Abstract

Project SIGMA's research on gay men's sexual behaviour and AIDS and HIV infection has posed complex ethnographic and methodological problems which have required unorthodox and innovative strategies for their solution. Three main problem areas included: value conflict between interviewer/HIV tester roles; issues concerning data confidentiality and legal interference, and the elicitation of detailed sexual behaviour. The procedures developed have clear applicability to other research concerned with covert, stigmatised and legally-sensitive behaviour or data.

Project SIGMA

All involved in trying to analyze, interpret, model or simply understand the development of the AIDS pandemic have called regularly for better data relating to the modes of transmission of the HIV virus, and in no domain more insistently that in sexual transmission (Coxon and Carballo, 1989). But few methodological innovations have been developed to help produce these better – more detailed, more reliable, more valid – data. In the West (or in the World Health Organization's terminology 'Type I' countries) quite new problems of sample definition have arisen in attempting to delineate the appropriate populations for studying high-risk behaviour. Although the appropriate populations may well be "all male-to-male sexual behaviour" (rather than 'homosexuals') or 'intravenous substance use activities' (rather than 'drug-takers'), it is unfeasible or grossly expensive to attempt to operationalise them, and it is equally beyond the resources of conventional research.
funding agencies to carry out population-wide studies to identify minority and socially invisible groups. Even when such general population studies are mounted, fairly trivial changes in wording or interviewer characteristics or instructions can produce prevalence estimates that differ by a factor of 2 or 3.1

Project SIGMA2 is a set of inter-related studies with the main aim of investigating the types and patterns of sexual behaviour and HIV sero-conversion among men who have sex with men, and to look at the changes over time in behaviour, HIV status, and relevant socio-psychological variables. This involves:

- studying the men’s lifestyles using a detailed face-to-face interview at yearly intervals.
- establishing the HIV (and Hepatitis B and other viral) status using blood (or other body fluid) donated by the men, with appropriate pre- and post-test counselling)
- a self-completed detailed sexual behaviour diary (Coxon, 1988, 1992) filled in on a daily basis.

together with

- subsidiary studies of casual open-air or public toilet (‘tearoom’ or ‘cottage’) sex, and of male sex-workers and sado-masochistic men.

The sampling of over 1000 men in eight sites in England and Wales poses interesting questions in its own right, but which will be ignored in this paper. Suffice it to say:

- that the two main sites were Greater London and South Wales4
- that subjects were recruited from the naturally-occurring population and not from Genito-Urinary Medicine clinics
- that a 2-factor design was used (3 Age Groups by 3 Relationship Types – Closed, Open, No Regular) in conjunction with snowball network sampling, and
- that the longitudinal design is of (currently) five waves at yearly intervals.

Bleeding

Originally the Project did not have taking of blood samples among its purposes; this became a requirement for the two main sites after initial discussions with the Medical Research Council, who wanted to obtain HIV-1 (then termed HTLV-3) sero-prevalence estimates among gay and bisexual men. Operating within the medical mode, the officers of the MRC assumed that this would be obligatory, and take place in a Clinic setting. But the Project had made a methodological point of not sampling from (or even, in one site, avoiding3) the local GUM clinics, and many of the more closeted subjects would never agree to come to a Clinic, so this posed difficulties. Moreover, at this time the issue of whether to take the test was highly contentious within the gay community, and many of the most vocal and articulate gay men were strongly opposed to it. A strategy had therefore to be adopted which would maximise the number of subjects consenting to be tested and make it possible to take the blood samples in a natural (interview) setting. It was decided therefore:

- to recommend to subjects that they be tested anonymously, ie without being told the result of the test, but to arrange for the result to be given if he wished it. In the event only 13 per cent were tested anonymously.

- to train interviewers in the main sites as phlebotomists, functioning under the medical authority of the Project’s Clinical Investigator (Dr T.J. McManus) and locally under the relevant clinical authorities.6 All the Project Principal Investigator were themselves trained (and operated) as interviewers and as phlebotomists.

