

**Warranted (good) and unwarranted
(bad) variation**

Towards solutions?

Glyn Elwyn

**IF YOU THINK YOU'RE TOO
SMALL TO MAKE A DIFFERENCE,
YOU HAVEN'T SPENT A NIGHT
WITH A MOSQUITO.**

- AFRICAN PROVERB



Radboud University Nijmegen Medical Centre



The Dartmouth Center for
Health Care
Delivery Science



Susan and Linda

Linda is 58 and healthy

Susan is 78 and has mild heart failure

Both have early breast cancer

Susan and Linda

Both dread having surgery, but proceed.

Linda Pathology results shows no sign of breast cancer. There has been a mix-up about needle biopsy slides. Hospital inquiry starts; Linda considers legal action.

Susan and Linda

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Susan Cancer is confirmed. A few days later, Susan learns of a friend in same situation that is offered hormones instead of surgery. Susan is angry, miserable and regrets having surgery. No one seems to care.

Susan and Linda

Linda. Mix up re needle biopsy – a diagnostic error.

Susan. Lack of information about options and lack of attention to what would have been Susan's informed preference is also a diagnostic error – a **preference misdiagnosis.**

Two diagnostic errors

Linda. Mix-up about needle biopsy is a classic **diagnostic error**.

Susan. Lack of attention to Susan's informed preference is a **preference misdiagnosis**.

But in **Susan's** case, it is a **silent misdiagnosis**. No one is worried, no one cares.

PATIENTS' PREFERENCES MATTER

Stop the silent misdiagnosis

Al Mulley, Chris Trimble, Glyn Elwyn

Nils and Bart have knee pain

- Nils is 65, cyclist, cares for his wife.
- Bart is 64, portrait painter.
- Nils wants to avoid surgery, dreads spending time in hospital, not being able to get about.
- Bart not so concerned about spending time recovering slowly from operation.

Potential Solutions

- Decision Support Intervention for Patients
- Shared Decision Making
- Long tools
- Short tools

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Elwyn G, Frosch D, Volandes AE, Edwards A, Montori VM. Investing in Deliberation: A Definition and Classification of Decision Support Interventions for People Facing Difficult Health Decisions. *Medical Decision Making*. 2010 Nov;30(6):701–11.

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D E L I B E R A T I O N

Long Type - Patient Decision Support

Patient Decision Support

In 86 trials, using tools that cover 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



[Display Settings:](#) Abstract[Send to:](#)

[Health Aff \(Millwood\)](#). 2012 Sep;31(9):2094-104.

Introducing decision AIDS at group health was linked to sharply lower hip and knee surgery rates and costs.

[Arterburn D](#), [Wellman R](#), [Westbrook E](#), [Rutter C](#), [Ross T](#), [McCulloch D](#), [Handley M](#), [Jung C](#).

Abstract

Decision aids are evidence-based sources of health information that can help patients make informed treatment decisions. However, little is known about how decision aids affect health care use when they are implemented outside of randomized controlled clinical trials. We conducted an observational study to examine the associations between introducing decision aids for hip and knee osteoarthritis and rates of joint replacement surgery and costs in a large health system in Washington State. Consistent with prior randomized trials, our introduction of decision aids was associated with 26 percent fewer hip replacement surgeries, 38 percent fewer knee replacements, and 12-21 percent lower costs over six months. These findings support the concept that patient decision aids for some health conditions, for which treatment decisions are highly sensitive to both patients' and physicians' preferences, may reduce rates of elective surgery and lower costs.

