

- <http://medicinex.stanford.edu/portfolio/medicine-x-roni-zeiger/>

**Imperial College  
London**

# **Patient Experience and Action**

Society and Health, Foundations of Clinical Practice

**Professor Sophie Day**

30th October 2012

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# Learning outcome 1.

To explore the relationships between patient experience and social movements for health

What, if any, is the relationship between an individual's experience of health care and broader health movements?

- citizen rights vs professional power (session 2 on the medicalisation of social life)
- See also session 5, 27<sup>th</sup> November on patient and professional activism

# Learning outcome 2.

To explore the relationships between patient experience, patient choice and consumerism

- Patient experience as one of three planks of Service Quality
- Measurement of patient experience, league tables & the market

# Learning outcome 3.

To understand the impact of healthcare on patient experience using specific examples

- preparing your PtEx survey (Module 2 FCA course)
- Imperial NHS Trust cancer services
- patient journeys: an example



# What is patient experience?

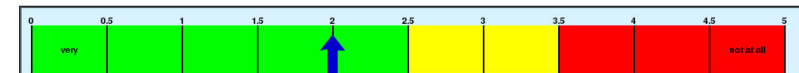
CPG Inner Ward	2010				2011			
	Sep10	Oct10	Nov10	Dec10	Jan11	Feb11	Mar11	Apr11
numbers	18	23	29	29	29	26	36	27
involved as much as you wanted to be in decisions about your treatment?	100.00	50.00	75.00	60.00	62.50	87.50	82.14	93.75
asked someone on the hospital staff to talk to about your worries and concerns?	0.00	50.00	75.00	66.67	65.63	86.67	76.92	76.67
given enough privacy when discussing your condition or treatment?	100.00	75.00	75.00	83.33	82.35	96.88	96.67	94.12
number of staff tell you about medication side effects to watch for when you went home?	0.00	0.00	100.00	50.00	65.38	89.29	69.23	84.62
staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	0.00	100.00	100.00	100.00	75.00	92.86	93.75	86.67
if you were first admitted to a bed on this ward, did you share a room with someone else, for example a room or a bay, with patients of the opposite sex?	88.89	100.00	96.55	100.00	100.00	100.00	97.22	100.00
if you rate the courtesy of our staff?	83.44	76.00	94.31	81.72	81.72	93.65	94.47	100.00
how would you rate the care you received?	73.61	79.35	81.90	78.45	78.45	86.54	81.25	88.89
if you know, did staff wash or clean their hands between touching you?	94.44	92.86	83.33	92.59	100.00	100.00	95.00	85.71
if staff talk in front of you as if you weren't there?	88.89	82.61	94.83	91.07	85.71	100.00	94.29	100.00
if staff talk in front of you as if you weren't there?	86.11	82.61	89.29	86.21	80.36	98.08	80.30	92.31
if hospital staff do everything they could to help control your pain?	91.67	94.44	82.14	100.00	85.71	60.00	95.45	75.00
if is your ward or room?	98.17	95.65	94.31	95.45	92.93	98.73	94.50	96.30
if information about your condition or treatment has been given to you?	93.33	86.36	50.00	44.64	52.00	61.54	63.79	53.85
if needed help from staff getting to the bathroom or toilet, did you get it?	94.12	93.48	60.71	64.29	77.78	85.00	58.70	56.25
if during your stay on this ward, did you ever use the same bathroom or shower as someone of the opposite sex?	100.00	100.00	100.00	92.86	100.00	100.00	91.43	100.00
if ever bothered by noise at night?	76.47	65.22	79.31	75.00	96.55	92.31	88.89	96.30
if got enough help from staff to eat your meals?	50.00	87.50	80.00	33.33	100.00	100.00	100.00	100.00
if have been treated with dignity and respect by staff on this ward?	94.44	97.83	94.83	86.21	94.83	94.23	87.50	90.74
if how long it takes you to get help after you used the call button did it usually take longer than you needed?	57.35	59.09	60.42	58.33	60.58	66.30	63.97	62.00

healthfeedback...

