

Erasmus School of
Health Policy
& Management

Experience Based Co-Design in Dutch hospitals

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Participation and the construction of patients voices

- Methods like EBCD part of a broader patient participation agenda
- Participation processes not neutral:
 - Who can participate
 - What sort of input can patients bring to the table
- Study on EBCD in Dutch hospitals to see how design choices impact patient voices

Ezafun

Experience Based Co-design (Bate & Robert)

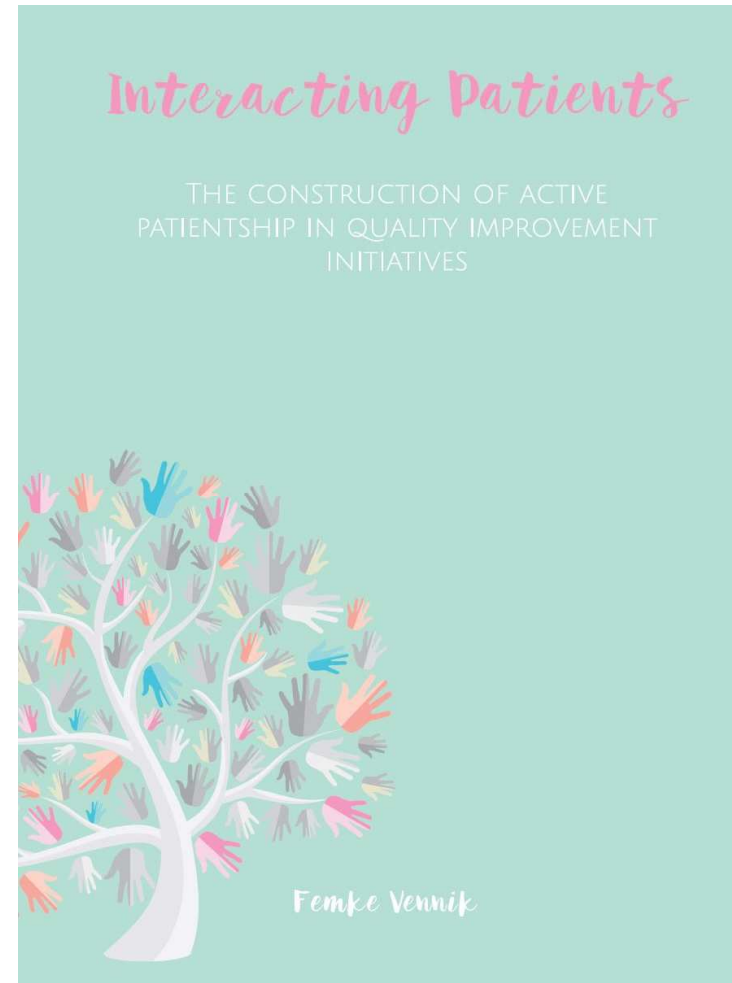
- Interviews with staff and patients (patient interviews are recorded on video)
- Patient and professional meeting
- Joint meeting to establish touch points that should be improved
- Working groups with patients and professionals who work on quality improvement together
- More information:
<https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/>

Interesting features EBCD

- EBCD goes against certain dominant ideas in health care:
 - From a focus on 'objective EBM' to a focus on emotions and subjective stories
 - From measuring quality in a quantitative way to qualitative information
 - Focus on deliberation and reflection
- Method and its implementation determine the patient perspective and the room for patient stories

EBCD in Dutch hospitals

- Phd. thesis Femke Vennik
<https://repub.eur.nl/pub/93075>
- Improvement project together with CBO, NFK
- EBCD in 4 hospitals
- Interviews, observations, document analysis



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Adapting EBCD and selecting patients

- Adaptations to the method: mostly to save time and money and limit impact on patients
- Selecting patients

I made a little document (on patient selection). I want differentiation in age, not only complainers but also happy people, you know a whole list... I could articulate that very well but (...) especially with sickle cell, half the patients don't speak Dutch and aren't very well educated, and of course you want to include them too. But, when you speak to them on the phone they are too tired, or simply don't have time, or they're really ill so they won't come (project leader)

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Selecting patient stories

- Selecting improvement points for the film
- Identifying improvement priorities and solutions among staff and patients

In the film, patients complained about the competence and attitude of apprentices. They explained that apprentices could have a very negative impact on the care they experienced. One patient suggested that apprentices should not be involved in oncology care: " yes apprentices, sure they need training. But I don't think they should be working with cancer patients. You're all nerves and then you get someone who knows nothing." However, staff did not select this as a key improvement priority, because they considered it a hospital-wide problem, broader than the quality of their department. As staff made the selection, patients had no influence on the final decision (observations).

Consequences of design choices

- Limit the depth of deliberation and reflection
- Influence the role of emotions within deliberation
- Influences whose voices are heard



Conclusions

- Need adaptations to fit EBCD to local context
- Adaptions and design choices have important consequences
- Deliberation aspects easily put aside but seem key to bring QI agenda forward
- EBCD project we are doing in long term care specifically focused on adapting EBCD with a focus on deliberation and reflection

The Erasmus logo, featuring the word "Erasmus" in a stylized, cursive script.