Person-centred care and the measurement of health service quality

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Our vision: the highest quality health and social care for all, always.

We:

- **Influence** policy and practice so that health and social care systems are always centred around people’s needs and preferences.

- **Inspire** the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.

- **Empower** those working in health and social care to improve experiences by understanding, measuring, and acting upon people’s feedback.
Contents

- Roots & evolution of ‘person centred care’ and ‘the patient experience movement’
- Why measure patient experience?
- What have we learnt so far?
- What are the challenges for the future?
Key messages

- *Person-centredness* is a desired quality of care; *patient experience* provides a means of measuring it.

- Good patient experiences are correlated to other elements of quality…

- …but are an important outcome in and of themselves.

- The evidence base is evolving fast – but more needs to be done to turn the policy focus on patient experience into actual improvements in care.
Evolution of person-centred care and patient experience
2015 – where we are today

- England
  - National Survey Programme since 2002
  - FFT – mandatory requirement for every contact
  - Patient experience part of nationally accepted definition of healthcare quality\(^1\)-\(^2\)

- United States
  - HCAHPS used since 2006 – linked to payments
  - 10m questionnaires circulated annually

- Major patient experience programmes operating worldwide, including via OECD member states

The roles of patients and clinicians

**patient**
- Passive
- Vulnerable
- Dependent
- Deferential

**doctor**
- Active
- Knowledgeable
- Authoritative
- Powerful
The Medical Model

- 19th century: development of **germ theory** replaces miasma theory of disease

- This and other advances arguably give rise to **medical professionalism** – where the focus is on:
  - Signs / symptoms / pathology
  - Expert knowledge
  - Patient compliance to medical advice
  - Disease – not social/psychological factors
He's one of the busiest men in town. While his door may say Office Hours 2 to 4, he's actually on call 24 hours a day.

The doctor is a scientist, a diplomat, and a friendly sympathetic human being all in one, no matter how long and hard his schedule.

According to a recent Nationwide survey:

More Doctors smoke Camels than any other cigarette
Criticism of the medical model

- Ignores non-medical factors

- Expertise of physician seen as inherently more valuable than that of the patient

- Carel (2008) describes this as an “epistemic injustice”

- Privileging of technical knowledge permits secrecy about performance and encourage ‘blind trust’ – patients have no way of understanding quality
Patient-centred care

- Puts users ‘at the heart of services’

- Encourages view of patients as participants, not recipients; active rather than passive

- Seeks to empower users to be involved
The seven principles (1993)

- Respect for patients’ values, preferences, and expressed needs
- Co-ordination and integration of care
- Information, communication, and education
- Physical comfort
- Emotional support & alleviation of fear & anxiety
- Involvement of family and friends
- Transition and continuity
Picker Principles of Patient-Centred Care (1997)

- Respect for Patients values, preferences and expressed needs.
- Coordination and integration of care.
- Information, Communication, and Education.
- Physical Comfort.
- Emotional support and alleviation of fear and anxiety.
- Involvement of friends and family.
- Continuity and Transition.
- Access to care.
Bristol heart surgery inquiry (1998)

- Inquiry found high mortality rates for some clinicians
- Contributing factors included “old boy’s culture”; protective way of thinking that defended medical profession; secrecy about performance

- “The trust that patients place in their doctors… will never be the same again, but that will be a good thing if we move to an active rather than a passive trust” (Richard Smith, 1998)

- “the end of the age of ‘the doctor knows best’” (Trevor Jones, 1998)
Who judges person-centredness?

Berwick defines patient-centred care as:

“The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care.”

Who judges person-centredness? (2)

- Similarly Gerteis et al (1993) describe patient-centred care as an “approach that consciously adopts the patient experience”

- Person-centredness is thus defined in terms of the *lived experience* of people using services

- Traditionally, quality is measured in medical terms

- Person-centred care by requires a different approach
A brief history of patient experience

- 1950s: first patient satisfaction surveys
- 1960s/1970s: limited interest; <10 published papers per year looking at patient satisfaction
- 1980s: ‘satisfaction’ becomes a priority in UK and US
- 1990s: criticism of ‘satisfaction’; focus moves to patient experience
- 1990s: Picker/Commonwealth work seeks to define ‘patient-centred care’

Experience vs satisfaction

- Satisfaction…
  - “Implies only that expectations have been met”
  - Is highly subjective
  - Is generally not actionable

- Good user experience is *both* related to clinical effectiveness *and* an end in its own right

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UNDERSTANDING ONLINE STAR RATINGS:

★★★★★ [HAS ONLY ONE REVIEW]
★★★★★ EXCELLENT
★★★★☆☆ OK
★★★☆☆☆ CRAP
★★☆☆☆
Wider evidence about measuring patient experience
2015 – where we are today

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Rapidly growing evidence base

`pubmed - "patient experience" OR "patient satisfaction"`
Transition from ‘satisfaction’….
…to ‘experience’
Intergroup variation