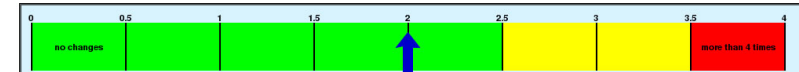
admin home Logout

## Report on indicator 7b

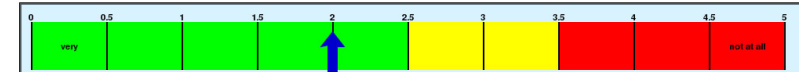
For dates: All dates  
For nodes: Norfolk  
Total responses in report: 1



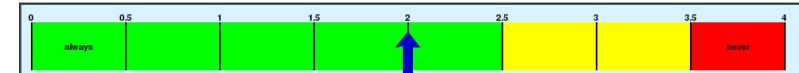
2. How involved have you been in the planning of care for your child?... 2.00



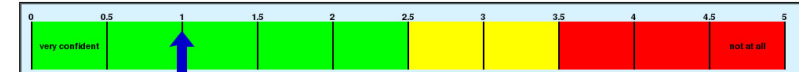
3. How often in the last 6 months has your allocation been changed and/or cancelled by the service?... 2.00



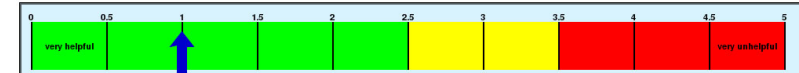
4. Where changes have been made to your allocation, how satisfied were you with the communication?... 2.00



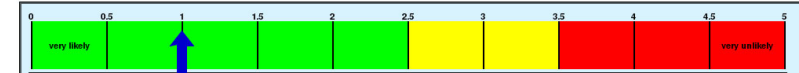
5. Do you feel your child has been treated with respect?... 2.00



6. How confident do you feel that your child's individual needs have been met?... 1.00



7. How helpful have the staff been?... 1.00



8. How likely or unlikely would you be to recommend to a friend or relative if they needed to a...? 1.00



**Red**

**Amber**

**Green**

## **HOSPITAL ASSESSMENT**

For people with learning disabilities.

# Lord Darzi's definition of quality in NHS (2008)

- Patient **safety** – means no harm is done to patients.
- Patient **experience** - the compassion, dignity and respect with which patients are treated.
- **Effectiveness of care** - understanding success rates from different treatments for different conditions (Also understanding effectiveness of care from the patient's own perspective which will be measured through patient-reported outcomes measures - PROMs)

[http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH\\_085825](http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085825)



# As usual lots of terms...

- Quiz. What is the difference between:-

Patient experience

Patient reported outcomes

Patient satisfaction

Patient involvement

Patient engagement

And - who is at the centre of care/treatment?

