CHSR

Cambridge Centre for Health Services Research

Measuring ethnicity in the NHS

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Summary

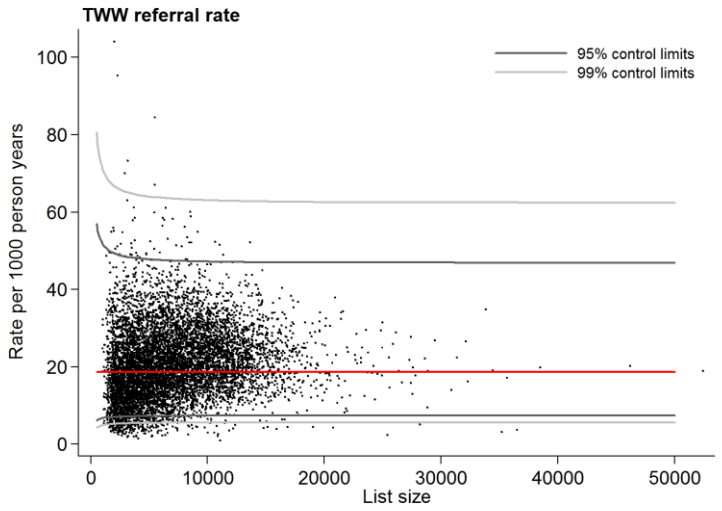
- HSR and what do statisticians working in HSR do?
- Cancer Patient Experience Survey
- Measuring Ethnicity
- Survey non-response

Health Services Research

- HSR explores access to, and the quality, costs, processes, and outcomes of health care
- Do health services work and how can we make them better?
- Health psychologists, economists, qualitative and quantitative, clinical and non-clinical, statisticians
- Universities, think tanks, consultancy, healthcare organisations

Statisticians in Health Services Research

- Inequalities in health and healthcare
- Variation between organisations in measures of performance and quality
- Case-mix adjustment, reliability of measures of performance
- Surveys and survey non-response
- Evaluation



Data

- Routine data captured electronically from clinical consultations, clinical activity, audit, costings …
- Feedback, complaints
- Surveys
- Lots of qualitative data as well

Patient experience

- Quality of care has three dimensions
- Access, Clinical quality, Patient experience
- Not the effectiveness of the clinical care, but the interpersonal aspects and the environment in which it is delivered

How is quality measured

- Routine data on waiting times
- Routine data on clinical outcomes
- Survey data on patient experience

