

# From *for* to *with* Partnership with patients

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# Twitter consents

- You have our consent to tweet the contents of this talk.
- You have our consent to take pictures of our slides.
- You have our consent to mention (@) us with feedback and your perspective on any of the concepts in this talk.

We have nothing to disclose.

**If patient engagement were a drug, it would be the blockbuster drug of the century and malpractice not to use it.**

Leonard Kish, 2012

# From god to guide



# From acute care (suffering) to chronic care (living)



# From body parts to whole people



Hello?

# From engagement to partnership

## **The Patients' Charter on Patient Empowerment**

- I am more than my health condition
- I am empowered to the extent I wish to be
- I am an equal partner in all decisions related to my health
- I have the information I need in an easily understandable format, including my own health records
- My health professionals and our health system actively promote health literacy for all
- I have the ongoing support I need to manage my own care
- My experience is a vital measure of healthcare quality
- I can participate in evaluating and co-designing healthcare services so they work better for everyone
- Through patient organisations, my voice becomes part of a bigger, united voice
- Equity and empowerment go hand-in-hand—I want a fair deal for all patients

*Source: European Patients Forum.*

# From "What's the matter with you?" to "What matters to you?"



ADELAIDE CITY EAST DAY HOSPITAL – SURVEY



## I was asked what matters to me and...

It is vital to me to have all the info to make an informed choice.

I want to know what procedure is about to happen + give my consent  
I don't want to be rushed.

I want to be treated gently. I want to be asked. I want written

information as I don't always remember what was said (step by step)  
I want the balance of what is important to me to be balanced with  
what is important for me. I want to be heard + respected.

"I want to be treated gently. I want to be asked."



# A model for partnership

	Plan	Implement	Evaluate
<b>At the visit</b>	Birth plans	Rounding with patients	Patient-reported outcome measures
<b>In clinical improvement</b>	Co-design Shadowing	Patient in improvement teams	Suggestion box
<b>Organisation</b>	Patients in leadership	Patients training staff	Surveys
<b>Region, state</b>	Co-developing policy		Voting

[Patient-Professional Partnership: Examples, best practices and recommendations,](#)  
Cristin Lind, QRC Stockholm, 2016.

# Interaction

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# Why is partnership important?