Interviewers . . . and counsellors and phlebotomists

It was relatively simple to arrange for training in counselling, though it was a novelty for research staff to be told that such training and the taking of blood was part of their Conditions of Appointment.7 Arrangements had also to be made for communicating the test results, and for safeguarding the data about a subject’s sero-status.8

The act of taking blood established a quite distinctive – and
sometimes almost proprietorial – bond between the interviewer and the subject (a good instance of Titmuss's (1973) thesis). This certainly increased rapport, but it also introduced interesting examples of role conflict. These were of various sorts.

In a few cases the conflict arose between job requirements and personal views: one interviewer disapproved of HIV testing, but agreed to take the subjects’ blood for testing as part of his job requirements. This manifestly led to a major interviewer effect both in lowering his rates of accession and of the proportion of subjects deciding to be told their HIV result.

When (as in the usual case) the same person took blood and interviewed the subject, there could be a more subtle conflict between evaluative (health) values and scientific strategy. When giving the pre-test counselling, the interviewer was obliged to articulate to the subject the ‘Safer Sex’ guidelines, under which certain activities such as unprotected anal intercourse were explicitly disapproved of as ‘high risk’. In the South Wales site it had been decided to take blood at the start of the interview, so that a pall of anxiety about giving a blood sample did not hang over it. However, an hour or so into the subsequent interview, the interviewer then had to elicit information about the subject’s infractions of the very Guidelines given in the course of pre-counselling. The interviewer skills here needed to be considerable if the subject were not to ‘shade’ (or, indeed, lie about) his sexual behaviour (see Pomeroy et al. 1982). Several strategies were tried; a fairly successful one was ‘collusion’. The questionnaire [Wave I] format is:

A lot is being talked nowadays about 'Safe Sex'... [C4.1.1] Being honest, how seriously do you take the idea of 'safe sex'?

But in some cases interviewers prefaced C4.1.1 by words such as the following:

We know a lot of guys don’t really pay any attention to Safe Sex in the heat of the moment...

which of course raises questions about comparability, but illustrates the need felt by interviewers to contrast the ‘eliciting proscribed behaviour’ approach from the earlier counselling approach.10

The London Site by contrast decided to locate blood sampling at the end of the interview, and this by and large avoided the above role-conflict. But it, too, had a disadvantage. In the South Wales case, the physical reaction of the subject to the test could be monitored over the two-hour long interview, and several instances of fainting did occur during the interview as a result of the earlier blood-taking. In the London case, there was often not enough time after the end of the interview and the subject leaving to rule out the possibility of later reaction.

Confidentiality

Confidentiality of data is of course always a problem in social science research, especially when dealing with sensitive areas like sex and income. It becomes doubly sensitive when the behaviour may be proscribed and/or illegal, where the sexual orientation of the subjects is often a closely-guarded secret (whose revelation could be catastrophic). This applies to almost all studies of gay men. The problems are aggravated when the study is longitudinal (since actual identity is need for tracking purposes and subjects might reasonably have fears about the security of that information). But when, as here, the question of HIV status is added, the problems are yet further aggravated.

The first set of issues of confidentiality concern recruitment and consent: how do you convince the subject that the information he will give is safe? Any undertaking has then to be matched with project procedures which will safeguard such secrecy. The initial recruiting leaflet contained a ‘Confidentiality Guarantee’ which promised that an individual’s identity could not be known outside the project, and when the subject came to be interviewed he was required to sign the following Statement of Informed Consent, which encapsulated a two-way contract.

STATEMENT OF INFORMED CONSENT

By my signature (or mark) below I give my informed voluntary consent to participate in a study of sexual lifestyles, conducted by: [Names and affiliations of Principal Investigators].

I understand:

– that the information will be used for research purposes only

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- that my identity will be kept entirely confidential
- that the identity of any persons I name in the interview will be totally anonymous
- that no names will be attached to any written or machine-readable schedules.

