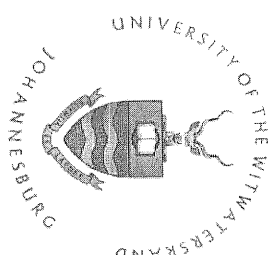




HSRC
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Fish but the Whites are Scarce! JEMS Research Challenges

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JEMS.... Caring for men's health

Overview

▶ Introduction to JEMS

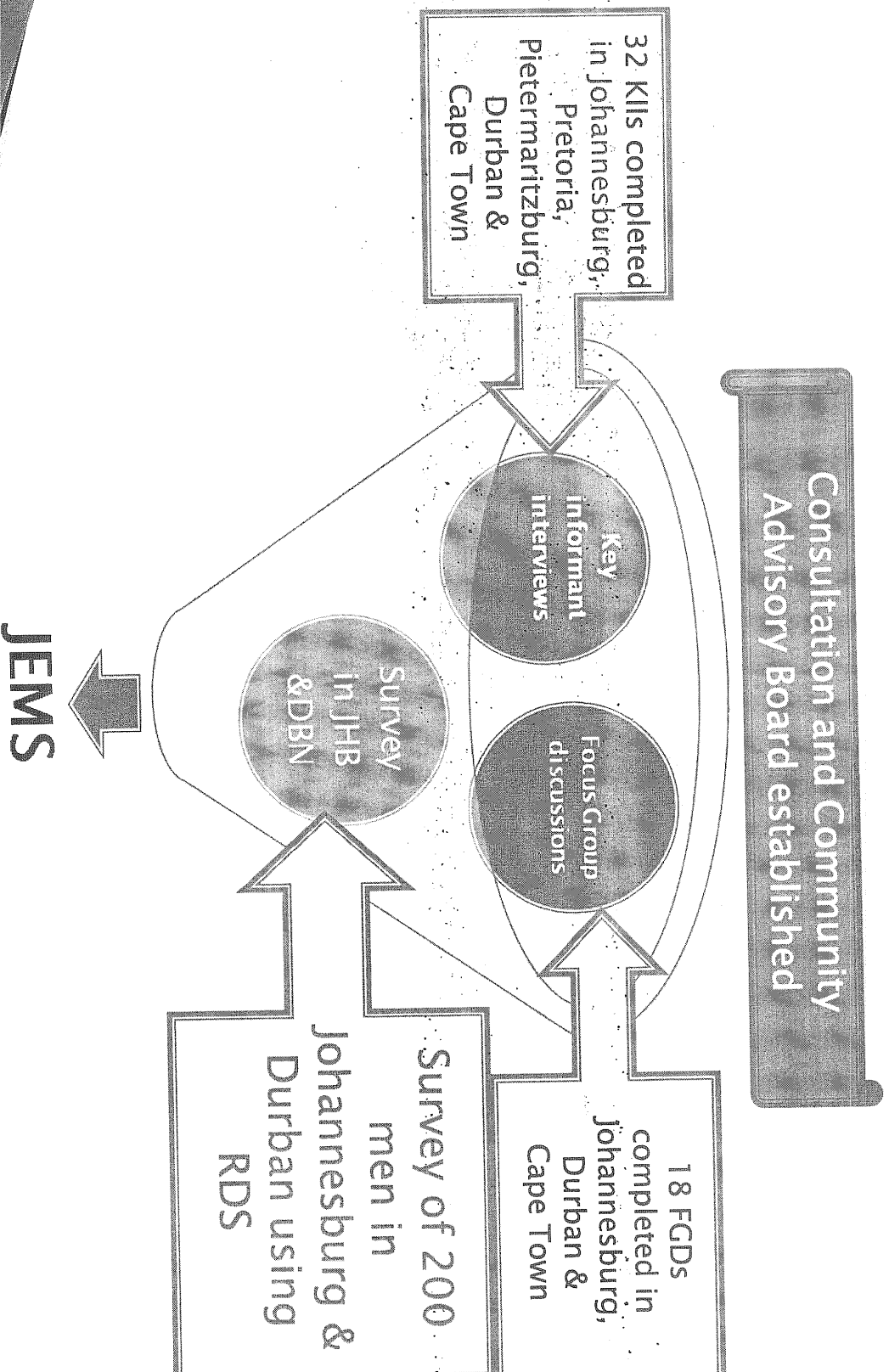
▶ Challenges

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

Aims of JEMS

- ▶ Develop a national surveillance system for HIV and other STIs among men who have sex with men (MSM) in Johannesburg and Durban
- ▶ Describe the epidemiology of HIV among MSM in Johannesburg and Durban (eThekweni)