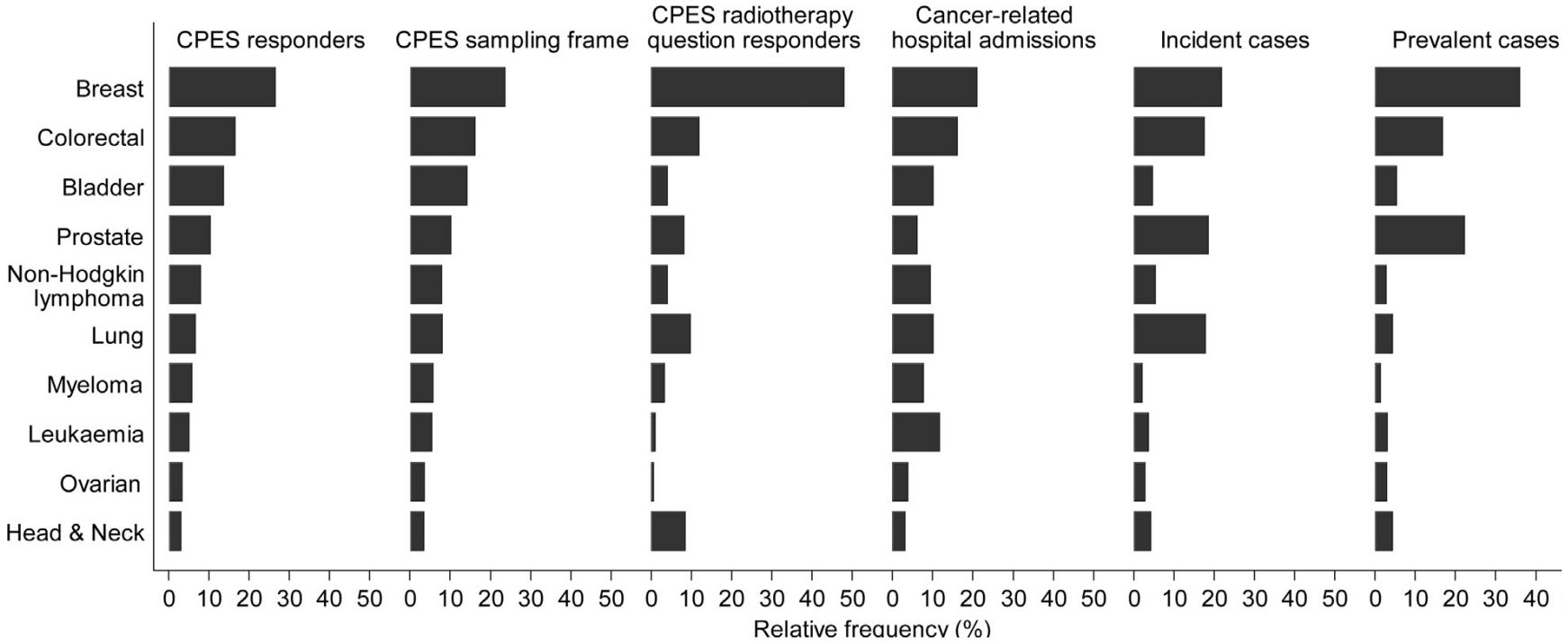
Cancer Patient Experience Survey

- About 60,000 responses are received each year
- Asks questions about experiences across the whole patient journey, from before diagnosis, to follow up care after discharge from hospital

Cancer Patient Experience Survey

- The survey is sent to all patients in England who are seen for treatment in an NHS hospital during a three month period, and who had a primary diagnosis of cancer
- Not incident or prevalent cases

Sent to all patients in England who are seen for treatment in an NHS hospital during a three month period, and who had a primary diagnosis of cancer



Abel GA, Saunders CL, Lyratzopoulos G. (2016) Post-sampling mortality and non-response patterns in the English Cancer Patient Experience Survey: Implications for epidemiological studies based on surveys of cancer patients. Can Epidemiol 41:34-41

Sampling

- Sampled from hospital records
- Sent a survey
- Hospital record recorded and survey reported ethnicity
- May be the same or different
- One or both may be missing

Why record ethnicity?

- 1976 the Race Relations Act made race discrimination unlawful
- In 2000 the Act was amended to introduce a clear duty for organisations to monitor and tackle discrimination
- The NHS starts to routinely record patient ethnicity

Recording ethnicity

- Shared culture or shared ancestry may be one element of how ethnicity is defined
- Language, national identity, religion and country of birth also play a part
- A single survey question
- Ethnicity, even on an imperfect scale, should be self-identified rather than assigned or classified by other people.

77. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British

2 ☐ Irish

3 ☐ Any other White background (Please write in box)

b. MIXED

4 ☐ White and Black Caribbean

5 ☐ White and Black African

6 ☐ White and Asian

7 ☐ Any other Mixed background (Please write in box)

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian

9 ☐ Pakistani

10 ☐ Bangladeshi

11 ☐ Any other Asian background (Please write in box)

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean

13 ☐ African

14 ☐ Any other Black background (Please write in box)

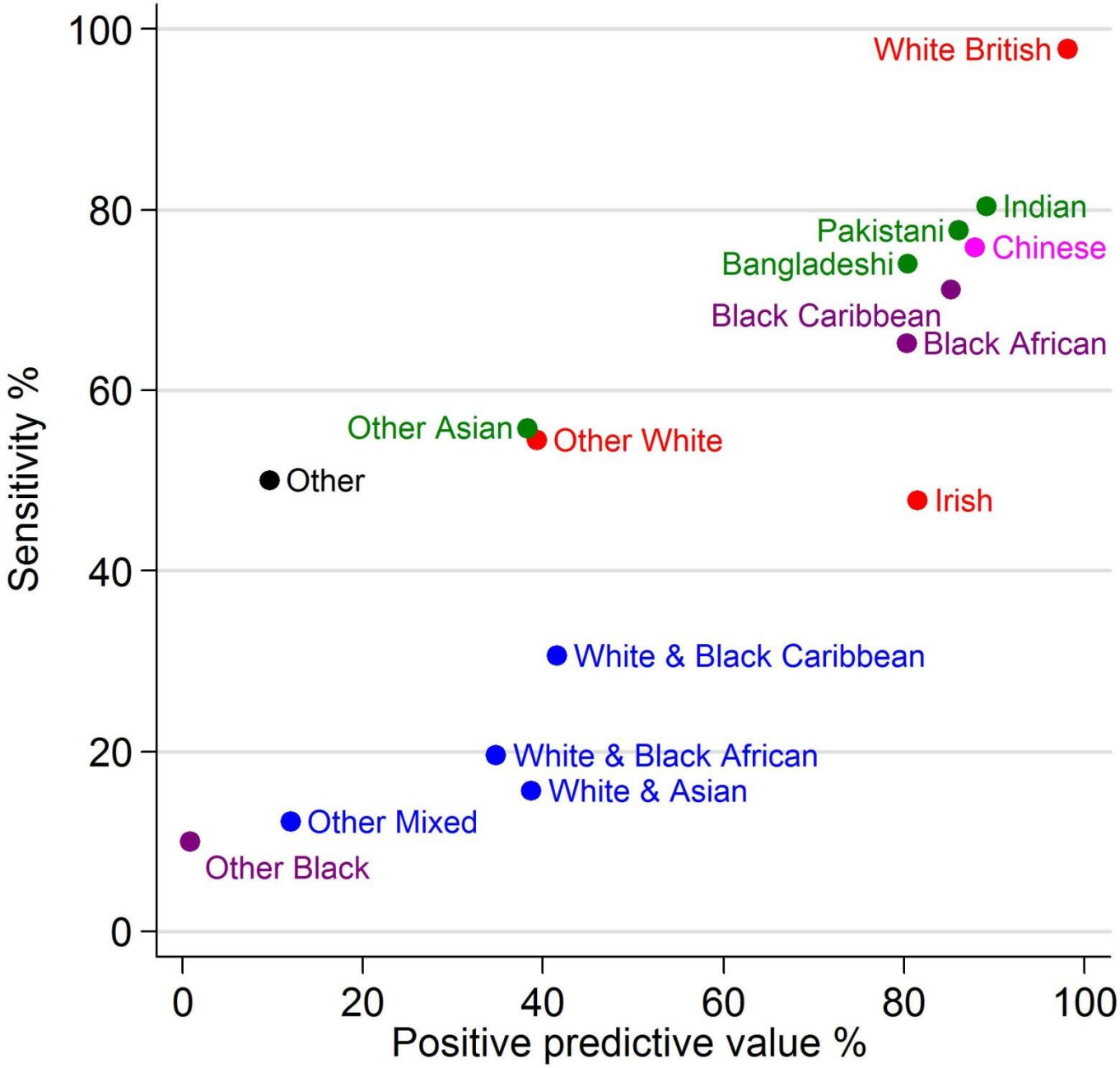
e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese

