

# **Gay Men and Aids: Project SIGMA's Approach and Method**

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## **Introduction and background**

Project SIGMA brought together a whole range of normally disparate concerns: scientific research on sexual behaviour and lifestyle, policy issues surrounding health and illness, applications concerned with changing behaviour – and personal involvement. It was originally given the accurate, but clumsy, title "Changing Socio-sexual Lifestyles of Non-Heterosexual Men" (note the deliberate descriptive and prescriptive ambiguity of 'changing'), which within a year gave way to the more memorable title of Project SIGMA (Socio-sexual Investigations of Gay Men and AIDS), which it has retained ever since. To give this inter-relationship more substance, a little history is in order (more substantial accounts are given in Davies *et al* 1993 and Coxon 1996). The Project pre-dated the AIDS pandemic and began as a research project in 1980 as an attempt to bring Kinsey findings and those of its successors (Bell and Weinberg 1978) up to date for the British situation with respect to homosexuality. The original Cardiff co-founders were myself and Dr Peter Davies, also a sociologist at the University of Wales, Cardiff. Involvement in FRIEND, the gay counselling service gave additional motivation, and through its Health sub-group, provided liaison with the Health and medical authorities. But the planned research project on sexualities was overtaken by the news of the advent of GRID (Gay-related Immune Deficiency) affecting the United States and this dramatically re-focussed the research on issues around the sexual lifestyles implicated in the transmission among the high-risk group of gay and bisexual men of what soon became identified as the HI Virus. In the terminology then used, "high-risk groups" were central to health-promotion thinking and the acronym MSM (originally called MWHSM – men who have sex with men) was not invented until considerably later. Despite the fact that the topic of AIDS and gay men rose rapidly in the medical and political agenda, there was little systematic reliable information and much ignorance and disinformation, even in epidemiological circles, about the "risk-practices" involved – their nature, their prevalence and incidence – and the contexts in which they occurred. Despite the

range of studies on sexual behaviour in the United States, many myths and misperceptions dispelled by those studies were regularly repeated, and not only on the political platform:

- 10 percent of men were gay (and were inherently 'promiscuous') (1);
- anal intercourse was universally practised by gay men (and by implication, not by heterosexuals) and
- gay men practised either the insertive role or the receptive role, and not both.

In addition to the ignorance and misperception there was also little systematic information about empirical variables necessary to model and predict the diffusion of HIV. In particular, Anderson (Anderson, Medley *et al*, 1986) had repeatedly drawn attention to the importance for modelling of:

- the sexual mixing-patterns and distribution of age-related sexual partner acquisition (the relational factor), and
- patterns of mixing within and between major risk groups (inter-group mixing).

Simple models, assuming random mixing, are deeply un-sociological, implying as they do that individuals select sex partners in an unbiased manner and without regard to attractiveness, friendship or risk of infection, and as a result they overstate the number of HIV infections that will occur (Kaplan, Cramton, & Paltiel 1989). By contrast, information about relationships and relationship-specific behaviour has crucial importance.

The Project really began in 1982 when a start was made on developing research instruments for the study of homosexual behaviour, but 1983 was the turning point. In this year, the first deaths from AIDS occurred, the television programme "Killer in the Village" brought the "gay plague" starkly to the public (and especially gay men's) attention, we organised one of the first conferences on the new AIDS threat at the Welsh National School of Medicine, and here encountered Dr Tom McManus and Dr Marian McEvoy (a G.U.M consultant and epidemiologist respectively) who had planned the first "gay men's sex survey" in the gay HIM magazine. It was talks between us and Dr Malcolm Macourt of Newcastle-upon-Tyne Polytechnic (himself a social scientist and organiser of Newcastle FRIEND) that led to the birth of SIGMA and the active search for research funds.

