

Les décisions médicales partagées dans la pratique clinique



Reproduced from cover page of JAMA, Users' Guide to the Medical Literature, 3rd ed.

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 [@ThomasAgoritsas](https://twitter.com/ThomasAgoritsas)

Conflits d'intérêts potentiels

- **FINANCIERS:** Aucun financement pharmas ou devices
- **INTELLECTUELS:** membre de plusieurs groupes EBM et guidelines
 - Expertise décision partagée
 - Membre de GRADE <http://www.gradeworkinggroup.org>
 - Deputy CEO of the MAGIC Evidence Ecosystem Foundation
<http://magicevidence.org>
Organisation à but non-lucratif pour l'amélioration de la création, dissémination, et mise à jour des guidelines, résumés d'évidences et aides décisionnelles.
 - Co-fondateur BMJ Rapid Recommendations
www.bmj.com/rapid-recommendations
 - Editeur de ACP journal club / Evidence Alerts
<https://plus.mcmaster.ca/evidencealerts>

Plan

- **Introduction: paternalisme & décisions**
- **Shared Decision Making (SDM)**
 - définition et application
 - approches et modèles
- **Evidence Based Medicine (EBM)**
 - Ingrédients à la décision
 - La place des recommandations (vs indications)
 - Evidence & Incertitude
- **SDM & EBM : les aides décisionnelles**
- **Considérations pratiques: la vraie vie**
- **Patients partenaires: une révolution**
- **Applications aux personnes trans***
 - De l'évidence à la décision
 - Une médecine personnalisée
 - Gestion du regret décisionnel
- **Conclusions**



Soins centrés patient



Médecine personnalisée

Décision partagée (SDM)



Barry et al. Shared decision making - pinnacle of patient-centered care. *NEJM* 2012;366:780-1.

Stigglebout et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ* 2012;344:e256.

Djulbegovic B et al. Evidence-based practice is not synonymous with delivery of uniform health care. *JAMA* 2014;312:1293-4.

Pourquoi des soins "centrés patient" ?

- Bénéfices documentés (*Revue par Rathert, Med Care Res Rev, 2013*)
- Amélioration du niveau de connaissances
- Compréhension, motivation et engagement et potentiellement de l'adhérence aux traitements (*Nieuwlaat, Cochrane 2014*)
- Contrôle sur sa santé et soins
« empowerment », « self-management », « responsabilisation »
« Education thérapeutique »
mais attention à la charge des mots
- Congruence et meilleure résolution des symptômes
(*Cedraschi, Allaz, 1998; Bass, Skelton 1996*)
- Satisfaction face aux soins
(*Glass, Patient Educ Couns, 2012, Rathert, 2013*)

La pratique clinique = myriade de décisions

Besoin de SDM

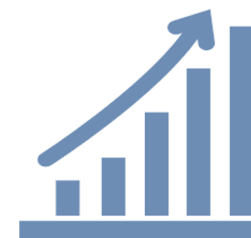
- Quand devrais-je consulter [Patient]
- Quand devrais-je hospitaliser [Médecine]
- Quand devrais-je appeler le médecin? [Infirmier.e]

- Quel test diagnostique effectuer/proposer?
- Que devrions-nous dépister et quand?

- **Quels sont les options thérapeutiques raisonnables?**
- Quel type et fréquence de suivi?
- Quels sont les aspects pratiques à mettre en oeuvre?

+ nombreuses interactions thérapeutiques non décisionnelles

→ **Champ de connaissances**



Enjeux et issues cliniques

➤ **Nature de la décision**

- Prévention
- Traitement
- Absence de traitement / délai, etc.

➤ **Issues cliniques:**

- Mortalité / Survie
- Besoin en soins critique (ex. intubation)
- Risque d'événement : nouveau ou récurrence (ex. AVC, infarctus)
- Symptômes
- Qualité de vie
- Fonctionnalité
- Fertilité
- Risque de suicide (tentamen ou réussi)
- Burn-out...

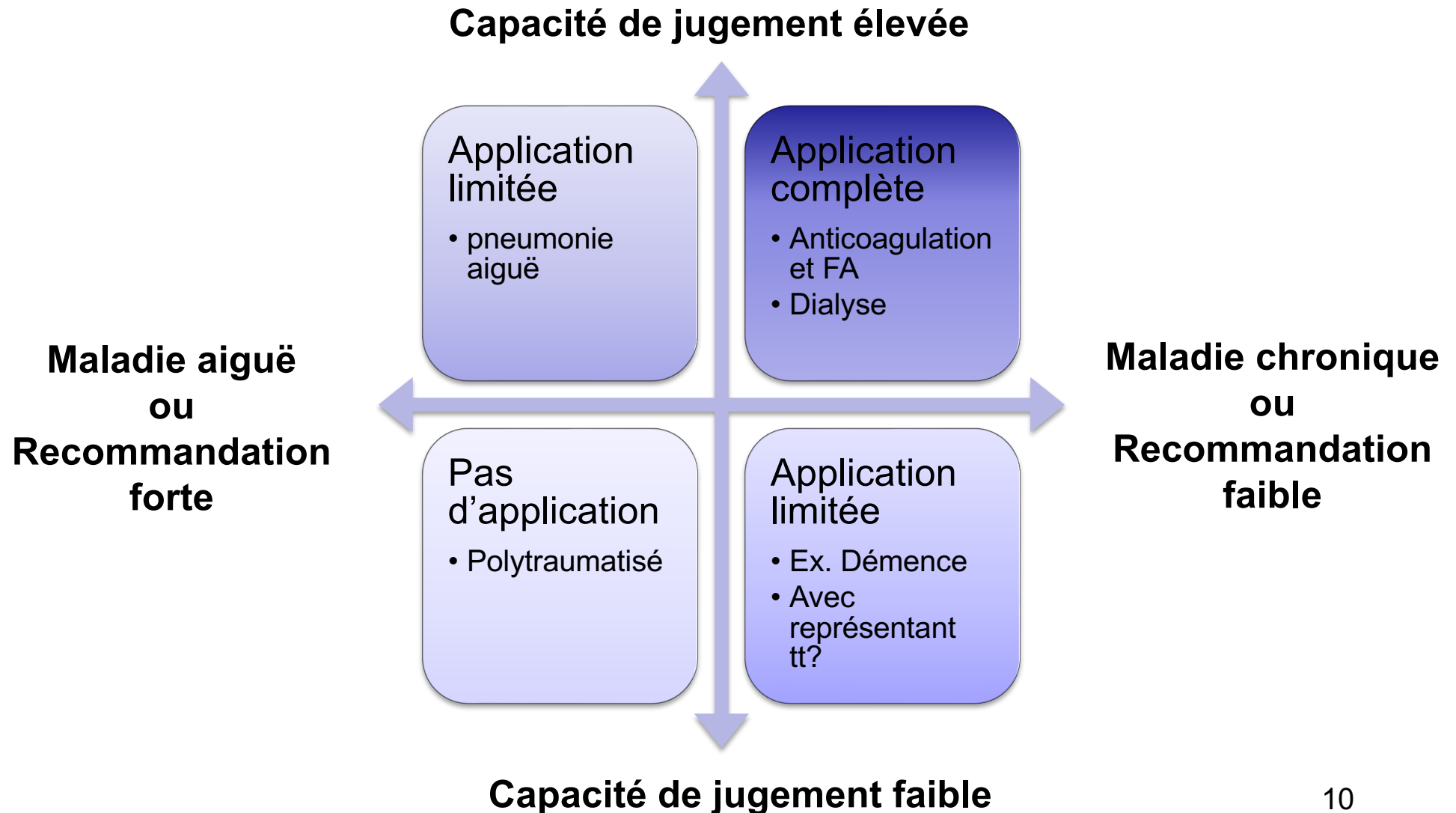
Shared Decision Making

Définition & Application

- Pour vous, que veut dire partager la décision
- Quand est-ce plus ou moins utile, opportun, nécessaire (ou pas) ?



Pertinence d'application SDM



La décision partagée est un processus par lequel
un **patient** et un **clinicien**
travaillent ensemble,
ont une **conversation**,
entrent en partenariat
afin d'identifier **la meilleure approche**,
le meilleur traitement ou test
dans une situation donnée.

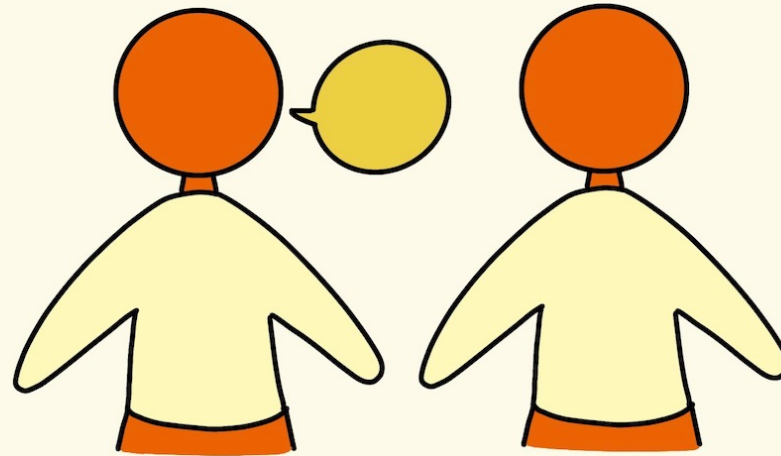
C'est un **partage de ce qui compte**

Les cliniciens partagent l'information sur les alternatives disponibles, les risques, bénéfices, implications pratiques.

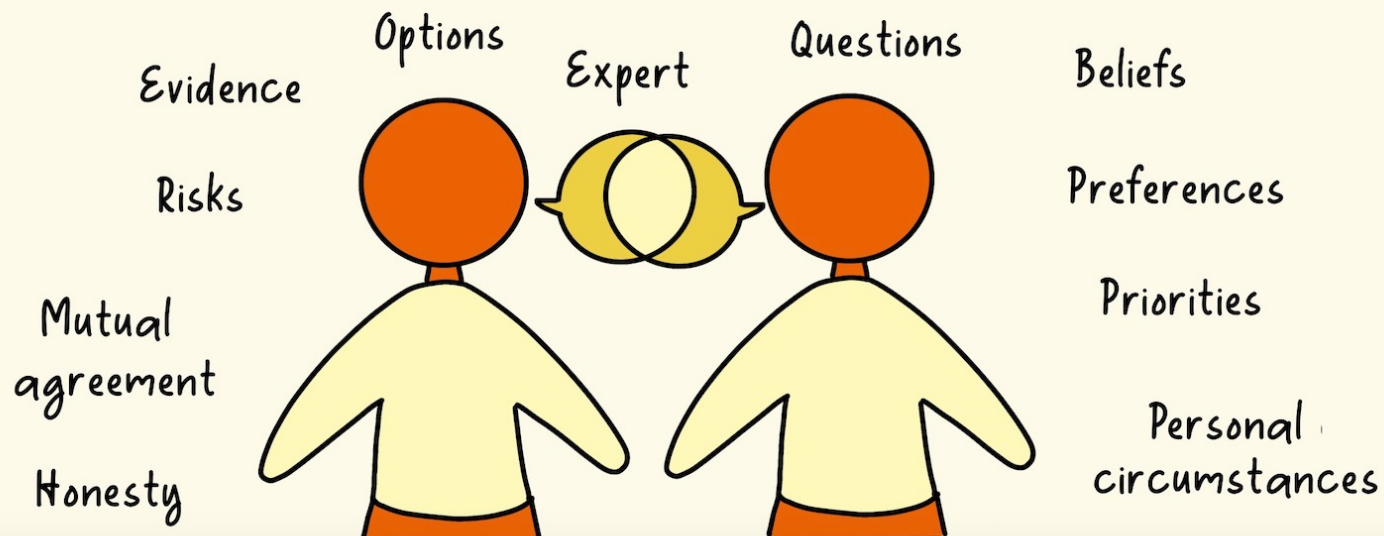
Les patients partagent les expériences, attentes, valeurs, préférences

Informed decision making is not...

Expert



Informed decision making is...



Décision partagée: croyances et objections

- Consultation plus longues?
 - Pas de rallongement systématique (3 revues systématiques)
- Les patients ne désirent pas partager la décision?
 - 70-90% préfèrent SDM (enquête européenne >8000 pat)
 - Time trend (50% avant les années 2000)
 - >50% insatisfaits (quantité d'info et implication)
- Les patients n'en sont pas capables?
 - Faux, y compris les populations vulnérables / illettrées
- Mais on le fait déjà!
 - Pas assez... »perception-reality gap «
 - Moyenne 23/100 sur OPTION scale (33 études internationales)

Shared Decision Making

Approches & Modèle



Dr's knowledge of the facts

The **SHARE** Approach

Essential Steps of Shared Decision Making

Step 1: **S**eek your patient's participation

Step 2: **H**elp your patient explore and compare treatment options

Step 3: **A**ssess your patient's values and preferences

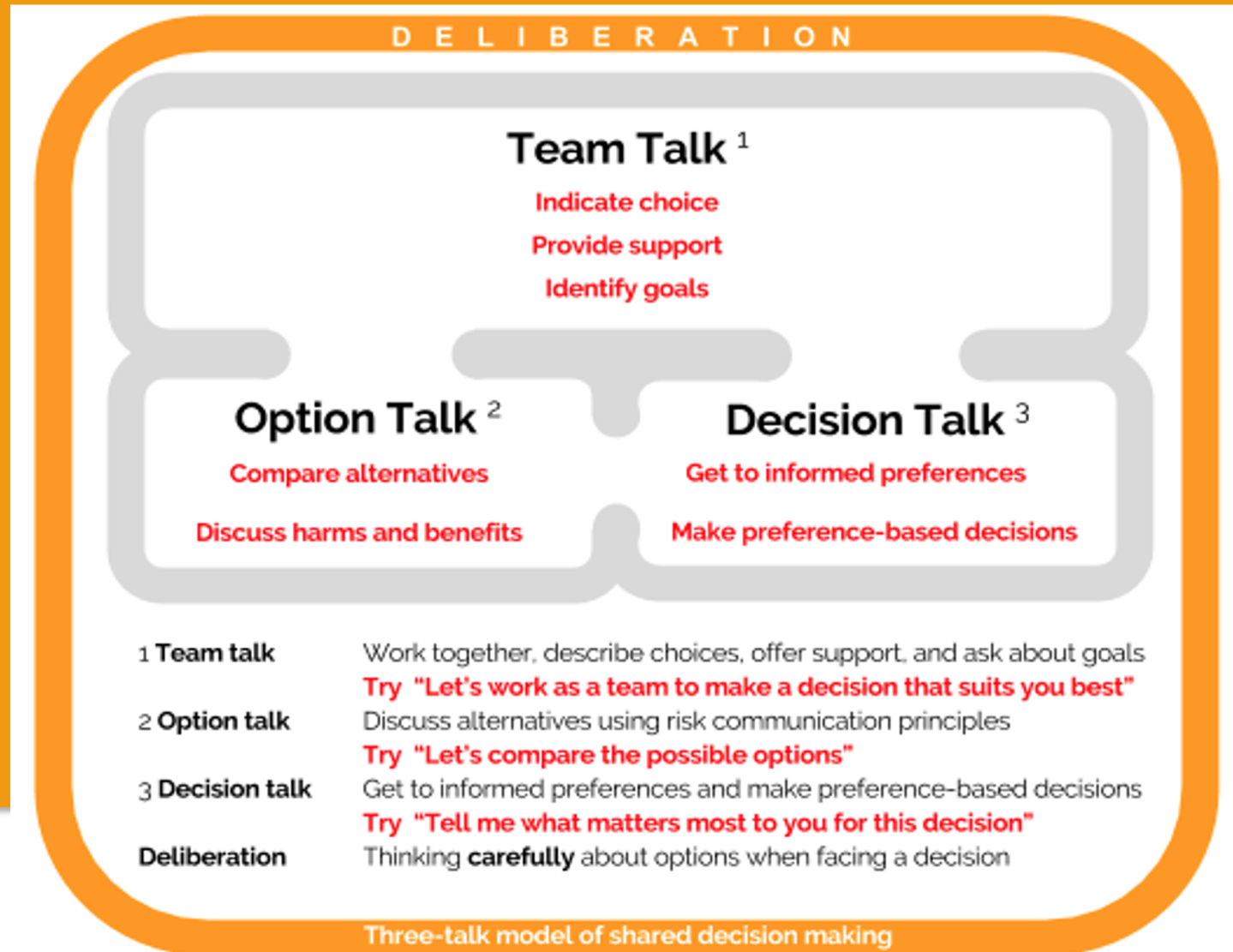
Step 4: **R**each a decision with your patient