16 ☐ Any other ethnic group (Please write in box)

What did we do?

- Sensitivity
  - If a patient self-reports that they belong to a particular ethnic group, then the sensitivity of the hospital record ethnicity coding is the probability that the hospital record will record the same (correct) ethnicity.
- Positive predictive value
  - If a patient's hospital record states that they belong to a particular ethnic group, then the positive predictive value of the hospital record ethnicity code is the probability that the patient will self-report the same ethnicity.


100
80
60
40
20
0
Sensitivity %
0
20
40
60
80
100
Positive predictive value %
White British
Indian
Pakistani
Chinese
Bangladeshi
Black Caribbean
Black African
Other Asian
Other White
Other
Irish
White & Black Caribbean
White & Black African
White & Asian
Other Mixed
Other Black

Further work

- Other measures; concordance, Cohen's Kappa
- Missing ethnicity / incorrect ethnicity
- Hospital variation
- Mixed model with incorrect or missing ethnicity as the outcome, age, gender, deprivation, ethnicity and cancer diagnosis. Random effect for hospital

Further work

- Work from the US uses surnames and addresses to get a “probability” for a patients ethnicity
- These can then be used where ethnicity is missing
- Table of probabilities that could be used in a similar analysis in the UK

Elliott MN, Fremont A, Morrison PA, et al. A new method for estimating race/ethnicity and associated disparities where administrative records lack self-reported race/ethnicity. Health Serv Res 2008;43:1722–36

Findings

- More missing ethnicity than incorrect ethnicity
- But for ethnic minority groups there is very poor concordance between records and self reported ethnicity
- Variation between organisations suggests that poor recording could be improved
- For analysis, consider using probabilities for missing ethnicity

Saunders CL, Abel GA, El Turabi A, Ahmed F, Lyratzopoulos G (2013) Accuracy of routinely recorded ethnic group information compared with self-reported ethnicity: evidence from the English Cancer Patient Experience survey. BMJ Open 3(6)

Statistics in health services research

- Mostly applied with a bit of methodology
- Performance comparisons
- Surveys and survey non-response

