Lecture 11: Presenting data
Generating Meaning from Data

- Noting patterns, themes
- Plausibility and Implausibility
- Making metaphors
- Counting
- Making contrasts/comparisons

Trustworthiness of findings

- Checking for representativeness
- Researcher effects
- Triangulating
- Weighting the evidence (observation/accounts)
- Outliers; Extreme cases; Following up surprises
- Negative evidence
- Making "if-then" tests
- Replicating a finding
- Checking out rival explanations
- Informant feedback

Quality of conclusions

- **Objectivity** - "Audit trail"
- **Reliability** - stability over time, between different researchers and between different methods.
- **Internal validity** - "thick description" and "vicarious presence"
- **External validity** - reports on threats to generalizability (limiting effects of sample selection, setting etc)
- **Application** - accessibility, usable knowledge, in whose interests?

Documentation

- How the study came about
- Entry stage of data collection
- Relations with informants
- Private feelings
- Data gathering
- How data analyzed
- How data presented
- Retrospective learning
- Adapted from: Miles, M. & Huberman, A. (1994)
Presentation of Data

Ethnicity and Screening for Sickle Cell/Thalassaemia

Lessons for Practice from the Voices of Experience
The main themes that emerged from the data included 1) frustration at delay in being given pain relief; 2) the pain people with sickle cell anaemia were suffering not being taken seriously by staff; 3) the feeling that they were being accused of being drug addicts; 4) having to wait for long periods in accident and emergency departments before being transferred to the haematology wards; 5) lack of knowledge of sickle cell on the part of health staff, especially junior doctors and; 6) staff not listening to the patients who have become experts in their own management and who know, for example, the best site and the best way to obtain a vein for injection.
Theme 1

Delays

All five of the respondents expressed the view that there had been unacceptable delays in waiting for ambulances; waiting in casualty or being transferred to the specialist haematology ward. For example, one woman with sickle cell disease reported:

“But at the hospital I remember being in casualty for ages and being constantly injected with different drugs over the course of a few hours because none seemed to be dulling the pain” Respondent A

This suggests that it is important not only for specialist staff in the haematology ward to be knowledgeable about sickle cell crises and their treatment, but for those staff who may first encounter the person with sickle cell to be equipped with at least sufficient knowledge to be able to refer the person quickly to the appropriate ward.
Furthermore, although such delays are reported as a feature of early treatment of people with sickle cell anaemia, it appears that problems still arise in 2005, especially if the person with sickle cell happens to be taken ill in a town where there are relatively fewer patients with sickle cell and no specialist knowledge has been built up through clinical experience by the staff. For example, one respondent taken ill whilst away from home said:

“… I caught a cold, which brought on a severe crisis; they took me to hospital. Casualty[...] they were taking so long to assess what type and dosage of analgesia to give me so I had to instruct them step by step” Respondent A

In this example, the respondent suggests that the staff were slow in implementing their care and that this was possibly due to their lack of knowledge such that the person themselves had to tell them what to do. This suggests that all staff in ambulance and casualty department need to be aware and to have protocols for dealing with patients suffering a sickle cell crisis. This is especially the case in London, where the leading cause of emergency admissions to Accident and Emergency units is now sickle cell crisis.

Introduction to the theme, setting it into context. Main text is double spaced and uses full width of margins

Quotation. Single spaced. Attributed to an (anonymous) respondent

Interpretation of the data. Data does not “speak for itself”. Begin to draw out implications for policy
Summarising Themes

Summary of Themes

- Interpretation Theme 1
- Interpretation Theme 2
- Interpretation Theme 3
- Interpretation Theme 4
- Interpretation Theme 5
Quality and Quantity

1. One
2. Two, a couple of
3. Three, less than a quarter, a few
4. One-fifth, a few, less then a quarter
5. A quarter
6. More than a quarter, several
7. About a third, several
8. Over a third, several
9. Nearly half
10. Half
11. Over half
12. Over half, many
13. About two-thirds, most of
14. Over two-thirds, nearly three-quarters
15. Three quarters, most of
16. Over three-quarters
17. The majority of this group
18. The vast majority of this group
19. Nearly all, with one exception
20. All, without exception in this study
Conventions of Presenting Discourse

When in doubt about accuracy put in parenthesis (like this)

When cannot hear speech put (inaudible) in parenthesis

When material omitted within same speech sequence put square brackets [ … ] like this

