Co-designing transparency
and public reporting with consumers and clinicians:
reporting data patients want and clinicians can use

Carl Shuker
When patients Google their surgeon (and they do)

'Name and shame' report upsets doctor

26 May, 2008 10:31pm

NZPA

KEY POINTS:
Wellington surgeon [REDACTED] is to complain to the Ombudsman about what she calls a "name and shame inquisition" following the death of one of her patients.

The post-operative care of Moira Simcock was severely criticised in findings made public at the weekend by Health and Disability Commissioner Ron Paterson.

The 64-year-old died in 2005, three weeks after [REDACTED] performed gynaecological surgery on her at Wakefield Hospital.

A subsequent hernia went undiagnosed for almost two weeks and Mrs Simcock died from septicaemia.

Surgeon [REDACTED] is also in the spotlight after Mr Paterson found that one of his patients, Beverley Malone, died from post-operative complications after abdominal surgery at the same hospital in 2003.

[REDACTED] has been referred for possible legal action, and Ms Iyengar faces a competence

More patients air complaints about Wellington surgeons

14:43, Jan 31 2009

HOSPITAL ORDEAL Patient Kat Maclaren had surgery for endometriosis and "woke up in the recovery room in absolute agony".

More former patients of two Wellington surgeons criticised by the health system watchdog have come forward complaining about their standard of care.

The names of [REDACTED] and [REDACTED] - who both worked at Wellington's Wakefield Hospital - became public after the families of
Elective surgery and Google: context

“New Zealand has one of the most trusted public sectors in the world.” Transparency International Corruption Perceptions Index

But:

“New Zealand lags behind other healthcare systems in disclosure of performance and outcomes information” - Ombudsman

Cf.

“Australia’s hospital system lags behind international peers in making this transition to greater transparency.” - Stephen Duckett
How do we do transparency?

“And I gave my heart to know wisdom, and to know madness and folly [and clinical outcomes]: I perceived that this also is vexation of spirit.”

- Ecclesiastes 1:17

• Would ignorance have been bliss?
• What would YOU want to know?
How do we think about transparency?

**Moral**: The ethical and moral imperatives – expectation of a public service; human right to autonomous informed consent; the future, generally

**Empirical**: what effects does transparency actually have?

It’s complex and there is no single answer either across or within jurisdictions
The tipping point in NZ: Official Information Act

- Health reporter OIAs named surgeons’ mortality and complications
- Refused, lodges complaint to the Ombudsman (as planned?)
“If you wish to remain in Bristol you should not disclose the results of paediatric cardiac surgery to people outside the unit ever again.” - James Wisheart to Steven Bolsin in 1990

All changed, changed utterly

British medicine will be transformed by the Bristol case

“The Bristol case,” in which judgment was passed last week will probably prove much more important to the future of health care in Britain than the reforms suggested in the white papers.
NHS England response – “My NHS”
Public reporting in the US: NY and heart bypass

- Variation leads to registries, hospitals leaked, media sues for surgeon names
- Sudden 41% decrease in risk-adjusted CABG mortality
Public reporting in the US

- Proliferation
- Premised on consumer choice and market effects
- But: multiple raters don’t agree*

* National Hospital Ratings Systems Share Few Common Scores and May Generate Confusion Instead of Clarity. Austin JM et al Health Aff 2015.
US transparency: ProPublica Surgeon Scorecard

- Relies on grasp of data (95% CIs)
- Year-on-year fall in unique views of 75% since 2015
- NZ consumers appalled
Public reporting: evidence for quality improvement

Empirical evidence: 2018 Cochrane review, syst revs, AHRQ tech assessment, early days in the literature but suggest public reporting incentivises QI at institutional level. No let-up in calls for more.

New Zealand: 2016 Ombudsman rules

By 2021: “select, develop and publicly report quality of care measures (including outcomes) that:

• are meaningful to consumers;
• are meaningful to the clinicians who provide their care;
• are meaningfully attributable to the clinicians or service providing that care.”
Issues with public reporting of outcomes

- **What outcomes?** Mortality for CABG but prostate resection?
- **Underpowered** data
- **Consumers don’t use it** to choose even when choice is an option
- Surgeons’ performance is not “portable”*
- **Risk aversion**: “I wouldn’t touch that patient with a ten-foot bargepole.”
- **Effects on training** – shouldn’t patients be spared the learning curve?

Public reporting of surgeon outcomes: low numbers of procedures lead to false complacency

Kate Walker, Jenny Neuburger, Oliver Groene, David A Cromwell, Jan van der Meulen

<table>
<thead>
<tr>
<th>Procedure</th>
<th>National postoperative mortality (%)</th>
<th>Median annual number</th>
<th>Number of procedures necessary to detect poor performance</th>
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</thead>
<tbody>
<tr>
<td>Hip fracture surgery</td>
<td>8.4%†</td>
<td>31</td>
<td>56 70 102</td>
</tr>
<tr>
<td>Oesophagectomy or gastrectomy</td>
<td>6.1%‡</td>
<td>11</td>
<td>79 109 148</td>
</tr>
<tr>
<td>Bowel cancer resection</td>
<td>5.1%§</td>
<td>9</td>
<td>95 132 179</td>
</tr>
<tr>
<td>Cardiac surgery</td>
<td>2.7%¶</td>
<td>128</td>
<td>192 256 352</td>
</tr>
</tbody>
</table>

“If 1/20 cardiac surgeons had poor performance, PPV over 3 years = 63%”

Walker et al 2013 The Lancet 382: 1674-7
What do consumers want? (we asked)

- Reassurance, trust and confidence in the system
- Information from a consumer perspective centred on the patient journey, such as wait times and cancellations
- Data on two to three key aspects of a procedure
- Details of the process
- Likelihood of different outcomes including quality of life
- Risks and benefits for themselves as individuals
- Stories from a mix of data and personal accounts
- Patient experience surveys and ‘expert patients’
A theory of transparency for New Zealand

- **Harvest** existing clinical registries for pre-existing (low-cost) data clinicians already trust
- **Co-design** measures, consumer-facing AND clinically relevant
- **Target consumers** with really good data presentation practices
- **Publish at aggregated level** to incentivise teamwork
- **Providers** improve, engage, learn - quality improvement activities spurred by reputational effects
Test case: cardiology

- ANZACS-QI: acute coronary syndrome registry – large, mature
- High burden of disease and cost
- Day-long workshop
- 14 consumers, 2 clinicians, central backing
Co-design

Everyone wants it, hardly anyone does it: what is it? “Unconferencing” produced big surprises: patients cared about discharge, not data.
First track - national cardiology dashboard in beta

Health board comparison.
Time series data behind.
Internal circulation to cardiac network.
Co-designed consumer version in progress.
Second track - discharge checklist

Support extant local project – find and help existing experts with skin in the game
Dormant registry module available to collect discharge data
Working with the willing (and hungry)
Start simple, start local
The future

Orthopaedic registries: hip fracture, arthroplasty: patient pathways on stave charts, device proliferation, unwarranted variation (as Aus)
The future in sum

- Ask people what they want
- Co-design from extant robust data
- Find and work with those with skin in the game
- Start now, don’t wait
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