A close-up, high-contrast photograph of a person's face, focusing on the right eye and forehead. The skin is a warm, golden-brown color. The eye is dark and looking slightly to the left. The background is dark and out of focus.

“cursed be he by  
day, and cursed  
by night ...”

# Dare to Share

## Sapere Aude 2.0



@glynelwyn

Glyn Elwyn

# Spinoza Lecture 2015

“cursed be he by day, and  
cursed by night; cursed be he  
when he lieth down, and  
cursed be he when he riseth  
up ...”

“no one can communicate with him, nor show him any favour, be within four cubits of him, nor read anything written by him ...”

“I value, above all things, the  
joining hands of friendship with  
those who are lovers of truth.  
Nothing brings more peace than  
the affectionate intercourse  
with such people” **Spinoza**



# How much effort was made to help you understand your health issues?

0

1

2

3

4

5

6

7

8

9

No effort  
was  
made

Every  
effort was  
made



**How much effort was made  
to listen to the things that  
matter most to you about  
your health issues?**

0

1

2

3

4

5

6

7

8

9

No effort  
was  
made

Every  
effort was  
made

**How much effort was made  
to include what matters  
most to you in choosing  
what to do next?**

0

1

2

3

4

5

6

7

8

9

No effort  
was  
made

Every  
effort was  
made

Sapere Aude

20 BC

Horace

**First Book of Letters**

1784

Immanuel Kant

**Answering the question: What is Enlightenment?**

1984

Michel Foucault

**What is Enlightenment?**







## Das erst Capitel.



Is ist die offinbarung  
Jhesu Christi. die yhm  
Gott geben hat / seynen knechten zu  
zeigen / was ynn der kurtz geschehen  
soll / vnd hat sie deutlicher vnd gefand  
durch seynen engel zu seynem knecht  
Johannes / der betzeuget hat das  
wort Gottes / vnd des zeugnis von  
Jhesu Christo / was er gesehen hat /  
Selig ist der da liest vñ die da horen  
die wort der weysagung / vnd behal-  
ten was drynnen geschriben ist / den  
die zeit ist nahe.

Johannes / Den sieben gemeynen  
ynn Asia / Gnad sey mit euch vnd fride / von dem der da ist / vnd der  
da war / vnd der da kompt / vñ von den sieben geystern / die da sind fur  
seyne stuel / vnd von Jhesu Christo / welcher ist der trewe zeugend  
erst gepomer von den todten / vnd eyn furst aller Konige auff erden /  
der uns geliebt hat vnd gewaschen von den sunden mit seynem blut /  
vnd hat uns zu Konigen vnd priestern gemacht fur Gott vnd seynem  
vater / dem selbigen sey pries vnd reich vñ ewickert zu ewickert Amē.  
Sihe / er kompt mit den wolcken / vnd es werden yhn sehen alle an-  
gen / vnd die yhn gestochen haben / vnd werden heulen alle geschlecht  
der erden / Ich / Amen / Ich byn das A vnd das O / der anfang vnd  
das ende / spricht der herre / der da ist / vnd der da war / vnd der da kom-  
pt / der almechtige.

Ich Johannes ewr bunder / vnd mitgenos am tribsel vnd am reys-  
ch vnd an der geduld Jhesu Christi / war ynn der Insulen Patmos  
vnd des wort Gottes willen vnd des zeugnis Jhesu Christi / ich war  
ynn geyst am sonstage / vnd horete hynder myr eyne grosse stym / als ey-  
ner posaunen / die sprach / Ich byn das A vnd das O / der erst vnd der  
letz / vnd was du schifst / das schreybe ynn eyn buch / vnd sende es zu  
den gemeynen ynn Asia / gen Epheson / vnd gen Smyrnen / vñ gen  
Pergamon / vnd gen Thyatyras / vnd gen Sardis / vnd gen Phila-  
delphian / vnd gen Laodicean.

Vnd ich wand mich vmb / zusehen nach der stym die mit myr re-  
det / vnd als ich mich wand / sahe ich sieben gulden leuchter / vnd mit-  
ten vnter den guldenen leuchtern / eynen / der war eyns menschen son-  
gleich / der war angethan mit eynem leynen bytel / vnd begurter vmb  
die bruste mit eynem gulde gurtel / seyn heubt aber vnd seyn har war  
weys wie eyn weisse wolle / als der schnee / vnd seyne augen wie eyn  
feyr flamme / vñ seyne fusse / gleich wie eyn glend ertz / vñ seyne stym  
wie gros wasserrauschen / vnd hatte sieben sterne ynn seynem hand /  
u ij vnd aus-

**1522**

“for we are removing  
impediments and difficulties  
so that other people may  
read it without hindrance”



# 382

In principio creavit Deus caelum et terram. Terra autem erat inanis et vacua, et tenebrae erant super faciem abyssi: et spiritus Dei ferebatur super aquas. Dixitque Deus: Fiat lux. Et facta est lux.

Vulgate

Am Anfang schuf Gott Himmel und Erde. Und die Erde war wüst und leer, und es war finster auf der Tiefe; und der Geist Gottes schwebte auf dem Wasser. Und Gott sprach: Es werde Licht! und es ward Licht.

# 1637

In den beginne schiep God den hemel en de aarde. De aarde nu was woest en ledig, en duisternis was op den afgrond; en de Geest Gods zweefde op de wateren. En God zeide: Daar zij licht: en daar werd licht.

**Statenvertaling**





Westermarkt 6

Je pense, donc je suis

1637



# 1637

The first was never to accept anything for true which I did not clearly know to be such; carefully to avoid prejudice, and to comprise nothing more in my judgment than what was presented to my mind as to exclude all ground of doubt.

Descartes    Discourse on the method



# Rationalism



---

THE

---

Dartmouth

INSTITUTE

---

FOR HEALTH POLICY & CLINICAL PRACTICE

Radboudumc



Scientific Center for  
Quality of Healthcare

# Competing Interests

- Financial – Adviser to Emmi Solutions – patient DA
- Non-financial – Option Grids
- Non-financial – Measures of Shared Decision Making



# Empirical Rationality





**EBM**

**Clinical Practice  
Guidelines**

Problems?

What problems?

- Competing Interests
- Plethora
- Resistance
- Delusion

# Competing Interests

## FEATURE

---

### EVIDENCE BASED MEDICINE

## Why we can't trust clinical guidelines

Despite repeated calls to prohibit or limit conflicts of interests among authors and sponsors of clinical guidelines, the problem persists. **Jeanne Lenzer** investigates

Jeanne Lenzer *medical investigative journalist*

New York, USA

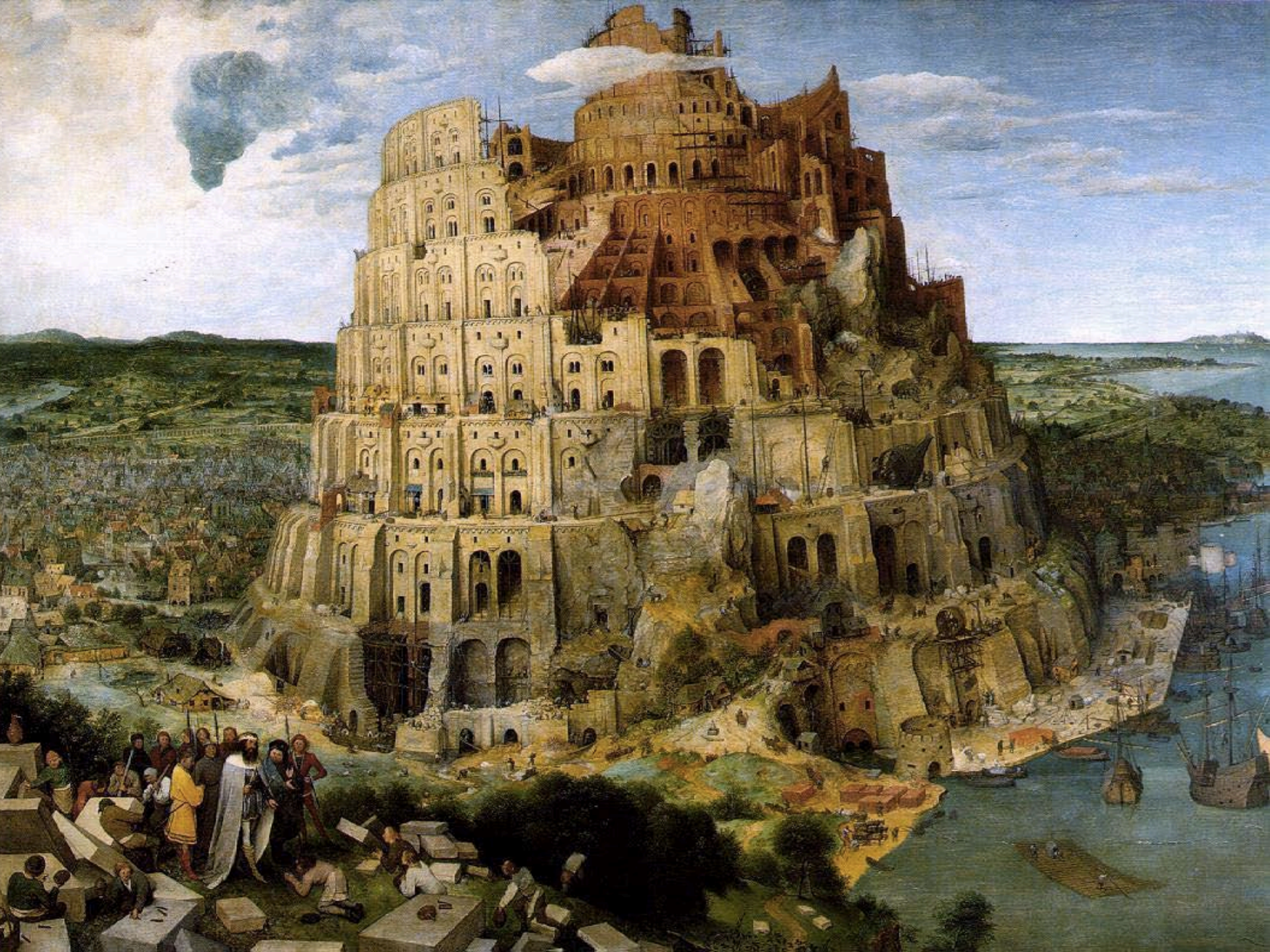
# Expanding disease definitions in guidelines and expert panel ties to industry: a cross-sectional study of common conditions in the United States.

Moynihan RN, Cooke GPE, Doust JA, Bero L, Hill S, Glasziou PP.

*PLoS Med.* 2013;10(8):e1001500.

Plethora







An avalanche of apple pie: too many guidelines?

BMJ 2010;340:c1208

# **US National Guideline Clearinghouse**

- Guidelines from 360 organizations
- Many for the same topic
- 471 hypertension guidelines
- 276 stroke guidelines

**\$ Millions**



# Resistance

# Perceived barriers to guideline adherence: a survey among general practitioners

Lugtenberg M, Burgers JS, Besters  
CF, Han D, Westert GP.

*BMC Fam Pract.* 2011;12:98

Practice guidelines in primary care, learning & usability in the physicians' decision-making process – a qualitative study.

Ingemansson M, Bastholm-Rahmner P, Kiessling A.

*BMC Fam Pract.* 2014;15(1):141

Is it time to drop the  
“knowledge translation”  
metaphor? A critical literature  
review.

Greenhalgh T, Wieringa S.  
*J R Soc Med.* 2011;104(12):501-509



# Delusion

# J Allison Glover 1938

10-fold variation in  
tonsillectomy rates

“... tendency for the  
operation to be  
performed for no  
particular reason and  
no particular result.”