Performance Comparisons using CPES

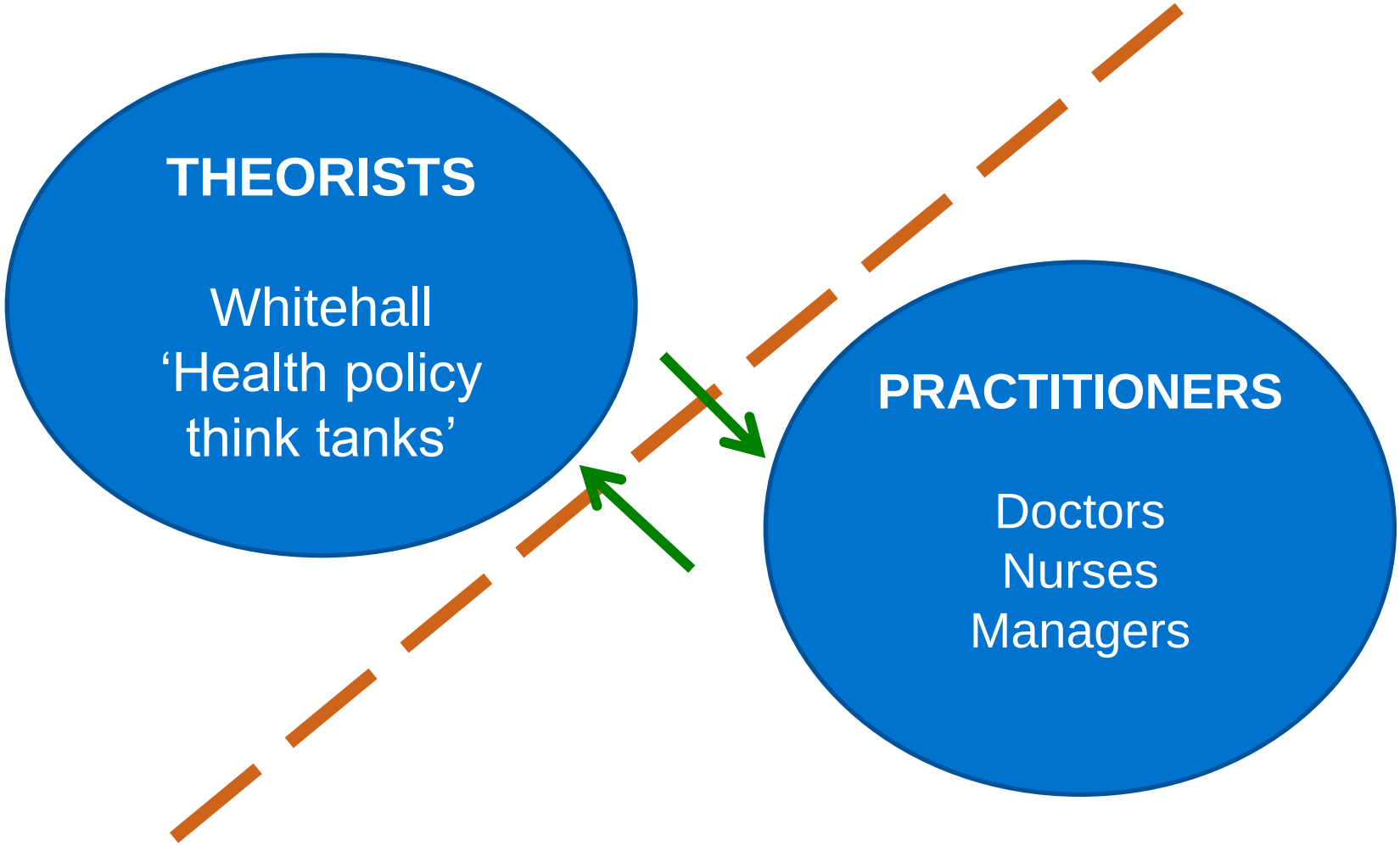
- Public reporting of performance
- Macmillan produce a league table
- Usually gets picked up by the press

What do hospitals do?

- Improve care based on the evidence from the survey
- Find reasons why the survey is wrong

