X PATIENT BARCELONA CONGRESS

EL CONGRÉS SOBRE EL CANVI DEL MODEL ASSISTENCIAL
EL CONGRESO SOBRE EL CAMBIO DEL MODELO ASISTENCIAL

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Impulsa:
XPA EXPERIÈNCIA DEL PACIENT BARCELONA

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Patient experience: history and context

- Explosion in interest (2 decades)

- Link to social movements (disability rights, patient activism)
- Shifting from paternalism towards empowerment
- Transfer responsibility for health from state to individual
- Growth in healthcare markets

Why is patient experience important?

- ''Patients' experiences should be the fundamental source of the definition of quality'' (Berwick, 2002)
- Patient experience associated with*
  - Improved adherence to medication (strongest evidence)
  - Better self-measured health outcomes (good evidence)
  - Better objectively measured health outcomes (less evidence)
  - More efficient healthcare resource use (weak evidence)
  - Safer care (weak evidence)

*Doyle, Lennox and Bell, *BMJ Open* 2013;3:e001570

What is patient experience?

- Subjective experience of the process of care
- Complex, changing
- Many components, for example
  - respect
  - information and communication
  - physical comfort
  - emotional support
  - access to care

Can you measure patient experience?

- **Specific elements**
  - "how long did you wait?"
- **Patient evaluation**
  - "did you wait too long?"
- **Summary measures**
  - "Overall, how would you rate your care?"

…What gets measured gets done…

Two examples

- Friends and family test in England (started 2013)
- National Cancer Patient Experience Survey at local trust (analysis 2010 – 16)

UK policy context

- Aiming to improve quality of care
- Patient experience key element
- Mid-Staffs Scandal – 1000 excess deaths
- Francis Enquiry
  - "Using Patient Feedback: Results and analysis of patient feedback including qualitative information needs to be made available to all stakeholders in as near "real time" as possible, even if later adjustments have to be made"
  - Aim to improve culture in hospitals
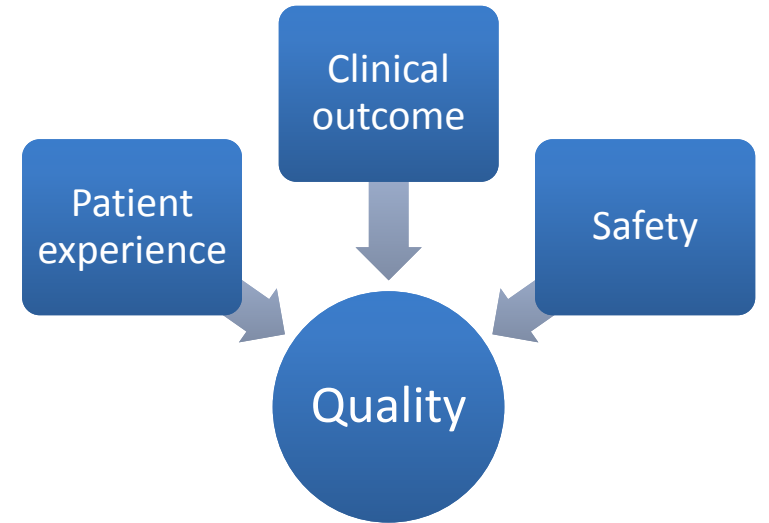
Announcement of Friends and Family Test (FFT)

– "In every hospital, patients are going to be able to answer a simple question: whether they'd want a friend or relative to be treated there in their hour of need. By making those answers public we're going to *give everyone a clear idea of where to get the best care* – and drive other hospitals to *raise their game*."

David Cameron, Prime Minister 25 May 2012

The Friends and Family Test

THE NHS FRIENDS AND FAMILY TEST

We would like you to think about your recent experience of our service.
How likely are you to recommend us to friends and family if they needed similar care or treatment?

Extremely Likely	Likely	Neither likely or unlikely	Unlikely	Extremely Unlikley	Don't know
☐	☐	☐	☐	☐	☐

Thinking about your response to this question, what is the main reason why you feel this way?