JEMS Approach & Methods



JEMS.... caring for men's health

Ethical Issues

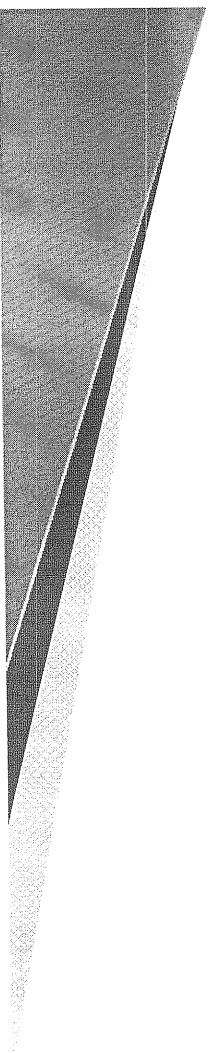
- ▶ MSM in South Africa continue to experience stigma and discrimination
 - Need to ensure anonymity of participants & to be extra vigilant about confidentiality
- ▶ RDS requires use of incentives
 - Balanced needed to ensure that incentives are not coercive but are adequate to ensure good recruitment
 - Balance also needed when trying to recruit people of different socioeconomic groups

Managing Ethical Challenges

- ▶ Ethics approval from Wits & HSRC
- ▶ Ensuring confidentiality & anonymity
 - Emphasised during staff training
 - Did not insist on giving name when signing consent
 - Participation anonymous – no names recorded on questionnaires or DBS specimens for HIV testing
 - Standard procedures followed in storage & access to data

▶ Use of incentives

- Advice from key informants, FGD participants & steering committee
- Use of mixture of shopping vouchers & cash (R40 cash & R40 voucher for participation; R40 voucher for each participant recruited)
- This did not manage to attract men in higher SE groups



Site Selection

- ▶ RDS requires use of fixed sites
- ▶ Site required to be:
 - Accessible
 - Easy to locate, but discrete (no signage suggesting visitors are gay or MSM)
 - Located in an area frequented by men of all racial groups
 - Adequate space and closed, sound-proof rooms for interviewing & VCT to ensure confidentiality
- ▶ Difficult to find suitable venue that allowed short-term lease
- ▶ Venues:
 - Johannesburg (NHL): worked reasonably well
 - Durban: Durban Lesbian & Gay Community & Health Centre problem (closeted men reluctant to visit, city centre perceived to be unsafe)

Staff Selection & Training

- ▶ Staff from LGBT sector or “gay friendly”
- ▶ Choice of Site Manager critical
- ▶ Initial 2-day training, followed by 2-day refresher training
 - Detailed procedure manual
 - ‘Dry runs’
 - Lots of preparation and hand-holding
 - Strong monitoring & supervision and ongoing support needed
- ▶ Challenges with:
 - Some study staff with own interpretation of study purpose
 - Closeted interviewers & interviewers not being comfortable with asking sexually explicit questions
 - Unable to provide ongoing onsite supervision at Durban site
 - Limited diversity of staff may have influenced diversity of participants
- ▶ Nurses were mature heterosexual women, but were well accepted

Sampling Challenges

- ▶ “Representative sample” of MSM challenging:
 - No census, register or sampling frame of MSM in South Africa
 - Sexual behaviour between men often a hidden activity
 - Many MSM do not identify as gay
 - Diverse race, age & socioeconomic backgrounds
- ▶ MSM who are openly gay, or who frequent gay venues, represent a subgroup of the larger MSM population
 - May differ in important respects e.g. behaviour, service access, etc.
- ▶ MSM a “hard-to-reach” population