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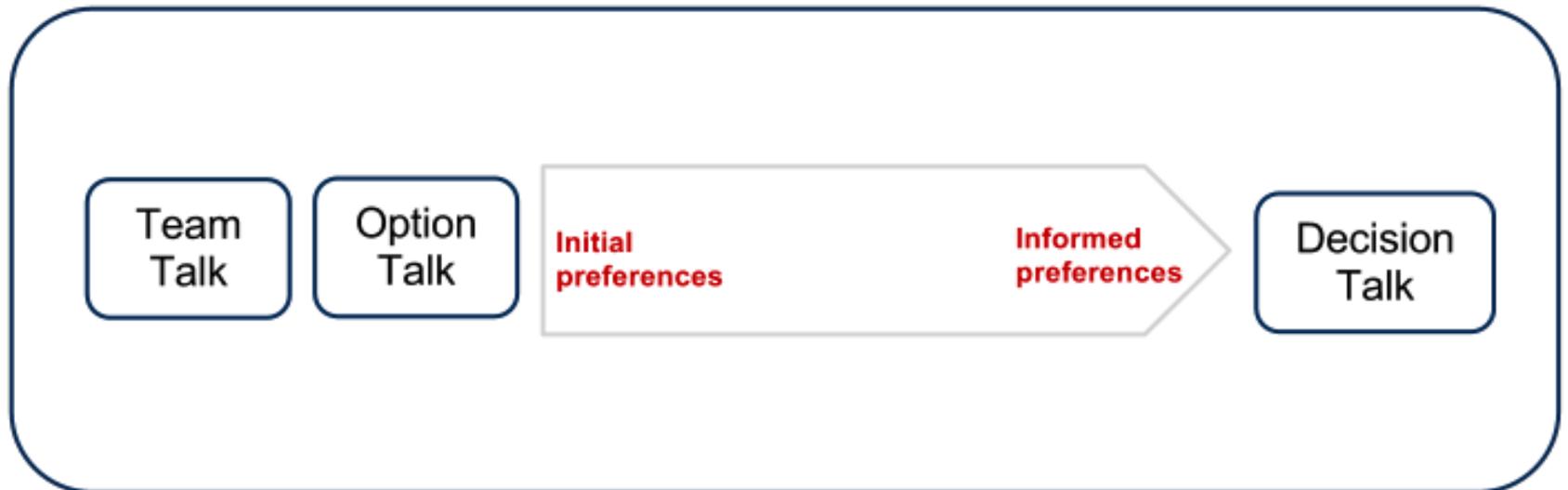
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Steps for Diagnosing Patient Preferences



Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: a model for clinical practice. JGIM. 2012;Epub ahead.

D E L I B E R A T I O N

Team
Talk

Option
Talk

**Initial
preferences**

Construction

**Informed
preferences**

Decision
Talk

Long Type - Patient Decision Support

D E L I B E R A T I O N

Long Type - Patient Decision Support

D E L I B E R A T I O N

Short Type - Patient Decision Support

Long Type - Patient Decision Support

Shared Decision Making: A Model for Clinical Practice. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, Cording E, Tomson D, Dodd C, Rollnick S, Edwards A, Barry M. J Gen Intern Med. 2012 May 23.

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Implementation Challenge

- We already do it ...
- It is too difficult
- Takes too much time
- Patient's don't want it

Implementation Challenge

- Measurement problems
- Workflow rigidity
- Attitudinal resistance





**Thanks for the decision
support ...**

I prefer this option



Option Grids

- One page **comparison** of treatment options
- Design **Frequently Asked Questions**
- Collaboration with **NICE**, UK
[Victoria Thomas & Gillian Leng](#)
- Evidence based **engagement** tools

Working on what matters most to you...

Osteoarthritis of the knee

This grid is designed to help you and your clinician decide how best to manage your knee pain and activity level. The first steps are to become as fit as possible, work to approach your ideal weight, and consider having physical therapy. Surgery is normally recommended only after non-operative treatments have been tried.

Frequently asked questions	Pain Relievers	Joint injections (steroids)	Knee replacement surgery
<p>Will this reduce the pain I have in my knee?</p>	<p>It depends on which pain relievers are taken and for how long. Tablets like ibuprofen are effective for 50 in 100 people. Other over the counter medications, like Tylenol (acetaminophen), including those that have codeine, are also effective.</p>	<p>It depends on the medicine injected. Some people get good symptomatic relief after an injection, which may include pain relief and/or reduced swelling.</p>	<p>About 90 in 100 people who have this operation say it leads to relief of most or all of their pain, over time. 10 in 100 people say it does not lead to significant pain relief.</p>

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Will this treatment help improve my ability to be active?	It may. As you get pain relief, you should be able to be more active and this in turn can also help to reduce pain. It may help to take pain relievers before being physically active.	Yes, usually for up to a month or so after each injection. Plan to be more active as a result of the pain relief. Advice from a physical therapist may help.	Yes, the majority of patients experience improvement in their activity level. However, not everyone sees differences in their ability to walk or climb stairs.