When material omitted covering more than one speech sequence put brackets on separate line

[ … ]

like this

To clarify to reader, put explanation in brackets [like this]

When noises or sounds of assent put in slashes /hmm/ /yes/

To maintain confidentiality refer to (name of hospital) or (name of person) like this
Artefacts of transcription reflecting interpretation

Absence of a gap between speakers with = marks at the end of one and the beginning of another utterance

Pause in speech with seconds in parenthesis (2) for two seconds and (.) for less than a second

Indicate extended sound with colon marks ye::s

Indicate emphases in speech by underlining like this

Indicate intake of breath before a word by putting a full stop before it .aah

Adapted from:
Dyson, SM (2005) *Ethnicity and Screening for Sickle Cell and Thalassaemia* Elsevier
Participants

From Julian’s work on heart disease and family relationships

- 20 unaffected siblings of PRAMIS cases
- White
- 10 male, 10 female
- Aged 30 – 58, mean age = 47
- From a limited range of occupational groups
- Of their affected siblings, 15 were male, and the age they had a heart attack ranged from 30-51 years
Findings: main themes identified

1. The experiences of premature heart attack in a sibling

2. Explanations for siblings’ heart attack

3. Inheritance and genetics

4. Experiences with health care professionals
The experiences of premature heart attack in a sibling

- Surprise / shock
- Vulnerability
- Detachment
- Complacency / indifference
- Beliefs about moderating risk
- Barriers to moderating risk
- Information and support
- Lifestyle changes following sibling’s heart attack
Detachment

“I’ve never thought about it. Just sort of put it to the back of your mind…you always think it will never happen to me, don’t you?”

(Female, 55, brother had an MI at 51, father died of MI at 58)

“Whatever happened to him was totally different to me because I’m a different person”

(Male 53, brother had MI at 30)
Explanations for siblings’ heart attack

Causal attributions

Life event
Inheritance and genetics

Nature of genetics
The nature of genetic testing
Views about susceptibility testing
Public interest in genetic research
Views about susceptibility testing

“No, I would not want to know that!… If somebody told me I’d got a high risk of having this I’d say “Oh ****- thank you very much – now how do I live my life?”, I’m 53 and now you’ve told me I’m 90% gonna die from heart problems”

(Male 53, brother had MI at 30)

“If I can’t do anything about it, I’d sooner not know… bury my head in the sand. What you don’t know, can’t hurt you!”

(Male, 47, brother had MI at 48)
Experiences with health care professionals

A particularly worrying finding of the qualitative phase was the experiences of participants when they visited their GP for an assessment of their personal risk or reassurance regarding their own health – many felt that their concerns were dismissed or trivialised.
“…my doctor …at the time didn’t seem to be all that interested…to be truthful it was almost like… I was asking him something totally pointless”

(Male 32, sister had an MI at 36)

“The practice nurse asked “what are you having this done for?” [cholesterol], so I thought I’m all right, I’ll be all right… so why bother?”

(Male, 34, brother had an MI at 36)
Consulting behaviour

“[If I said to my GP] “now look, my brothers had a heart attack, I’d like to be checked over” “Why?” would be what I think I would get… it seems as if the doctor thinks that I’m trying to convince myself that I’m going to have one – which I’m not! I would be saying, you know, I just wanna make sure I’m OK”

(Female 51, brother had an MI at 49)
Numerical Data
Table 1

GPs’ Responses

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>Neither</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>100</td>
</tr>
</tbody>
</table>
Table 1

Number of GPs Reporting Satisfaction with Changes to Out-of-Hours Services in the NHS in England, 2005

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>116</td>
<td>38.7</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>103</td>
<td>34.3</td>
</tr>
<tr>
<td>Neither</td>
<td>81</td>
<td>27.0</td>
</tr>
<tr>
<td>Total</td>
<td>300</td>
<td>100</td>
</tr>
</tbody>
</table>
Cross-Tabulation

Table 2: Reported Smoking Habits of 25-year-olds in England, 2005

<table>
<thead>
<tr>
<th></th>
<th>Smoker</th>
<th>Non-Smoker</th>
<th>Row Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>25</td>
<td>75</td>
<td>100</td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
<td>85</td>
<td>100</td>
</tr>
<tr>
<td>Column total</td>
<td>40</td>
<td>160</td>
<td>200</td>
</tr>
</tbody>
</table>
A Comparison of Average Cases per annum of Meningitis and Mumps Among University Students in the UK, 1990s and 2000s
A Comparison of Average Cases per annum of Meningitis and Mumps Among University Students in the UK, 1990s and 2000s
Pie Chart

