W. Van Biesen

Ghent University Hospital

Patient Centred Care: Nothing about us without us

FROM THE EDITOR-IN-CHIEF

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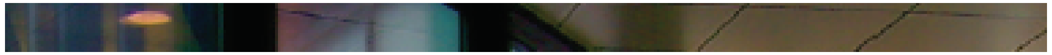
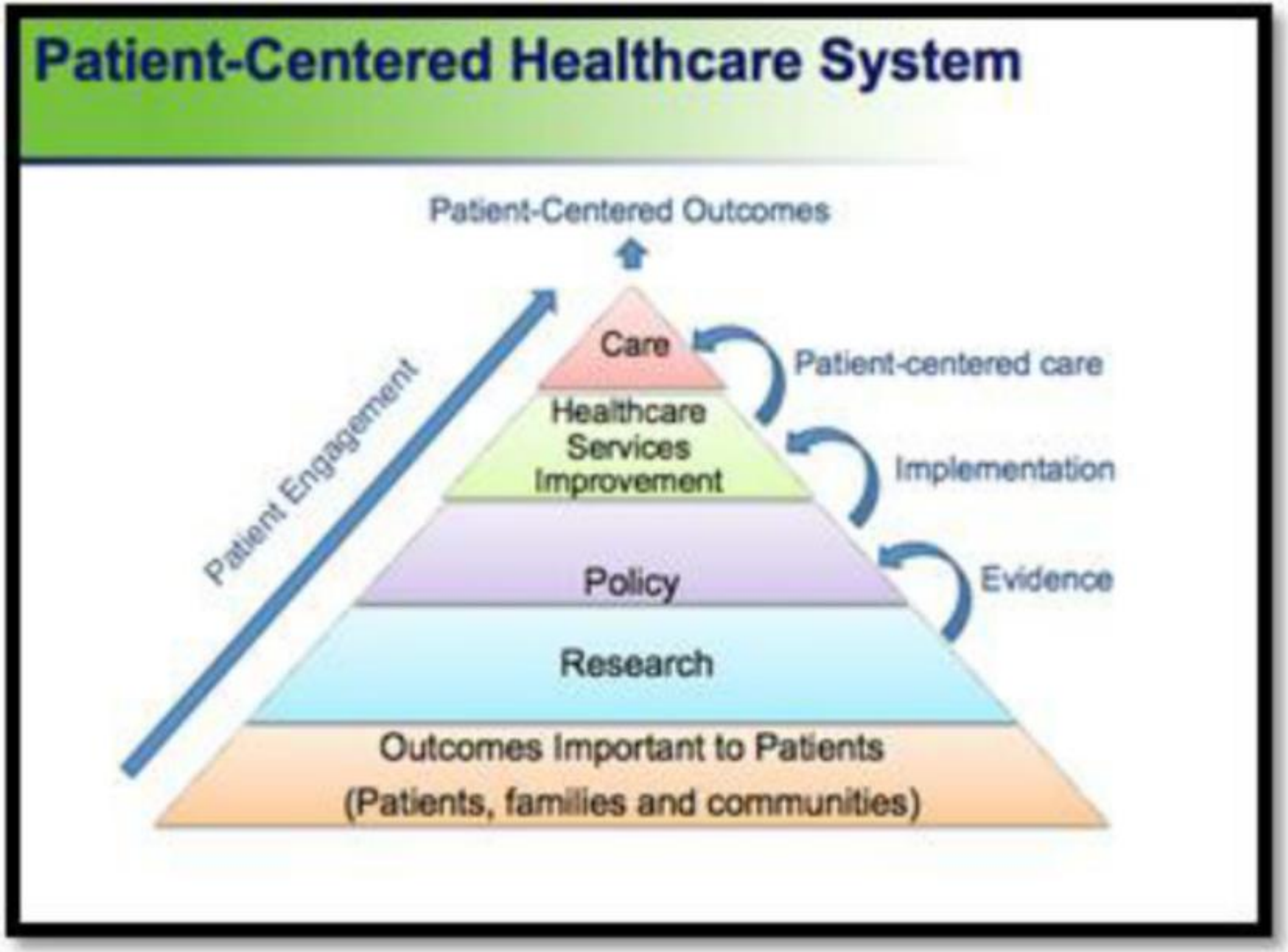
Rx For The 'Blockbuster Drug' Of Patient Engagement