For my part, I promise that I will give answers which are to the best of my ability honest and accurate. I also understand that I may withdraw my participation in the study at any time if I choose to do so.

[Signature/mark, name address and 3rd person information]

It will be noted that the Statement promises confidentiality of the subject's name and address; by this is meant that they appear within internal Project records, with due security of access, and a guarantee that it cannot be known outside. But it also promises anonymity for the names of anyone he chooses to mention; this means that the identity of his friends and of his partners did not even appear on interview schedules, and in many cases was not even mentioned to the interviewer except under labels like ‘PI’ (partner 1). This was done because subjects were by and large more concerned about protecting the identity of their friends and nominees than protecting their own.12

Implementing the undertakings of confidentiality given to the subjects poses more difficult issues. First, all staff signed an Undertaking on Confidentiality which formed part of their Job Conditions, and it was made explicit that infraction of these undertakings could form the basis for dismissal.13

[STAFF] UNDERTAKING ON CONFIDENTIALITY

I, the undersigned, understand that in having access to the data of the Project I agree to be bound by confidentiality in the following ways:

1. The information on the names and identity of subjects is entirely confidential and may neither be divulged to any person, nor even to the subject unless he himself makes the identification.

In particular, the (stated) HIV antibody status of a subject must not be divulged to any person even any member of the Project

2. Other information (on background, behaviour etc) may never be given to any person or body outside the Project

when any individual is identifiable. In case of doubt, the issue shall be raised with the Project Investigator.

(Signed by staff member and Investigator and dated)

(Note: Although only the Investigator knew the actual blood test results, subjects were asked in the Interview what they knew (or believed, or suspected) their HIV status was at the time, and therefore interviewers were aware of the subject’s (stated) HIV status).

The same Undertaking was signed by all Interviewers and clerical and data-processing staff of the Project – indeed by any and all staff who would, or could, come into contact with data or transcripts. With very few exceptions, the Undertaking was faithfully kept by staff.

Keeping track

As with any panel study, problems of attrition (and sadly of genuine mortality) were considerable, and given the interest which police and other authorities had in compiling lists of known homosexuals (see 3.3 below), a number of subjects were unwilling to give their actual name and address, despite the undertakings of confidentiality. The most sensitive characteristics concern identity (name and address) and HIV sero-status. Subjects were allowed therefore to use a pseudonym, with a warning that they should remember what name they had chosen, as they would be contacted in the next wave by that pseudonym. In a few cases, subjects were not even willing to do this and in this case only the interviewer knew their identity. At a later stage this decision was regretted, too, when a disaffected interviewer who had left the Project refused to give any information on such subjects and they were lost to the panel.14

Keeping track of subjects was often easier in South Wales than in London even though the overall response rate was lower. In Cardiff there is only one gay club and two gay pubs, so the ‘scene’ is fairly compact and close-knit and by being regularly on the scene, Project researchers often encountered their subjects and knew how they could be reached if contact was lost. In London, with a much more dispersed and large scene, it was much more difficult to keep contact.

At each interview the subject was therefore asked to give the
name and address of a third person (typically a relative, partner or friend) who would know their whereabouts if they moved or lost contact. A surprisingly large number of subjects (more than 75 per cent) were prepared to do this, so long as a promise was given that any contact made did not identify the Project or its nature. Only rarely was this information actually used.

In terms of project procedures, Statements of Informed Consent (which contained Identifier, Name, Address and 3rd Person Contact information) were kept physically separate from schedules and under secure lock and key away from the project, and no data files bore anything but the code identifier.