Friends and Family Test

NHS England

July 2017

This month there were **1,214,528** responses to the Friends and Family Test. The following numbers show the proportion of responses that would recommend or not recommend these services to a friend or family member.*

Recommend
Not Recommend
Neither/ Don't know

Service	Recommend	Not Recommend
Inpatient and Daycases	96%	2%-
A&E, walk-in centres and minor injury units	86%	8%-
Outpatients	94%	3%-
Ambulance (including patient transport)	89%	5%-
Maternity (Birth)	96%	1%-
Community Health	96%	1%-
Mental Health	89%	4%-
Dental	97%	1%-
General Practice	89%	6%-

*Please note that some of these people may have responded to adapted versions of the Friends and Family Test recommend question to support an inclusive approach.

www.england.nhs.uk/FFTdata

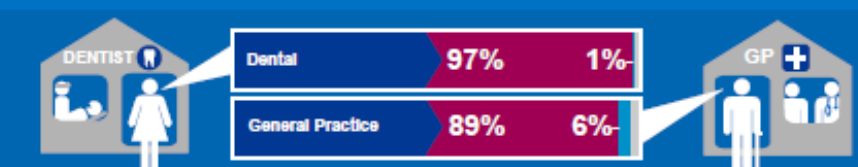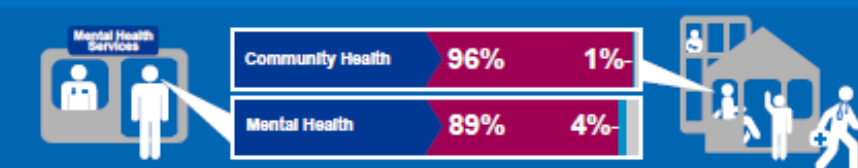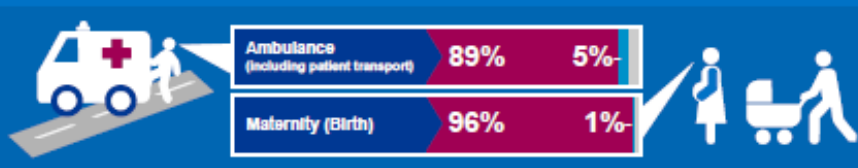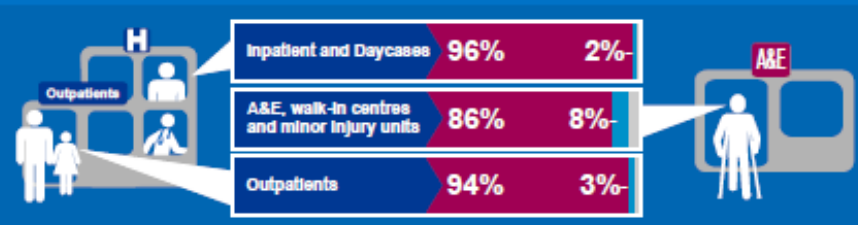# Friends and Family Test

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Outpatients

H

A&E

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FFT analysis, 2014-15 data from 534 hospitals

- 3,749,692 responses

- Little variation

- Detected outliers

- Under-representation of young (1%), old (3%), Black (3%) and other (5%) ethnic groups