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Are there any risks to this treatment?	All medications have some side effects. For example, codeine may lead to constipation and prolonged use of tablets like ibuprofen (and other NSAIDs) increases your risk of stomach bleeding.	<p>There is a small risk of frequent injections causing cartilage damage, especially in weight-bearing joints.</p> <p>Allergic reactions and infections due to joint injections are uncommon.</p> <p>You might feel slight pain at the injection site for a few days.</p>	<p>Wound infection needing treatment occurs in 5 in 100 people. Joint infection occurs in fewer than 1 in 100 people. Blood clots in the leg occur in 2 in 100 people.</p> <p>The risks of surgery increase if you have other conditions, such as heart or lung disease, are a smoker or are overweight.</p>

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How long will it take me to feel better after the treatment?	You may start experiencing pain relief within a few days of when you start taking the medication.	Most people who experience relief feel better within the first week or so after the injection.	Pain relief is gradual. You will stay in the hospital for around three to five days. Most people walk unaided after 3 months. Full recovery usually takes between 6 and 12 months.

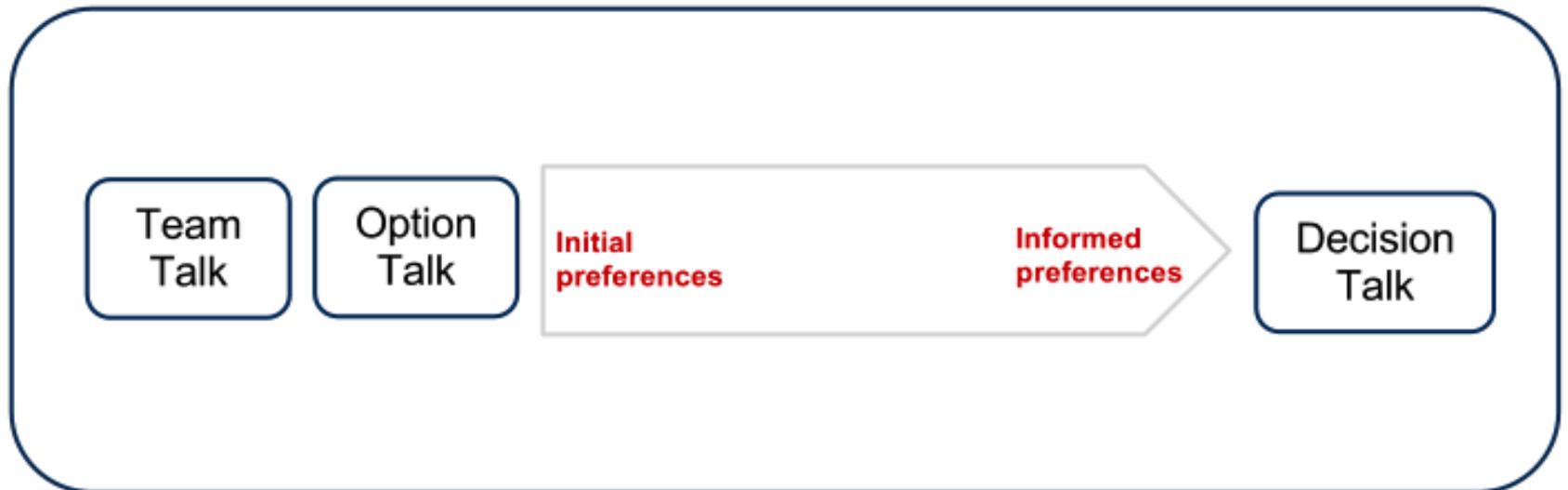
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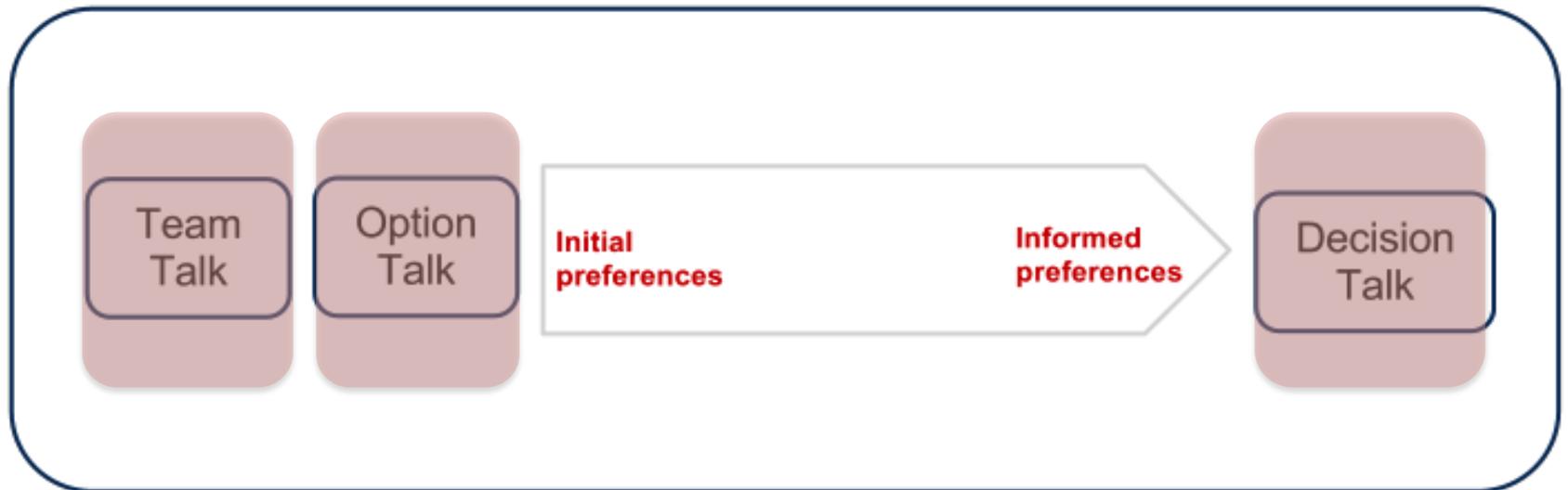
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What are the outcomes for people with arthritis who have this treatment?	Many people cope well by using medication, being active, and losing weight. Reducing your pain may help you achieve the benefits of exercise.	Some people have good relief by having injections when swelling and pain cause problems.	Surgery is usually considered after other options have been tried. About 80 to 85 in 100 people are satisfied after having a knee replacement. About 15 to 20 in 100 are not satisfied.