The search was for funding a British – ultimately an England and Wales – study of gay men's behaviour; it was fraught. Not only did national interests arise, but political ones as well.(2) Mrs Thatcher's

government was not well disposed to this stigmatised disease and its bearers and the Economic and Social Research Council, threatened at Cabinet level with the excision of the Sociology committee and even its own dissolution, was not inclined to be seen to support research on gay men. (3) Consequently, it was to medical sources that we turned, and here, too, there were problems that in this case led to three years delay. The retroviral association with AIDS was established experimentally in 1983 (Barre-Sinoussi *et al.*, 1983) and confirmed by tracing studies shortly after (Auerbach *et al.*, 1984). Preventive measures against transmission of HIV concentrated almost exclusively on discouraging anal intercourse (AI), with the subsidiary message that if AI were insisted on, or persisted in, it should be condom-protected. Hence the success of the prevention campaigns for gay men focussed almost entirely on the adoption of condoms. This was of special concern to the Department of Health, who needed empirical evidence of the extent to which such messages were heeded. At the same time, the Medical Research Council (MRC) was concerned to have estimates of the rates of HIV-1 infection in the "gay population" – other than derived from STI Clinics where such incidence rates are of course recorded; once again it was a matter of the "denominator problem". The project we were proposing could be a vehicle for such testing, although a social research interview including phlebotomy is, to say the least, highly unusual and the notion of "taking the [HIV-1] test" was highly contentious at the time in the gay community.

The long delay in obtaining funding meant that important – some would say the most important – changes in sexual behaviour among gay men were taking place during this period, without systematic monitoring. Fortunately, we were able to use "seed-corn" research support from the Social Research Unit of the University of Wales, Cardiff to carry through preliminary studies and pre-testing in this period 1983-1986. We were thus able to observe (see Coxon 1986) that in 1984 in Cardiff (the location of the pre-test) the use of condom-protected AI, by now recommended on all sides, was minimal and that the remarkable "conversion" to condom-protection in fact took place in 1985-87 and was almost complete by the time of the famous "Don't Die of Ignorance" Lilies and Gravestones Public Television Advertisement (see <http://www.avert.org/tombstone2.htm>). In 1986, there was a dramatic acceleration in the campaign against AIDS, at both the scientific and policy levels, and we were informed in December 1986 that we had been awarded funding for the Project, virtually in full, by the Medical Research Council and Department of Health for a 3-year community based longitudinal study of seroprevalence of HIV, condom-adoption and sexual behaviour change among gay men. (4)

## **Salient Features of Project SIGMA**

By the end of the pre-test period, and the beginning of funding, we knew that whilst we were subject to restraints, we had developed a research plan which was viable. Unusually for such a Project, for instance, we made it quite explicit that the Principal Investigators (P.I.s) were themselves gay and that as members of the community under research observation, we also shared their concerns and sensitivities. We similarly undertook to keep the gay community informed through the Gay Press, and to feedback relevant information both to subjects and to the relevant authorities (at a suitable level of aggregation). For obvious reasons, our research proposal had a somewhat "empiricist" slant – we were committed to an interview/survey format and to taking blood for epidemiological purposes – but we were also committed to methodological pluralism and innovation.(5) Nowhere, we believed, was this more important than in investigating sexual behaviour, where we knew from pre-testing that differences of wording, context (interview vs self-report), interviewer gender and orientation and presence of other persons within hearing range all had the potential to affect answers. More than that, we needed to ensure that there were two distinct methods for eliciting the detail of sexual behaviour in order to have some estimate of convergent validity (Coxon *et al* 1999).

## **Methodological and statistical issues**

Of particular interest are the following three foci of methodological and statistical interest:

- Sampling the "population" of gay and bisexual men
- Developing a general schema of sexual behaviour, to inform all our measures of sexual activity
- Structured sexual diaries as a research instrument.

## **Sampling gay and bisexual men (6)**

Although the project specified gay and bisexual men as the population of interest, the effective population of interest is males who engage in sexual activity with other males, where that behaviour is actually or potentially likely to result in HIV-1 infection. As such, self-definition as gay or bisexual is irrelevant, and as Kinsey (1948, pp. 650-7) rightly points out, prevalence of "homosexual behaviour" can be made to vary by a factor of 10 depending on the generality of the criteria used. The effective contrast sought was the "gay community" (or more accurately

the "constituency ") versus those presenting at STI clinics with HIV infection.

The key factor in our judgments about sampling was the connected network structure of the gay community, reflected in the saying "we are all related through insertion". But, short of an expensive and then unfeasible general population estimate, as achieved in the UK by the National Survey of Sexual Attitudes and Lifestyle (Johnson, Wadsworth, Wellings *et al.*1994), we decided to structure the "sampling " – the quotation marks are used deliberately – by first defining a nine-fold typology, consisting of two factors (each trichotomized), defined by those variables believed most to affect variation in gay sexual behaviour: Age Group and Relationship-Type.