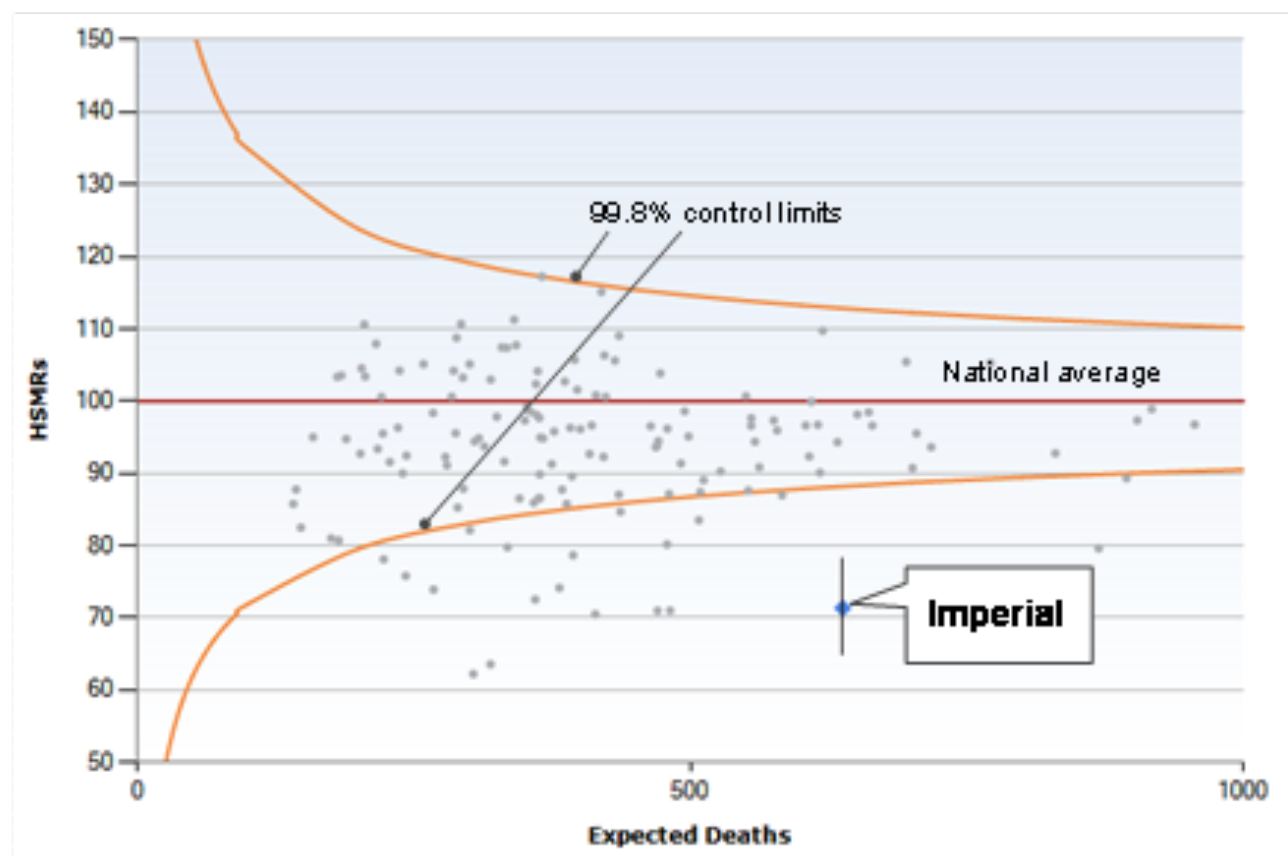
# Another definition of PtEx

Patient experience - the direct experience of treatment or care, closely related to and in turn influencing clinical effectiveness and safety

Goose M. Defining patient experience. The Kings Fund,  
[www.kingsfund.org.uk/document.rm?id=9374](http://www.kingsfund.org.uk/document.rm?id=9374)

## Acute Trust HSMRs Apr 2012-Jul 2012

Dr Foster



Source: Dr Foster

# 10 Best and 10 Poorest Performing NHS Trusts in England, 2011

Rank, Trust, SHA, Number of questions falling into the top/bottom 20%

Top 10 Best Performing Trusts - ranked by number of times in top 20%, then number of times in bottom 20%				
Rank	Trust	Strategic Health Authority	No. of times the trust falls within bottom 20%	No. of times the trust falls within top 20%
1	Harrogate and District NHS Foundation Trust	Yorks & Humber	0	55
2	South Tyneside NHS Foundation Trust	North East	1	55
3	Papworth Hospital NHS Foundation Trust	East of England	3	46
4	Northumbria Healthcare NHS Foundation Trust	North East	0	44
5	Gateshead Heath NHS Foundation Trust	North East	1	42
6	Chesterfield Royal Hospital NHS Foundation Trust	East Midlands	3	37
7	Barnsley Hospital NHS Foundation Trust	Yorks & Humber	4	37
8	St Helens and Knowsley Teaching Hospitals NHS Trust	North West	3	36
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3	King's College Hospital NHS Foundation Trust	London	45	2
4	The Princess Alexandra Hospital NHS Trust	East of England	42	4
5	North West London Hospitals NHS Trust	London	41	0
6	University College Hospital London NHS Foundation Trust	London	41	2
7	Ealing Hospital NHS Trust	London	41	4
8	Newham University NHS Trust	London	40	3
9	Barking, Havering and Redbridge University Hospitals NHS Trust	London	39	1
10	North Middlesex University Hospital Trust	London	38	3

Source: Analysis based on Department for Health - National Cancer Patient Experience Survey 2011.  
See Annex A for the Top 10 and Bottom 10 NHS trusts in 2010.

# Current emphasis on PtEx (1)

1. The impact of patient or health movements
  - Citizenship and civil rights; democracy; participatory medicine associated with growing distrust science, medicine, government; dehumanising aspects of biomedicine & bureaucracies (1960s-)
  - Turn to ‘person centred’ alternative and complementary treatments and to self care (especially since 1980s)

# Current emphasis on PtEx (2)

## 2. Customer service ('patient satisfaction')

- Consumer society (related to civil rights movements above)
- The growth of markets in NHS
- Patient experience as a management tool for audit (2000s-) associated with de-professionalisation, ratings, constant change

