

## History of the National Survey of Sexual Attitudes and Lifestyles

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# HISTORY OF THE NATIONAL SURVEY OF SEXUAL ATTITUDES AND LIFESTYLES

The transcript of a Witness Seminar held by the Wellcome Trust Centre for the History of Medicine at UCL, London, on 14 December 2009

Edited by C Overy, LA Reynolds and E M Tansey

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## ABBREVIATIONS

AIDS	acquired immune deficiency syndrome
CAPE	Committee on AIDS Public Education
CAPI	computer-assisted personal interviewing
CASI	computer-assisted self interview
CESA	Committee on Epidemiological Studies of AIDS
DHSS	Department of Health and Social Security (DoH after 1988)
DoH	Department of Health
ESRC	Economic and Social Research Council
HEA	Health Education Authority
HIV	human immunodeficiency virus
HPV	human papillomavirus
MRC	Medical Research Council
NatCen	National Centre for Social Research
NATSAL	National Survey of Sexual Attitudes and Lifestyles
ONS	Office for National Statistics
OPCS	Office for Population, Censuses and Surveys
SCPR	Social and Community Planning Research
SIGMA	Socio-sexual Investigations of Gay Men and Aids
STI	sexually transmitted infection

### WITNESS SEMINARS: MEETINGS AND PUBLICATIONS<sup>1</sup>

In 1990 the Wellcome Trust created a History of Twentieth Century Medicine Group, associated with the Academic Unit of the Wellcome Institute for the History of Medicine, to bring together clinicians, scientists, historians and others interested in contemporary medical history. Among a number of other initiatives the format of Witness Seminars, used by the Institute of Contemporary British History to address issues of recent political history, was adopted, to promote interaction between these different groups, to emphasize the potential benefits of working jointly, and to encourage the creation and deposit of archival sources for present and future use. In June 1999 the Governors of the Wellcome Trust decided that it would be appropriate for the Academic Unit to enjoy a more formal academic affiliation and turned the Unit into the Wellcome Trust Centre for the History of Medicine at UCL from 1 October 2000 to 30 September 2010. The History of Twentieth Century Medicine Group has been part of the School of History, Queen Mary, University of London, since October 2010, as the History of Modern Biomedicine Research Group, which the Wellcome Trust continues to fund.

The Witness Seminar is a particularly specialized form of oral history, where several people associated with a particular set of circumstances or events are invited to come together to discuss, debate, and agree or disagree about their memories. To date, the History of Twentieth Century Medicine Group has held nearly 50 such meetings, most of which have been published, as listed on pages xiii–xvii.

Subjects are usually proposed by, or through, members of the Programme Committee of the Group, which includes professional historians of medicine, practising scientists and clinicians, and, once an appropriate topic has been agreed, suitable participants are identified and invited. This inevitably leads to further contacts, and more suggestions of people to invite. As the organization of the meeting progresses, a flexible outline plan for the meeting is devised, usually with assistance from the meeting's chairman, and some participants are invited to 'set the ball rolling' on particular themes, by speaking for a short period to initiate and stimulate further discussion.

<sup>&</sup>lt;sup>1</sup> The following text also appears in the 'Introduction' to recent volumes of *Wellcome Witnesses to Twentieth Century Medicine* as listed on pages xiii–xvii.

Each meeting is fully recorded, the tapes are transcribed and the unedited transcript is immediately sent to every participant. Each is asked to check his or her own contributions and to provide brief biographical details. The editors turn the transcript into readable text, and participants' minor corrections and comments are incorporated into that text, while biographical and bibliographical details are added as footnotes, as are more substantial comments and additional material provided by participants. The final scripts are then sent to every contributor, accompanied by forms assigning copyright to the Wellcome Trust. Copies of all additional correspondence received during the editorial process are deposited with the records of each meeting in archives and manuscripts, Wellcome Library, London.

As with all our meetings, we hope that even if the precise details of some of the technical sections are not clear to the non-specialist, the sense and significance of the events will be understandable. Our aim is for the volumes that emerge from these meetings to inform those with a general interest in the history of modern medicine and medical science; to provide historians with new insights, fresh material for study, and further themes for research; and to emphasize to the participants that events of the recent past, of their own working lives, are of proper and necessary concern to historians.

#### Members of the Programme Committee of the History of Twentieth Century Medicine Group, 2010–11

**Professor Tilli Tansey** – professor of the history of modern medical sciences, School of History, Queen Mary, University of London (QMUL) and chair

Dr Sanjoy Bhattacharya – reader in the history of medicine, University of York

Sir Christopher Booth – former director, Clinical Research Centre, Northwick Park Hospital, London

Dr John Ford – retired general practitioner, Tonbridge

**Professor Richard Himsworth** – former director of the Institute of Health, University of Cambridge

**Professor Mark Jackson** – professor of the history of medicine and director, Centre for Medical History, Exeter

Professor John Pickstone – Wellcome research professor, University of Manchester

Mrs Lois Reynolds – senior research assistant, QMUL, and organizing secretary

**Professor Lawrence Weaver** – professor of child health, University of Glasgow, and consultant paediatrician in the Royal Hospital for Sick Children, Glasgow

### ACKNOWLEDGEMENTS

'The History of the National Survey of Sexual Attitudes and Lifestyles' was suggested as a suitable topic for a Witness Seminar separately by Professor David Gordon, Professor Anne Johnson and Sir Mark Walport. We are very grateful to Professor Johnson for her assistance in planning the meeting, and we thank Professor Michael Adler for his input and his excellent chairing of the occasion. We are particularly grateful to Professor Clive Seale for writing such a useful introduction to these published proceedings, and to Sir Nicholas Partridge, who was unable to attend the meeting but read through a draft of the transcript and offered helpful comments and advice. Our additional thanks go to Mr Bob McLean, information governance manager, and Ms Lindsay Ince, project archivist, at the Wellcome Trust for providing information from the Trust records. We thank Professor Johnson and Mrs Julia Field for help with illustrations. For permission to reproduce images included here, we thank Mrs Field, Mr Julian Simmonds, The Sunday Times, Wellcome Images, Wiley-Blackwell and Mr Kipper Williams; material is also reproduced under the Open Government Licence. Permission was requested from Nature and Wolters Kluwer/Lippincott Williams and Wilkins as copyright holders but no reply was received.

As with all our meetings, we depend a great deal on colleagues at the Wellcome Trust to ensure their smooth running: the Audiovisual Department, Catering, Reception, Security and Wellcome Images; Mr Akio Morishima has supervised the design and production of this volume; we thank our indexer, Ms Liza Furnival, and our readers, Ms Fiona Plowman and Mrs Sarah Beanland. Ms Stefania Crowther assisted in the editorial stage, Mrs Deborah Gee transcribed the seminar, and Ms Stefania Crowther and Mrs Wendy Kutner assisted us in running this meeting. Finally, we thank the Wellcome Trust for supporting this programme.

Tilli Tansey

Lois Reynolds

Caroline Overy

School of History, Queen Mary, University of London

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## UNPUBLISHED WITNESS SEMINARS

## 1994 The early history of renal transplantation 1994 Pneumoconiosis of coal workers (partially published in volume 13, *Population-based research in south Wales*) 1995 Oral contraceptives

#### 2003 Beyond the asylum: Anti-psychiatry and care in the community

#### 2003 Thrombolysis

(partially published in volume 27, *Cholesterol, atherosclerosis and coronary disease in the UK, 1950–2000*)

#### 2007 DNA fingerprinting

The transcripts and records of all Witness Seminars are held in archives and manuscripts, Wellcome Library, London, at GC/253.

## OTHER PUBLICATIONS

**Technology transfer in Britain: The case of monoclonal antibodies** Tansey E M, Catterall P P. (1993) *Contemporary Record* **9**: 409–44.

**Monoclonal antibodies: A witness seminar on contemporary medical history** Tansey E M, Catterall P P. (1994) *Medical History* **38**: 322–7.

## Chronic pulmonary disease in South Wales coalmines: An eye-witness account of the MRC surveys (1937–42)

P D'Arcy Hart, edited and annotated by E M Tansey. (1998) *Social History of Medicine* **11**: 459–68.

#### Ashes to Ashes - The history of smoking and health

Lock S P, Reynolds L A, Tansey E M. (eds) (1998) Amsterdam: Rodopi BV, 228pp. ISBN 90420 0396 0 (Hfl 125) (hardback). Reprinted 2003.

Witnessing medical history. An interview with Dr Rosemary Biggs Professor Christine Lee and Dr Charles Rizza (interviewers). (1998) *Haemophilia* 4: 769–77.

#### Witnessing the Witnesses: Pitfalls and potentials of the Witness Seminar in twentieth century medicine

Tansey E M, in Doel R, Søderqvist T. (eds) (2006) *Writing Recent Science: The historiography of contemporary science, technology and medicine.* London: Routledge: 260–78.

#### The Witness Seminar technique in modern medical history

Tansey E M, in Cook H J, Bhattacharya S, Hardy A. (eds) (2008) *History* of the Social Determinants of Health: Global Histories, Contemporary Debates. London: Orient Longman: 279–95.

#### Today's medicine, tomorrow's medical history

Tansey E M, in Natvig J B, Swärd E T, Hem E. (eds) (2009) *Historier om helse* (*Histories about Health*, in Norwegian). Oslo: *Journal of the Norwegian Medical Association*: 166–73.

### INTRODUCTION

The advent of AIDS and the discovery of HIV in the 1980s and the knowledge that this was a blood-borne virus that could be acquired through sexual contact prompted a great deal of interest in knowing more about sexual behaviour. The National Survey of Sexual Attitudes and Lifestyles (NATSAL) was a UK response to this need for information, first carried out in 1990, and subsequently in 2000 and 2010, with changes to provide extra information relevant for the prevention of a range of sexually transmitted diseases. The survey, based on face-to-face interviewing with a separate self-completion questionnaire for more sensitive questions, in part drew on the experience of Project SIGMA, which had used diaries to investigate homosexual behaviour.<sup>2</sup>

Unlike the pioneering US work of Kinsey,<sup>3</sup> and later surveys such as those reported by Hite,<sup>4</sup> which attempted to provide statistical pictures of sexual behaviour using volunteer samples, the 1990 NATSAL was based on a large random sample, so aimed to be representative of the population. It was one of several such national surveys of sexual behaviour being carried out at the time, with similar surveys done for similar reasons in Norway, Denmark, the USA and France.<sup>5</sup>

This Witness Seminar brings together many of the key people involved in the first and subsequent NATSAL studies and, in particular, tells the dramatic story of the search for funding for the first, 1990, survey. As the *Nature* editorial<sup>6</sup> that accompanied the publication of the first major paper reporting NATSAL results<sup>7</sup> points out, in contrast to the French survey,<sup>8</sup> public funding for the UK survey was blocked. After a successful pilot study funded by the Economic and Social Research Council (ESRC), a proposal that the UK Department of Health would fund the main survey, after scientific scrutiny by the ESRC, was vetoed at government level – some say by Mrs Thatcher herself – on the grounds that

<sup>5</sup> Summarized in Anon (1992).

<sup>7</sup> Johnson *et al.* (1992).

<sup>&</sup>lt;sup>2</sup> Coxon (1988, 1990).

<sup>&</sup>lt;sup>3</sup> Kinsey et al. (1948, 1953).

<sup>&</sup>lt;sup>4</sup> Hite (1976).

<sup>&</sup>lt;sup>6</sup> ibid.

<sup>&</sup>lt;sup>8</sup> ACSF investigators (1992).

this would be an unacceptable intrusion into private lives. This decision hit the headlines (first in *The Sunday Times*), as did the decision, some four weeks after the story broke, by the Wellcome Trust to step in and fund it instead. There is a similar story to be told of obstruction from the Bush White House,<sup>9</sup> which forbade funding from the National Institutes for Health (NIH) for the American survey.<sup>10</sup> In the US, a consortium of charitable foundations stepped in to fund it instead.

Since then, NATSAL and its decennial repeat performances have provided a wealth of information that has contributed to understanding and predicting the spread of HIV/AIDS in the UK, to sexual health education in schools and elsewhere, and to preventive health measures. Recent waves of the survey, because physical samples can be used to test for the presence of, for example, HIV, chlamydia, HPV and *Mycoplasma genitalium*, have related patterns of sexual behaviour to the prevalence of these infections.<sup>11</sup> Ethnic variations have been studied through inclusion of numerically 'boosted' sub-samples.<sup>12</sup> The opportunity to study trends over time has revealed a growth in riskier sexual practices since the first survey, as fear of AIDS has declined. The survey's findings about the relationship between alcohol consumption and sexual behaviour in younger age groups has more recently been highlighted as a topic requiring better understanding.<sup>13</sup>

NATSAL has been so useful that it is even harder, now that we can see this, to countenance the refusal by the UK government of the time to fund it. While not quite matching the AIDS denialism of such political leaders as Thabo Mbeki, whose blockage of the roll-out of antiretroviral drugs is said to have led to the loss of 330 000 lives in South Africa,<sup>14</sup> does this not now look like an example of some kind of denialism? We learn in this Witness Seminar from Mike Durham, *The Sunday Times* journalist who broke the story, that, as well as discovering the beneficial effect the story had on his reputation as a 'newshound', he hopes his

<sup>12</sup> See page 51.

<sup>14</sup> Chigwedere et al. (2008).

<sup>&</sup>lt;sup>9</sup> Lewontin (1995).

<sup>&</sup>lt;sup>10</sup> Michael et al. (1994); Laumann et al. (1994).

<sup>&</sup>lt;sup>11</sup> See page 56.

<sup>&</sup>lt;sup>13</sup> See page 58.

story 'may have saved a few lives'.<sup>15</sup> Professor Mike Adler comments ruefully on the contrast between this ambition and the previous behaviour of that newspaper, whose editorial line in denying the heterosexual transmission of HIV had up until then been so damaging to health prevention efforts.<sup>16</sup> We hear, too, from Professor David Gordon, who presented the project to the scientific Trustees of the Wellcome Trust, that the 'opportunity to poke the politicians in the eye' was a 'bonus' after the scientific case for the survey was deemed satisfactory.<sup>17</sup>

As Virginia Berridge's contribution to this seminar hints, *The Sunday Times* version of the story ('Thatcher halts survey on sex') may have suited everybody at the time.<sup>18</sup> Mrs Thatcher herself may have allowed the perception that she had become personally involved to go uncorrected in order to boost her reputation as a defender of conservative moral values. It was also consistent with the assault her government had mounted on the social sciences and social statistics, attempting to exclude sociology from ESRC funding on the grounds that it was not a science, and suppressing the production of Office for Population, Censuses and Surveys (OPCS) statistical reports that would allow the public to see the health consequences of policies that widened inequality.

Journalists gained too: as Mike Durham notes, they had a chance to combine sex, the prime minister and disease in a single sensational headline. People so inclined could poke Mrs T (herself a science graduate) in the eye and righteously claim it as a side effect of the proper application of scientific standards. The researchers themselves, in spite of protestations that 'it's an area you might leave well alone...if you're the sort of scientist who anticipates a meteoric career progression',<sup>19</sup> could anticipate just the kind of career rewards that highly cited papers in *Nature* and television documentaries about their work tend to bring about. The BBC *Horizon* programme could intersperse interviews with researchers with archive film made by Masters and Johnson of the 'entire body... covered by...vascular flush...the involuntary contraction of the outer vaginal ring' during orgasm and claim it 'necessary to include this material' although it might offend 'some viewers'.<sup>20</sup>

- <sup>17</sup> See page 45.
- <sup>18</sup> See footnote 106 in Appendix 1.
- <sup>19</sup> Wellings, quoted in BBC (1992).
- <sup>20</sup> BBC (1992).

<sup>&</sup>lt;sup>15</sup> See page 24.

<sup>&</sup>lt;sup>16</sup> See page 49.

A smaller theme is the impetus that the survey provided for a rapprochement between quantitative and qualitative methods in social research, on which subject this Witness Seminar provides some fascinating evidence. At first, 'turf wars' between the different disciplines had to be resolved, as it became clear to the natural scientists and survey researchers involved that it was not going to be possible to communicate meaningful information without understanding linguistic contextual variation. What does one do with a man who uses different terms to describe the same sexual practice according to whether his wife or another partner is involved? How can one establish a terminology that makes people feel most comfortable with talking about these matters, but is nevertheless unambiguous? Clearly these matters needed to be resolved by exploratory qualitative research work to establish a satisfactory interviewing method that would also solve the related matter of getting people to trust interviewers enough to tell the truth.

In fact, revelation of some of the ways in which this survey has been cast as 'the truth about sex' is perhaps one of the enduring underlying contributions of this Witness Seminar. Lewontin, in his 'Sex, lies and social science', in which he responded to reports of the early American surveys in this field, presented a somewhat over-the-top critique of such attempts to enumerate sexual practices, largely because he did not trust people to tell the truth.<sup>21</sup> Yet statistics, however they have been produced, have a remarkable capacity to capture the attention of general public, mass media and policymakers, because they appear to be objective and therefore true. When they relate to practices that express some of our most intensely felt human desires, they have a particular – almost magical – power to frighten and instruct. This Witness Seminar brings together people who, taken together, are telling the gripping and dramatic story of how this process works.

Clive Seale Queen Mary, University of London

<sup>&</sup>lt;sup>21</sup> Lewontin (1995).

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The transcript of a Witness Seminar held by the Wellcome Trust Centre for the History of Medicine at UCL, London, on 14 December 2009

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# HISTORY OF THE NATIONAL SURVEY OF SEXUAL ATTITUDES AND LIFESTYLES

Participants

Professor Michael Adler (chair) Professor Virginia Berridge Professor Tony Coxon Dame Karen Dunnell Mr Mike Durham Mr Bob Erens Mrs Julia Field Dr Kathy French Sir Roger Gibbs Professor David Gordon Sir Graham Hart Dr Bobbie Jacobson Professor Anne Johnson Dr Catherine Mercer Professor Sir Stanley Peart Dr Pam Sonnenberg Professor Tilli Tansey Professor Kaye Wellings Mrs Wendy Williams

**Among those attending the meeting:** Ms Jessica Burnett, Ms Natalie Collyer, Professor Graham Hart, Ms Debbie Holland, Ms Cynthia Kahlenberg, Dr Ruth Lewis, Dr Cicely Marston, Mr John McEwan, Ms Briony Rayfield, Dr Christine Robinson, Dr Clare Tanton

**Apologies include:** Professor Sir Roy Anderson, Dr Simon Barton, Ms Toni Belfield, Professor Dame Valerie Beral, Professor Sir David Cox, Professor Nicholas Day, Professor Anna Glasier, Professor Sir Roger Jowell, Professor Sally Macintyre, Sir Nicholas Partridge, Professor Peter Smith, Dr Peter Williams, Dr Sandra Williams, Ms Sharon Witherspoon **Professor Tilli Tansey:** I would like to begin by welcoming you all to this Witness Seminar on the first National Survey of Sexual Attitudes and Lifestyles (NATSAL) and thanking you all for coming. I'm Tilli Tansey and I'm a medical historian at UCL, and head of the History of Twentieth Century Medicine Group, which was established by the Wellcome Trust. The purpose of these Witness Seminars is to gather together people who were involved in particular medical discoveries or debates, to get them to talk among themselves about what happened, what didn't happen that should have happened; why things happened the way they did and who was involved; and to get the stories behind the written records, behind the published papers (see Table 1).

This subject was suggested as a suitable topic by David Gordon, Anne Johnson and also Sir Mark Walport, and we've been thinking for some years how to do it. We're delighted that we have finally got the funding and support to be able to hold it this afternoon. If you want to look at any of our previous meetings, they are all available – we've published nearly 50 of them so far.<sup>1</sup> An important part of planning our meetings is to identify a suitable chairman. We're delighted that Professor Michael (Mike) Adler has agreed to chair this meeting, although he is a very major participant in the story himself. So, without further ado, I'll hand over to Mike.

**Professor Michael Adler:** It's rather salutary to have been part of something and now to be told that it's history! There are quite a number of us in this room who are now history. I think this should be a really fascinating meeting this afternoon and that you will find that it highlights the history of the ability to be able to do research on sexual behaviour and attitudes. We'll learn quite a bit about the science and about what was done previously and how inadequate it was in terms of using proper randomly selected household samples. For me, the politics and funding of NATSAL are absolutely fascinating and I hope we will be able to get to that, because it was a very bruising and exciting time for a few days. Finally, we'll discuss the policy implications of the work that was done by the team. Those were very important to those of us who were working in sexually transmitted infections (STIs) and human immunodeficiency virus (HIV), because we actually had minimal data regarding sexual behaviour, partner change, transmission and sexual networks, and the basic data such as what proportion of men in the UK were having sex with other men – basic information that

<sup>&</sup>lt;sup>1</sup> Freely available at www.history.qmul.ac.uk/research/modbiomed/wellcome\_witnesses/ (visited 18 July 2011).