**John E Wennberg**

**1973**

17-fold variation in  
tonsillectomy

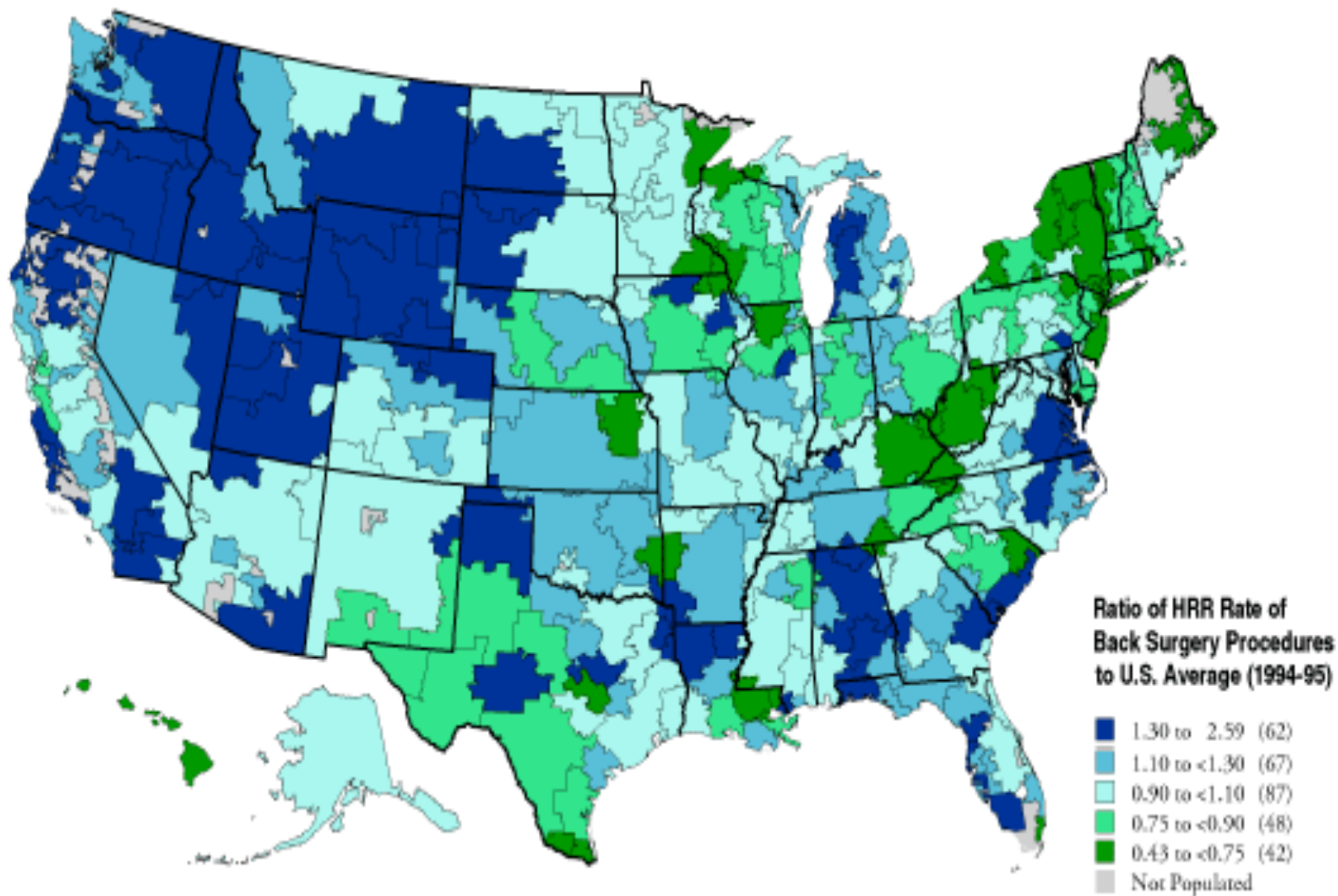
6-fold variation in  
hysterectomy

“... the problem of  
supplier-induced demand”



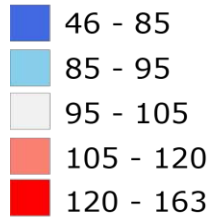


# United States - Back surgery 306 regions 1984

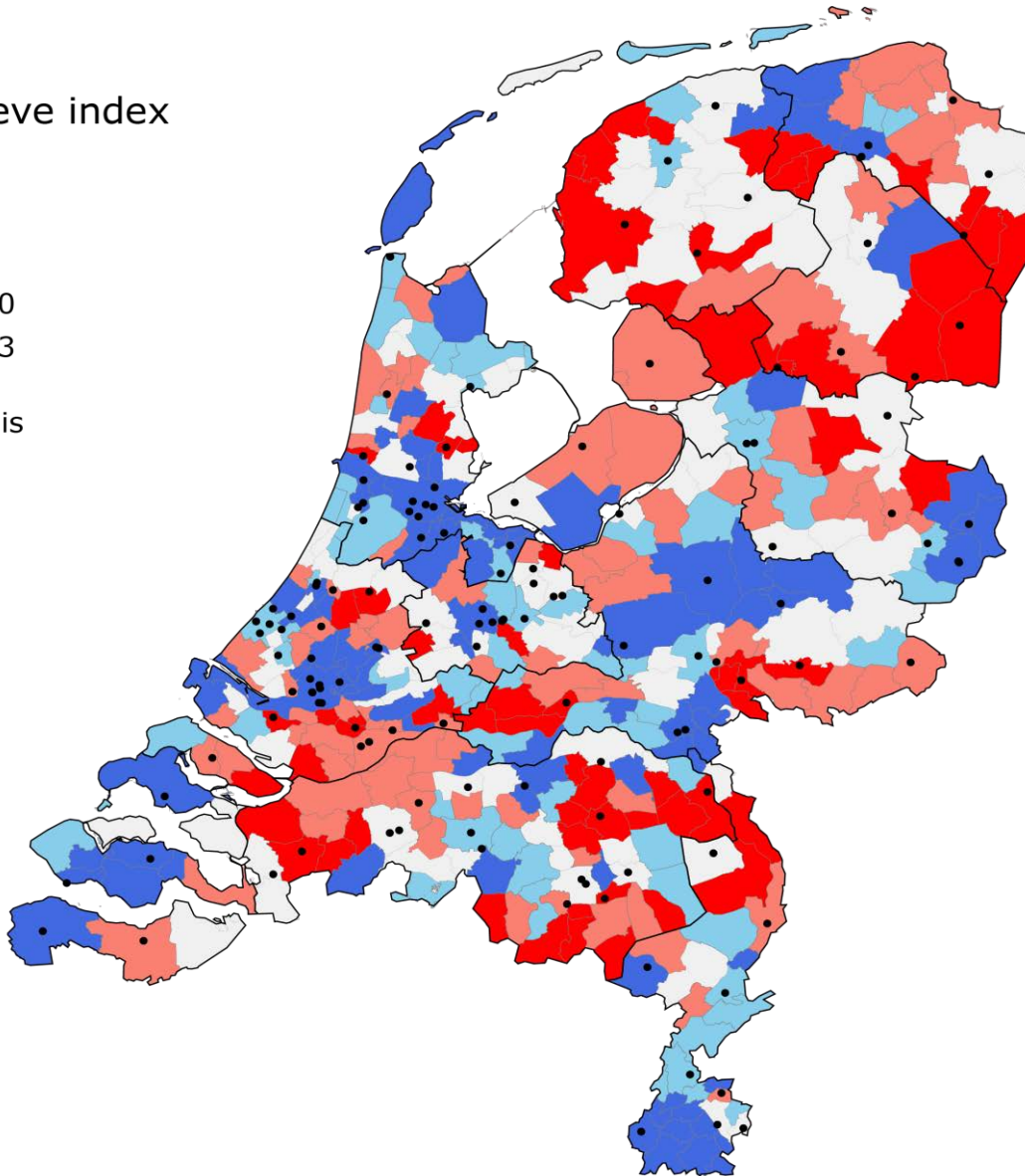


# Netherlands - 8 surgical procedures

Cumulatieve index



• ziekenhuis



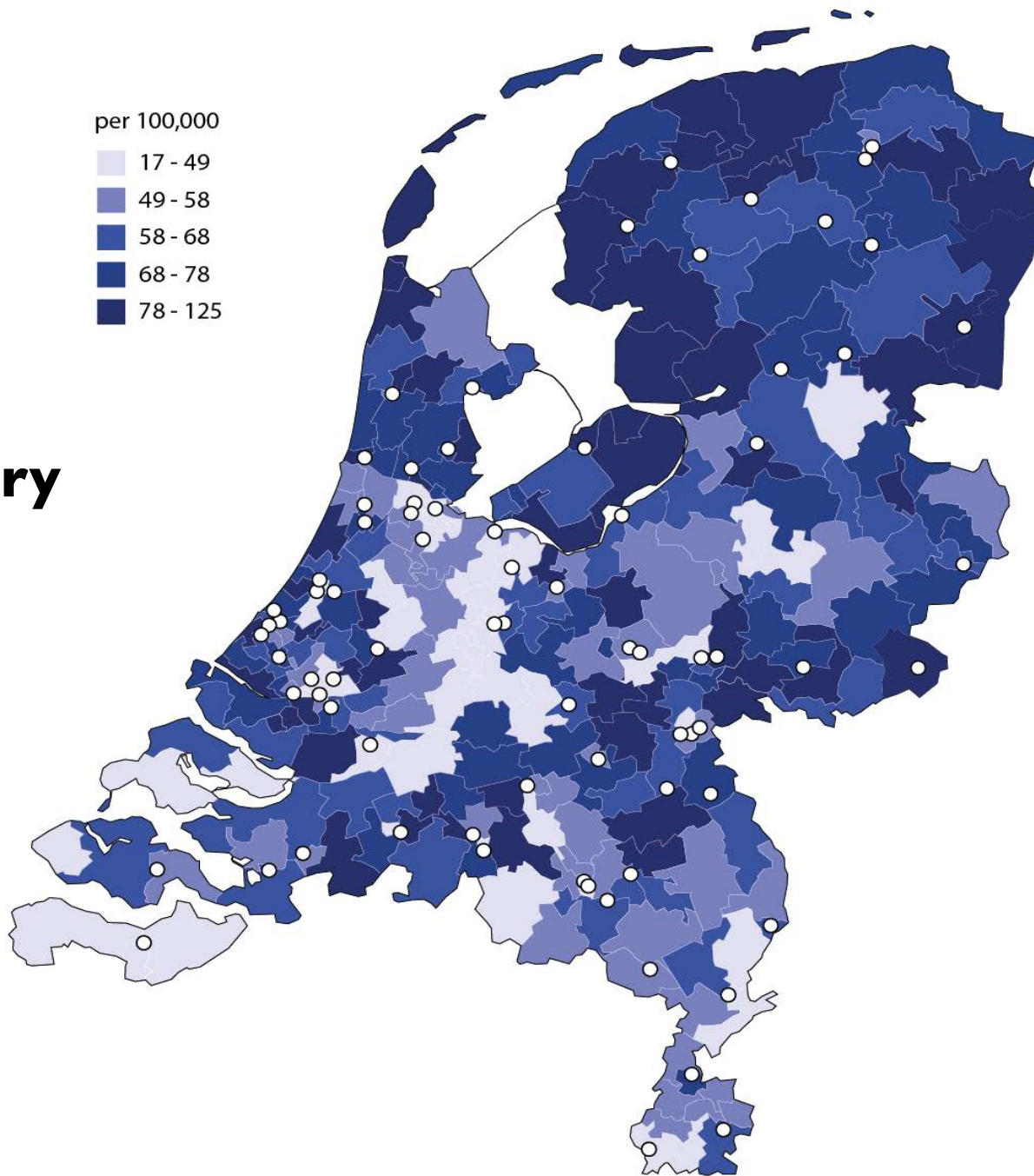
Back hernia,  
Carpal tunnel  
Prostate  
Gallbladder  
Varicose veins  
Tonsillectomy  
Cataract  
Knee replacement