**HIV Sero-status**

As mentioned in Section 2, information about the subject’s HIV status came from the actual blood and saliva tests (Hunt et al. 1990) and from the subject’s reported (or believed) HIV status, stated in the interview. Although HIV status information has always been sensitive, it became increasingly so in the United Kingdom as insurance and house mortgage schemes increasingly asked the ‘Aids question’, when even to have taken the HIV antibody test can be sufficient presumptive evidence to refuse cover or charge higher rates. Although there are signs that this policy may be moderating, it seems unlikely that a subject’s open avowal of homosexual practice will be taken as anything but evidence of inherent risk. Initially, subjects often agreed to be bled only if it were anonymous; then as ‘early intervention’ became a favoured notion, others wanted to be bled and know their results and finally, a number agreed to be interviewed in order to get their result in a manner which would escape Insurance attention; it became increasingly important to ensure that HIV status information was secure and watertight. The manner and techniques by which this was done must remain unreported; suffice it to say that information linking identifiers and HIV status were kept on a separate machine, in a different location and fully accessible only by the Principal Investigator. The contract to respect anonymity and confidentiality brought with it a number of ethical problems for the Investigator (who knew the status and identity of those who had chosen not to know their result). For example, should a subject who is (unknown to him) HIV antibody positive and who is engaging in penetrative or other risky sex with others be forewarned? Should a subject who had been (unknowingly) positive for several years be given hints about early intervention? The answer in both cases must clearly be ‘no’ given the undertaking the Project gave, but in some cases it was hard to resist the temptation to hint at hidden knowledge.

**The police, politics . . . and paranoia?**

Much of the work of the Project has been against a background of highly political issues and events. Some issues were highly specific: blood sampling for HIV antibodies was for a long time a highly contentious and divisive issue in the gay community, and views were expressed in the gay press that the Project was doing a disservice to the gay community by collaborating with scientific and medical authorities – even that by publishing clinic vs non-clinic HIV rates the Project was encouraging gay men to relax their adherence to Safer Sex Guidelines.

More potent, however, was the political and legislative background in which perceived anti-gay and homophobic reactions were embodied in 'Section 28' and 'Section 25' legislation. This formed a background when the Project was recruiting respondents or persuading them to be re-interviewed. Some were understandably concerned about their identity becoming known and/or their data accessed if they co-operated, and about the use which could be made of our scientific results by hostile authorities.

Section 28 of the Local Government Act refers explicitly to the illegality of local government authorities undertaking any support or funding of activities which could in law be construed as 'promoting' homosexuality, or which presented non-heterosexual alliances as 'pretended family relationships'. Its chief effect was not legal action so much as a diffuse threat which blighted a wide range of activities: it was often sufficient for local councillors to threaten action for initiatives and funding to be dropped. In our case it was suggested that the research itself could be in breach of Section 28 (but at the London site only, since it is located at South Bank University which then depended on local authority funding), and it was specifically brought to the attention of the Editorial Board of the academic journal carrying our first published account of the Sexual Diary method. Section 25 refers to the Criminal Justice Bill. Among the provisions of an act which aims to ‘protect the public from serious harm’, victim-
less crimes relating to homosexual men are singled out for especial attention, and the 'serious harm' referred to includes the 'risk of death or serious mental or physical injury caused by further sexual offences committed by the offender', including a possible reversion to the use of compulsory psychiatric treatment for sex-related crimes. A further indication of legal background which directly affects our respondents and topics of the Project Research is the so-called 'Operation Spanner', where Police had been investigating SM videos, including some ostensible 'snuff' videos involving bondage, corporal punishment, body-piercing and other activities. The men's defence was based on the fact that they had all consented to the activities. The judge ruled that sexual behaviour is not an area where a person can consent to an assault, despite the fact that one can thus consent to assault in games such as boxing or football, as well as in medical contexts. Moreover, if in sexual activities the pain, marks or injuries are 'more than trifling', even consensual activity is illegal. It would appear that a love-bite between a man and wife is now illegal in England and Wales, and a yet higher fraction of sexual activities of homosexual men are thus criminalised. Although the appeal judgement is likely to go to the European Court of Justice, it puts wide ranges of behaviour (which 34 per cent of our subjects say they have engaged in at some time) into the illegal category in the mean time and makes it difficult to secure truthful, explicit and detailed data on this topic.

