



**Maastricht University**

*Leading  
in Learning!*

**DECIDE 03-06-2014**

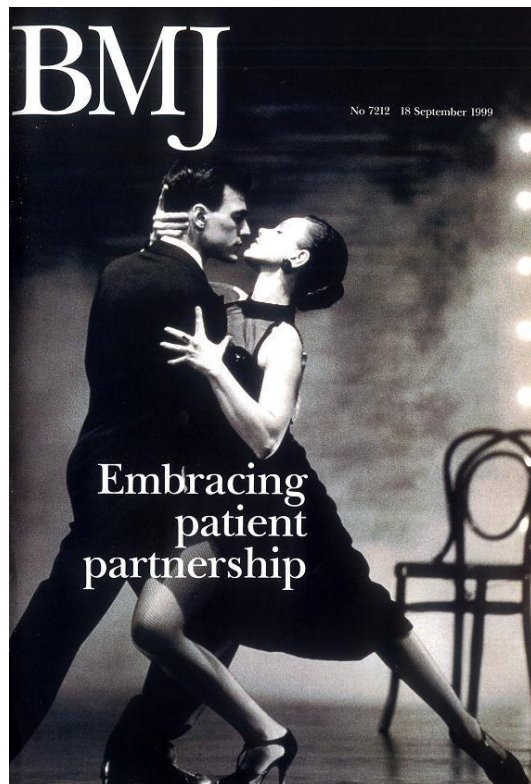
***SDM* ↔ *CPG***

Trudy van der Weijden  
Professor Implementation of Guidelines  
Dept Family Medicine  
School CAPHRI, Maastricht University

# SDM ↔ CPG



# Shared decision making



# Clinical practice guidelines

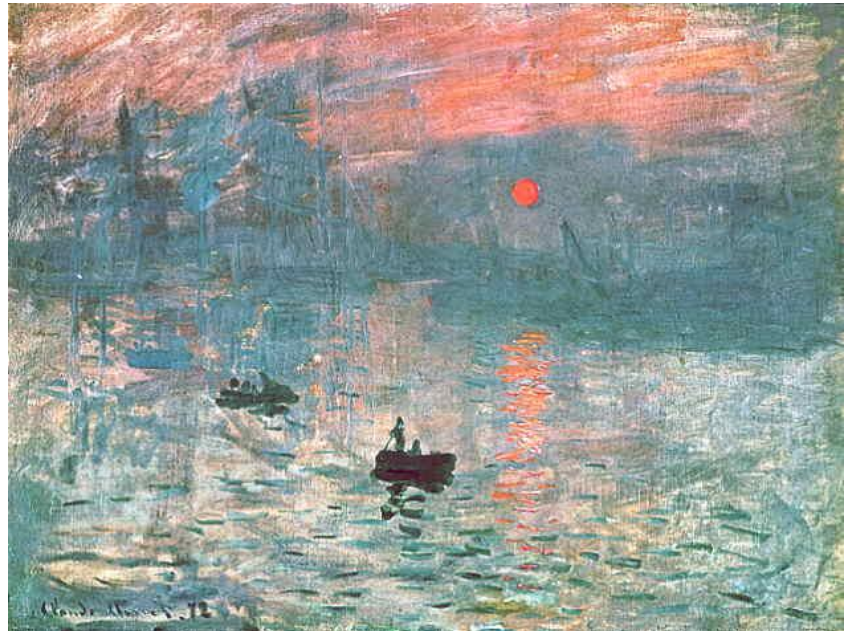
## GRADE DECIDE





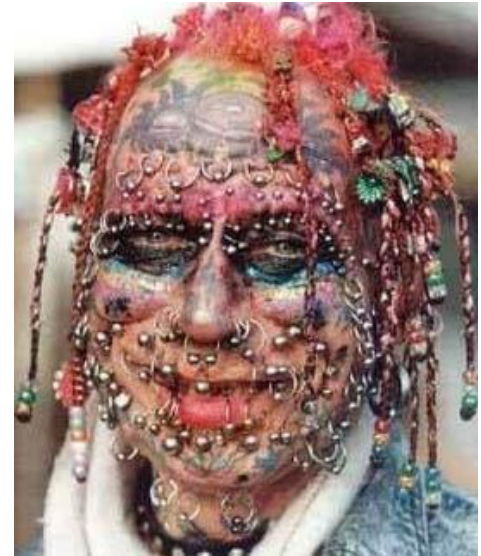
# Clinical practice guidelines

## GRADE DECIDE



# content

- Drivers for SDM
- What is it?
  - Patient decision aids
- Clinical practice guidelines
  - Collective patient preferences
  - Individual patient preferences
- Key message



# content

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# What would you do?

## Vignet: surgical scenarios colon ca

Outcome probability	Option 1	Option 2
Cure without complications	80%	80%
Cure with persistent stoma	1%	-
Cure with chronic diarrhoea	1%	-
Cure with intermitten ileus	1%	-
Cure with wound infection	1%	-
No cure, † within 2 years	16%	20%

ORIGINAL INVESTIGATION

# Physicians Recommend Different Treatments for Patients Than They Would Choose for Themselves

Peter A. Ubel, MD; Andrea M. Angott, PhD; Brian J. Zikmund-Fisher, PhD

*"Misdiagnosis of preferences"*  
Mulley A. et al BMJ 2012

**Background:** Patients facing difficult decisions often ask physicians for recommendations. However, little is known regarding the ways that physicians' decisions are influenced by the act of making a recommendation.

**Methods:** We surveyed 2 representative samples of US primary care physicians—general internists and family medicine specialists listed in the American Medical Association Physician Masterfile—and presented each with 1 of 2 clinical scenarios. Both involved 2 treatment alternatives, 1 of which yielded a better chance of surviving a fatal illness but at the cost of potentially experiencing unpleasant adverse effects. We randomized physicians to indicate which treatment they would choose if they were the patient or they were recommending a treatment to a patient.

**Results:** Among those asked to consider our colon cancer scenario ( $n=242$ ), 37.8% chose the treatment with a higher death rate for themselves but only 24.5% recommended this treatment to a hypothetical patient ( $\chi^2=4.67$ ,  $P=.03$ ). Among those receiving our avian influenza scenario ( $n=698$ ), 62.9% chose the outcome with the higher death rate for themselves but only 48.5% recommended this for patients ( $\chi^2=14.56$ ,  $P<.001$ ).

**Conclusions:** The act of making a recommendation changes the ways that physicians think regarding medical choices. Better understanding of this thought process will help determine when or whether recommendations improve decision making.