# Netherlands

## Lumbar disc surgery 2011

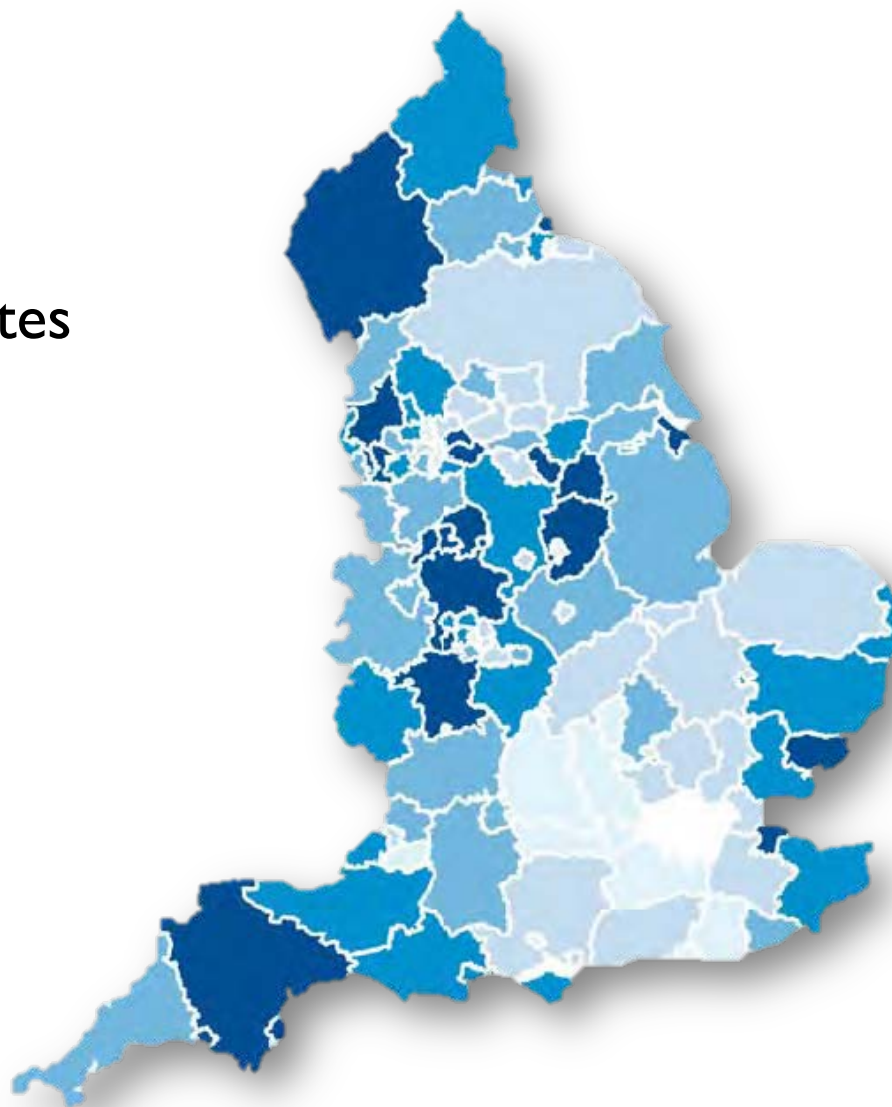
N per 100,000

Range 17 – 125

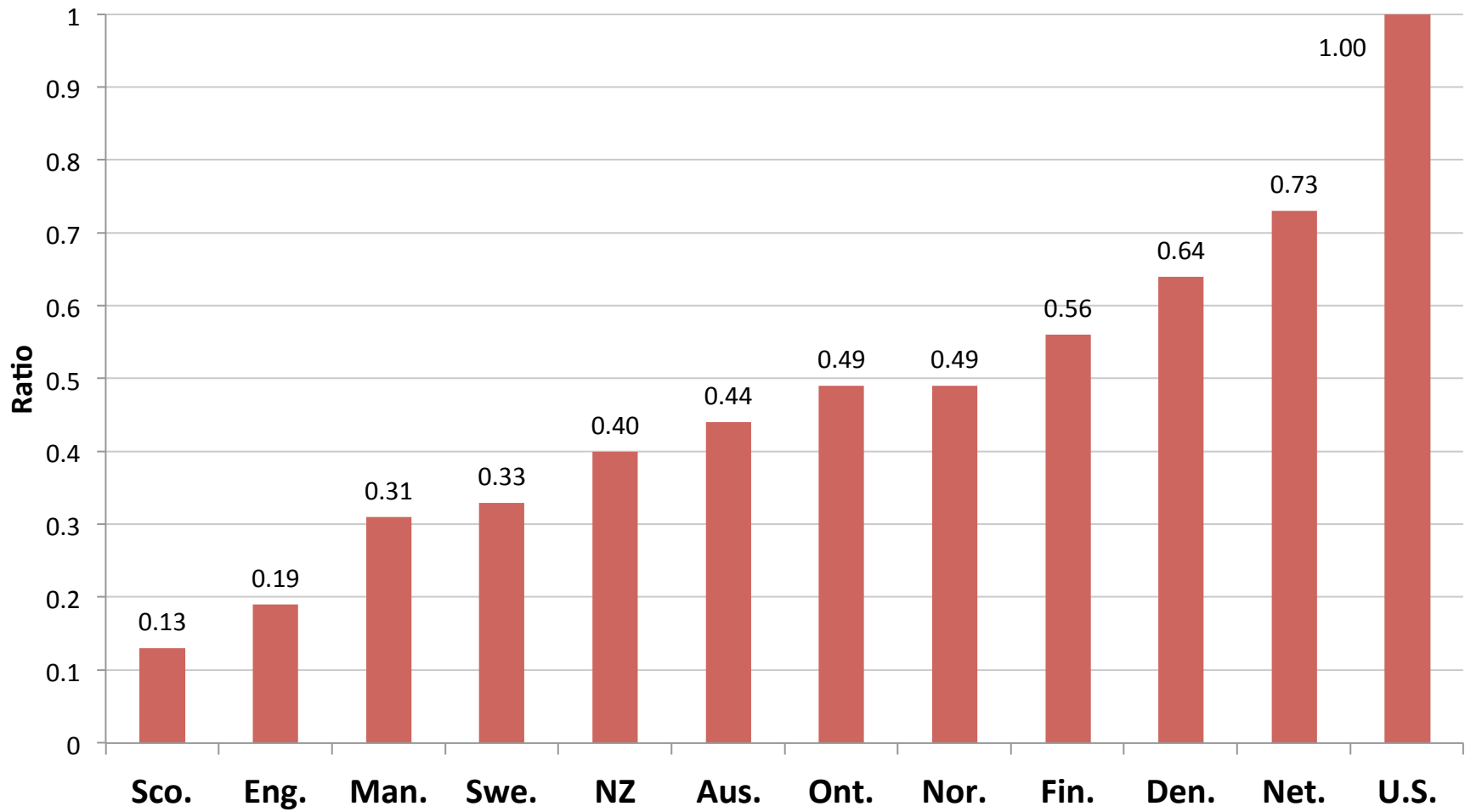


# England 2010 - Hysterectomy

Greater than threefold  
variation in hysterectomy rates



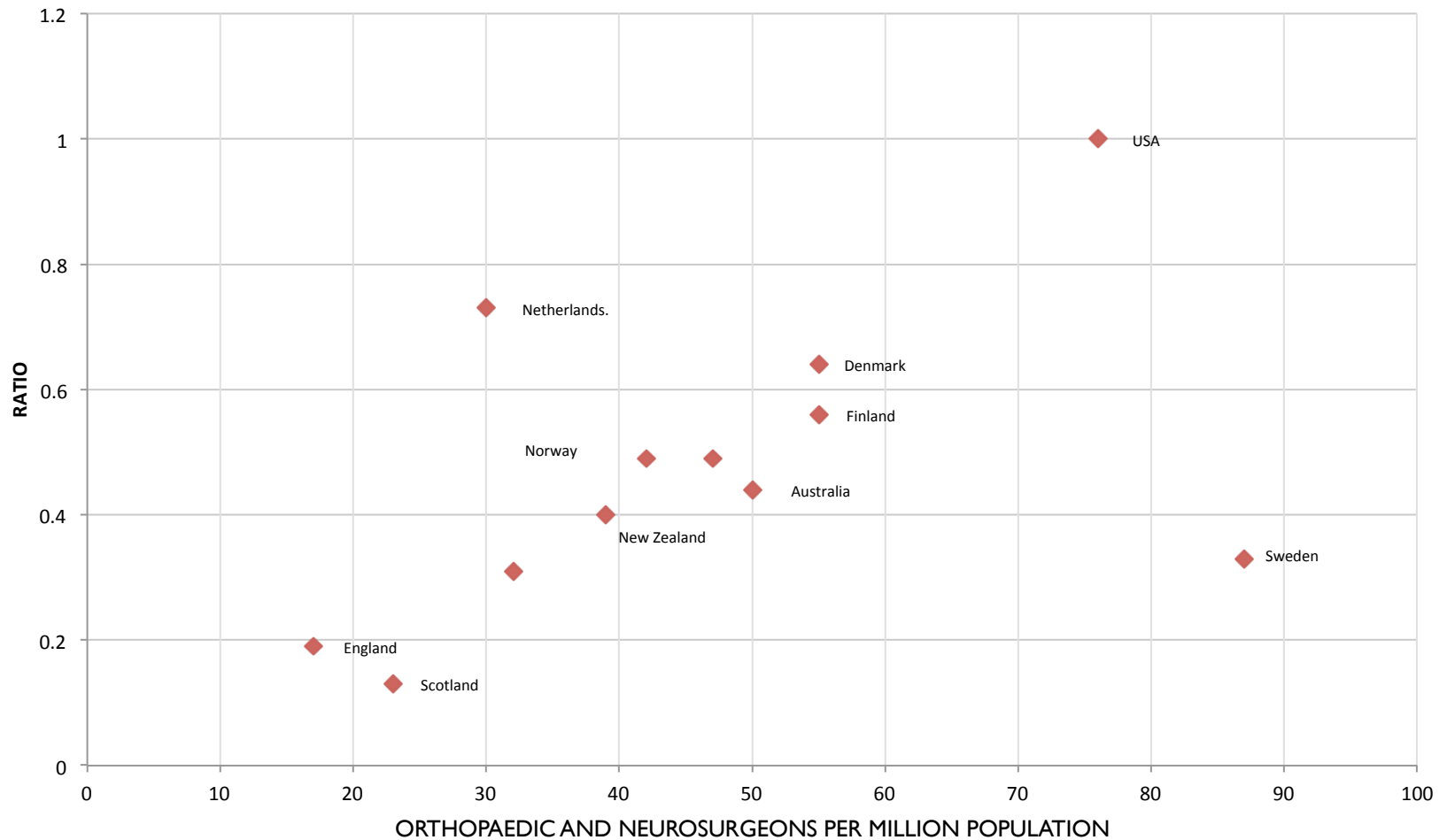
# Back surgery: inter-country variation



Cherkin et al, Spine, 1994



# Back surgery: correlation with available specialists



Cherkin et al, Spine, 1994

# Delusion

Evidence based guidelines or  
collectively constructed “mindlines?”  
Ethnographic study of knowledge  
management in primary care

Gabbay J, le May A.  
*BMJ*. 2004;329(7473):1013

“Socially constructed “knowledge in practice”, collectively reinforced, brief reading, internalised, tacit *mindlines* ... clinicians interacting with each other, with patients, and pharmaceutical representatives”

10 years of mindlines: a systematic review and commentary.

Wieringa S, Greenhalgh T.  
Implement Sci. 2015;10(1):45

“The concept of mindlines challenges the naïve rationalist view of knowledge implicit in some EBM publications”

Greenhalgh 2015

**Guidelines**

**Wrong tool**

**Wrong audience**







## Das erst Capitel.



Is ist die offinbarung  
Jhesu Christi. die yhm  
Gott geben hat / seynen knechten zu  
zeigen / was ynn der kurtz geschehen  
soll / vnd hat sie deutlicher vnd gefand  
durch seynen engel zu seynem knecht  
Johannes / der betzeuget hat das  
wort Gottes / vnd des zeugnis von  
Jhesu Christo / was er gesehen hat /  
Selig ist der da liest vñ die da horen  
die wort der weysagung / vnd behal-  
ten was drynnen geschriben ist / den  
die zeit ist nahe.