Step 5: **E**valuate your patient's decision

Steps (not strictly sequential!)	Goals
1. Prepare	Knowing facts, EBM
2. Partnership with patient	S eek patient participation
3. Barriers to communication	
4. Nature of decision	
5. Patient's role in decision	
6. Patient's decision making capacity	
7. Options	H elp the patient explore and compare options
8. Benefits and risks	
9. Questions	
10. Patient understanding	
11. Patient preference	A ssess patient values and preferences
12. Shared decision	R each decision
13. Action plan	E valuate decision
14. Documentation (file)	
15. Teaching	

Collaborative Deliberation

*Une danse
en 3 temps...*



*Elwyn G et al. **Shared decision making: a model for clinical practice.**
J Gen Intern Med. 2012 Oct;27(10):1361-7.*

Evidence Based Medicine

Ingrédients à la décision

Evidence-Based Medicine

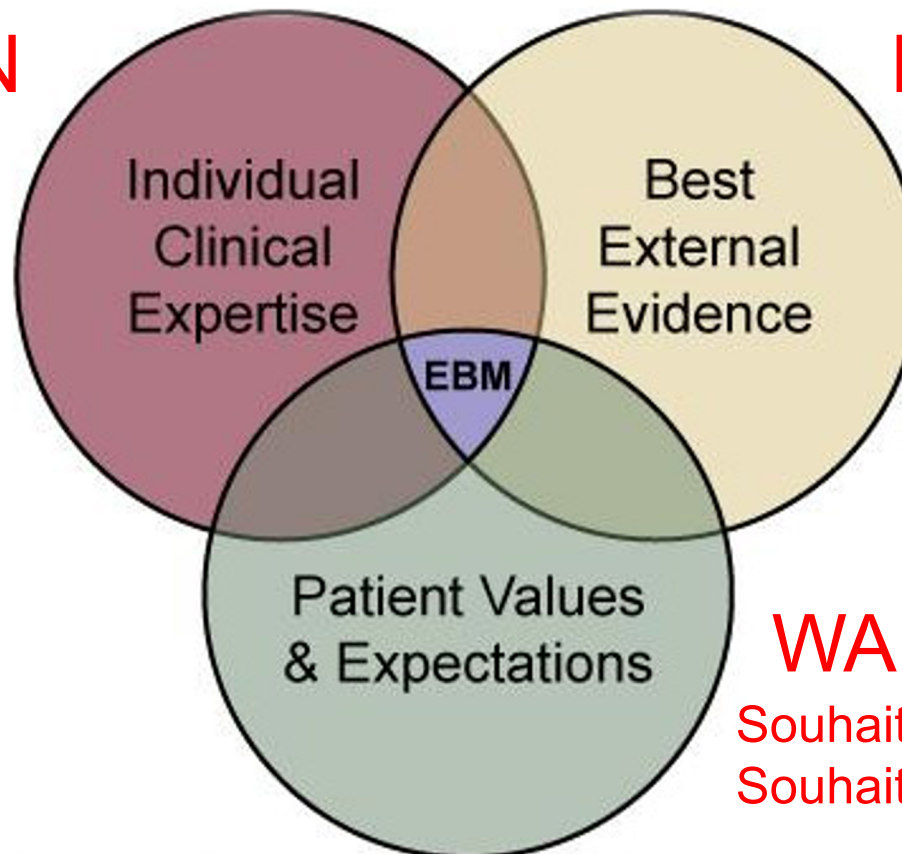
A New Approach to Teaching the Practice of Medicine

Evidence-Based Medicine Working Group

A NEW perspective is emerging in medicine, one that de-emphasizes clinical experience and emphasizes rational clinical decision-making based on a systematic examination of the medical literature. This approach requires new teaching methods, including efforts to apply evidence evaluation to clinical practice.

An important competency program in the practice of medicine. Strathclyde Medical Academy has voted to let its residents recruit medical students who are interested in medicine; and providing faculty with feedback on their performance as role models and teachers of evidence-based medicine. The influence of evidence-based medicine on clinical practice and medical education is increasing.

CAN
Faisable?



NEED
Approprié?

and at 3 and 60%. 18 months likely be this information with a record of medication 18 months. far idea of

WANT
Souhaitable?
Souhaité?

scientific ing at the problems that d and the that may defects in late to the no longer

in a state of vague trepidation about his risk of subsequent seizure.

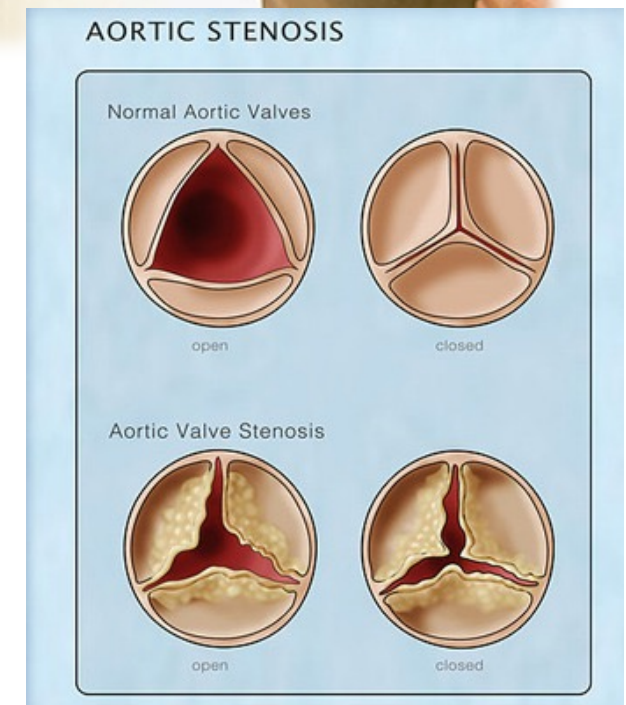
The Way of the Future

The resident asks herself whether she

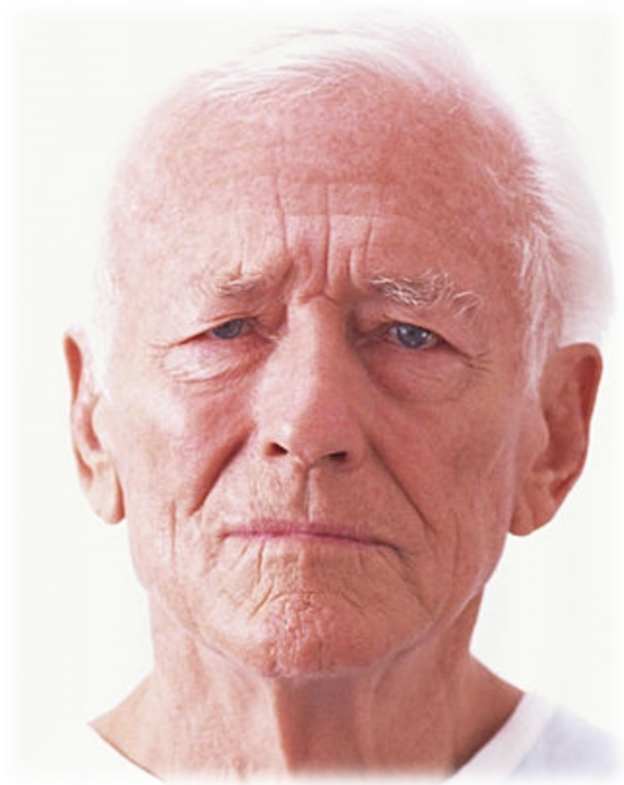
tenable, the paradigm is challenged and replaced by a new way of looking at the world. Medical practice is changing, and the change, which involves using the medical literature more effectively in

Daniel, 66 ans

- Récemment retraité
 - Essoufflement à l'effort
 - Très limitant au quotidien
 - A perdu connaissance
-
- Souffle à l'auscultation
 - Echographie du coeur:
 - **Sténose aortique sévère**



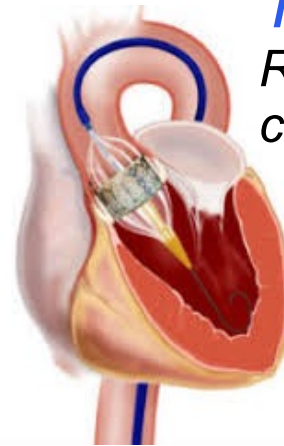
Selon vous, quels sont les ingrédients à la décision dont Daniel et ses médecins ont besoin?



Les ingrédients utiles à la décision?

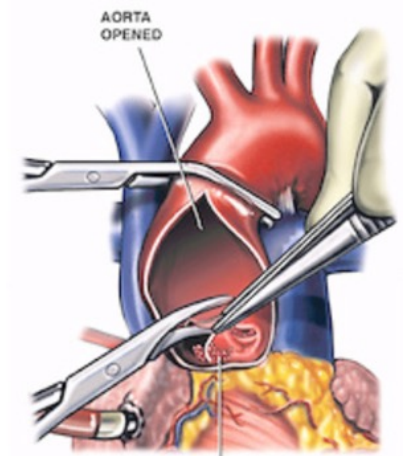
Quels options?

Le menu



TAVI

Remplacement par cathétérisme



SAVR

Remplacement par chirurgie

Bénéfices & Risques

La pesée



Certitude

« L'indice de confiance »

Aspects pratiques



Ingredient à la décision n°1

Equilibre Risque / Bénéfice



January 9, 2017

Clinicians' Expectations of the Benefits and Harms of Treatments, Screening, and Tests

A Systematic Review

Tammy C. Hoffmann, PhD¹; Chris Del Mar, MD, FRACGP¹

» Author Affiliations

JAMA Intern Med. Published online January 9, 2017. doi:10.1001/jamainternmed.2016.8254

In this systematic review, $\geq 50\%$ of clinicians...



BENEFITS

7 (32%) of 22 outcomes

3 (11%) of 28 outcomes

2 (9%) of 22 outcomes

overestimated

correctly
estimated

underestimated

HARMS

5 (5%) of 58 outcomes

9 (13%) of 69 outcomes

20 (34%) of 58 outcomes

Hoffmann TC, Del Mar CB. Clinicians' expectations of the benefits and harms of treatments, screening, and tests: a systematic review. *JAMA Int Med.* doi:10.1001/jamainternmed.2016.8254

Pourquoi des effets absolus ?

Intervention vs. Comparaison

Avec une réduction de 50 % de mortalité (relative)

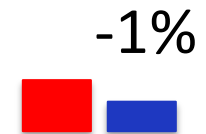
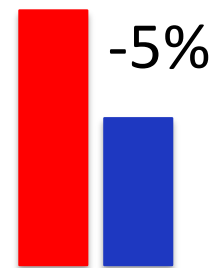
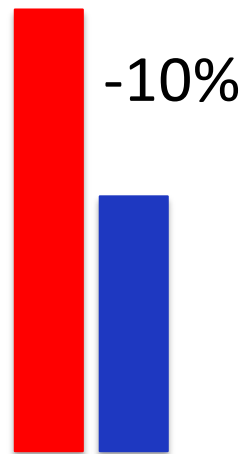
RR = 0.5

Scénario 1
20 % → 10%

Scénario 2
10 % → 5%

Scénario 3
2 % → 1%

Différence
absolue:



Patients
sauvés:

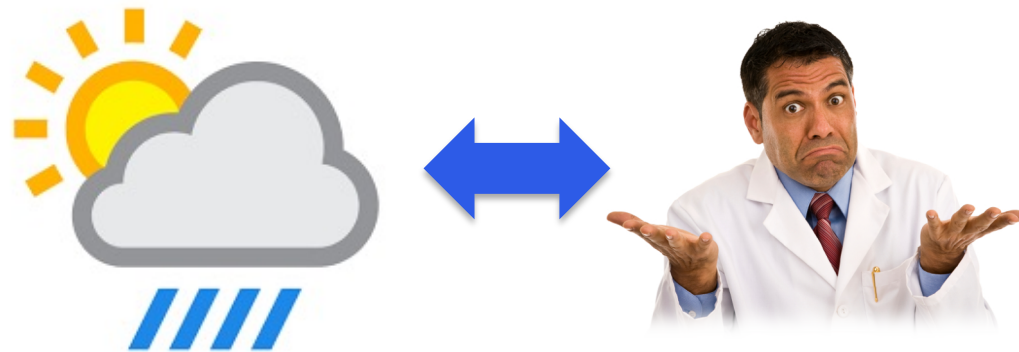
10 patients
sur 100

5 patients
sur 100

1 patients
sur 100

Ingredient à la décision n°2

Certitude de l'évidence
*(...c-à-d dans l'estimation
des risques et bénéfices!)*



<http://www.gradeworkinggroup.org/index.htm>

ANALYSIS

GRADE

RATING QUALITY OF EVIDENCE AND STRENGTH OF RECOMMENDATIONS

GRADE: an emerging consensus on rating quality of evidence and strength of recommendations

Guidelines are inconsistent in how they rate the quality of evidence and the strength of recommendations. This article explores the advantages of the GRADE system, which is increasingly being adopted by organisations worldwide

Guideline developers around the world are inconsistent in how they rate quality of evidence and grade strength of recommendations. As a result, guideline users face challenges in understanding the messages that grading systems try to communicate. Since 2006 the *BMJ* has requested in its "Instructions to Authors" on bmj.com that authors should preferably use the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system for grading evidence when submitting a clinical guidelines article. What was behind this decision?

Gordon H Guyatt professor,
Department of Clinical
Epidemiology and Biostatistics,
McMaster University, Hamilton,
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Andrew D Oxman researcher,
Norwegian Knowledge Centre for
the Health Services, PO Box 7004,
St Olavs Plass, 0130 Oslo, Norway
Gunn E Vist researcher,
Norwegian Knowledge Centre for
the Health Services, PO Box 7004,
St Olavs Plass, 0130 Oslo, Norway

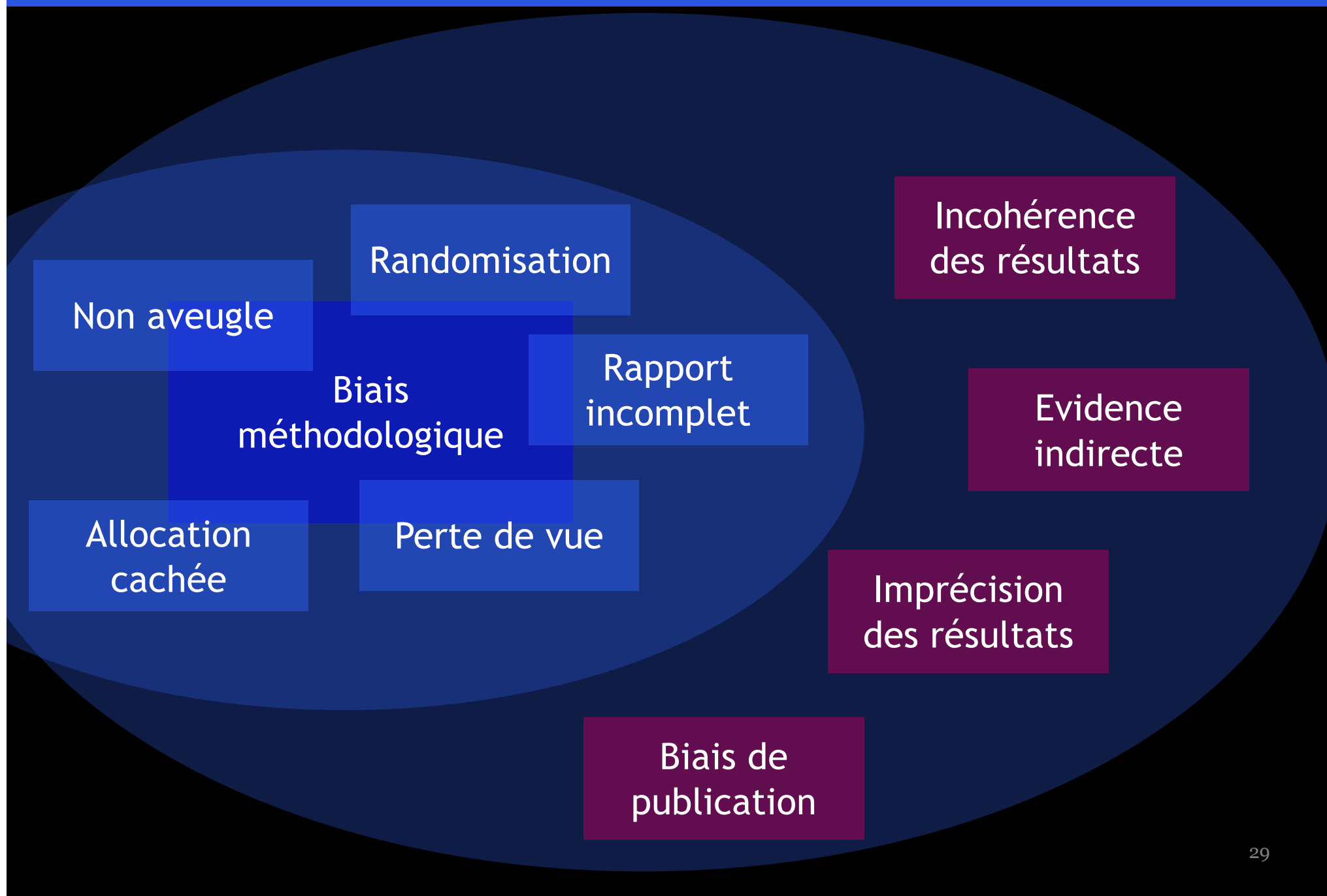
advantages and disadvantages but also by their confidence in these estimates. The cartoon depicting the weather forecaster's uncertainty captures the difference between an assessment of the likelihood of an outcome and the confidence in that assessment (figure). The usefulness of an estimate of the magnitude of intervention effects depends on our confidence in that estimate.