There has been widespread fear, then, that information about identity or behaviour could be accessed or obtained from Project files - and especially by the Police authorities. Was (and is) this a justified fear?

Homosexual behaviour is illegal in Britain. which is not in private, or
- which involves more than two men, or
- where either partner is under 21
- or a member of the Armed Forces (or the Merchant Navy).

On these criterion probably more than a quarter of the data of the Project could be construed as referring to illegal activity; the fear of this information falling into the wrong hands is therefore fully understandable. It was believed initially that, being under the funding andegis of the Medical Research Council, Project data had the status of 'medical records' and hence were not seizable by the police. Except for the data in the possession of our Clinical Investigator, it seems unlikely that they are thus protected. But is the possibility of such access or seizure even credible? Unfortunately, yes. The Project had already encountered problems of HM Customs and Excise seizing Project training videos,21 and Project interview schedules being subject to confiscation by postal authorities.22

More disturbing were police attempts to obtain names and addresses of friends and contacts of a large number of gay men in their investigations of a murder in South Wales involving a gay male victim. Although this did not involve the Project directly, a subsequent investigation in Bristol alerted the police to the fact that the Project was studying gay men and might therefore have information from or about the dead man that may prove useful in their enquiries. Only because the Project was alerted to this by a phone call from the Bristol police were staff able to be fully prepared - in a manner it would be counter-productive to divulge - when asked to confirm or deny that the dead man had been an informant, and when the Police visited the Project to enquire further.23 It was not sufficient - or even sensible - to encrypt all data, since they did not include any identifier. Rather, steps were taken to ensure that the identifier/name link file could be permanently and unrecoverably erased very swiftly (ensuring that a readable, regularly updated copy disk existed in a foreign location). So far, the Project has not encountered the need to destroy data in this way, but it means that Project literature can confidently re-assure subjects about the security and confidentiality of their identity and data.

Collecting sensitive data

Questioning sexual behaviour

A large part of the Core Interview Schedule consists of detailed, systematic investigation of sexual behaviour over given periods of time, together with information on the use of prophylactics (eg condoms, surgical gloves), associated alcohol and drug use (especially nitrates, 'poppers') and 'toys' (eg dildoes). In the interview schedule, this section appears about half an hour into the interview, after preliminary sections dealing with facesheet and 'fed forward' information required for updating tracking files, and general sections concerned with identity, 'outness', partners and relationships. Data collection about sexual activity is unified by
using a single schema, the Sexual Behaviour Code (SBC), and compatible variants of this are used in many other studies (Coxon et al., 1992), including the eight national Homosexual Response Studies of the World Health Organization’s Global Program on AIDS.

If such a schema is to be generally useful it must be capable of being used in a variety of data-eliciting situations. In particular, it must be applicable:

when the subject makes his own descriptions (self-reports)
when the sexual activity is observed (and/or participated in)
in the interview or self-completed questionnaire.

It must also be easily comprehensible, if subjects are going to be able to use it, and it should be encryptable, so that secrecy and confidentiality can be assured. A more important requirement is that the schema must be detailed enough and also open to modification; it must be complex enough to encompass all common (and more rare) sexual behaviour and situations, and allow the addition of new behaviour as it occurs.

The Inventory of Sexual Behaviour (ISB) was designed primarily for use in an interview situation, but was quickly adapted to use both as a self-administered instrument and as a Clinic-based checklist for use in taking a sexual history. Because it is based on the simple structure of the SBC (Sexual Behaviour Code) it is easily memorisable and can also be (and is) used to report sexual behaviour in covert contexts such as locations of casual sexual encounters.

Forms of the ISB vary from the simplest (designed to elicit information on anal intercourse only, which is 4 items long), through the basic heterosexual/homosexual behaviour (covering the four most common behaviours; 16 items long) and the fullest - so far! (which explores the 3 principal modalities for 6 main behaviours, looking at different genders of partners, condom use and differential behaviour between partners; this amounts to 720 items, but averages a completion time of only 18 minutes).