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da war / vnd der da kompt / vñ von den sieben geystern / die da sind fur  
seyne stuel / vnd von Jhesu Christo / welcher ist der trewe zeugend  
erst gepomer von den todten / vnd eyn furst aller Konige auff erden /  
der uns geliebt hat vnd gewaschen von den sunden mit seynem blut /  
vnd hat uns zu Konigen vnd priestern gemacht fur Gott vnd seynem  
vater / dem selbigen sey pries vnd reich vñ ewickert zu ewickert Amē.  
Sihe / er kompt mit den wolcken / vnd es werden yhn sehen alle an-  
gen / vnd die yhn gestochen haben / vnd werden heulen alle geschlecht  
der erden / Ich / Amen / Ich byn das A vnd das O / der anfang vnd  
das ende / spricht der herre / der da ist / vnd der da war / vnd der da kom-  
pt / der almechtige.

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vmb des wort Gottes willen vnd des zeugnis Jhesu Christi / ich war  
ynn geyst am sonstage / vnd horete hynder myr eyne grosse stym / als ey-  
ner posaunen / die sprach / Ich byn das A vnd das O / der erst vnd der  
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Pergamon / vnd gen Thyatyras / vnd gen Sardis / vnd gen Phila-  
delphian / vnd gen Laodicean.

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det / vnd als ich mich wand / sahe ich sieben gulden leuchter / vnd mit-  
ten vnter den guldenen leuchtern / eynen / der war eyns menschen son-  
gleich / der war angethan mit eynem leynen bytel / vnd begurter vmb  
die bruste mit eynem gulde gurtel / seyn heubt aber vnd seyn har war  
weys wie eyn weisse wolles / als der schnee / vnd seyne augen wie eyn  
feyr flamme / vñ seyne fusse / gleich wie eyn glend ertz / vñ seyne stym  
wie gros wasserrauschen / vnd hatte sieben sterne ynn seynem hand /

“for we are removing  
impediments and difficulties  
so that other people may  
read it without hindrance”





**2015**

We the people

# Guidelines for people



# WIKIPEDIA

## English

*The Free Encyclopedia*

4 966 000+ articles

## Español

*La enciclopedia libre*

1 200 000+ artículos

## Deutsch

*Die freie Enzyklopädie*

1 853 000+ Artikel

## Русский

*Свободная энциклопедия*

1 253 000+ статей

## 中文

*自由的百科全書*

840 000+ 條目



## 日本語

*フリー百科事典*

982 000+ 記事

## Français

*L'encyclopédie libre*

1 661 000+ articles

## Italiano

*L'enciclopedia libera*

1 223 000+ voci

## Português

*A enciclopédia livre*


887 000+ artigos


## Polski

*Wolna encyklopedia*

1 133 000+ haseł

English







# Guidelines for the public

- Design problems
- Literacy obstacles
- Option blindness
- Difficult to find
- Search engine elusive

A search input field with a thin blue border. A small vertical line is visible on the left side, and a microphone icon is on the right side.

Google-Suche

Auf gut Glück!

Google.de angeboten auf: [English](#)



**1982**

# **Shared Decision Making**

Helping a person develop  
an informed preference

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

Team  
Talk

Option  
Talk

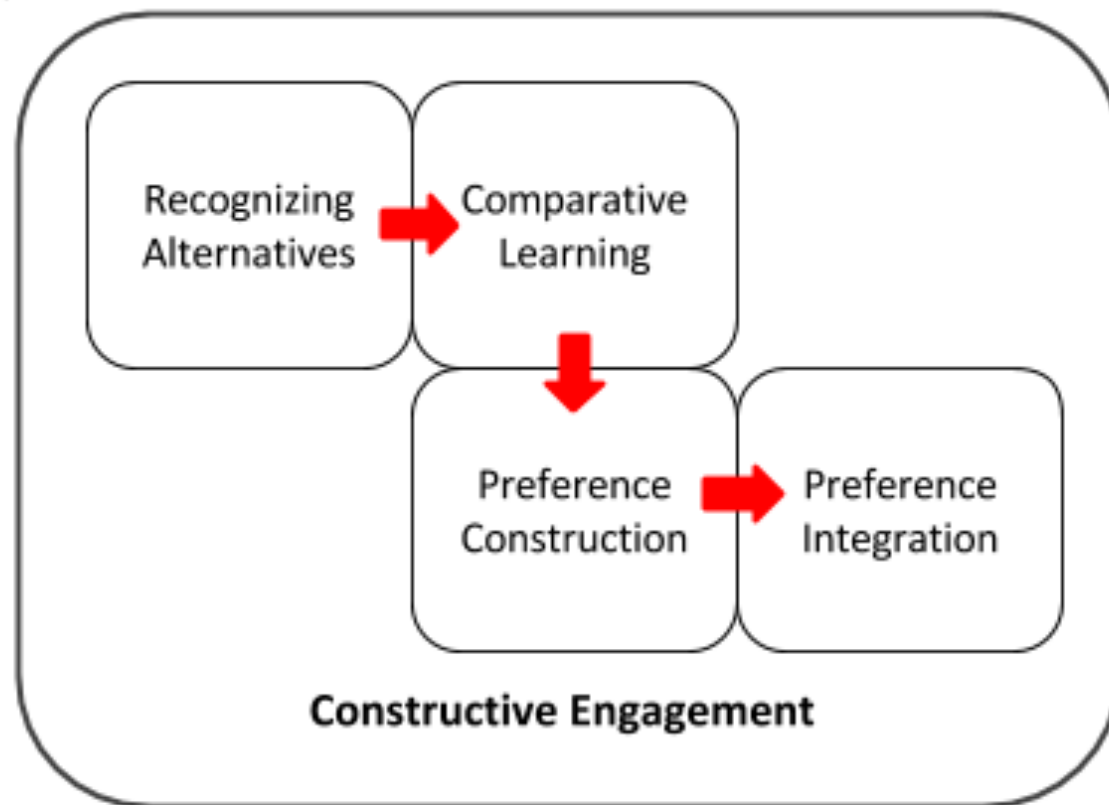
**Initial  
preferences**

Preference  
Construction

**Informed  
preferences**

Decision  
Talk

## Collaborative Deliberation



### Context

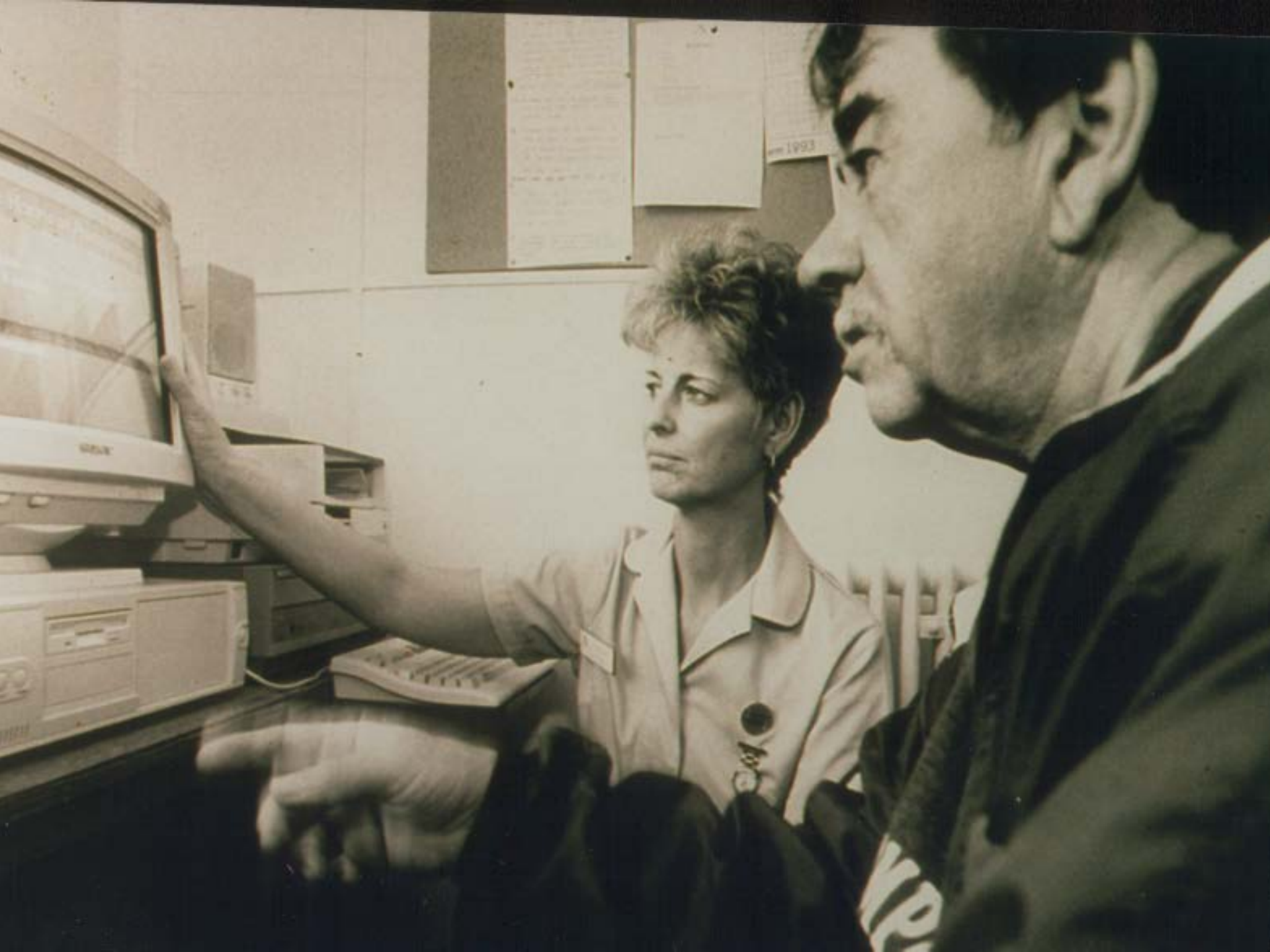
Emotional states of participants

Resources, constraints, capacities

The range and accessibility of alternatives

Social norms shaping the construction of preferences





# **Patient Decision Support**

Data about options and outcome probabilities

# Decision aids for people facing health treatment or screening decisions

Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L, Wu JH.