Expert clinicians and organisations offering recommendations to the clinical community have often erred as a result of not taking sufficient account of the quality of evidence.² For a decade, organisations recommended

GRADE: 100+ Organisations

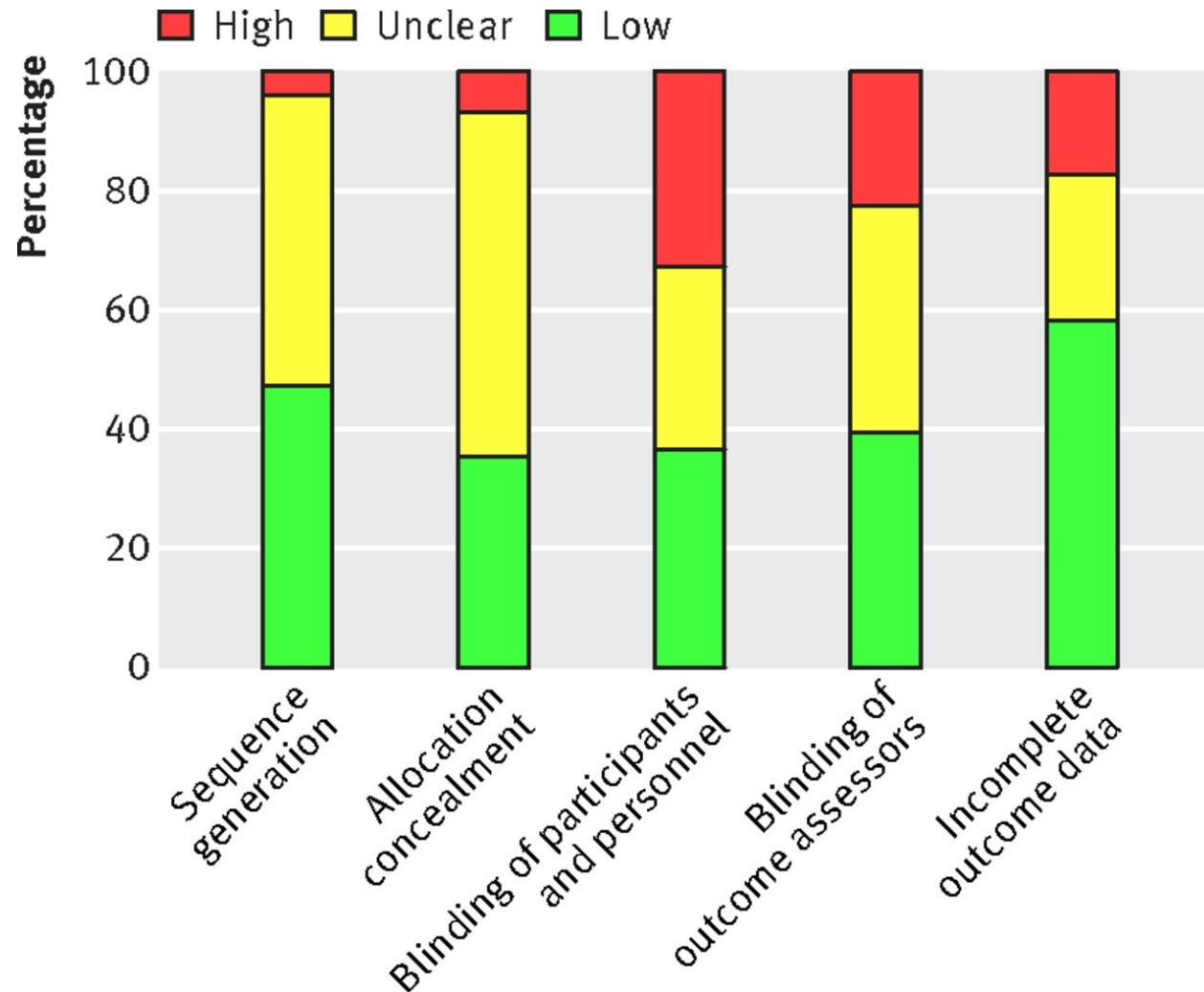


2005 2006 2007 2008 2009 2010 2011

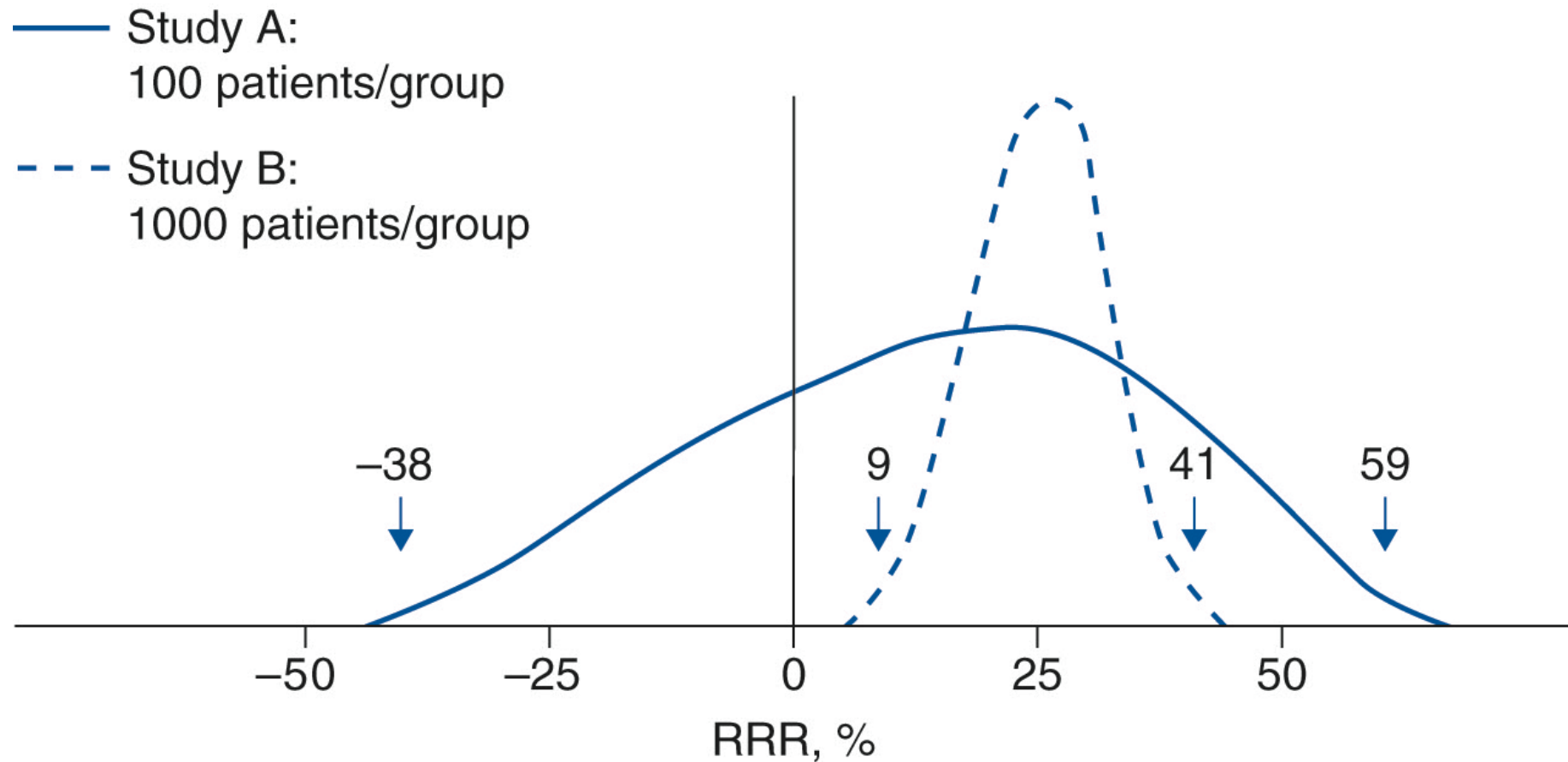


Biais méthodologique

Example for each key
methodological item in 20 920 trial articles.

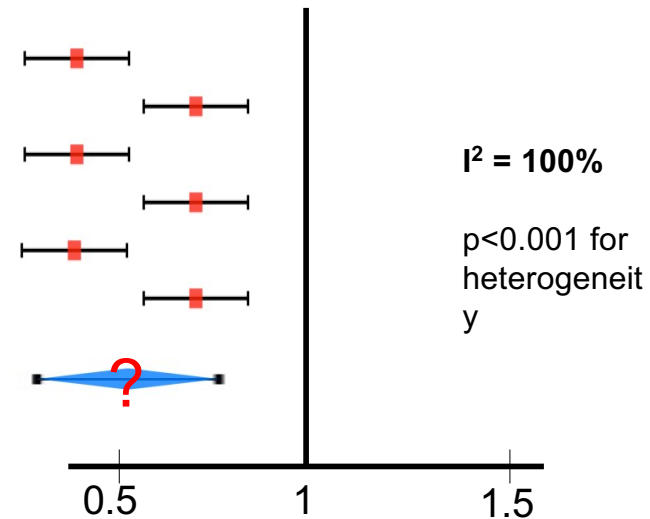
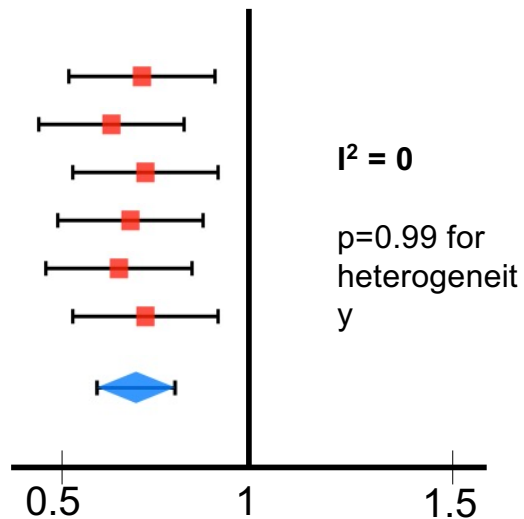


L'effet du traitement est-il précis?



Incohérence des résultats

Les résultats entre les études sont-ils hétérogènes?



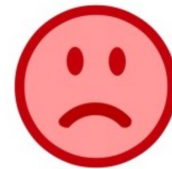
Evidence
indirecte

Etudie-t-on la bonne question?

Notre
question
clinique



P	Patients	Q
I	Intervention	Q
C	Comparison	Q
O	Outcomes	Q



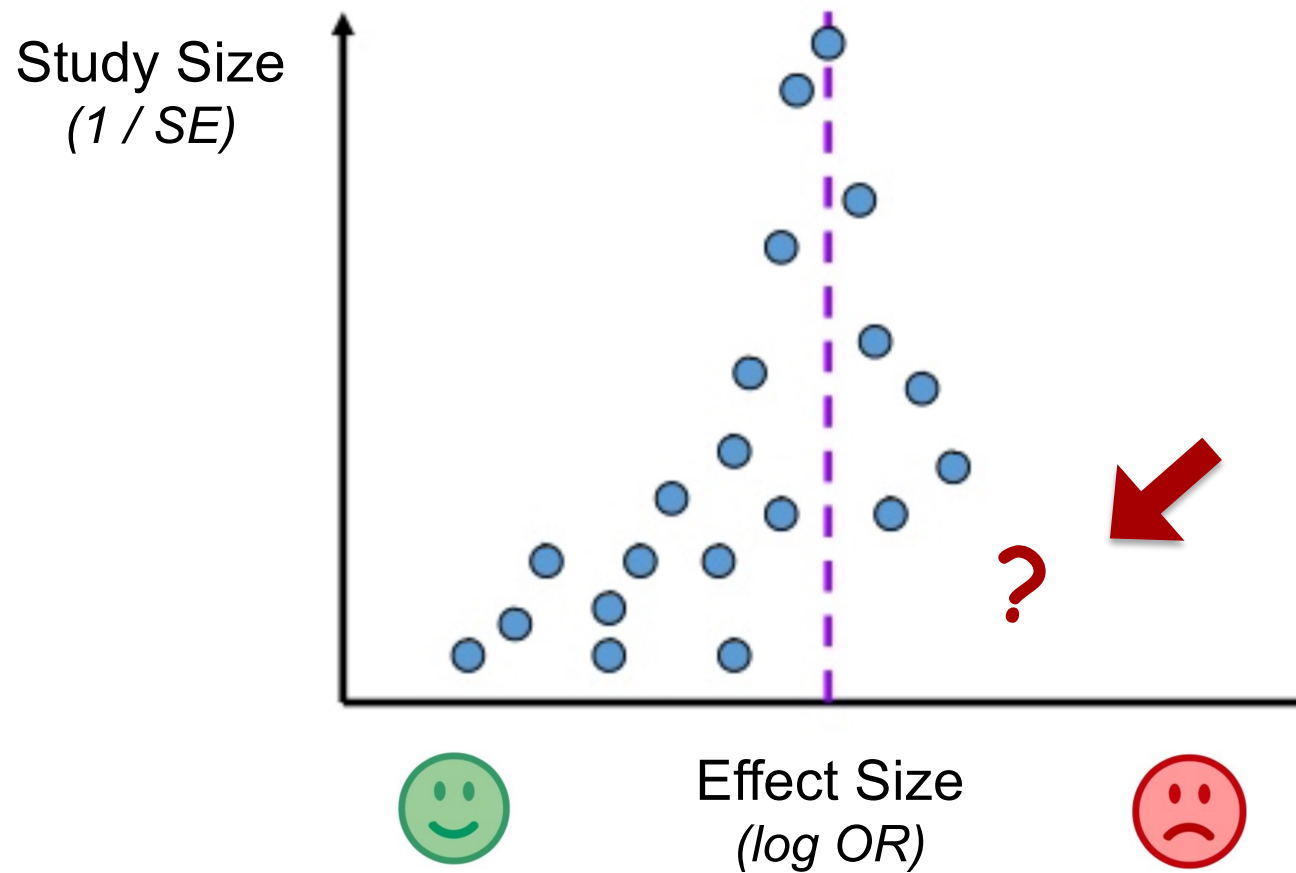
L'étude



P	Patients	Q
I	Intervention	Q
C	Comparison	Q
O	Outcomes	Q

Biais de publication

Est-ce que toutes les données sont publiées?



Essais randomisé & Etudes observationnelles?

Table: GRADE's approach to rating quality of evidence (aka confidence in effect estimates)

For each outcome based on a systematic review and across outcomes (lowest quality across the outcomes critical for decision making)

1. Establish initial level of confidence		2. Consider lowering or raising level of confidence		3. Final level of confidence rating
Study design	Initial confidence in an estimate of effect	Reasons for considering lowering or raising confidence		Confidence in an estimate of effect across those considerations
		↓ Lower if	↑ Higher if*	
Randomized trials →	High confidence	Risk of Bias Inconsistency Indirectness Imprecision Publication bias	Large effect Dose response All plausible confounding & bias • would reduce a demonstrated effect or • would suggest a spurious effect if no effect was observed	High ⊕⊕⊕⊕
				Moderate ⊕⊕⊕○
Observational studies →	Low confidence			Low ⊕⊕○○
				Very low ⊕○○○

*upgrading criteria are usually applicable to observational studies only.



Essais randomisé & Etudes observationnelles?

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				Low ⊕⊕○○
				Very low ⊕○○○

*upgrading criteria are usually applicable to observational studies only.



Ingredient à la décision n°3

Valeurs et Préférences des patients

Concernant les
interventions
elles-mêmes

Ex.

- Hormonothérapie
- Chirurgie
- Radiothérapie...