- 28% of negative ratings associated with positive comment

	Median	Interquartile range
Response rate (%)*	28.0	18.9-42.3
Percentage Recommended (%)**	97.5	95.6-100.0
Percentage Not Recommended (%)***	0.6	0.0-1.4
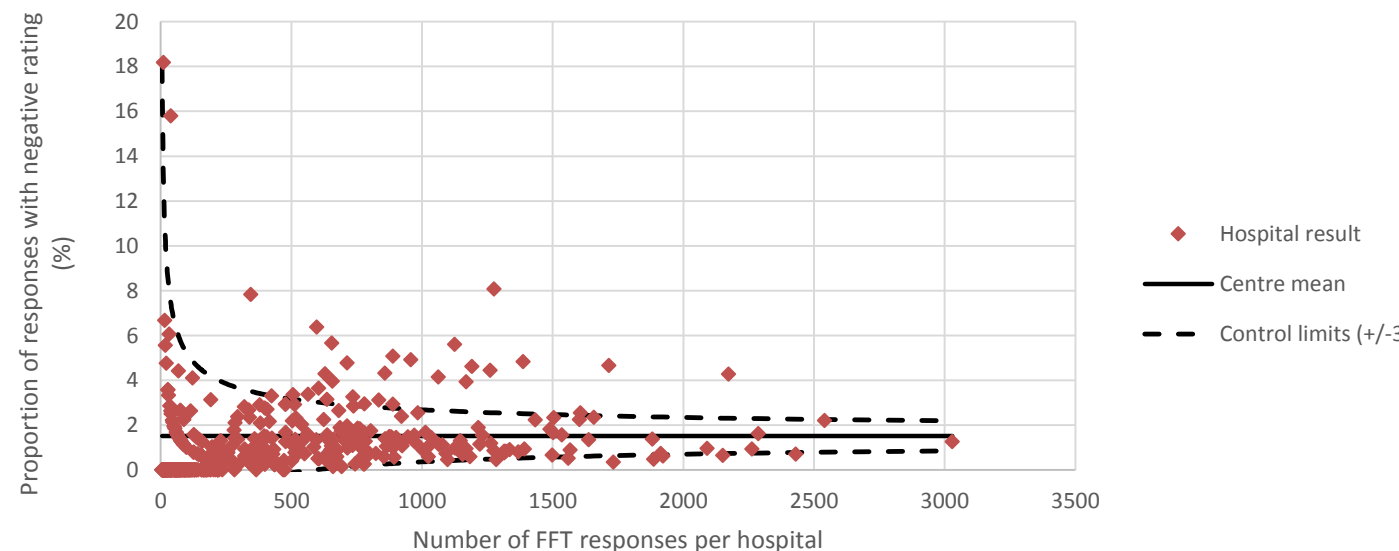
Is it useful?

- Nationally might detect some poor quality care
- Locally numbers too small – but still used for performance management
- Feedback and analysis difficult
- Comments most useful

FFT numeric responses, A&E, April 2013 n=400

…What gets measured gets done…

But difficult to use FFT scores to improve patient experience

CANCER PATIENT EXPERIENCE

Rank	Trust	Strategic Health Authority	No. of responses in the Trust	No. of times the trust falls within bottom 20%	No. of times the trust falls within top 20%	Ranking in bottom 10 Trusts in 2010
10	West Suffolk Hospitals NHS Trust	East of England	320	1	27	

Rank	Trust	Strategic Health Authority	No. of responses in the Trust	No. of times the trust falls within bottom 20%	No. of times the trust falls within top 20%	Ranking in bottom 10 Trusts in 2010
1	Imperial College Healthcare NHS Trust	London	757	56	1	1
2	Whipps Cross University Hospital NHS Trust	London	223	51	1	-
3	King's College Hospital NHS Foundation Trust	London	352	45	2	-
4	The Princess Alexandra Hospital NHS Trust	East of England	345	42	4	6
5	North West London Hospitals NHS Trust	London	260	41	0	-
6	University College Hospital London NHS Foundation Trust	London	939	41	1	-
				41	2	7
				41	4	9
				39	1	-
				38	3	-

SHMI* and HSMR* by provider (all non-specialist acute providers) for all (13) cancer of pancreas admissions in April 2011 to Mar 2012