Cochrane Database Syst Rev. 2014 Jan 28;1:CD001431

# **Patient decision tools - 115 RCTs**

## **Strong evidence**

- Increase knowledge
- Accurate risk perceptions
- Conservative decisions

# **Patient decision tools - 115 RCTs**

## **Strong evidence**

- Increase knowledge
- Accurate risk perceptions
- Conservative decisions

## **Weak evidence**

- Reduce cost
- Improve adherence
- Better communication







# Fiction







# Hope

# Implementation

**Giving Patient Decision Tools**

**is not**

**Shared Decision Making**

**Shared Decision Making**

**is about**

**Supporting Informed  
Preferences**



**I 597**

scientia potentia est

**is**

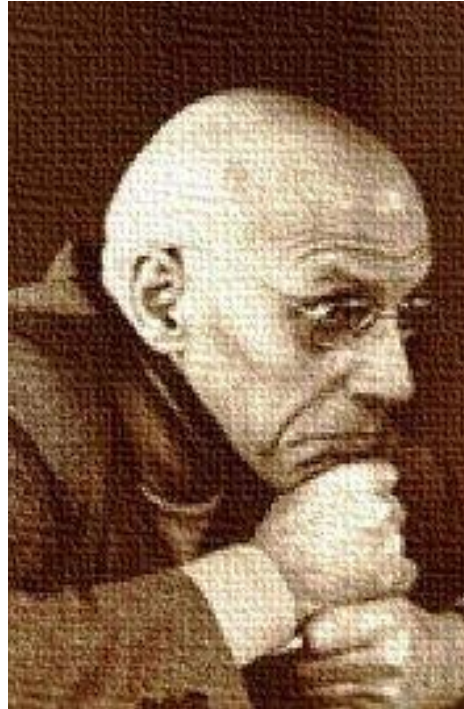
**Power**



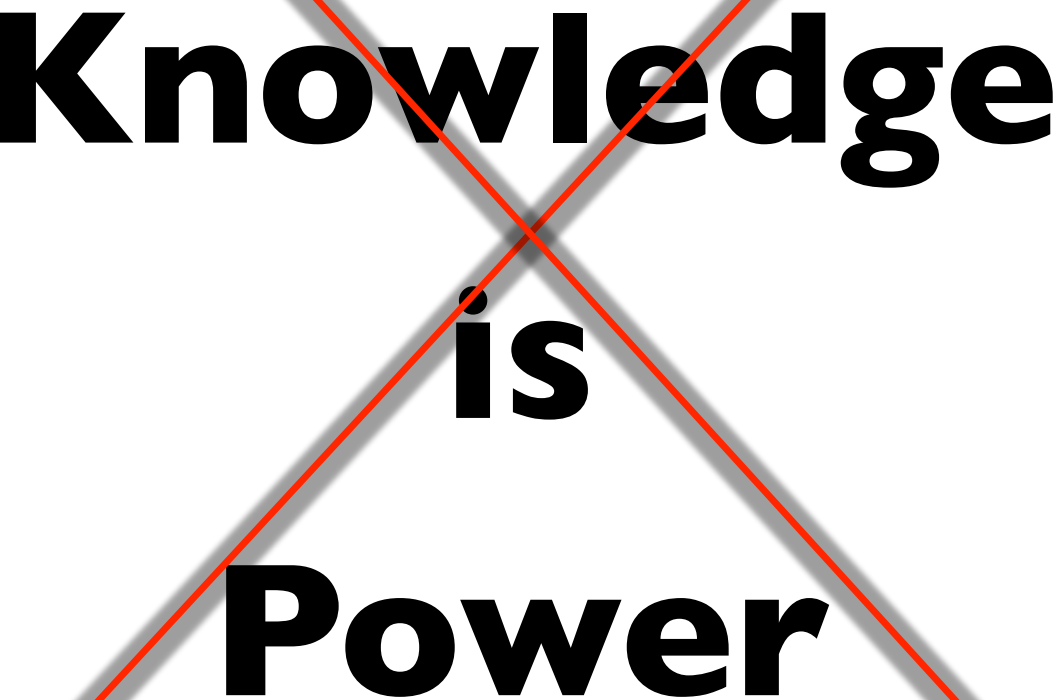
**Knowledge**

**is**

**Power**



**Power**



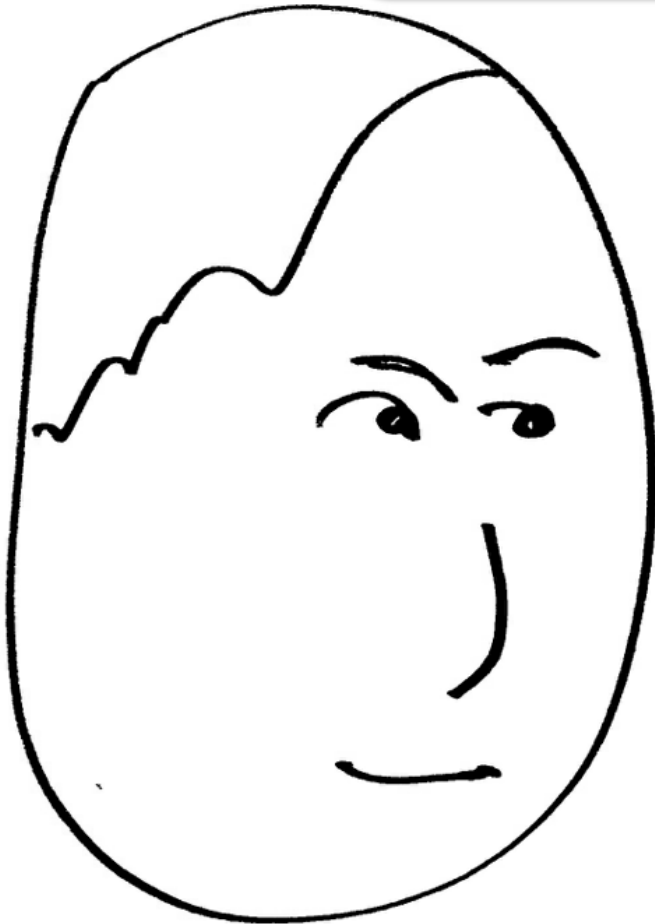
**Knowledge  
is  
Power**

# **Authoritarian Physicians & Patients' Fear Of Being Labeled “Difficult” Among Key Obstacles To Shared Decision Making.**

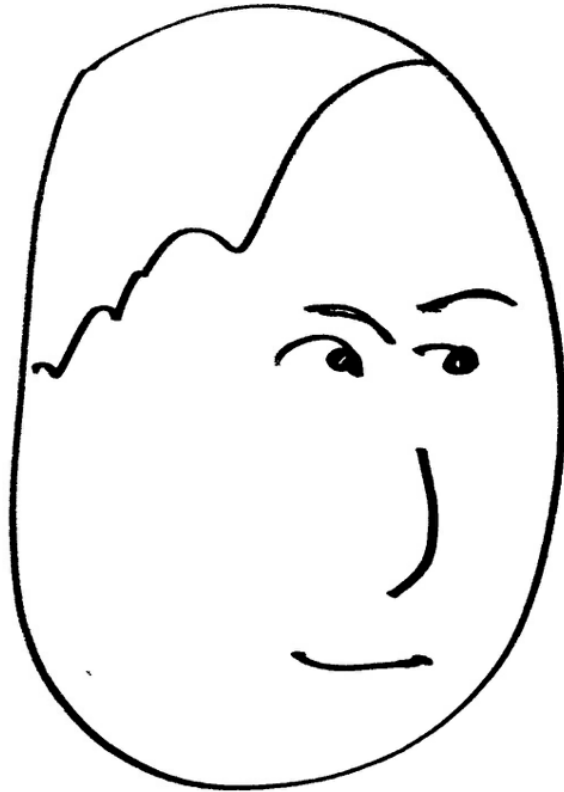
Frosch DL, May SG, Rendle K, Elwyn G.

Health Affairs 2012;31:1030–8

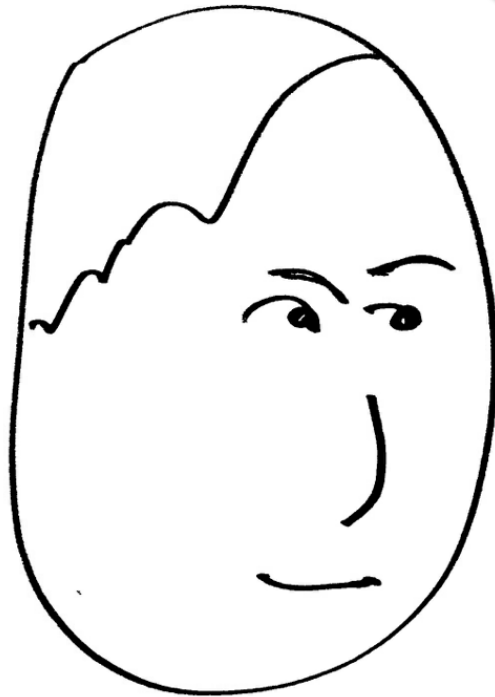
Will I be considered  
a trouble maker if I  
ask questions ?



Will I be considered a  
difficult patient if I  
disagree ?



Will I get worse  
care if I have a  
different opinion?



Frosch DL, May SG, Rendle K, Elwyn G. Authoritarian Physicians & Patients' Fear Of Being Labeled "Difficult" Among Key Obstacles To Shared Decision Making. *Health Affairs* 2012;31:1030–8.

# **Power imbalance prevents shared decision making**

Joseph-Williams N, Edwards A, **Elwyn G**

**BMJ** 2014 May 14; 348: g3178





More useful tools?

**2<sup>nd</sup> Generation**

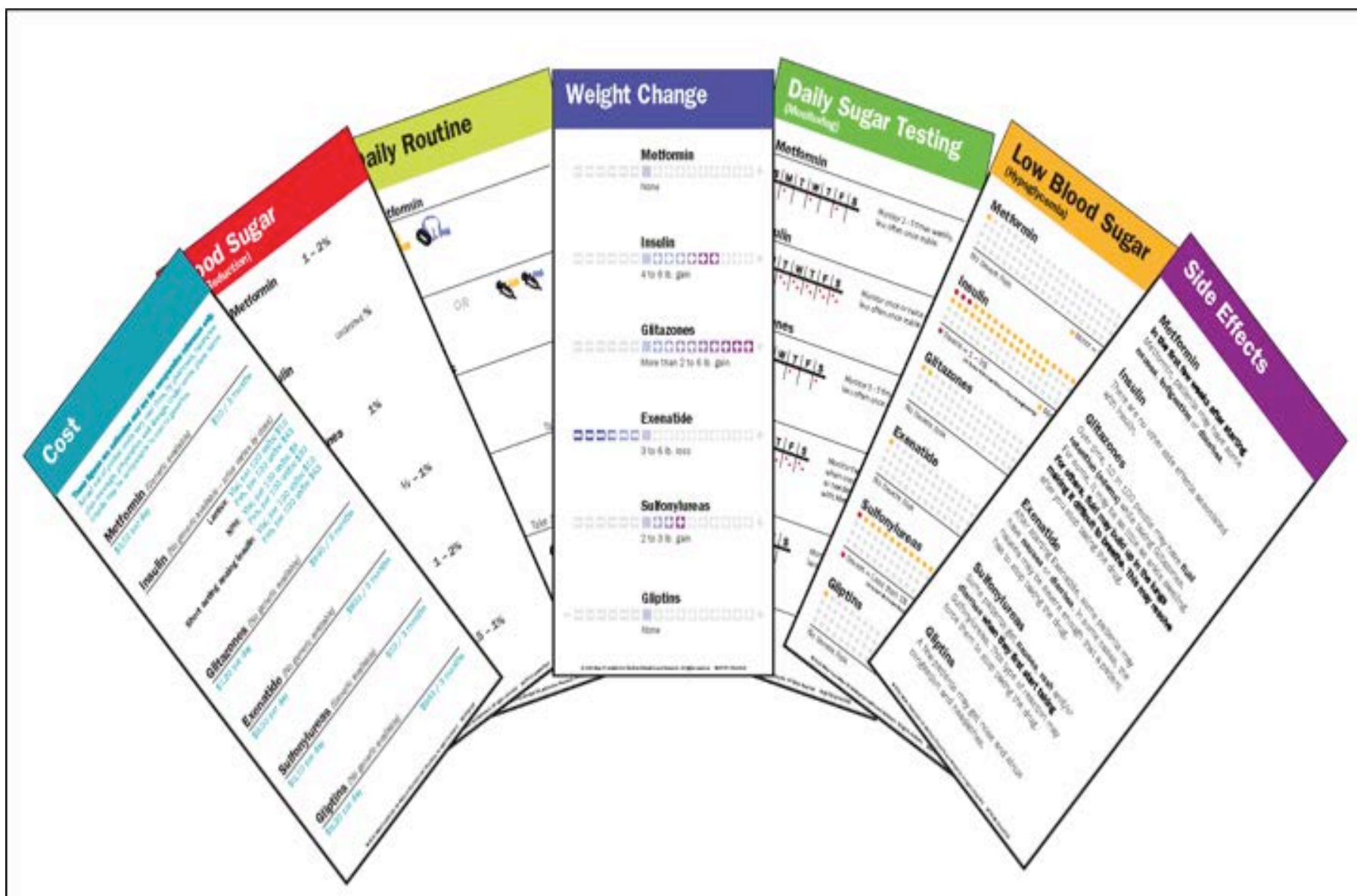
**Encounter Tools**

**Enable Comparison**

**Generate mindlines**







## Weight Change

## Low Blood Sugar (Hypoglycemia)

## Blood Sugar (A1c Reduction)

## Side Effects

### Daily Routine

### Daily Sugar Testing (Monitoring)

### Cost



#### Metformin



#### Insulin



#### Glitazones



#### Exenatide



Take in the hour  
before meals.

#### Sulfonylureas



Take 30 min. before meal.

#### Gliptins



#### Metformin



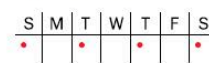
Monitor 2 - 5 times weekly,  
less often once stable.

#### Insulin



Monitor once or twice daily,  
less often once stable.

#### Glitazones



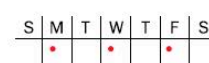
Monitor 3 - 5 times weekly,  
less often once stable.