Importance
relative des
issues
cliniques

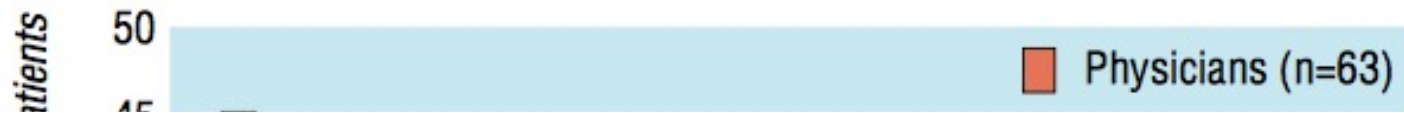
Cette recommandation accorde
une valeur élevée à [#1],
et une valeur relativement moindre à [#2].

Patient Values and Preferences in Decision Making for Antithrombotic Therapy: A Systematic Review

**Antithrombotic Therapy and Prevention of Thrombosis,
9th ed: American College of Chest Physicians
Evidence-Based Clinical Practice Guidelines**

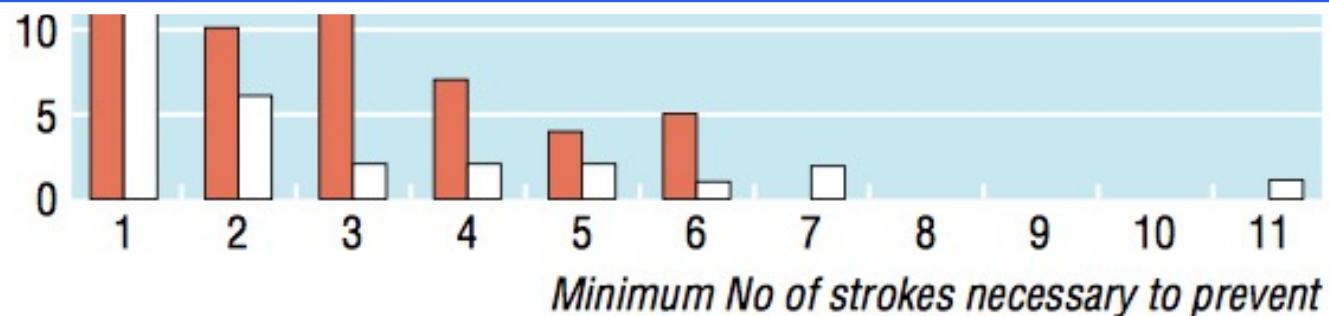
*Samantha MacLean, MSc; Sohail Mulla, BHSc; Elie A. Akl, MD, MPH, PhD;
Milosz Jankowski, MD, PhD; Per Olav Vandvik, MD, PhD; Shanil Ebrahim, MSc;
Shelley McLeod, MSc; Neera Bhatnagar, MLIS; and Gordon H. Guyatt, MD, FCCP*

Sur 100 patients, combien de saignements sévères seriez vous prêt à accepter pour continuer à anti-coaguler un patient à risque d'événements thrombotique?



Éléments clés de la revue de valeurs et préférences

- Infarctus = embolie = TVP = saignement sévère
- 1 AVC = 3 saignements (et donc 3 événements auxquels les patients accorde une valeur analogue)



Value and preference statements

- Stroke guideline: patients with TIA clopidogrel over aspirin (Grade 2B).
- Underlying **values** and preferences: This recommendation to use clopidogrel over aspirin places a relatively high value on a small absolute risk reduction in stroke rates, and a relatively low value on minimizing drug expenditures.

RESEARCH

Open Access



Using patient values and preferences to inform the importance of health outcomes in practice guideline following the GRADE

Yuan Zhang¹, Pablo Alonso Coello^{1,2}, Jan Brožek^{1,4}, Joerg J. Meerpohl^{5,6}, Waleed Alhazzani^{1,3}, Alonso J. Viera^{1,9}, John J. Riva^{1,9}, Ainsley Moore^{1,9}, Juan José Yepes ^{1,9}, Veena Manja^{13,14}, Maicon Falavigna^{15,16}, Ignacio Garcia-Grimola^{1,4}, Bram Rochwerf^{1,3}, Andrea Darzi⁴, Maria Ximena Viera^{1,9} and Holger J. Schünemann^{1,3*}

Abstract

Background: There are diverse opinions and concepts of patient values and preferences (i.e. the importance people place on health outcomes). This article aims to provide an overview of a process for systematically incorporating values and preferences in guideline development.

Table 1 Eligibility criteria for the systematic review of patient values and preferences

Category	Measurement
Utility/Health Status Value	Standard Gamble
	Time Trade Off
	Visual Analogue Scale
	Multi-attribute instruments (i.e. EQ-5D utility, HUI utility)
Non-utility, quantitative information	Utility or health status values transformed (mapping) from quality of life measurements (both generic or disease specific tools) ^a
	Direct/Forced Choice exercise: choice from a set of options
Qualitative information	Non-utility measurement of health states: other self-developed questionnaires and scales
	Qualitative research

^a Referring to transforming scores from quality of life measurement into a utility or health status value based on transformation equations

Evidence Based Medicine

La place des recommandations

PANDEMIE & INFODEMIE



Global Coronavirus COVID-19 Clinical Trial Tracker

Cytel

2914

Trials selected*

Trial status

Recruiting, Completed, Comp

Count Country

488 United States

384 China

278 Iran

263 India

172 Spain

126 France

108 United Kingdom

? FAQ * Details

2020-11-02 3:28 PM PDT

Trials Protocols

ID URL PDF Count

NCT04594330 Link NA India

NCT04594460 Link NA China

NCT04593641 Link NA South

NCT04513470 Link NA Israel

NCT04591600 Link NA Iraq

NCT04591210 Link NA Canada

World Map

Treatment Network

Cumulative registration

Cumulative recruitment

Summary plots

Secondary filter

Treatment

Treatment	Count
Other	411
(hydroxy)chloroquine	341
Alternative therapy	252
Plasma based therapy	164
Traditional Chinese Medicine	126
Vaccine	118
Lopinavir/ritonavir	111
Stem cell therapy	94
Azithromycin	92
mAb	80

Partners About

Data

Reset

Outcome

Clinical Improvement Score (Any SpO2

Radiographic Findings

Mortality, Hospitalization, Serious Mortality

Mortality, ICU Admission, Hospi

Back in (pre-covid) time !

>4000 new publications in PubMed every day

> 100 trials &
> 20 systematic reviews

Failure of Clinical Practice Guidelines to Meet Institute of Medicine Standards

Kung et al. Arch Intern Med. 2012

* Evaluation on 18 criteria (from 25) – N=130 guidelines

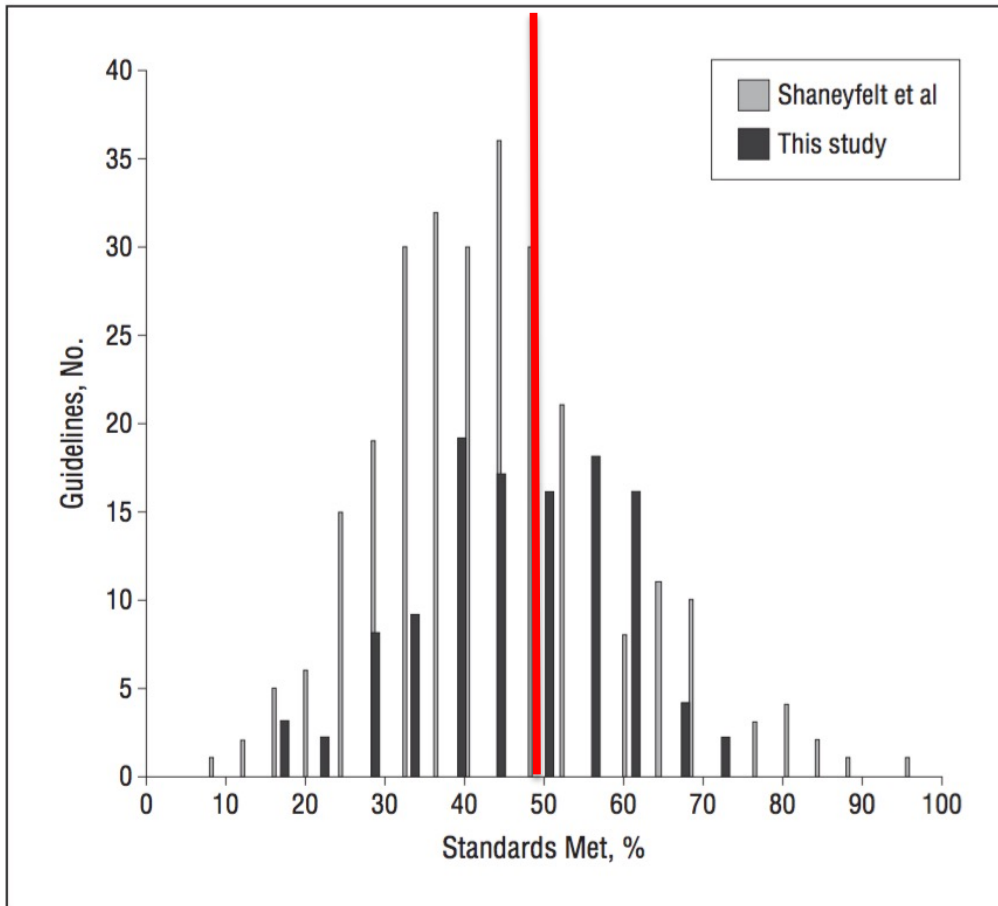


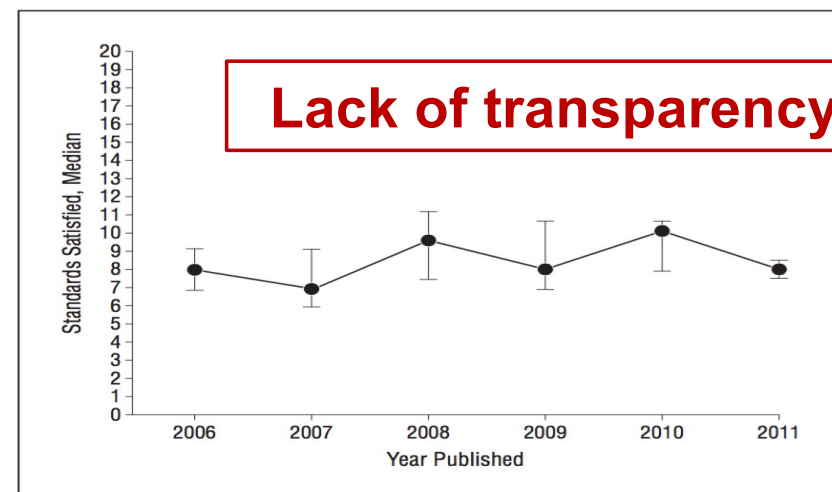
Table 1. Frequency of Adherence to Institute of Medicine Standards by Organization Type and Subspecialty Area

Organization Type (No. of Guidelines)	Standards Met, Median	Guidelines Meeting >50% of Standards, No. (%)
All (114)	8 (44.0)	56 (49.1)
United States (68)	8 (44.0)	34 (50.0)
Non-US (46)	9 (50.0)	22 (47.8)
US government agency (15)	9 (50.0)	10 (66.7)
Subspecialty societies (41)	8 (44.0) ^a	16 (39.0) ^b
Subspecialty area		
Infectious diseases (21)	9 (50.0)	11 (52.4)
Oncology (17)	9.5 (52.8)	9 (52.9)
OB/GYN (12)	8 (44.0)	3 (25.0)
All other (64)	8 (44.0)	36 (56.2) ^c

Financial COI

- 71% of guideline chairs
- 91% of co-chairs

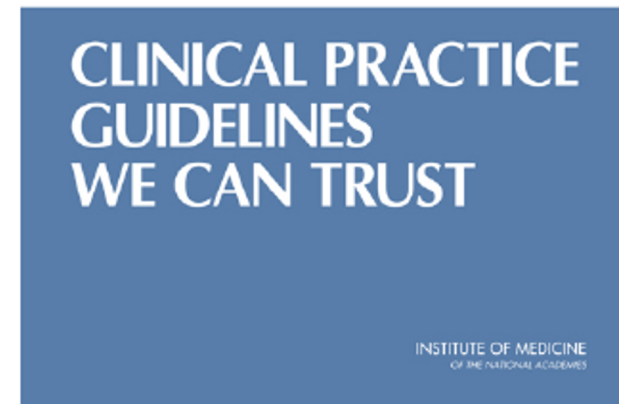
Patients included – 15%



Institute of Medicine (IOM) – 2011

Trustworthiness standards (25 items)

1. Establish transparent process
2. Manage conflict of interest (COI)
3. Panel composition: balanced, multidisciplinary, including patients
4. Based on SR for each question
5. Clarify the “ingredients” for each recommendation
 - Summaries of benefits and harm
 - Quality of the evidence (or lack thereof)
 - Role of values and preferences
6. Articulation of the recommendation :
 - Clarity, strength, rationale
7. External review, patient involvement
8. Updating strategy



AGREE



ANALYSIS

GRADE

RATING QUALITY OF EVIDENCE AND STRENGTH OF RECOMMENDATIONS

GRADE: an emerging consensus on rating quality of evidence and strength of recommendations

Guidelines are inconsistent in how they rate the quality of evidence and the strength of recommendations. This article explores the advantages of the GRADE system, which is increasingly being adopted by organisations worldwide

Guideline developers around the world are inconsistent in how they rate quality of evidence and grade strength of recommendations. As a result, guideline users face challenges in understanding the messages that grading systems try to communicate. Since 2006 the *BMJ* has requested in its "Instructions for Authors" on bmj.com that authors should use the Grading of Recommendations Assessment and Evaluation (GRADE) system when submitting a clinical guidelines article. What was behind this decision?

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Andrew D Oxman researcher,

advantages and disadvantages but also by their confidence in these estimates. The cartoon depicting the weather forecaster's uncertainty captures the difference between an assessment of the likelihood of an outcome and the confidence in that assessment (figure). The use of intervention that estimate. as offering recommendations have often erred as a result of not taking sufficient account of the quality of evidence.² For a decade, organisations recommended

→ BMJ 2004, BMJ 2008, JCE 2010-present
→ continued evolution

Lien avec l'évidence?

GRADE

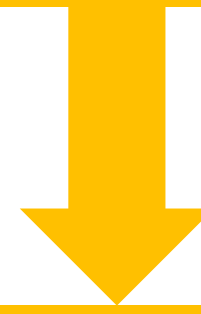
Recommandations forte



Just do it



Recommandations faible



*Décision
Médicale Partagée*



VIEWPOINT

Evidence-Based Practice Is Not Synonymous With Delivery of Uniform Health Care

Benjamin Djulbegovic, MD, PhD

Division of Evidence-Based Medicine,
Department of Internal Medicine, Morsani
College of Medicine,
University of South Florida, Tampa; and
H. Lee Moffitt Cancer Center and Research
Institute, Tampa, Florida.

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McMaster University,
Hamilton, Ontario, Canada.

Current clinical practice is characterized by substantial variation in delivery of health care for the same conditions.¹ In turn, clinical variation is considered one of the major drivers of ever-increasing health care costs¹ contributing to the estimated 30% of inappropriate or wasteful health care.² Perhaps as a natural response to this unsatisfactory situation, a widespread and influential school of thought has emerged contending that greater uniformity of clinical practice is desirable.^{1,3} Advocates maintain that by achieving uniformity in care, practice variation can be decreased, in turn leading to large cost reductions. The suggested mechanism to achieve uniformity in part involves clinician adherence to practice guidelines, which is seen as synonymous with evidence-based practice.³ In this Viewpoint, we explain that this position is based on a misunderstanding of trustworthy guidelines⁴ and that striving for uniformity of practice as an end is misguided.