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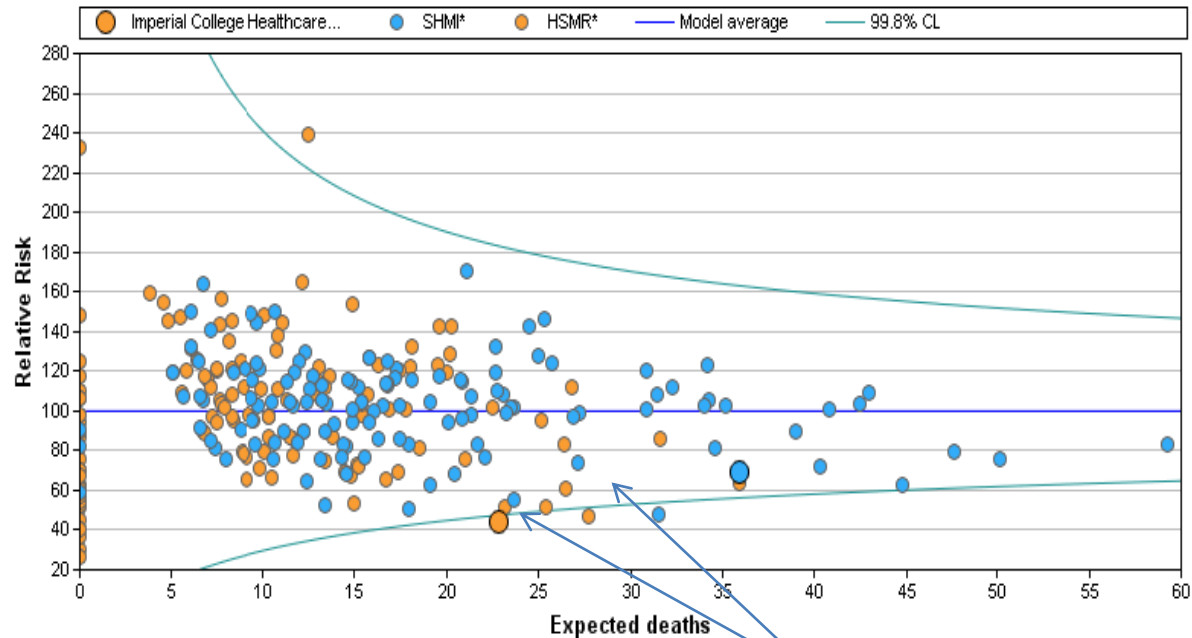

'you will have a good outcome if you survive the experience'

Imperial

Service evaluation, cancer 2012-13

- Approach: rapid assessment, ethnographic and statistical
  - Quantitative analysis of National Cancer Patient Experience survey data
  - Thematic analysis of comments
  - Participant observation and semi-structured interviews
  - 40 hours in 2 chemotherapy units, diagnostic and oncology clinics
  - Discussions with 28 patients, 14 companions, 10 staff in chemotherapy

# NCPES data Q70: Overall, how would you rate your care?

- 5 possible answers
- 30/575 individuals made no response
- Of 545 respondents:
  - 430 (79%) rated overall care positively (i.e. very good or excellent)
  - 83 (15%) good
  - 27 (5%) fair
  - 5 (1%)poor
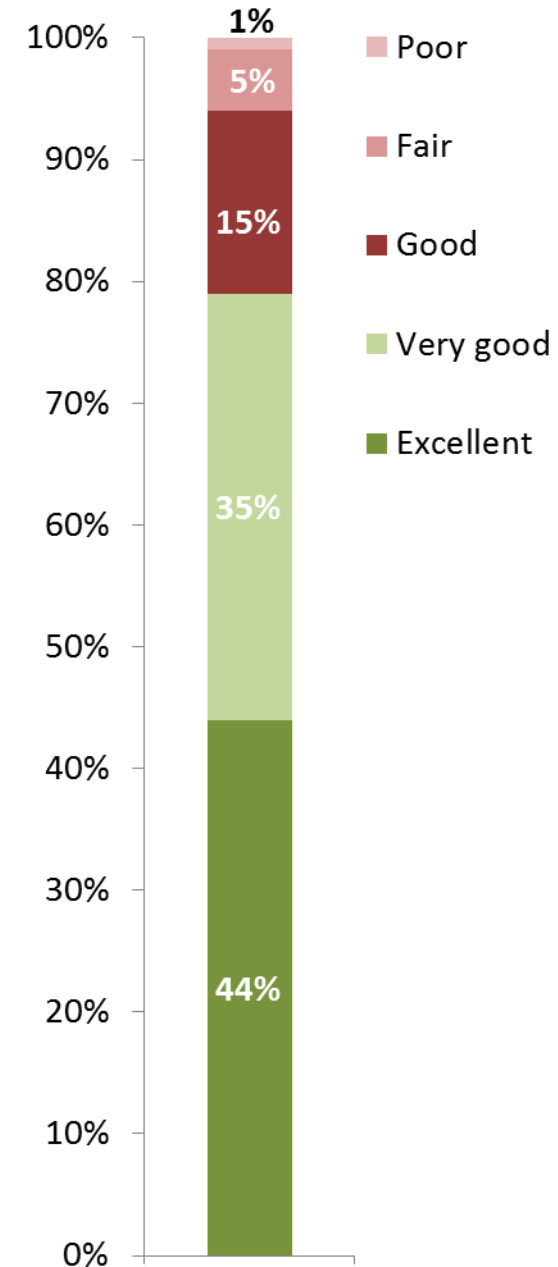
Statistical analysis