#### Exenatide



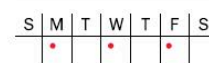
Monitor twice daily after meals  
when used with Sulfonylureas,  
as needed when used  
with Metformin.

#### Sulfonylureas



Monitor 2 - 5 times weekly,  
less often once stable

#### Gliptins



Monitor 2 - 5 times weekly,  
less often once stable.

These figures are estimates and are for comparative reference only.  
Actual out-of-pocket costs vary over time, by pharmacy, insurance  
plan coverage, preparation and dosage. Under some plans name  
brands may be comparable in cost to generics.

#### Metformin (Generic available)

\$0.10 per day

\$10 / 3 months

#### Insulin (No generic available - price varies by dose)

**Lantus:** Vial, per 100 units: \$10  
Pen, per 100 units: \$43

**NR:** Vial, per 100 units: \$6  
Pen, per 100 units: \$30

**Short acting analog insulin:** Vial, per 100 units: \$10  
Pen, per 100 units: \$43

#### Glitazones (No generic available)

\$7.20 per day

\$650 / 3 months

#### Exenatide (No generic available)

\$9.00 per day

\$800 / 3 months

#### Sulfonylureas (Generic available)

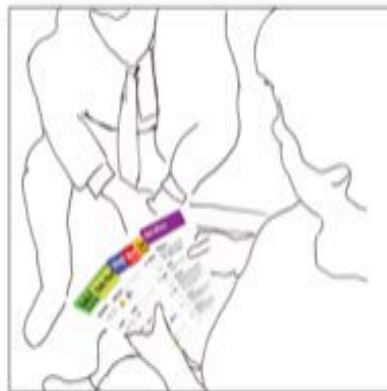
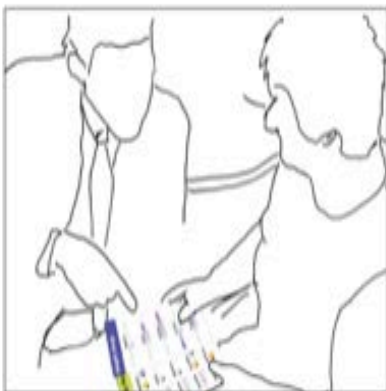
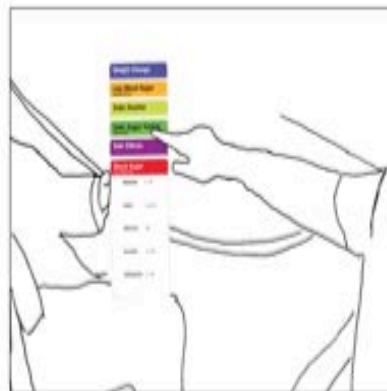
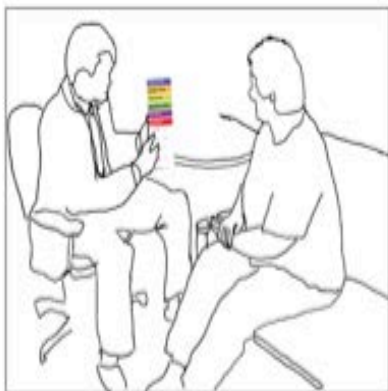
\$0.10 per day

\$10 / 3 months

#### Gliptins (No generic available)

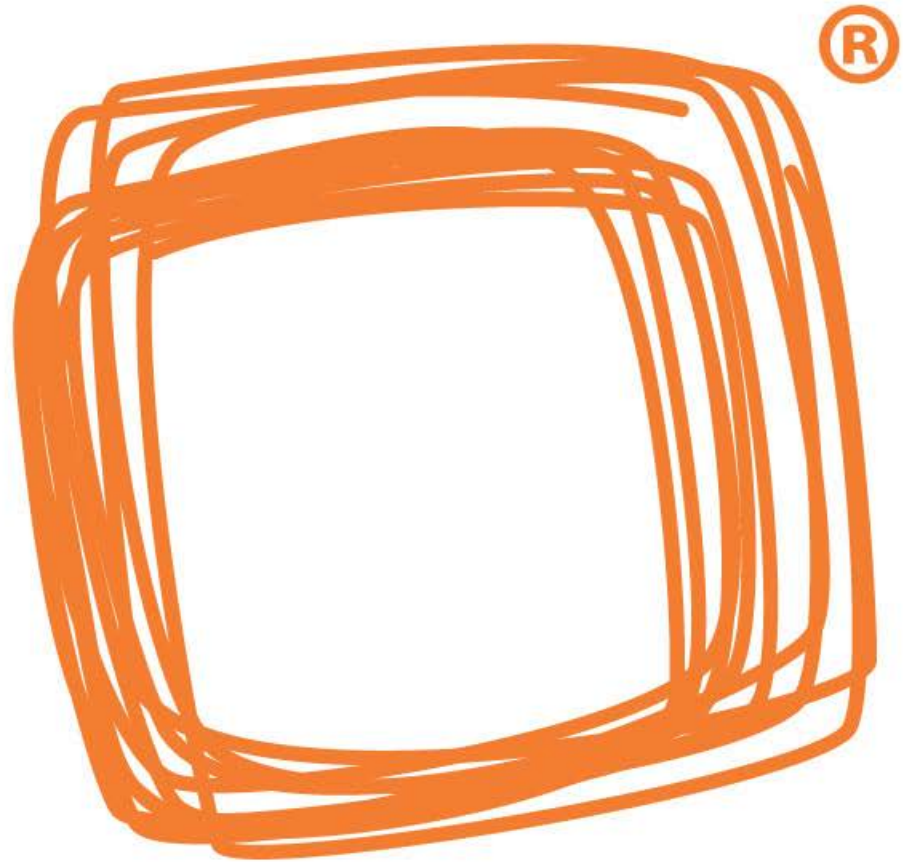
\$6.20 per day

\$560 / 3 months





**option**  
grid



## Breast cancer surgery

Use this grid to help you and your healthcare professional decide whether you should have a mastectomy, or a lumpectomy with radiotherapy.

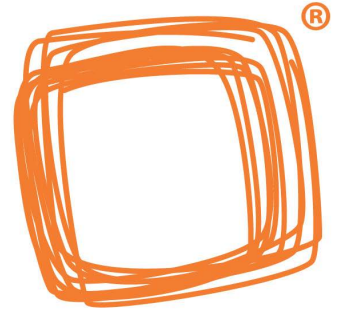
Frequently asked questions	Lumpectomy with radiotherapy	Mastectomy
What is removed?	The cancer lump is removed, with	The whole breast is removed.
Which surgery is best for long-term survival?	Survival rates are the same for both options.	Survival rates are the same for both options.
coming back in the breast?	breast in about 10 in 100 women (10%) in the 10 years after a lumpectomy. Recent improvements in treatment may have reduced this risk.	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.

## Breast cancer surgery

Use this grid to help you and your healthcare professional decide whether you should have a mastectomy, or a lumpectomy with radiotherapy.

Frequently asked questions	Lumpectomy with radiotherapy	Mastectomy
<b>What is removed?</b>	The cancer lump is removed, with some surrounding tissue.	The whole breast is removed.
<b>Which surgery is best for long-</b>	Survival rates are the same for both	Survival rates are the same for both
<b>What are the chances of cancer coming back in the breast?</b>	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.
<b>operation?</b>	in the breast after the lumpectomy. This can occur in up to 20 in 100 women (20%).	reconstruction.

**option**  
grid



Explain it

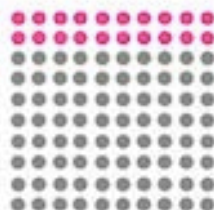
Give it

Use it



#### 4. Will I need more than one operation?

##### Lumpectomy with radiation



Possibly, 20 in 100 women (20%) might need another operation to remove more tissue or lymph nodes that have cancer.

##### Mastectomy



Delayed



Immediate

Yes, if you choose breast reconstruction.  
Possibly, if your lymph nodes have cancer.

#### 5. How long will it take to recover?

##### Lumpectomy with radiation



Most women are home on the same day as surgery, but this may vary.  
It will take about a week before you can resume usual activities.

##### Mastectomy



Most women are home on the same day as surgery (longer with reconstruction).  
It will take several weeks, or longer, before you fully recover and can resume usual activities.



# **Using Option Grids: steps toward shared decision-making for neonatal circumcision.**

**Patient Educ Couns. 2015, Epub.**

Fay M, Grande SW, Donnelly K, Elwyn G.

# Summary

- Frame shift
- Increased collaboration
- No extra time



**Supporting shared decision making using an Option Grid for osteoarthritis of the knee in an interface musculoskeletal clinic: a stepped wedge trial.**

**Patient Education and Counseling. Epub.**

Glyn Elwyn, Tim Pickles, Adrian Edwards,  
Katharine Kinsey, Kate Brain, Robert G.  
Newcombe, Jill Firth, Katy Marrin, Alan Nye,  
Fiona Wood

# Summary

- Knowledge gain
- Increased collaboration
- No extra time

**Trustworthy**  
COI & Evidence

**User Based Design**

**Fast Frugal**

**Gist & Visual**

**Easy to Use**

# **Evidence synthesis 2<sup>nd</sup> generation**

- Communication improves
- Patients ask more questions
- Gain knowledge
- Better decisions
- Better adherence

- Mindline generation
- Evidence into practice
- Informed clinicians
- Team coherence

**Guidelines**

**Wrong tool**

**Wrong audience**

“... we are removing  
impediments so that people  
may read without hindrance”





# Attitude

# Problem

No generic, valid, scalable,  
patient-reported measure of  
shared decision making