Age-Group Legal constraints defined the cutting points, generating

Under 21 (then the age of homosexual consent),

21 -39 and

Over 39 (those coming sexual maturity before the Sexual Offences Act of 1967)

Relationship Type

Closed/Exclusive (defined by the subject; this did not always accord with his partner/s' definition)

Open (comprising regular and/or casual partner/s)

No regular relationship.

The type of sample sought was actually a balanced quota sample. Recruitment to the "sample" took place in a number of national sites (crucially Greater London and Greater Cardiff, but supplemented for the first wave by a number of other England and Wales sites, funded by the Department of Health). Members of the gay community satisfying the 9 types were identified and, on the assumption that "like attracts like" (or at least "like is likely to know more people like himself "). Each "seed" is then asked to nominate other gay men like himself. The logic here was what is loosely referred to as "snowball" sampling (more accurately link-tracing or chain-referral sampling (Biernacki & Wald 1981) to "burrow into the iceberg" (gay men conceived of as forming an identifiable small proportion of "out" men, with an larger proportion of increasingly "hidden" men). The explicit assumption was that used by Rapoport in his study of random and biased nets (Rapoport & Horvath 1961) that so long as the number of nodes N is large and the sociogram is connected, a set of starting samples of size

$n$  ( $n \ll N$ ) will asymptotically yield unbiased estimates of the tracing distribution.

It has to be said that the exercise was not a resounding success (Coxon 1993, p 19), for a number of interesting reasons:

- Often a gay man's sexual partners (and to a lesser extent his friends) are not of his age and relationship type, and even if they were, it often turned out to be difficult to nominate a partner who was less "out" than himself
- Respondents were often reluctant to identify their friends/partners to the Project and due to undertakings we gave of anonymity, it was left to the respondent to contact and recruit his contacts. This was neither a very successful strategy, nor was it unbiased.

In some cases, and especially in Cardiff where the gay community is smaller and more close-knit than London, we were able to monitor the tracing process to some degree by matching contact characteristics (see Coxon 1995), and we were able to verify that the length of the links was very rarely larger than three, and that most chains ended in 0, 1 or 2 links.

- because the Cardiff network was primarily a set of weakly linked close-knit clusters, there was both inefficiency due to redundancy (contacts kept looping back rather than moving on to new ones), and the success depended on whether liaison individuals (bridges), who linked the clusters, were present in the "sample". Because these were often men who came in and out of the scene on an occasional basis (including heterosexually married "cottagers") it is possible, but unlikely, that significant clusters were missed.

To check on this we initiated a number of studies of PSEs ("Public Sex Environments"), first in Cardiff in 1985 (Coxon 1993, ch 7), also in London (<http://www.sigmaresearch.org.uk/projects09.html>) and subsequently as a main research and policy focus, in collaboration with Peter Scott (<http://www.racoon.dircon.co.uk/bbh/act1.htm>). These studies, perhaps surprisingly, confirmed that "cottagers" were not a disconnected or different subgroup as has often been assumed but rather resemble other gay men to a very considerable extent. So this problem is not as great as initially suspected.

Future studies using sampling procedures would do well to follow the much more recent and better founded random-walk strategies through relational networks (Klov Dahl 1995, Cox & Ensor 1996), and even random-number dialling, used with success at least in the USA.

## **The Structure of Sexual Behaviour**

What initially alerted us to the need for a formal schema of sexual behaviour was the manifest inability of respondents to recall with any accuracy the detail of their sexual activity, and their tendency to "gross-up" from short-term recall in order to arrive at estimates of the frequency of their activities (Coxon 1988). Moreover, since the focus of the research was explicitly that of HIV transmission, attention had to be given not simply to the usual aspects of sexual behaviour "who did what, and with what, and to whom" – but more relevantly to "who does what to whom and with what outcome", since both the agency (modality) and what is sometimes euphemistically referred to as "the destination of the ejaculate" – where the semen goes! – have to feature explicitly in the accounts of sexual activity.