*Arch Intern Med.* 2011;171(7):630-634

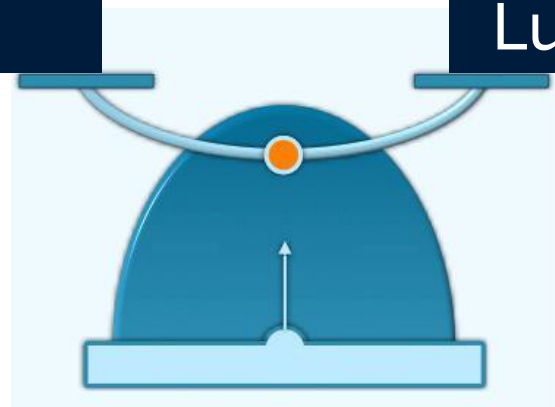


Survival =

QoL  $\approx$  (?)

*Litière S et al. Lancet Oncology 2012*

Mastectomie



Lumpectomie + R

# Top 3 concerns for breastca decisions

Condition: Goal	Patient	Provider	p
Keep your breast?		71%	
Live as long as possible?		96%	
Look natural without clothes		80%	
Avoid using prosthesis		0%	

*Sepucha K et al. Pat Educ Couns 2008;73:504-10*



# Top 3 concerns for breastca decisions

Condition: Goal	Patient	Provider	p
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 K et al. Pat Educ Couns 2008;73:504-10*

# UK 2011

## MAKING SHARED DECISION-MAKING A REALITY

No decision about me, without me

Angela Coulter, Alf Collins

TheKingsFund>






# content

- Drivers for SDM
- What is it?
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- Clinical practice guidelines
  - Collective patient preferences
  - Individual patient preferences
- Key message

# SDM

*Charles et al. Decision-making in the physician-patient encounter.  
Soc Sci Med 1999;49:651-61.*




	Paternalism	SDM	Informed patient
Information-transfer			
Deliberation	clinician	clinician and patient	patient
Decision making	clinician	clinician and patient	patient



# SDM

*Rapley T. Soc Health&Illness  
2008;30:429-44.*

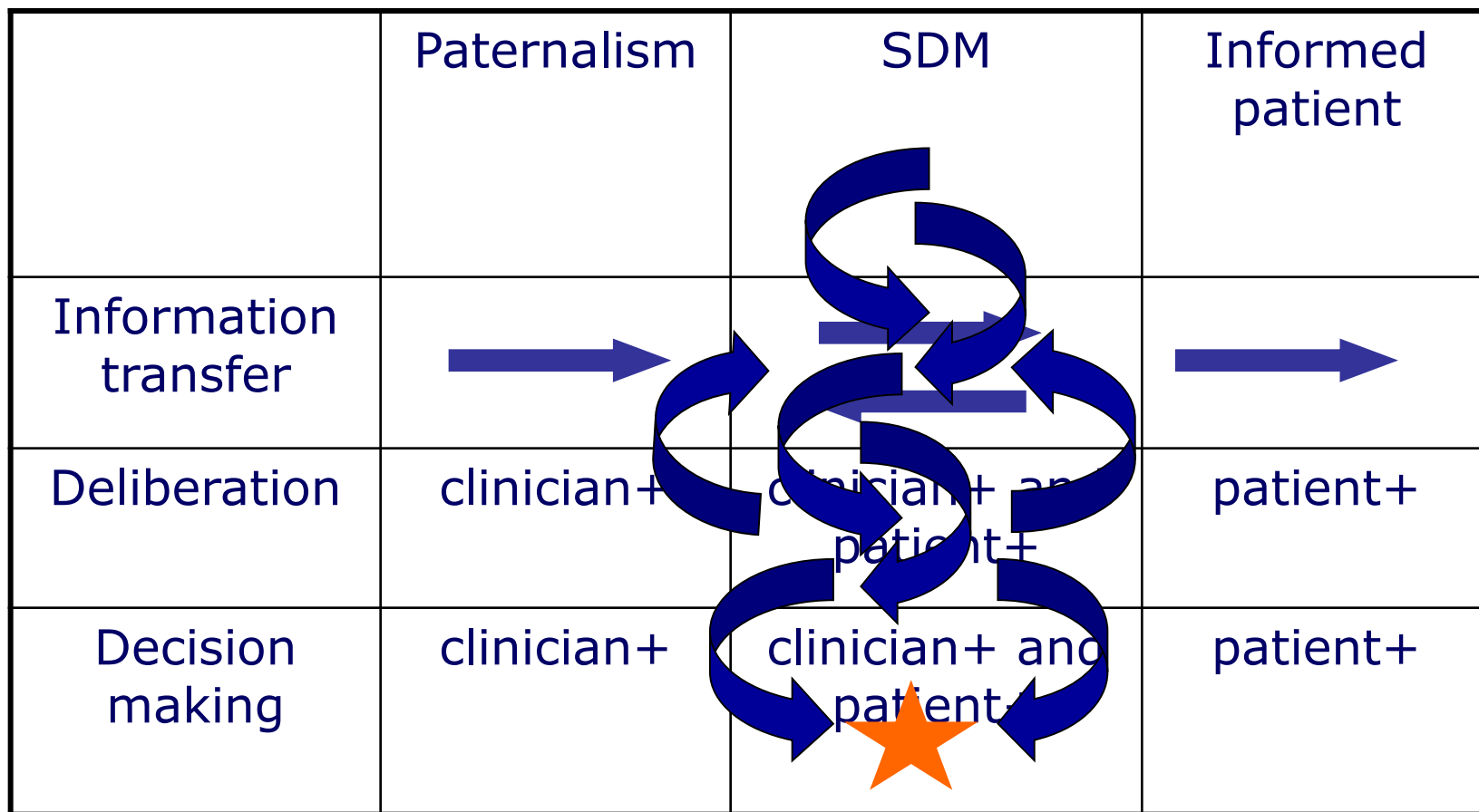
*Légaré F, et al. BMC Health Serv  
Res 2008;8:2.*

	Paternalism	SDM	Informed patient
Information transfer			
Deliberation	clinician+	clinician+ and patient+	patient+
Decision making	clinician+	clinician+ and patient+	patient+