A question of terminology

The major question underlying ensuring the validity and viability of questions about sexual behaviour (which even in communities of sexual minorities are likely to be perceived as intrusive or at least delicate) is: ‘How is sexual behaviour to be named?’ Such naming covers two different senses:

how is continuous sexual behaviour to be ‘chunked’ into recognisable and stable categories?

and

what are the categories to be called?

Fortunately for the anthropologist and survey researcher, the succession of (continuous) bodily movements that actually make up ‘sexual behaviour’ are, or can be, ‘chunked’ into identifiable and (well-nigh) universally recognizable sexual activity and given a common name. For instance, whilst the act of masturbation will usually have at least some unique components (for no-one does it exactly the same way, and no-one repeats the act identically), the manual stimulation of the penis by the hand is usually taken to be a necessary part of the definition. As in so many other aspects of sexual behaviour, even such a behaviourist as Kinsey insists that the definition must also have an intentional aspect (Kinsey, 1948:497–8) so that random, unintended, rubbing of the penis is excluded from the category of ‘masturbation’. Yet recognition of the act of masturbation would be virtually universal, at least within a given culture, and although the exact temporal bounds (especially the exact point at which it may be said to begin) are rarely entirely agreed on, that the act occurred is universally acknowledged. Given that it is without doubt the most prevalent male sexual act, this is as it should be.

Despite its virtual universality and the early age at its first appearance, the nomenclature for masturbation is far from universal. Because it is often taboo among children, and frequently discouraged or prevented, it comes to be referred to by all sorts of euphemisms and code-names (often unique to the family concerned). There thus arises a hierarchy of terms of differing acceptability, from the medical terminology used by professionals (and often by subjects when talking to professionals) through a widely-used set of common vernacular terms to largely idiosyncratic ones. In SIGMA studies such terminology has been elicited before questioning detail of sexual behaviour. The purpose of this is not only to gather information on ‘street’ terminology, but
also to make the respondent more at ease in asking detailed information about what may be an embarrassing topic. In Question Schedule 1 of Project SIGMA, subjects were asked in the interview context to give their 'preferred name' for a range of common sexual terms. These were then substituted in questions using the terms. Although there was some differences in usage by areas (eg South Wales especially used terms like 'bonking' for (anal) intercourse), distributions were markedly similar.

Preferred term for sexual terms

Preferred term for 'penis'
53% XXXXXXXXXXXXXXXXXXXXXXXX Cock
18% XXXXXXXXX Prick
15% XXXXXXXX Penis
8% XXXX Dick
5% XXX Willy
1% X Other

Preferred term for 'semen'
44% XXXXXXXXXXXXXXXXXXXXXXX Come/Cum
38% XXXXXXXXXXXXXXXXXXXXXXX Spunk
8% XXXX Sperm
5% XX Semen
6% XXX Other

Preferred terms for sexual behaviours

Preferred terms for 'masturbation'
77% XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX XXX Wank
18% XXXXXXXXX Masturbation
4% XX Pull/Toss off
1% X Other

Preferred terms for 'fellatio' (oral sex)
61% XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX Suck
21% XXXXXXXXXXXXX Blow-job
8% XXXX Fellatio
8% XXXX Oral sex
2% X Other

The full complexity of this approach to collecting information on sensitive sexual behaviour is described in (Coxon, 1988, 1992); suffice it to say here that it neatly combines the need to keep equivalence of meaning, ensuring compatibility and not unnecessarily embarrassing the respondent.

Further strategies

Finally, other strategies have been learned, taught by experience or tested out. They form an heterogeneous collection, so no attempt will be made to systematize them at this point.

Co-operation with the Gay community As a matter of principle the Project has worked directly with the gay community from the earliest planning stages of the Project, and most Investigators and staff have been involved at some level in gay social, counselling or health organizations. The project has also reported back to the gay press, circulated a regular Newsletter, organised meetings in gay venues and talked at gay conferences. The Principal Investigators have all been up-front in avowing their sexual identity as gay men in all contexts, and have both interviewed and been interviewed as subjects themselves. Moreover, the Project has been able to give something back to the gay community by providing Hepatitis B vaccination free to subjects in the Project setting.