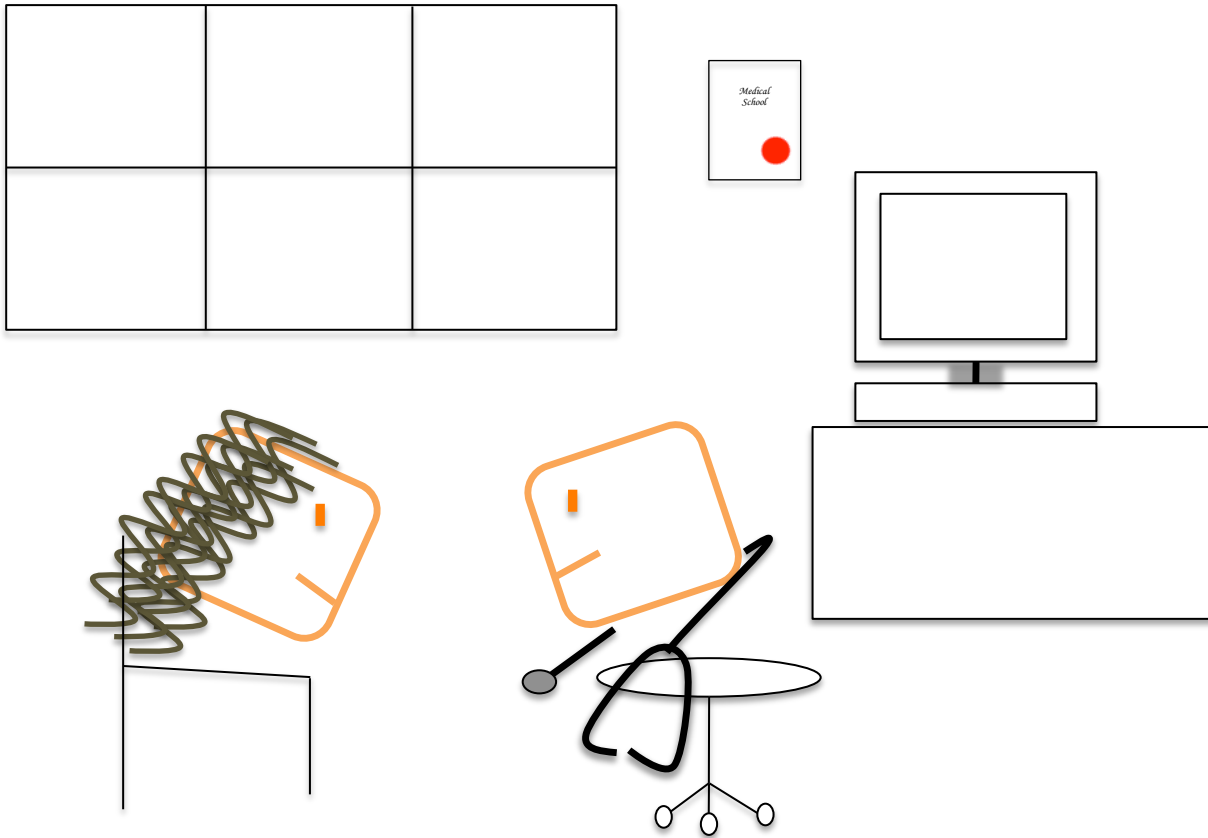
collaboRATE<sup>TM</sup>

# **Psychometric Testing**

# Psychometric Testing

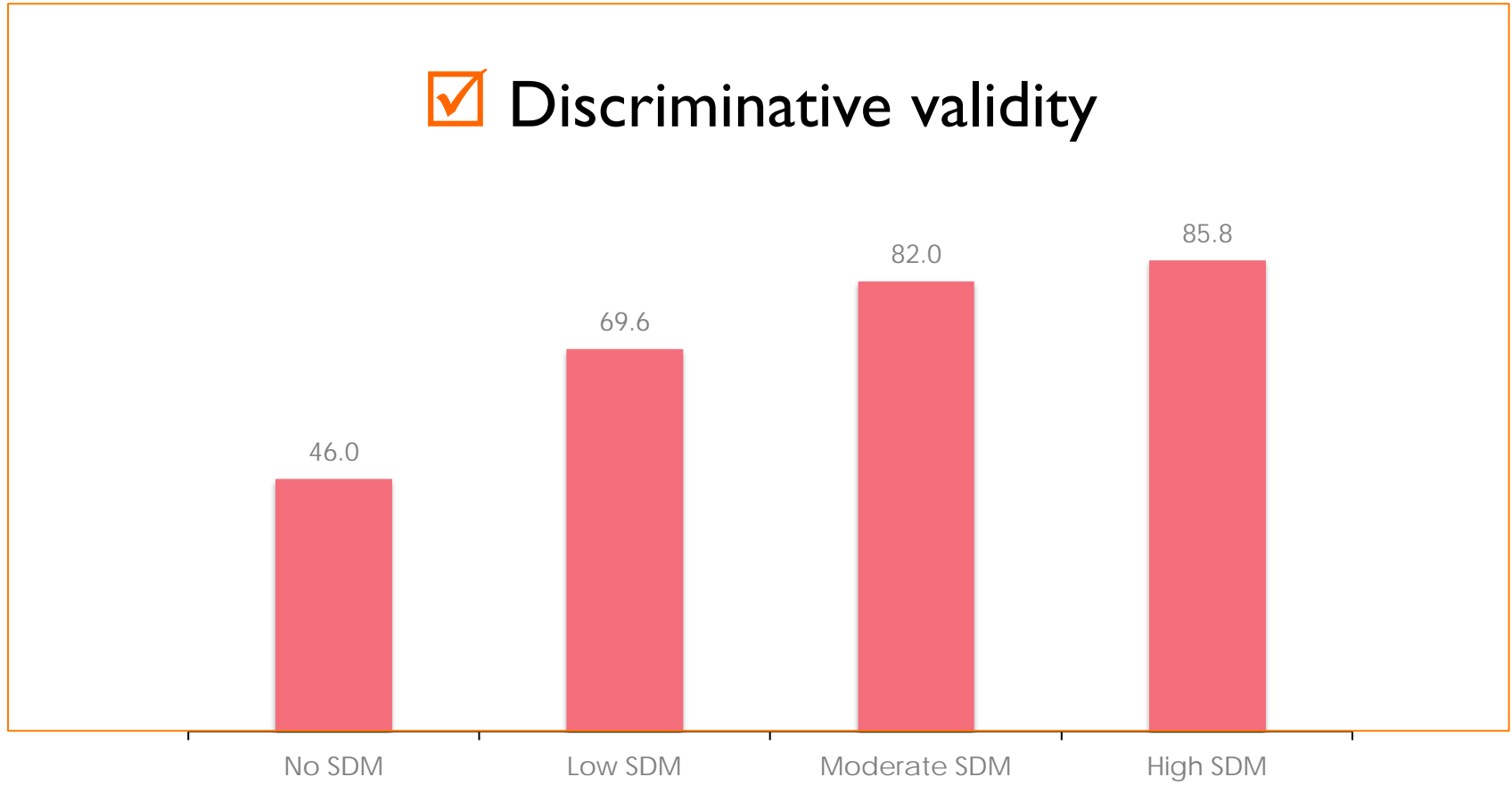
1,341 adults randomised to view  
animated clinical encounter  
and completed battery of surveys

# Psychometric Testing



# Psychometric Testing

☑ Discriminative validity





# Psychometric Testing

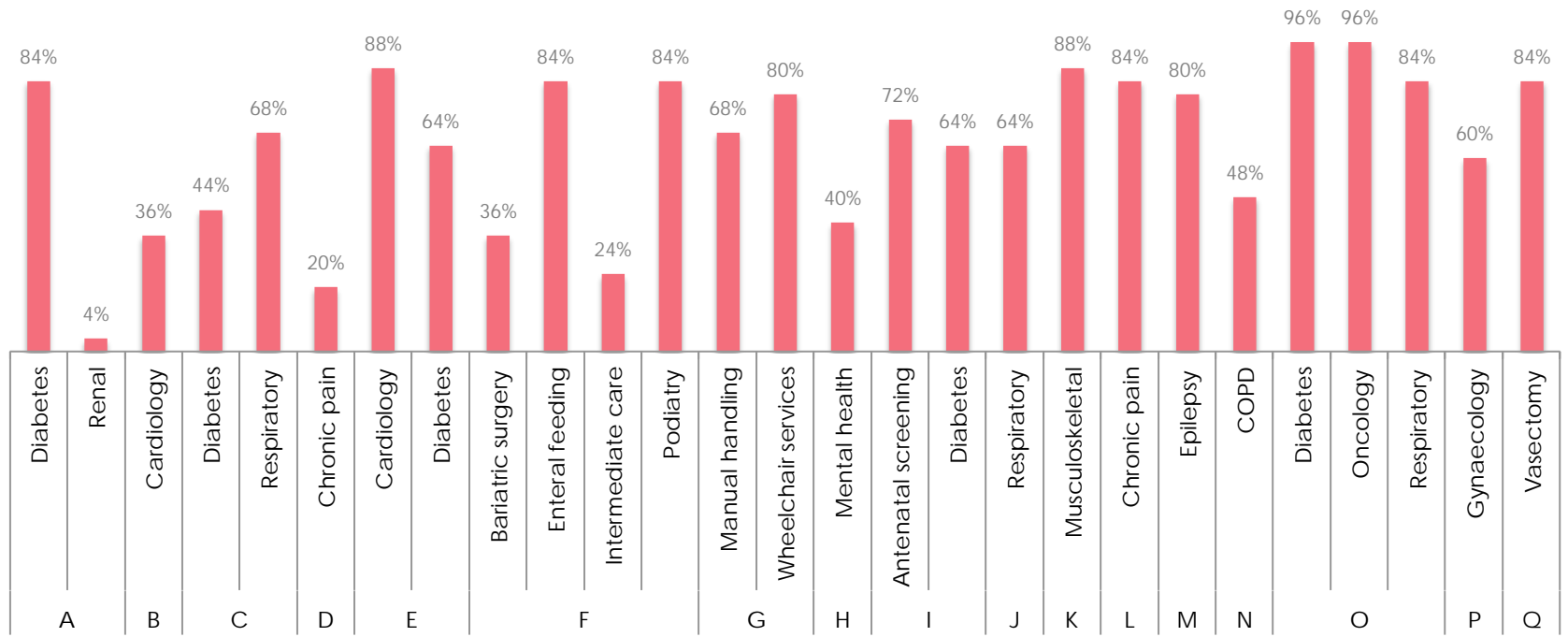
- ☑ Concurrent validity
- ☑ Intra-rater reliability
- ☑ Responsiveness to change

# Pilot Implementation

5,167 patients completed  
CollaboRATE immediately following  
visit to NHS clinical team

