“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?

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?
How much effort was made to include what matters most to you in choosing what to do next?
Sapere Aude
20 BC  Horace
First Book of Letters

1784  Immanuel Kant
Answering the question: What is Enlightenment?

1984  Michel Foucault
What is Enlightenment?
Die Offenbarung

Johannis des Theologen

Das erste Capitel.

Ist die Offenbarung des Herrn Jesus Christi, die ihm zum Zeichen und zur Erinnerung von dem der ewige Gott, und der da steht und sieht, durch seinen Engel zu erzählen, und Johannes, der Bezeuger der wahrer Worte des Herrn Jesus Christi, was er gesehen hat, und was er gesehen hat.

Johannes, der Prophet, der das erste Kapitel des Herrn Jesus Christi, was er gesehen hat, und was er gesehen hat, und was er gesehen hat, und was er gesehen hat, und was er gesehen hat, und was er gesehen hat, und was er gesehen hat, und was er gesehen hat, und was er gesehen hat.

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

Dartmouth

INSTITUTE

FOR HEALTH POLICY & CLINICAL PRACTICE
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
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.

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.

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”
Netherlands - 8 surgical procedures

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

Cumulatieve index

- 46 - 85
- 85 - 95
- 95 - 105
- 105 - 120
- 120 - 163

ziekenhuis
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

ORTHOPAEDIC AND NEUROSURGEONS PER MILLION POPULATION

USA
Netherlands
Denmark
Finland
Australia
New Zealand
England
Scotland
Sweden

RATIO
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.

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

Greenhalgh 2015
Guidelines
Wrong tool
Wrong audience
Dieoffinbarung

Johannis des theologen.

LXXIII

Das erst Capitel.

Es ist die offinbarung

Ihesu Christi. die yhm

Hott geben hat/ seinen flechten zu

legen/ was ym der kurts geschen

fall/ und ym der deyter ym gefunden

durc ym engel zu ym flechten

Johannes/ der betrachtet hat das

wort Hottis/ und der zeugnis von

Ihesu Christo/ was er geheint hat.

Hesstis der da liefer zu die das zeiden

die ym der werflustung/ und bebaus

ten was ym ym geschriven ist/ den

todt ist ym nache.


Johannes/ Den sieben gemernen

von Asia/ Buad fer mit eyn vnd fridte/ von dem der das ist/ und der
davara/ und der da Kompt/ von von den sieben gestern/ die yssand
für seinem zaeft/ und von Ihesu Christo/ welcher ist betrave jugend
er gestorben von ym todten/ und ym hift aller sonsen aus erden/
der von gelte hat/ und geworden von den ym ein mit ym einen what/
und ym zu dornen und ym gestern gemacht für hertz und ym einen

vevater/ dem selbigsten ym vnd regis ym erckerter zu ercktert ist.

Sis/er Kompt mit den ym wolken/ und ym ers werden ym ym leben alle

valler/ und die ym geschoschen haben/ und ym werden ym alle geschriven

der erden/ sab/ Amen./ Ich bin das A vnd das O/ der anfang

das ende/ spitz der horne/ des das ist/ und der das war/ und der da kom

ps/ der allemachtige.

Ich Johannes/ ewr bader/ und mitgenos am trubfeld/ und am regen

und der geburd Ihesu Christi/ war ym der zirel Patimos

und des wort Hottis vellen/ und des zeugnis Ihesu Christi/ ich war

yngest am sonagge/ und berette nyder meiner gron grande som/ als
ees

plasen/ die sprach/ Ich bin das A vnd das O/ der erste und der

letzte/ und was du hals/ das schryhe ym ein buch/ en/ sendt es co

den gemeinen ym Asia/ gen Eplision/ gen Schnyrn/ en/ gen


Und ich wand mich rymb/ zu seben nach der shrif/ die mir

redete/ und alles mich wand/ fayde ich seben gelde lechtter/ und

muts ten unter den guldten lechttern/ eynen/ der war eyn menschen son

gleich/ der war angenah mit einem leym die/ und borgzert rymb

die bunte mit eym guld garthe/ semy hebet aber wern war war

weys wie ein weysse wolhe/ als der keine/ eym angew wie ein

feur flamme/ semy healte/ gleich wie ein grind ert/ semy heyte

wie gros wassersauce/ und hatte seben sternen von eynern band/
“for we are removing impediments and difficulties so that other people may read it without hindrance”
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

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
Guidelines for the public

- Design problems
- Literacy obstacles
- Option blindness
- Difficult to find
- Search engine elusive
1982
Shared Decision Making
Helping a person develop an informed preference
Collaborative Deliberation

Recognizing Alternatives → Comparative Learning → Preference Construction → Preference Integration

Constructive Engagement

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


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
1597

scientia potentia est
is Power
Knowledge is Power
Power
Knowledge is Power

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?