Saunders CL (2015) How to help surveys have more impact . Statistics Views

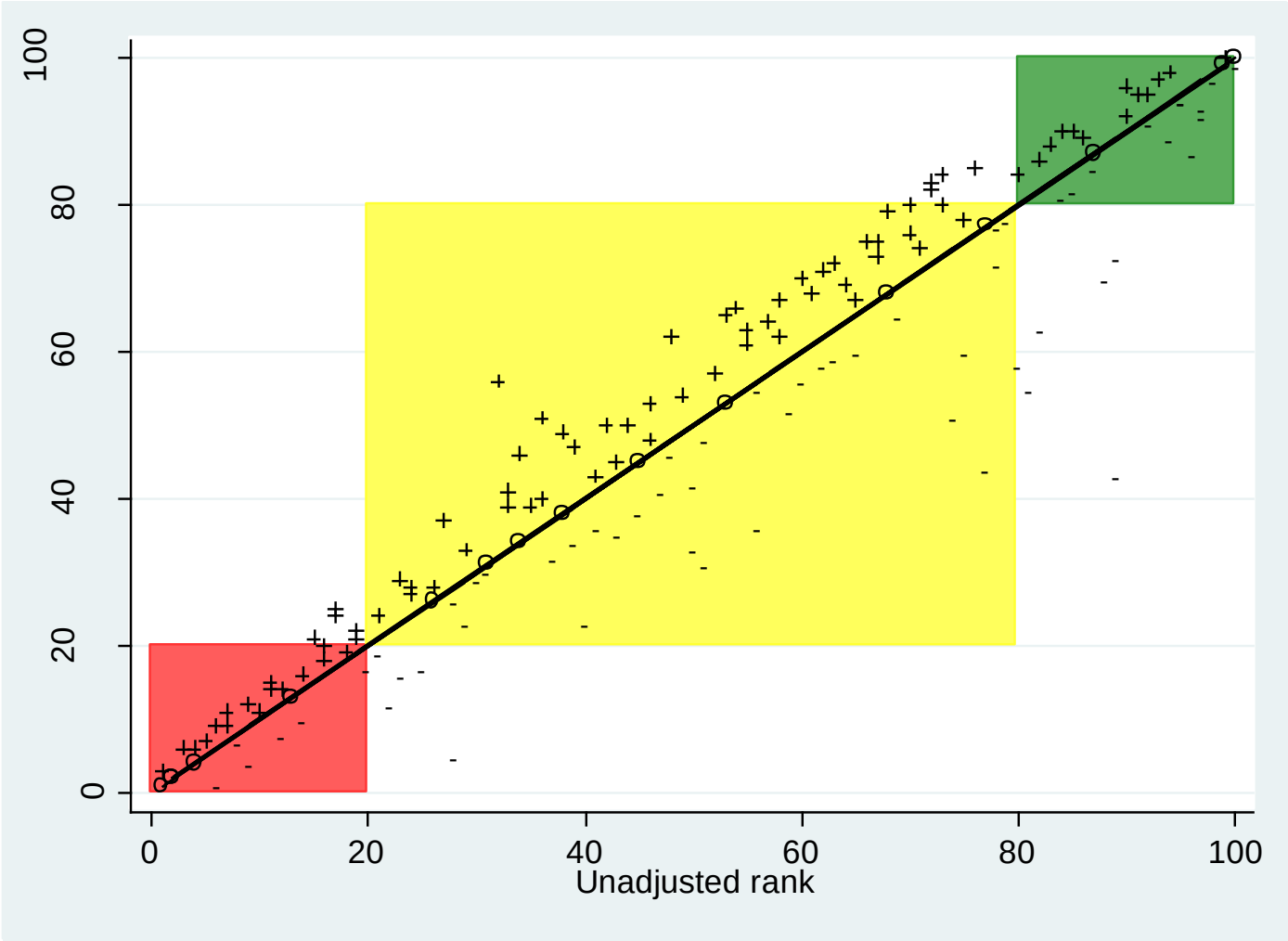
What statisticians try to do



In CPES one of the big challenges is case-mix

- Our patients are different, our hospital is different, we work in London
- We did some case-mix adjustment, comparing performance before and after
- Kendall's Tau (percentage concordance in rank)
- Proportion of variation in performance between hospitals explained by case-mix

Probably not a huge concern, varies by question – example overall rating of care



Abel GA, Saunders CL, Lyratzopoulos G. (2013) Cancer patient experience, hospital performance and case mix: evidence from England. Future Oncol 10(9):1589-98

Reliability of organisation level scores is probably more of a concern, but people don't tend to worry about this

$$\text{Reliability} = \frac{\text{between organisation variance in measured scores}}{\text{between organisation variance} + \left(\frac{\text{within organisation variance}}{n}\right)}$$

- Spearman-Brown reliability
- Performance indicators need to vary between hospitals (i.e. room for improvement) and be accurately enough measured in each hospital
- When n=1 in an organisation this is the ICC
- Low reliability means that correlations are attenuated
- People are performance managing to statistical noise

Saunders CL, Elliott MN, Lyratzopoulos G, Abel GA (2016) Beyond the ecological fallacy: potential problems when studying healthcare organisations. JRSM

Perceived challenges to credibility of feedback from GPs

Responders are not representative

> *"Over-representation of infrequent attenders and people with extreme views; under-representation of those with literacy/language difficulties, older people, single parents, and busy working adults"*

Low response rate

> *"Not a 'fair reflection' of all patients"*

Asprey A, Campbell J, Newbould J, Cohn S, Carter M, Davey A, Roland M. Challenges to the credibility of patient feedback in primary healthcare settings: qualitative study. British Journal of General Practice 2013; 63: 137-138

Why does nonresponse matter?

- Sometimes it can go very wrong

Literary digest poll, 1936

Literary digest

- 2.5 million responses
- 24% response rate
- Subscribers, car owners, telephone owners
- Landon

Gallup

- 50,000 responses
- Nationally representative sample
- Roosevelt

Why does nonresponse matter?

- Sometimes it can go very wrong
- Journals won't publish your papers
- People don't act of the findings of the survey because they are worried about non-response

Dream of a *100% response rate*?

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John Sinclair managed this

Dream of a *100% response rate*?

John Sinclair managed this

for his survey of *Scottish ministers*

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John Sinclair managed this

for his survey of Scottish ministers

With *23 reminders*

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John Sinclair managed this

for his survey of Scottish ministers

With *23 reminders*

In 1788

Dream of a *95% response rate* for your surveys?

An unnamed
senior
research
leader at
RAND Europe

Dream of a *95% response rate* for your surveys?

An unnamed senior research leader at RAND Europe

"so we had an 85% response rate and the committee said that this wasn't good enough"

Dream of a *95% response rate* for your surveys?