Tobacco 442,000
All other deaths 288,000
Box-and-Whisker Plot

- Maximum value
- 75th percentile
- Median
- 25th percentile
- Minimum value
Scatterplot

Correlation Matrix: Test Marks
Maths & Physics
Quantitative methods

• The quantitative phase of the study aimed to quantify some of the findings of the earlier qualitative phase

• A postal questionnaire was developed utilising questions / statements from previously published research and a small number of questions developed specifically for this study

• Sample source: PRAMIS cases and controls, which allowed comparison with a group where there was no family history of CHD
Main questionnaire: sent to all participants

Demographic  Current health status
Risk factors  Knowledge of heart disease
Perception of risk  Disease feared
Attitudes to genetic research
Attitudes to genetic susceptibility testing

Supplementary questionnaire: unaffected siblings only

Consultation  Sources of information
Access to health care professionals / adequacy of service
Current smoking behaviour
10) Please indicate how much you agree or disagree with each of the following statements by ticking the box that best represents your view.

a) Cholesterol increases the risk of heart disease
b) Genetic factors increase the risk of heart disease
c) Stress or worry increases the risk of heart disease
d) Eating fatty foods increases the risk of heart disease
e) Smoking increases the risk of heart disease
f) Lack of exercise increases the risk of heart disease
g) High blood pressure increases the risk of heart disease
h) Chance or fate is involved in the development of heart disease
i) Being overweight increases the risk of heart disease
j) High cholesterol increases the risk of heart disease

11) Of the following 10 factors, please pick the 8 that you think are the most important in increasing the risk of heart disease. Please list them in the order that best represents how important you think they are (1 being the most important).

- Diabetes
- Eating fatty foods
- Genetic factors
- Smoking
- Stress or worry
- Lack of exercise
- High blood pressure
- Chance / fate
- High cholesterol

12) Please list any other things that you think are important risk factors for heart disease:

13) More people die from cancer than heart disease.
14) A man over age 65 is much more likely to die from heart disease than a woman over age 65.
15) Having a parent with heart disease increases my risk of developing the disease.
16) Having a brother or sister with heart disease increases my risk of developing the disease.

17) Compared with other people of your age and sex, what do you think are the chances of you getting the following diseases in the next 15 years?

- Heart disease
- Stroke
- Cancer

18) Do you think it is possible for you to do anything to reduce your risk of the following diseases?

- Yes, definitely
- Yes, maybe
- No, probably not
- No, definitely not

19) Which one of the following illnesses do you fear most? (Please tick one box only)
- Heart disease
- Stroke
- Cancer
PRAMIS Controls 209

Posted 209

Retuned 152

Not returned 56

Retuned unused1

Withdrawn from analysis 4

Total number of questionnaires = 148
PRAMIS cases 224

Initial posting 166

Reply slips returned 61

Reminders sent 14

Questionnaires returned 54

Reply slips returned 8

Questionnaires returned 5

Total questionnaires returned = 59

Not posted 45

- Siblings all affected
- Died since PRAMIS
- Siblings known to live abroad
- Half-sibling of PRAMIS case
- No living siblings

- PRAMIS case now deceased
- Requested no follow-up
- Doesn’t speak to sibling / Cannot contact sibling
- Sibling now deceased
- Moved away
Table 6.7: Description of views of unaffected siblings and comparison group regarding beliefs about risk factors for heart disease