***“It is associated with***

***Improved patient outcomes***

***Shorter hospital stays***

***Reduced readmission***

***Improved functional status***

***Reduced mortality.***

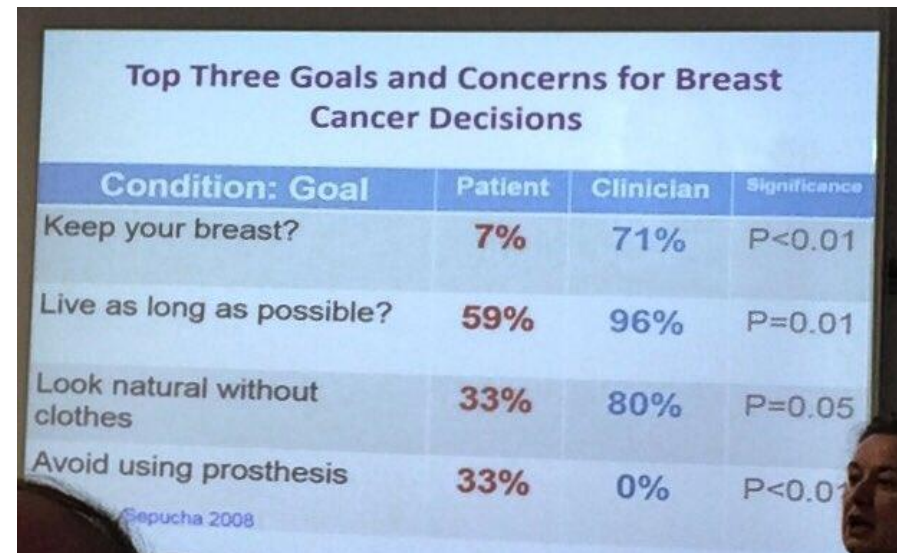
***It contributes to***

***Enhanced decision-making,***

***Reduced medical error and adverse events***

***Improved adherence and optimized self-management***

***Increased staff retention.”***

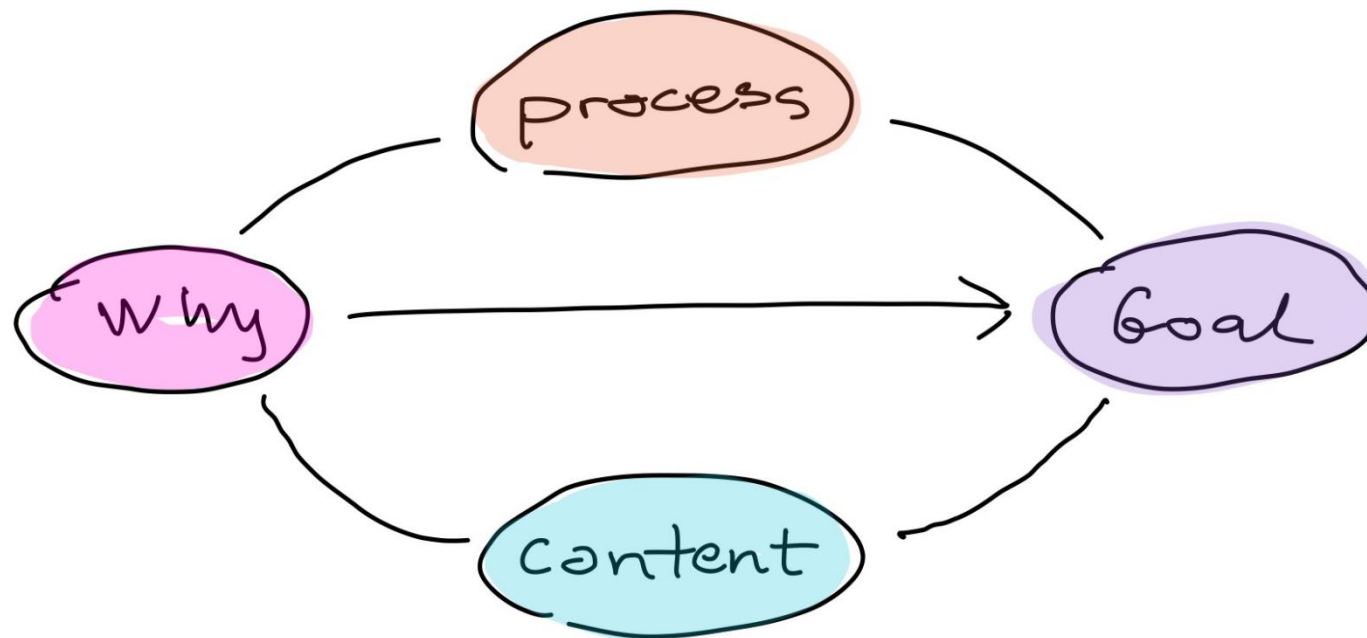


Condition: Goal	Patient	Clinician	Significance
Keep your breast?	7%	71%	P<0.01
Live as long as possible?	59%	96%	P=0.01
Look natural without clothes	33%	80%	P=0.05
Avoid using prosthesis	33%	0%	P<0.01

Sepucha 2008

[A systematic review of reliable and valid tools for the measurement of patient participation in healthcare. BMJ Qual Saf 2016;25:110-117 doi:10.1136/bmjqs-2015-004357](#)

# Partnership needs QI...and QI needs partnership



# Quality improvement needs partnership

## Patient partnership helps QI to:

- Identify the unknown unknown
- Shift the focus
- Discuss and define new indicators of quality
- Challenge existing roles
- Reduce power differentials



Susanne Gustavsson

*"Patient involvement in quality improvement"*

# Partnership needs quality improvement

## QI helps partnership to:

- Act after listening
- Help patients getting feedback after co-production
- Provide processes to partnership outcomes
- Increase curiosity



# Culture eats strategy for lunch

“Patients have no understanding of what [it takes] to run an office....They have no idea what goes into seeing a patient.”