Historical introduction
1980s: Before the first NATSAL
Social and sexual context
Development of the planning group
Planning
The first NATSAL
Membership
Objectives
Methods
Main study
Choice and training of interviewers
Conduct of survey
Data processing
Consequences, immediate and long term
Reflections from participants
Funding the first NATSAL
Subsequent NATSALs
Differences
Impact
Consequences

Table 1: Outline programme for 'History of the National Survey of Sexual Attitudes and Lifestyles' Witness Seminar

we needed if we were going to develop effective public health programmes and strategies for service delivery. One of the things about HIV, even though there was tremendous stigma around it and many of us had to grapple with trying to de-stigmatize this area, was that HIV legitimized doing this type of research, gave it a sort of impetus and allowed it to be funded. Now, to put this into some sort of historical context, Virginia Berridge is going to make some opening remarks about the historical context immediately around the survey.

**Professor Virginia Berridge:** I'll start with an anecdote. When I was researching acquired immune deficiency syndrome (AIDS) policy-making as part of what was then called the AIDS Social History Programme at the London School of Hygiene and Tropical Medicine, a lot of the work was based on interviews, because there was no Freedom of Information Act in those days. You couldn't

ask for government archival material, which, of course, we can do nowadays. While I was doing that, people kept coming up to me in the lunch queue to tell me about what was going on with the sex survey – the politics of what was going on. At the time, it seemed almost like a diversion. I was researching things that had happened in the early 1980s, up to about 1986, and things that were happening at the time were a bit of a distraction, but I did end up interviewing people and writing about the survey in my book, and, of course, as Mike said, it's now more distant history.<sup>2</sup> That's an interesting reflection of the interweaving between present and near past, and the translation between the two, which is part of doing contemporary history. It has now become what we might call 'real history'.

But let me set the stage for the survey and how it fitted into policy-making around AIDS at that time. I think there were three stages of AIDS policymaking that one can identify: first of all from the early 1980s to about 1986: there was a period of what one can call policy-making from below, where AIDS wasn't a central government issue and it gradually edged onto the agenda of the Department of Health and Social Security (DHSS) (Department of Health, DoH, after 1988). A lot of that was due to pressure from outside government, from the gay community and from clinicians and others. Gradually, the DHSS and Sir Donald Acheson took that issue on.<sup>3</sup> And then a very interesting period of national crisis followed in 1986/7 where it was really thought that AIDS was going to overwhelm the nation. There was a top-level central government response with a cabinet committee on AIDS, and very important in that, I think, was the role of William Whitelaw as Deputy Prime Minister. Civil servants were also important in that response: Acheson himself, Ken Stowe as permanent secretary at the DHSS, and Sir Robert Armstrong as Cabinet Secretary. The importance was of one of the traditional dynamics of British policy-making helping to form a liberal consensus around HIV. A lot of things flowed from that: the change from the Health Education Council to the Health Education Authority (HEA); the AIDS-directed programme at the Medical Research Council (MRC); the national health education campaign; research funding and so on. But from 1988 onwards, things quietened down a bit. We talk about the 'normalization of AIDS'. Some of the key politicians moved on, things became more ordered and professionalized, and AIDS began to be seen as a chronic disease rather than an epidemic or immediately fatal disease. Some of the civil

<sup>&</sup>lt;sup>2</sup> Berridge (1996).

<sup>&</sup>lt;sup>3</sup> Sir Donald Acheson (1926–2010) was Chief Medical Officer from 1983 to 2001.

servants, I think, became a little wary of the issue. There was a feeling that perhaps they'd been duped: the media had stories about a 'gay conspiracy', which had hyped AIDS to be more of an issue than it merited. Well, where did the sex survey fit into all that? I think it was part of what I call the 'repoliticization of AIDS' where politicians started to take a more independent line: they weren't just following the line that was set by civil servants. The idea of a national survey had originated in several different groupings in 1986/7:4 Kaye Wellings and Julia Field on the one hand; and another group involved Roy Anderson at Imperial College, Anne Johnson at the Middlesex, and Jane Wadsworth, who'd been involved in an epidemiological survey funded by the millionaire property developer, Godfrey Bradman, who had a keen interest in AIDS.<sup>5</sup> That survey was run by Gallup, and so there were debates about whether to continue or not with a commercial model for the survey. In the end the HEA and Economic and Social Research Council (ESRC) funded a feasibility study in the autumn of 1988 and the DHSS agreed to join with them for funding. Then the progress of the survey halted and eventually it was funded by the Wellcome Trust.

One question I would like to throw out at the start is why the idea of the survey as the one that Mrs Thatcher cancelled has gained such credence. If you read Kenneth Baker's autobiography, and he was then the Education Secretary, you get a rather different story.<sup>6</sup> He says the proposal for the survey came from David Mellor and Ken Clarke, who were then health ministers, but Baker, George Younger and Douglas Hurd all opposed the study and stopped it. So he said it was stopped at a junior ministerial level rather than by the Prime Minister. So perhaps today we'll hear more about that. But I think also the survey and its publication had a more general significance, which Mike alluded to just now: both in terms of British society and the impact that AIDS had on that society. With hindsight, we can see AIDS as having been a tremendous liberalizing force. It helped to normalize what was then exceptional or difficult to talk about or to research. It was what the Australian sociologist Denis Altman called 'legitimation through disaster' as far as homosexual men and their visibility were concerned. We can also see now how things that were then exceptional or couldn't be done very easily, like discussion of sexual knowledge or research into sexual practices, have become mainstream. The survey itself, of course, is now into its third version. So I look forward to hearing about its early years today.

<sup>&</sup>lt;sup>4</sup> See Berridge (1996): 252–4.

<sup>&</sup>lt;sup>5</sup> See Berridge (1996): 139–40, 191, 252; Johnson et al. (1989).

<sup>&</sup>lt;sup>6</sup> Baker (1993).

Adler: We should probably start where Virginia left off, talking about the 1980s, before the first NATSAL, afterwards we can talk about that, and then subsequent NATSALs. Unfortunately, we are not going to look at the funding issue that we've both touched on - a very interesting political story - until after tea because Sir Roger Gibbs, who was the chairman of the board of the Wellcome Trust at the time, can't be here until then. I think it would be right for him to be here because he will be able to give us an insight. So we'll have to postpone that discussion, unfortunately, so there won't be the natural flow.

Now, Julia, Kaye, Anne: do you want to talk a little bit about the early days? I'd forgotten about the Gallup poll and who funded it.<sup>7</sup> Kaye, do you want to talk a little bit about your early work, before we get into NATSAL, and tell us about what those original surveys were doing?

**Professor Kaye Wellings:** I think Julia should start with the study that she was carrying out on sex education that predated my overture to see if she might be interested.

**Mrs Julia Field:** I can't actually remember the name of that study.<sup>8</sup> The first time I met Kaye, we were at a launch of a research report and Kaye, whom I'd never met before, came up to me at the end of that event and asked: 'How would you and Social and Community Planning Research (SCPR, as we were called then) like to collaborate on a survey of sexual behaviour?'<sup>9</sup> My jaw completely hit the floor.

Adler: Do you know what year that was? Do you remember?

**Field**: That would have been 1987. I said, 'Yes, of course, OK,' gulping, and I assumed that I would probably hear nothing further, but Kaye got in touch with me a couple of months later and it all took off from there.

Wellings: Well, it took off. We wrote a proposal and our focus was much more on health behaviours and health promotion than on surveillance. So, I suppose that if we could divide up the team at that point, it would be along that axis.

<sup>&</sup>lt;sup>7</sup> Professor Johnson wrote 'The Gallup survey preceded the eventual NATSAL team getting together by a year. The history of the survey development is carefully documented in chapter 1 of Johnson *et al.* (1994).' Note on draft transcript, 2 February 2011. See also Johnson *et al.* (1989).

<sup>&</sup>lt;sup>8</sup> Allen (1987). Mrs Julia Field wrote: 'I was research director at SCPR (Social and Community Planning Research) who carried out the fieldwork and part of the design of that study.' Note on draft transcript, 13 July 2010.

<sup>&</sup>lt;sup>9</sup> National Centre for Social Research (NatCen) from 1999. See www.natcen.ac.uk/history (visited 13 July 2010).

We wrote a proposal, quite a lengthy one, and took it to the HEA and we saw the research officer, a man called Peter Linthwaite. He said that he thought that there would be quite a lot of interest, it was certainly needed and would fit in with their programme of research, but that there was a job coming up as a senior research officer in AIDS. It seemed to me a sort of Faustian bargain: if I applied for this job we might be able to push the survey through. So, with some trepidation really, because I wasn't sure how well I'd fit into what was a quasi-governmental bureaucracy, I did apply for the job and I got it, and then, together with Julia, we assumed that we could then work up this study. The HEA then began a whole programme taking it forward, which I think is going to take us to a date that coincides with the other groups.

Adler: Julia, do you want to say anything more about that?

Wellings: We actually began a qualitative survey with SCPR to inform the study, or were starting development work at that point?

Field: At that stage, I was a general survey researcher rather than a specialist in this particular topic. I had no particular knowledge of it at all, so it was a new area for me.

**Professor Anne Johnson:** My memory of how I got involved in this is that I'd come to work at the Middlesex Hospital Medical School with Mike Adler in 1985 when he was studying the very early days of transmission of HIV in gay communities. I did my MD on the transmission of HIV to heterosexual populations.<sup>10</sup> I think this is in the right chronological order: I joined Sir David Cox's committee, which did the first projections of AIDS and there was a bunch of illustrious statisticians, including David Cox and Roy Anderson, who produced an interesting range of graphs over several orders of magnitude, suggesting what the future of the AIDS epidemic might be (see Figure 1).<sup>11</sup>

There was tremendous uncertainty. So I came at the sexual behaviour survey very much from an HIV angle. What was clear was that we had no idea of the parameter estimates that would drive an epidemic of HIV. We didn't know what proportion of the population had gay partners, we didn't know the number of partners that people had. I think it was at that point that the idea of a random sample survey of sexual behaviour was mooted and that was how the first (private) funding came forward.

<sup>&</sup>lt;sup>10</sup> Johnson (1991). See also, Gilbart et al. (2006).

<sup>&</sup>lt;sup>11</sup> See Department of Health and the Welsh Office (1988); see also Rees (1990); Berridge (1996): 157, 182, 200, 209–10, 211, 232.

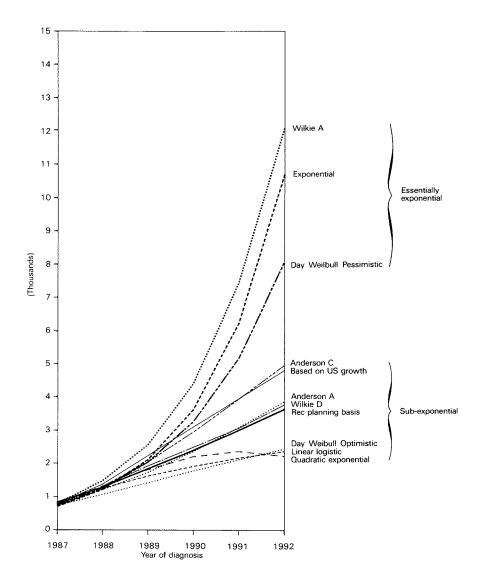


Figure 1: Summary of predictions of numbers of new cases of AIDS diagnosed in England and Wales.<sup>12</sup> Reproduced from Department of Health and the Welsh Office (1988): 29.

<sup>&</sup>lt;sup>12</sup> Professor Johnson wrote 'This graph shows the wide range of predictions of future AIDS cases produced by members of the first working group chaired by Sir David Cox. Most predictions were based on mathematical extrapolation of the shape of the epidemic curve to date. All were hampered by the lack of data on the population distribution of sexual behaviours driving the epidemic, for example, the proportion of the male population having homosexual sex and rates of sexual partner change.' Note on draft transcript, 2 February 2011.

## A pilot study of sexual lifestyle in a random sample of the population of Great Britain

Anne M. Johnson, Jane Wadsworth<sup>\*</sup>, Paul Elliott<sup>\*</sup>, Linda Prior<sup>§</sup>, Paul Wallace<sup>\*</sup>, Sally Blower<sup>†</sup>, Norman L. Webb<sup>§</sup>, Gordon I. Heald<sup>§</sup>, David L. Miller<sup>\*</sup>, Michael W. Adler and Roy M. Anderson<sup>†</sup>

Figure 2: First pilot study for NATSAL-1, published in AIDS (1989), 3: 135-41.

This first pilot (Figure 2) involved Roy Anderson, Paul Elliott, Paul Wallace, Jane Wadsworth and myself. We carried out a random sample survey through Gallup, who were very unused to doing random sample surveys and they nervously said: 'Ooh, we're going to "do a random."" [Laughs] And they 'did a random' in 1987. We had a poor response rate – it was less than 50 per cent, but still, we did show that you could do a random sample survey.<sup>13</sup> And around that time – and I can't remember the order, but I hope Karen Dunnell might remember – there was a meeting in James Pringle House, Middlesex Hospital, London. Mike was there, Karen was there, and we talked to the Office for National Statistics (ONS) [then the Office for Population, Censuses and Surveys (OPCS)] about doing a random sample survey, but Karen said that there was no way that ONS would be able to do it on the rapid timeframe. We didn't, of course, know then how long the timeframe would be, in the context of the subsequent delay in funding. It was also probably around that time that I met Kaye and Julia - it would have been about 1987. We were clearly coming at the same problem from different angles, and I think that was the point at which we planned the feasibility study together.

Adler: Karen, do you want to add anything about that meeting? Was it the speed with which we were asking you to do something, or was it that you thought that, as a government department, which it was at that time, it would be too sensitive?

**Dame Karen Dunnell:** The reason that I had a great interest in this was that I'd carried out the Family Formation Survey in 1976. This was the first survey in the UK that ever asked about cohabitation, the breakdown of non-marital relationships, age of first intercourse and pregnancy history, including abortions.<sup>14</sup> So, I had some experience of such surveys. Actually, the sampling and the

<sup>&</sup>lt;sup>13</sup> Johnson *et al.* (1989), See Figure 2.

<sup>&</sup>lt;sup>14</sup> Dame Karen Dunnell designed, project managed and was the principal researcher on the study. Dunnell (1979); Botting and Dunnell (2000).

fieldwork on that had been very successful, but that was in the 1970s when 80-90 per cent response rates were common, which, of course, they are no longer.<sup>15</sup> If you get 50 per cent now, you're doing quite well. I can't remember the exact dates, but it was a period of quite a lot of turmoil in what was then the OPCS (later the ONS), because of reviews and the move to different ways of financing surveys.<sup>16</sup> In fact, we only did surveys for other government departments and public bodies. Also, of course, there was the issue about timing - I remember when I did the Family Formation survey, I think it was a year in gestation, as it were. We had to work things out, talk to people, pilot and conduct feasibility studies; it was a very slow process. Also, there was always, and there still is, a lot of very difficult government feeling about asking sensitive questions of the general public, even if it is voluntary. We still had some difficulties getting good monitoring questions about contraception and relationships but we managed to do so because we'd already shown that it could be done. The Office for National Statistics (ONS), as it is now, is at present in the middle of a debate about whether or not it's appropriate to have a question about sexual orientation on the census.<sup>17</sup> So, nothing ever changes! All of those issues would have been around at the time; great nervousness about asking these things of the public, but, overcome-able if you're determined.

Adler: Tony Coxon, will you introduce yourself? Tony was the doyen of sexual behaviour research, particularly with gay men.

**Professor Tony Coxon:** It struck me that there are one or two things that, historically, have subsequently come out that might be relevant to this meeting, and which also indicate the relationship between SIGMA and NATSAL.<sup>18</sup>

<sup>&</sup>lt;sup>15</sup> Response rates to surveys have fallen all over the world and there is a huge methodological literature on it; see, for example, Groves and Couper (1998); Singer (2006).

<sup>&</sup>lt;sup>16</sup> Dame Karen Dunnell wrote: 'Changes in the OPCS followed a review by Derek Rayner which first reallocated OPCS survey budget to other Government Departments and later led to competitive tendering for Government Surveys.' E-mail to Ms Caroline Overy, 16 February 2011. See also p 30.

<sup>&</sup>lt;sup>17</sup> For more on the debate on the census, see the Sexual Identity Project at www.ons.gov.uk/about-statistics/ measuring-equality/equality/sexual-identity-project/index.html (visited 22 February 2011).

<sup>&</sup>lt;sup>18</sup> Professor Coxon wrote: 'Project SIGMA (Socio-sexual Investigations of Gay Men and Aids) originated in 1982 and was funded 1969–92 by MRC and the Department of Health. It was a 5-wave prospective, community-based study centred primarily on Cardiff and London. The PIs were Professor Tony Coxon, Dr Peter Davies and Dr Tom McManus (Clinical).' E-mail to Ms Caroline Overy, 7 February 2011. The current SIGMA-Research moved to the Department of Social and Environmental Health Research at the London School of Hygiene and Tropical Medicine in 2011.

Actually the group that became SIGMA originally began in the late 1970s, in what was intended to be a replication of the Kinsey Report for the UK.<sup>19</sup> In the end, that didn't get funded because it was overtaken by AIDS (you will remember the famous television programme with tombstones, in the 1982/3 period).<sup>20</sup> So the project turned instead into an attempt to look at gay men's sexual behaviour and transmission of HIV. There are one or two things that might be worth throwing in because, historically, SIGMA comes at research from a different angle. Although SIGMA actually began in 1982 to research homosexual behaviour in a multi-site context, the project wasn't fully funded until 1986. It's worthwhile, I think, to say that at one point, the ESRC was asked why it had not funded research in sexual behaviour and AIDS in that crucial period, and they said they had received no grant applications.<sup>21</sup> Now, that included us - in fact we had submitted an application, and I was subsequently able to get them to withdraw that statement. But they were certainly worried about the intentions of Mrs Thatcher, who had quite publicly threatened to get rid of sociology from the ESRC on the grounds that it was not scientific.<sup>22</sup> Therefore, for the ESRC to be seen to be paying for a project that was so strongly controversial simply wasn't on. In the end, what happened is that we got the funding from the Department of Health (DoH), primarily for looking at condom adoption, and only secondly from the MRC. Nonetheless, while we had seedcorn funding to begin in 1982, one of the things that we found out was absolutely crucial for later studies. We were able to demonstrate that in Cardiff (and in London, where we were also able to mount a systematic study) the adoption of condoms by gay men took place in the early part of the period and that by 1986, when we got funding to look at this, the process of condom adoption was virtually finished.<sup>23</sup> I'm glad – and we can say it now – because

<sup>&</sup>lt;sup>19</sup> Kinsey et al. (1948) and (1953).

<sup>&</sup>lt;sup>20</sup> The first television documentary on AIDS the BBC *Horizon* programme, *The Killer in the Village*, was broadcast on 25 April 1983. The 'tombstone' advertisement appeared on television in 1987, organized by the Central Office of Information for the Department of Health; this can be viewed at www.nationalarchives. gov.uk/films/1979to2006/filmpage\_aids.htm (visited 8 March 2011).

<sup>&</sup>lt;sup>21</sup> Personal communication from the then Chairman of ESRC, Professor Sir Howard Newby.

<sup>&</sup>lt;sup>22</sup> In 1981, Sir Keith Joseph, Secretary of State for Education and Science in Mrs Margaret Thatcher's government, asked Lord Rothschild to conduct an independent review into the scale and character of the work of the Social Science Research Council (SSRC, 1965–83; restructured as the Economic and Social Research Council, ESRC). See Gaber *et al.* (2005); see also Reynolds and Tansey (eds) (2000).

<sup>&</sup>lt;sup>23</sup> Weatherburn *et al.* (1991); Davies *et al.* (1992, 1993).

what it meant was that before the MRC took up the offer, we had four years of discussion with them and hence four years of delay, on the issue of taking blood and saliva samples from our respondents. What the MRC was particularly concerned with was HIV prevalence in the non-clinic-attending population of gay men, and we appeared to be able to provide that information. SIGMA was therefore committed from the beginning to MRC funding for taking blood and saliva samples from all, or as many as possible, of the sample members.

There are other issues about this that are interesting, but which are probably irrelevant at this moment. However, it is worth commenting that, with respect to taking blood in particular, it certainly seemed to us that the main focus had to be on HIV prevalence in the non-clinic-attending population, together with the adoption of condoms. These became the primary issues, rather than what we took to be primary, which was the development of systematic measurement of sexual behaviour. But those issues raised earlier on, particularly about the involvement of the Cabinet Office, were very interesting because clearly SIGMA was also being viewed at that time as forming a dangerous precedent.<sup>24</sup> It was only because of the medicalization of the research problem that we got the funding to mount the project. With the social sciences we wouldn't have, in fact, got any funding.

