

Process of Care Research Branch Cyber Discussion Series Part 4

*Challenges in Implementation of Shared
Decision Making in the Process of Cancer
Care Care*

Glyn Elwyn MD MSc PhD

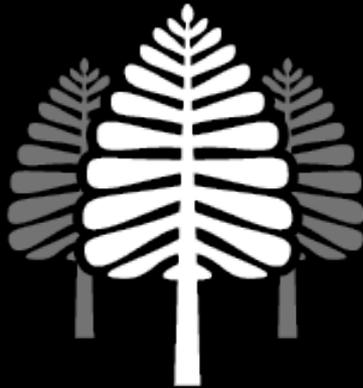


Series Purpose – for NCI

- Solicit opinions from three sectors of the community regarding problems in the quality of cancer care
 - Providers, Researchers, Health Care Purchasers
- Identify potential research topics that might address those problems
- Focus the research agenda of PCRFB upon major underlying factors affecting the processes of cancer care.

For Participants

- Understand the perspectives of three communities with respect to problems in cancer care delivery
- Learn conceptual, analytic, and practical approaches to understanding and addressing problems in cancer care delivery
- Contribute to the development of NCI's research agenda



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DELIVERY SCIENCE

Case Discussion- Misdiagnoses

1. Linda: A 58 yo woman Rxed for breast cancer
 - Active support by others with breast cancer
 - After mastectomy – no cancer found in breast

2. Susan: 78 yo woman Rxed for breast cancer
 - S/p mastectomy – sadness, anxiety, regret
 - Friend who chose no Rx



Patient Decision Support

In 86 trials, 35 different screening or treatment decisions, use has led to:

- Greater knowledge
- More accurate risk perceptions
- Greater comfort with decisions
- Greater participation in decision-making
- Fewer people remaining undecided
- Fewer patients choosing major surgery

Stacey et al.

Cochrane Database of Systematic Reviews, 2011



Elwyn G, Scholl I, Tietbohl C, et al. “Many miles to go ...” A systematic review of the implementation of patient decision support interventions into routine clinical practice. BMC Medical Informatics and Decision Making 2013; Accepted.

Lloyd A, Joseph-Williams N, Edwards AG, Elwyn G. Patchy “coherence”: using Normalization Process Theory to evaluate a broader approach to implementing shared decision making (MAGIC Programme). *Submitted Implementation Science.*

Challenges

Implementation Barriers

Patients' Reluctance

Information Load

Implementation Barriers

Systemic

- Competing clinical demands
- Time pressure
- Difficulty identifying patients eligible for decision support
- Lack of organizational support

Implementation Barriers

- Provider level**
- Providers resistant to patient decision support tools and how to use them
 - Provider view that patients don't want to be responsible for making decisions
 - Provider belief that patient decision support tools 'compete' with other information
 - Provider view that distributing these tools is not part of their role or responsibility

Normalization Process Theory

Coherence

Cognitive Participation

Collective Action

Reflexive Monitoring

May CR, Mair F, Finch T, et al. Development of a theory of implementation and integration: Normalization Process Theory. *Implementation Science* 2009;4:29.

Generative Mechanism		Key Question
Coherence	The sense-making work that people do individually and collectively when they are faced with the problem of operationalizing some set of practices.	What is the work?

Members of the same team often offered conflicting views on their approach to decision making with patients.

Some proposed that the team had “always involved patients in decision making” (Allied Health Professional, Head and Neck Cancer); others stated that this approach was neither beneficial nor appropriate.

One consultant suggested that the role of the clinical team was to protect patients from the “agony” of choice:

“I think the function of the MDT [multidisciplinary team] should definitely be to quite clearly help people to make what we think is the best decision”

(Consultant, Head and Neck Cancer)

“What [involvement in the programme has] caused lots of people to do is actually think about the process of imparting information from themselves to a patient when that patient has a choice to make...

And it's been a surprise for me how I'd always believed that we all roughly thought the same way because we're all roughly taught the same way, but in fact we have polarised views about how that should happen.”

(Consultant, Head and Neck Cancer)

Questions?

What are the research questions this issue offers?

What measures do we have of 'coherence' , or similar issues?

How might these issues relate to existing ideas of measurement?

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Reflexive Monitoring	The appraisal work that people do to assess and understand the ways that a new set of practices affect them and others around them.	How is the work understood?

Investigating Possible Solutions

Option Grids

Fast & frugal tools that may increase patient **engagement** in clinical encounters

Measurements

1. Observer measures of provider and patient encounters
2. Short Patient Reported Measures of Engagement

Breast cancer surgery

Use this grid to help you and your clinician decide whether to have mastectomy or lumpectomy with radiotherapy.