An unnamed senior research leader at RAND Europe	"so we had an 85% response rate and the committee said that this wasn't good enough"
	"so we got the response rate up to 95% and said that would have to do"

Everyone else?

Things that can help improve survey response rates

- Incentives

Incentives

- Money
- Sent at the same time better than on return
- Non-money

Things that can help improve survey response rates

- Incentives
- Length

Length

- Short

Things that can help improve survey response rates

- Incentives
- Length
- Appearance

Appearance

- Coloured ink
- Personalised
- University sponsorship

Things that can help improve survey response rates

- Incentives
- Length
- Appearance
- Delivery

Delivery

- Recorded delivery
- Include a return envelope
- Colour of the envelope doesn’t matter

Things that can help improve survey response rates

- Incentives
- Length
- Appearance
- Delivery
- Contact

Contact

- Pre-contact
- Follow up
- Send the survey again in case it got lost

Things that can help improve survey response rates

- Incentives
- Length
- Appearance
- Delivery
- Contact
- Content

Content

- Interesting
- User friendly
- Factual questions only get a better response than surveys about attitudes
- Put relevant questions first
- No sensitive questions
- Put general questions last

Still not quite at 100%?

Still not quite at 100%?

- Assess the impact of nonresponse bias on your findings

What is nonresponse?

- Moved house
- No further information
- Died
- Ineligible
- Refused
- Too sick to take part
- Too upset to take part

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Nonresponse

- AAPOR definition
- Make sure it is the same if you are comparing response rates across organisations
- With a multi-stage sample – include nonresponse at all stages in your final calculation

Evaluating nonresponse

- Look at the response rate

Evaluating nonresponse

- Look at the response rate
- Follow up nonresponders

Evaluating nonresponse

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- Compare responders with a reference population

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Evaluating nonresponse

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- Compare responders with a reference population
- Compare responders with the sampling frame
- Compare findings with other sources
- Wave analysis
- Interest question