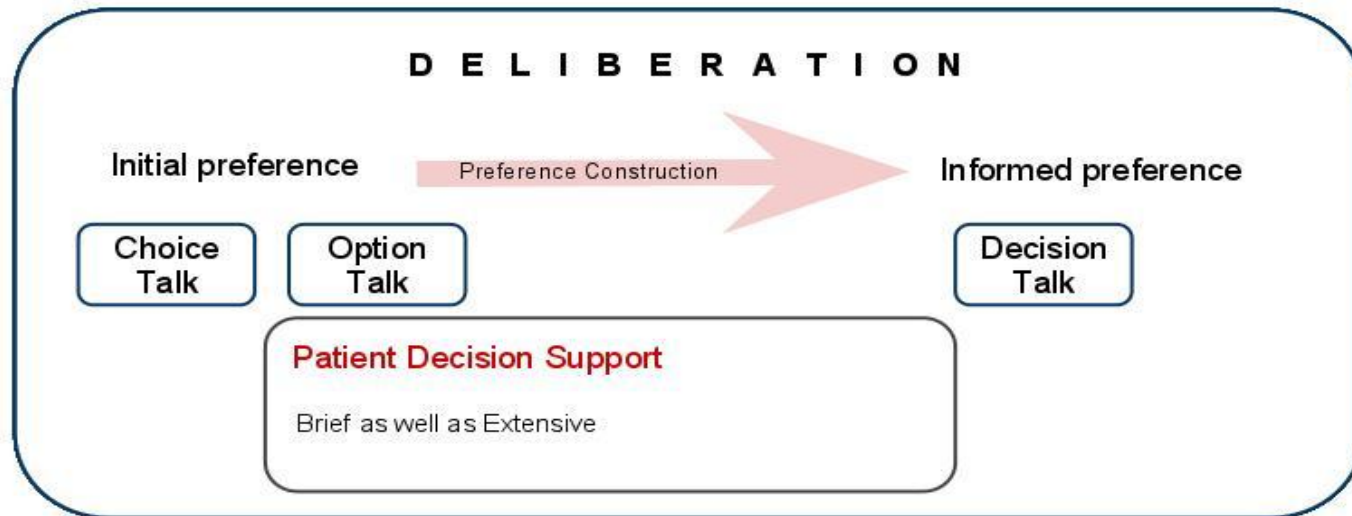
# SDM

*Rapley T. Soc Health&Illness  
2008;30:429-44.*

*Légaré F, et al. BMC Health Serv  
Res 2008;8:2.*



## Shared decision making : a model for clinical practice



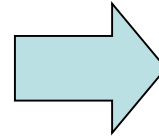
*Elwyn et al . J Gen Intern Med 2012*

# content

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# Patient Decision Aids



*IPDAS criteria*

<http://ipdas.ohri.ca>

- Info on options and relevant outcomes for a specific decision
  - on disease
  - on choice
  - on options: outcome probabilities, neutrally framed, including wait-and-see
  - value elicitation method
  - info on process of decision making



# Review Cochrane Library

- Knowledge (options, pros cons) ↑
- Involvement in decision ↑
- Preference => decision ↑
- Patient adherence ≈
- Invasive treatments ↓
- Health =
- Anxiety =

*Stacey D, et al.  
Cochrane Library 2014*



Helping **you** choose...



Welcome to BresDex

[Enter Site](#)

This site is being developed for women who have been diagnosed with early breast cancer and who have been given a choice of surgery.

BresDex Research Team :

029 2068 7195  
[bresdex@cf.ac.uk](mailto:bresdex@cf.ac.uk)

Department of Primary Care and Public Health, School of Medicine, Cardiff University,  
Neuadd Meirionnydd (2nd Floor), Heath Park, Cardiff, CF14 4YS.



Helping you choose...

[Click here to send comments](#)

Search...

Search



Surgery Options



Weighing it Up



Forum

Ctrl +  
Ctrl -  
changes  
text size

[Home](#)

[It's Your Choice](#)

[Surgery Options](#)

[Further Information](#)

[Patient Photos](#)

[What's Next?](#)

[Glossary](#)

**BresDex** is for women recently diagnosed with breast cancer and who have been given a choice between:

**Lumpectomy\* with Radiotherapy**

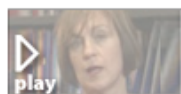
or

**Mastectomy**

*\*also known as Wide Local Excision or Breast Conserving Surgery*



**Professor Malcolm Reed**  
Consultant  
Breast Surgeon



**Julietta Patnick**  
Director, NHS Cancer  
Screening Programmes



**Helen McGarrigle**  
Clinical Nurse Specialist  
in Breast Care



**Helen Sweetland**  
Consultant  
Breast Surgeon

In many cases women will have been offered this choice if the cancer is less than 5 centimetres wide.

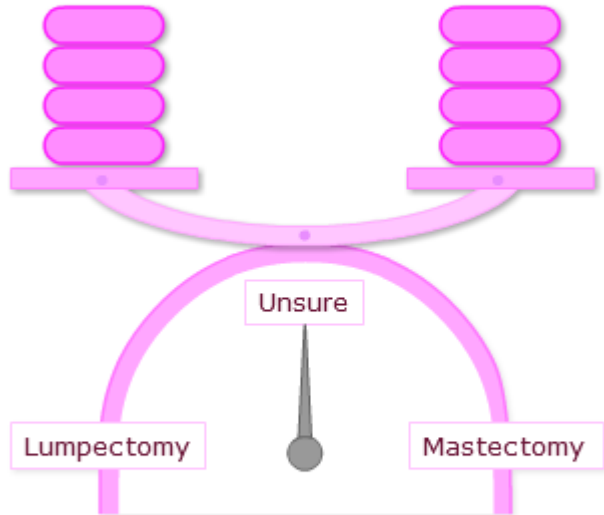
In some cases, women may have chemotherapy to try and make the cancer smaller to allow the possibility of lumpectomy.

Many women diagnosed with DCIS (Ductal Carcinoma in Situ or pre-invasive cancer) also have the choice between lumpectomy and mastectomy and can use this website.

BresDex is not for you if you have two or more cancers in the breast, or if you are a man with breast cancer.

**Here are a list of issues many women think about when choosing surgery.**  
Click in the box next to the ones that are important to you. You do not have to click in every box.

Avoid looking lop-sided	<a href="#">info</a>	<input type="checkbox"/>
Avoid mastectomy	<a href="#">info</a>	<input type="checkbox"/>
Avoid more unexpected surgery	<a href="#">info</a>	<input type="checkbox"/>
Remove the breast	<a href="#">info</a>	<input type="checkbox"/>
Less chance of cancer returning	<a href="#">info</a>	<input type="checkbox"/>
Avoid radiotherapy	<a href="#">info</a>	<input type="checkbox"/>
Smaller scar and less change to breast size	<a href="#">info</a>	<input type="checkbox"/>
Keep the breast	<a href="#">info</a>	<input type="checkbox"/>



Unsure

Lumpectomy      Mastectomy

[Reset](#)      [Next >](#)

Weighing It Up

CLOSE X

## Breast cancer surgery

Use this grid to help you and your healthcare professional talk about how best to treat breast cancer.