Frequently asked questions	Lumpectomy with Radiotherapy	Mastectomy
Which surgery is best for long term survival?	There is no difference between surgery options.	There is no difference between surgery options.
What are the chances of cancer coming back in the breast?	Breast cancer will come back in the breast in about 10 in 100 women in the 10 years after a lumpectomy. Recent improvements in treatment may have reduced this risk.	Breast cancer will come back in the area of the scar in about 5 in 100 women in the 10 years after a mastectomy. Recent improvements in treatment may have reduced this risk.
What is removed?	The cancer lump is removed with a margin of tissue.	The whole breast is removed.
Will I need more than one operation on the breast?	Possibly, if cancer cells remain in the breast after the lumpectomy. This can occur in up to 5 in 100 women.	No, unless you choose breast reconstruction.
How long will it take to recover?	Most women are home within 24 hours of surgery	Most women are home within 48 hours after surgery.
Will I need radiotherapy?	Yes, for up to 6 weeks after surgery.	Unlikely, radiotherapy is not routine after mastectomy.
Will I need to have my lymph glands removed?	Some or all of the lymph glands in the armpit are usually removed.	Some or all of the lymph glands in the armpit are usually removed.
Will I need chemotherapy?	You may be offered chemotherapy, but this does not depend on the operation you choose.	You may be offered chemotherapy, but this does not depend on the operation you choose.
Will I lose my hair?	Hair loss is common after chemotherapy.	Hair loss is common after chemotherapy.

More information can be found at www.bresdex.com

Editors: Glyn Elwyn, Lisa Caldon, Kari Rosenkranz, Dale Collins Vidal, Marie-Anne Durand, Stephanie Sivell, Malcolm Reed

Evidence document: <http://www.optiongrid.co.uk/evidence>

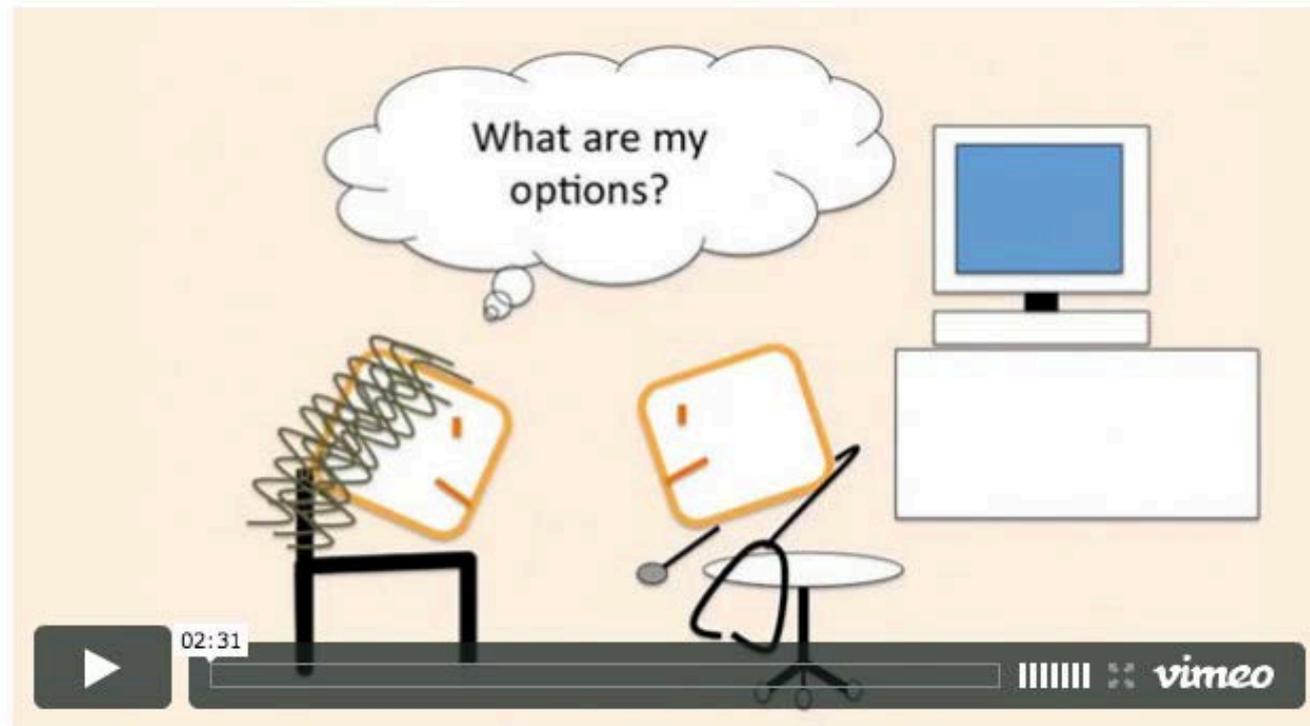
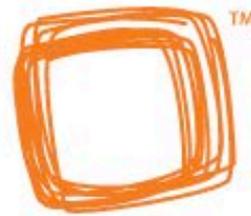
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[Go to the Grids](#)

Option Grids: short tools for comparing health options.

Patients' Reluctance

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Authoritarian Physicians And Patients' Fear Of Being Labeled 'Difficult' Among Key Obstacles To Shared Decision Making

[→ Expand](#)

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