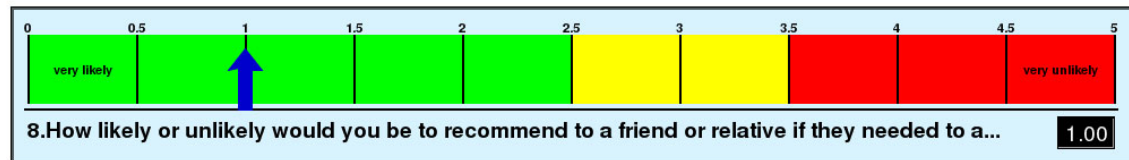
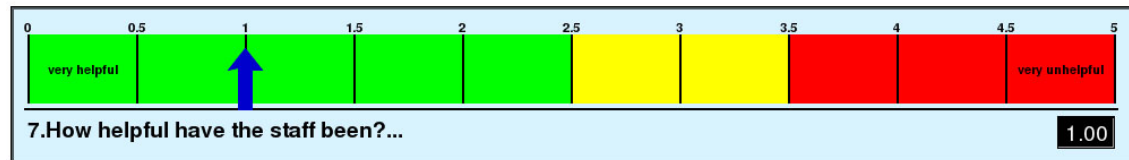
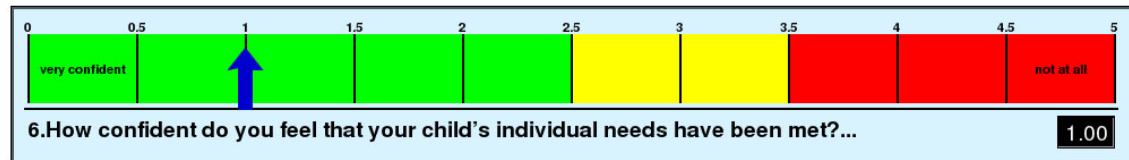
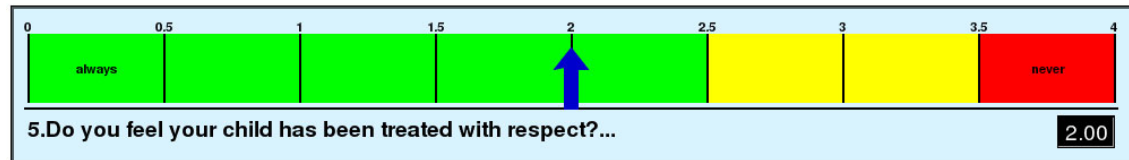
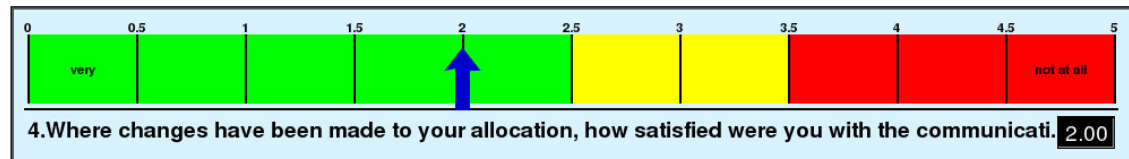
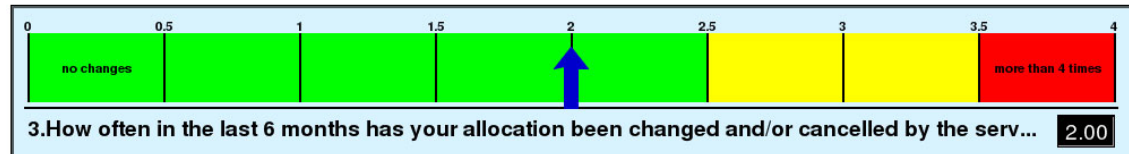
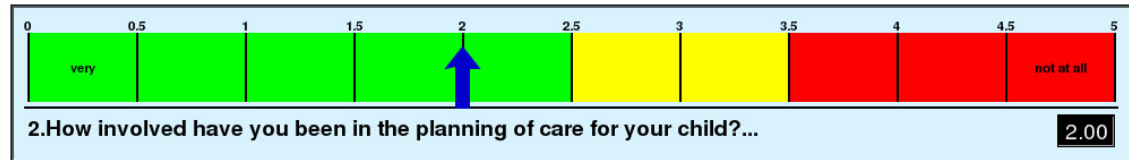
# Tesco 5 item score