The first limitation in the drive for uniformity is a failure to appreciate the need for guidelines that achieve a

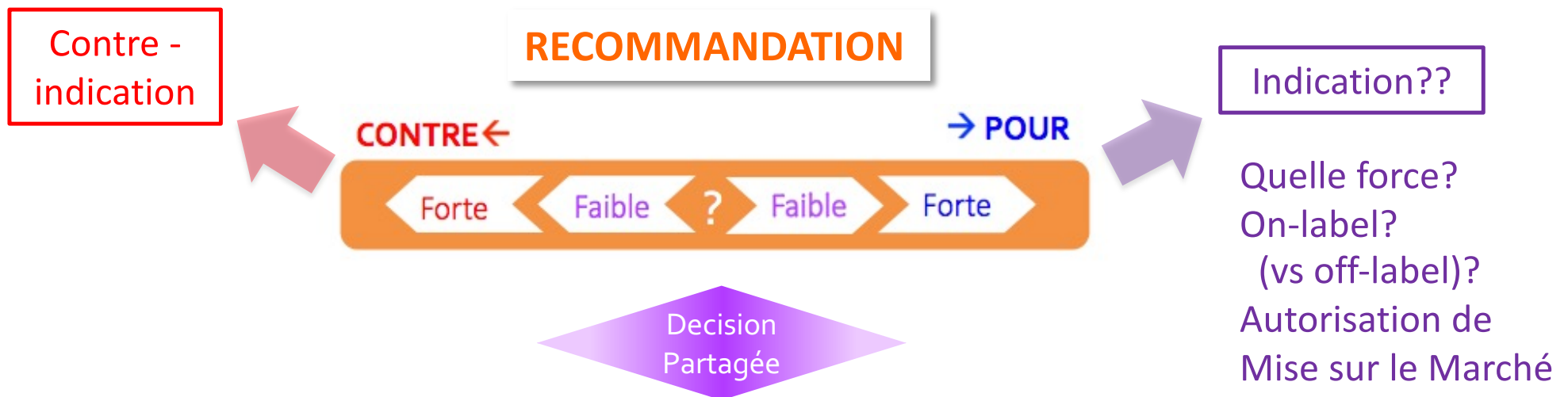
terms of benefits, harms, and costs.⁶ Studies directly addressing the relevant questions may not have been undertaken, or if they have, they may be small, poorly designed or implemented, show inconsistent results, be limited by publication bias, or have enrolled idiosyncratic populations of questionable applicability. In these cases, the confidence in the estimate of effects will often be low or very low. In addition, if values and preferences differ widely across patients (which is often if not uniformly the case), the right decision for one patient may be the wrong decision for another. For example, Montori et al⁷ illustrated how recent guidelines by the American College of Cardiology and the American Heart Association for the use of statins for primary prevention of heart disease do not mandate uniform practice—some patients informed about cardiovascular disease risk reduction will choose the recommended course of action and use statins, but others will not.

Organizations that produce guidelines should distinguish between situations in which confidence in



Evidence to Decision Framework

1. Signal Bénéfices + Certitude
2. Signal de Risque + Certitude
3. Valeurs et Préférences
4. Ressources \$
5. Accessibilité
6. Équité, justice distributive
7. Faisabilité



Evidence Based Medicine
Incertitude

Most important decisions in health care are not clear cut

Strength of recommendations in UpToDate (n=9451)

	All Recommendations
	N (%)
Low confidence	4701 (49.7%)
Moderate confidence	3759 (39.8%)
High confidence	991 (10.5%)
Total	9451 (100%)

Most important decisions in health care are not clear cut

Strength of recommendations in UpToDate (n=9451)



All Recommendations

N (%)

4701 (49.7%)

3759 (39.8%)

991 (10.5%)

9451

(100%)

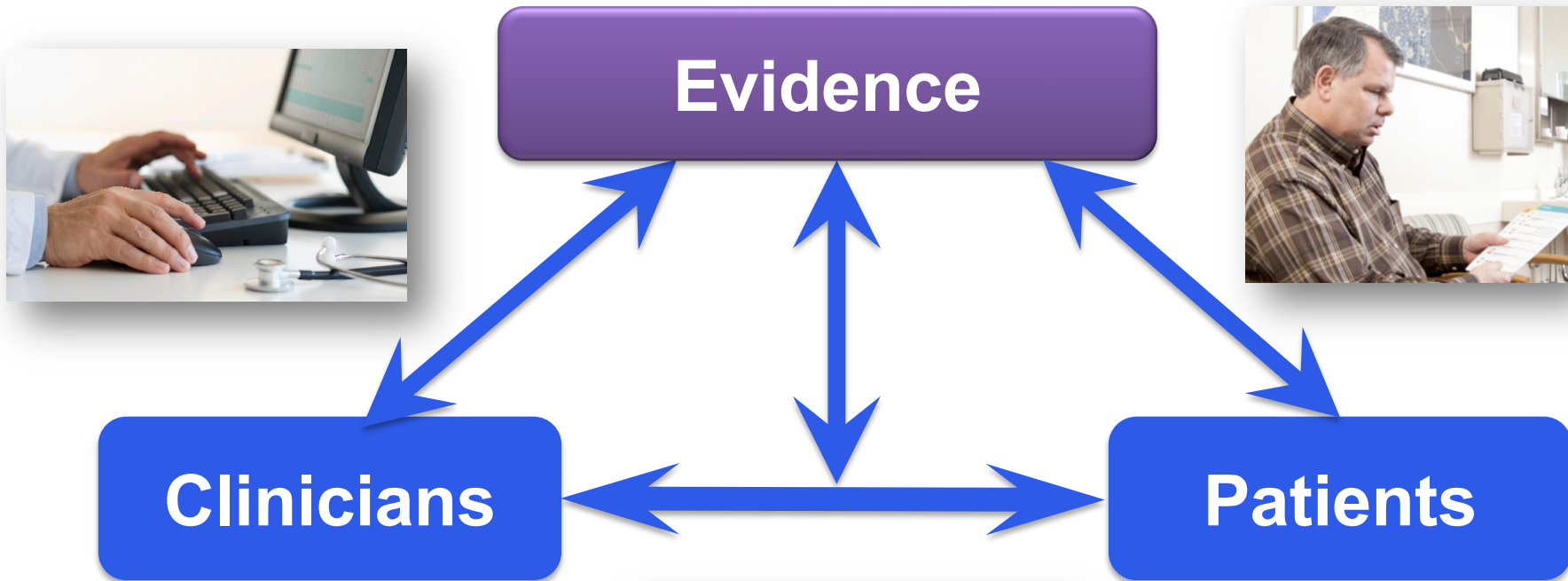


SDM & EBM

Les aides décisionnelles

AIDES DECISIONNELLES: une aide?

Patient Decision Aids



Consultation Decision Aids

Blood Sugar

Daily Routine

Daily Sugar
Testing

Low Blood
Sugar

Weight Change

Side Effects

Costs

Blood Sugar

Metformin 1 – 2%

Insulin Unlimited %

Pioglitazone 1%

**Liraglutide/
Exenatide** 0.5% – 1%

Sulfonylureas 1 – 2%

Gliptins 0.5 – 1%

Daily Routine

Metformin



Insulin



Pioglitazone



Liraglutide / Exenatide



Take in the hour
before meals.

Sulfonylureas



Gliptins



Weight Change

Metformin



Insulin



Pioglitazone



Liraglutide/Exenatide



Sulfonylureas



Gliptins



Consultation Decision Aids



1

Clinician and patient discuss the “What You Should Know” card.



2

Clinician asks, “What issues concerning a medication to treat depression symptoms would you like to discuss first?”
Patient selects first card.



3

Patient and clinician review this card.



4

Patient selects a second card and compares the two.



5

Medication options are discussed.



6

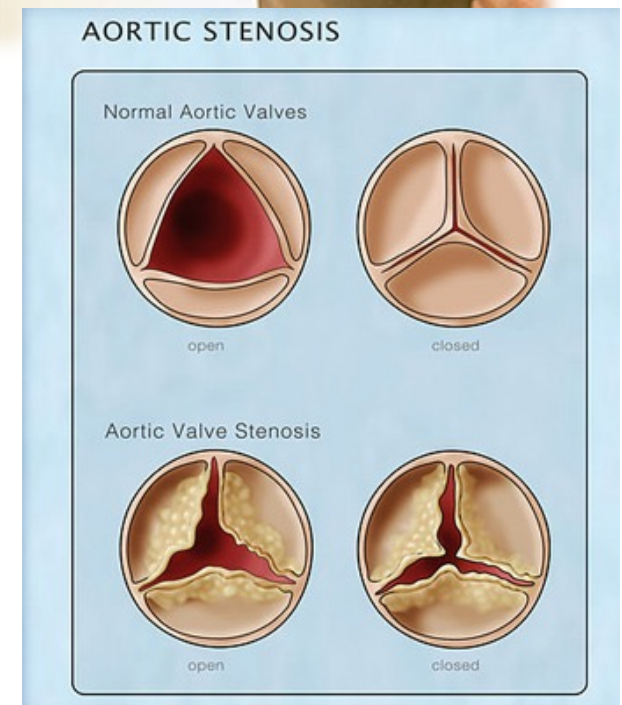
Medication choice is made— brochure given to patient to take home.

Evidence quant à l'usage des Aides décisionnelles (DA)

- ◆ Increase
 - Knowledge (+ 13% absolute increase)
 - Accurate risk perceptions (+ 82% relative increase)
 - Congruence with values (+52% relative increase), Satisfaction
- ◆ Lower
 - Decisional conflict (-7% absolute decrease)
 - Passivity in decision making (-34% relative decrease)
- ◆ Mean duration + 2 min (95% CI -8 min à + 23 min)
- ◆ No impact on adherence
- ◆ No impact on cost

De retour vers Daniel, 66 ans

- Récemment retraité
- Essoufflement à l'effort
- Très limitant au quotidien
- A perdu connaissance (2x)
- Souffle à l'auscultation
- Echographie cardiaque:
- **Sténose aortique sévère**



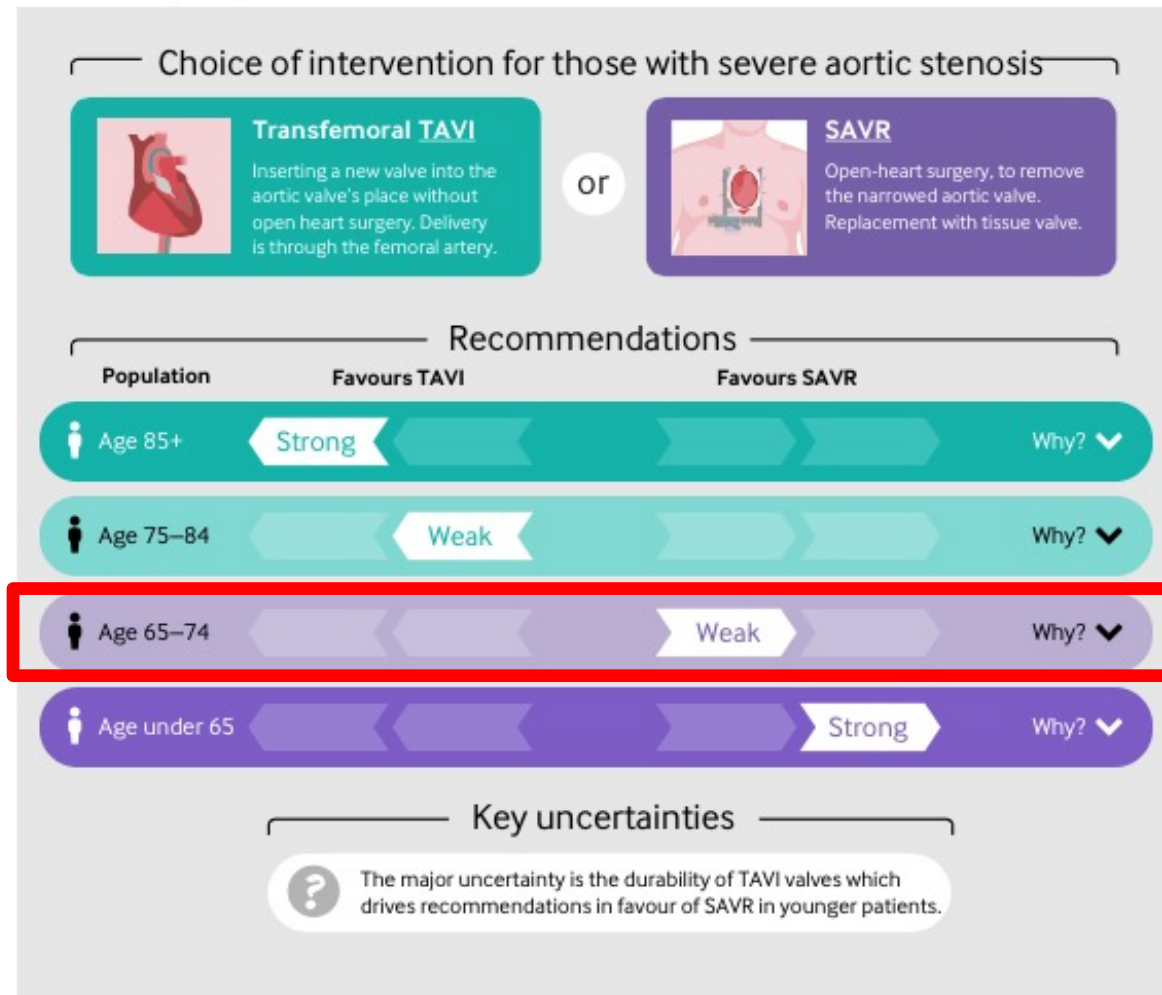
Practice

Rapid Recommendations

Transcatheter or surgical aortic valve replacement for patients with severe, symptomatic, aortic stenosis at low to intermediate surgical risk: a clinical practice guideline

BMJ 2016 ; 354 doi: <http://dx.doi.org/10.1136/bmj.i5085> (Published 28 September 2016)

Cite this as: BMJ 2016;354:i5085



Comparison of benefits and harms

	Favours transfemoral TAVI		Favours SAVR		
Events per 1000 people— within 2 years					Quality of evidence
Deaths	73	19 fewer		92	★★★★ Moderate
Strokes	56	14 fewer		70	★★★★ Moderate
Aortic valve reinterventions	10		7 fewer	3	★★★★ Moderate
Pacemaker insertions	226		134 fewer	92	★★★★ Moderate
Life-threatening bleeds	161	252 fewer		413	★★★★ High
New onset atrial fibrillation	134	178 fewer		312	★★★★ High
Moderate / severe heart failure	87		18 fewer	69	★★★★ Moderate
Events per 1000 people— within 10 years					
Aortic valve reinterventions	198		137 fewer	61	★★★★ Very low
Length of hospital stay					
Median days in hospital	8	4 fewer		12	★★★★ High

See all 14 outcomes **MAGIC** app

Preferences and values

People who wish to avoid open-heart surgery are likely to favour TAVI. People who place more value on avoiding a second aortic valve placement are likely to choose surgery.

Resourcing

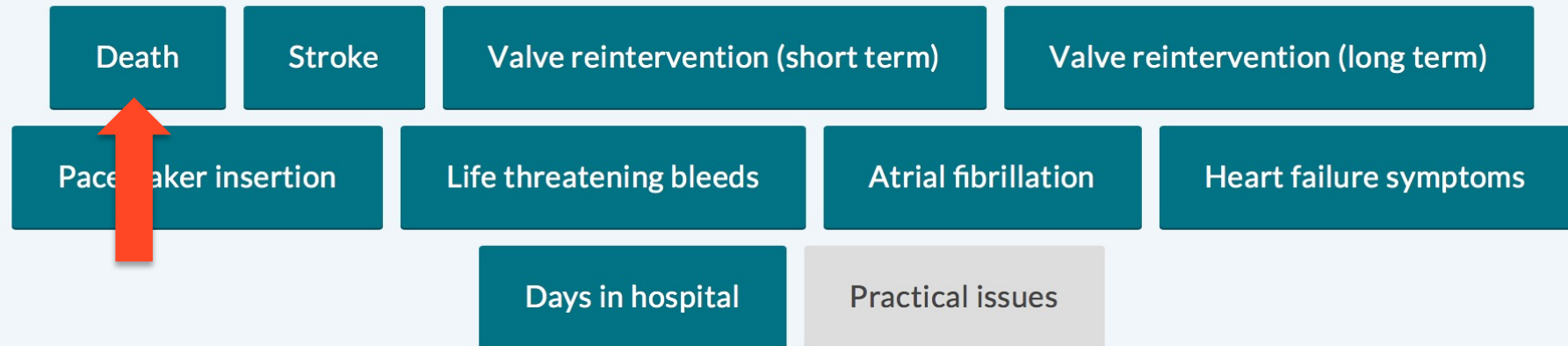
TAVI is likely to be a cost-effective alternative to SAVR for patients at low to moderate perioperative risk, but we have not identified any cost-effectiveness analyses to support this.

Other

Only centres with sufficient expertise and an established TAVI team with experienced general and interventional cardiologists and cardiac surgeons should offer TAVI.

SHARE-IT Decision Aids

What aspect of your treatment would you like to discuss next?