Adler: Would anyone else like to make any observations about this early period, before we actually get into the development and planning of NATSAL?

Wellings: I've got a file here that has a couple of documents that I'll briefly outline. There was quite a high-level committee at the Department of Health, the Committee on AIDS Public Education (CAPE) and it met on 15 January 1988.<sup>25</sup> The note of the meeting is as follows: '...In the view of the DHSS, there should be one coordinated group of projects. These studies are costly and present major methodological problems, and there's no justification for repetition as a result of national studies being undertaken by the various funding organizations.' So it was a plea for rationalization, really. 'It's therefore essential that the MRC, ESRC, HEA and health departments work together towards a common national research programme.' That was followed very shortly by another meeting. I have a note here from 21 January 1988 that the DHSS was about to present approval for a survey of sexual behaviour to

<sup>&</sup>lt;sup>24</sup> See page 12.

<sup>&</sup>lt;sup>25</sup> See Berridge (1996): 165–6, 194, 264.

its departmental research committee. The note, which is an internal HEA document, says that 'the decision-making process of the department is slow and approval was for the 1988/9 financial year. However, it might be of interest to follow up what the department is planning.' Then there was a meeting on 15 February 1988 with all parties present, which was coordinated by the ESRC, with Alan Marsh representing the ESRC.<sup>26</sup> That was the meeting at which the SCPR group, the HEA group, those at Imperial, the Middlesex and the St Mary's groups<sup>27</sup> were all obliged to sit together and hammer out how they could combine their resources and carry out this piece of work most effectively and with the best use of public funds, and with the broadest outcomes in terms of the use of the data. But it is interesting and I'll just briefly read this note of the meeting, and obviously it's couched very carefully. It says, 'The meeting followed the Chief Scientist's AIDS meeting on 1 February and was called to consider how qualitative studies being prepared by SCPR for HEA might be developed to coordinate with a national quantitative study of sexual behaviour which ESRC is to manage.<sup>28</sup> The following preliminary points were noted with regard to the proposed survey of sexual behaviour: 'Ministers wish to avoid direct departmental funding involvement, but would want their interests to be represented in the planning and carrying out of a survey. Any study involving large government expenditure must be assessed in a way which stood up to scientific scrutiny. This made management by research council appropriate. A steering group of eminent people would not necessarily be the group exercising scientific oversight of the study' [Laughs]. So, in other words, they weren't quite senior enough, perhaps. The agencies with money to support the study were the Health Department, ESRC and HEA. The MRC's behavioural forum also had an interest. So that's really the start of the coming together of the two groups and the sanctioning of that steering group.

Adler: Well, that's very interesting. For those of you who were there at that meeting: was it easy? Was it head-banging? Did you all feel you wanted to do your own thing? Were you prepared to cooperate?

<sup>&</sup>lt;sup>26</sup> Professor Alan Marsh was ESRC director of research, later deputy director of the Policy Studies Institute at the University of Westminster.

<sup>&</sup>lt;sup>27</sup> Roy Anderson was at Imperial College, Anne Johnson at the Middlesex Hospital Medical School and Jane Wadsworth was at St Mary's.

<sup>&</sup>lt;sup>28</sup> Document in Professor Wellings' personal archive.

Field: Obviously, my memory of the meeting itself is fairly hazy, but it was quite tense, as I remember, and people were very concerned to protect their...

## Adler: Turf. [Laughs]

Field: Exactly. But I don't remember the details of how. You [Anne Johnson] might remember a bit more.

Johnson: I remember very little. I do remember the meeting, and I do remember there being turf. There's always turf among academics. There was turf about who should do the survey and whether it should be done publicly, which would have been the OPCS, or whether it should be done by SCPR as a charitable organization. And there was a lot of disciplinary turf, would you say? But we've been mowing the grass ever since. There is disciplinary turf, because the HEA and clearly Kaye and Julia had come at it from different disciplines (social sciences), differing from the biomedical discipline that Jane Wadsworth, myself and Roy had come from; ours was a sort of quantitative reductionist approach. But I would say the amalgamation of the two disciplines has been to our mutual benefit over the years and has given us a much broader view of things. We decided to work together fairly rapidly as I remember. We submitted a grant to ESRC in May 1988, which was awarded. And you were interviewing people in the autumn of 1988, Julia? One of the interviewers is here.

## Adler: Kaye, your memories of that meeting?

Wellings: I remember there being turf too, but I do remember that we all wanted the survey to go ahead and we realized that we would have to swallow our disciplinary pride. I remember some examples of the turf wars. One, for example: Julia and I, the SCPR were doing some wonderfully careful work looking at how people wanted to be asked questions and what they thought about sex. I remember there was a slight feeling that 30, or it was 50, individuals – wasn't quite the biscuit, really, wasn't quite the ticket. What can you do with 50, you know? It wasn't quite academic to look at what 50 people thought. By the same token, we thought that some of the questions that we wanted to have answered in relation to motivation and behaviours weren't coming out very easily in a huge quantitative survey. So, I think we learnt a lot from one another and continue to do so.

Johnson: Well, I suppose, you, Kaye, are talking about the qualitative work. When we designed the Gallup study, we just made up the questions as we went along and, looking back on them, a lot were rather badly worded. One of the

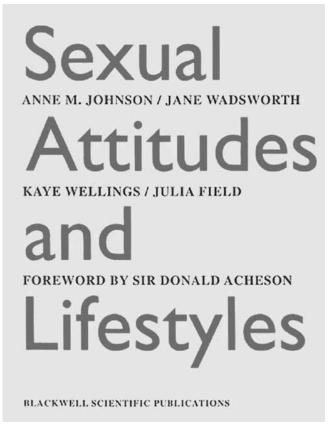


Figure 3: Front cover of Johnson et al. (1994)

most interesting pieces of work was the work done by SCPR called *Talking about Sex* where you interviewed a number of people about what kind of language they prefer to use: whether they wanted to use the vernacular or biological language.<sup>29</sup> That was fundamental to the subsequent design of the survey and probably was my first real exposure to good qualitative research. So, I think we gained a lot of mutual respect from seeing how the work of SCPR could enormously improve the quality of the survey instrument.

Adler: Anne, remind me of the next step: you got a small grant from ESRC, is that right?

Johnson: Kaye will read out the proper minutes, but I've got the book.<sup>30</sup>

<sup>&</sup>lt;sup>29</sup> Spencer *et al.* (1988).

<sup>&</sup>lt;sup>30</sup> Johnson *et al.* (1994); paperback published as Wellings *et al.* (1994). See Figure 3.

COMMENTARY
Sexual lifes tyles under scrutiny
K. Wellings, J. Field, J. Wadsworth, A.M. Johnson, R.M. Anderson and S.A. Bradshaw
Much useful information can be obtained from a knowledge of people's sexual habits, not least information about
AIDS. Such studies should be judged by scientists, not by politicians.

Figure 4: Sexual lifestyles under scrutiny. Nature (1990): 276.

In May 1988 we got the money from the ESRC and we did the feasibility survey in 1988. We interviewed 977 people, aged 16–59, all over the UK. That was done by SCPR and that work really looked at the methodology and whether we could achieve decent response rates, which we did. We achieved a response rate of 65 per cent. Actually, SCPR achieved a response rate of 65 per cent and we were able to show high levels of internal consistency, external validity and low item nonresponse. All of that was published in a paper in *Nature* in 1990.<sup>31</sup> Around that time, actually, I think the paper was already with *Nature* (Figure 4) and we had prepared an account of the work being feasible, and that formed the basis of the submission for the main stage survey, which I think, Kaye, went to ESRC?

Wellings: It did.

Johnson: The grant was to be reviewed by the ESRC but was funded with money from the DHSS. That submission was for a survey of 20 000 people and it included the data from the feasibility study. And then, there was a terrible silence.

Adler: Silence.

Wellings: Silence.

Johnson: Silence. After the submission was put in.

Adler: Silence, right. As I said, we're going to have to delay talking about the funding. Anyone – Tony – is there anything else you want to introduce at this point?

**Coxon:** Very briefly, that when we were justifying our sample design, since it was clearly not clinic-based, but, on the other hand, it was not an attempt to do a genuine random sample as we would have done later on. What we actually adopted was a two-factor quota design, taking 'type of relationship' and 'age' as

<sup>&</sup>lt;sup>31</sup> Wellings *et al.* (1990).

the two factors, and then using various network procedures to snowball from there.<sup>32</sup> In doing this, we were encouraged by the MRC themselves to state that the calibration of estimates could later be provided by the NATSAL study. In fact, that suggestion came from the MRC rather than from us, and I don't think that got the publicity it deserved, because it was part of the justification for what SIGMA was doing as well.

Adler: Anyone else want to add anything at this point?

Johnson: I was just wondering if Wendy had any comment, having been an interviewer on that very first feasibility study?

Mrs Wendy Williams: I interviewed on the first survey, the second one and the pilot for the next one (2010). The main difference in this particular survey is that when we approach people on the door, they decide within seconds whether or not they're going to take part, whatever the subject is. I think they decide that very quickly. But quite often, when you got into the survey itself, and they realized that it was unlike asking about a product or something else, then they reacted in two ways: either because they felt this was of use or of benefit to the nation, that everybody should take part; or I'm afraid quite a few people thought that it was nice to talk about this subject, as it gave them a bit of - I don't know – excitement? It was definitely, you had to start off by making the questionnaire very separate from you as an individual. It had to be very sort of professional, otherwise it could deteriorate into something that was not intended. [Laughter]

Adler: You mean anecdotal? [Laughter] Thanks, Wendy. So we're now in 1990, yes? Sorry, 1989, I thought that *Nature* was 1990.

Johnson: Yes, but I think the Nature paper wasn't published until after the ban.

Wellings: It was certainly published after we submitted the proposals.

Johnson: It was published after we submitted the proposals, and Mike Durham's article on the front page of *The Sunday Times* (Figure 5).

Adler: We're going to have to hold off.

Johnson: I know we're going to have to hold off, but you're asking me to be chronological, and I think it was 1989, wasn't it? So the *Nature* paper wasn't published until after the ban.

<sup>&</sup>lt;sup>32</sup> Professor Coxon wrote: 'This technique, known as "link-tracing" begins by choosing respondents who fulfil the criteria, and then using their sexual partners as the next step, continuing until no new contacts are found.' E-mail to Ms Caroline Overy, 7 February 2011.

Adler: Alright, fine. Sounds like the organizers should put a bowl of *Aricept* out there for all of us when we come in.<sup>33</sup> So that's a proposal going to the ESRC for a sample of 20 000 funded by the DHSS?

Johnson: Correct.

Adler: The next step was a long wait and silence.

**Johnson**: Yes, but we're not allowed to talk about the next bit yet. Would you like to talk about the results of the first survey? We'll talk about the ban later.

Wellings: We should talk about the feasibility survey and its very good response rate, and the fact that we took it to the Chief Scientist's office at the Department of Health and we all sat round a very large table, and pretty well anybody who knew anything about statistics was there, and they signed it off. They said that this was a good study; that it was carefully conducted, that it was likely to produce results that would be worthwhile and valuable in the context of public health. This is before it got political; they said they would take the recommendation that it should be funded to the appropriate people in the Department of Health, presumably Ministers, you know, beyond the civil servants. So, before it got political, it was actually passed by the Chief Scientist.

Johnson: Yes, it was, it went to the ESRC AIDS steering group, who reported being satisfied with the scientific standard, and the proposal went forward to the ESRC full council at the end of January 1989.<sup>34</sup> That's right: it approved the study and sent it on to the DoH, with the suggestion that a larger sample was necessary to meet the epidemiological objectives. I'd forgotten that.

Wellings: That's right, because at the Alan Marsh meeting (15 February 1988; see page 14, we got the meeting agreed with Alan Marsh's proposal, as a sample size of 20 000 people up to age 50 was needed for the national survey.<sup>35</sup> I have a reference from Tony Coxon for the main stage, in which he says we are a formidable team, which was very nice. He also says something very nice about Jane Wadsworth: 'Given the centrality of analysis in the proposal, I would have expected a more detailed and wide-ranging specification of forms of multivariate analysis and modelling to be used, apart from conventional

<sup>&</sup>lt;sup>33</sup> *Aricept*<sup>®</sup> (donepezil HCl tablets, Pfizer), a treatment for mild, moderate and severe dementia and memory loss of the Alzheimer's type.

<sup>&</sup>lt;sup>34</sup> Letter in Professor Wellings' personal archive.

<sup>&</sup>lt;sup>35</sup> Letter in Professor Wellings' personal archive.

principal components analysis. Given the competence of Wadsworth, I'm not too concerned about this, but the applicants should have given more attention to it.' He also says, 'Output: the proposed publications and dissemination methods are appropriate, if a little pedestrian.'<sup>36</sup>

Adler: Right, I think you can meet Tony Coxon outside about that one. [Laughs]. A two-edged sword there, Tony, I'm sure you hold by it. So, the Chief Scientist passed it. Where do we go next?

Wellings: Well, we wait a long time.

Adler: We wait a long time. OK, so we're going to have to skip now, aren't we because, and I know, Mike, that we're going to have to keep you out of this, because you had a very important part to play in terms of the story around the funding. Do you want to say anything?

Mr Mike Durham: Well, I've got quite a lot to say. I think I've got a good story to tell, from an altogether different perspective than most people in this room. My name is Mike Durham. I'm a journalist. At that time this was a story that actually came to me almost by accident. It was something in which I was immersed for a few days, and then, unlike most other people in this room, it was something that I visited really for just a few days – perhaps made an impact - and then was able to forget it for many years, until today. So I had no involvement or knowledge of the planning or background to any of this. Many people had been working and beavering away in the background for a long time when this came to my notice. So what I will do, I don't know whether you want me, at this stage or later, to tell my side of the story about what I heard, what I was told, and what I was able to put into print. I can anyway, at this stage, produce in evidence the original copy of the front page of The Sunday Times for 10 September 1989 (Figure 5), all of which relates to a few hours' work on 8 September 1989. The fact that it's framed, and the fact that it's been hanging on the wall of my study for nearly 20 years, gives you an indication that this story was pretty important to me as well, because it was one of the most entertaining that I've ever written, the biggest and one of the stories I felt had a significant impact and I was very proud of it. So if you'd like me to go into more detail now, let me know, otherwise later, as you wish.

Adler: I'm looking at Tilli – it's hard to sit on something like this, isn't it?

Tansey: Please carry on.

<sup>&</sup>lt;sup>36</sup> Letter in Professor Wellings' personal archive.

of a similar pilot project will be unveiled this week. Resear-chers say these prove that the



## **Thatcher halts** surve Sex

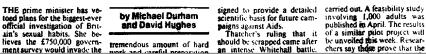


Figure 5: Top: Mike Durham displays his framed copy of the front page of The Sunday Times taken at the Witness Seminar, 14 December 2009; bottom: headline of his article.

Adler: It's so exciting. Mike, I think you should go ahead and, after tea, we will just add why the funding was in fact picked up by Wellcome. Sir Roger Gibbs and Sir Stanley Peart are here as well and were Trustees. I can't imagine who your sources of information were, Mike.

Durham: Yes, and I think that some people here may be surprised in some respects at the way in which the story came to me and how it developed for me, because, in fact, I knew and even today I know very little about the true background to the funding crisis that you'll be describing later. At that point, I had been a journalist for about ten years; I was quite experienced and during my career I have been a health services and health affairs correspondent for various newspapers, including *The Sunday Times*, the *Observer* and the *Independent*, at various times. At that stage in my career I was the new boy on the block at *The Sunday Times*; I had no official position at all. I had recently been fired by the *Daily Telegraph*, probably for not being sufficiently onside with a certain Mrs Thatcher, and I had gone through the revolving door and found myself in the portals of *The Sunday Times* looking for a job, and I was on a contract at the time.

To put you in the picture of what Sunday journalism was like then, and what it's like now, I think: it's a fairly nail-biting job. You work on a weekly basis, mostly, doing the sort of job that I was doing; you are expected to turn in stories and therefore I wasn't really feature writing or, at that stage, writing specifically on health for the paper. However, you rather hope that by Friday you'll have turned up a story that is going to turn into a really cracking article for that weekend's paper and go round the world. There's a saying among journalists that you're only as good as your next story, and on that particular Friday afternoon of 8 September, I seem to remember, for me that week there was no next story. By about 3 o'clock in the afternoon, I still had no story and things were not looking good. All of this is from memory – the timings and the exact sequence may be a little bit hazy – but as I recall, some time after lunch on that Friday, I received a phone call, and my source was somebody from deep inside the City and East London Health Authority, I seem to remember, who is here right now and may be able to tell you a bit more about it in due course. It was Bobbie Jacobson, now my wife, who said to me: 'I think I've heard an interesting story. I wonder if you might like to take a look at this.' If I recall, all she really told me was that Margaret Thatcher had vetoed a survey that had something to do with the HEA about sex and AIDS. I'm sure I'll be corrected on all of this, but she gave me, if I recall, a very brief summary of what she'd heard and the names of two or three people who I might perhaps check it out with.

Well, I thought, perhaps this was worth looking into. My first step was to go over to the news desk, the masters who run the daily news-gathering empire, and say: 'I think I might have a bit of story here. I understand that Margaret Thatcher's stopped this survey.' At which there was a little bit of doubt expressed, I think that would be a fair view. There was enormous interest but it is fair to say that it seemed just too good a story to be true. After all, in the space of a single sentence I had managed to explain a story, which had Margaret Thatcher, AIDS and sex all in one headline. [Laughter] If it was true, I couldn't believe my own luck. And, of course, I had excellent contacts. At this point my instructions were to make a few basic checks, which of course I could do, and also to talk

to one of the political editors, David Hughes, who is co-bylined with me on the story. Well, again, I forget the exact sequence, but I do recall that my job would have been to ring one or two of the contacts that Bobbie may have given me and also to put a call into the Department of Health, where I think I must have spoken to Romola Christopherson, now sadly no longer with us, but then the chief head honcho of news at the Department of Health.<sup>37</sup> I remember her saying something to me along the lines of: 'Oh yes, hmm, yes, I think I can tell you something about this - I'll get back to you.' I knew at that point that it was true. I then went off to see David Hughes, in the next room. You have to remember, I was the new boy on the block then, nobody really knew who I was. I went to see him and explained the story and he gave me the same look of slightly guarded cynicism, you know. Was I turning up with a story that had been hyped up beyond belief? He said, 'I'll just put a call in to No. 10.' Well, about 20 minutes later he came running back into the news room with a gleam in his eye, the gleam that you only see in a reporter's eye when they know they've got a cracking good story, and he said: 'It's true! It's true!' At which point all I need say is that the story then moved up a gear. It was, I think, the easiest and quickest of that nature that I've ever had to substantiate because it took, I think, three phone calls to have the whole story in my notebook. And by seven or eight o'clock that evening the story had been written and sorted. I remember, after speaking to Romola Christopherson, I certainly spoke to Kaye Wellings who's quoted in the article.<sup>38</sup> I also spoke to Professor Roy Anderson. I don't remember whether I spoke to other sources, whom I didn't name, but those were the people that I recall speaking to and then quoting in the article. I was delighted when Kaye Wellings, as it were, fell into my lap, because she was able to tell me in great detail, enough to completely substantiate the story and make it sound as important as it was, as did Professor Anderson. I think that if it had gone to the Department of Health, they (the press office) would have given me a statement too. The whole thing simply tumbled out and I was able to go home at ten o'clock or so that night, feeling that I'd done a good week's work, and a good job done.

<sup>&</sup>lt;sup>37</sup> Dowman (1996).

<sup>&</sup>lt;sup>38</sup> Mr Mike Durham wrote: 'The veto has angered AIDS researchers. "This is not a survey motivated by prurient curiosity into people's private lives," said Kaye Wellings, a research officer at the Health Education Authority. "It is unthinkable that this study should not go ahead. A tremendous amount of hard work and careful preparation has gone into making it reliable. The data is urgently needed for prediction and prevention of HIV."" *The Sunday Times* (10 September 1989), front page. For the complete story, see Appendix 1, pages 61–3.

When I woke up the following Sunday morning, as I had expected, the story was a splash on The Sunday Times, and when I turned on the radio, the story was being repeated on all the morning political and Sunday morning news programmes. It was on the BBC World Service, on every single news programme, it was the lead news on every single TV channel that day, and I thought: 'Well, I think I'll have a day off.' I have to say, it was every journalist's dream: a story that tells itself and actually is true and can be confirmed within three or four phone calls. And there we are. I've met almost nobody in this room before. I'm probably the only person here without any kind of medical qualification. All the same, I like to think that the work I did then by giving this story a little bit of a push, it may have saved a few lives. It may have had a little bit of an impact on medical advancement. And I must add that I'd be interested to hear what others have to say. I don't personally believe that I was hand-picked or set up in any way to be given this story. It would have come out anyway at some point. But I had a reputation then as being a little bit of a newshound and I was perfectly happy to follow anything up and find the truth about it, and this had just come my way. I probably got there a little bit earlier than anybody from the HEA or any of the funding bodies might have expected, but I'm sure they would have found their own way of revealing this story in due course. But I was lucky. As I say, I didn't have time or the opportunity to follow the story through, I wasn't a feature writer at the time, so it was something that crossed my desk only for a matter of a few days and I've had very little to do with it since, although I remained aware of what happened. The coda for me, the outcome, was a good one because about three or four months later I was actually appointed health affairs correspondent to The Sunday Times and I think this story may have had something to do with it.