Sampling Challenges

- ▶ Use of RDS did not succeed in obtaining a diverse sample despite extensive efforts to recruit diversity of seeds
 - Most participants young, black Africans of low socioeconomic status
- ▶ No clear alternative sampling method that would ensure a more diverse & representative sample

Survey Recruitment Process (RDS)

- ▶ Screened for eligibility → consent & enrolment
- ▶ Participated in behavioural & biological surveillance (questionnaire & HIV testing)
- ▶ Received incentive for participating (R40 cash & R40 voucher)
- ▶ Given 3 recruitment coupons with which to recruit additional participants from social networks
- ▶ Coupons carried unique identifying numbers
- ▶ Secondary incentive given (later) for each recruit enrolled in the study (up to maximum of 3 recruits)

Recruitment Challenges

- ▶ Recruitment took much longer than anticipated
- ▶ Many “seeds” did not recruit additional participants despite initial enthusiasm & support – few recruitment chains with multiple “waves”
- ▶ Few men who were not black Africans & few older men, despite extensive efforts to enrol older men & men from other race groups as seeds
- ▶ Recruitment goal not attained at Durban site due to combination of site character/location, site manager with limited initiative, & lack of onsite supervision (21 participants enrolled in 3 days with supervision, 3 participants enrolled in 1 month without supervision)
- ▶ Closeted men underrepresented due to requirement to be part of a social network of MSM in order to be recruited, rather than just a sexual network

Questionnaire administration

- ▶ Detailed questionnaire with multiple skips (e.g. if reported “never had sex with a woman” then questions about sex with women skipped).
- ▶ Anonymous (coupon number used as an identifier)
- ▶ Participant given a choice of self-administered or interviewer-administered

Interviewing & questionnaire challenges

- ▶ Interviewer-administered
 - Some interviewers not comfortable with asking explicit questions about sex, despite repeated training and role play – may have affected responses given (interview bias)
- ▶ Self-administered
 - Difficulty with following skip patterns
 - Some questions not well understood
- ▶ Questions about “casual partners” caused confusion
 - Concept alien to many participants & did not know whether to count brief, once-off sexual encounters as “casual partners”
- ▶ Questionnaire too complicated for some participants

Questionnaire recommendations

- ▶ Need to compromise between collecting rich data & having simple understandable questionnaire
- ▶ More extensive piloting necessary (including piloting translated versions)
- ▶ ALWAYS have serial number in addition to coupon number
- ▶ Consider computer-assisted self interview (CASI)
 - Eliminates interviewer bias
 - Skip patterns pre-programmed so no errors in following skip patterns
 - Can also pre-programme checks for consistency of responses

HIV Testing

- ▶ Used dual/parallel approach
 - Anonymous unlinked testing in lab using DBS specimens
 - Offered free onsite VCT (provided by New Start) as a service to participants (not part of research)
- ▶ High uptake (95%) of DBS overall
 - 202/204 (99%) in Jo'burg
 - Lower uptake in Durban may have been due to staff attitudes
- ▶ Low uptake of VCT
 - 25/285 (of whom 6 HIV positive)

Challenges in Data Analysis

- ▶ RDS requires special methods of analysis to adjust for recruitment bias
 - Tendency to recruit like participants
 - Probability of recruitment affected by network size
- ▶ Long coupon numbers a challenge
 - Nightmare in linking HIV results to questionnaire data and in correctly documenting recruitment chains
 - ALWAYS use a dual numbering system with a simple serial number in addition to a coupon number
- ▶ Learning curve
 - Preliminary analysis complete but adjustment for RDS ongoing
 - No consensus among experts about how to do regression analyses in RDS surveys

Conclusions

- ▶ RDS a relatively new method of sampling for surveys in South Africa
 - Not the answer to obtaining a “representative sample” of MSM
 - Many challenges
- ▶ May need to settle on a diverse sample rather than a representative sample when conducting surveillance in MSM
- ▶ Variety of sampling methods may be required
- ▶ Dual HIV testing strategy a success
- ▶ Careful planning needed to manage ethical, methodological & logistic challenges

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