- Some groups consistently report poorer experiences
  - Black and minority ethnic (BME) groups\(^1\)
  - People with (multiple) long-term conditions\(^2\)
  - Younger people – and people over 80\(^3\)
  - Proxy respondents\(^4\)
  - People with mental health problems\(^5\)

- How data is collected also very important – eg FFT\(^6\)

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4 Graham, C. (in press)


Relationship with other measures

- Pt exp correlates with safety and effectiveness\(^1,2\)
- Better pt exp related to higher levels of adherence, better outcomes, fewer complications, & lower service utilisation\(^3\)
- Correlation with quality of staff experiences\(^4\)
- But correlations are typically modest – need to measure each separately

Criticism of patient experience

- Fenton et al (2012) report higher patient satisfaction is associated with...
  - Greater (inpatient) health service utilisation
  - Higher costs of care and prescriptions
  - Increased all-cause mortality

- Reductions in primary care antibiotic prescribing associated with poorer patient reported experiences²

What do we know about the **quality** of patient experience in England?
NHS inpatient survey: in numbers

- 1.5m patients invited
- Over 800,000 responses received
- Including > 60,000 responses every year
- 156 trusts take part
- 78 questions
Headlines are generally positive…

- Hospital room was "very clean" 69%
- "Completely" told what would happen during operation 76%
- "Always" had confidence and trust in nurses 77%
- "Always" had confidence and trust in doctors 81%
- "Always" treated with respect and dignity 81%
... but with some noticeable exceptions

- "rarely or never" or only "sometimes" enough nurses: 11% vs. 30%
- did not "always" get understandable answers from nurses: 31%
- didn't get enough emotional support: 43%
- wanted to be more involved in decisions about care and treatment: 44%
- not "completely" told about medication side effects to watch for: 61%
Improvements

- Biggest improvements correspond to national policy initiatives:
  - Mixed sex accommodation
  - Cleanliness & hand hygiene
  - Copies of letters from consultants to GPs
Did you share a sleeping area, for example a room or bay, with patients of the opposite sex?
Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?
In your opinion, how clean was the hospital room or ward that you were in?
System pressures have been evident in results around waiting times
From the time you arrived at the hospital, did you feel that you had to wait a long time to get to a bed on a ward?
How many minutes after you used the call button did it usually take before you got the help you needed?
What matters most to patients?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors know enough about my medical history &amp; treatment</td>
<td>1.18</td>
</tr>
<tr>
<td>Doctors can answer questions about my condition and treatment in way that I can understand</td>
<td>1.19</td>
</tr>
<tr>
<td>I have confidence and trust in the hospital staff who treat me</td>
<td>1.20</td>
</tr>
<tr>
<td>Doctors wash or clean their hands between touching patients</td>
<td>1.23*</td>
</tr>
<tr>
<td>Nurses know enough about my medical history &amp; treatment</td>
<td>1.25</td>
</tr>
<tr>
<td>Before my operation or procedure, I get a clear explanation of what will happen</td>
<td>1.25</td>
</tr>
</tbody>
</table>

* NB: scores as of 2006, following shortly after peak in media coverage of ‘superbug’ MRSA.
When you had important questions to ask a doctor, did you get answers that you could understand?

When you had important questions to ask a nurse, did you get answers that you could understand?
Did you have confidence and trust in the doctors treating you?

Did you have confidence and trust in the nurses treating you?
When you had important questions to ask a doctor, did you get answers that you could understand?
Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?
### Table 3

OR of reporting a complication (any) associated with 1 SD change in PREM

<table>
<thead>
<tr>
<th>PREM—difference of 1 SD in:</th>
<th>Hip replacement</th>
<th>Knee replacement</th>
<th>Groin repair</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall score</td>
<td>0.72 (0.68 to 0.77)</td>
<td>0.71 (0.67 to 0.75)</td>
<td>0.64 (0.57 to 0.71)</td>
</tr>
<tr>
<td>Consistency/co-ordination</td>
<td>0.81 (0.75 to 0.86)</td>
<td>0.77 (0.72 to 0.81)</td>
<td>0.76 (0.69 to 0.84)</td>
</tr>
<tr>
<td>Respect/dignity</td>
<td>0.86 (0.81 to 0.92)</td>
<td>0.83 (0.78 to 0.88)</td>
<td>0.93 (0.84 to 1.03)</td>
</tr>
<tr>
<td>Pain control</td>
<td>0.83 (0.78 to 0.89)</td>
<td>0.81 (0.76 to 0.86)</td>
<td>0.84 (0.75 to 0.93)</td>
</tr>
<tr>
<td>Explanation/involvement</td>
<td>0.80 (0.75 to 0.85)</td>
<td>0.80 (0.75 to 0.85)</td>
<td>0.69 (0.62 to 0.76)</td>
</tr>
<tr>
<td>Doctors: trust/communication</td>
<td>0.74 (0.69 to 0.79)</td>
<td>0.72 (0.68 to 0.77)</td>
<td>0.66 (0.60 to 0.74)</td>
</tr>
<tr>
<td>Nurses: trust/communication</td>
<td>0.72 (0.68 to 0.77)</td>
<td>0.72 (0.68 to 0.77)</td>
<td>0.66 (0.60 to 0.73)</td>
</tr>
<tr>
<td>Cleanliness/hygiene</td>
<td>0.83 (0.78 to 0.86)</td>
<td>0.80 (0.76 to 0.85)</td>
<td>0.80 (0.72 to 0.88)</td>
</tr>
<tr>
<td>Discharge information</td>
<td>0.83 (0.78 to 0.89)</td>
<td>0.92 (0.90 to 0.94)</td>
<td>0.89 (0.85 to 0.92)</td>
</tr>
</tbody>
</table>

