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JEMS Research Challenges

Ethnicity, the Whites are Scarce!
Introduction to JEMS

Overview

• Analysis of challenges
• HIV testing
• Interviewing & questionnaire challenges
• Recruitment challenges
• Sampling challenges
• Staffing
• Site selection
• Ethical challenges

JEMS... caring for men's health
Aims of JEMS...caring for men's health

Describe the epidemiology of HIV among MSM in Johannesburg and Durban (Ethekwini)

Aims of JEMS
JEMS: Caring for Men's Health

JEMS Approach & Methods

RDS
Durban using Johannesburg & men in survey of 200

Cape Town
Durban & Johannesburg, completed in 18 FGDs

Survey
HIV

CD4

Focus Group Discussions

Interviews

Key Informants

Established Advisory Board
Consultation and Community

32 KIlls completed in Johannesburg, Pretoria, Pretoria,
different socioeconomic groups
Balance also needed when trying to recruit people of
corrective but are adequate to ensure good recruitment
Balanced needed to ensure that incentives are not
RD5 requires use of incentives
vigilant about confidentiality
Need to ensure anonymity of participants & to be extra
stigma and discrimination
MSM in South Africa continue to experience
Ethical Issues
This did not manage to attract men in higher SE groups

Recruited

Voucher for participation; R40 voucher for each participant

Use of mixture of shopping vouchers & cash (R40 cash & R40 committee

Advice from Key Informants, FGD participants & steering

Use of incentives

Standard procedures followed in storage & access to data

Questionnaires or DBS specimens for HIV testing

Participation anonymous – no names recorded on

Did not insist on giving name when signing consent

Emphasised during staff training

Ensuring confidentiality & anonymity

Ethics approval from Wits & HSRC

Managing Ethical Challenges
Site Selection

Site Required to be:

RDMS requires use of fixed sites

Venue:

Difficult to find suitable venue that allowed short-term lease

Venue (closed for men reluctance to visit, city centre perceived to be unsafe)

Problem: Durban Lesbian & Gay Community & Health Centre

Johannesburg (NHL2): worked reasonably well

Site Required to be:

Easy to locate, but discreet (no signage suggesting visitors are accessible

Adequate space and closed, sound proof rooms for interviewing gay or MSM

8 VCT to ensure confidentiality

Located in an area frequented by men of all racial groups
Nurses were mature heterosexual women, but were well accepted. Limited diversity of staff may have influenced diversity of participants. Unable to provide ongoing onsite supervision at Dunbar site. Sexually explicit questions. Closed-ended interview questions not being comfortable with asking. Some study staff with own interpretation of study purpose.

Challenges with:

- Strong monitoring and supervision needed.
- Lots of preparation and hand-holding.
- "Dry runs."
- Detailed procedure manual.
- Initial 2-day training, followed by 2-day refresher training.
- Choice of Site Manager critical.
- Staff from LGBT sector or "gay friendly."

Staff Selection & Training
MSM a "hard-to-reach" population

etc.

May differ in important respects e.g. behaviour, service access.

MSM who are openly gay, or who frequent gay venues,

represent a subgroup of the larger MSM population.

Diverse race, age & socioeconomic backgrounds.

Many MSM do not identify as gay.

Sexual behaviour between men often a hidden activity.

No census, register or sampling frame of MSM in South Africa.

Rerepresentative sample of MSM challenging.

Sampling Challenges.
JEMS: Carrying for men's health

No clear alternative sampling method that would ensure a more diverse & representative sample

Status

• Most participants young, black Africans of low socioeconomic status
• Despite extensive efforts to recruit diversity of seeds
• Use of RDS did not succeed in obtaining a diverse sample

Sampling Challenges
Screened for eligibility (RDS) > consent & enrollment

Survey Recruitment Process (RDS)

1. Screened for eligibility
2. Participated in behavioral & biological surveillance
3. Received incentive for participation (R40 cash & R40 voucher)
4. Consent and eligibility given for recruitment (later) for each recruit
5. Compensated with unique identifying numbers
6. Enrolled in the study (up to maximum of 3 recruits)
Rather than just a sexual network part of a social network of MSM in order to be recruited, Closest men underrepresented due to requirement to be

1 month without supervision enrolled in 3 days with supervision, 3 participants enrolled in limited initiative, lack of onsite supervision (21 participants combination of site character/location, site manager with Recruitment goal not attained at Durban site due to

Other race groups as seeds despite extensive efforts to enroll older men Few men who were not black Africans & Few older men, multiple "waves"

Initial enthusiasm & Support - Few recruitment chains with Many "seeds" did not recruit additional participants despite Recruitment took much longer than anticipated

Recruitment Challenges
Participants given a choice of self-administered or interviewer-administered anonymous (coupon number used as an identifier). Questions about sex with women skipped if reported "never had sex with a woman" then. Detailed questionnaire with multiple skips (e.g.)
Questionnaire too complicated for some participants. "Casual partners" whether to count brief, once-off sexual encounters as concept alien to many participants. It did not know. Confusion. Questions about "casual partners" caused. Some questions not well understood. Difficulty with following skip patterns. Self-administered interviewers may have affected responses given (interview bias). Questions about sex, despite repeated training and role. Some interviewers not comfortable with asking explicit questions. Interviewing & questionnaire challenges.
Responses

- Can also pre-programme checks for consistency of skip patterns
- Skipped patterns pre-programmed so no errors following elimination interviewer bias

Consider computer-assisted self-interview (CASI)

ALWAYS have serial number in addition to coupon

More extensive piloting necessary (including piloting translated versions)

Having simple understandable questionnaire

Need to compromise between collecting rich data & questionnaire recommendations
Low uptake of VCT

- 25/285 (of whom 6 HIV positive)
- Attitudes
- Lower uptake in Durban may have been due to staff
- 202/204 (99%) in Jo'burg

High uptake (95%) of DBS overall

- Service to participants (not part of research)
- Offered free on site VCT (provided by New Start) as a
- Specimens
- Anonymous unlinked testing in lab using DBS
- Used dual/parallel approach

HIV Testing
Learnings curve

- Ongoing analyses in RDS surveys
- No consensus among experts about how to do regression
- Preliminary analyses complete but adjustment for RDS
  learning curve

Long coupon numbers a challenge

- Long coupon numbers with serial numbers in addition to a coupon number
- ALWAYS use a dual numbering system with serial numbers
- and in correctly documenting recruitment chains
- Nighttime in linking HIV results to questionnaire data

Probabilty of recruitment affected by network size

Tendency to recruit like participants

Adjust for recruitment bias

RDS requires specific methods of analyses to

Challenges in Data Analyses
Caring for men’s health

Methodological & logistic challenges

Careful planning needed to manage ethical

Dual HIV testing strategy a success

Variety of sampling methods may be required

Surveillance in MSM

A representative sample when conducting

May need to settle on a diverse sample rather than

Many challenges

Not the answer to obtaining a “representative sample”

Surveys in South Africa

RDS a relatively new method of sampling for

Conclusions
Institutional support (Wits, HSRC, MRC)
Steering committee members for input and support
and Durban sites
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