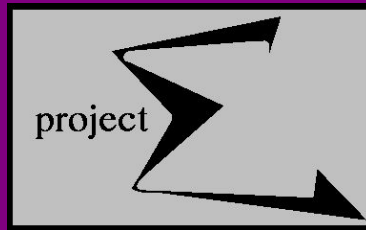


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Innovation and Incentives: *Health Research among sexual minorities*

Professor A.P.M. Coxon
University of Edinburgh &
University of Wales



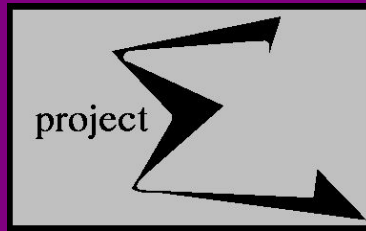
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Evidence-based policy in Health Research usually requires:

- Clear specification of what is required ; then researched using routine **Clinic-based tests, surveys , interviews ..**

BUT there exists a whole swathe of health conditions and **problems which cannot be researched this way**, because they involve

- **Illegal behaviour** (under-age sex, drug-use)
- **Stigmatised groups** (illegal immigrants, minority ethnic groups [MEGs], men-who-have-sex-with-men [MSM])
- **Socially inaccessible groups** (Travellers, homeless, truants), & less obviously ... People with learning difficulties, lack of basic skills (literacy, hearing etc)
- **(and often a combination of them: “multiply disadvantaged”).**



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In social science research these respondent groups are known as ...

Hard-to-reach, Marginalised, Hidden , Populations, who

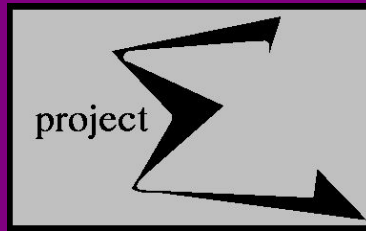
- form the bulk of “non-response” in surveys & are therefore major contribution to serious error/bias in estimating & reliable generalisation
- Are more-costly-to-reach (and often need to use monetary incentives)

Many traditional recruitment methods are flawed:

- Random sampling impossible: no sampling frame, self-identification issues
- Volunteer subjects (surveys) are strongly biased to white, professional, better-educated
- Location sampling (e.g recruitment in ‘specialist’ locales like saunas, clubs) biased to younger, better-off, “out” sections) ... so

Methods that DO succeed in reaching “hidden populations” are crucial

Even if they require more complex design, methods, data-collection, analysis.



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Developments in such methods are now illustrated by MSM as a risk-group with respect to Aids/HIV transmission in UK

PROJECT *SIGMA, UK

Funded (MRC & DoH) to Conduct (5-wave) longitudinal study (1987-93).

Methods:

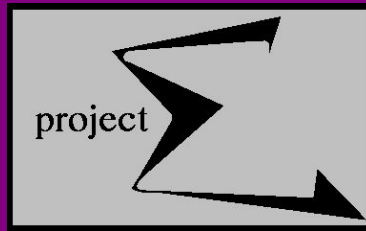
- HIV & other viral [blood & saliva] tests,
- 3-hour extended interview
- 1-month sexual diary (see <http://www.sigmdiaries.com>)

Set up to investigate:

- HIV-1 prevalence & sexual transmission in the gay community (*not* just STI Clinics)
 - *needed representative sampling & blood-testing of a hidden population*
 - *needed detail of MSM's sexual behaviour , with both M & F*
 - *involving intrusive, sensitive , truthful measurement*
- With respect to over-time trends, contexts, correlates (poppers?) concentration of risk-behaviour from a hidden, hard-to-reach, stigmatized, population
 - *defined by sexual behaviour only recently & partially legalised,*
- ... and in face of political opposition
 - *to any such research, and to Social Sciences in general (Mrs Thatcher)*

QUITE A PROBLEMATIC UNDERTAKING!!

- * Socio-Sexual Investigations of Gay Men and Aids



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The basic sampling problem:

How can a representative sample of MSM be created?