## **Sexual Diaries**

Sexual diaries were developed primarily at the Cardiff site from the outset of the Project and became an important and innovative component of SIGMA's repertoire (see Coxon 1996, chapter 2 and [www.sigjadiaries.com](http://www.sigjadiaries.com) for full information and documentation). They were intended to provide a naturalistic method for eliciting detailed sequential information about sexual behaviour, without the biases of autobiographic memory-lapse. As with Cecily in *The Importance of being Earnest*, diaries exist as a useful aide-memoire, but among gay men sexual diaries are also a widespread social practice and serve more specific functions.<sup>(7)</sup> The diaries are actually one step removed from the fully discursive open-ended "stream-of-consciousness" diary, being specific in focus and systematic in form, relating common information about a sexual encounter as if a set of questions were being asked about the behaviour in question (Who? Where? When? What?). The diaries of Roger Casement and of Joe Orton's provide most notorious examples.

Following a linguistic analogy, the diaries were the first method used by the Project to implement the Schema of Sexual Behaviour (Coxon et al 1992) and were found to be enjoyable by the respondents and to provide critical and insightful information by the researchers. Diarists were initially pre-trained in the interview situation (though latterly were also instructed differently in the postal and e-mail versions), allowed to use code if they wished (nosey parents, landladies and partners were an added hazard) and encouraged to add evaluative information where appropriate. The diaries were designed primarily to be month-long (to provide stable estimates of behaviour), and be

written ego-centrally (so that it is always the diarist who is the agent in describing the behaviour).

In terms of the structure the unit of sexual behaviour is the Sexual Session, the "sentence" of sexual which occurs at a given (specified) time and place and is made up of one or more sexual. Each Session consists of:

- the Setting (when, where) that contextualises the sexual act,
- the Antecedents (such as alcohol and drugs)
- the Accompaniments (like sex toys, nitrites), and
- the Partner Specification (name or code, gender, age and relationship).

The core component in describing sexual activity, the "atom" of sexual behaviour, is what actually happens -- in our terminology, the "sexual act".

The sexual act is the "word" in the sentence, and sexual act(s) make up the sexual session. It is the sexual act which specifies "Who Does What and with What Effect". These three components of the sexual act are referred to as :

- the Behaviour (or behaviours) which refers to the actual sexual activity itself ("what" is done)
- the Modality which refers to "who [does the activity], and to whom"), and
- the Outcome which refers to the "effect" of this sexual activity, which in the context of HIV transmission becomes the question of whether ejaculation of sperm occurs, and if so, who ejaculates, and in what manner.

As an example, suppose a Sexual Session were described as follows:

We deep kissed, and then moved into a "69". Whilst doing it I began to finger him. Then he wanked me (we were both using poppers) and I came. Then I wanked him till he came.

The four constituent acts in the session are then interpreted in terms of the Schema, and encoded:



<b><u>SEXUAL ACTS</u></b>	→	<b><u>INTERPRETATION</u></b>	→	<b><u>ENCODING</u></b>
(i) we deep kissed	→	Mutual Deep-Kissing (no outcome)	→	<b>MDK</b>
(ii) ...."69" (and whilst doing it), I fingered him	→	Mutual suck (no outcome)	→	<b>MS &amp;</b>
	→	Active Fingering (no outcome)	→	<b>AFG</b>
(iii) He wanked me and I came (both using poppers)	→	Passive Wank, Ego- came Alter did not (destination elsewhere?)	→	<b>PW,XN /p</b>
(iv) I wanked him till he came	→	Active Wank, Ego(not come) Alter(did come)	→	<b>AW/NX</b>

So the entire session is encoded as:

**{ MDK MS&AFg PW,XN/p AW,NX }.**

A set of programs were specially developed for analysis of such encoded data. SDA (Sexual Diary Analysis) was written in C++ operating under MS-DOS(8) As well as conventional operations such as counting the prevalence or incidence of sexual acts, the format also makes it possible to use the sexual act or session (rather than the individual) as the unit of analysis, and thus estimate such things as the concentration of sexual risk behaviour (Coxon 2000) or the tendency toward gendered (role-specific) sexual activity (Coxon & Coxon 1993).