Frequently asked questions	Lumpectomy with radiotherapy	Mastectomy
What is removed?	The cancer lump is removed, with some surrounding tissue.	The whole breast is removed.
Which surgery is best for long-term survival?	Survival rates are the same for both options.	Survival rates are the same for both 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 (10%) 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 (5%) in the 10 years after a mastectomy. Recent improvements in treatment may have reduced this risk.
Will I need more than one operation?	Possibly, if there are still cancer cells in the breast after the lumpectomy. This can occur in up to 20 in 100 women (20%).	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 of surgery.
Will I need radiotherapy?	Yes, for up to six weeks after surgery.	Radiotherapy is not usually given after a 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.

*Elwyn et al. Pat Educ Couns 2013*

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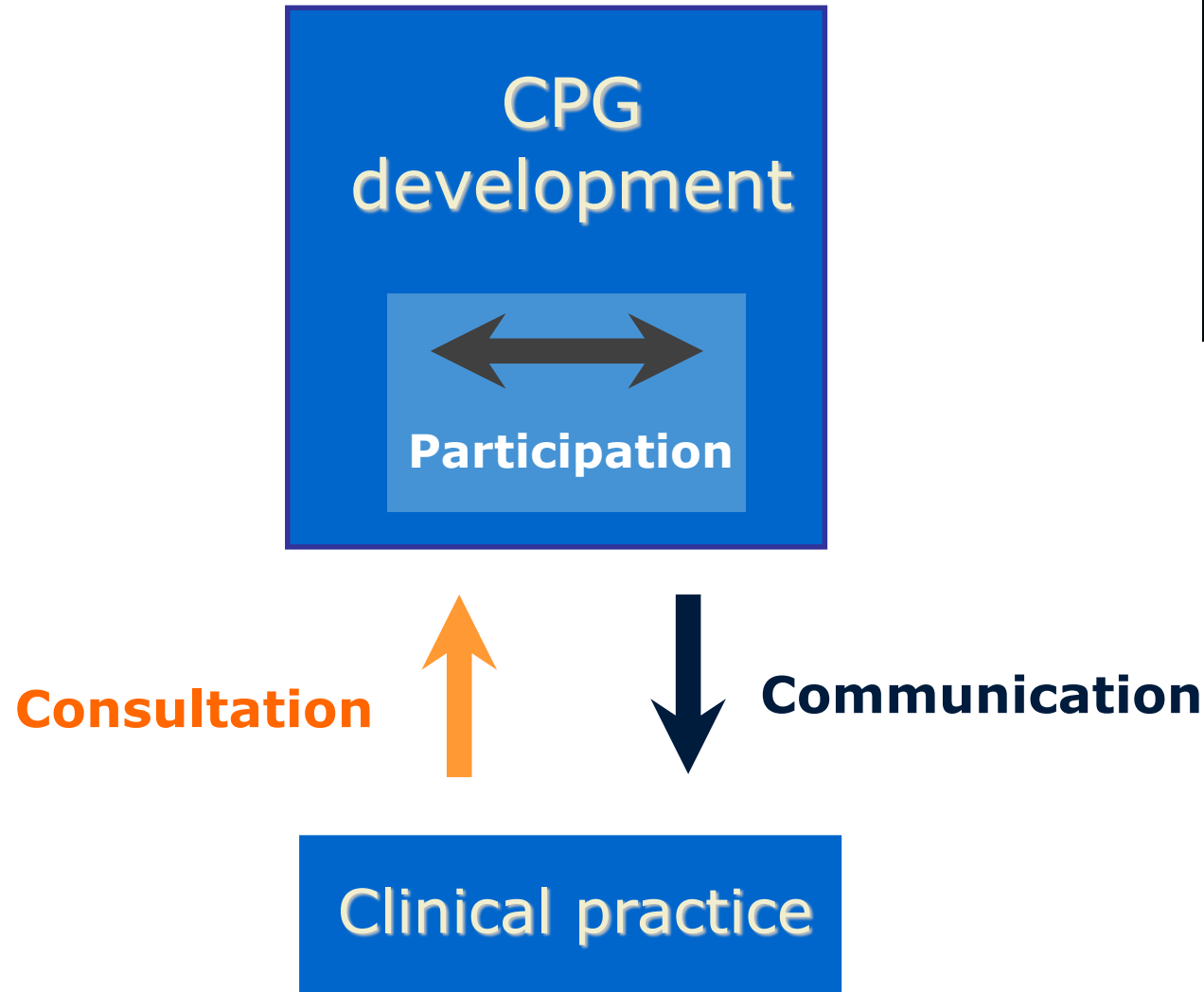


# GIN PUBLIC



[www.g-i-n.net/activities/gin-public/toolkit](http://www.g-i-n.net/activities/gin-public/toolkit)