Adler: That's a really fascinating story, Mike, thank you very much indeed. You did make a very significant contribution in terms of opening a log jam. Maybe we should hear from Deep Throat?<sup>39</sup> Bobbie, do you want to say something?

Dr Bobbie Jacobson: I want to say two things: one is that memory does play tricks on you, doesn't it? It's not the *Aricept* type,<sup>40</sup> but the more important

<sup>&</sup>lt;sup>39</sup> 'Deep Throat' was the pseudonym given to Mark Felt (1913–2008), former deputy director of the FBI, who gave information to Robert Woodward, reporter for the *Washington Post*, regarding the involvement of Republican President Richard Nixon and senior White House staff in an attempted burglary at the Democratic campaign offices at the Watergate Hotel, Washington DC, in 1972. The name was an allusion to a pornographic film (dir. Gerard Damiano, 1972) that had gained notoriety at the time.

<sup>&</sup>lt;sup>40</sup> See note 33.

point I want to make, and particularly as there are quite a lot of researchers here today, is that we should never forget the front line in public health, because that's where important things get found out, understood and delivered. I've got a slightly different recollection from Mike: I recall that I heard the rumour - I believe I've worked it out backwards - when I was working as a trainee in public health medicine, along with Anne [Johnson] and some others. That's my recollection of 1989. We were in the then City and Hackney Health Authority in their public health department, which has since been reorganized about four, five or six times. We did a little bit of research among colleagues before today's event and I believe the person who told me the story was somebody called Lynda Jessopp, who was the women's health lead in the then health promotion department of City and Hackney.<sup>41</sup> She was a very passionate woman who believed very strongly in equality: equality of access to information. She was therefore considered a thorn in everybody's side, because she was seen to be more politically correct than anybody else. What she told me was not that she had understood that Mrs Thatcher had stopped this going ahead, but that the Department of Health, she thought, had stopped it going ahead. Now, I can't remember how many sources back from that she got that information from, but she obviously had good sources for the information that I gave to Mike. I usually think three times before giving him, or any journalist, any information, [Laughter] I never talk in my sleep and haven't ever done since, because, as you know, The Sunday Times has all kinds of ethical codes that are not always in the interest of public health. But this was one, I thought, that if there was any truth in it, absolutely should be pursued to the front page, although I thought then that it was quite a low-key rumour that there was something going on in the Department of Health that had stopped this piece of work, or had stopped the funding for this piece of work. That was the information that I gave to Mike. I believe that he may have spent more than a couple of hours finding out that it was actually Mrs Thatcher who had stopped it, because when Mike came home and told me that, I was absolutely amazed that we had initiated this profound story that then led to the consequences that it has had.

Durham: Can I just add, I'm sorry, I'm sure that Bobbie is right that the initial information that I had was that it had been blocked by the Department of Health, which is why, when I rang the Department of Health, they were quick to confirm it directly to me. Presumably they were on the phone to No. 10 straightaway, but were very happy to shift the blame to No. 10.

<sup>&</sup>lt;sup>41</sup> Lynda Jessopp left City and Hackney in 1990 and went to work in south London.

Adler: It is funny how selective memory works, because, Bobbie, I was your moral tutor when you were a medical student and obviously I have set a very fine example for you. [Laughter]

Wellings: Lynda Jessopp did her Master's degree with me but that has absolutely nothing to do with it. Just to fill in on this business of the timing. Mike suggests that it was luck on his part, but let's just think about that year, because we're moving forward. The ESRC wrote to the team in January 1989 saying that their response for the proposal had been positive and that they were going ahead. So that was January 1989. Then plans started to be made and the sample was drawn. In March 1989 Professor Howard Newby of the ESRC<sup>42</sup> wrote to Julia and said, 'I'd like to alert you to the current need for extreme caution in giving information about this survey to anyone outside the main participants. This need arises because of the present delicate stage reached in the negotiations to fund this study and the extreme sensitivity of the Government to any publicity at this moment.' This is in March, and your article, Mike, (see Figure 5/Appendix 1), was in September. 'Should the popular press, or indeed the serious press, pick up on the survey ahead of any announcement, there is a possibility that funds might be jeopardized. I'm particularly concerned that the press might give attention to the outcome of the pilot work. I don't want to appear alarmist, but nevertheless feel the need to proceed very carefully for the next few weeks.<sup>43</sup> So he urges Julia, and those to whom the letter was copied, not to speak publicly about the survey. So we were really gagged at that point and it was made very clear to us also by the Department of Health that we must not speak about it. And we didn't speak about it, but I think it's fair to say that morale in the team became very low over the next seven months because the sample was dying on its legs. Julia will say more about it. We did remain quiet but we tried to find out; indeed because I was at the HEA I quite often came across civil servants, and there was a particular civil servant at the Department of Health,<sup>44</sup> and one day over lunch I said, 'What's happened to our survey?' 'Ooh,' he said, 'It's reached astronomical levels of decision-making.' So I said, 'What do you mean? Ministerial?' 'Oh no, beyond that.' [Laughter] So, you

<sup>&</sup>lt;sup>42</sup> Sir Howard Newby (b. 1947) was director of the ESRC Data Archive (1983–88), chairman of the ESRC (1988–94), and chief executive (1994).

<sup>&</sup>lt;sup>43</sup> Professor Howard Newby, personal communication to Julia Field, March 1989. Letter in Professor Wellings' personal archive.

<sup>&</sup>lt;sup>44</sup> We believe this was a senior medical officer in what was then the Department of Health's AIDS Unit.

know, beyond ministerial only means one thing or one person.<sup>45</sup> But just to say, about the luck, by September we were all getting very, very fed up and we no longer believed that if we were quiet and kept our counsel that we would have this thing funded. So I actually had lunch with Thomson Prentice of *The Times*,<sup>46</sup> only a couple of weeks before you got the story, and we were fed up of being quiet and well behaved and thought that we hadn't achieved anything by that means. So I told Thomson about it. Thomson said, 'I would run that story if I could possibly believe it'.

Adler: Did you know that, Mike? [Mike shook his head]

Field: I would just like to say that in the February/March period, the funding, as far as we were concerned, had been agreed. We had pretty much been given the go-ahead in the sense that we had all our documentation printed, we had dates arranged for interviewer briefing conferences and we were absolutely ready to go ahead, having already spent quite a bit of money, which is not something that a research organization can afford to do unless their funding is secure. It was then that we had to put everything on hold. So for us it was a very serious situation indeed, because our money was just not forthcoming. Then we were left in limbo for six or seven months.

Johnson: I think over that time there was also quite a lot of footwork to try to persuade the Department of Health to release the funds, and I know Nick Day, who was then chair of the Committee on Epidemiological Studies of AIDS (CESA) at the MRC, wrote to Donald Acheson in support of the study and expressing dismay at the delay. There was also a letter to David Mellor from our advisory group.<sup>47</sup> Also, I'm sure we'll come to this later, I'm looking now to the Wellcome Trust people because perhaps it will be after tea, but I think Donald Acheson had a big role in trying to persuade ministers that this was an important study to fund. My memory is hazy, but I think I remember speaking to Acheson over the summer and it was quite clear that he was pushing hard, and I think I remember saying that we were finding it difficult to keep quiet, but I was counselled then to keep my mouth shut for a bit longer. I also remember Kaye

<sup>&</sup>lt;sup>45</sup> Mrs Margaret Thatcher, Prime Minister (1979–90).

<sup>&</sup>lt;sup>46</sup> For uncorroborated background information on Prentice's activities around this time, see www.whale. to/b/walker\_ch26.html (visited 22 September 2010). Thomson Prentice went on to work for the WHO press office and has been involved in the organization of the Wellcome Trust-funded Global Health Histories seminar series.

<sup>&</sup>lt;sup>47</sup> Letter to David Mellor, 20 July 1989. A copy is deposited in the Wellcome Library GC/253.

ringing me on that Friday afternoon, saying that a chap from *The Sunday Times*, a mate of Bobbie Jacobson's, had been on the phone. I was quite concerned, you know; I think we wanted to see the story resolved, but we were also nervous that it was going to put the thing on the floor. We'll hear about that later. I got very cross when I had to get out of bed to buy *The Sunday Times*, which was against my principles.

Adler: I think maybe we should park it there, because it's very interesting, and then come back to it. Graham Hart, I know you weren't at the department; you were permanent secretary from 1992. Is there anything that you might have picked up that you could throw into this mix at all?

Sir Graham Hart: No, as I've explained to Tilli Tansey, I certainly wasn't in any way involved with it. I was actually in the Department of Health in 1989, but I was trying to sort out one or two little issues that we had with the management of the health service,<sup>48</sup> and all this was dealt with on the public health side. I'm sure that Donald Acheson was absolutely deeply involved in all this at the time. So, I haven't really got that much to say, but I have one or two questions. A lot of these doubts about exactly what happened and who said what to whom, would be answered, or might be answered, if one now had access to the official papers about this, and the 30-year rule is about to become the 20-year rule, is it not?<sup>49</sup> And there must be some papers somewhere that might cast some light on this, although, God knows whether they can ever be found, in an old warehouse up in Lancashire or somewhere. I'm just speculating, indeed asking questions. It was interesting that we were told – I haven't read the source myself - that Kenneth Baker said that one of the people involved was George Younger, who was the Secretary of State for Scotland, I think, at the time. So I guess a question is, presumably, was this survey to cover Scotland as well as England and Wales? So the Scots would have been in on it. So that is another line of, shall we say, discussion in government that would have been, I think, quite close

<sup>&</sup>lt;sup>48</sup> See, for example, Flynn *et al.* (1990), and the Witness Seminar held at the LSHTM on the NHS management reforms, in which Sir Graham took part, http://history.lshtm.ac.uk/Griffiths%20Inquiry%20 Witness%20Seminar%20final%20versionsecure.pdf (visited 8 February 2011).

<sup>&</sup>lt;sup>49</sup> The 30-year rule is a legal arrangement under which government documents are made available to the public at the National Archives, Kew, by the time they are 30 years old. A review chaired by Paul Dacre (editor of the *Daily Mail* since 1992), with Professor Sir David Cannadine and Sir Joseph Pilling, conducted between January and April 2008, found the 30-year period to be 'anachronistic and unsustainable' (page 26) and recommended reduction to 15 years (page 30), Dacre *et al.* (2009). On 25 February 2010 the Ministry of Justice announced its decision to reduce the time period to 20 years, (Ministry of Justice (2010)).

to the Prime Minister of the day, because George Younger was, I think, quite close to her. What his views on this were, I don't know, obviously, but that's an interesting question that arises.

The next point is that I don't know who your colleague at *The Sunday Times* spoke to in No. 10 – are we in the Bernard Ingham era?<sup>50</sup> Would that be the era? Government departments often, when they're asked questions of this kind, react with embarrassment: 'Oh dear, how can we avoid answering the question?' Or 'How can we kick it into the long grass?' But I should think that No. 10 were absolutely delighted to confirm the truth of this story, actually. I think that it would not have given them a moment's hesitation, because there would be certain elements there, including for all I know the then Prime Minister, who would be pleased to be named as having done it. I mean it's very shocking to all of us, no doubt, but there is not necessarily a great downside from her point of view in the politics of this. And we are in a period at the end of 1989, again looking at the politics of it, when life wasn't too easy for her. She'd been in office for ten years and I'm not sure how this links up with her losing some of her greatest lieutenants, but when was Geoffrey Howe?<sup>51</sup> Certainly, things were quite troubled at that time, politically.

My third question is whether the story breaking precipitated a final decision, and clearly from what a number of people have said, it was going to break in some way from somebody very soon, so I don't want our friend over there [Mike Durham] to feel bad about this in any way. Let me say this, it may be, for all I know, and only the documents would tell you this, or some of the participants, that at that point, the episode was not done and dusted. We are in, when did we say, middle of September? They had all been away, you see, for August. Not much happens in the political process in August normally, at least it didn't in those days – it's a bit different now. It may be, for all I know, that Ken Clarke, who was a doughty fighter, hadn't accepted the view, if it was the view of No. 10 at that point, that this should not go ahead or that the DHSS shouldn't pay for it. That was actually the point, wasn't it? It may be that, at that point, he

<sup>&</sup>lt;sup>50</sup> Sir Bernard Ingham was chief press secretary to Mrs Margaret Thatcher from 1979 to 1990.

<sup>&</sup>lt;sup>51</sup> The Rt Hon Sir Geoffrey Howe resigned from the Cabinet on 1 November 1990 and strongly criticized the Prime Minister in his resignation speech to the House of Commons on 13 November. Thatcher resigned nine days later, on 22 November, and Howe's speech is widely held to have been a factor. See biographical note on page 80. Howe's resignation speech of 13 November 1990 can be found at col. 461 (www.publications. parliament.uk/pa/cm199091/cmhansrd/1990-11-13/Debate-1.html (visited 1 February 2011)).

didn't regard the issue as settled. You don't necessarily accept the first view that you get from anybody. Maybe he was hoping to return to it, and maybe that was Donald Acheson's view, that they could return to it, and they could, by persuasion, win the argument. I mean, going back in history to the earlier stuff, you remember the iceberg and all that business, those fantastic adverts, which were absolutely groundbreaking.<sup>52</sup> They just didn't happen because somebody thought, 'Oh, it's a good idea to do this.' There was a hell of an argument about all that before it was done. So, it may be that the argument was still going on and the phone call precipitated what probably was inevitable, in due course. But it all happened on a Friday afternoon. We all know what Friday afternoons are like. So there are quite a few questions, I think, that are still unanswered.<sup>53</sup>

Adler: Thank you, Graham. I think we'll come back to this. Mike, just let me clarify this: No. 10 did not deny it when your colleague went back?

Durham: No, they didn't.

Adler: They just said, 'Yes, this is true.' And Romola Christopherson?

**Durham:** Yes, my recollection is that Romola passed the buck, as it were, to No. 10. We got confirmation, the political editor got confirmation directly from No. 10, which surprised him because he'd originally doubted that the story was true, so I remember him being rather surprised that No. 10 was so immediate about going to it. I think probably the Department of Health came up with a rather lame statement of some sort afterwards, also confirming it.<sup>54</sup>

Dunnell: I wanted to say a bit more about the context, particularly in relation to social surveys, because this was the decade when Mrs Thatcher's big Rayner review was conducted.<sup>55</sup> As Graham has just said, the Rayner Report very much emphasized that the government shouldn't be collecting data from anybody unless somebody could make a very, very strong case for financing it. It was also

<sup>&</sup>lt;sup>52</sup> See note 20. The Wellcome Library has digitized nearly 3000 AIDS posters from 99 countries. See, for example, http://library.welcome.ac.uk/aidsposters (visited 28 July 2010).

<sup>&</sup>lt;sup>53</sup> For Virginia Berridge's comments, see note 106, page 61.

<sup>&</sup>lt;sup>54</sup> Professor Virginia Berridge wrote: 'This contribution is interesting as it shows there is no real evidence that Mrs Thatcher cancelled the survey, only that Mike Durham's intervention caused No. 10 to claim the credit.' Note on draft transcript, 14 April 2010.

<sup>&</sup>lt;sup>55</sup> Sir Derek Rayner, later Lord Rayner, adviser (1979–83) to Mrs Margaret Thatcher, was responsible for conducting a series of reviews aimed at promoting efficiency in government (Rayner Report (1980)). See Reynolds and Tansey (eds) (2008): 107.

the time when the government prevented the then chief medical statistician in OPCS from properly publishing the decennial review of class differences in mortality, which created another great big scandal. It was something that had been done every ten years since 18-something.<sup>56</sup> It was also a time when we were not allowed to collect information about social class on things like drinking and smoking surveys. My understanding of it, and I was quite junior then, was that this was coming right from the top; Mrs Thatcher was very sceptical about the value of this kind of information, and particularly about government financing of it. Officials, certainly those in OPCS, got into trouble for standing up in public about decennial supplements, social class analysis, all that kind of stuff. I'm pretty sure that lots of people in the Department of Health would have been in exactly the same position, feeling that they couldn't really do their job without this information. It was very difficult.

Wellings: Just a clue as to what was going on during that year. In June 1989, I have a letter on file from Professor Howard Newby to Jack Barnes, who was director of the research management division at the Department of Health, who would have been, if it was June,<sup>57</sup> that's three months, four months on, he would have been asked to just check out why such a big survey, such a costly survey, was necessary, and also whether people would remember. It would have been easy for them to have banned it on the grounds that it was too expensive and wasn't necessary, and people wouldn't remember anyway, which actually is what was reported later. So this letter from Howard Newby says - he answers the question of why such a big sample is needed, and then he says, regarding recall: 'The questions that make appreciable demands on memory... I hope this letter serves to clarify the points you raised, and that it will provide the information we and all the public health agencies involved in AIDS and HIV require.' Now it's already been through the Chief Scientist's office, so it's odd that the head of research at the Department of Health (Barnes) should be asking Howard Newby these questions, and it suggests that it would have been easier to veto it on scientific grounds, so I think that's strongly suggestive that an excuse was being looked for at that stage.<sup>58</sup>

Adler: Right. I think Graham Hart's point about trying to get access to some of the papers is important. I think we could spend the rest of the afternoon

<sup>&</sup>lt;sup>56</sup> The first data collected on class related to mortality was in 1837 by the General Register Office (civil registration of death) overseen by William Farr, as compiler of abstracts. See Magnello (2006).

<sup>&</sup>lt;sup>57</sup> See Appendix 2, pages 64–5.

<sup>&</sup>lt;sup>58</sup> Letter in Professor Wellings' personal archive.

on this particular issue and we will come back to it when we talk about the Wellcome Trust and how they picked up the funding. So could we move to the first NATSAL study? I think we ought to talk a little bit about the science now, and a little bit about the first NATSAL, the objectives and methodology.

Wellings: The explicit objective was easily condensed into the phrase of 'providing data which would help predict and prevent HIV transmission'. You know, as Anne said, the focus was HIV. Even as we were writing the proposal, I think we realized that it was going to answer a whole host of questions of relevance to public health policy, which there hadn't been data available to answer before. So, even though we were pinning it on HIV for obvious reasons, we were very aware that it would answer a lot more questions. Indeed, in the subsequent surveys, we've made far more of that – this is for sexual and reproductive health generally.

**Johnson:** That's right. I'd like to think back to what it was like planning the survey. We spent an enormous amount of time together. As I remember, at SCPR, sometimes we were followed by Celia Lowenstein with her camera crew making a BBC Horizon programme about us.<sup>59</sup> It was fairly new territory, doing a study like this, and we spent an awful lot of time designing the questions and talking about exactly how to word them, and laughing quite a lot. It was immense fun and very interesting. We also spent a lot of time briefing interviewers and talking to them about the experience of introducing this survey on the doorstep and interviewing them in a way that people felt able to answer accurately and comfortably about areas of their lives that had not been part of the usual sort of scientific enquiry. I was reminded about how po-faced we had to become about the whole area, because this was not, as we used to say, seen as a 'legitimate area for scientific enquiry'. We wrote about the survey in very dry language, I think, because we were so keen to make this OK for scientific study. I think Tony said it was OK to study the gay epidemic, but it was actually quite difficult to study, as it were, the population level of sexual behaviour. I wrote an e-mail to Tilli Tansey before I came here, reminding myself of the media coverage when we first published the surveys. We had a lot of help from the Wellcome Trust in that, in selling a story about the results of the study, which was actually seen as rather dull. 'Everybody's not doing it' was one of the headlines and actually that turns out to be, in retrospect, exactly what this first survey showed. We didn't

<sup>&</sup>lt;sup>59</sup> The BBC2 *Horizon* Special, *The Truth About Sex* (directed by Celia Lowenstein, produced by Max Whitby), was first broadcast on 12 October 1992 (Wellcome Library, Moving image and sound collections, 453V).