Power imbalance prevents shared decision making

Joseph-Williams N, Edwards A, Elwyn G

BMJ 2014 May 14; 348: g3178
More useful tools?
2nd Generation

Encounter Tools

Enable Comparison

Generate mindlines
I prefer this one…
<table>
<thead>
<tr>
<th>Weight Change</th>
<th>Low Blood Sugar (Hypoglycemia)</th>
<th>Blood Sugar (A1c Reduction)</th>
<th>Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Metformin</strong></td>
<td>Daily Routine</td>
<td>Daily Sugar Testing</td>
<td>Cost</td>
</tr>
<tr>
<td>None</td>
<td>Metformin</td>
<td>Monitor 2–5 times weekly, less often once stable.</td>
<td>Metformin (Generic available)</td>
</tr>
<tr>
<td>Insulin</td>
<td>4 to 6 lb. gain</td>
<td>Monitor 2–5 times weekly, less often once stable.</td>
<td>Insulin (No generic available – price varies by dose)</td>
</tr>
<tr>
<td>Glitazones</td>
<td>More than 2 to 6 lb. gain</td>
<td>Monitor once or twice daily, less often once stable.</td>
<td>Glitazones (No generic available)</td>
</tr>
<tr>
<td>Exenatide</td>
<td>3 to 6 lb. loss</td>
<td>Monitor 3–5 times weekly, less often once stable.</td>
<td>Exenatide (No generic available)</td>
</tr>
<tr>
<td>Sulfonylureas</td>
<td>2 to 3 lb. gain</td>
<td>Monitor 2–5 times weekly, less often once stable.</td>
<td>Sulfonylureas (Generic available)</td>
</tr>
<tr>
<td>Glitpints</td>
<td>None</td>
<td>Monitor 2–5 times weekly, less often once stable.</td>
<td>Glitpints (No generic available)</td>
</tr>
</tbody>
</table>

Note: 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.

---

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.
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.

<table>
<thead>
<tr>
<th>Frequently asked questions</th>
<th>Lumpectomy with radiotherapy</th>
<th>Mastectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is removed?</td>
<td>The cancer lump is removed, with some surrounding tissue.</td>
<td>The whole breast is removed.</td>
</tr>
<tr>
<td>Which surgery is best for long-term survival?</td>
<td>Survival rates are the same for both options.</td>
<td>Survival rates are the same for both options.</td>
</tr>
<tr>
<td>Coming back in the breast?</td>
<td>Breast in about 10 in 100 women (10%) in the 10 years after a lumpectomy. Recent improvements in treatment may have reduced this risk.</td>
<td>Scar in about 5 in 100 women (5%) in the 10 years after a mastectomy. Recent improvements in treatment may have reduced this risk.</td>
</tr>
<tr>
<td>Will I need more than one operation?</td>
<td>Possibly, if there are still cancer cells in the breast after the lumpectomy. This can occur in up to 20 in 100 women (20%).</td>
<td>No, unless you choose breast reconstruction.</td>
</tr>
</tbody>
</table>
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.

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<tr>
<td>Which surgery is best for long-term survival?</td>
<td>Survival rates are the same for both</td>
<td>Survival rates are the same for both</td>
</tr>
<tr>
<td>What are the chances of cancer coming back in the breast?</td>
<td>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.</td>
<td>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.</td>
</tr>
</tbody>
</table>

operation? | in the breast after the lumpectomy. This can occur in up to 20 in 100 women (20%). | reconstruction. |
Explain it
Give it
Use it
4. Will I need more than one operation?

<table>
<thead>
<tr>
<th>Lumpectomy with radiation</th>
<th>Mastectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="Diagram" /></td>
<td><img src="image2" alt="Diagram" /></td>
</tr>
<tr>
<td>Possibly, 20 in 100 women (20%) might need another operation to remove more tissue or lymph nodes that have cancer.</td>
<td>Yes, if you choose breast reconstruction. Possibly, if your lymph nodes have cancer.</td>
</tr>
</tbody>
</table>

5. How long will it take to recover?

<table>
<thead>
<tr>
<th>Lumpectomy with radiation</th>
<th>Mastectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image3" alt="Calendar" /></td>
<td><img src="image4" alt="Calendar" /></td>
</tr>
<tr>
<td>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.</td>
<td>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.</td>
</tr>
</tbody>
</table>
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 2nd 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
Psychometric Testing
Psychometric Testing

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

- No SDM: 46.0
- Low SDM: 69.6
- Moderate SDM: 82.0
- High SDM: 85.8

- 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

<table>
<thead>
<tr>
<th>Hospital and Clinical Speciality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
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<tr>
<td>Renal</td>
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<tr>
<td>Cardiology</td>
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<tr>
<td>Diabetes</td>
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<tr>
<td>Respiratory</td>
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<tr>
<td>Chronic pain</td>
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<tr>
<td>Cardiology</td>
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<td>Diabetes</td>
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<tr>
<td>Bariatric surgery</td>
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<td>Enteral feeding</td>
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<td>Intermediate care</td>
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<tr>
<td>Podiatry</td>
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<tr>
<td>Manual handling</td>
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<td>Wheelchair services</td>
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<tr>
<td>Mental health</td>
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<tr>
<td>Antenatal screening</td>
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<td>Diabetes</td>
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<td>Respiratory</td>
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<td>Musculoskeletal</td>
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<td>Chronic pain</td>
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<td>Epilepsy</td>
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<td>COPD</td>
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<tr>
<td>Diabetes</td>
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<tr>
<td>Oncology</td>
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<tr>
<td>Respiratory</td>
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<tr>
<td>Gynaecology</td>
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<tr>
<td>Vasectomy</td>
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</tbody>
</table>
Pilot Implementation

☑ Variation between teams

<table>
<thead>
<tr>
<th>Hospital and Clinical Speciality</th>
<th>A</th>
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<th>D</th>
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<tr>
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Pilot Implementation

☑️ Variation between teams

Hospital and Clinical Speciality

- Diabetes
- Renal
- Cardiology
- Diabetes
- Respiratory
- Chronic pain
- Cardiology
- Diabetes
- Bariatric surgery
- Enteral feeding
- Intermediate care
- Podiatry
- Manual handling
- Wheelchair services
- Mental health
- Antenatal screening
- Diabetes
- Respiratory
- Musculoskeletal
- Chronic pain
- Epilepsy
- COPD
- Diabetes
- Oncology
- Respiratory
- Gynaecology
- Vasectomy
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 Recordings


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