- Clear aisles
- No queues
- Stocked
- Helpful staff
- Clean



### Report on indicator 7b

For dates: All dates  
For nodes: Norfolk  
Total responses in report: 1



A sample CQUIN style report using linear meters

[http://www.healthfeedback.co.uk/wp/?page\\_id=23](http://www.healthfeedback.co.uk/wp/?page_id=23)



# CQUIN Framework

- CQUIN framework links a proportion of English healthcare providers' income to local quality improvement
- ICHT's local CQUIN goal of improving staff courtesy and three of the national CQUIN questions:-

# What do the questions mean?

***Local ICHT patient experience CQUIN and ICHT core question:***

*Q1 How would you rate the courtesy of the staff?*

***National patient experience CQUIN and ICHT core questions:***

*Q2 Were you involved as much as you wanted to be in decisions about your care and treatment?\**

*Q3 Did you find someone on the hospital staff to talk to about your worries and fears?*

*Q4 Were you given enough privacy when discussing your condition or treatment?*

(3 or 4 categories of response from excellent to poor, yes to no / na.)

# Maternity & GUM

- Some women drew a distinction between care and treatment. Some women did not think that they should or could be involved in decisions about certain aspects of medical treatment:
- *“your treatment has to be given; it's a set treatment really, isn't it”* (Maternity - 2<sup>nd</sup> baby, birth centre)
- *“I don't know what it means by were you involved as much. I mean it's basically their decision that I should do the test, so you know there's nothing to be involved with really”* (GUM – male, over 29 years)

# Pancreatic cancer

Another example from Founder of Healthtalkonline.org – it can be inappropriate to involve a patient any further

[http://www.healthtalkonline.org/Improving\\_health\\_care/shared\\_decision\\_making/People/Interview/2577/Category/503](http://www.healthtalkonline.org/Improving_health_care/shared_decision_making/People/Interview/2577/Category/503)

# Difficulties of interpretation

- Commonly more than one care or treatment interaction in journey
- The best or worst may be most salient and overshadow the others
- It may be difficult to calculate an average across your journey
- PtEx response can also refer to clinical outcome and safety

# The family and friends test

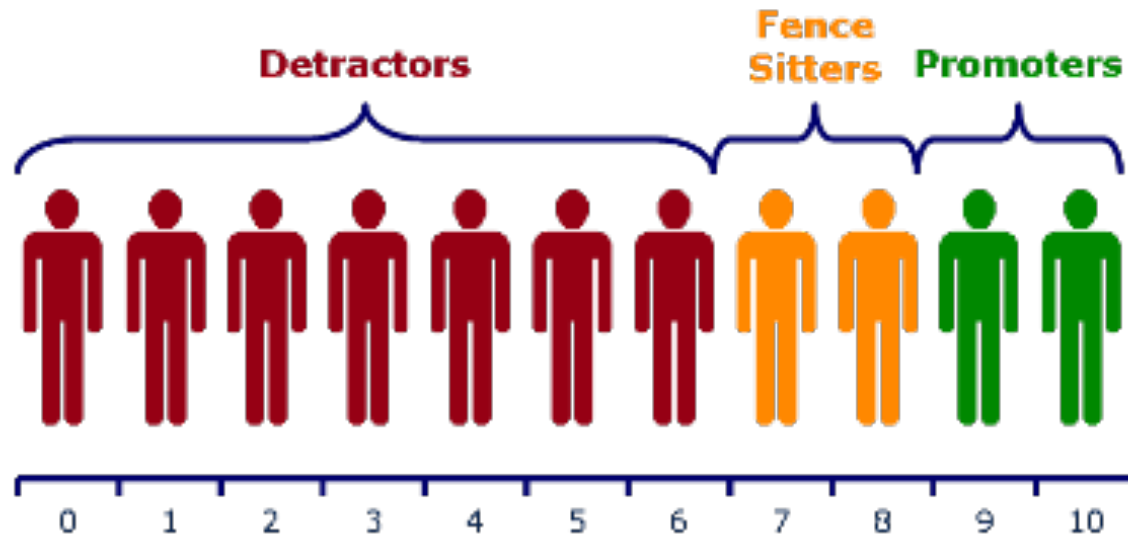


- From April 2013, every NHS hospital will be required to ask patients in A&E & on wards whether they would want a friend or relative to be treated there. The Prime Minister says the results will be made public so 'everyone will have a really clear idea of where to get the best care' which will 'drive other hospitals to raise their game'.