“It’s useful, but it’s extra work—if it’s another minute on every patient, well that’s more than we have.”

“If you ask, there’s the implication that you’ll do something with the answer and that you’ll try to give them what they say they want.”

The feedback is “overwhelmingly positive” and “our patients seem happy.”

Han et al, 2013.

*We were in the process of re-designing our adolescent unit's website. We were really pleased with how it was turning out...until we asked a young woman how she would search for info about us. 'I'd just look on my cell phone,' she said.*

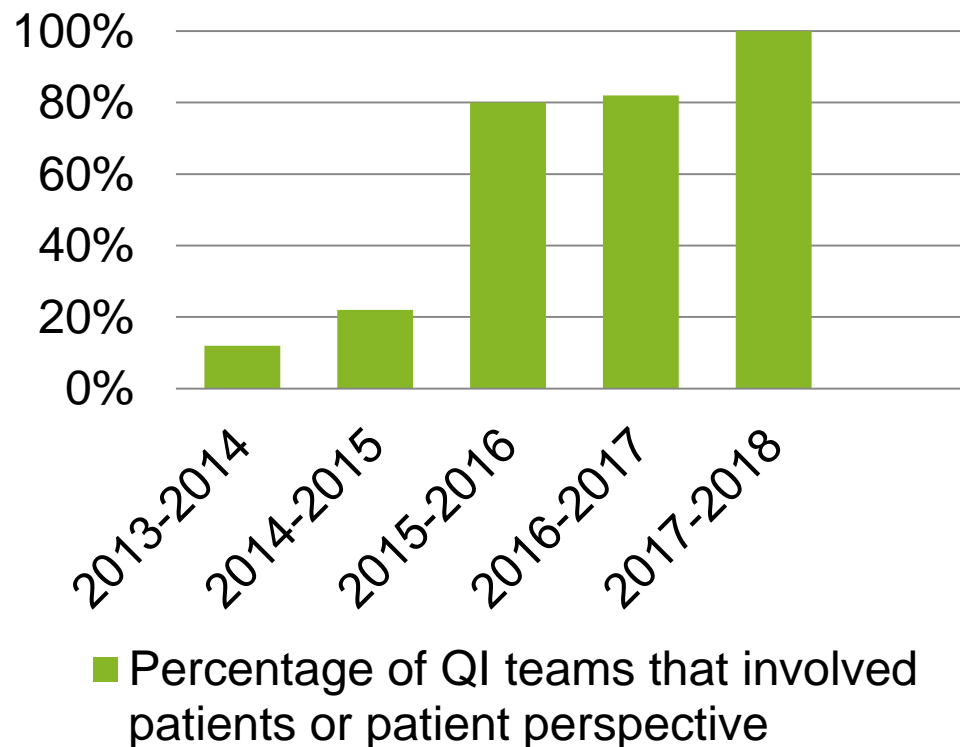
*At that moment we realized that our website wasn't optimized for viewing on mobile phones—it only worked when viewed on a computer. What a mistake on our part.*





So how do we do it?

# Patient partnership in Coachingakademin



*The purpose:*

*Every team should Involve patient or have patients perspective in their QI-project in a way that feels meaningful and adds value.*

