

Consumer participation in the development of the Quality of Care Report

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Purpose of our report

- to give a transparent public account of the quality of care at The Royal Women's Hospital
- to provide women and public with relevant information so that they are more fully informed about our clinical performance and the processes and systems that we have in place to constantly improve the quality and safety of care
- to enable women to be active participants and decision-makers about their own health care.

Consulting with consumers

- Involving consumers on the reference group
- Talking to the Community Advisory Committee
- Basing the report on information from a large sample of consumers and what they wanted from the hospital
- Doing focus groups about the response to the report
- Using lay readers to edit the report

Content design decisions

- The Report is designed around how women use the hospital, not how we organise the hospital. This decision was made in discussions with the Community Advisory Committee.
- The Report is based on a number of 'community principles' which emerged from consultation with over 1000 women about the redevelopment of the hospital. This suggestion came from the Community Advisory Committee.

Deciding what to report

- We spelt out the detail from the community consultation about what issues made up the 'community principles', from cultural and religious respect through to specialist care and research, and looked for evidence relating to those issues.
- We listed all the clinical/performance indicators/audit data that we knew were collected across the hospital.
- We combined these lists and created the detailed report plan from these sources and the framework

Clinical indicators

- Maternity Services have a set of performance indicators that involved consideration of evidence and consultations with clinicians and consumers
- The set includes clinical and consumer issues
- Breast cancer indicators are similar, although more process oriented
- There is lots of research and consultation about what matters to consumers, eg pain, access, discharge etc to draw on as well as local information

Use of indicators

- We try to convey how we use indicators to improve our care
 - identifying how we use to data to work out what we need to improve, post partum haemorrhage for normal vaginal birth, caesarean section for first birth
 - Identifying who we compare ourselves against, eg other Victorian hospitals, Women's Hospital's Australasia, international research
 - Identifying how we will respond to the data, eg additional technical training and support for doctors
 - Providing graphs of our results over time
 - Commenting on the good and the 'not so good'

Clinicians involvement

- Early engagement of clinicians in the report and providing data
- Continually putting drafts back for consultation and editing – is this correct, is that what you mean?
- Putting drafts back – are you happy to have this published?

What do consumers think?

- Attractive but daunting to pick up and read.
- Once they started reading, written in a friendly relaxed style and very interesting.
- “I wanted to read more.” “I felt empowered”
- Impressed with the honesty and transparency and the use of standards and indicators beyond what was mandatory.
- Concerned that the concepts and terms used could make it inaccessible to some women who use the hospital, “women from my country wouldn’t understand all those words”.

Comprehensive

- It was rich, multifaceted, covered everything, treated women as a whole, provided important information.
- For some women, all their questions were answered; others said it left them with some questions.

- “I felt empowered as a consumer. I wish I had read this, I wish I had known all this, when I was in the hospital having issues, that there is a structure for safety and quality. I would have felt more confident to raise issues, knowing that the hospital has obligations and wants to improve”.

Readable

- Women agreed that once they started reading, the information in the report was accessible, easy to read and generally targeted to an audience with “fairly low level medical expertise” and “the general public”.

Tables

- The tables were described as “user friendly”, good for a “non-tables kind of person”
- “you can visualise the improvements”, “you can see improvements immediately”,
- From the tables “you get the feeling that this is honest”.
- Information in the tables often led people to read the discussion in the text.
- A mistake in the 2003 report in a 20 row table on neonatal survival rates by gestation was picked up by several lay readers

Transparency

- Women commented that the report was more transparent, honest and detailed in particular chapters.
- They commented particularly on the tone in the chapters on safety and doctor's qualifications and that it started to answer the reader's questions.
- Women were reassured by the balanced information and that the hospital reported publicly on areas for improvement, "I really admired that".

Standards and indicators

- Women liked performance against voluntary as well as mandatory indicators, and with international benchmarks when there were not local standards.
- “That’s good when people take on stuff they don’t have to and measure it”.
- Women found the comparisons engendered confidence in the hospital’s integrity, especially where results were not as good.
- “Even when you want the indicators to be better, it’s reassuring to see (that the information is provided)”.

Personalising the information

- When asked what they most liked, women consistently highlighted the personal stories and that they read chapters relating to their own experience first. The first person story in the chapter on neonatal care was popular; they enjoyed reading it because “it wasn’t all rosy”.

Summary

- Involvement of consumers in setting the overall framework and the yearly themes
- Actively informing consumers and using this to engage in a conversation
- Being able to lever off performance indicators with consumer involvement in their development, eg maternity, breast cancer
- Building on what matters to clinicians and what matters to consumers
- Using consumer readers and commentary

The last word

- We see it as a dialogue
- This is ‘transformative politics’!