- ‘what gets measured gets managed’
- Net Promoter Score (NPS) – a customer loyalty metric that businesses including Apple, Philips and American Express used to test customer views

The King’s Fund Blog (Jocelyn Cornwell)





Net promoter score = % promoters - % detractors\*

The 7DS Net Promoter Score (NPS) is a client survey system used to measure customer loyalty for companies in and around the real estate and mortgage industries.<http://www.renps.com/>

Satisfaction-profit chain aims to improve customer retention, loyalty & repeat business often using proxy of quality of personal interactions



# So: what might you be measuring?

- Difficulties of designing questions and interpreting answers
- Timing, e.g. 2-6m after discharge
- Relationship to safety and outcome. Not the same as Tesco satisfaction?
- Ratings and pay, making markets

# For healthcare workers – ‘cost’?

Reported poor experiences of doctor-patient interactions in a London NHS Trust Hospital

1. Poorly designed questionnaire
2. Badly analysed (statistics)
3. Aren't the others (e.g. nurses) as bad as us?

This ‘3-stage denial’ shifts to ‘patient experience is everyone’s business!’

# For healthcare workers – or ‘opportunity’?

A focus on PtEx allows you to think about

What is the doctor’s role and influence when -

A disease is also an illness and a sick role?

A health problem is embedded in a person’s everyday life and social networks?

- Your assumptions about people
- The time it takes to listen and respond eg to take a social history
- The issue of social distance, stereotypes, the active patient, Joint investment in ‘therapeutic optimism’
  - See the ‘terminology’ clip at [http://www.healthtalkonline.org/heart\\_disease/Congenital\\_Heart\\_Disease/Topic/2198/](http://www.healthtalkonline.org/heart_disease/Congenital_Heart_Disease/Topic/2198/)
  - Different diagnostic procedures /ethnicity (cancer, USA): Krupat E, Irish JT, Kasten LE, et al. Patient assertiveness and physician decision-making among older breast cancer patients. *Soc Sci Med.* 1999;49:449-457.

# Impact of PtEx

- The relationship between experience, safety and clinical outcome is complex
- A study in USA\* showed better patient satisfaction scores associated with fewer readmissions. The effect was higher than for clinical performance measures
- Goals to improve PtEx ratings may also promote tests and therapies which affect safety or equity negatively

\*Boulding et al, Am J Manag Care. 2011;17(1):41-48

# The cost of satisfaction\*

- Prospective US study of 51,946 adults (2000 – 2007)
- Patients with highest satisfaction were
  - Less likely to have an emergency dept visit
  - More likely to have an inpatient admission
  - Greater total expenditures including drug costs
  - Higher mortality (adjusted hazard ratio, 1.26)
- Difficult to interpret - ?overtreatment of satisfied people

\*Fenton JJ et al. Arch Intern Med 2012;172:405–11.

# Patient reported outcomes



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Source: Analysis based on Department for Health - National Cancer Patient Experience Survey 2011.

See Annex A for the Top 10 and Bottom 10 NHS trusts in 2010.

# Chemotherapy examples

The staff are great BUT

- missing notes and muddles in e.g. referral, diagnosis, treatment
- transport: cost, parking, infirmity
- waits, waits and waits along with lack of information and communication
- poor integration of different services and hospitals

The staff are great BUT

- if they weren't so busy and if it weren't that they had to deal with this 'system', I might complain
- Varying boundaries between them and us
- High PtEx scores, why?



# Free text comments from patients in NCPES

- Point one - listen to patients

Breast cancer patient: "Just one thing. I know my body better than anyone, if I say to the doctor something is not normal or wrong, then it`s not normal. Doctors should realise our concerns about something and try to rectify it to our satisfaction, not say leave it, it`ll go in time...it doesn`t and all the time there is discomfort and pain."

- Point two - patients can help you improve the services
  - Gynae cancer patient: "Fast track to a cancer specialist when temperature goes up whilst in the chemo cycle. Going to A and E and spending 6 hours waiting for doctors/test results/bed in ward is a nightmare."
  - Lung cancer patient: "It would be good to have much more information given about - financial support etc available. Wigs on NHS. Support groups and services. Exercise we should do after specific operations - that would also speed up recovery. Leaflets re: the above would be very, very useful."

- Point three - many patients are "grateful" and may have low expectations

Lung cancer patient: "I did not die, anything else would be a little picky."