- We explored associations with overall rating of care
  - demographic, clinical
  - internal associations in questionnaire
- Produced crude and adjusted odds ratios (and 95% confidence intervals) using logistic regression

Summary question

70. Overall, how would you rate your care?
- 1 ☐ Excellent
- 2 ☐ Very good
- 3 ☐ Good
- 4 ☐ Fair
- 5 ☐ Poor
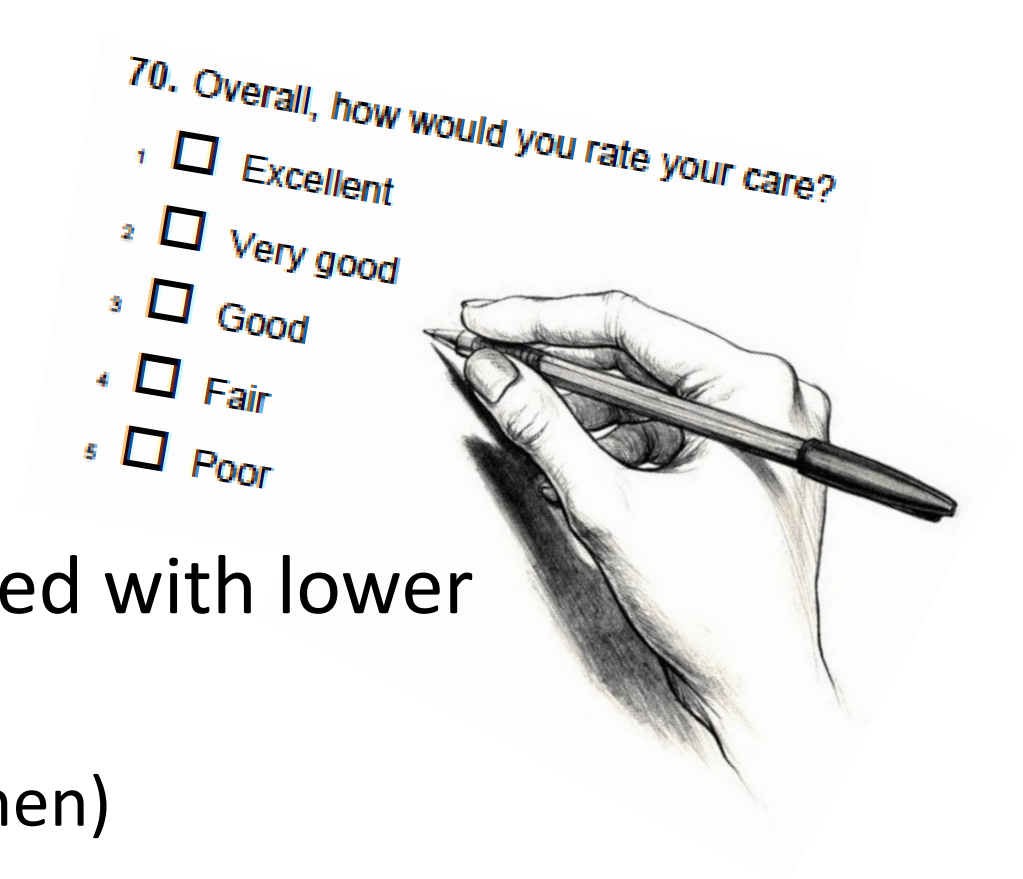
- What factors were associated with lower overall rating?
  - Gender (poorer among women)
  - Ethnicity (poorer among Black, Chinese/other patients)
  - Patients with mental health conditions