In all, 2,000 month diaries were collected during the course of the Project (see below) and because the diarists overlapped with SIGMA interviewees it provided unique source of data on gay men's sexual behaviour and on the comparability of the diary and interview data for the same individuals and the same time-period (Coxon 1999) and the results strongly suggests that diary data are more accurate and reliable than retrospective questionnaire data. Perhaps more importantly, only diary data could reveal that risk behaviours are differentially estimated according to whether the person reporting is engaged in the insertive (active) or receptive (passive) variants of anal intercourse. This shows up as a sort of "Social desirability" effect: "perpetrators" (active partners) under- estimate and "victims" (passive partners) over-estimate the amount of highest-risk sex.

## **Accessibility of data and archiving (9)**

The main phase of Project SIGMA finished in 1994 with the fifth wave of the Panel. Thereafter, it divided into Sigma-research, London (<http://www.sigmaresearch.org.uk/> ) and Project SIGMA, Essex, and recently these sections have to all intents re-merged, with the latter – having undergone a Hebridean shift of 600 miles north! – concentrating on archiving and documenting the original data.

The diary data consist of information on 1258 individuals from 25 sites in the UK producing 1975 month-long sexual diaries consisting of 32,142 sexual sessions. The natural-language version in anonymised (but linkable) fiche format is lodged with the assistance of QUALIDATA at the Wellcome Contemporary Medical Archives Centre, Euston Road, London, and are thereby accessible to any bona fide researcher. The encoded data-base version of the diary data are being lodged at the Data Archive at the University of Essex. The main panel survey data is also being lodged at the Data Archive and will hopefully be made accessible via NESSTAR.

## **Final Comments**

SIGMA occupied a unique and important niche in the research field surrounding AIDS, being the largest UK study of gay and bisexual men's response to the impact of the pandemic. Because of its international links it meant that data were always comparable across national studies.(10) The irony is that much of the change it was set up to monitor had happened by the time proper funding was secured, and once it was considered politically that "gay men had responded", funds were not available for the perhaps more serious issues of perseverance in behaviour change, in how to motivate and galvanise new generations coming on to the scene, and how to monitor the dramatic impact of new medical regimes. The interplay of scientific, policy and community factors during this stormy political period meant that the Project had an image and impact well outside its scientific concerns and certainly made its ethos very different to the normal research project. Coming out of, and feeding back into, the gay community also gave an action, policy and public health role which we believe to be unique.

## Notes

1. A humorous saying used to counteract this assertion was that the term 'promiscuous' was actually used to mean "someone having more sex than I am".
2. Initial approaches for funds were turned down by the Welsh office on the grounds that it was not simply a Welsh study, and by the then Scottish Office on the grounds that AIDS "was not likely to be a problem in Scotland".
3. The ERSC subsequently claimed that no worthy funding application had been made for funds on AIDS research; given that SIGMA's was turned down, it was either because of our unworthiness, or political temerity.
4. Subsequently extended by two years. A similar project (the Fitzpatrick, Bouton, Hart Oxford Project) was funded at the same time and ran parallel with SIGMA indifferent sites.
5. Interviewers were trained as phlebotomists to take blood in "natural" settings. Project sample members were not (could not!) be required to give blood, but if they agreed, they gave signed informed consent, and chose whether or not to know their HIV results, given by the Principal Investigator in their site, but not accessible to others. If they agreed to testing for Hepatitis B, they were required to know the result, and the project organised for vaccination to be given at the project.
6. See Davies *et al* 1993 and Coxon, 1995, 1993
7. When told by Miss Prism "You must put away your diary, Cecily. I really don't see why you should keep a diary at all," Cecily replies: "I keep a diary in order to enter the wonderful secrets of my life. If I didn't write them down, I should probably forget all about them." Act II.
8. The programme and documentation are downloadable from:  
<http://www.sigmadiaries.com/files.htm>
9. Funding for these activities is gratefully acknowledged from the Department of Health (Diary analysis programs), ESRC (natural-language diaries) and MRC (main survey, and encoded diary files).
10. An interesting finding from these studies was that whilst rates of unsafe sex were fairly similar across the nations concerned, the cultural "Mediterranean factor" was evident. In brief, cultures where the major sexual divide is between *insertive vs receptive* sexual behaviour rather than being based on *different vs same gender of the partner* tend as a result to have higher role separation among MSM. The effect of this is paradoxically to lower the mixing rate, and thus concentrate risk more in

sorts of men (those exclusively or predominantly receptive) rather than be spread across men who mix their sexual modality.

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