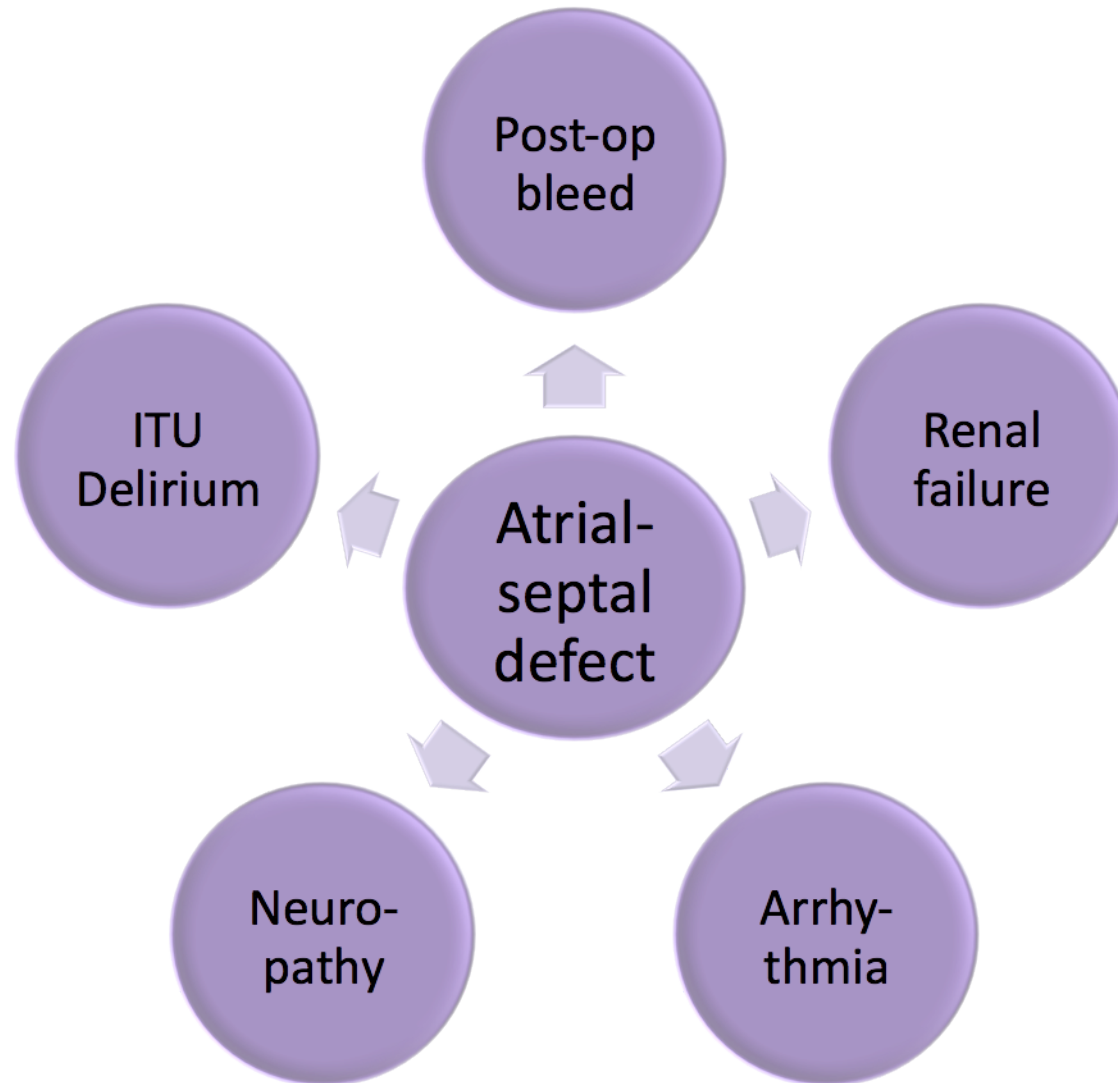
# A patient journey

Introducing an experience and its relationship to safety and clinical outcome

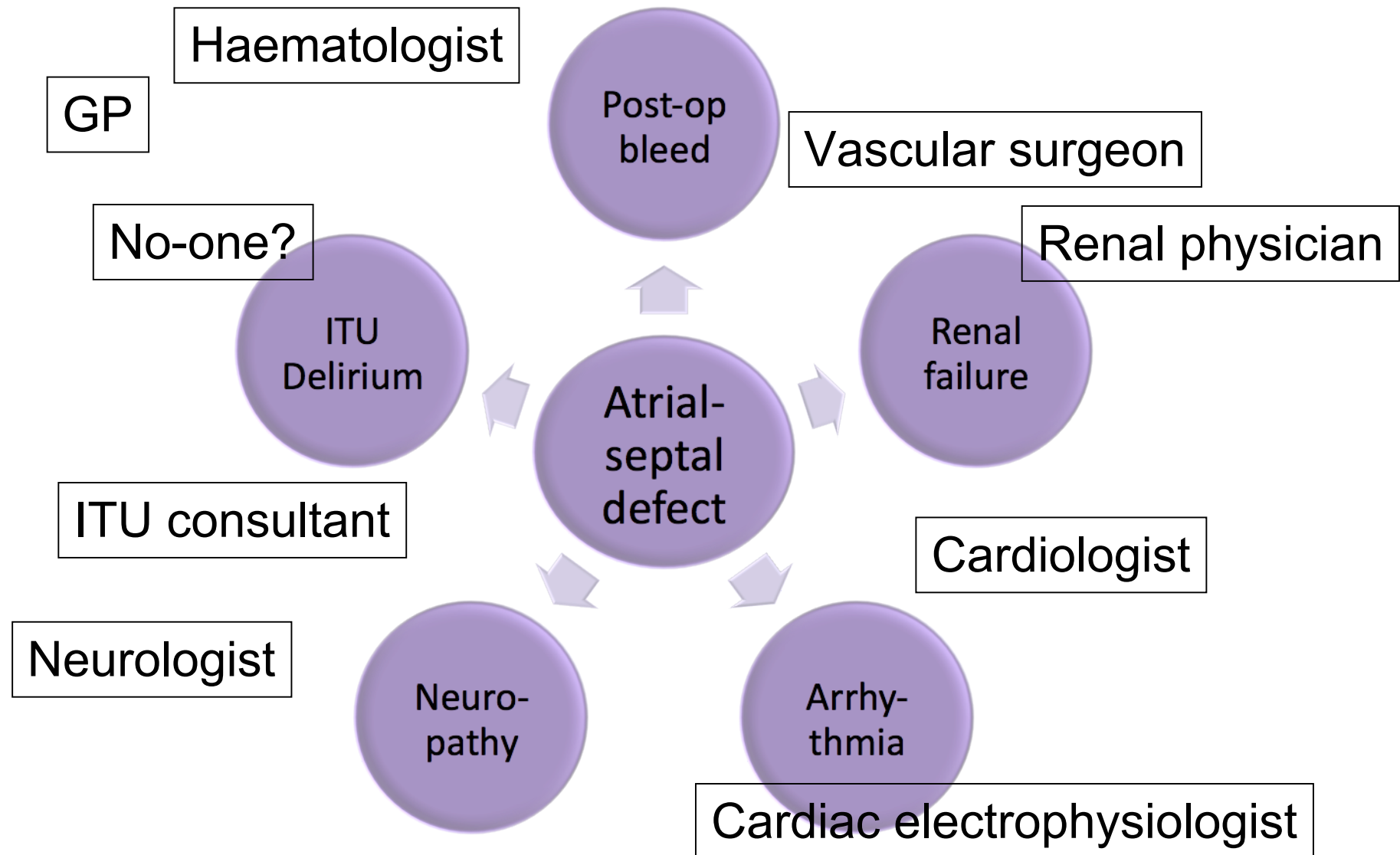
What can be measured and said?



# An experienced patient



# An experienced patient – “and a cast of thousands”



# Summing up my experience (1)?

- I'm alive
- Serious complication
- Inadequate explanations
- Difficult decisions
  - Where to go if...
- Additional difficulties as a doctor/colleague
  - Self-management
  - Informal network of other doctors

# Summing up my experience (2)?

- One of the most interesting experiences of my life
- Ongoing care remains difficult
  - The system often forgets
  - it is up to me to make things happen
- The huge contribution to healthcare made by
  - Other patients
  - Family and friends



# Domains of Patient Experience

- Respect for patient-centred values, preferences and expressed needs
- Co-ordination & integration of care
- Information, communication & education
- Physical comfort
- Emotional support
- Welcoming the involvement of family & friends
- Transition and continuity
- Access to care

(Adapted from NHS PtEx Framework in Matthews & Cornwell 2012)