need for research to guide interventions due to challenges to their well being:
Why research adolescents?

- By age 20, at least 80 percent of sub-Saharan African youth are sexually experienced. Seventy-three percent of all Liberian women ages 15 to 19 have had intercourse, as have 53 percent of Nigerian, 49 percent of Ugandan, and 32 percent of Botswana women.1

- STD’s & HIV
- Alcohol and substance abuse
- Violence (Justification of wife-beating among adolescents (40%) (2002-2011)
- Mental health problems is becoming an issue

2013 BIOMEDICAL HIV PREVENTION FORUM
When to Research

- However only research if:
- Adults cannot provide required information/data
- Knowledge gained will be relevant for advocacy, policy, direct service provision etc for adolescents
- Risks are minimal- & benefits outweigh risks
- Confidentiality and privacy can be maintained
- Institution doing research has the sensitivity and facility to address adolescent need
- Will provide opportunity for participation and empowerment
Ethical challenges

- Informed consent/assent – How, written, oral?
- Privacy and Confidentiality
- Incentives – benefits
- Ethics review boards across the country are diverse in terms of culture, board composition and context and this may affect the kinds of adolescent SRH studies that will be given approval
Informed consent

- Legal age for consent for research participation– 18 years
- Children are considered a vulnerable population, and unable to provide “legally effective informed consent” as required by the regulations in the 2006 National Code for Health Research Ethics. They provide assent to participate in research, to the extent that they are able, and parents/guardians give permission for a child to participate in research. The regulatory requirement of assent and permission involving children are intended to make sure that investigators respect the decisions of both children and their parents. Consent is obtained in written form.
- Within the Nigerian legal context, parental consent and child assent will need to be sought for adolescents 10-15 years before participation in any form of research.
Informed consent

• There are however challenges with adolescents considered as matured minors (married, fend for themselves, head of households). Many national laws considers these individuals as independent enough to give consent and make decisions about their self care including health care.

• Evidence exist to support the approval of national study protocols that include adolescents 15 years and above in study protocols by ethics committees, e.g. DHS, NARHS, HIV SENTINEL SURVEY, IBBSS (FSW)
Informed consent

- Anecdotal and published evidence in Nigeria- sexual debut below 15 years, pregnant teenagers below 15 years (HIV sentinel survey 2010-3 pregnant teens below 15 years were turned back), key target population (MSM, IDU, FSW) below 15 years-legal context constitute a challenge to engaging these group of adolescents in SRH research.

- The act of mandating parental consent may be problematic for some adolescent. In respect to sexual health research, their desire to participate in a study may be interpreted as admitting to being sexually active and/or having accessed sexual health services. In instances where this is true, it puts those adolescent at risk of losing access through increased parental supervision or monitoring.
Confidentiality and Privacy

- Privacy and confidentiality important
- Balancing between what information will be shared with parent/guardian and how this will be done?
- What happens when adolescent may harm self / another?
- Not well informed or matured to make a decision
- Adolescent being sexually abused for example by relatives and such information is volunteered in the cause of a research (practically its difficult to manage when the abuse is ongoing and the adolescent involved wants the information treated as confidential)
Risks

- Determine the risk-benefit calculus for the research to ensure adolescents are not exposed to undue risk taking cognizant of age and cultural peculiarities-ethics committees and researchers
- Space to share personal issues—raising expectations?
- Sharing sensitive information about—violence among group members, drug use, sexual activity
- Cultural sensitivities/norms/values? Respect
- Conflict of interest, ? Financial expectations
Benefits

- What benefits are available?
  - information
  - referrals
  - tea / snacks
  - small gifts? Monetary? Not coercive
  - Interventions
Cultural Barriers

- Sexuality and sexual health are often difficult topics for parents to discuss with their children, which may force parents/guardians to withdraw consent and deny adolescents opportunities of participating in SRH research initiatives that may serve to improve their health.

- The sensitive nature of ASRH Issues—STIs, HIV, teenage pregnancy, etc— which may limit the level of information volunteered by adolescents.

- Prevailing norms in some countries like Nigeria. Proscribe young, unmarried people having sex. This may prevent adolescents from participating in SRH researches to avoid being branded as being “promiscuous”.
Addressing gaps

- Legal framework should be amended to create opportunities for parental consent waivers for adolescents below the age of 15 years in situations such as pregnancy, members of key target populations, adolescent accessing friendly SRH services irrespective of age, etc to participate in beneficial SRH researches.

- It is important for adolescent sexual health researchers to be cognizant of sociopolitical and regulatory realities that shape local decisions around ethical review and how to address this.

- Role of donors in promoting research, ensuring/demanding ethical standards in all funded projects.
Addressing gaps

• There is need for greater involvement of institutional review boards as partners, i.e. getting them involved when and arranged face-to-face meetings during the review process, where possible. It creates room for a thorough and thoughtful approach to protocol review and better understanding of study objectives by the ethics review board.

• Involving adolescents as research assistants- The survey content, length, format, structure of the questions, and administration process is heavily influenced by the opinions and suggestions of the adolescent involved. KAP adolescents studies conducted in the country particularly in–school SRH program where peer educators are used to collect information from their peers.
Addressing gaps

- Involve the community ... In schools – PTA groups (Parents- need to be educated on the importance of adolescent participation)
- In Communities – Community Advisory boards (Adolescents involved in research process (formation of community advisory boards with strong representation of adolescents- (Gokana Study in Rivers State, Nigeria))
- Promote Sexuality Education – the greater the acceptability of sexually education by the general public, the more the support for adolescent involvement in SRH research
Conclusion

- Adolescent access to the benefits of research is an issue of justice and beneficience. Adolescents differ from adults in biology, social status, developmental capacity and behavior, and therefore research results from adult studies are often not applicable to adolescent populations.

- Institutional review boards and researchers should be encouraged to adopt localized context-dependent strategies that attend to the unique vulnerabilities of adolescents. Ongoing, open, and honest, dialogue and debate throughout the research process on potential harms and benefits can mean that sometimes protocols need to be adapted and changed. This attention to flexibility, vulnerability, and community-specific needs is key to ensuring that we continue to do all that we can to attend to the health and well-being of adolescent through the conduct of evidence based SRH research involving adolescents.
• Thank you so much for listening.
• Na gode
• Ese
• Imela