# Patient partnership toolkit

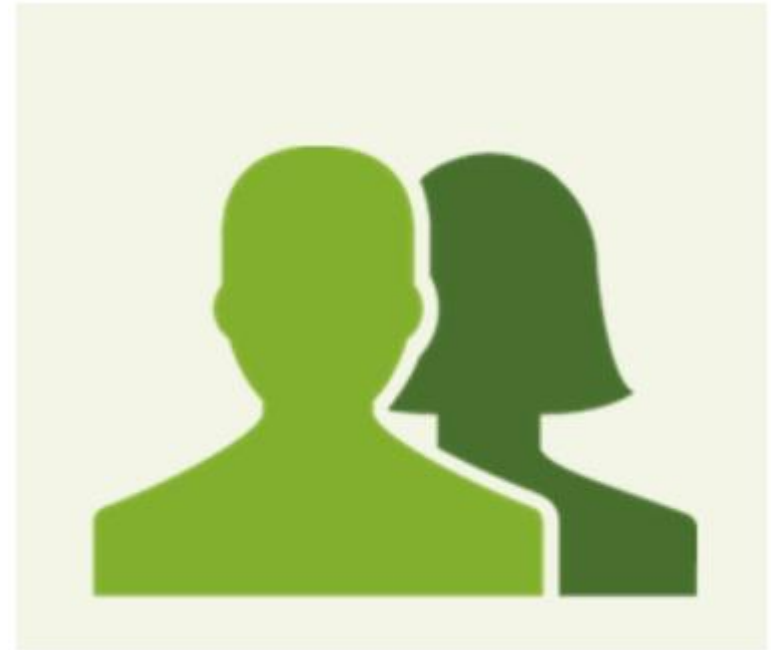
- There is no single perfect method
- Each method has its own requirements and its own results
- Using more than one method gives a greater depth of understanding



<http://qrcstockholm.se/patientsamverkan/verktygslada-2/>

# Shadowing

- Shadowing the patient through a healthcare process by observing the environment and events from a patient perspective
- It is a easy method for beginners to learn about the patient's experience of healthcare processes
- Increase empathy and understanding and can inspire improvement ideas



# Love and nuts

- What do you love? What drives you nuts?
- Playful tool to gain insight and spark conversation
- Works well as a warm-up for a focus group or workshop
- Supplement with more structured methods



# Patient/user-led audit

- A patient/user driven evaluation of a unit
- A way to get a deeper insight into how your unit is viewed from a patient's perspective
- In the case of user audit, the unit can find things that would otherwise not be detected.
- Complement to other audit methods





# Patient interviews

- A deep, open interview with a patient who describes themselves and their experiences in their own words
- Increases understanding of experiences, needs, expectations and of a life beyond being a patient.



# Patients as partners in Improvement teams

- Sends a strong signal that patients knowledge is valuable
- Gives the opportunity to continually exchange thoughts and ideas. Patients have experience that can complement the team in unexpected ways
- Organizations involving patients and relatives in a team have higher patient satisfaction than in other patients





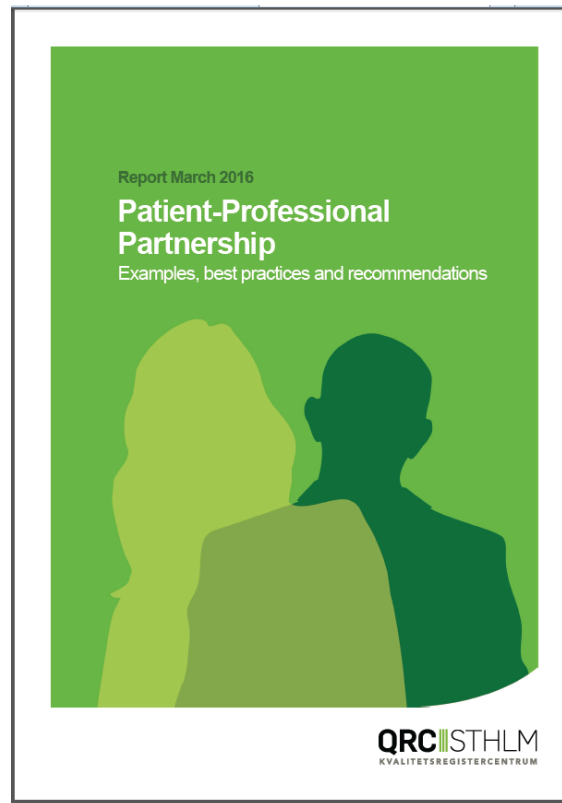
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# Read more!



[Patient-Professional Partnership](#)