# Pilot Implementation

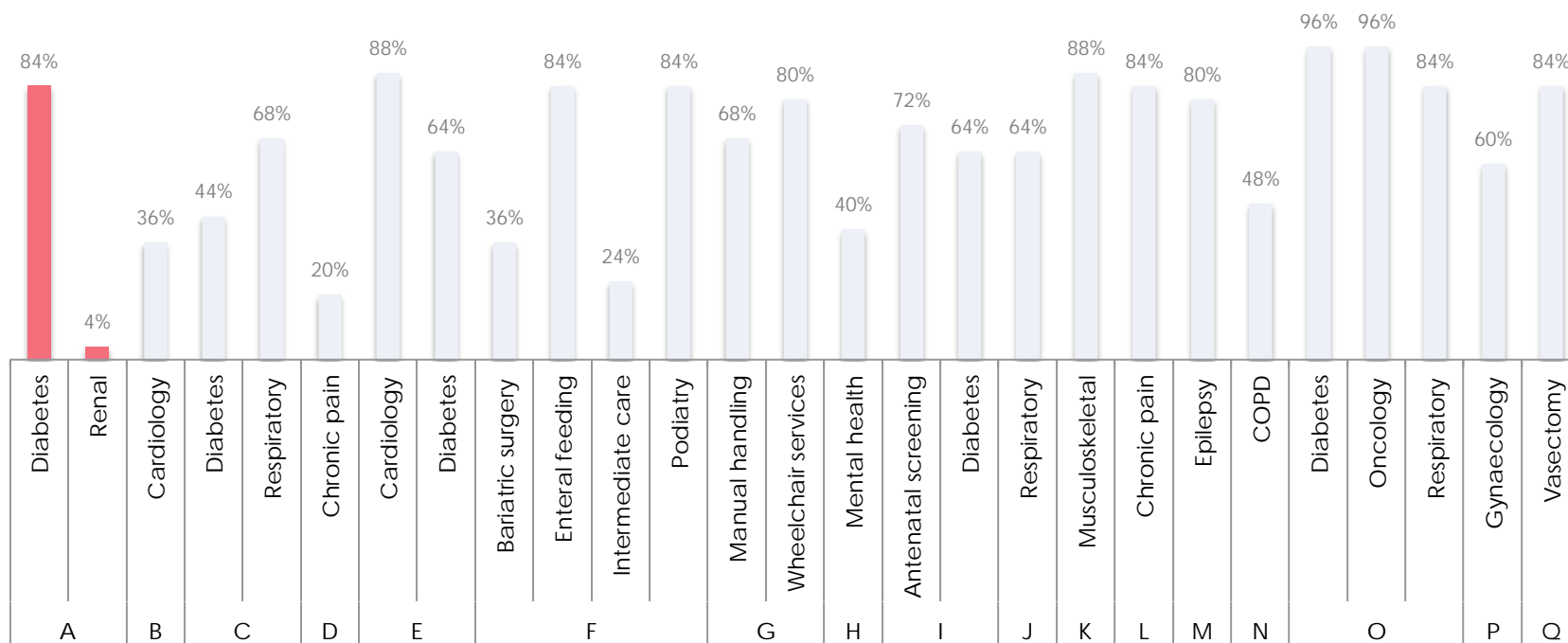
☑ Variation between teams



Hospital and Clinical Speciality

# Pilot Implementation

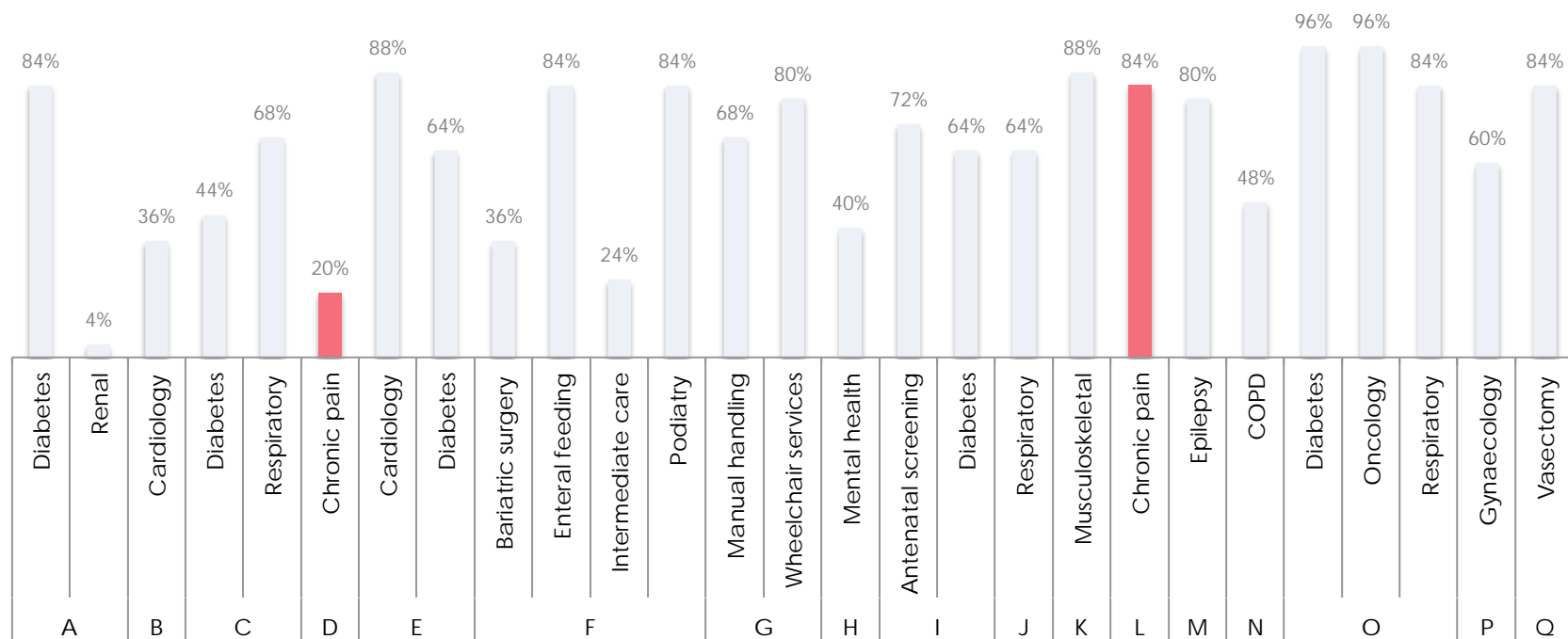
☑ Variation between teams



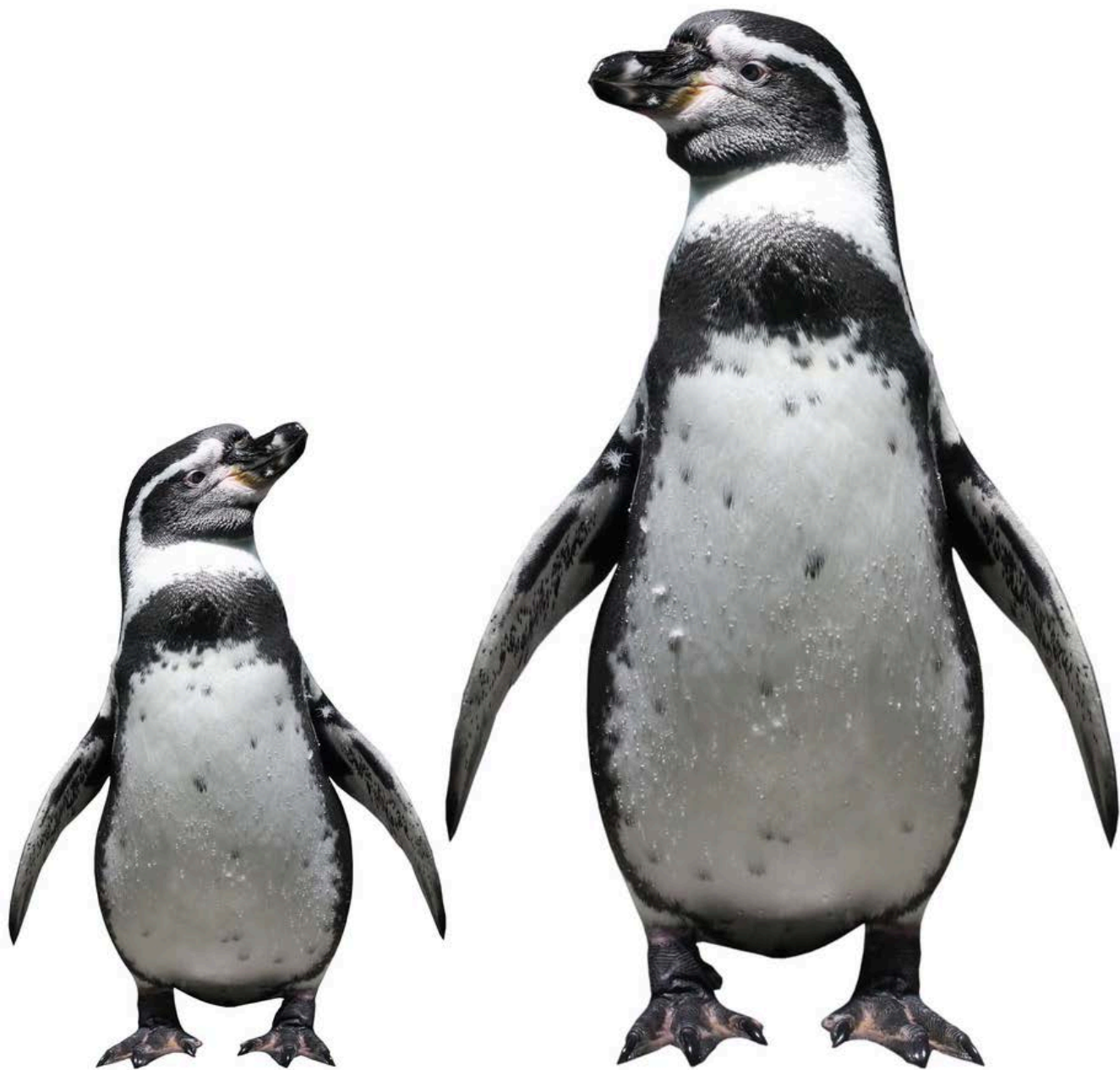
Hospital and Clinical Speciality

# Pilot Implementation

☑ Variation between teams



Hospital and Clinical Speciality



# More ...

Psychometric evaluation  
in real world clinical setting

Uptake and representativeness  
using various channels of delivery

# CollaboRATE publications

Thompson R, Nye A, Walker E, Elwyn G

Prevalence and patterns of shared decision-making in the United Kingdom

In development.

Barr PJ, Thompson R, Walsh T, Grande S, Ozanne E, Elwyn G

The psychometric properties of CollaboRATE: A fast and frugal patient-reported measure of the shared decision-making process

Journal of Medical Internet Research. 2014;16(1):e2

Elwyn G, Barr PJ, Grande SW, Thompson R, Walsh T, Ozanne EM

Developing CollaboRATE: A fast and frugal patient-reported measure of shared decision making in clinical encounters

Patient Education and Counseling. 2013 Jun 11;93(1):102–7







Elwyn G. “Patientgate”-digital recordings change everything. BMJ. 2014;2078(March):10-11. doi:10.1136/bmj.g2078.

# Patient Recordings

Elwyn G. 'Patientgate'--digital recordings change everything. *BMJ* 2014;**348**:g2078.

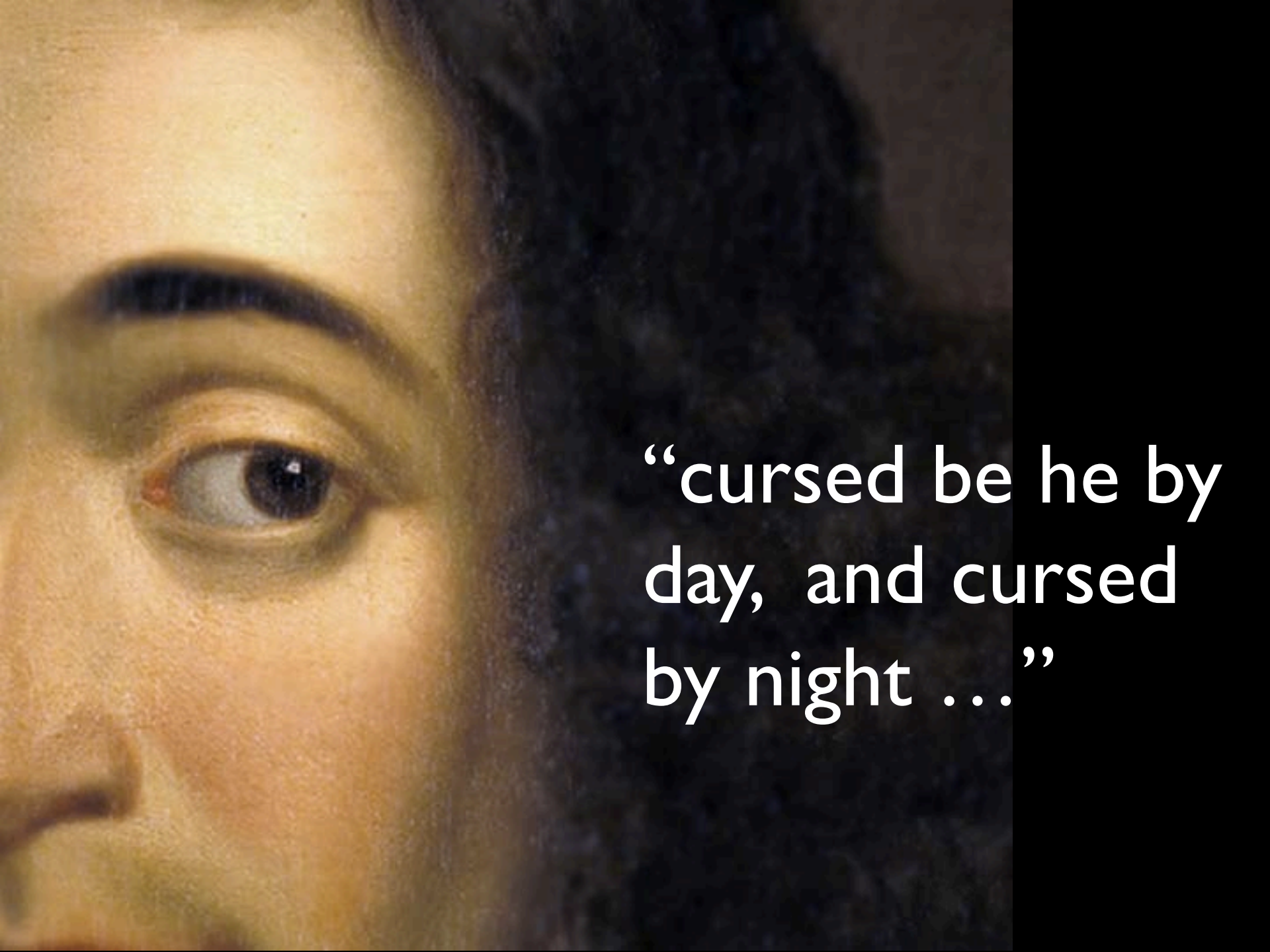
Tsulukidze M, Grande SW, Thompson R, *et al*. Patients covertly recording clinical encounters: threat or opportunity? A qualitative analysis of online texts. *PLoS One* 2015;**10**:e0125824.

Elwyn G, Barr P, Grande S. Patients' recording clinical encounters: A path to empowerment? Assessment by mixed methods. *BMJ Open* 2015;**In Press**.

# Summary

- Dare to share
- Use collaborative tools
- Measure performance
- Feedback intelligently
- Empower patients
- Put on organizational agenda

Sapere Aude



“cursed be he by  
day, and cursed  
by night ...”

[glynelwyn@gmail.com](mailto:glynelwyn@gmail.com)