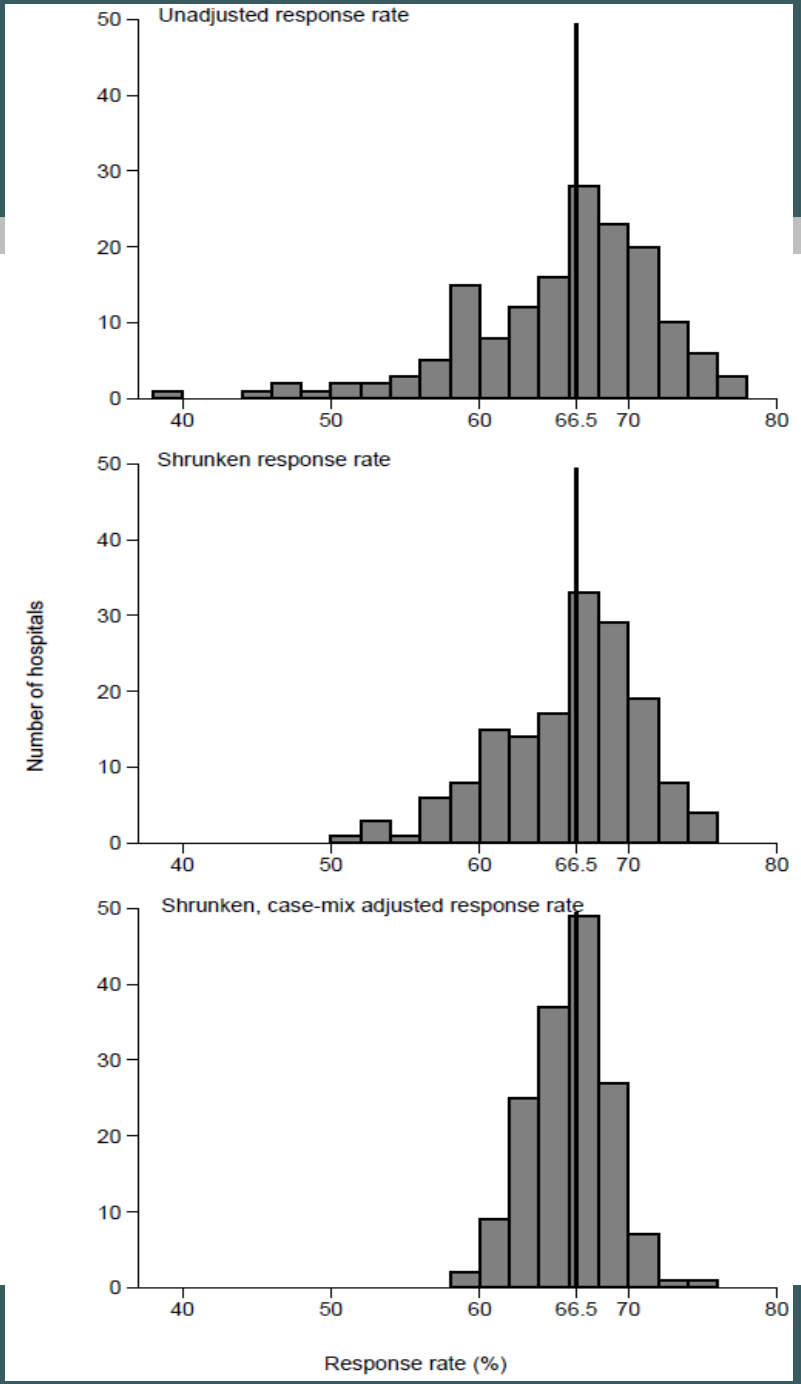
Non-response in CPES

- 67% response rate
- Variable between hospitals (38%-78%)
- If response rate is not correlated with organisation performance we would probably not be worried about bias in performance comparisons
- Otherwise, maybe those sceptical survey users have a point …
- Survey responses, PLUS sampling frame (age, gender, deprivation, ethnicity, cancer diagnosis), time to respond

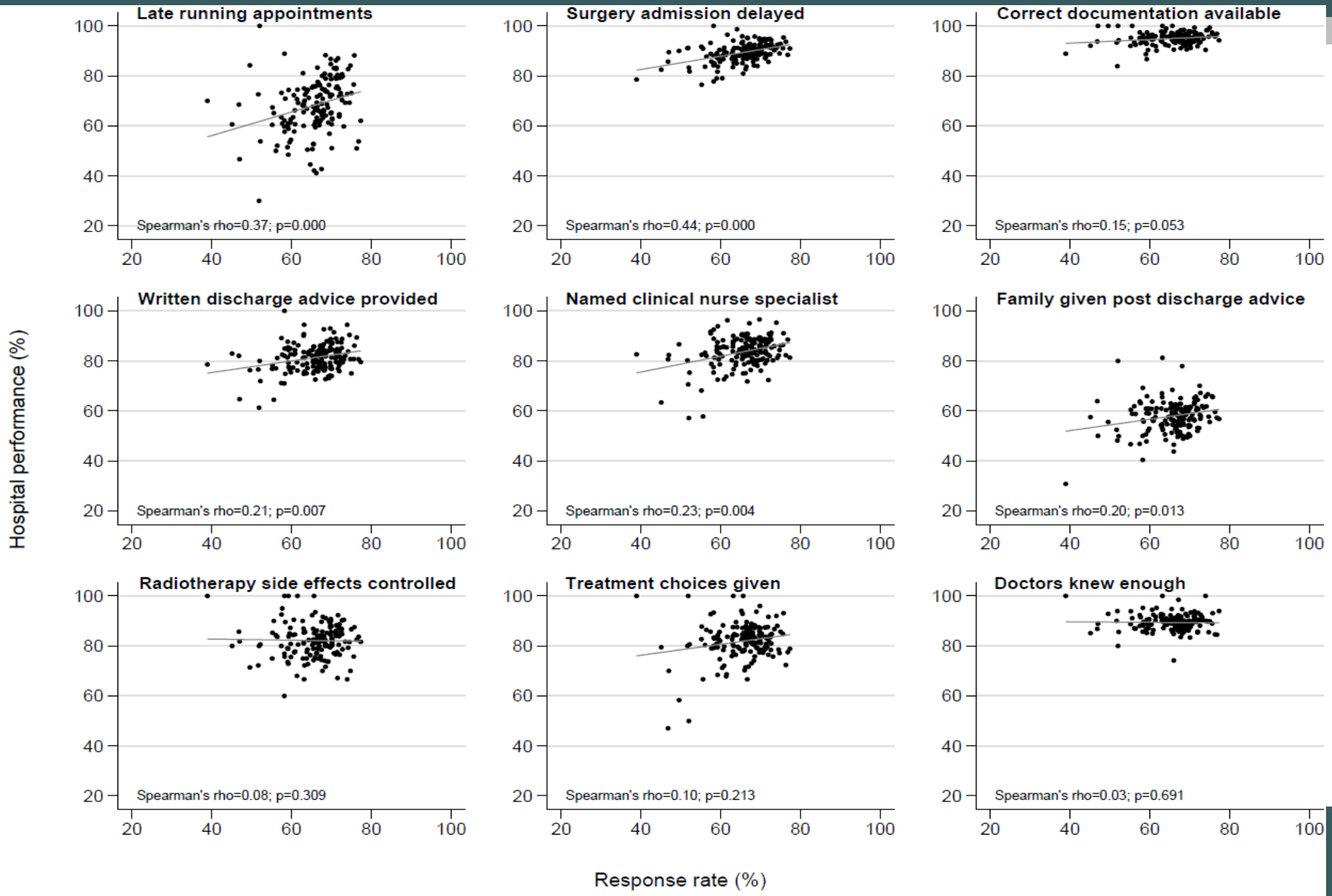
Could variable non-response be due to case-mix or chance?