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Strongly Disagree*</th>
<th>Tend to Disagree</th>
<th>Neither</th>
<th>Tend to Agree</th>
<th>Strongly Agree</th>
<th>Mean**</th>
<th>Difference in mean (95% CI)</th>
<th>P-value</th>
<th>Adjusted difference in mean</th>
<th>Adjusted P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes increases the risk of heart disease</td>
<td>Unaffected Sibling</td>
<td>(0%)</td>
<td>(0%)</td>
<td>(20%)</td>
<td>(19%)</td>
<td>(16%)</td>
<td>(-0.12)</td>
<td>(0.40)</td>
<td>(-0.07)</td>
<td>0.69</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(2%)</td>
<td>(13%)</td>
<td>(31%)</td>
<td>(63%)</td>
<td>(39%)</td>
<td>(-0.41 to -0.17)</td>
<td>(0.27)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic factors increase the risk of heart disease</td>
<td>Unaffected Sibling</td>
<td>(0%)</td>
<td>(1%)</td>
<td>(0%)</td>
<td>(3%)</td>
<td>(3%)</td>
<td>(0.05)</td>
<td>(0.70)</td>
<td>0.02</td>
<td>0.89</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(0%)</td>
<td>(17%)</td>
<td>(3%)</td>
<td>(47%)</td>
<td>(47%)</td>
<td>(-0.19 to -0.28)</td>
<td>(0.29)</td>
<td>(-0.26 to -0.29)</td>
<td></td>
</tr>
<tr>
<td>Stress or worry increases the risk of heart disease</td>
<td>Unaffected Sibling</td>
<td>(1%)</td>
<td>(0%)</td>
<td>(12%)</td>
<td>(38%)</td>
<td>(38%)</td>
<td>(0.34)</td>
<td>(0.02)</td>
<td>0.29</td>
<td>0.069</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(1%)</td>
<td>(9%)</td>
<td>(12%)</td>
<td>(44%)</td>
<td>(44%)</td>
<td>(-0.02 to 0.61)</td>
<td>(0.61)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating fatty foods increases the risk of heart disease</td>
<td>Unaffected Sibling</td>
<td>(0%)</td>
<td>(17%)</td>
<td>(3%)</td>
<td>(35%)</td>
<td>(35%)</td>
<td>(0.17)</td>
<td>(0.10)</td>
<td>0.10</td>
<td>0.48</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(2%)</td>
<td>(3%)</td>
<td>(3%)</td>
<td>(55%)</td>
<td>(55%)</td>
<td>(-0.08 to 0.41)</td>
<td>(0.51)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking increases the risk of heart disease</td>
<td>Unaffected Sibling</td>
<td>(0%)</td>
<td>(0%)</td>
<td>(17%)</td>
<td>(71%)</td>
<td>(71%)</td>
<td>(0.05)</td>
<td>(0.01)</td>
<td>(0.19 to 0.40)</td>
<td>0.94</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(2%)</td>
<td>(2%)</td>
<td>(2%)</td>
<td>(75%)</td>
<td>(75%)</td>
<td>(-0.17 to 0.27)</td>
<td>(0.27)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of exercise increases the risk of heart disease</td>
<td>Unaffected Sibling</td>
<td>(0%)</td>
<td>(17%)</td>
<td>(3%)</td>
<td>(51%)</td>
<td>(51%)</td>
<td>(0.06)</td>
<td>(0.02)</td>
<td>(0.28 to 0.29)</td>
<td>0.99</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(2%)</td>
<td>(2%)</td>
<td>(2%)</td>
<td>(40%)</td>
<td>(40%)</td>
<td>(-0.30 to 0.17)</td>
<td>(0.29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High blood pressure increases the risk of heart disease</td>
<td>Unaffected Sibling</td>
<td>(0%)</td>
<td>(17%)</td>
<td>(3%)</td>
<td>(47%)</td>
<td>(47%)</td>
<td>(0.06)</td>
<td>(0.06)</td>
<td>(0.27 to 0.28)</td>
<td>0.97</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(2%)</td>
<td>(2%)</td>
<td>(2%)</td>
<td>(58%)</td>
<td>(58%)</td>
<td>(-0.17 to 0.29)</td>
<td>(0.28)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chance of fate is involved in the development of heart disease</td>
<td>Unaffected Sibling</td>
<td>(15%)</td>
<td>(22%)</td>
<td>(20%)</td>
<td>(32%)</td>
<td>(32%)</td>
<td>(0.20)</td>
<td>(0.26)</td>
<td>(-0.15 to 0.55)</td>
<td>0.98</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(10%)</td>
<td>(27%)</td>
<td>(24%)</td>
<td>(10%)</td>
<td>(10%)</td>
<td>(-0.15 to 0.40)</td>
<td>(0.40)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being overweight increases the risk of heart disease</td>
<td>Unaffected Sibling</td>
<td>(5%)</td>
<td>(17%)</td>
<td>(1%)</td>
<td>(40%)</td>
<td>(40%)</td>
<td>(0.04)</td>
<td>(0.72)</td>
<td>(0.30 to 0.23)</td>
<td>0.79</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(3%)</td>
<td>(2%)</td>
<td>(2%)</td>
<td>(37%)</td>
<td>(37%)</td>
<td>(-0.18 to 0.27)</td>
<td>(0.23)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High cholesterol increases the risk of heart disease</td>
<td>Unaffected Sibling</td>
<td>(5%)</td>
<td>(17%)</td>
<td>(1%)</td>
<td>(33%)</td>
<td>(33%)</td>
<td>(0.13)</td>
<td>(0.27)</td>
<td>(0.007)</td>
<td>0.96</td>
</tr>
<tr>
<td></td>
<td>Comparison group</td>
<td>(2%)</td>
<td>(2%)</td>
<td>(2%)</td>
<td>(33%)</td>
<td>(33%)</td>
<td>(-0.10 to 0.36)</td>
<td>(0.28)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Footnote to Table 6.7:
* Numerical values were assigned to the responses, for example, Strongly Disagree being 1 → Strongly Agree, being 5
*** Therefore, the Mean figure is the mean score on the scale described above
**** Calculated using a T-test
Compared with other people of your age and sex, what do you think are the chances of you getting heart disease in the next 15 years?