Figure 6: Julia Field, Jane Wadsworth, Kaye Wellings and Anne Johnson pictured in the Wellcome Building, *Sunday Telegraph*, 30 January 1994.

know at the time, but in 1990 we were probably studying sexual behaviour at its most conservative since before the 1960s. Maybe that's why we found those apparent declines in numbers of lifetime partners in recent years, which we thought might just be an age-related bias in our measurement as younger people had been sexually active for a shorter period, but actually turned out to be true. The headline that I think I remember most portrays the four of us, myself, Kaye, Julia and Jane – sadly, very sadly, Jane Wadsworth is not with us today, she died in 1997. The four of us are standing in the old Wellcome Trust building with a large headline over us, looking straight as a die, with our dangly earrings saying: 'No sex please: we're scientists.' [Laughter]

Wellings: You've got to mention the caption. It was: 'Four women in search of vital statistics.'

**Field:** There was certainly a lot of nervousness around our organization about tackling this subject; also within the research team designing the questionnaire. It's hard to think back now to the fact that there was very little openness, even in the media, about the use of any kind of sexual terminology. Nobody knew

what language to use or how open it was possible to be, and all of that kind of discussion was certainly very important in our early meetings and trying to decide what might be possible to ask about and in what kind of terms. It was a very nervous situation and, for example, when it came to organizing interviewers, we were very careful, in a way, that we didn't have to be with any other surveys, to invite them to take part and then to make clear to them that they should not sign up to do this survey if they were going to be in the least bit embarrassed about asking the questions. So, those kinds of issues were very, very much around then. I don't think it's just our familiarity with the survey now, but the general familiarity with the subject and the openness that perhaps HIV itself generated, has made it so much easier to talk about these subjects, which, 20 years ago, was quite a different scene.

Adler: Do you want to say anything more about the development of the tools and the methodology?

Williams: Julia, do you remember that for the interviewers, we had to go up and be what was called 'desensitized'? Do you remember that? We had to go in to the National Centre for Social Research (NatCen) office for two days and sit there while every term connected with sexual activities was told to us, because the project managers were concerned that when we all went out to do the interviews, we would come across all these sorts of things and we were not supposed to respond, obviously. We had to be separate from it. Do you remember that? Two days we were there. The interesting point was that at the end of that time, we were asked whether we wanted to continue to be put forward to do this survey at all, and loads of the men refused to take part. The male interviewers dropped out at that point; the women didn't mind, but the men dropped out.<sup>60</sup>

Johnson: One thing to say about the measurement of sexual behaviour is that there was – and there still is, actually – tremendous questioning by people about whether you can ever get accurate information. We did a great deal of work trying to work out how to ensure that people were consistent in what they

<sup>&</sup>lt;sup>60</sup> Julia Field later added the following explanation, quoting directly from the unpublished report of the pilot and feasibility studies: 'Before embarking on the qualitative research phase, researchers and all interviewers involved, including those who were only to recruit respondents, attended a day long familiarization/ desensitization day arranged for us by the Family Planning Association...designed to reduce embarrassment in talking about sex and in hearing various words and phrases that might crop up in questions about sexual behaviour. Although it proved to be an interesting day, nobody felt that it provided training that was really appropriate to our needs.' E-mail to Ms Caroline Overy, 14 February 2011.

said and designed the questions in such a way that privacy and confidentiality would be at a maximum, and that terms were clearly defined and so on.<sup>61</sup> There is still a lot of work being advanced to try to improve measurement in sexual behaviour, but I think what always struck us was that there is an enormous amount of measurement error in almost any area of science, be it measuring people's income, how much they eat, how much they sleep. Indeed, there is an enormous amount of measurement error of the same sort in the laboratory, where you haven't got much attention to test–retest, observer reliability and repeatability, and so on. That has been something that we've had to pursue doggedly for the last 20 years, and still do. But we've always argued that it was no different from any other area of science.

Wellings: Following on from that point, Anne mentioned the efforts made to improve reliability and also validity, at the time when SCPR were doing the very, very careful work with us on language. Many of the terms that we were asking people to define, and were asking them what they meant, and to describe what they meant for them, were in common use in the AIDS campaigns. We found in our qualitative interviews that there was a tremendous lack of comprehension of many words like 'heterosexual', 'homosexual' and 'oral sex'. People didn't understand those words and phrases although they were in common currency in all the public education works. So, in a way, it was much more than simply measuring the behaviours and finding out where the risk groups were and what was needed – we learnt a lot about the words people use. The Times picked it up in a really bad way, which was very unfortunate. But it was the case that all the Latin-sounding names, or any word with more than three syllables, was thought of as something completely weird and unorthodox. [Laughter] What people usually said was: 'We did it. You know, we had it.' And so words like 'vaginal' caused confusion – I remember a man, I'm sure Julia will too – he was 35, he had children; and when asked what vaginal meant, he said, 'Ooh, no, no, no. I wouldn't do that, I don't like the sound of that.' It was really because it sounded so strange to him. There was that mismatch between the public health language and the language of everyday, which was so full of euphemisms. We started doing this because we'd read the Kinsey Report and Kinsey's advice was that you should use the language that people use, but it was very difficult.<sup>62</sup> Of course, Tony said the same thing, and it was completely understandable when

<sup>&</sup>lt;sup>61</sup> The issue of data reliability is addressed in Wellings *et al.* (1990); see Spencer *et al.* (1988) for the use of language.

<sup>&</sup>lt;sup>62</sup> Kinsey et al. (1948): 52; and (1953): 60–1.

you've got a homogeneous population, but when you've got a heterogeneous population and you start using street terms with the lady who lives in Penrith, who has been married for 50 years, it doesn't always work in the same way as when you're interviewing someone very young. So, we took a completely different view from Kinsey based on that very important qualitative work. We tailored the language, but we used a glossary. We described in very operational terms what we meant, rather than leaving it to individuals to try to understand.<sup>63</sup>

Adler: Wendy, let's go back to you, because you were at the sharp end. All these academics sitting in their ivory towers were telling you what to do, but you were the one out there in the field with your colleagues. Just tell us a little bit about how you were received. I know you can't generalize, but give us a flavour of that.

Williams: As I said before, generally, to encourage people to take part, you emphasized that this was necessary for society.

Adler: Can you remind us, this wasn't cold-calling, was it? Do you want to talk about that?

Williams: I can't remember whether we had sent letters beforehand or whether we took them with us. I think we took them.

Field: The sampling was pre-selected addresses so that the interviewers knew which addresses they would be going to. But on the doorstep it was up to the interviewers to introduce the survey, introduce themselves and persuade people to participate.

Adler: So for the respondents it was cold-calling?

Field: Yes.

Williams: We did have a letter we could leave with people. We also had to make a selection of the people, you didn't interview everybody in the house. You had to select one individual.<sup>64</sup> Sometimes it was a bit of a problem when it was a man who was required and one of the interviewers was a young lady and the wife was not particularly keen on her husband discussing sex with this lady who has just knocked on the door, but when you actually got in and were doing the interview it wasn't too bad. As I said, normally you would establish rapport

<sup>63</sup> See Johnson et al. (1994): 349.

<sup>&</sup>lt;sup>64</sup> Mrs Field wrote: 'Which individual in the household to interview was determined according to a strict randomizing procedure, not just convenience or the choice of the interviewer.' E-mail to Ms Caroline Overy, 14 February 2011.

with the subject quickly so that they would give us any information, but, in this survey, there had to be a distance between you and the interviewee. Not so much with the women, but if it was a male subject and a female interviewer. We had the self-completion booklets that the subjects were supposed to fill in by themselves. We were told that we had to make ourselves busy doing something else so we weren't watching them, so we were told to, you know, have a newspaper, and I think one lady actually did her knitting while they were doing that part – I used to do a crossword. But, invariably subjects, especially the ladies again, used to ask us: 'Well, what does this mean? Does it mean when I was doing so and so with such and such?' This is what we were saying about the language. They did not understand some of the definitions, which just didn't mean anything to them. So they had to ask us to verify that what they said fitted into the particular section.

Field: Obviously, we had been concerned as to whether it would be a problem for interviewers and whether they would get into awkward situations. But I think the experience was such that, even with the huge sample that we interviewed, in the end it actually wasn't really any different from a survey on any other subject in those terms. There were hardly any more difficult incidents than would happen on any other survey.

Adler: Tony, you must have been through all of this in a slightly different context. Was this familiar to you?

**Coxon**: Very familiar, yes. We in SIGMA finished up having a sheet with terminology for sexual behaviour, including both medical name and 'street' name, and going through the list with each respondent before we started, asking them whether they understood what each term meant. They were also asked to give their preferred term for each. Then a set of their preferred substitutions was used throughout the interview. Yet usage was by no means predictable. There were some people who would, in their ordinary language talking among themselves, use street terminology, but wanted to be interviewed using medical terminology – that was not an uncommon response. So, what we did was to establish the preferred terminology and description first, and, yes, indeed, it was a very important issue.

Wellings: Sorry, there is another point here; it may be getting too methodological, but another concern was that people used different terms in different contexts. One interview I did, in the qualitative interviews, was with a man who described three different terms and said, 'it depends what you mean'. He used three

different terms for the same activity with three different partners. So, you can imagine how the terms he used might have varied. [Laughs] I won't have them put on record, but they were different with the different partners.

Coxon: With different partners - indeed so. Indeed so.

Wellings: So using the same term all the way through was inappropriate. One of his was 'got her pants down'; if we'd used that term all the way through, when asking about his wife, as opposed to what he was talking about, with his girlfriend at the time, it may have been problematic.

Coxon: Yes, partner-specific language is interesting.

Wellings: Partner-specific language also concerned us, didn't it?

Adler: And, of course, we'll talk later about how the methodology has actually moved on with subsequent NATSALs and some very interesting developments in terms of how you collect data, which we'll talk about later when we talk about future NATSALs.

Johnson: I wonder whether we should say anything about impact, about whether it's been any use, about what the impact has been? Because the expectation was that it would serve some kind of public health function and I wondered if you wanted us to reflect on whether it's been used?

Adler: David, is there something you want to say before we move on?

**Professor David Gordon:** I was formerly at the Wellcome Trust. I was very struck by Tony Coxon's comment early on – his published reference now<sup>65</sup> – about how the presentation of the first NATSAL was a little bit pedestrian.<sup>66</sup> I think when we from the funding side were concerned about how the survey would appear, not the paper in *Nature* but the press and the television reports, an awful lot was done that, in the end, made it rather dull, but very factual. Some of us went through a kind of desensitization process such as has been described for the interviewers. I remember being stuck in a television studio with Keith Hatfield, who was doing media training for the Trust at the time, and Valerie (Val) Beral and another colleague were behind a glass partition. We were pretending to be a radio phone-in programme and Val and her colleague were trying to get me to corpse by asking me about the most obscure sexual practices and what would I advise, and they succeeded.

<sup>65</sup> i.e. in this volume.

<sup>&</sup>lt;sup>66</sup> See page 20.



Figure 7: Kipper Williams' cartoon, The Sunday Times, February 1994.

We also spent quite a bit of time – I'm sure the team will remember – talking about the extent to which the outputs from the survey would be of interest. Would the book sell a lot? What would happen to the royalties, and so on? I think the outcome of those discussions was that lawyers made quite a bit of money talking to us about it, and because we'd been so exact about the terminology and so clinical about the presentation that no one made any fortunes. So, in the end, reflecting on it in terms of the impact, that was probably the right outcome. It was discussed and the public got to see it, but no one seized on it in a prurient way.

Adler: In retrospect, was it wrong to make it dull and not a potboiler?

Johnson: Well, I think that in the end it was the right thing to do. Although we didn't make much money out of it, we were trying to produce reliable statistics based on good science. It was very important to us that this was good science. I've actually got the Kipper Williams cartoon, which I shall pass round, that appeared in *The Sunday Times* and recommended our wonderful book, that we'd worked so hard on, as a sort of cure for insomnia or as a passion killer, because it was so boring (Figure 7).

Adler: But, Anne, you haven't answered the question.

Johnson: So, I haven't answered the question.

Adler: So, good science. No one's disputing that it was good science, but I'm asking you: was it wrong, in retrospect, or do you regret, in retrospect, that it was dressed up in this very dull manner?

Wellings: No, not really. I think it has to be contextualized, doesn't it? By the time the book came out, the public was very well aware of everything that had happened with Mrs Thatcher. Why had Mrs Thatcher banned it? It was assumed to have been a very titillating and scurrilous thing. What was this book going to be about if the Prime Minister should ban it? I don't think you can help but see it in the context of what preceded it in terms of public expectations. In terms of what followed, we were funded subsequently by the MRC. Now if we had made far more popular use of the data, I think that might have jeopardized its continuation. We can relax a little bit more now, but even now, I still think there's enough daftness made out of sex to warrant something sensible.

**Johnson:** I think this is a question I have to address with respect to the third survey, planned for 2010: how do we communicate these results most effectively? Kaye, you've always talked about the importance of normalizing sex and of the perception out there among 16-year-olds that everybody is having sex except them. That comes from magazine surveys, whereas we know from the NATSAL-1 survey that we got much more conservative population estimates of behaviour. There is a question of how we communicate the results better. Those who used the books found them extremely useful, because all the data were there, but they went out of print. We've published the second survey in a tranche of some 50 academic papers in very different journals and made the data available on a website, but it isn't a public facing website.<sup>67</sup> Kaye and I came to this Witness Seminar after a meeting with the Wellcome Trust today about how we might disseminate the data from the third survey. It is incumbent on us to make the data available beyond the academic and policy arena in a way that people can use in their everyday lives, or can be used through NHS websites, or used in a more popular format. So I think we should most definitely work on that aspect, now that we have a little bit more confidence that the data are very widely valuable. Luisa Dillner, who writes a column in the Guardian, is a great fan of ours and constantly quotes NATSAL figures in her sex and relationships column.<sup>68</sup> We should make the data more widely available and more approachable.

Wellings: I think that is probably different; we can still be serious about it, but simpler. You know, we can put the data into a form, we can get others to help us

<sup>&</sup>lt;sup>67</sup> See www.natcen.ac.uk/natsal/pubs.htm (visited 15 November 2010); the dataset is available from the Data Archive at the University of Essex, www.data-archive.ac.uk/ (visited 25 January 2011). Registration is required to access the data.

<sup>&</sup>lt;sup>68</sup> Dr Luisa Dillner wrote a statistics-based relationship advice column in the *Guardian* until 2009; Dillner (2009).

put the data into a form that's more easily understood. That doesn't necessarily mean making it appear to be sensational.

Adler: There is another audience out there: the punters. Actually making it accessible when they don't read the *Lancet* and your tomes, in terms of helping them to understand what's going on around them, and normalizing their own behaviour. But don't let's go there now, because I think we can come back to that.

I haven't forgotten your point (Tony Coxon) about whether any of this was useful, or how it was used. I think we'll come back to that, if we may, towards the end, because I think that it is very important. What were the policy implications and how was this used to develop strategies?

Let's go backwards a little bit now, because we've talked about the first NATSAL, we've talked about some of the methodology, we've talked about the interviewing and some of the problems there, and we've talked about how attempts were made to validate the data, but we had to stop slightly short in terms of funding. I'm delighted that Sir Roger Gibbs is here. He was chairman of the Wellcome Trust, he insists, after September 1989 – is that right? 1 October 1989?<sup>69</sup> Well, we have three of you here (Sir Roger Gibbs, Professor Sir Stanley Peart and Professor David Gordon), so we're going to make you talk. Sir Roger, since you weren't here, we've got as far as talking about Mike Durham's story, about the fact that the story was that Mrs Thatcher had personally intervened to stop the survey taking place, or being funded. We think that some phone calls must have taken place, probably with the CMO, Donald Acheson, and we're uncertain whether it would have been the then Director of the Wellcome Trust, Peter Williams, or not. I think it would be really interesting, because we as investigators know that things moved extremely quickly in terms of turning round the application and having it vetoed – is that right? And then saying 'yes', in a very, very short period of time. So it would be really interesting to get a feel for what actually happened. And, as always happens in these events, it looks like the junior is going to be the cannon-fodder. Is that right, David?

**Gordon:** I was going to say that now I've got my backing group, I can start to sing.<sup>70</sup> [Laughter] We've been comparing notes during tea, and of course, as retired servants of the Wellcome Trust, we've all of us left the papers behind so

<sup>&</sup>lt;sup>69</sup> Sir Roger Gibbs became a Trustee of the Wellcome Trust in 1983 and was chairman of the Board of Governors (1989–99).

<sup>&</sup>lt;sup>70</sup> Professor David Gordon was seated in front of Professor Sir Stanley Peart, Trustee (1975–94) and Sir Roger Gibbs (chairman 1989–99).

we are working from our very, very astute memories. So exactly how long after the story appeared it was that papers appeared at the Trust, I'm not sure, but we could clearly find that from the records.<sup>71</sup> The other thing that I think is not clear to us is by whom the first approach was made. It was to Peter Williams, who was director of the Trust at the time, but whether the papers were sent to him by Roy Anderson,<sup>72</sup> who was, if you like, part of the backing group for the survey, or whether they came from the Department of Health, we're not sure. We certainly know that Peter Williams had a lot of telephone discussions with Sir Donald Acheson at the time.<sup>73</sup> Anne and I both have a clear recollection that there was a little bit of regret that the story had got out when it did, because I think Donald felt that with a few more weeks he might have been able to persuade the Department of Health and No. 10 to change their points of view. However, the papers appeared at the Trust with the message: 'Would the Wellcome Trust consider funding the proposal?' So, out of the blue, I got a phone call from Peter asking if I could come and see him in his office in the old building in Park Square West, and there was the outline of the application and could we look at it? There were a number of things to be done. Obviously, the first was to make sure that the proposal was of a nature that could actually fit within the Trust's remit. That was fairly easy to do, to put it into a format that could be considered. Quite early on, we had a meeting with some members of the team, and some members of the steering group in the old boardroom at the Wellcome Trust with the big circular table. I think Anne was there and I'm pretty sure Julia was too. Whether everybody was present at that time, I'm not sure. But I certainly remember Anne Johnson, Roy Anderson and Kaye Wellings. This was around the time of considering the funding, but, anyway, we had to get the proposal refereed. We went to a number of people who'd already seen it, including one or two people who are here, and we went to other referees who hadn't seen it before. That is always rather a difficult thing to do because there had been such huge publicity and such a groundswell among many of the people who knew about the story that whatever happened, it should be funded. One or two of the

<sup>&</sup>lt;sup>71</sup> The relevant dates have been supplied by Mr Bob McLean, information governance manager at the Wellcome Trust; see Appendix 2. In accordance with the Wellcome Trust's archive access policy there is no general access to material from the meeting. E-mail to Ms Caroline Overy, 21 December 2010.

<sup>&</sup>lt;sup>72</sup> At that time Roy Anderson was a member of the Tropical Medicine and Infectious Diseases Panel (later the Tropical Medicine Interest Group) for the Wellcome Trust (1986–91; chairman (1991–99). He became a Wellcome Trustee in 1991.

<sup>&</sup>lt;sup>73</sup> For Dr Peter Williams' account of the events leading up to the Wellcome Trust's funding of the proposal, see Appendix 3.

new referees were, nevertheless, really quite carefully analytical about what was proposed and why it was worth doing. I think one should also say that it felt to me that the team was not absolutely unanimous that this was the right thing to do. Was the Wellcome Trust somehow too contaminated by its involvement with the Wellcome pharmaceutical company to be an appropriate body to fund this project?<sup>74</sup> Julia might be able to comment on that feeling at that time.

The referees were interesting. At an outfit like the Trust we had a feeling for things like statistics and epidemiology, and the referees reassured us that the statistics and epidemiology were clearly very strong. It was also very clear that the referees who knew about survey methodology knew that SCPR was absolutely the ideal organization to be responsible for a study of this size. The Wellcome Trust being the Wellcome Trust, the bit that caused the most puzzlement was, if you like, the social science, which is a bit of an oddity, because in many ways the social science – behaviour – is one of the main reasons for doing the piece of work. Nevertheless, it was really quite strongly supported by the referees as they saw it, and so it went to the Trustees with a group of opinions, I think about eight or nine, about a week and a half after it had appeared at the Trust. It went to a Trustees' meeting. I'm not sure whether it was the scientific Trustees or the Trustees as a whole, but they are here so they can sing to that bit. It was agreed pretty much at that time. But, after the agreement in principle, it did involve a lot of discussion with members of the team about how the funding should work, and with the advisory group, yourself [Adler], our chairman, Roy Anderson, David Miller and Roger Jowell, all of whom, I think, were quite behind the Trust and what it was doing. So, it actually sailed along quite easily.

Adler: Sir Stanley, you were a Trustee at the time. Were you involved in that decision?