Explain some of the variation in response rate between hospitals

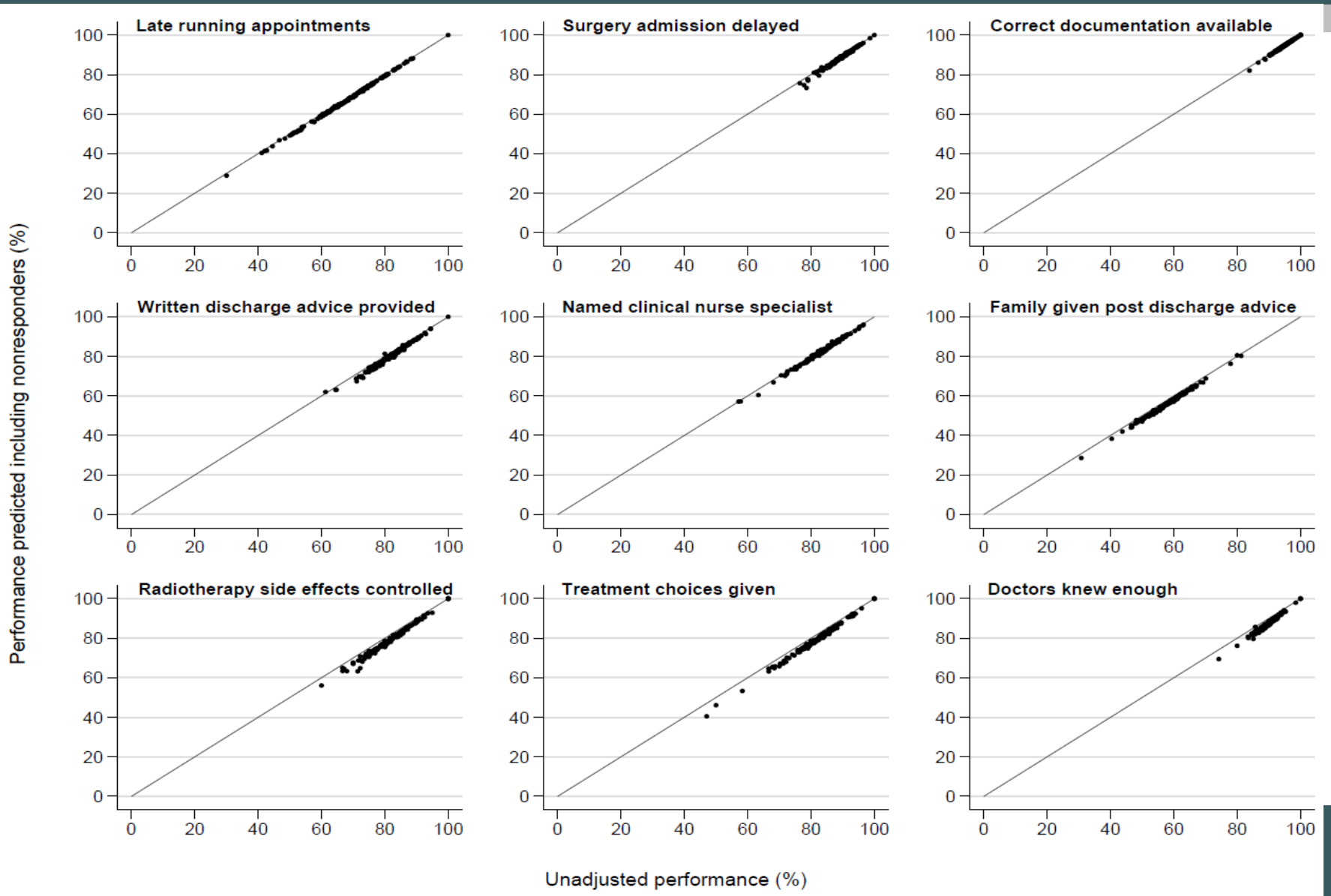
But don't explain the correlation between hospital response rate and performance



For almost all questions in CPES patients report better patient experience in higher response rate hospitals



If non responders did respond, overall national experience would be lower but the correlation with RR would be stronger



Findings

- Not a reflection of case-mix or chance
- Nor the characteristics or poorer experience of non responders
- If non responders did respond, overall national experience would be lower but the correlation would be stronger
- Hospital level factors or administrative systems – indirect measure of quality. Should not be adjusted away in reporting

Saunders CL, Elliott MN, Lyratzopoulos G, Abel GA (2015) Do differential response rates to patient surveys between organizations lead to unfair performance comparisons? Evidence from the English Cancer Patient Experience Survey. Medical Care

Summary

- HSR and what do statisticians working in HSR do?
- Cancer Patient Experience Survey
- Measuring Ethnicity
- Survey non-response

CCHSR

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Thanks to Gary Abel, Marc Elliott, Faraz Ahmed, Anas El Turabi, Yoryos Lyratzopoulos

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