Death

Among a 1000 patients like you, with Transfemoral TAVI



19 fewer

2 years

SAVR

92

per 1000

Transfemoral TAVI

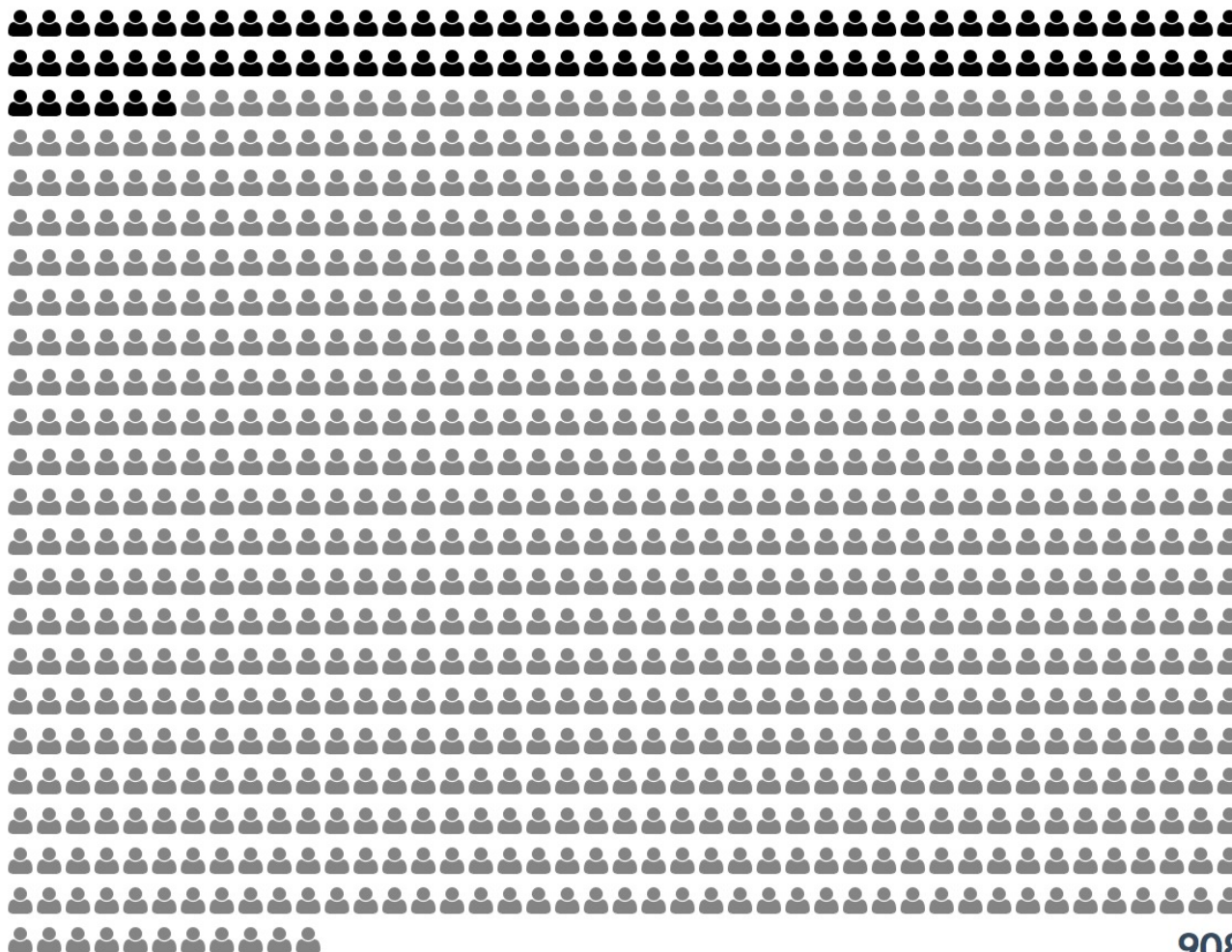
73

per 1000

Certainty



MODERATE



908

Death

Among a 1000 patients like you, with Transfemoral TAVI



19 fewer

2 years

SAVR

92

per 1000

Transfemoral TAVI

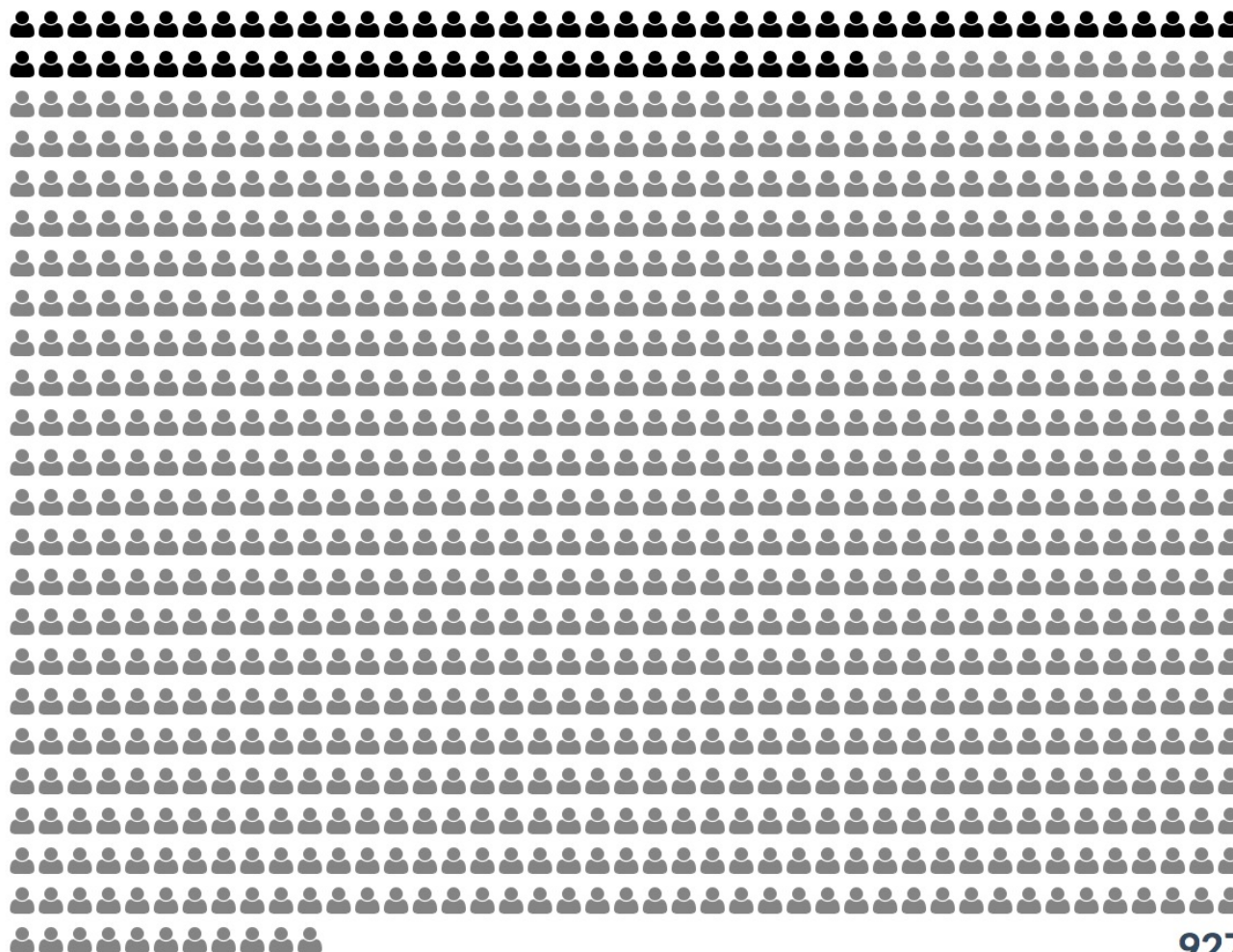
73

per 1000

Certainty



MODERATE



927

Death

Among a 1000 patients like you, with Transfemoral TAVI



19 fewer

2 years

SAVR

92

per 1000

Transfemoral TAVI

73

per 1000

Certainty



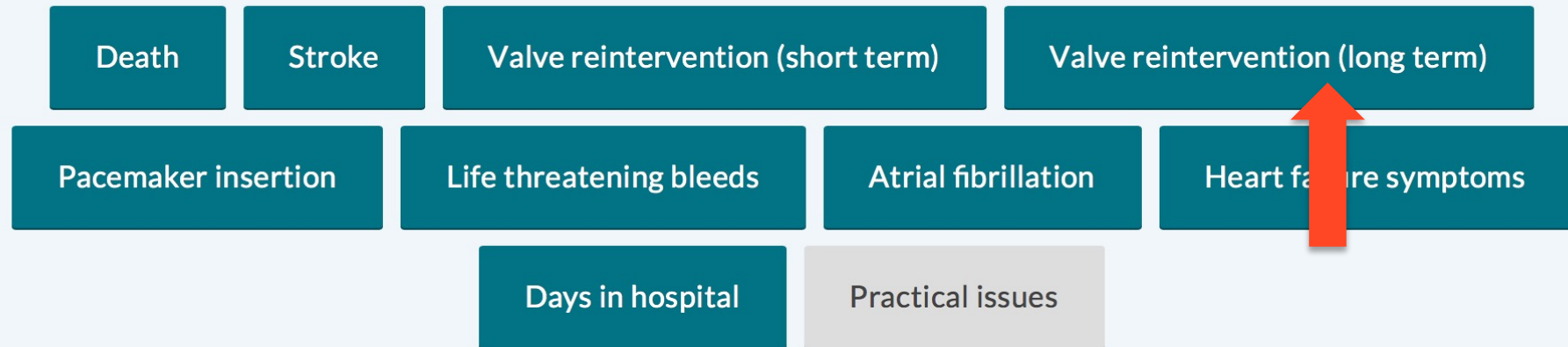
MODERATE



908

SHARE-IT Decision Aids

What aspect of your treatment would you like to discuss next?



Valve reintervention (long term)

Among a 1000 patients like you, with Transfemoral TAVI



137 more

10 years

SAVR

61

per 1000

Transfemoral TAVI

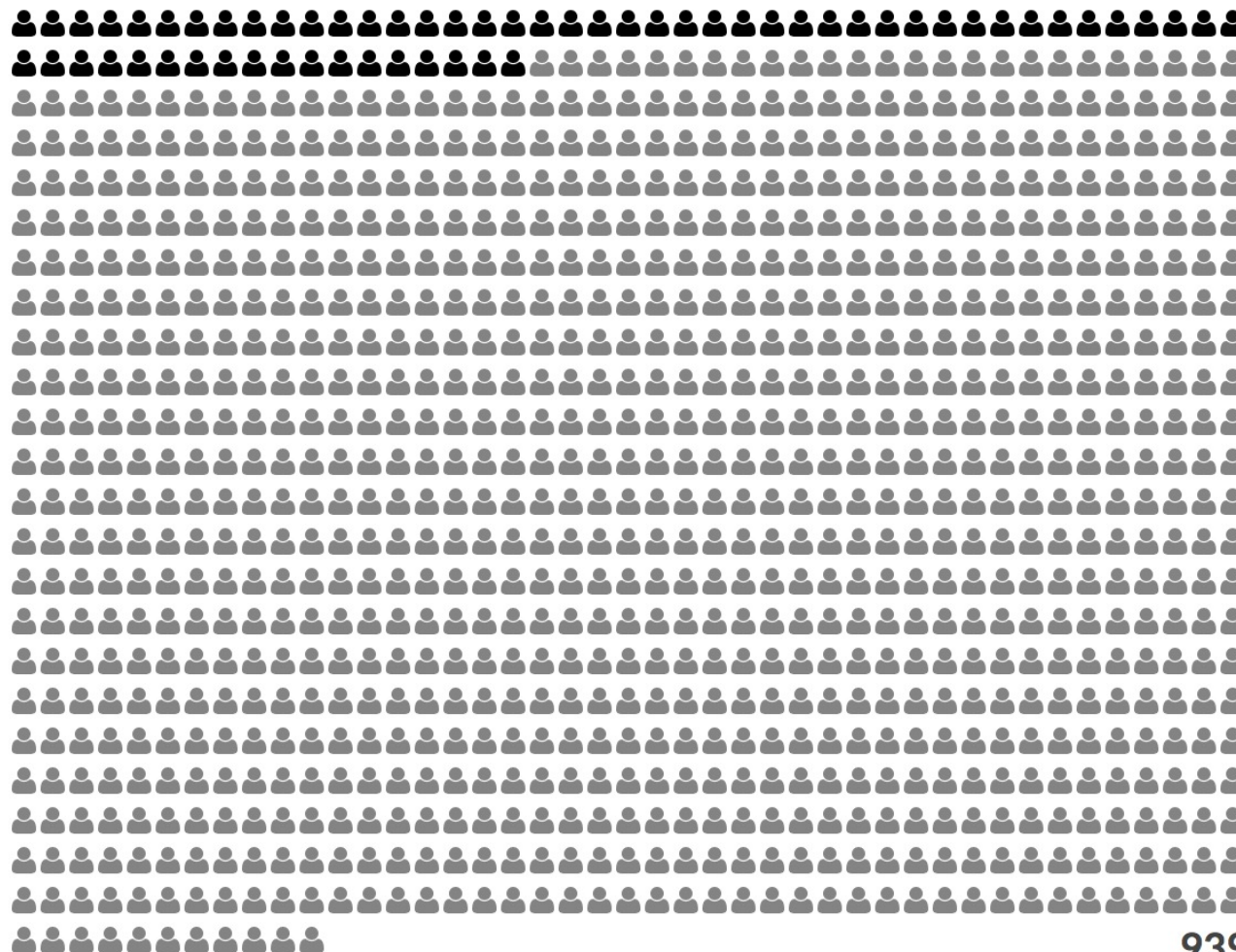
198

per 1000

Certainty



VERY LOW



939

Valve reintervention (long term)

Among a 1000 patients like you, with Transfemoral TAVI



137 more

10 years

SAVR

61

per 1000

Transfemoral TAVI

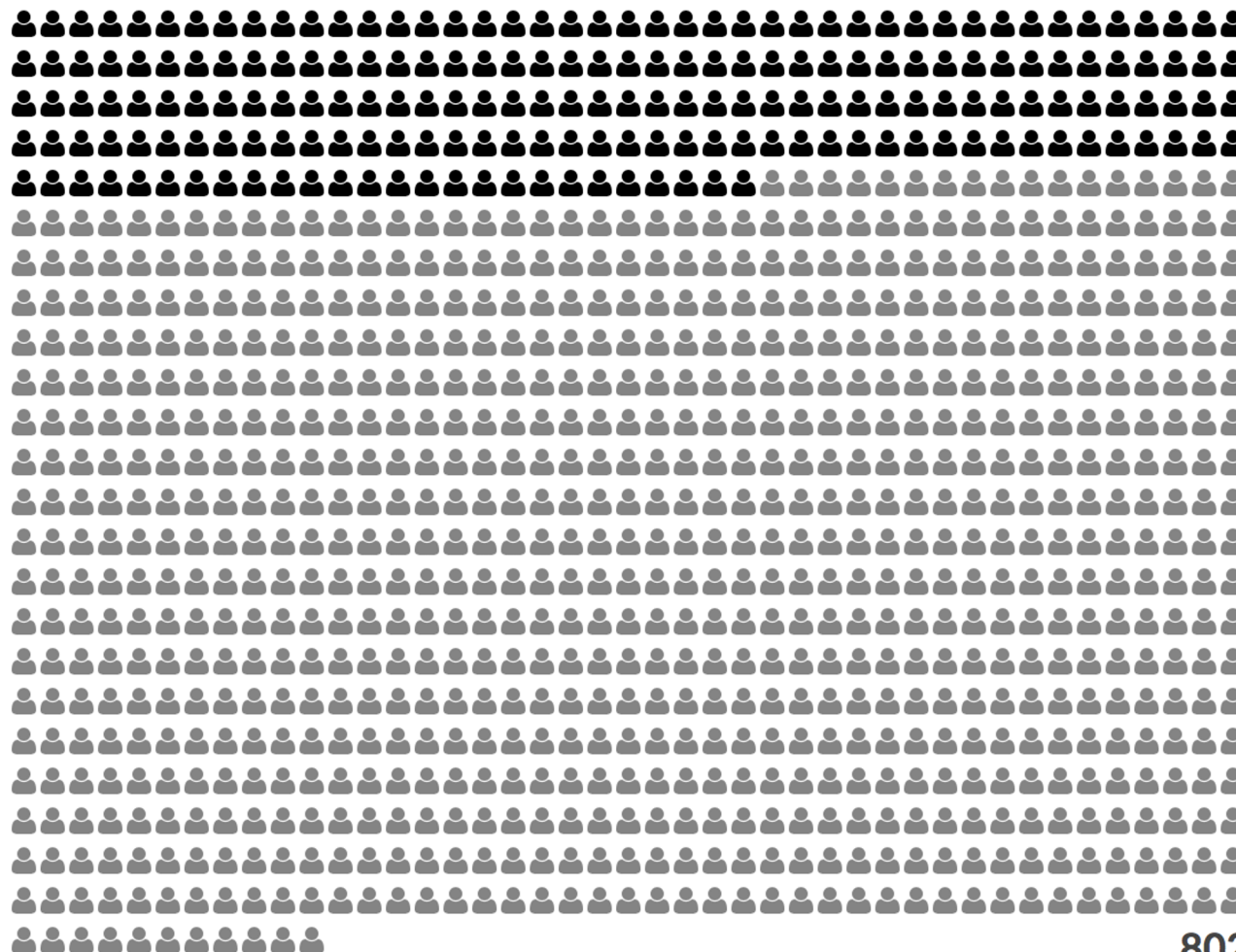
198

per 1000

Certainty



VERY LOW



802

Valve reintervention (long term)