- **Essential for accurate prevalence estimates**
 - How define MSM/gbm? How locate / how identify?
 - In absence of population frame or estimate
 - Truth-telling / evasion, shame / interviewer effect

SIGMA solution:

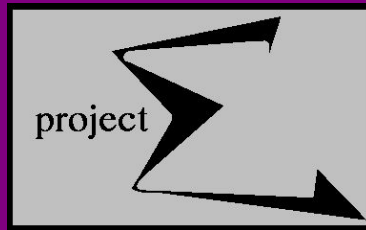
MSM world is a **social/sexual network** (“we are all related by insertion”), so

1. define typology

- by 2 Factors most affecting variation in MSM sexual behaviour

2. network/tracing sampling strategy [Rapoport 1961, Coxon 1995]

TYOLOGY:



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	<u>Age Group:</u>		
<u>Relationships:</u>	<u>Under 21</u>	<u>21 - 39</u>	<u>Over 39</u>
Closed/ Monogamous	I	II	III
1 or more regular partner and other/s	IV	V	VI
No regular	VII	VIII	IX

AGE-GROUP:

<21 Under Age of Homo. Consent

21-39 Over Age of consent

>39 Sexual Maturity before SOA*

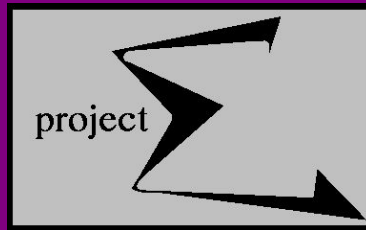
*[*Sexual Offences Act 1967, legitimising some same-sex behaviour]*

RELATIONSHIP TYPE:

“Closed”: Single excl. sexual partner

“Open” : Regular + other partner/s

“No reg. :” Only casual partner/s



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Procedure: Link-Tracing (aka "Snowball" / Chain-referral) sampling:

- Identify/interview men satisfying "types"
- Ask them to nominate MSM (of same type)
- Contact & interview their (new) nominees

Intention:

to "burrow into the iceberg" (of increasingly 'hidden' men) to establish unbiased / representative sample of MSM

Plus -- Identify/recruit from PSEs = presumed source of hidden , occasional (often married) sexual players.

Figure 1. Illustration Of Network Tracing

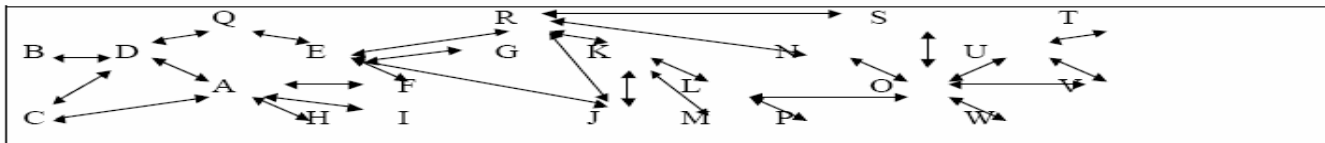
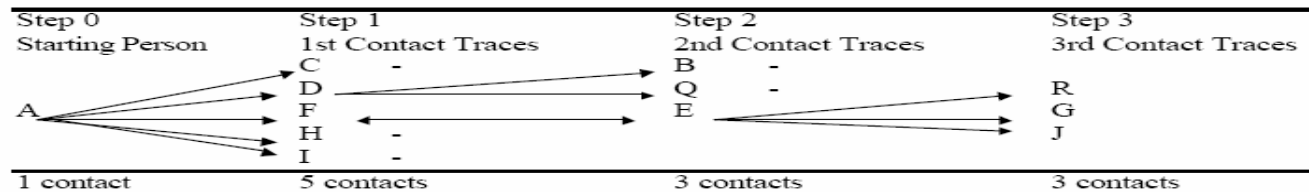
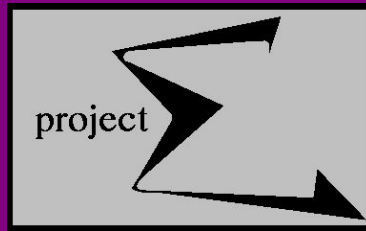


Figure 2. Sociogram Of Network Tracing





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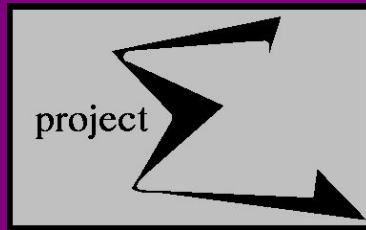
BUT shortcomings/ problems encountered :

- MSM's sexual partners turned out rarely to be either of the same "type", or more closeted,
- Respondents often reluctant to identify/ 'recruit' nominees
 - though response rate significantly affected by incentives!
- Contact chains were rarely longer than 2
 - need at least 4, and up to 8 for full stability
- Contrary to expectation
 - PSE "Cottagers" rarely actually disconnected

Was this failure?