All ORs p<0.001 apart from: *Not significant.
People’s experiences of cancer care
Cancer Patient Experience Survey

- England has a national cancer patient survey: CPES
- Conducted four times: 2010, 2011/12, 2013, 2014
- Covers all patients in active treatment for cancer

In 2014:
- 153 NHS organisations participating
- 109,760 patients in sample
- 70,141 responses (64% response rate)
Headlines are generally positive…

- Felt they were told they had cancer sensitively
- Doctors did not talk in front of patients as if they weren't there
- Had confidence and trust in all doctors treating them
- Doctors have understandable answers "all or most of the time"
- Overall care was "excellent" or "very good"
... but with some noticeable exceptions

- 'Definitely' involved in decisions about care and treatment
- Different care professionals 'always' working well together
- 'always' enough nurses to care for them in hospital
- 'definitely' told about possible side effects of treatment
Breast cancer patients are particularly positive about the care they receive…

- Reporting quick referrals
  - 92% see GP no more than twice before referral
  - 91% say they were seen ‘as soon as necessary’
  - Only 7% report that health worsened while waiting

- Receiving good information
  - 79% given understandable explanation of diagnosis
  - 82% given understandable explanations of test results
  - 77% given written information about breast cancer
  - 90% given written information about side effects
  - 84% given written information about operations
Given written information about side effects

But…

- Breast cancer patients less likely to say that…
  - Staff asked what name they preferred (54% vs 60%)
  - They didn’t feel treated like “a set of symptoms” (79% vs 81%)

- Other areas for improvement:
  - Wide variation between providers
  - Care co-ordination between providers
  - Patients with emergency entry to treatment (versus screening or referral) report worse experience
Future challenges for patient experience
Future direction & challenges

- International consensus on importance of patient experience\(^1\)

- Barriers remain around the use of evidence\(^2,3\)

- Challenge for the future is moving from measurement to improvement

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2 Coulter, A., Locock, L., Ziebland, S., & Calabrese, J. (2013) Collecting data on patient experience is not enough: they must be used to improve care. *BMJ* 348(mar26 1), g2225–g2225. [http://doi.org/10.1136/bmj.g2225](http://doi.org/10.1136/bmj.g2225)
Barriers to use

- Mistrust of patient feedback
- Limited resources
- Results not considered granular/local enough – eg “that doesn’t happen on my ward”
- Demand for more rapid reporting of results
- “Lack of serious and sustained local attention to improving patient experiences”
- “Simply providing… feedback does not automatically have a positive effect on quality standards”


Addressing the challenges

- Patient experience data may have to become...
  - More **granular**
  - More **rapid**
  - More **connected**

- Each of these has pros and cons and needs careful consideration

- Be wary of specious solutions
Greater granularity

**Benefits**
- Detailed view of intra-organisational variation in performance
- Improved sense of ownership from local clinical teams

**Costs**
- Requires much larger samples (e.g., GP patient survey)
- Much greater costs of administration
- Patients may end up receiving multiple surveys
More rapid reporting

Benefits

- Sense of immediacy
- Opportunity to act on results before they are updated
- Problems can’t be dismissed as “already fixed”

Costs

- Less time for cleaning/standardising data – thus higher risk of errors
- ‘Near real-time’ measures may produce biased, unduly positive results
Better connected data

Benefits
- Opportunity for richer understanding of trends & differences
- Potential for innovative approaches – eg following patients longitudinally

Costs
- Implications for ethics and confidentiality
- Greater complexity of analysis
- May be difficult to relate to local agendas
There’s probably no ‘golden bullet’

- Answers may lie in tailored, differentiated use of range of tools and measures.
- This may include not just structured, systematic, quantitative collections – but rather organisations having a holistic strategy for use of all patient experience information – eg:
  - National surveys
  - Patient Opinion
  - FFT comments
  - Patient stories
  - Compliments and complaints
- This may require upskilling/extra expertise locally.
Conclusions
Conclusions

- Patient experience provides a means of measuring the extent to which care is person-centred.

- Focus on patient experiences now internationally accepted as a core component of service quality.

- Robust methods for measurement exist, but improvements in care have proven elusive.

- Future development of patient experience should focus on improving utility and precision.