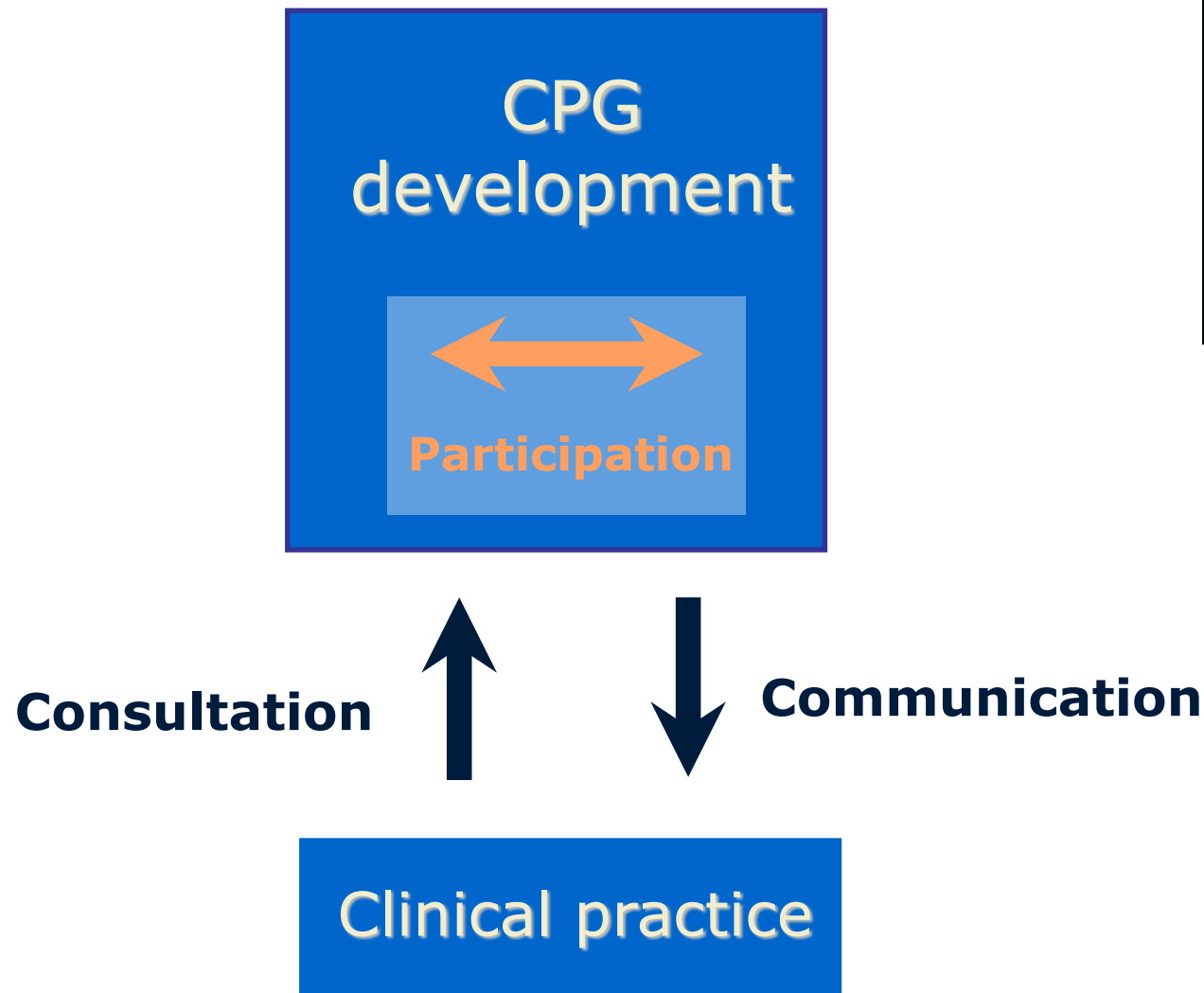


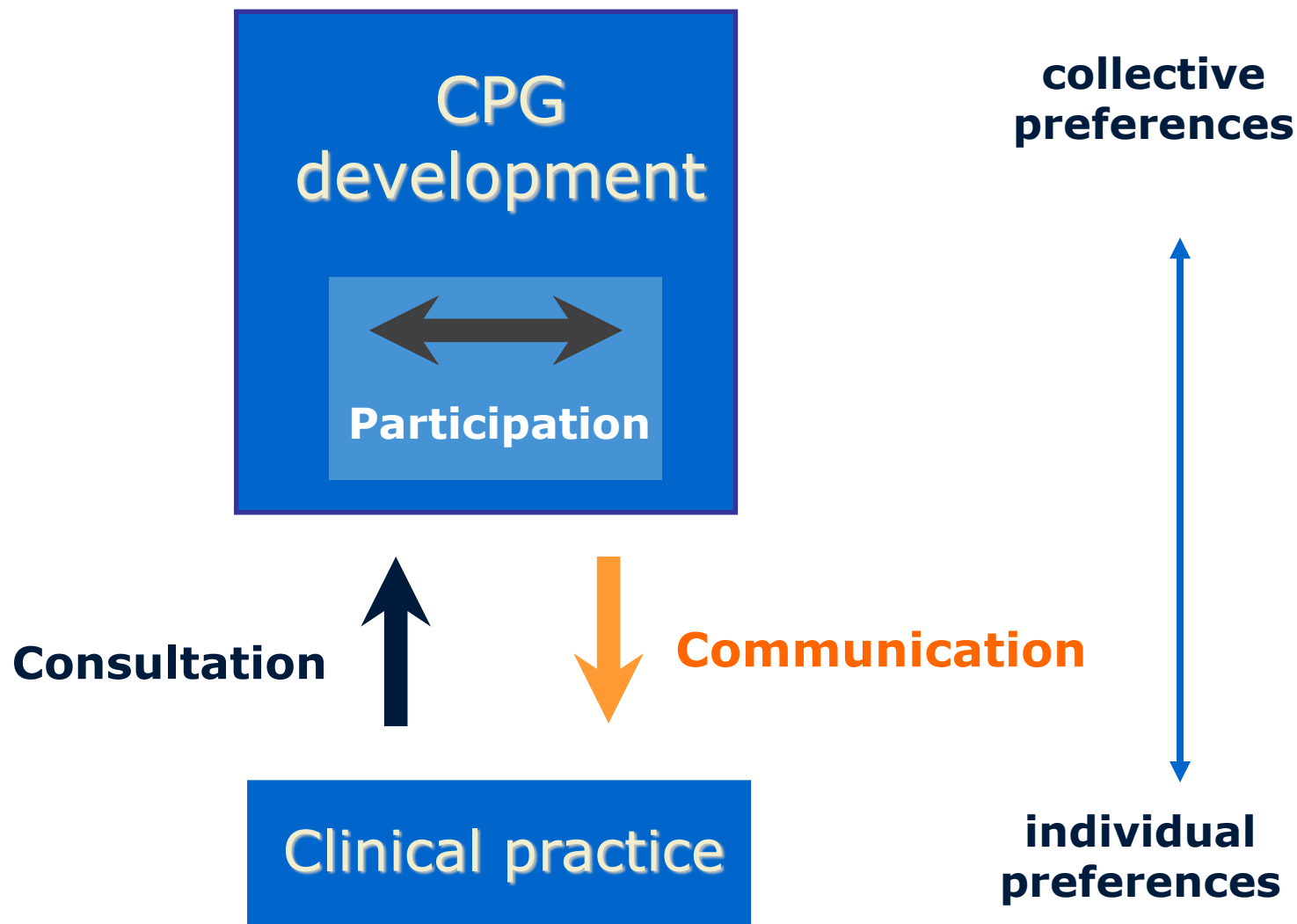


# Treatment burden



*BMJ 2009;339:485*





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Population  
level



Individual  
level

# Clinical Practice Guideline



Strong one-option  
recommendation



Supporting optimal  
behaviors

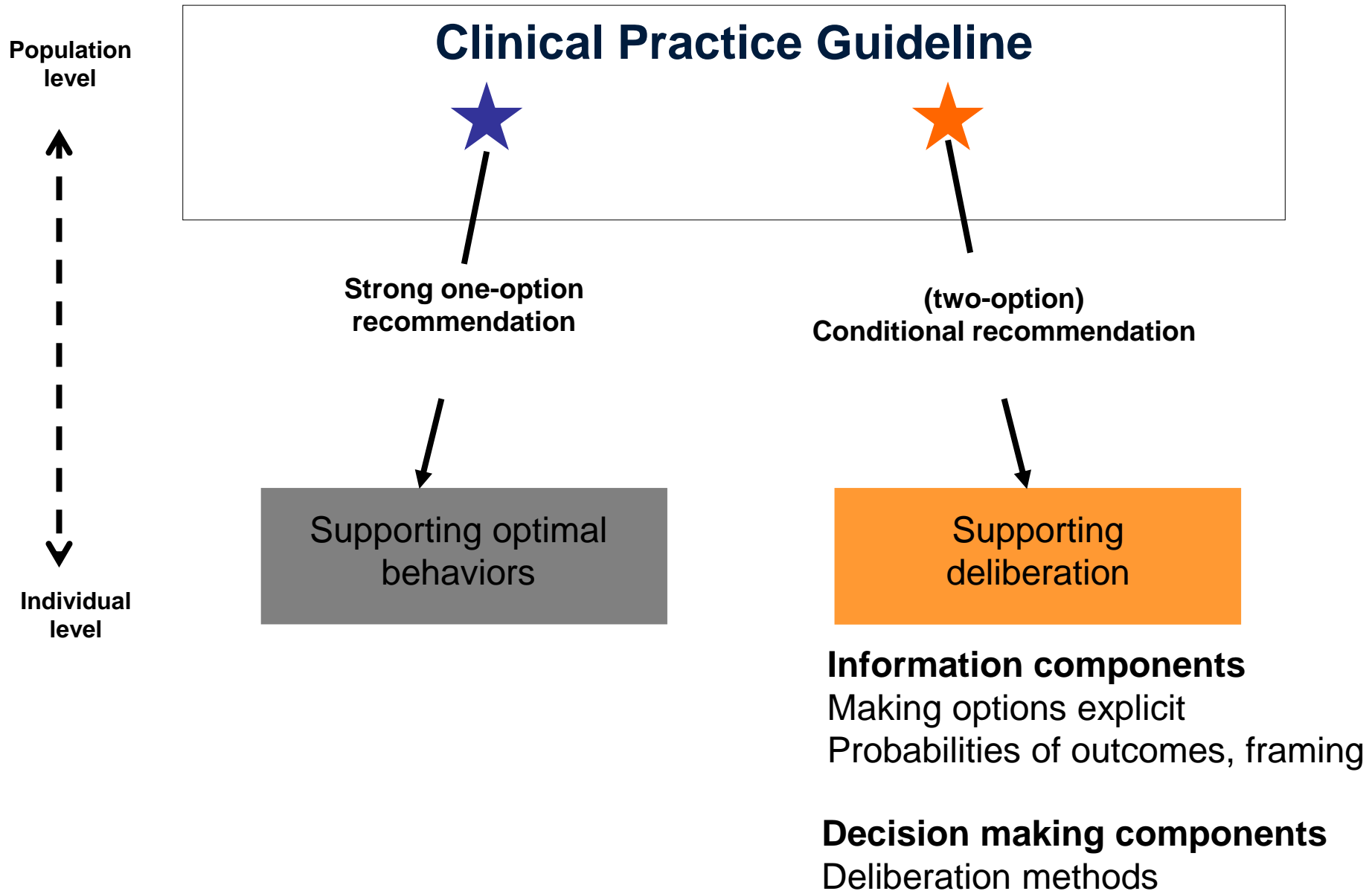
## Information components

Clear recommendation

Explanation of rationale, persuasive

## Behavior change components

Implementation strategies



# Initiative Dutch government / GPs

- CPG and patient decision aids
  - Dutch College of GPs
  - [www.thuisarts.nl](http://www.thuisarts.nl)



# Initiative Dutch hospital specialists

- CPG and Option grids
  - Epilepsy
  - Otitis media
  - Tonsillecetomy
  - Osteoarthritis hip / knee
  - dysmenorroe