Among a 1000 patients like you, with Transfemoral TAVI



137 more

10 years

SAVR

61

per 1000

Transfemoral TAVI

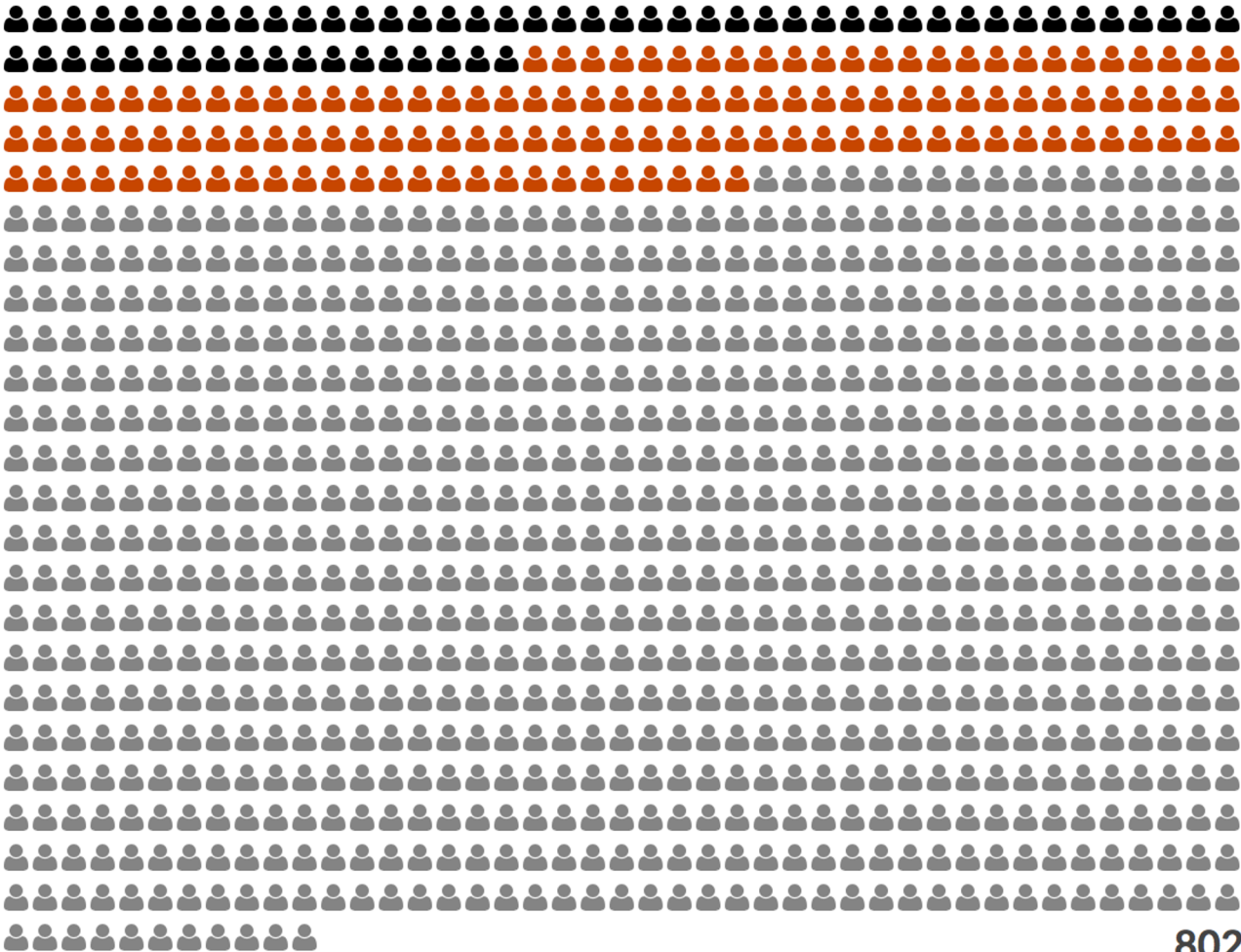
198

per 1000

Certainty



VERY LOW

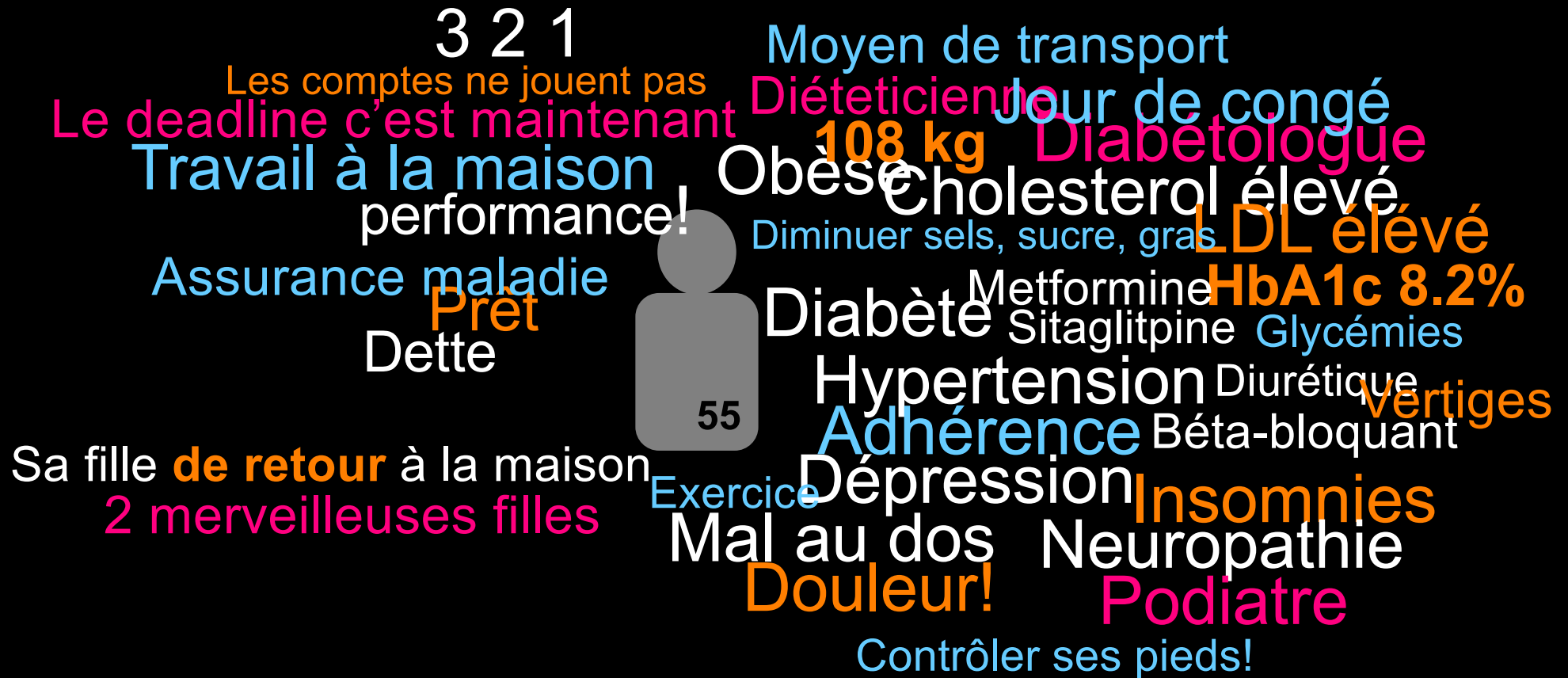


802

Considération pratique

La vraie vie

Voici Jean, 55 ans



40%

Des patients rapportent des **contraintes**
importantes ou insurmontables
liées au traitement

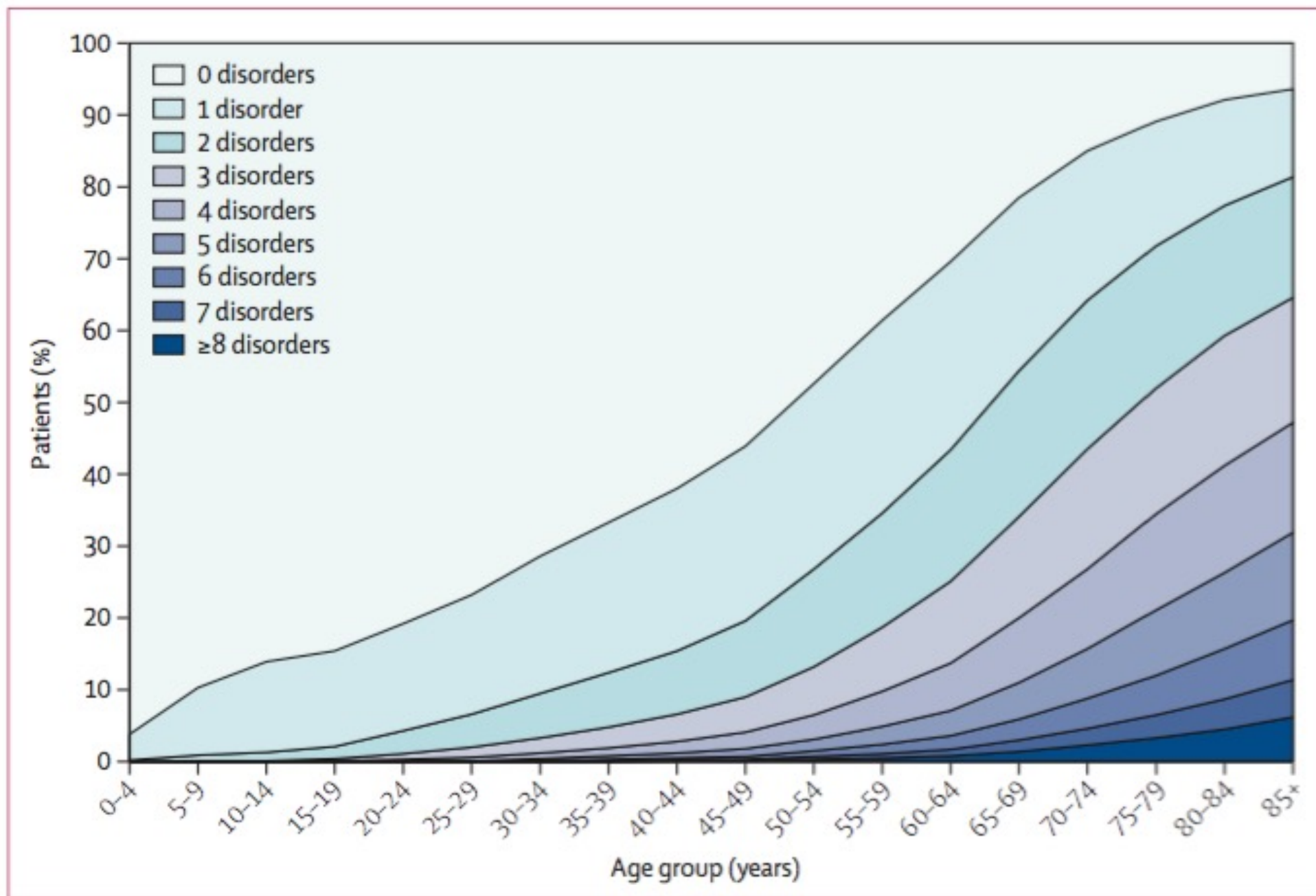


Figure 1: Number of chronic disorders by age-group

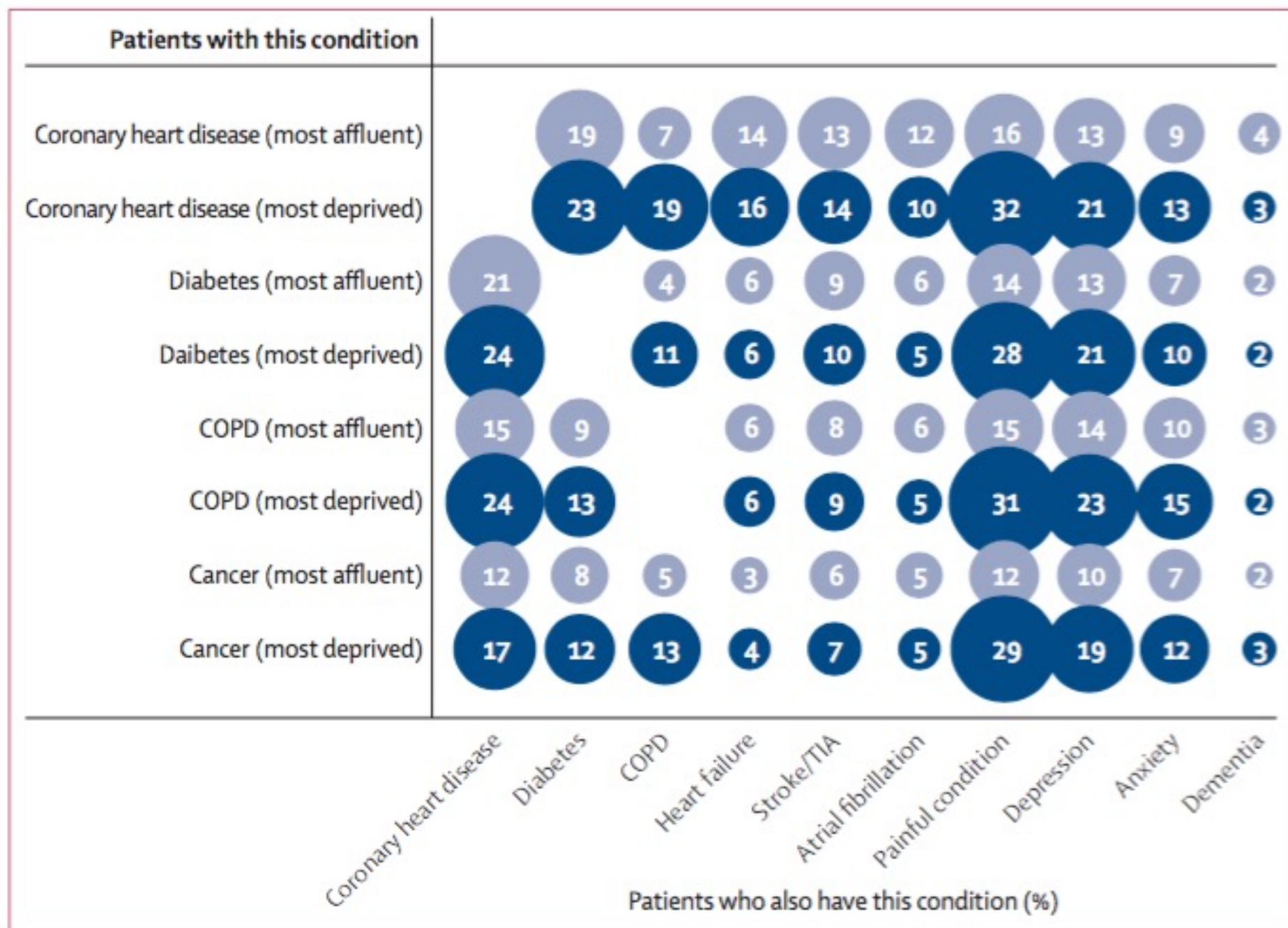


Figure 4: Selected comorbidities in people with four common, important disorders in the most affluent and most deprived deciles

COPD=chronic obstructive pulmonary disease. TIA=transient ischaemic attack.

Barnett et al. Lancet 2012; 380: 37–43

NOVEMBER 2014

check to see if

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

2

30W, the Hospital
Higher Ground

4TBI CCC

5 Salvation Army started

Get capt of rent amount from
DAYLIGHT SAVING TIME ENDS

9 call
6:11 at 6A, about Rent

10 6 day con
Mancina 8:30a

11 HCMC
Rheumatology 9 AM
Saw Marcel emerge
REMEMBRANCE DAY

Bring Nurse
Med Robin in Sal Army

16

17 HCMC
DT-1 PM
SLP-KRC-1 PM
speech Lang 2 PM

18 HCMC
CCC 2 PM
Mobic 7.5

19 Sunnath
In at 7:30 AM
call Chris

23

10/24
off
CCC 8 PM

24 10/24
off
Speech Pathology 6 AM
2 PM Chang
5 PM Purple

25 10/24
off
6 AM for
Do-60!