**Professor Sir Stanley Peart:** I was involved, but my background, of course, was in clinical research and I was used to seeing patients with a disease with unknown origins. That tells you how long ago that was. So when this application came up to us, what concerned me was the fact that a veto had been put upon an investigation into a medical calamity. So that it wasn't difficult at all for me. It is not just due to antagonism to Margaret Thatcher, it's because the idea that somebody should veto a perfectly reasonable investigation without good

<sup>&</sup>lt;sup>74</sup> See, for example, Williams (2010). Chapter 11, written by Neil Collins, describes the first tranche flotation of 25 per cent of the Wellcome Trust's stake in the Wellcome Foundation in 1986, the rise in the share price of the Foundation as a result of the AIDS scare and the company's anti-AIDS drug AZT (*Retrovir*), see pages 87–9.

grounds was absolutely appalling. Nobody else in the Trust, among the Trustees in particular, was really opposed to it, as I remember. So it was with no difficulty that we agreed to support it. Now Roger Gibbs, as he says, was not quite the chairman at that time, but he had come across it, and I think that his view would be more interesting than mine.

Sir Roger Gibbs: Well, that is so wide of the mark it's hardly true. The way the Wellcome Trust worked in those days was that the Trustees – there were five scientific Trustees and only two laymen (the Trustees are now called Governors) – all took the view that the scientific Trustees should discuss all the intricacies of these important applications, then they would tell us, the two laymen, what they had decided. So I can't say that I played a major part in all this, nor did my predecessor David Steel, or the other lay Trustee, Peter Cazalet. It was the scientists who decided, but they always put forward the most important proposals to the main board of Trustees for a full discussion. I was always involved there. It was very rare that any of their proposals was turned back. In fact, I think there was only one occasion in the 17 years that I was a Trustee or governor of the Trust that this happened. Then our Director, Peter Williams, brought it back to us in a different and more detailed form. Then it went through on the nod.

Adler: Stan, it sounded like there were two reasons for Wellcome going ahead. One was to spit in the eye of Margaret Thatcher and the other was the science. Or am I teasing you too much? It sounded like you were delighted that you could. It's rather like the David Nutt situation now, isn't it, with drugs?<sup>75</sup>

**Peart:** We ought to separate those two factors. My political views had nothing to do with the decision. The decision was made on scientific grounds. You know, working among patients makes a big difference. If you see patients who are suffering from a disease that initially, when you saw it, didn't have a known cause, quite apart from the sexual aspect of it, then you have a very different view. What I personally wanted to see was backing for the research into this disorder, an ability to tackle it and prevent it.

<sup>&</sup>lt;sup>75</sup> In October 2009, Professor David Nutt was dismissed from his position as head of the Home Office Advisory Council on the Misuse of Drugs (ACMD) by Home Secretary Alan Johnson immediately after Nutt delivered a paper to the Centre for Crime and Justice Studies, King's College, London, in which he called for greater transparency about drug classification. A further five members of the committee resigned in protest, and Professor Nutt formed the Independent Scientific Committee on Drugs (ISCD), with financial backing from hedge fund manager Toby Jackson in January 2010. See www.crimeandjustice.org. uk/estimatingdrugharms.html (visited 23 September 2010).

Adler: I'm sure that's what you said. Peter Williams has written to us and obviously a telephone conversation did take place between Donald Acheson and Peter Williams about trying to expedite this application and to fund it.<sup>76</sup>

Gordon: Yes, that is certainly the case. And there were other conversations later on. I think Anne can remember more than I can, Peter Williams going out of the room to talk to No. 10. Just to follow the question that you asked, Stan. Of course, as I said before, the political cloud, or storm, that was raging over this was very important and very interesting, the epitome of the kind of political storm that rages over all sorts of other bits of science. But it was very important to try and dissociate that from the decision on purely academic grounds. Was this a good piece of research? Was it researching a worthwhile problem? Was the team appropriate for the task? Were they asking for the resources they needed? Were they going about it the right way? And on all those points, the answer was a very clear 'yes', on expert advice. And so that was the basis for the decision. Then, it's a little bonus that you can poke the politicians in the eye.

Adler: I'm sure that was it. I'm sure being Wellcome Trust, it was the science that counted.

Gordon: It certainly was, yes.

Adler: I remember a meeting and Peter Williams going out of the room to take a call from No. 10, and being told not to announce that this was going ahead until after the party conference.<sup>77</sup> Is that right?

Johnson: Were you there? I remember that.

Adler: Well, I was at that original meeting.

Johnson: I know. Were you at that meeting?

Adler: I can remember him going out and coming back irate.

Johnson: That's right, he did come back. He came back rather pleased, didn't he. [Laughs] So here is my version of the story between the story in *The Sunday Times* on 10 September, and the announcement of the funding on 15 October. It was just over four weeks. What I think David has alluded to was the tremendous amount of support in the scientific press for the study to go forward, or perhaps dismay at it having been banned. For example, the All-Party

<sup>&</sup>lt;sup>76</sup> See Appendix 3.

<sup>&</sup>lt;sup>77</sup> The Conservative party conference was held at Blackpool, 10–13 October 1989.

Parliamentary Group on AIDS wrote to the Secretary of State, Ken Clarke, in protest.<sup>78</sup> I remember that John Maddox, then editor of *Nature*, wrote quite extensively about the survey; indeed published the papers from it and wrote an editorial in Nature about it.79 Sir Claus Moser expressed concern about the decision at the British Association, which was in September.<sup>80</sup> It also happened that Sir David Cox was at that meeting - I think it was in Sheffield that year - and there was a press conference which was to release the papers, the AIDS projections, the modelling projections for AIDS – there was a series of papers in the Philosophical Transactions of the Royal Society of London and the press were assembled.<sup>81</sup> Sitting on the front row was Chris Mihill, then at the Guardian.<sup>82</sup> I was on the panel, meant to be supporting Sir David Cox and the statistical report. But Chris said to me, 'Ah, Dr Johnson, you're one of the investigators on this banned survey. Now you've had government funding banned - would you consider private funding?' That was a question for which I was completely unprepared. No one had given me a briefing or told me what to say! So I said, 'Well, I suppose we might. Well, I hadn't thought about it, but, maybe.' The next day on the front of the Guardian it said, 'Researchers defy ban.'83 So, there was a tremendous amount, you know, of public support in the media as well as support from scientists and from politicians, who weren't friends of Maggie's. Then we had that meeting at the Wellcome Trust, which I well remember, the day after the governors had made the decision. They<sup>84</sup> were telling us that the Wellcome Trust would fund it, and that was when somebody - Peter Williams was there - and I thought he'd gone off to ring No. 10. And he went out and he

<sup>80</sup> The British Association for the Advancement of Science (British Science Association from 2009) meeting was held in Sheffield on 12 September 1989.

<sup>81</sup> A series of papers on predicting the spread of HIV was published in the *Philosophical Transactions of the Royal Society of London*; see Cox *et al.* (eds) (1989).

<sup>82</sup> Chris Mihill was medical correspondent on the *Guardian* for eight years, and for four years on *Today* newspaper; he was news editor on *Pulse* and *GP* before founding, in 2001, Second Opinion Communication Consultancy, now Clew, a public relations agency specializing in health and science communication.

<sup>83</sup> Anon. (1989).

<sup>84</sup> Professor Johnson wrote: 'Peter Williams and someone else from the Wellcome Trust (it may have been Roy Anderson?)'. Note on draft transcript, 2 February 2011.

<sup>&</sup>lt;sup>78</sup> Letter from Lord Kilmarnock, chairman of the All-Party Parliamentary Group on AIDS, to the Secretary of State, Kenneth Clarke, 15 September 1989.

<sup>&</sup>lt;sup>79</sup> Maddox (1989); Webb (1989). John Maddox was editor of *Nature* (1966–73 and 1980–95).

said, 'We're going to tell No. 10 we're going to fund it.' Then he came back and said, 'OK. They (i.e. No. 10) said: "OK, but please don't release the news until after the Tory party conference."<sup>85</sup>

**Gordon:** Let's put some dates on it, because the Trustees' meeting would have been in the second week of October. Roger's first meeting in the chair. The request to the Trust came the preceding Monday (2 October), eight days before, or maybe the Friday (29 September) before that, so we had a week to sort it out.<sup>86</sup>

Wellings: On 5 October 1989, David Mellor wrote to Sir Donald Maitland, who was the chairman of the HEA and said: 'Thank you for your letter of 25 August about the proposed National Study of Sexual Attitudes and Lifestyles. Since then the Government has announced its decision not to allow the use of public funds for this study, and Norman Hale has, I understand, written to you explaining our reasons for this."87 That was on the 5 October. 'As Mr Hale also explained, we are considering what further measures are needed to ensure our data on HIV are as full and comprehensive as possible.' The Norman Hale letter was sent out on 14 September, so just three days after the decision not to fund. So, on the Wednesday a letter was sent by Norman Hale to Sir Donald Maitland saying: 'I'm writing to you to convey the decision taken about government financial support for, and endorsement of, the proposed national survey. As you know, ministers have given considerable thought to the case on this and for the justification for asking people intimate questions about their personal lives. While they fully understand the basis of the survey proposed, they've concluded that in all the circumstances, it is not appropriate for Government to support it. They have decided not to provide finance and not to sponsor it.' That was very quick.

Gordon: While that was going on, we were dealing with the application and were able to get it funded.

Field: I think it's possible to just firm up on the fact that there are several strands to the publicity and the media reporting that went on about the funding withdrawal. One strand was that this piece of research was needed, but the other strand was very definitely the outrage at political interference of the scientific process. Those two are quite distinct things.

<sup>&</sup>lt;sup>85</sup> See Berridge (1996): 253.

<sup>&</sup>lt;sup>86</sup> The request came on Monday 2 October, the Trustees meeting was on the 11 October; see Appendix 2.

<sup>&</sup>lt;sup>87</sup> David Mellor, personal communication to Sir Donald Maitland, 5 October 1989, in Professor Wellings' personal archive.

Adler: Julia, I remember you had some reservations about it being funded by Wellcome. Am I wrong?

Field: I've got a sort of vague memory of this, that there may have been some concern that it was not the usual kind of funding; we'd not dealt with Wellcome at all before. The SCPR had not had any funding for any projects. I don't think we knew anything about the Wellcome Trust at that stage, really. There was, I think, a little bit of concern about it being connected with a commercial pharmaceutical company, which might be detrimental to reactions to the survey. But I think that was quickly allayed.

Adler: So there was a distinction made between the Wellcome Trust and the Wellcome pharmaceutical company, as such.<sup>88</sup>

Field: I think that may have been the problem, but I can't remember very clearly.<sup>89</sup>

**Gibbs:** The Wellcome Trust was relatively small compared with the MRC at that particular time, wasn't it? I imagine we were about a quarter of the size of the MRC, so we weren't as well worth knowing as we were later on.

Adler: Please don't take it personally. [Laughter]

**Gordon**: I think the only other thing to say is that, certainly in that era, the Wellcome Trust very much had a practice of making sure it was involved with the people it was funding. So there was a lot of interaction between the Trust and the survey team. One of the delights of working at the Wellcome was the opportunity to talk to researchers and listen to what they were doing, their worries and to try to do something to help. This was a particularly rewarding case to do and it meant that things like handling the publicity, albeit extremely dull, we were able to do together, which would have been more difficult with a more impersonal organization.

<sup>&</sup>lt;sup>88</sup> The umbrella organization, the Wellcome Foundation, was formed in 1924 by Henry Wellcome to absorb his libraries, museums, research laboratories and the pharmaceutical company of Burroughs Wellcome & Co. Henry Wellcome's will created the medical charity, the Wellcome Trust, which owned the Foundation until it was floated on the stock market, eventually merging with Glaxo in 1995 and becoming GlaxoSmithKline in 2001. For the company history for the years until 1940, see Church and Tansey (2007); for the history of the Wellcome Trust, see Williams (2010). See also note 74.

<sup>&</sup>lt;sup>89</sup> Mrs Julia Field wrote: 'Interviewers were briefed that the Trust was charitable/non-commercial and quite separate from the pharmaceutical company.' Note on draft transcript, 13 July 2010.

Adler: Yes, I'm sure that's right. Does anyone else want to say anything else about this funding? Mike, do you want to come back at all on that? I know you went on holiday to Tenerife – but did you ever pick up this story again?

Durham: Well no, oddly enough, because, as I said, you're only as good as your next story, and for me there were another thousand next stories. The issue for The Sunday Times was, first of all, that by coincidence the very day that the story appeared, I did get on a plane to go on holiday. So when I came back I was told by the rest of the staff that, you know, I'd been a popular guy, but I wasn't there. Otherwise I'm sure that I would have done a follow up then, perhaps a feature or whatever to explain the background to the story, which I would then have been in a position to acquire, to learn. A week later it was really too late, things moved on. Another issue was that The Sunday Times then, as now, has a tradition of campaigning on issues. It could have taken this story to the level of a campaign – in other words, in some way rooting for money for this work to be funded, or something similar, week in and week out. But in fact that proved unnecessary, because the funding was quite quickly in place. So it then left the agenda, I think, as far as the paper was concerned. Had I known about the story, had the story actually dropped for me on a Tuesday or a Wednesday, the outcome could have been completely different, because first of all, there was always the danger that another newspaper might somehow have got hold of it, so The Sunday Times would never have run it. But the alternative would have been if I'd had three or four days in which to actually do the research and would have been able to turn over stones, we might well have discovered who was really on which side in this issue within the Cabinet, for example. But there was never any opportunity to do that in the few hours available.

Adler: *The Sunday Times* certainly moved on to trying to persuade people that HIV was not heterosexually transmitted and didn't necessarily have a marvellous track record. Right, any more about funding? Shall we move on then? The next NATSAL was 2000. So just give us a flavour of how that survey was different.

Johnson: Before that, I would like to say something about what NATSAL-1 was used for, which was quite extensively for sex education; for the AIDS projections, so it was used year after year to estimate the likely spread of HIV; it was used in legislation.

Wellings: It was used to underpin the whole of the national HIV and sexual health strategy. And also the teenage pregnancy strategy, because the 2000 data were not available. So both those strategies run right through.



Figure 8: The NATSAL-2 team in October 2002. Back row, L to R: Wendy Macdowall, Andrew Copas, Catherine Mercer, Sally McManus, Kiran Nanchahal. Front row, L to R: Bob Erens, Anne Johnson, Kaye Wellings, Julia Field, Kevin Fenton.

Johnson: Then the 2000 survey came; the stimulus for some of it came from the Day Report.<sup>90</sup> The data was extensively used for HIV projections and at that time Nick Day in Cambridge was chairing the HIV Projections Group.<sup>91</sup> That group, in a sense, urged the collection of a new set of data because all their estimates were relying on the 1990 survey. From about 1995 onwards, we saw a rapid increase again in sexually transmitted infections (STIs), which had declined precipitously – in fact a sort of exponential decline. Between about 1984 to 1990, the STI rates went down enormously to well below levels in the 1960s, as a result, I think, of the major education campaigns in minority groups and in the general population. So there was a need for another survey to get contemporary estimates. What we did that was different was that we focused on the younger population, 16–44, instead of 16–59, and we added in collection of urine specimens to look for the prevalence of chlamydia, because

<sup>&</sup>lt;sup>90</sup> See Public Health Laboratory Service (1996).

<sup>&</sup>lt;sup>91</sup> Public Health Laboratory Service working group, chaired by Professor Nicholas Day, Medical Research Biostatistics Unit at Cambridge University.

at that time there was a lot of concern about chlamydia and the introduction of chlamydia screening was being proposed. Those were the two innovations, together with, I think, more information on contraception, and more interest in sexual function.

Wellings: Yes, we definitely broadened the objectives the second time round. We didn't hang it quite so exclusively on the HIV peg, did we?

Johnson: It was much more on the methods, yes. Perhaps Bob can talk about the methods, which are critical.

**Mr Bob Erens:** Firstly there was an ethnic boost that was quite key. There was increasing interest in the health of ethnic minority groups around that time, so although it wasn't in the original application, at a later stage we decided to try to obtain funding to boost the samples of black African, black Caribbean, Pakistani and Indian ethnic groups. Because they are all small minorities in the population, the numbers would be too small to analyse separately, without 'boosting' their numbers for the survey. So that was quite a unique feature with lots of challenges. But the other thing was the data collection methodology had moved on quite a lot over that decade, so the interviewers used pen and paper questionnaires and there was a paper self-completion booklet in the 1990 survey. By 2000 CAPI (computer-assisted personal interviewing) was very common, so all our surveys were done using CAPI.

Adler: People may not understand that.

**Erens:** That's where the questionnaire is in the computer. The interviewer reads out the questionnaire and types the answers directly into the computer, so there's no scope for missing questions accidentally and so on. It's quite useful. Then came the self-completion CASI (computer-assisted self interview). Instead of giving a paper self-completion questionnaire to the respondents, they would turn the laptop round and let the respondent read the questions on the screen and type in the answers. When they got to the end it says: 'When you press this key, the questions will disappear, your answers will disappear, and the interviewer won't be able to see what you've done', which I think was quite reassuring to a lot of respondents.

Williams: They had the opportunity to change anything that they wanted before it was locked in.

Erens: It was really locked. You could not unlock it until it got to the office.

Field: May I interrupt Bob for a moment? Very briefly to remind everybody, the questionnaire for the first survey was actually typed on typewriters, not even typed on a computer, even though it was paper. It was actually typed on typewriters. That is how much things had changed in those intervening ten years.

**Erens:** The other advantage of having it on computer is that you can have very complicated routing and filtering, so depending on how you answer, you can get routed to different questions in the questionnaire. Now if it's on paper, you can't expect a respondent to say, well if you said 'yes' to that and 'no' to that, then go to that question. With the computer questionnaire you can have very complex routing and you avoid all missing answers and you get much higher quality data. You can build in range checks and consistency checks. If somebody gives an answer at question five that contradicts something they said at question two, you can get them to sort it out right there in the interview instead of having to live with that problem.

Adler: We didn't talk about response rates of the first survey. What was the response rate? Do you think developing a slightly – anonymous is not the word I'm looking for – depersonalized approach helped the response rate?

Johnson: The response rate was 63.5 per cent.

**Erens:** It was 65 per cent, I think, in the first one, so it had hardly changed. But I do remember the fieldwork went on twice as long as it was supposed to in order to get to that, so it was quite a struggle.

Johnson: I don't think the computer-assisted interviewing helped the response rate, but what it did do – which we discovered because we did a randomized experiment in 1000 people: 500 filled in using pen and paper, compared with 500 who filled in using a computer – was to improve (lower) rates of item non-completion and produce much more consistent data. We think that the data were better. There have been some experiments that suggest people are more likely to report socially censured behaviours if you give them a computer as against pen and paper.<sup>92</sup> We didn't find that in our own work, but others certainly have. We did find that the data from computer-assisted interviews were much more complete.

<sup>&</sup>lt;sup>92</sup> For example, Weeks (1992); Turner *et al.* (1998).

Gordon: A question on the section on the computer-based questionnaire that the individual fills in himself or herself. We were hearing earlier on about how the purpose of the self-filled questionnaire was sometimes vitiated by the subject saying to the interviewer: 'What does this mean and what does that mean?' Did you get the same queries with the computer-based questionnaire?

Johnson: We should perhaps say something about the funding? The second survey was funded by the Medical Research Council, so it did get public funding. I was just remembering, David, that we applied to the Wellcome Trust for a second survey and, you will correct me if I'm wrong, but they said, 'Go and ask the MRC. This should be publicly funded.'

Gordon: I had forgotten that, but I think that is true. Actually that's not bad, because the Wellcome Trust, having funded the first one, unlocked the public money that was appropriate for the work.

Johnson: Till the third time round. I should hasten to add that the Wellcome Trust did not want to be left out the third time round. The third survey's funded jointly by the MRC and the Wellcome Trust.

Adler: OK, let's stick with the second for the moment. Anything else you want to raise about the second? Wendy, were you involved in the fieldwork? Did it feel different from the first time round?

Williams: Only that it was on computer. When you get the respondent to complete the self-completion on that, for people who consider they're not computer literate, we give them instructions to help them for the first bit. Then we say to them: 'You can carry on...', but you also say: 'If you've got any problems, come back and we can sort it out.' Sometimes they make a mistake and don't know how to get up or down or back to the previous question, so we help out. But apart from that... It's slightly quicker, in some cases. Young people, they're so used to computers that they do it very quickly, but the older people take a bit longer than doing it by paper, but that's all. No other difference.

Johnson: One thing about the results: Cath Mercer did all the analysis, so she might like to tell us what was surprising about the next set of results, if that's not putting her on the spot?

Dr Catherine Mercer: I think one of the most interesting results was when we compared the results from the 2000 survey to the 1990 survey, seeing the huge increase in the reporting of risk behaviours. Although Anne has already said that the 1990 survey happened at a time when risk behaviour, we think now, was

at pretty much an all-time low. So thinking ahead, it will be interesting to see whether we find from the third survey that there is a continued increase in risk behaviours or whether risk behaviours stabilize. Talking about risk behaviours, we found an increase in the reporting of partner numbers; an increase in the reporting of same-sex partnerships; and of unprotected sex. Age at first sex had stabilized at around 16 years for men and for women. Another interesting finding from the 2000 survey was our ability to link the behavioural data with biological data, because as Bob said, for the first time we'd collected biological samples. We'd collected urine samples from a random half of sexually active 18to 44-year-olds, which had gone down very well. We achieved a response rate of 71 per cent for the urine samples, and this enabled us to get the first population prevalence estimates of genital chlamydia which, linked to the behavioural data, was very informative, in terms of how risk behaviour is associated with the prevalence of chlamydia.<sup>93</sup>

Adler: Staying with the chlamydia data, presumably that was before the national programme, so that was very important in terms of setting up the National Chlamydia Screening Programme, is that right?