Far from it ... The method revolutionized sampling of such groups

Turned out to be highly appropriate to all hidden/hard-to-reach/ populations



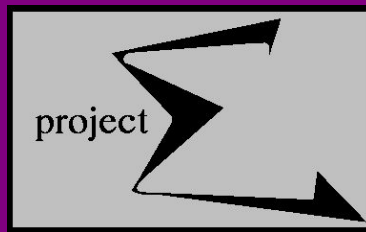
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Subsequent work has developed new form of network probability sampling for hidden populations:

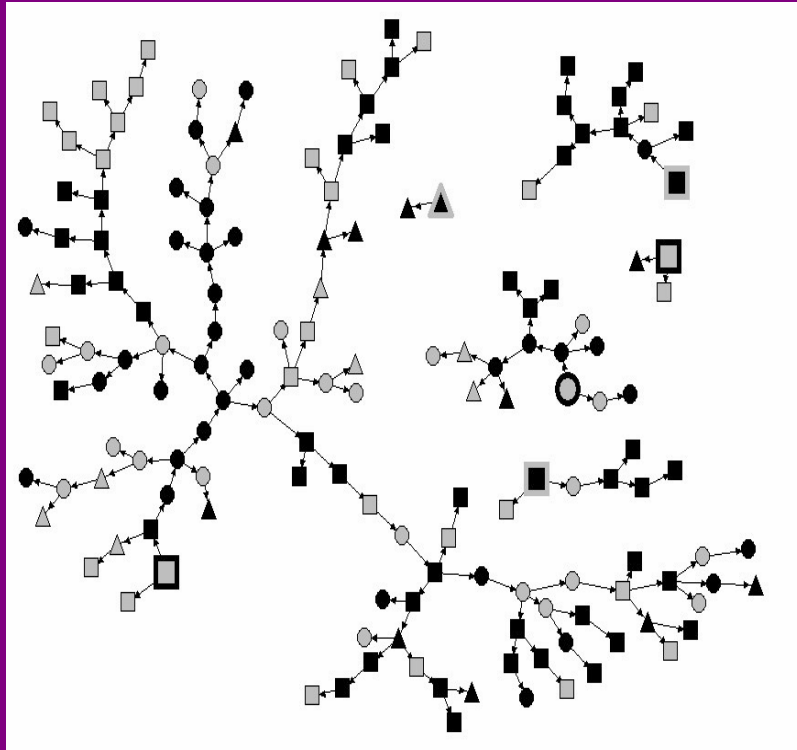
“Respondent-driven” and random walk sampling (RDS)

[Klov Dahl 1977, Coxon 1995, Heckathorn 1997, <http://www.respondentdrivensampling.org/>]

- Single “seed/s” begins sample-tracing (no prior conditions)
- S/he chooses [specified] number of “contacts” in nominated population
- Incentives work & are crucial to RDS:
 - Primary (for interview etc) & sometimes Clinical consultation
 - 3 “coupons” given to Respondent when contact nominations made . Nominator receives secondary incentive when nominee appears and is interviewed
- Random walk variant: (Fixed number, say 4) randomly sampled from (new) contacts
- Each new contact forms next step
- Continue till enough (or exhaustion of new contacts).
- RDS can be /is adapted for WWW sampling.
- **This process guarantees probabilistic and unbiased sampling even in medium run.**



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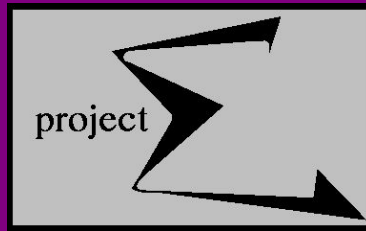


RDS (Drug-sample)

Recruitment chains of all 6 productive seeds :

(enlarged & highlighted with opposite colour borders)

- The nodes are colour-coded for gender
 - male = black, female = white)
- and shape-coded for race/ethnicity
 - White = square, Asian = circle, Other = triangle).



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So, my example (and talk) finish.

- Hopefully we now see how
 - policy issues can generate adequately sophisticated research,
 - which in turn can produce answers to apparently insuperable problems
 - which have enormous practical, scientific and policy consequences:

“RDS represents an advance in sampling methodology because it resolves what had previously been an intractable dilemma, a dilemma that is especially severe when sampling hard-to-reach groups ... for which no exhaustive list of population members is available. This includes groups relevant to public health, such as drug injectors, prostitutes, and gay men, groups relevant to public policy such as street youth and the homeless” [Heckathorn]

This talk is available both in this presented version, and also in a longer version with references at: <http://apmc.newmdsx.com>