26 10/24
off
1 PM DT
Blue Bull
wakk Pathology

30

work

8 AM CCC
10 AM CCC

Pen-A

work 3:30 PM Speech

call to confirm Dr. Schesinger appointment
tomorrow the Tuesday 11th

THURSDAY

FRIDAY

SATURDAY

8 PM
NA @ Sal.
Army

612-
321-3429

OCTOBER 2014

S M T W T F S
1 2 3 4
5 6 7 8 9 10 11
12 13 14 15 16 17 18
19 20 21 22 23 24 25
26 27 28 29 30 31

NOVEMBER 2014

M T W T F S
1
2 3 4 5 6 7 8
9 10 11 12 13 14 15
16 17 18 19 20 21 22
23 24 25 26 27 28 29
30

DECEMBER 2014

S M T W T F S
1 2 3 4 5 6
7 8 9 10 11 12 13
14 15 16 17 18 19 20
21 22 23 24 25 26 27
28 29 30 31

JANUARY 2015

S M T W T F S
1 2 3
4 5 6 7 8 9 10
11 12 13 14 15 16 17
18 19 20 21 22 23 24
25 26 27 28 29 30 31

FEBRUARY 2015

S M T W T F S
1 2 3 4 5 6 7
8 9 10 11 12 13 14
15 16 17 18 19 20 21
22 23 24 25 26 27 28

Pick up at
Tramadol Park CVS

13 8:30 AM
Disinfect

14 HCMC
BI-N

15 Sussanah
Laquan 20-25.90
COST

16 1 PM
Emerge

17 1 PM
Dr. bench

18 Purple Build

19 Marcel

20 Josh

21 House

22 House

23 House

24 House

25 House

26 House

27 House

28 House

29 House

30 House

REVOLUTION ANNIVERSARY (MEX)

27 10/24

28 10/24

29 10/24

THANKSGIVING DAY (US)

worked worked

Don't tell me just say I am done

TRAVAIL additionnel

Préparer la consultation

Voir les vidéos éducationnelles

Amener ces questions, être prêt à des nouvelles

Enregistrer l'entrevue ou prendre des notes

Revoir son dossier médical

Transmettre données via le portail internet

Self-measure, self-monitor, self-manage

Gérer les rendez-vous, ordonnances, factures

Garder ses proches informés

Ménager, prendre soins de ses proches

Partenariat patients, activisme

NONCOMPLIANCE



► A-Z

► Categories

► Young people

○ Search

Home

Health Professionals

Patients' experiences shared on film.

Related:

- Using healthtalk.org for training
- Trigger films for service improvement
- Patients tell us what makes good healthcare

PEOPLE'S EXPERIENCES OF HEALTH



Journal of
Clinical
Epidemiology

Journal of Clinical Epidemiology 129 (2021) 104–113

ORIGINAL ARTICLE

A framework for practical issues was developed to inform shared decision-making tools and clinical guidelines

Anja Fog Heen^{a,*}, Per Olav Vandvik^b, Linn Brandt^a, Victor M. Montori^c, Lyubov Lytvyn^d, Gordon Guyatt^d, Casey Quinlan^e, Thomas Agoritsas^{d,f}

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Accepted 6 October 2020; Published online 10 October 2020

Abstract

Objectives: The objective of the study was to develop and test feasibility of a framework of patient-important practical issues.

Study Design and Setting: Guidelines and shared decision-making tools help facilitate discussions about patient-important outcomes of care alternatives, but typically ignore practical issues patients consider when implementing care into their daily routines. Using grounded theory, practical issues in the HealthTalk.org registry and in Option Grids were identified and categorized into a framework. We integrated the framework into the MAGIC authoring and publication platform and digitally structured authoring and publication platform and appraised its use in The BMJ Rapid Recommendations.

Results: The framework included the following 15 categories: medication routine, tests and visits, procedure and device, recovery and adaptation, coordination of care, adverse effects, interactions and antidote, physical well-being, emotional well-being, pregnancy and nursing, costs and access, food and drinks, exercise and activities, social life and relationships, work and education, travel and driving. Implementation in 15 BMJ Rapid Recommendations added 283 issues to 35 recommendations. The most frequently used category was procedure and device, and the least frequent was social life and relationship.

Conclusion: Adding practical issues systematically to evidence summaries is feasible and can inform guidelines and tools for shared decision-making. How this inclusion can improve patient-centered care remains to be determined. © 2020 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Keywords: Shared decision-making tools; Decision aids; Patient experience; Clinical practice guidelines; Patient-important outcomes



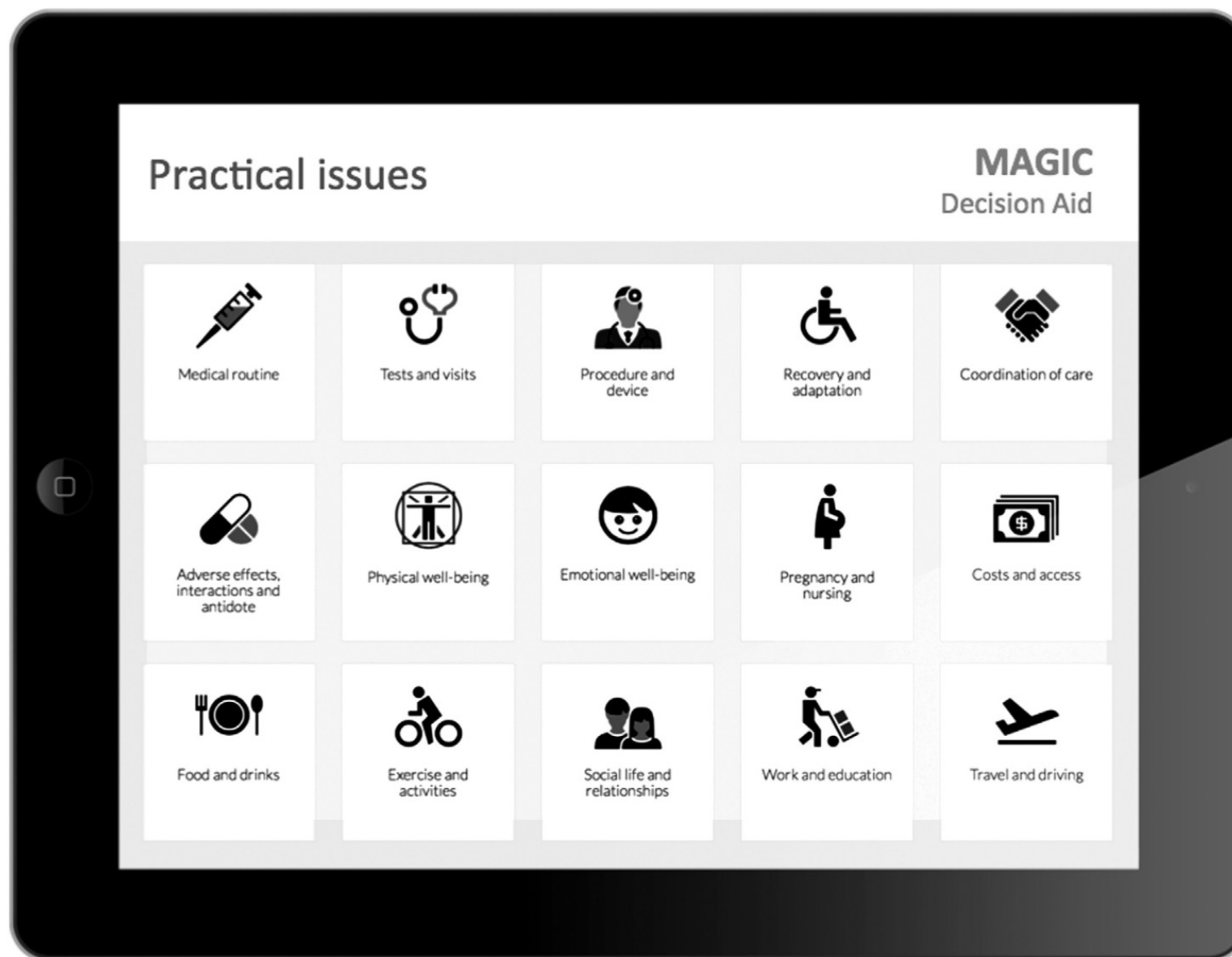


Fig. 2. The final practical issue framework including 15 categories and corresponding icons in SDM tools.



Procedure and device



with PFO closure plus antiplatelet therapy

The PFO device will be implanted using a catheter (long, thin, flexible, hollow tube), inserted through a small cut made at the inner thigh (groin), with local anesthesia and moderate sedation or under general anaesthesia.

The procedure takes under 2 hours. In-hospital stay is usually one day.



Medication
routine



Coordination of
care



Adverse effects,
interactions and
antidote



Physical well-being



Emotional well-
being



Pregnancy and
nursing



Costs and access



Food and drinks



Exercise and
activities



Social life and
relationships



Work and
education



Travel and driving

Le travail de patient

Charge

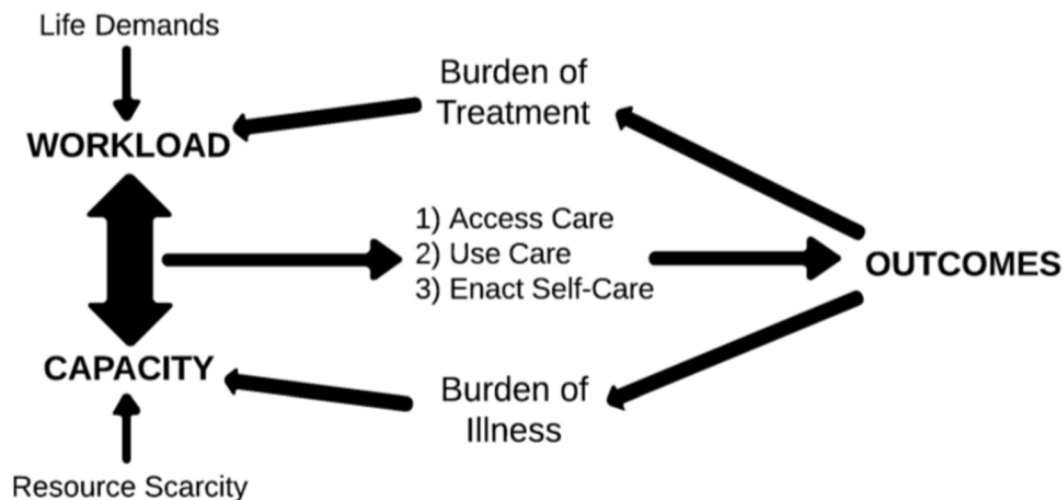


Figure 1. The cumulative complexity model.

Capacité



Soins < Besoins



Sous-utilisation

Besoins > Soins



Sur-utilisation

Soins
appropriés

Soins < Souhaits



Soins > Souhaits



Sous-traitement

Sur-traitement



Soins
souhaitables

Patients partenaires

Une révolution

“Careful and Kind Care”



In a series of brief and personal essays, **Why We Revolt** describes what is wrong with industrial healthcare, how it has corrupted its mission, and how it has stopped caring. Montori rescues the language of patient care to propose a revolution of compassion and solidarity, of unhurried conversations, and of careful and kind care.



Projet patient partenaires



Promotion du partenariat à tous les niveaux. Changement de culture.

De 2016 à 2020 :

- 523 patients partenaires pour améliorer la qualité des soins
- 748 actions de partenariat

www.hug-ge.ch/patients-partenaires/decouvrez-partenariat-aux-hug



Patients for Patient Safety



Partnerships for safer care

- “Telling our story” to catalyse improvements and organizational learning
- Raising awareness on patient safety in WHO Member States through collaboration
- Partnering with professionals to ensure patient-centred care
- Facilitating a positive patient safety culture through educating medical students and health-care workers
- Providing support and information to patients about keeping safe in the health-care system

Patient involvement in the development, regulation and safe use of medicines

Report of the CIOMS Working Group XI

Council for International Organizations
of Medical Sciences (CIOMS)



Geneva 2022

Niveaux de partenariat

Individuel

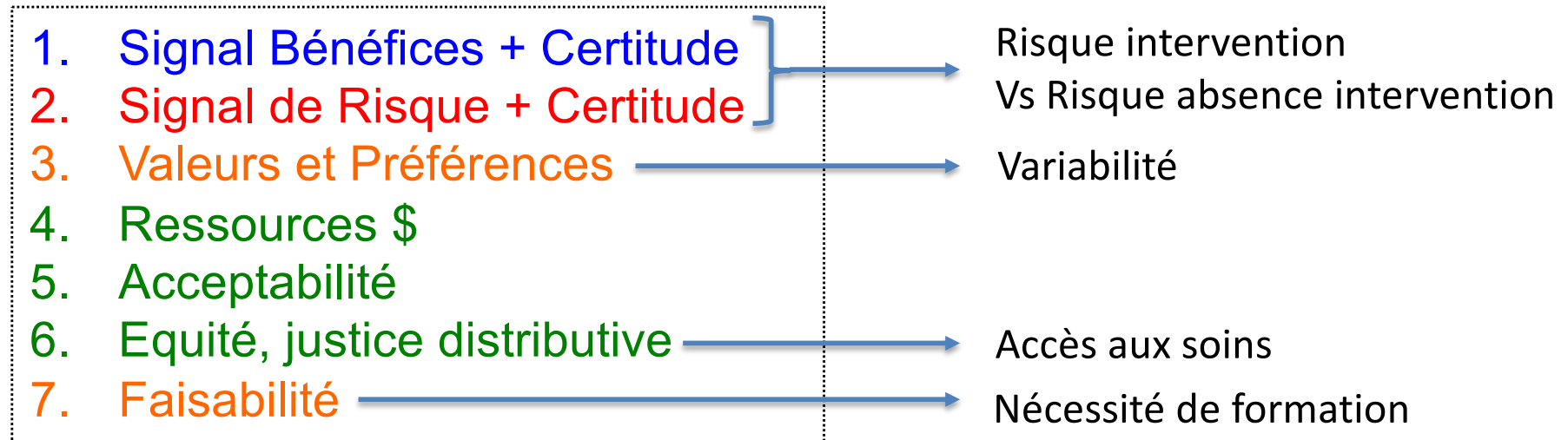
1. Partenariat dans mes soins
→ *ex. décision partagée, advanced care planning*
2. Partenariat pour l'amélioration de la qualité des soins, formation & recherche
→ *eg. Projets, cours, études cliniques*
3. Partenariat dans la gouvernance
4. Partenariat citoyen

Communauté

Applications aux personnes trans*

De l'évidence à la décision

Evidence to Decision Framework



- **Pas de différence avec d'autres décisions médicales**
- **Nombreuses décisions à fort enjeux**
 - **Bénéfice vs risque**
 - **Réversibilité ou irréversibilité**
 - **Impact sur des issues telles que la fertilité**
 - **Degré d'incertitude toujours présent**
 - **Présence/absence d'alternatives**

Applications aux personnes trans*

Une médecine personnalisée

Médecine personnalisée... *... mais sur quels critères?*

Stratification du risque

variable clinique

- Age
- Sévérité
- Comorbidities

Médecine de précision

- Prédiction de la réponse à un traitement
- Guidée par des marqueurs biologiques ou phénotypique

Valeurs et préférence

- Concernant les interventions
- Importance relative des issues
- Contexte et situation personnelles



Applications aux personnes trans*

Gestion du regret décisionnel

Regret décisionnel

- Efficacité de la décision partagée sur
 - Regret décisionnel
 - Conflit décisionnel
- Communiquer sur ces issues dans le cadre de la décision
- SDM est probablement parmi les meilleurs approches pour minimiser le regret éventuel lié à une décision.

-
- The Relationship Between Decisional Regret and Well-Being in Patients With and Without Depressive Disorders: Mediating Role of Shared Decision-Making. *Front Psychiatry*. 2021 Jun 16;12:657224.
 - Shared decision-making and the lessons learned about decision regret in cancer patients. *Support Care Cancer*. 2022 Jun;30(6):4587-4590.
 - Influence of Shared Decision Making on Decisional Conflict and Regret in Postpartum Mother-Infant Care: A Randomized Controlled Trial. *Value Health*. 2021 Sep;24(9):1335-1342.
 - Regret in Surgical Decision Making: A Systematic Review of Patient and Physician Perspectives. *J Surg*. 2017 Jun;41(6):1454-1465.

Conclusion

- La majorité des recommandations cliniques en médecine se fonde sur des connaissances incertaines et en constante évolution.
- Les décisions doivent se baser sur la totalité des connaissances à un temps donné (et non une sélection partielle, voir anecdotique)
- La décision médicale partagée:
 - est un processus par lequel un patient et un clinicien entrent en partenariat afin d'identifier la meilleure approche thérapeutique ou diagnostique, dans une situation donnée;
 - permet de s'assurer d'une bonne perception des bénéfices et risques potentiels d'une intervention;
 - est une des meilleures approches pour minimiser le regret décisionnel.

Merci de votre attention