Johnson: The screening was beginning to be rolled out around the time we did the survey.<sup>94</sup> Of course, the National Audit Office said in their recent 2010 report that there are concerns about how that's been delivered.<sup>95</sup> It hasn't been a screening programme; it's opportunistic screening. I think the most important result from NATSAL-2 was that we showed that there was as much asymptomatic chlamydia in men as there was in women, which wasn't previously understood.

Ms Kathy French: May I ask: did you use interpreters? Do you envisage the next round needing to use more interpreters?

Erens: We didn't, no.

Mercer: We didn't use translators, but for the ethnic boost sample, we translated the questionnaire into Urdu and Punjabi.

Erens: And Hindi.

<sup>&</sup>lt;sup>93</sup> Fenton *et al.* (2001, 2005); McCadden *et al.* (2005).

<sup>&</sup>lt;sup>94</sup> A Department of Health-funded pilot opportunistic screening programme to investigate how best to implement chlamydia screening, was carried out between September 1999 and August 2000; the phased implementation of the National Chlamydia Screening Programme began in September 2002. See, for example, LaMontagne *et al.* (2004).

<sup>&</sup>lt;sup>95</sup> National Audit Office (2010).

Mercer: And Hindi. So the questionnaire was available in those three languages, but we didn't have interpreters.

Gordon: May I ask a question? We've heard about a substantial increase in risk behaviours between NATSAL-1 and NATSAL-2, and therefore for the modellers, you're modelling not against one set of figures, but you're modelling against a set of figures that is changing. Presumably that must mean that the range of estimates of future prevalence must be wider. Is it getting so wide that it's becoming difficult to interpret?

Adler: No, I would have thought it was the other way round, wouldn't it? The more data you have...

Gordon: Yes, but if you're having to factor in a rate of change as well, rather than a static position?

Johnson: They would say that they're using more up-to-date data. They've been modelling from that second time point. The models have become a bit more sophisticated and they're using a lot more mixing data, so I'm not sure that applies. Arguably if you've got more data, you should have greater precision. They're using more stochastic rather than deterministic models, which allows you more variation and different parameters. That might not be true though.

Adler: Should we just move on finally to NATSAL-3.

**Erens:** NATSAL-3, what's new? We've extended the age range so now it goes from 16- to 74-year-olds. There was a lot of concern about whether older respondents would be willing to take part. We haven't found that in our first test, which is good, because I think NATSAL-1 is the first survey I've ever seen where the response rate was lower among older respondents than younger respondents, because it's usually older respondents who are more willing to take part in surveys. It wasn't true in NATSAL-1 and fortunately, so far, in NATSAL-3 we're finding no difference in response rates by age. We're doing urine samples again. We have an exciting new collection, which Pam can tell you about, which is called the FirstBurst<sup>TM</sup>.<sup>96</sup> I won't go into the details. We have saliva samples to test for testosterone, which I'll leave Kaye to tell you about. What else is new? There are new questions: we have a sexual function questionnaire now, which has been validated by the London School of Hygiene. We have a lot more general health questions, looking at health problems to see how they affect people's sexual behaviour as they get older.

<sup>&</sup>lt;sup>96</sup> See, for example, Wisniewski et al. (2008).

Dr Pam Sonnenberg: The major change in the sexually transmitted infection (STI) component is that this time we will be testing for five STIs as opposed to chlamydia as in the last one. The key thing is that we are also testing directly for HIV. Whereas the idea in the first survey was to obtain estimates of behaviour linked to HIV, now we actually will be testing for HIV. This is all going to be done with urine samples. In addition, we will be testing for chlamydia, gonorrhoea and human papillomavirus (HPV), so that this can inform the HPV vaccination programme.<sup>97</sup> The last STI that we'll be testing for is Mycoplasma genitalium, partly to assess whether it is an STI on a population level. The other key differences from NATSAL-2 are that we will be taking urine using FirstBurst<sup>TM</sup>, which is a urine device that concentrates the first 5ml of urine.<sup>98</sup> We will not be giving results back to people. So it is going to be anonymous testing that is then linked, but we're not going to give people their results. There has been a large ethical debate and we believe it is the way forward.<sup>99</sup> In the pilot so far, we have a nearly 80 per cent response rate for people giving urine, which looks very positive.

Adler: Now that it is funded, you said the Wellcome didn't want to miss out on this one, so it's jointly funded by Wellcome/MRC, is that right? The MRC ethics people were happy with that?

Johnson: Through the MREC.<sup>100</sup>

Gordon: Same as in the Genome Project.

<sup>99</sup> Dr Sonnenberg added the following explanation for the justification for anonymized testing of STIs from the NATSAL-3 proposal: 'We plan to test for a range of STIs in urine, which respondents will provide on the understanding that tests will be anonymised, such that we will be unable to report back their individual results, but we will be able to link these results to the survey data.... This strategy is preferred because... [s]ince Natsal 2000, when we conveyed positive Chlamydia results, there is now more widespread testing for Chlamydia in the community, as part of the NCSP, in GUM clinics, GP practices and pharmacies. Indeed, we will specifically provide details of the availability of STI/HIV testing services, as well as general sexual health information'. E-mail to Ms Caroline Overy, 14 February 2011; this e-mail contained a longer explanation from the NATSAL-3 proposal, which will be deposited along with other papers from the meeting in archives and manuscripts, Wellcome Library, London at GC/253.

<sup>100</sup> Multi-centre Research Ethics Committees. See, for example, Central Office for Research Ethics Committees (2000). The Central Office for Research Ethics Committees is responsible for MRECs.

<sup>&</sup>lt;sup>97</sup> See Reynolds and Tansey (eds) (2009): 5.

<sup>&</sup>lt;sup>98</sup> See note 96.

Johnson: Yes, it's the same as Biobank. But we had a long debate about it.<sup>101</sup>

Tansey: I'm aware that there are quite a few people who haven't said very much. I wondered whether there were other voices? I'm particularly interested in what Wendy has been saying about the interviewers. Are there any other interviewers here? We tried to invite quite a few of them. Can I ask you, Wendy, when you had the computer: you made a very interesting point about when the interviewers were being trained and after your two days of immersion the men went away. Did having a computer make any difference? Is there still that gender imbalance in the interviewers?

Williams: No, I wouldn't say it has made any difference. By now, interviewers are used to using the computer. The only problem with the computer is that you don't have so much eye contact, but in this particular survey, it's probably just as well that you don't have the eye contact. [Laughter] Because, as I said, on this type of survey you have to stand a little bit back. You don't get so involved with the people whom you're interviewing, just keep it professional and scientific, as opposed to a chat about sex.

**Tansey:** I wondered if that had made it easier for men to feel more comfortable? It sounded as if it was the men who weren't being comfortable being the interviewers. Whether with the computer they actually felt more comfortable?

Williams: I don't think men found it difficult to be interviewed at all. As I said, some of them found it stimulating; the fact that you were discussing it. And some of them, you know, may have replied to the question 'how many sexual partners have you had?' and told you '2000' and so on, but you can't acknowledge that this seems improbable, so you just say 'yes' and go on to the next question.

Tansey: Perhaps I misunderstood: I thought when you were talking about your two days of immersion...

Williams: Oh, it was the male interviewers who wouldn't do it. But I think male interviewers are working on, have worked on, the other surveys. Once it became CAPI, yes.

<sup>&</sup>lt;sup>101</sup> Two of the Wellcome Trust's major funding initiatives are the Human Genome Project and the UK Biobank, a long-term research programme to create a national database to improve the prevention, diagnosis and treatment of serious illness.

**Erens:** For the respondents, though, I think if somebody refuses, we ask if they'll have an interviewer of the opposite sex, and women will quite often say they want a female interviewer but the men are much less likely to say they want a male interviewer. I mean they are happy with a man or a woman.

#### Adler: Are there any other points that people would like to raise?

Wellings: We could tell you about the hormone measures in NATSAL-3? Wendy Macdowall at the London School of Hygiene and Tropical Medicine is leading on this work, but we're in NATSAL-2010 where we're developing a salivary assay for testosterone, with Fred Wu in Manchester.<sup>102</sup> The purpose of collecting this is two-fold. Firstly, there is no data on the normative range in women in a general population sample. Secondly, we want to look at the relative contribution of hormonal status and other lifestyle and behavioural factors to sexual function, so we need to be able to measure it. There are numerous problems which are becoming apparent. One is that there's a diurnal range, so that makes it difficult for interviewers in the morning because they've got to be there before 10 o'clock. And there's not much testosterone to measure in women, and there's only 2 per cent in any of us that is freely available and not bound to proteins. But nevertheless, Fred Wu has established that it is possible to measure testosterone in saliva almost as well as you can in serum. That's a major breakthrough in itself, and they'll be reporting that work. Previously it has only been measured with precision, reliably, in serum. That's a pretty notable piece of work, even if the Wellcome Trust decide that we can't go ahead in the main sample, which I don't think they will. But the other thing that we're doing this time is that we're combining qualitative with quantitative. So we're going back to look at some of the statistical associations that we found, and we'll be going back to particular people of interest and discussing with them in depth, what some of the associations that we're finding mean. For example, if we find that young people who have a lot of sex also drink a lot, we want to know whether that's situational, whether they're in a place where they have loads of partners or whether it's just that they've got a high risk tolerance (what they do in one context, they do in another) or whether alcohol is just a psychotropic substance that makes them lose their inhibitions. So the qualitative work will be extremely important in teasing out some of those associations.

**Coxon:** I'm particularly interested in what you said, because one of the things we found with our original funding was that HIV testing costs were ring-fenced,

<sup>&</sup>lt;sup>102</sup> Fred Wu is Professor of Medicine and Endocrinology at the University of Manchester.

but over time they got much cheaper. We finished testing for 23 viruses in order to use the money. But it's fascinating to have that list. Will they be made available in aggregate form?

Wellings: We want to archive the data more rapidly. It's important to get this right, I think. The dissemination strategy: I think each time we've learnt a little more. The first time I think the books were very useful to have the whole data set all in one place. The second time was very good for the research assessment exercise (RAE),<sup>103</sup> because of all the papers we got out. But this next time, I think we all feel we shouldn't hang on to the data so long. We should get more academics involved in working with us to disseminate the data during a two-year period following completion of data collection, and really get as many as possible out there in the public domain and then archive the data.

Coxon: Whereabouts will it be archived? At Essex?<sup>104</sup>

Wellings: We're not sure yet. It probably will be archived in the ESRC archives, wherever else, but it may be archived elsewhere.

**Coxon**: Another question follows from that: if you're getting qualitative data – will they be anonymized and be available for bona fide researchers too?

Wellings: We haven't discussed that at all, and we certainly didn't when we put it into Essex, so they would. But I think all of us would be open to suggestions to get the data out.

**Coxon**: All the SIGMA diaries were anonymized and lodged here at the Wellcome Trust, which was a very useful facility.<sup>105</sup>

Wellings: If we were to do that, we'd have to ask the researchers what questions they would want to interrogate the data with, otherwise we'd collect data that wouldn't be useful.

<sup>&</sup>lt;sup>103</sup> The Research Assessment Exercise, first undertaken in 1986, is a peer review exercise to assess the quality of research in UK higher education institutions; see www.rae.ac.uk/ (visited 25 January 2011).

<sup>&</sup>lt;sup>104</sup> UK Data Archive, University of Essex, Colchester; see www.data-archive.ac.uk/ (visited 24 January 2011).

<sup>&</sup>lt;sup>105</sup> See www.sigmadiaries.com (visited 11 August 2010); Coxon (1988, 1990). The diaries have been indexed, documented and reduced to micro-fiche, under funding from the ESRC, and are archived in the Wellcome Contemporary Medical Archives Centre, now part of archives and manuscripts, Wellcome Library, London, GC/260 (permission to quote from this material must be sought from the Project SIGMA website). SIGMA are also depositing material in LSHTM archive at www.lshtm.ac.uk/library/ (visited 11 April 2011).

Gordon: There's a lot more in each survey as it goes along: how is the cost per subject going?

Erens: Up.

Gordon: But by how much?

Wellings: A drawing in of breath.

**Johnson:** The bill for the Wellcome Trust in 1990 was about  $\pm 0.9$  million and this time it's  $\pm 7.2$  million – with fewer people.

Adler: Any other points that people would like to raise? It's been an absolutely fascinating afternoon. I think we've all learned a lot. Those who were there, I think, have learned quite a lot as well about what happened and I think it's been really good that people have been so open and have talked so freely about what happened. Tilli, thank you and your staff for organizing it. I hope you feel it has been a very useful event.

Tansey: I would like to add our thanks to all of you for coming and, yes, for being so frank and open. We've learnt an awful lot this afternoon. I'd particularly like to thank Mike for chairing it so well.

# Appendix 1

Thatcher halts survey on sex106

# By Michael Durham and David Hughes, *The Sunday Times*, 10 September 1989<sup>107</sup>

The prime minister has vetoed plans for the biggest-ever official investigation of Britain's sexual habits. She believes the  $\pounds750\ 000$  Government survey would invade the privacy of the 20 000 people due to be questioned.

The decision has angered medical researchers, who say the inquiry would have produced the most comprehensive picture of sexual activity yet compiled and provided valuable information for the battle against AIDS.

Interviews should have started last April but the project, enthusiastically supported by Government medical officers, was postponed by the Department of Health after resistance from 10 Downing Street.

Thatcher has now rejected the project, which would have involved adults answering detailed and explicit questions about their sex lives.

Authoritative sources say Thatcher doubted whether such intimate questioning would produce accurate responses, and questioned the credibility of the exercise.

Professor Virginia Berridge wrote: 'The seminar sheds some interesting light on the question I raised in my introductory comments: Why did the idea that Mrs Thatcher cancelled the sex survey gain credence when one of the ministers concerned, Kenneth Baker, states in his autobiography that the decision was taken at a lower ministerial level after dissension among ministers from different departments? From the evidence given here by Mike Durham and also by Bobbie Jacobson, it is clear that a journalist looking for a story may have stimulated the Thatcher story. Bobbie had actually told Mike that the cancellation had originated in the Department of Health, but when Mike rang with his Thatcher story, responsibility was shifted from the department. Sir Graham Hart's comment, as a former permanent secretary, although not at this time, gives us a clue as to why No. 10 might have been happy to bear it. The Department of Health may have wanted to deflect the story, to "kick it into the long grass" and No. 10 could have seen political advantages in claiming a role. Finance and who was going to pay could also have been a factor. The seminar discussion makes it clear that the slogan about Thatcher may well not have represented total reality. But many parties, including the researchers, saw advantages in having the survey's funding difficulties characterised in that way. This episode gives an interesting insight into the way decisions are actually made in government. Our final understanding of the complexities must await access to the relevant papers.' E-mail to Ms Stefania Crowther, 30 April 2010. See also Dr Peter Williams' reminiscences in Appendix 3, pages 66-8.

<sup>&</sup>lt;sup>107</sup> © The Sunday Times, London, 10 September 1989.

It was also said she feared the Government could be 'tainted' by undertaking the survey which could have given rise to 'unseemly speculation' in the popular press.

The veto has angered AIDS researchers. 'This is not a survey motivated by prurient curiosity into people's private lives,' said Kaye Wellings, a research officer at the Health Education Authority.

'It is unthinkable that this study should not go ahead. A tremendous amount of hard work and careful preparation has gone into making it reliable. The data is urgently needed for prediction and prevention of HIV.'

Last night a political row broke over Thatcher's veto, with Labour claiming it was vital the survey goes ahead.

Harriet Harman, Labour's health spokesman, said: 'It does not ring true for this government to be ditching this survey on the basis of privacy and confidentiality. I do not accept this contention from a Government which has shown itself to be no respecter of privacy anywhere else. This survey must go ahead on scientific and medical grounds.'

The survey, funded by the Health Education Authority, the Economic and Social Research Council (ESRC) and the Department of Health, was designed to provide a detailed scientific basis for future campaigns against AIDS.

Thatcher's ruling that it should be scrapped came after an intense Whitehall battle. Her opposition means the inquiry could only proceed if the Economic and Social Research Council was able to press ahead independently.

The intention was to ask a random sample of 20 000 adults to fill in a confidential questionnaire describing their first sexual experience, the frequency of recent sexual activity, whether it was homosexual or heterosexual, within or outside marriage, and what type of activity was engaged in.

A separate section dealt with attitudes towards permissiveness, homosexuality and abortion; awareness of health education issues; and personal assessments of their risk of contracting HIV or other sexually-transmitted diseases.

Two pilot studies have been carried out. A feasibility study involving 1000 adults was published in April. The results of a similar pilot project will be unveiled this week. Researchers say those prove that the proposed survey is scientifically sound.

Staff at two London medical colleges, at Imperial College London, and at a research agency, have been standing by to begin the study. Funding from the Health Education Authority and the Economic and Social Research Council has been guaranteed.

Leading academics who have spent more than two years preparing the ground say the information sought would be of enormous value in estimating how many could be at risk from AIDS and other sexually-transmitted diseases.

It would enable AIDS workers to plan future levels of hospital care and to judge the effectiveness of education campaigns.

Professor Roy Anderson, professor of epidemiology at Imperial College, London, and one of the project's four-man steering group, said yesterday: 'I'm very disappointed if the Government's scientists have been unable to persuade politicians of the value of this work.'

'It is an important survey. It would put us in a better position to assess how the epidemic will spread in coming decades and to see whether behaviour has changed after five years of anti-AIDS campaigns.'

# Appendix 2

# Timeline of events leading up to Wellcome Trust support for NATSAL

Date	Event
January 1989	ESRC letter to the team saying the response was positive
March 1989	Howard Newby (ESRC) letter to Julia Field advising caution in giving information about the survey owing to the delicate stage reached in the negotiations
June 1989	Letter from Howard Newby to Jack Barnes, defending the size of the sample and that participants could be expected to recall their experiences
25 August 1989	Letter from Donald Maitland to David Mellor
Early September 1989	Kaye Wellings lunches with Thomson Prentice of <i>The Times</i>
Friday 8 September 1989	Bobbie Jacobson informs Mike Durham that the funding was stopped
Sunday 10 September 1989	The Sunday Times article published
Wednesday 13 September 1989	Guardian article by Chris Mihill: 'AIDS researchers may defy ban'
Thursday 14 September 1989	Letter from Norman Hale to Donald Maitland
Monday 2 October 1989	Letter from Anne Johnson to Peter Williams (after she had spoken with Roy Anderson), enclosing the original ESRC application, made on 12 December 1988, for funding consideration <sup>108</sup>
Thursday 5 October 1989	Letter from David Mellor to Donald Maitland confirming Government's decision not to fund the survey

<sup>&</sup>lt;sup>108</sup> Wellcome Trust Archives, Scientific Committee, WT/SCI/Pap/B.35.

Wednesday 11 October 1989	Meeting of the Scientific Committee – Dr Gordon explained the history of the application and the committee discussed the proposals based on the original application and recommended to the Trustees to fund the survey in full <sup>109</sup> Trustees' meeting – acknowledged it had been discussed at the Scientific Committee earlier in the day. All relevant aspects and political implications of the study discussed, but unanimous agreement to fund £900 000. Press statement agreed. Detailed arrangements to be formalized later <sup>110</sup>
Thursday 12 October 1989	Phone call between Peter Williams and Donald Acheson informing him that the Trust would be supporting the NATSAL <sup>111</sup> Peter Williams reported that Sir Peter Cazalet (Wellcome Trustee) spoke to the Prime Minister's office informing them of the same <sup>112</sup>
13 December 1989	Meeting of the Scientific Committee – members were reminded of the commitment to fund as sole funders (£900 000). Precise costing had now been provided and an extra £61 474 requested and this was agreed <sup>113</sup>

<sup>&</sup>lt;sup>109</sup> Wellcome Trust Archives, WT/SCI/Pap/B.35.

<sup>&</sup>lt;sup>110</sup> Wellcome Trust Archives, Trustees' Minutes, WT/TRU/Mins/25.

<sup>&</sup>lt;sup>111</sup> Wellcome Trust Archives, WT/DIR/PW/B.14/6.

<sup>&</sup>lt;sup>112</sup> Wellcome Trust Archives, WT/SCI/Pap/B.37.

<sup>&</sup>lt;sup>113</sup> Wellcome Trust Archives, WT/SCI/Pap/B.37.