Choice of interviewer Respondents have from the outset been able to choose (or refuse) a given interviewer, either by name or in terms of their gender and/or sexual orientation. Although most research staff have been gay or bisexual, staff include heterosexual and lesbian women and heterosexual men. Although this allocation is of course far from random, there are no clear interviewer effects due to this factor. Interviewer recruitment, selection and training has been rigorous, and involves regular monitoring and de-selection where necessary.
One notable interviewer effect, due to gender, was that men interviewed by a woman were less likely to report vaginal intercourse than men interviewed by a man.

**Debriefing procedures** It became apparent that despite general willingness (and even enthusiasm) for a subject to share a good deal of intimate detail with the interviewer, there were certain areas of sensitivity, 'shading' and even downright lying. Impressionistically, these included minority sexual behaviour (e.g. lindinism ('water-sports'); ano-branchial insertion ('fisting')); sexual practices (e.g. transvestism) and sexual pursuits (e.g. outdoor or toilet sex). Less expectedly, it also turned out that probably the most sensitive issue of all was sex for money (in either direction). This fact was discovered primarily in a de-briefing procedure where we concluded in lying by saying 'Well, we know people sometimes lie through their teeth about some things in the interview . . . would you like to say where you did (lie)?'

**Conclusions**

In this sensitive area of research an especial debt is owed to the much-maligned influence of Kinsey and his team; there were situations when his question format: 'When did you last . . . ?' (i.e. assuming the activity involved), was by far the best option. Even though co-operation has been maximised by methodological, strategic and other means outlined here, there is a strong relativity here: within a marginalised or socially invisible group the same issues arise as in the general population - there are still sensitive areas (but different ones) which require much the same techniques to overcome; it is simply that a conventional approach would be doubly insensitive. Estimates in these areas of sensitivity lead to prevalence and incidence figures which are systematically downwardly biased. Whilst Project estimates of (say) anal intercourse among gay men are very good ones which stand up to convergent validation, our estimates of male prostitution, casual sex, SM sex etc are biased downwards, and for this reason have mounted separate sub-projects to investigate them, using yet more innovative methods.

**University of Essex**

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**Notes**

1. The experience of the Wellcome-funded UK study of general population sexual behaviour shows differences of this order in identifying those with homosexual experience.
2. Socio-sexual Investigations of Gay Men and AIDS. We are grateful for the (UK) Medical Research Council and the (UK) Department of Health for funding this study. The views expressed are however those of the Investigators and not necessarily those of these agencies.
3. Usually a blood sample, but also - alternatively or additionally - a saliva or (rarely) a semen sample.
4. The exact area of the latter was the old county of Glamorgan, centred on Cardiff.
5. Permission had, of course, to be gained from area Ethical Committees, but in the South Wales sample there had been a long history of hostility between the gay community and the GUM Clinic, so it was imperative not to be seen to be associated with it.
6. In the case of London, this was directly under Dr McManus, but in Cardiff it was done under the authority of the University Occupational Health service. Since blood samples needed to be stored temporarily before dispatch for testing in London, a medical 'hazard-room' was designated and equipped. It is symptomatic of 'AIDS hysteria' that since the samples were potentially HIV antibody positive, this gave rise to fear among some academic - mostly social science - staff about the unlikely (indeed bizarre) conditions under which they might be at risk of infection, and in some cases led to formal complaints being laid against the Project to the University. Blood testing and training has been provided by the Virology Department at Dulwich Hospital, London, under the supervision of Dr Sheena Sutherland, whose help we gratefully acknowledge.
7. Several of the investigators and staff were (or had been) active in local gay community counselling organizations, and the health officers of the local Clinic (who themselves gave HIV test results) also helped in the training scheme. The arrangement was that all subjects who agreed to give a blood sample were pre-counselling about the nature of the test and its results, whilst those who wished to know their results were given further counselling and allowed to change their mind about being told. They were also post-counselling by the Principal Investigator after the result had been given in a face-to-face session.
8. Blood tests results were given only to the Principal Investigator at the site concerned. He then called the subject in (whether the result was positive or negative) gave a summary of the meaning of each outcome, told him the result and counselled him about its implications. Blood test results were kept in a secret file in a separate micro-computer and could not be accessed by individual researchers. When it came to data analysis, a subfile was created which contained only the required variables, the subject identifier was stripped off, and order of cases randomised. Blood test results were only given to the national (UK) Communicable Diseases Surveillance Centre in aggregate form.
9. There were a few female interviewers, and subjects were allowed to opt for either male or female interviewer but, as it happened, no female interviewers happened to be phlebotomists. Where they occur, gender terms are used descriptively and not generically in this paper.
10 This conflict has never been successfully resolved, and to the charge that it is likely to produce downwards estimates of risky behaviours, we can only reply that the multiple reports on sexual behaviour in the interview/s and sexual diaries, and some cross-referencing from sexual partners indicates that this does not often occur.