Questions associated with overall rating of care

Question	OR*
49: Were you able to discuss any worries or fears with staff during your .. visit?	33.3
Q66: Did the different people treating and caring for you (…) work well together to give you the best possible care?	20.0
Q15: Before your cancer treatment started were you given a choice of different types of treatment?	16.7
Q36: When you had important questions to ask a doctor, how often did you get answers that you could understand?	16.7
Q32: Before you had your operation, did a member of staff explain what would be done during the operation?	14.3
Q48: Were you given enough privacy when being examined or treated?	14.3
Q37: Did you have confidence and trust in the doctors treating you?	12.5
Q69: Patients did not feel that they were treated as a "set of cancer symptoms"	12.5
Q06: Before last diagnostic test, did a member of staff explain purpose of test(s)?	11.1
Q07: Before last diagnostic test, did a member of staff explain what would be done during the test procedure(s)?	11.1

Positive response rate (% qs answered positively)
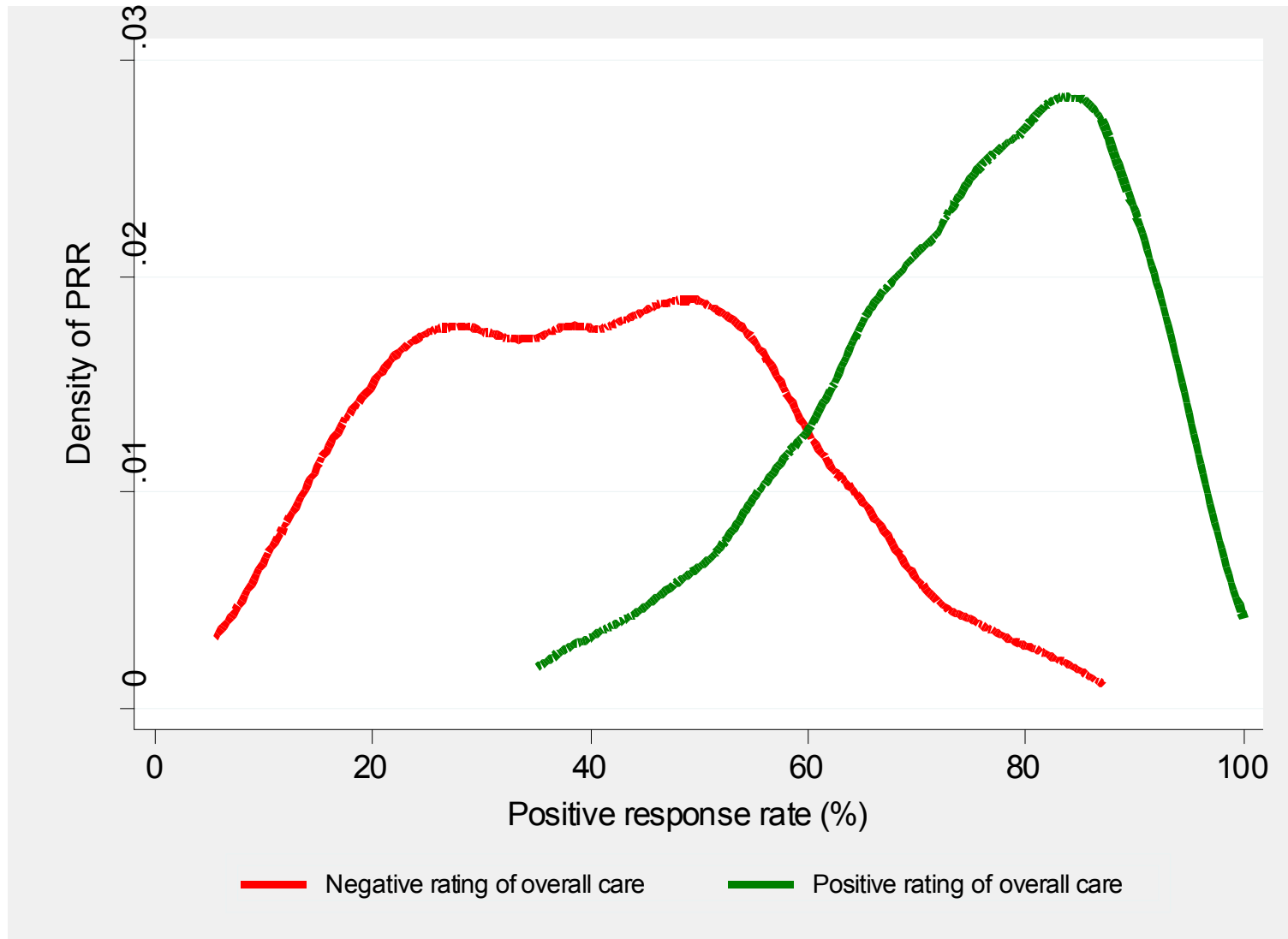
Overall rating positive: PRR range 35% – 100%
Overall rating not positive: PPR range 5% – 87%

