

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? 1. 0-4 2. 4-8 3. 8-12 4. 12-16 5. 16-20 6. 20-24 7. 24-28 8. 28-32 9. 32-36 10. 36-40 11. 40-44 12. 44-48 13. 48-52 14. 52-56 15. 56-60 16. 60-64 17. 64-68 18. 68-72 19. 72-76 20. 76-80 21. 80-84 22. 84-88 23. 88-92 24. 92-96 25. 96-100

5. (a) Have you ever smoked cigars regularly? 1. No (If "No", go to question 10) 2. Used to smoke cigars but not now (Go to 10) 3. Now smokes cigars regularly

(b) If you smoke cigars now, about how many cigars do you smoke per week? 1. 0-4 2. 4-8 3. 8-12 4. 12-16 5. 16-20 6. 20-24 7. 24-28 8. 28-32 9. 32-36 10. 36-40 11. 40-44 12. 44-48 13. 48-52 14. 52-56 15. 56-60 16. 60-64 17. 64-68 18. 68-72 19. 72-76 20. 76-80 21. 80-84 22. 84-88 23. 88-92 24. 92-96 25. 96-100

6. (a) Do you inhale? 1. Yes 2. No

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

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

9. How many minutes do you walk or bicycle on the way to work each day? (single journey) 1. 0-10 2. 10-20 3. 20-30 4. 30-40 5. 40-50 6. 50-60 7. 60-70 8. 70-80 9. 80-90 10. 90-100 11. 100-110 12. 110-120 13. 120-130 14. 130-140 15. 140-150 16. 150-160 17. 160-170 18. 170-180 19. 180-190 20. 190-200 21. 200-210 22. 210-220 23. 220-230 24. 230-240 25. 240-250

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

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

12. 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

13. 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

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

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

16. Have you ever had any pain or discomfort in your chest when you do any of the following? 1. Stop 2. Slow down 3. Continue at the same pace

17. Does it go away when you stand still? 1. Yes 2. No

18. How long? 1. 10 minutes or less 2. More than 10 minutes

19. Where do you get this pain or discomfort? (a) In the middle of the chest (b) In the lower part of the chest (c) In the upper part of the chest (d) In the left side of the chest (e) In the right side of the chest (f) In the back of the chest (g) In the neck (h) In the shoulder (i) In the arm (j) In the hand (k) In the foot (l) In the leg (m) In the back (n) In the neck (o) In the shoulder (p) In the arm (q) In the hand (r) In the foot (s) In the leg (t) In the back (u) In the neck (v) In the shoulder (w) In the arm (x) In the hand (y) In the foot (z) In the leg (aa) In the back (ab) In the neck (ac) In the shoulder (ad) In the arm (ae) In the hand (af) In the foot (ag) In the leg (ah) In the back (ai) In the neck (aj) In the shoulder (ak) In the arm (al) In the hand (am) In the foot (an) In the leg (ao) In the back (ap) In the neck (aq) In the shoulder (ar) In the arm (as) In the hand (at) In the foot (au) In the leg (av) In the back (aw) In the neck (ax) In the shoulder (ay) In the arm (az) In the hand (ba) In the foot (bb) In 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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.



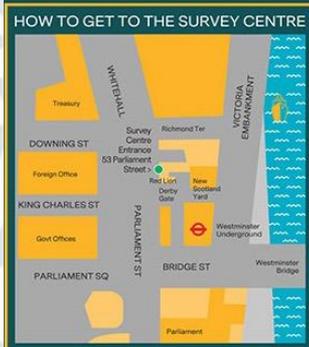
The sample included
civil servants from

37

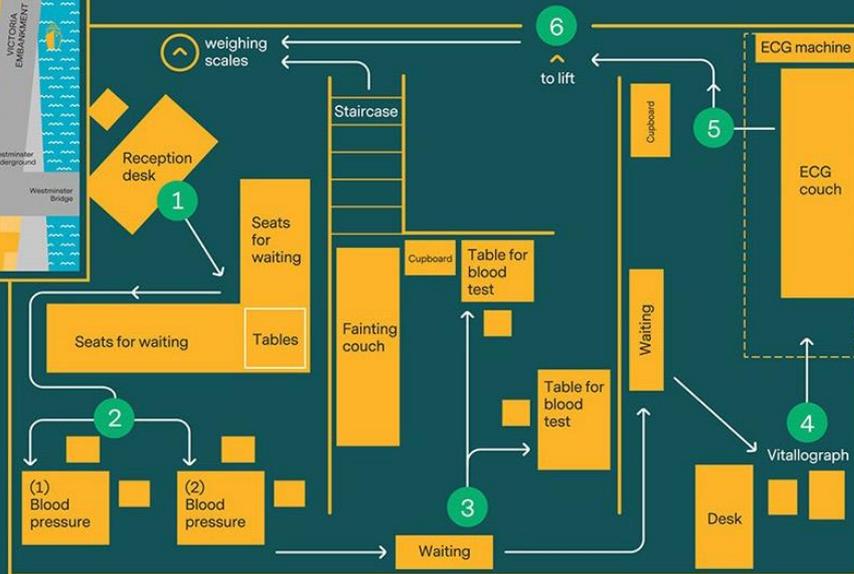


departments including the British Museum, Diplomatic Service, Inland Revenue, Ministry of Defence, Ministry of Public Building and Works, Ministry of Power, and Scotland Yard.

Health screening, 1967-1970



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



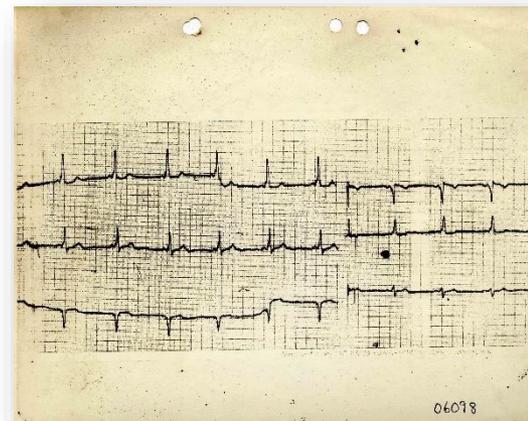
- 1) Survey
- 2) Isolate
- 3) Review

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 medical history. A diagram of a human torso is included on the second page, 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.