- Unaffected siblings: 3.35
- Comparison group: 2.55

*p = 0.001*
Compared to other people of *your* age and sex, what do you think are the chances of you getting cancer in the next 15 years?

![Bar chart showing percentages for very low, average, and very high levels of risk. The chart compares unaffected siblings and the comparison group, with p=0.78.]
Which disease do you fear most?

- Heart disease
- Stroke
- Cancer

Comparison group:
- Unaffected siblings

p = 0.001
Table 6.10  Compared with other people of your age and sex, what do you think are the chances of you getting the following diseases in the next 15 years?

<table>
<thead>
<tr>
<th></th>
<th>Very low*</th>
<th>Low</th>
<th>Average</th>
<th>High</th>
<th>Very high</th>
<th>Mean **</th>
<th>Difference in mean</th>
<th>p-value ***</th>
<th>Adjusted difference in mean</th>
<th>Adjusted p-value ****</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Heart disease</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unaffected Sibling</td>
<td>2 (3.5%)</td>
<td>1 (1.8%)</td>
<td>32 (56.1%)</td>
<td>19 (33.3%)</td>
<td>3 (5.3%)</td>
<td>3.35</td>
<td>0.80 (0.55-1.05)</td>
<td>0.001</td>
<td>0.94 (0.65-1.22)</td>
<td>0.001</td>
</tr>
<tr>
<td>Comparison group</td>
<td>16 (10.9%)</td>
<td>45 (31.3%)</td>
<td>75 (51.0%)</td>
<td>8 (5.4%)</td>
<td>2 (1.4%)</td>
<td>2.55</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Stroke</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unaffected Sibling</td>
<td>2 (3.4%)</td>
<td>6 (10.3%)</td>
<td>34 (58.6%)</td>
<td>16 (27.6%)</td>
<td>0 (0%)</td>
<td>3.1</td>
<td>0.54 (0.55-1.05)</td>
<td>0.001</td>
<td>0.63 (0.36-0.91)</td>
<td>0.001</td>
</tr>
<tr>
<td>Comparison group</td>
<td>14 (9.5%)</td>
<td>47 (32.0%)</td>
<td>75 (51.6%)</td>
<td>9 (6.1%)</td>
<td>1 (0.7%)</td>
<td>2.56</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cancer</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unaffected Sibling</td>
<td>2 (3.4%)</td>
<td>9 (15.5%)</td>
<td>42 (72.4%)</td>
<td>5 (8.6%)</td>
<td>0 (0%)</td>
<td>2.86</td>
<td>-0.02 (-0.24 - 0.19)</td>
<td>0.84</td>
<td>-0.04 (-0.29 - 0.22)</td>
<td>0.78</td>
</tr>
<tr>
<td>Comparison group</td>
<td>6 (4.1%)</td>
<td>29 (19.7%)</td>
<td>91 (61.9%)</td>
<td>18 (12.2%)</td>
<td>3 (2.0%)</td>
<td>2.88</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Footnote to table 6.10:
* Numerical values were assigned to the responses, for example, Very Low Disagree being 1 → Very High being 5
** Therefore, the Mean figure is the mean score on the scale described above
*** Calculated using a T-test
**** Adjusted for gender and occupation