Thematic analysis of comments

- *Great majority were* positive comments about staff
- Negative feedback was about process & system; the most commonly cited specific area to improve was waiting time in out patients
- Specific comments suggest areas for improvement

"There are exceptional (staff) but they are let down by the system"

"I did not die, anything else would be a little picky"

Excellent
(and could be improved)

Could I pass on my thanks and appreciation to all the wonderful nurses/doctors/surgeons ... the only down thing was the food (231 - Gynaecological)

The care is...marvellous. The only adverse criticism is in relation to very long waits for outpatient appointments in uncomfortable waiting rooms (98 - Breast)

The care given by my consultant was always very good; courteous and informative...possibly the pre-operative tests could have been organised better (390 – Other)

Interviews & participant observation

- Similar emphasis on *staff vs system*
- System hard to manage over the longer term
- New patients find visits hard to understand
- Many players *"a cast of thousands"*
- A general concern about *Who is thinking of me when I am not here?*

Patient voices: staff vs system

- No-one complained about members of staff
  - *"I cannot fault the service they've given me"*
- Emphasized the difference made by *individual* staff
  - Patients valued acts of kindness & compassion

- Everyone complained about 'the system'
  - Waits, delays,
  - Lost letters, notes, scripts
  - Seeing different people
- Recognise staff also suffer
  - *"she* [nurse] *isn't able to do anything much when things go wrong"*
  - *"if they weren't so busy and … that they had to deal with this system, I might complain"*

Quality of care as seen by patients

- *"This is a fantastic hospital – you can quote me on that"*
- This man compared his care with 3 other Trusts where he felt staff were often rushed, and he was concerned about adverse events e.g. bruises, infections
- *"nursing is all about care, taking time and doing it well"*
  - patient pointed to the neat IV cannula placement as example

Navigation

- Patients find it hard to navigate a complex system
- Key workers/ CNS not always empowered to solve problems
- Important of establishing one or more key relationships[1]

Summary

- Surveys can rate institutions
  - Use pre-defined categories
  - Don't always capture what is important to patients
  - Can silence patient voices in summary measures
- Qualitative methods can give voice to patients
  - Many sources, eg. comments, complaints, blogs
  - Research: interviews and focus groups

How to listen to patient voices?

- Staff are great resource - just listen and hear, and provide forums where staff can discuss

- Patients are great resource – ask the in groups, waiting rooms, post-discharge interviews

- Involve patients in service re-design

Case studies – measure things not captured in surveys

- Sexual health *"they made me feel comfortable"*
  - Overall ratings good
  - Patients valued being made to feel comfortable, important in stigmatised areas
- Maternity care
  - Experience changed along the pathway; women often felt abandoned after the baby was born
  - *"I think after the birth they seemed so busy and they kind of go on to the next birth. Once the baby is out it's kind of, they're not that caring any more"*
  - This related to comments about the environment being *"grotty and outdated"* with staff *"stretched too thinly"*

Numbers and narratives - conclusion

Patient experience is not a "thing"

Measuring elements is possible

Scores are used to rate and rank

Improving experience requires understanding

Mixed methods, context, conversations

FFT: 92% likely to recommend

★★★★★ 75%
★★★★☆ 17%
★★★☆☆ 2%
★★☆☆☆ 1%
★☆☆☆☆ 2%
Don't know 3%

Thank you!

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