

The Whitehall Study:

Sensitive records within a longitudinal health survey



4. (a) Have you ever smoked a pipe? 1. No (If "No", go to question 9) 2. Used to smoke a pipe but not now (Go to 9) 3. Now smokes a pipe

(b) If you smoke a pipe now, about how many ounces of tobacco do you smoke per week? Ounces per week

9. (a) Have you ever smoked cigars regularly? 1. No (If "No", go to question 13) 2. Used to smoke cigars but not now (Go to 13) 3. Now smokes cigars regularly

(b) If you smoke cigars now, about how many cigars do you smoke per week? Number per week

(c) Do you inhale? 1. Yes 2. No

10. At work, do you spend most of your time... 1. Sitting? 2. Standing? 3. On the move?

11. Do you own a car? 1. Yes 2. No

12. How many minutes do you walk or bicycle on the way to work each day? (single journey) minutes

13. In an average week in the summer do you work as much as 2 hours in the garden? 1. Yes 2. No

14. Do you usually bring up any phlegm from your chest first thing in the morning? 1. Yes 2. No (Go to question 15)

15. Do you bring up phlegm like this on most days for as much as three months in the winter each year? 1. Yes 2. No

16. In the past three years, have you had a period of increased cough and phlegm lasting for 3 weeks or more? 1. Yes—1 period 3. No 2. Yes—2 or more periods

17. Do you get short of breath walking with people of your own age on level ground? 1. Yes 2. No

18. Does your chest sound wheezy or whistling on most days (or nights)? 1. Yes 2. No

19. Does the weather affect your breathing? 1. Yes 2. No

If "Yes", specify type of weather: _____

20. (a) Have you ever had any pain or discomfort in your chest? 1. Yes 2. No (Go to 21)

(b) Do you get this pain or discomfort when you walk uphill or hurry? 1. Yes 2. No (Go to 21)

(c) Do you get it when you walk at an ordinary pace on the level? 1. Yes 2. No

(d) When you get any pain or discomfort in your chest what do you do? 1. Stop 2. Slow down 3. Continue at the same pace

(e) Does it go away when you stand still? 1. Yes 2. No

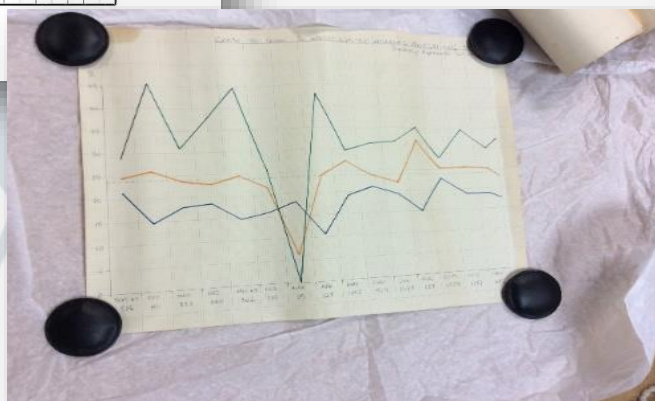
(f) How long? 1. 10 minutes or less 2. More than 10 minutes

(g) Where do you get this pain or discomfort? Mark the place(s) with X on the diagram.