# Appendix 3

# Comment by Dr Peter Williams<sup>106</sup>

# Dr Peter Williams wrote:

A government department normally produces the funding for the enquiries it needs to make in order to determine policy. In the case of the sex study it must have been obvious to the Ministry of Health that it could not decide what it needed to do to provide for the treatment and containment of AIDS unless it had more facts about the sexual behaviour of the British population. It therefore assumed that if a study was designed, support would be forthcoming from the government. This did not turn out to be the case for the reasons that will be apparent in the report of this meeting. The Chief Medical Officer, Sir Donald Acheson, therefore undertook the task of finding another source. He may well have thought along the following lines. What pharmaceutical company is in the AIDS field? He would then have been bound to think of Burroughs Wellcome (the Wellcome Foundation Ltd). I think it perfectly possible that he did not distinguish between the pharmaceutical company and the Wellcome Trust, the charity that owned the company. Very few people ever did. When he phoned me he might have thought he was speaking to the company. I took it that he knew the difference as he made no reference to the company.

The Wellcome Trust is a charity that operates under charity law to support subjects stipulated in the will of Sir Henry Wellcome. The Trust's main asset at the time of this application was the majority ownership of the Wellcome pharmaceutical company. There was, however, no link between the Trust and the company other than as a shareholder and in fact it would contravene charity law and the provision of tax relief by the Inland Revenue if there had been any such link. The support of the survey would come under the heading of medical research. The Trust's support for medical research at that time was mainly centred on basic and clinical science and its board of Trustees were five scientists and two laymen, who were responsible for financial and administrative aspects. The scientific programme was under my directorship and I had a staff with specialist knowledge of different disciplines who handled particular subjects. Since we had never been involved in surveys or subjects such as NATSAL, it was appropriate that an enquiry would come to me in the first place. Donald Acheson phoned

<sup>&</sup>lt;sup>106</sup> Dr Peter Williams was the director of the Wellcome Trust (1965–91).

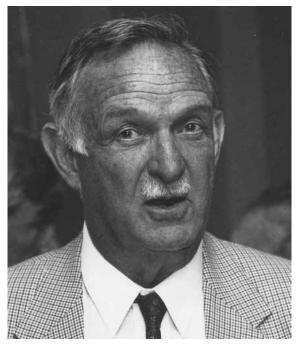


Figure 9: Dr Peter Williams.

me and asked whether the Trust could consider an application to support the survey. He stressed the importance in relation to the AIDS problem and said that the plan had been scrutinized and refereed by the Department of Health. He said that the Prime Minister had vetoed support from Government funds. The need for the information that such a survey would supply was obvious and it certainly was medical research and scientifically based. The cost would be £1 million. I decided that I would ask the Trustees if they could see any reason not to consider the proposal and I raised the question at a meeting in the following week. They could see no objections, so I asked Donald Acheson to send me the papers and put the applicants in touch with the Trust. The application would have to come from the people who would do the work and not the Department of Health. At this stage I passed over the processing of the application to David Gordon, who would undertake the normal procedure at the Trust of assessing projects. He brought the results to the next meeting of the scientific Trustees. They decided that the project merited Trust support and passed it up to the full board to sanction the funding and discuss any side issues, such as the relationship to the Government and the Prime Minister in particular. The grant was approved. No one ever thought to ask how the Trust came to hear of the project. I suppose it was assumed that the survey's researchers had approached us themselves as this was how it was handled. The truth is, of course, that Sir Donald Acheson's part was very important but, I am sure, highly improper for a civil servant. Reference was never made to our conversation but I am sure that what he was able to tell me was highly relevant to us making the decision to give it support. This symposium gives me the opportunity to pay tribute to him for his strength. This support is an important illustration of the need for a nongovernment structure, which can be independent of politics. If the Wellcome Trust or another charity had not made the grant, the project could never have been undertaken.

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# Biographical notes\*

# Professor Sir Donald Acheson

KBE FRCP FFPH FFOM FRCS FRCOG HonFRSM (1926–2010) trained at the University of Oxford and the Middlesex Hospital, and subsequently specialized in public health. From 1968 until 1983 he was professor of clinical epidemiology at Southampton University, and also served as foundation dean of the faculty of medicine. He was Chief Medical Officer of England (1983–91), dealing with the HIV/ AIDS crisis.

# Professor Michael Adler

CBE FRCP FFPH (b. 1939) is professor of genitourinary medicine and sexually transmitted diseases at the Royal Free and University College Medical School. His main research interests are in the field of epidemiology, with particular interest in the development of models of care. He is an adviser to the UK Government, the World Health Organization, the UK Department for International Development (DFID) and UNAIDS (the United Nations programme on HIV/AIDS). He was awarded a

CBE in 1999 for services to HIV/AIDS.

# Professor Sir Roy Anderson

FRS FMedSci (b. 1947) was professor of infectious disease epidemiology, division of epidemiology, public health and primary care, Imperial College London (2000–04), chief scientific adviser, Ministry of Defence (2004–07), rector, Imperial College London (2008–09). He was a governor of the Wellcome Trust (1991–2000).

# Professor Dame Valerie Beral

DBE FRCP FMedSci FRS (b. 1946), epidemiologist, was born, educated and qualified in medicine in Australia. She was lecturer and reader at the London School of Hygiene and Tropical Medicine and has been the head of the cancer epidemiology unit for Cancer Research UK since 1989. For further details on the Million Women Study, the largest study of women's health, with the participation of one in four UK women who were aged 50–64 during the period of recruitment (1996–2001), see Beral, Million Women Study

<sup>\*</sup> Contributors are asked to supply details; other entries are compiled from conventional biographical sources.

Collaborators (2003), and http://info.cancerresearchuk. org/cancerandresearch/ ourcurrentresearch/ researchbygrantee/beral/ (visited 30 September 2009).

Professor Virginia Berridge PhD FFPH AcSS HonFRCP FRHistS (b. 1946) is professor of history at the London School of Hygiene and Tropical Medicine and director of the Centre for History in Public Health. She was appointed senior lecturer there in 1988 as co-director of the AIDS social history programme. She previously worked at the Institute of Historical Research (1979–88), the Economic and Social Research Council (1986–88) and the addiction research unit. Institute of Psychiatry (1974–79).

# Romola Christopherson

CB (1939–2003) was director of press and publicity at the DHSS (later DoH) from 1986 to 1999. See Langdon (2003), and Dowman R. (1996), freely available at: http://prweek.com/uk/ news/search/92606// (visited 22 September 2010).

# Sir David Cox

FRS (b. 1924) studied mathematics at St John's College, Cambridge, and obtained his PhD from the University of Leeds in 1949. He was reader and then professor of statistics at Birkbeck College, London (1956–66); professor of statistics at Imperial College London (1966–88); warden of Nuffield College and a member of the department of statistics at Oxford University (1988–94).

# Professor Tony Coxon

PhD (b. 1938) was trained in sociology at the University of Leeds and MIT. He taught at the Universities of Leeds, Edinburgh and Cardiff where he specialized in research methods and subsequently in sexualities and health studies, and was co-director of the Institute for Behavioural Research on AIDS, University of Wales College of Medicine, Cardiff and professor in the Bro Tâf Health Authority. He was a member of the health education subcommittee of the DHSS expert advisory group on health education and AIDS and a member of the Welsh Office Health Education advisory committee, subcommittee on AIDS. He was co-founder with Dr Tom McManus and Dr Peter Davies of the panel study funded by the MRC and DHSS, Project SIGMA (Sociosexual Investigations of Gay Men and Aids) and was principal investigator in south Wales and Essex sites (1982–2002); consultant and adviser of WHO Special (later, Global) Programme on AIDS (1987–92) and coordinator of the

seven nation International Studies of Gay and Bisexual Behaviour and Aids and a member and chair of the ESRC Steering Group on AIDS. He was also consultant to Barnet, Brent and Harrow, Bro Tâf, South-East London and North Essex Health Authorities' HIV/AIDS research advisory and Education Units on PSE (Public Sex Environment) and Outreach Project (1996–2002). He has been director of the British Household Panel, University of Essex, since 1989 and subsequently professor of sociology and health studies (1997 - 2002).

# Professor Nicholas Day

CBE FRS (b. 1939), statistician, was director of the MRC biostatistics unit (1986–89), and remained honorary director there until 1999. He was also professor of public health at the University of Cambridge (1989–99) and MRC research professor of epidemiology (1999–2004). He was chairman of the MRC committee on the epidemiology and surveillance of AIDS (1988–92).

# Dame Karen Dunnell

DCB MA (b. 1946) member of the Faculty of Public Health (Hon). She was a researcher at the Institute of Community Studies (1967–72); lecturer in the department of epidemiology, St Thomas' Hospital Medical School (1972–74), survey officer, chief medical statistician, director of social statistics (1974– 2009), chief executive and national statistician (2005–09). She was awarded a DCB in 2009. For an interview with Dame Karen Dunnell in 2006, see http:// network.civilservicelive.com/pg/ pages/view/258060/ (visited 22 September 2010).

# Mr Mike Durham

(b.1952) is a journalist and author. After reading English at the University of Kent at Canterbury, he trained as a journalist on local newspapers in Kent and Somerset, before moving to the *London* Evening Standard where he entered Fleet Street. He has since enjoyed a varied career taking in diary writing, general news, education, health, consumer affairs and investigations, and worked for titles including the Daily Telegraph, The Sunday Times and Observer. He has written a book for teenagers, Need to Know – Painkillers and Tranquillizers (Heinemann, 2004). In late 1989 he was a freelance casual general reporter for the Sunday Times, and was appointed Health and Social Service Correspondent the following year, staying for three years. He is now owner of Hungry Fox Media, supplying news and features in the UK and internationally.

# Mr Bob Erens

BA MA (b. 1953) graduated from the University of Colorado and with a Master's from New York University in social anthropology. He started his research career at the National Centre for Social Research (NatCen) in 1986 (Social and Community Planning Research, until 1999), becoming the director of NatCen's health research group in 1997, where he directed the Health Survey for England (1998– 2003), a series of patient experience surveys for the Department of Health (1998-2002), the first study on the prevalence of problem gambling in Britain in 1999 and the first study on the prevalence of elder abuse in Britain in 2006. He was director of NatCen's highly regarded Survey Methods Unit from 2007 to 2010. In 2011, he became deputy director of the Policy Innovation Research Unit at the London School of Hygiene and Tropical Medicine (funded by the Department of Health). He was a co-applicant on the second NATSAL in 2000 and the third in 2010.

# Mrs Julia Field

BA (b. 1935) graduated in sociology and social anthropology in 1955, from Rhodes University, Grahamstown, South Africa and studied social administration at Barnet House Delegacy for Social Training, St Anne's College, Oxford (1956/7). She worked in the audience research department of the BBC for two years before returning to her home country, Zambia. She joined Research Services Ltd (London) as a market research officer (1961-66). After a career break for childrearing she joined the SCPR in 1975 and continued to work there (by then NatCen) as research director until her retirement in 1998. She was one of the principal investigators on both NATSAL-1 and -2, continuing her involvement in NATSAL-2 on a freelance, parttime basis until 2001.

# Dr Kathy French

BSc (Hons) PhD MPhil PGDip Cert Ed (b. 1948) has a background in nursing, qualifying at Kings College Hospital London in 1974. She has spent most of her career in sexual health, in clinical practice, education and management. She undertook an MPhil in medical law and ethics at the University of Glasgow and completed a PhD at City University London in 2008. She was appointed sexual health adviser to the Royal College of Nursing in 2002 and later that year as a nurse member of the Independent Advisory Group

(IAG) at the Department of Health. She is currently working parttime as clinical director at Brook Advisory Centre.

#### Sir Roger Gibbs

HonFRCP HonFMedSci (b. 1934) went into the money markets in the City of London in 1954, joining Jessel Toynbee (1954–64), becoming a director in 1960. He then joined the stockbroker de Zoete & Gorton (later de Zoete & Bevan, 1964–71), becoming a partner in 1966. He re-entered the London discount market with Gerrard & National as a director, chairman (1974-89). He was chairman of the London Discount Market Association (1984–86). In 1983 he became a Trustee of the Wellcome Trust and was chairman of its Board of Governors (1989–99). He has been a director of various companies, including Arsenal Football Club (1980-2006) and Howard de Walden Estate (director 1989–98; chairman, 1993–98). He was a special trustee of Guy's Hospital (1983–92), a trustee of the Royal National Pension Fund for Nurses (1975–2002), the London Clinic (1975–2002), the Imperial Cancer Research Fund (later Cancer Research UK, 1985-2002) and a wide variety of other charities, notably as chairman of the St

Paul's Cathedral Foundation (1999–2006), which raised £40m to clean and restore the cathedral. He was on the main committee of the Marylebone Cricket Club (1988–94) and was president of the Cresta Run, twice, and also of the City Road Runners Association (1984–88) and of the London Bankers' Golfing Society (1985– 89). He holds honorary degrees from the Universities of Dundee and London.

# Professor David Gordon

FRCP FMedSci (b. 1947) is a general physician. He began his academic career in the medical unit at St Mary's Hospital Medical School. In a prolonged break from his conventional academic medical career he was a member of the staff of the Wellcome Trust, London, responsible for support of biological and medical research across a wide range of subjects, and for the career development of clinical and basic biomedical scientists. He worked at the University of Manchester (1999– 2007), most of that time as dean of the medical faculty. He was chair of the Council of Heads of Medical Schools and also the president of the Association of Medical Schools in Europe. He has been visiting professor at the University of Copenhagen since 2007.

#### Sir Graham Hart

KCB (b. 1940) spent most of his working life in the Department of Health, ending up as permanent secretary (1992–97). In retirement, he has chaired the King's Fund and Citizens Advice, is on the advisory committee of the Centre for History in Public Health, and is now working for a PhD in early modern history.

# Rt Hon Richard Edward Geoffrey Howe (Baron Howe of Aberavon)

CH QC PC (b. 1926) was Margaret Thatcher's longest serving Cabinet Minister. He was Minister for Trade 1972–74; shadow Treasury spokesman 1975–79; Chancellor of the Exchequer (1979–83); Foreign Secretary (1983–89) and Leader of the House and Deputy PM (1989–90).

# Dr Bobbie Jacobson

OBE FFPH (b. 1950) gained a BSc in biochemistry from the University of Sussex (1972); MB BS from Middlesex Hospital Medical School (1982); MFPH Faculty of Public Health Medicine (1990); FFPH Faculty of Public Health (1996). She was deputy director of Action on Smoking and Health (1973–77); undertook junior hospital doctor posts (1983–85); became research fellow in health promotion, London School of Hygiene and Tropical Medicine (1985–87); consultant in public health medicine, City and Hackney Health Authority 1989–90); director of public health, City and Hackney Health Authority (1990–93); director of Public Health, East London and the City Health Authority (1993–2001); and is director of the London Health Observatory, now part of Commissioning Support for London (since 2001). She was a member of Sir Michael Marmot's Independent Review of Health Inequalities (published February 2010) and NICE's Advisory Committee on NHS Evidence (dates?); and is vice chair of the Association of Public Health Observatories (APHO) of the UK and Ireland, and spearheaded APHO's national lead role on tobacco and tackling social and ethnic inequalities in health. She was awarded an OBE in 2006.

#### Professor Anne Johnson

MD FMedSci FRCP FFPH FRCGP (b. 1954) is professor of infectious disease epidemiology and head of the division of population health at UCL and co-director of the Institute for Global Health, UCL. After training in medicine in Cambridge and Newcastle, she specialized in epidemiology and public health. She has worked in research in epidemiology and prevention of HIV and sexually

transmitted infections and other infectious diseases for over 20 vears. She co-directed the Medical Research Council UK centre for coordinating epidemiological studies of HIV and AIDS (1985–1999), and was principal investigator on the 1990, 2000 and 2010 National Surveys of Sexual Attitudes and Lifestyles. Her current research portfolio includes international HIV cohort studies, behavioural intervention studies and a community study of the epidemiological and immunological determinants of seasonal influenza transmission (MRC Fluwatch). Her studies include collaborations with colleagues in Europe, Africa and China. She has advised a number of national and international bodies, as deputy chair of the MRC infection and immunity board (2004-07), been a member of the Department of Trade and Industry expert advisory group, foresight detection and identification of infectious diseases project (2004-07), a member of the Department of Health's specialist advisory committee on antimicrobial resistance (2001–07), member of the working party on public health: ethical issues (Nuffield Council for Bioethics, in 2007). She is currently a member of the Wellcome Trust populations and public health committee, chair

of the MRC population health sciences group and member of the MRC strategy board and member of the Department of Environment, Food and Rural Affairs (DEFRA) adaptation subcommittee on climate change. She is a former non-executive director of the Whittington NHS trust. Since the Witness Seminar, she was appointed a governor of the Wellcome Trust in late 2010.

# Rt Hon David Mellor

QC (b. 1949) was MP for Putney (1979–97), served in the Home Office, as minister of state for criminal justice policy, the Treasury and the Foreign Office, was in charge of East–West relations and the Middle East, before being appointed to the Cabinet in 1990, initially as chief secretary to the Treasury, before becoming the founding Secretary of State for National Heritage two years later.

# Dr Catherine Mercer

MSc PhD (b. 1974) read population sciences at the University of Southampton before completing her MSc in social statistics and her PhD in demography there. In 2000 she joined the then department of sexually transmitted diseases (Centre for Sexual Health and HIV Research from 2004) at UCL to lead the analysis of the data from the 2000 NATSAL. She has published extensively and is the author of over 80 scientific articles. In 2007, she secured funding to undertake the third NATSAL study and will lead the statistical analyses.

# Rt Hon Claus Moser (Baron Moser from 2001)

KCB CBE FBA (b. 1922), British statistician, born in Berlin, moving to Britain with his parents in 1936, and educated at LSE, where after returning from the war he was appointed assistant lecturer in statistics, then lecturer (1946–55); reader in social statistics (1955–61); professor of social statistics (1961– 70); and visiting professor of social statistics (1970–75). Moser was director of the Central Statistical Office from 1967 until 1978. He was made a Knight Commander of the Bath in 1973.

# Professor Sir Stanley Peart

Kt FRCP FMedSci FRS (b. 1922) was professor of medicine at St Mary's Hospital Medical School, University of London (1957–87), later emeritus. He was master of the Hunterian Institute, Royal College of Surgeons of England (1988–92); Trustee of the Wellcome Trust (1975–94), deputy chairman (1991–94) and consultant (1994–98); and a Beit trustee (1986–2003). He delivered the Goulstonian Lecture in 1959, the Croonian Lecture in 1979, and was a founder member of the Academy of Medical Sciences in 1998.

#### Professor Clive Seale

PhD (b.1955) is professor of medical sociology at Barts and the London School of Medicine and Dentistry, part of Queen Mary University of London. He was previously professor of sociology in Brunel University and Goldsmiths. During the 1980s he worked on a variety of social surveys in the education and health fields. His work at present focuses on communication issues in the delivery of healthcare in multi-ethnic communities, and on decision-making in end-of-life care. For this, he employs a variety of social research methods, including both social survey and qualitative approaches.

# Dr Pam Sonnenberg

MBBCh DTM&H DPH MSc PhD FFPH (b. 1965) is an infectious disease epidemiologist and consultant in public health medicine. Since 2006, she has been senior lecturer in HIV/STI epidemiology in the Centre for Sexual Health and HIV Research at UCL, where she leads the epidemiology and social science group. She is a co-applicant on the National Survey of Sexual Attitudes and Lifestyles (2010), leading on the STI component.

#### Professor Tilli Tansey

PhD PhD HonMRCP HonFRCP FMedSci (b. 1953) is convenor of the History of Twentieth Century Medicine Group and professor of the history of modern medical sciences at Queen Mary, University of London.

#### Professor Kaye Wellings

MA MSc FFPH FRCOG (ad eundem) FFSRH (b. 1948) is professor of Sexual Health at the London School of Hygiene and Tropical Medicine. She was one of the founders of NATSAL and was the LSHTM lead researcher on the 1990 and 2000 studies. She is also the LSHTM lead researcher on NATSAL 2010–12.

#### Dr Peter Williams

CBE FRCP (b. 1925) trained as a physician and for two years was a medical specialist in the Royal Army Medical Corps. He was appointed a medical officer on the headquarters staff of the MRC (1955–60). He was recruited to the Wellcome Trust in 1960 and was its director (1965–91) and director of the Wellcome Institute for the History of Medicine (1981–83).

#### Mrs Wendy Williams

(b. 1941) completed a business studies course at college. After working initially for Barclays Bank, she did promotional work for a large international company. She later returned to education as a mature student, obtaining a BA (Hons) degree at the University of North East London in 1981, and several university diplomas (all in environmental sciences). She began working as an interviewer with NATSAL when it was inaugurated in 1969 and has continued to do so ever since.

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