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Option Grids are brief tools to help patients take part in making decisions

To download a pdf of the Option Grid, click on Option Grid title:

- [Amniocentesis](#) - to help you and your clinician decide whether or not to have an amniocentesis test.
- [Breast cancer surgery](#) - to help you and your clinician decide whether to have a mastectomy or to have a 'lumpectomy with radiotherapy'.
- [Chronic kidney disease](#) - to help you and your clinician choose the dialysis treatment that suits you best.
- [Crohn's Disease Treatment](#) - to help you and your clinician decide on the best initial treatment for your disease.
- [Down's Syndrome Screening](#) - this screening test is optional. Only you can decide whether to have it done. This grid is a tool to help you decide.
- [Early cancer of the tonsil](#) - to help you and your clinician choose between two treatment options for early cancer of the tonsil.
- [Early cancer of the vocal cords](#) - to help you and your clinician choose between two treatment options for early cancer of the vocal cords.
- [Glue ear](#) - to help you and your clinician decide what best to do to if your child has glue ear.
- [High cholesterol](#) - to help you and your clinician decide what best to do to lower your cholesterol.
- [Osteoarthritis of the Knee: Self Management](#) - to help you manage the pain that is related to your knee joint. (An Option Grid for more invasive treatment options for osteoarthritis of the knee is currently in development and will be published on this website in 2014 following the conclusion of a Bupa Foundation funded trial.)
- [Tonsillectomy](#) - to help you and your clinician decide whether or not your child (under 16) should have a

Option Grid Collaborative

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