21. Have you ever had a severe pain across the front of your chest lasting for half an hour or more? 1. Yes 2. No

INDEX

SURVIVOR NUMBER	ADDRESS	CLASSIFICATION
06099	6.4	Wald-Parkinson-White Syndrome
08601	6.2	
09741	4.2, 5.3, 8.5	Distal Fibrillation
10511	7.1	Complete Left Bundle Branch Block
13946	8.1	Wandering Pacemaker
14539	6.5	Wenckebach's Phenomenon
14716	8.5	
14644	8.1	Atrial Ectopic Beats and Ventricular Ectopic Beats. Coupling
15297	7.1, 8.1, 8.3	Left Bundle Branch Block. Multiple Ventricular Ectopic beats. Atrial Fibrillation
16690	8.1	Skilting Pacemaker, Atrial Ectopic Beats
20618	2.1, 7.5, 8.3	Atrial Fibrillation
16796	6.4	Wald-Parkinson-White Syndrome
17633	6.4	Wald-Parkinson-White Syndrome
18297	1.1, 4.1, 5.2, 8.7	
19819	7.1, 6.7, (could be 6.4)	
20236	6.2	Wenckebach's Phenomenon
80936	8.1	
21655	8.1	
23197	8.7	Breastfeeding
21288	5.6	
21556	1.1, 7.4, 8.3	Coupling Atrial Ectopic beats
21945	8.1	
28183	1.3, 1.5, 6.2, 8.1, 8.1	at Survey } Intermittent } Wolff-Parkinson-White syndrome



CIVIL SERVICE HEALTH SURVEY

CIGARETTE SMOKING + NUMBER OF CIGARETTES SMOKE PER WEEK BY AGE

AGE GROUP	CIGARETTE CONSUMPTION (per 1000 men)		NUMBER OF CIGARETTES SMOKE PER WEEK		MORBIDITY
	1948	1968	1-9	10-19	
40-44	2520	2024	68	17	12
45-49	2518	2116	67	17	12
50-54	2518	2116	67	17	12
55-59	2518	2116	67	17	12
60-64	2518	2116	67	17	12
65-69	2518	2116	67	17	12
70-74	2518	2116	67	17	12
75-79	2518	2116	67	17	12
80-84	2518	2116	67	17	12
85-89	2518	2116	67	17	12
90-94	2518	2116	67	17	12
Total	2518	2116	67	17	12

* EXCLUDES MARIJUANA.

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What was the Whitehall Study?



The Whitehall Study, a longitudinal health study of male middle aged civil servants. The study conducted by the School and Guy's Hospital surveyed over 18,000 civil servants, aged 45-60, based in London from 1967-1970.

Population: **18,403**

middle-aged male Civil Servants
in London volunteered for the study.

Around
75%

of the chosen sample agreed to participate.



The sample included
civil servants from

37



departments including the British Museum, Diplomatic Service, Inland Revenue, Ministry of Defence, Ministry of Public Building and Works, Ministry of Power, and Scotland Yard.

Health screening, 1967-1970



HOW TO GET TO THE SURVEY CENTRE



Survey in Civil Service



- 1 **Station 1:** Check appointment time. Measure height and weight
- 2 **Station 2:** Measure blood pressure, tricep skinfold thickness and check questionnaire
- 3 **Station 3:** Take blood samples (0.1ml for blood sugar/0.5ml cholesterol)
- 4 **Station 4:** Vitalograph (FEV. 1.0) F.V.C.
- 5 **Station 5:** Electrocardiogram
- 6 **Station 6:** X-ray examination

Appointment



2 subjects every 5 minutes



24 subjects every hour



Max per morning



Average per morning



per week

Impact of the study



- **Identifying risk factors in volunteers:** The study identified a number of men who showed signs of cardiovascular and respiratory diseases, as well as diabetes.
- **Positive intervention with at risk individuals:** Randomised control trials of anti-smoking counselling and effect of diet on borderline diabetes showed positive long term health benefits.
- **Social gradient and mortality:** The main impact was demonstrated by Marmot et al (1982): the study demonstrated that the risk of mortality increased further down the social gradient, where lower grade employees were a third more likely to die from the disease than the highest grade employees.

Project methodology

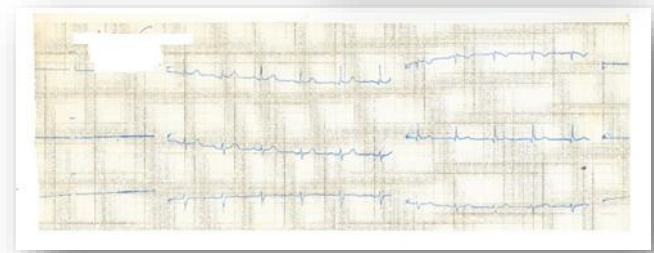


- 1) Survey
- 2) Isolate
- 3) Review

What sensitive records are within the collection?