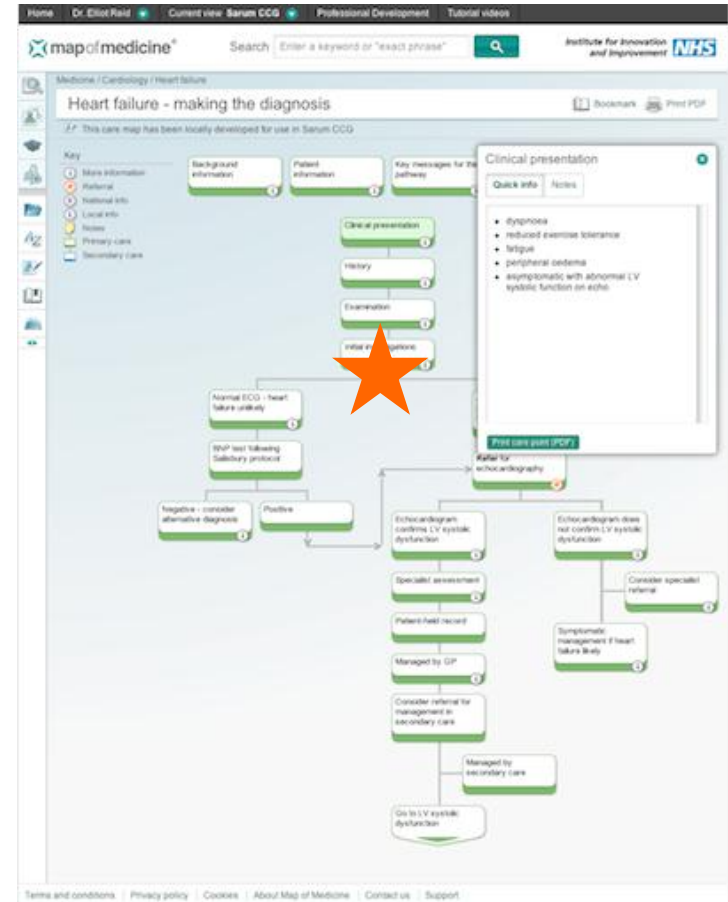


# Initiative Dutch Healthcare Institute

NHS:  
MapOfMedicine.com

## Highlight preference-sensitive decisions

## Indicate timing of patient decision aid



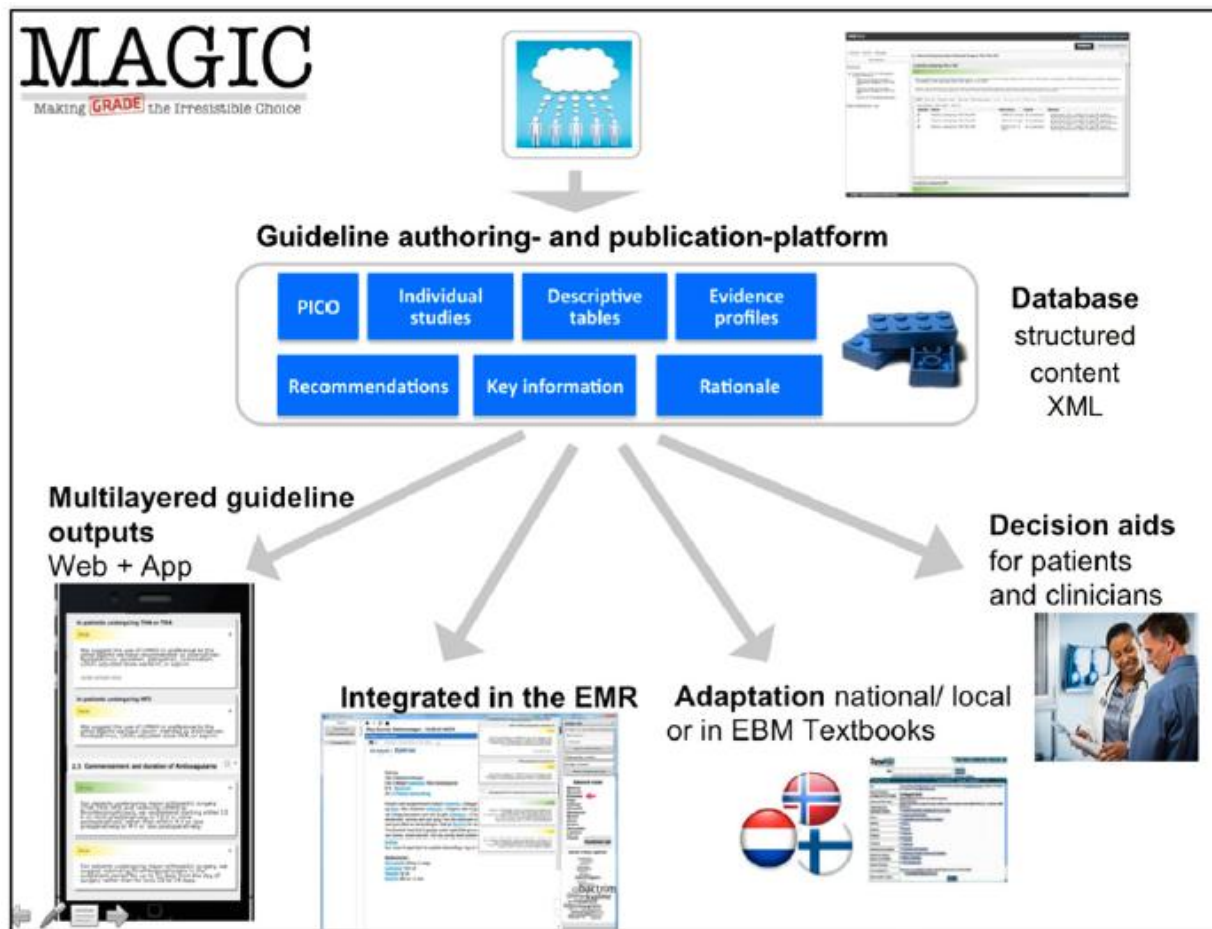


- Adding tools to CGP?
- Reshaping CPG?
- Reshaping recommendations?


## Reshaping CPG?

- Using the same recommendations and evidence tables for decision support, with language and format that is understandable and easy to use, for both clinicians and patients.






*Vandvik P et al. Creating guidelines we can trust, use and share. Chest 2013;144:381*



## SHARE IT

(Sharing Evidence to Inform Treatment decisions)



**DECISION AIDS LINKED TO RECOMMENDATIONS IN  
GRADE GUIDELINES TO IMPROVE SHARED DECISION  
MAKING IN CLINICAL CONSULTATIONS**

- Weak recommendations: Shared decisions becomes key but how?
- We develop decision aids that
- ✓ *Display benefits, harms, burdens to clinicians and patients, to **create discussions***
- ✓ *Based on best current published research evidence*
- Research ongoing with development (user-testing) optimal presentation formats in consultations

Among a 1000 patients like you, with new oral anticoagulants



Choose and compare outcomes

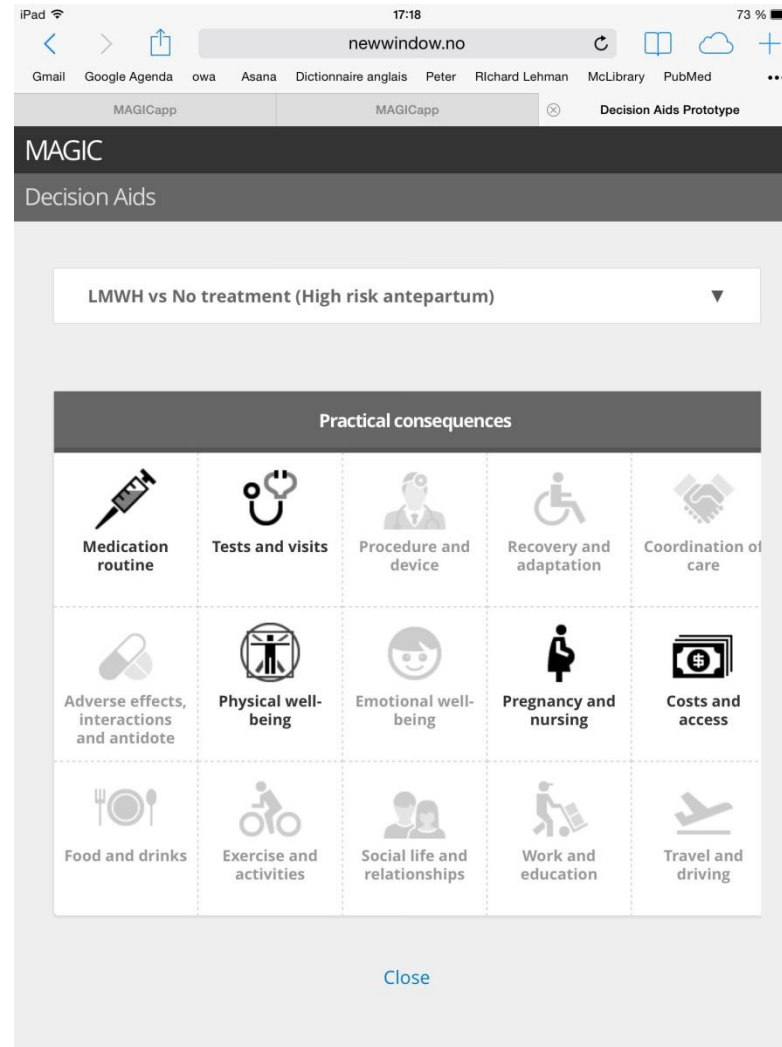
Mortality

Stroke

Major bleeding

Practical consequences

# Pitfall of risk communication



# Reshaping recommendations?

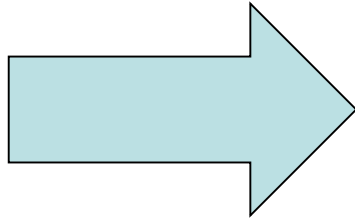
Pediatric palliative care NL 2013

- *CPG 2013 Palliative Care for Children*
- *Provides recommendations on how to engage parents and children in the decision making process.*
- *Interview study to measure attitudes of end users (n=15 pediatricians)*
- *Disappointing results*