11 This read as follows:

A CONFIDENTIALITY GUARANTEE
Each volunteer taking part in the project is identified only by a code number when the data is analyzed. No individual is identifiable and published results will refer only to groups. Using physical precautions and 'encryption' we can guarantee that an individual's identity cannot be known.

12 In the event, we most regretted making this a universal prescription on identification, since it meant that no record linkage could be made to sexual partners, and it was therefore impossible (normally) to estimate important epidemiological parameters (such as the number of partners of partners) and investigate contact networks. In the latest wave we have modified the undertaking, asking subjects to name partners and we then guarantee the confidentiality of that information.

13 Dismissal for such infraction did occasionally take place, in conjunction with the University's disciplinary procedures.

14 Without identification it was not even possible to be sure that the interview scripts were genuine.

15 The question asks prospective applicants a variety of questions, which can be as vague (and presumptive) as 'Have you ever had a blood test?', or 'Have you ever been a patient at a Genito-Urinary Medicine Clinic?' as well as the more obvious 'Have you ever taken a test for HIV infection?'.

16 The wording in quotation marks is that of the relevant legislation and confirms both its badly-briefed nature and striking resemblance to some US state's legislation.

17 This refers to Coxon 1988, which includes sexually explicit language. The link to Section 28 was that subscribers included educational institutions under local funding, whose trustees might claim that the article 'promoted' homosexual behaviour. The Editorial Board, strongly supported by the publisher, firmly resisted this threat and published the article in its entirety. Needless to say, no prosecution followed.

18 Sado-Masochist or 'Slave and Master' sexual activity.

19 This ruling was upheld on appeal to the House of Lords, though it is still subject to appeal to the European Court of Justice.

20 In Scotland, the restriction to only two men is not written into the law.

21 These included sexually explicit scenes of homosexual behaviour, used to check the reliability and concordance among interviewers of use of the Sexual Behaviour Code (Coxon 1988). After intervention by the Department of Health, the videos were released on an annual basis on signature of an official form entitled 'Release of Pornographic Material for Medical Research' [sic].

22 Some (unknown) person sent a xerox copy of the First Wave Question Schedule through the post to a man whose wife intercepted it, and referred it to the police. After negotiations with the Medical Research Council legal staff, no further action was taken when we were able to prove that we, the Project, had not sent it. Prima facie the Schedule, it appears, was 'pornographic' and hence was illegally being transmitted through the post.

23 Suffice it to say that we instituted a regular practice simulation of an office raid as part of staff training.

24 It is amusing that the WordPerfect spelling checker is very puritanical and/or culturally specific in allowing few of these terms and suggesting some bizarre alternatives; but this is left as an exercise...

25 The cost in each case has been borne by the area health authority, and we thank them for their cooperation, and the University Occupational Health Service at Cardiff for supervising the vaccination.

References


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