- Questionnaires (contain personal details, medical information about physical and mental health).
- Clinical data (ECG strips, X-ray analysis, blood pressure readings etc.)
- Clinical observations from control studies [report cards on subjects attending smoking/dieting clinic]
- Correspondence with subjects regarding health matters
- Sickness absence records [some listing medical conditions]
- Death certificates

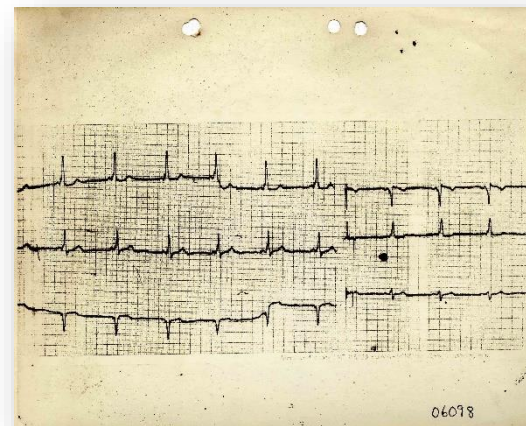


Sensitivity Survey



- Sensitivity survey conducted during cataloguing initially to identify sensitive and restricted record groups
- Majority of sensitive records, were covered by DPA legislation e.g. questionnaires without death certificates
- Some ambiguities, such as electrocardiograms and death certificates.

The image shows a two-page questionnaire form. The first page contains questions 1 through 11, and the second page contains questions 12 through 25. The questions are related to health and safety, such as 'Have you ever smoked or drunk?', 'Do you get a pain in your chest?', and 'Have you ever been in hospital?'. The form includes checkboxes for 'Yes', 'No', and 'Don't know'. The second page also includes a diagram of a human torso with a line indicating the location of the heart.



Questionnaires



Contain various forms of personal data:

- Personal information (name, address, date of birth, marital status)
- Medical history (and family medical history)
- Questions relating to cardiovascular and respiratory conditions (e.g. winter phlegm, shortness of breath)
- Questions relating to diabetes
- Questions about prescribed medication
- Clinical data from medical tests, including weight, blood pressure, cholesterol

Death certificates



Photocopies of death certificates include information:

- Personal information (name, address, date of birth, NHS number)
- Causes of death
- Possible verdicts from coroner's inquest
- Personal data of informant (name, address)

What guidelines exist for this type of record?



- Death certificates were the records that caused the most difficulty.
- Death certificates are public documents and can be ordered from General Registry Office
- Ambiguities emerge with recorded deaths. Suicides include method of death, as does accident and/or murder.
- Causes of death are listed, sometimes relating to alcoholism, mental illness or from potential hereditary disease.
- Should these be open?

Isolation and Review process



- 70 standard archive boxes to review. 33 boxes checked so far.
- 57 questionnaires have been isolated so far. Each record removed is retained within original box in separate file.
- Review will take place at end of project involving Archives team. Some items pulled are low risk e.g. cirrhosis cases, accidental deaths whilst others require further thought e.g. medical history of psychiatric disorders, open verdicts.

Reflections regarding sensitivity guidance



- Some useful resources are available: Wellcome Library, NHS Code of Practice, National Archives and London Metropolitan Archives.
- Resources tend to focus on providing framework to looking into sensitivity, or dealing with particular record groups.
- Most guidance focuses on access restrictions as a whole e.g. concentrates on DPA Act, restrictions by donors, conservation and not sensitivity. Which is usually described as being undertaken on a 'case by case' basis.
- Sensitivity decisions are likely to always come down to judgement and acceptable risk, but more guidance and support would provide a greater consistency in decision-making.