# Reshaping recommendations?

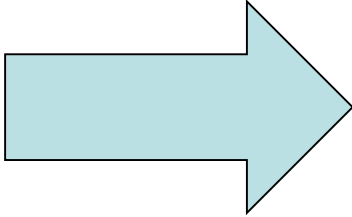
## Pediatric palliative care NL 2013

- *First choice recommendation for pain relief is drug X in dose A.*
- *First choice recommendation for pain relief is drug X in dose A.*
- *Together with child/parents one can opt for lower dose B.*
  - *For some children the side-effects of dose A do not counterbalance the pain relief effects (ref xxx).*
  - *There is heterogeneity in preferences: 65% opt for dose A, 35% for B. (ref. xxx)*



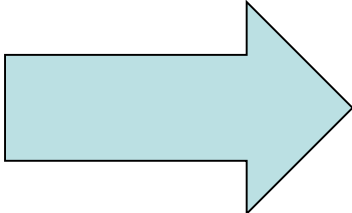
# Reshaping recommendations?

## Diabetes NL 2014

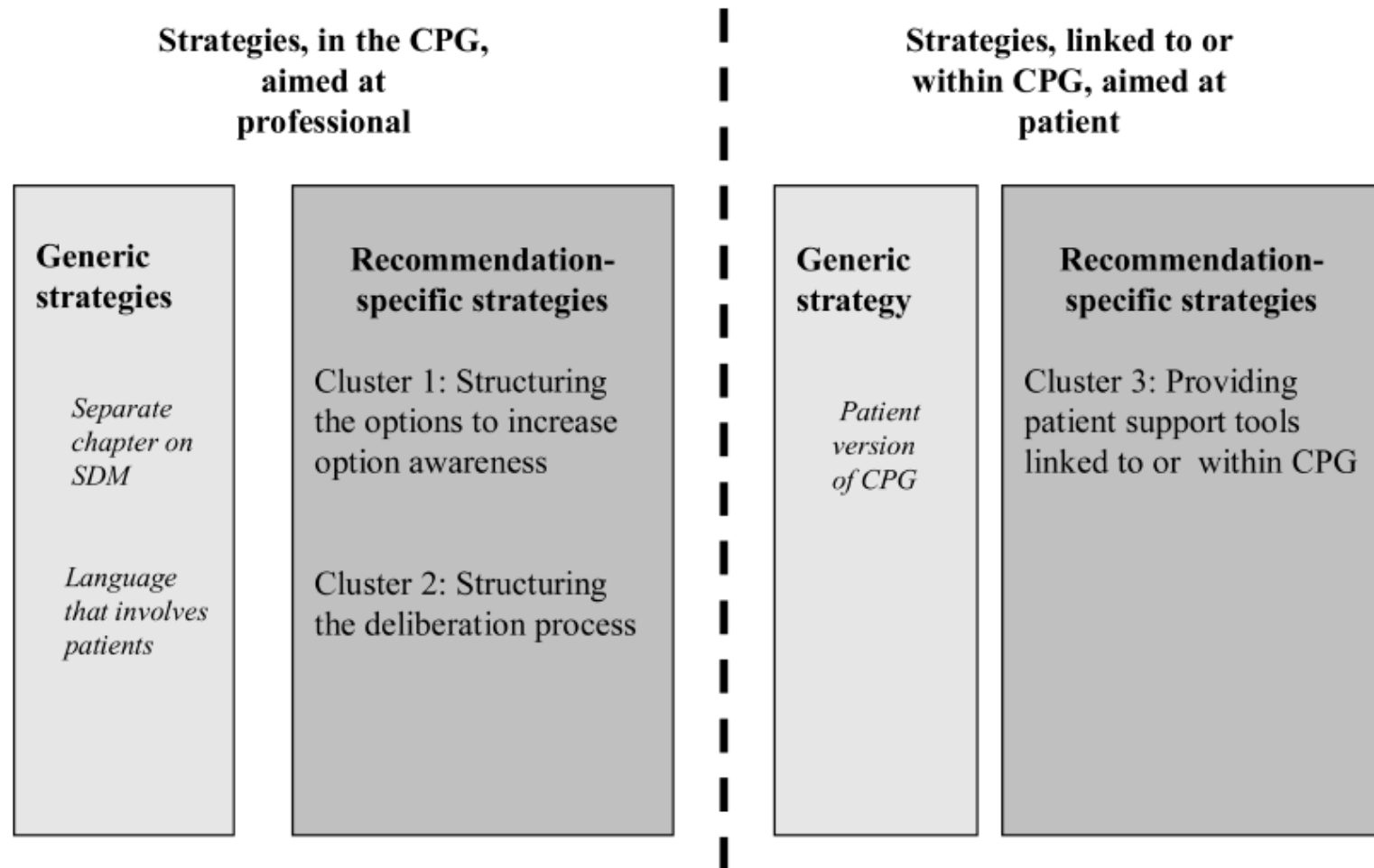
- *For patients with diabetes type II, without symptoms and well-regulated on glucose: 3-monthly fasting glucose.*
  - *For patients with diabetes type II, without symptoms and well-regulated on glucose: 3-monthly fasting glucose.*
  - *For patients with diabetes type II, without symptoms and well-regulated on glucose/HbA1C, lipids, RR: 6-monthly fasting glucose.*
- 

# Reshaping recommendations?

## Mamma ca screening USA 2010

- *The decision to start biennial screening mammography before the age of 50 yrs should be an individual one and take into account the patient's values regarding specific benefits and harms.*
  - *Routine screening mammography in women aged 40-49 is NOT recommended.*
  - *For women 40-49 who still opt for screening:*
    - *Prescribe the patient decision aid*
    - *Refer to the mamma care nurse for coaching*
    - *With final decision making in a follow-up visit*
- 

*Steven Woolf GIN Chicago 2010*



**Figure 1** Classification of strategies of how clinical practice guidelines can be adapted to facilitate shared decision making. CPG, clinical practice guideline; SDM, shared decision making.



## Key message

- Merge between CPG and SDM
- Integrating SDM add complexity
- Conflicts with urge for simplicity
- Reshape CPG or recommendations
  - Let's start with choice talk