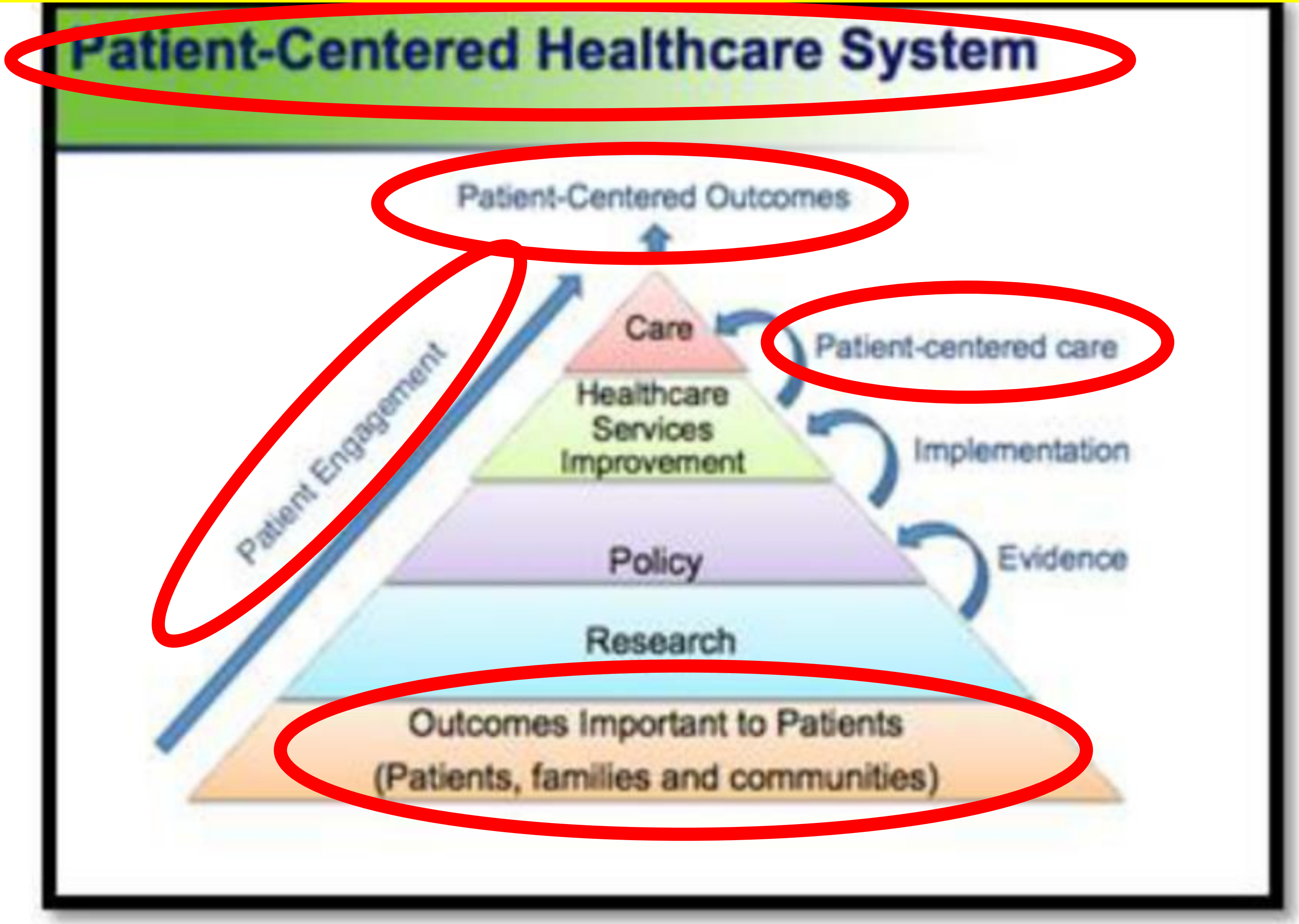
BY SUSAN DENTZER



Patient-Centered Healthcare System



Words Words Words Words……..



This presentation:

- **Patient representation and why it is of importance**
- **Research vs service provision**
- **Patient centered outcomes in nephrology**

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Las Meninas by Picasso

Las Meninas by Velazquez

Las Meninas by Picasso

Ceci n’est pas “LE PATIENT”

Ceci n'est pas "LE PATIENT"

⇒ **EVERY INITIATIVE CAN BE CRITIZED "NOT TO BE REPRESENTATIVE"**

ACTING FOR	Taking actions for		
	Defending Interests	Petitioning/advocacy	I explained the relevance as they did not understand
		Walking in their shoes	“what is it going to mean to them”
	Authorised by	Appointed by	Informal
		Elected by	Formal
		Nominated by	As a representative of an established group in another group
	Accountable to	Reporting back to those represented	
STANDING FOR	Being a small selection of a certain group		
	SYMBOLIZING	Make people aware/reflect about certain (patient/disease/condition) groups	
	SHARING EXPERIENCE	Having the related experience on the condition (rather than just being “a non professional”	

When is/What makes patient representation legitimate?

ACTING FOR	Taking actions for		
	Defending Interests		they
			them”
	Authorised by	Appointe	
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But

1/ Whose interests? Societal? Other patients? Individual?

2/ What about industry manipulation?

When is/What makes patient representation legitimate?

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		Walking in their shoes	“what is it going to mean to them”
	Authorised by	Appointed by	Informal (the friends of the friends)
		Elected by	Formal
		Nominated b	As a representative of an established group in another group
		Reporting ba rep	
STANDING FOR	Being a small selection of a certain group		
	SYMBOLIZING	(p	

$ Higher probability to find the right qualities and capacities
$ Not democratic
$ who appoints?

$ democratic
$ not always right capacities and qualities
(but not right from whose point of view)

When is/What makes patient representation legitimate?

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	Defending Interests	Petitioning/advocacy	I explained the relevance as they did not understand
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		Nominated by	As a representative of an established group in another group
		Reporting back t repr	
STANDING FOR	Being selection of a certain		
	SYMBOL G	(	

Some background and (life and/or professional) experience is necessary

Simply impossible

Perfect patient representation is

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Patient engagement/involvement in **research**

- include as members of
  - Steering groups
  - Funding committees
  - Informed consents/understanding
  - Prioritisation initiatives

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- Include as co-producers
  - Collect data
  - Analyse data
  - Recruit fellow patients
  - Interconnect with other organisations they are involved in (networking)

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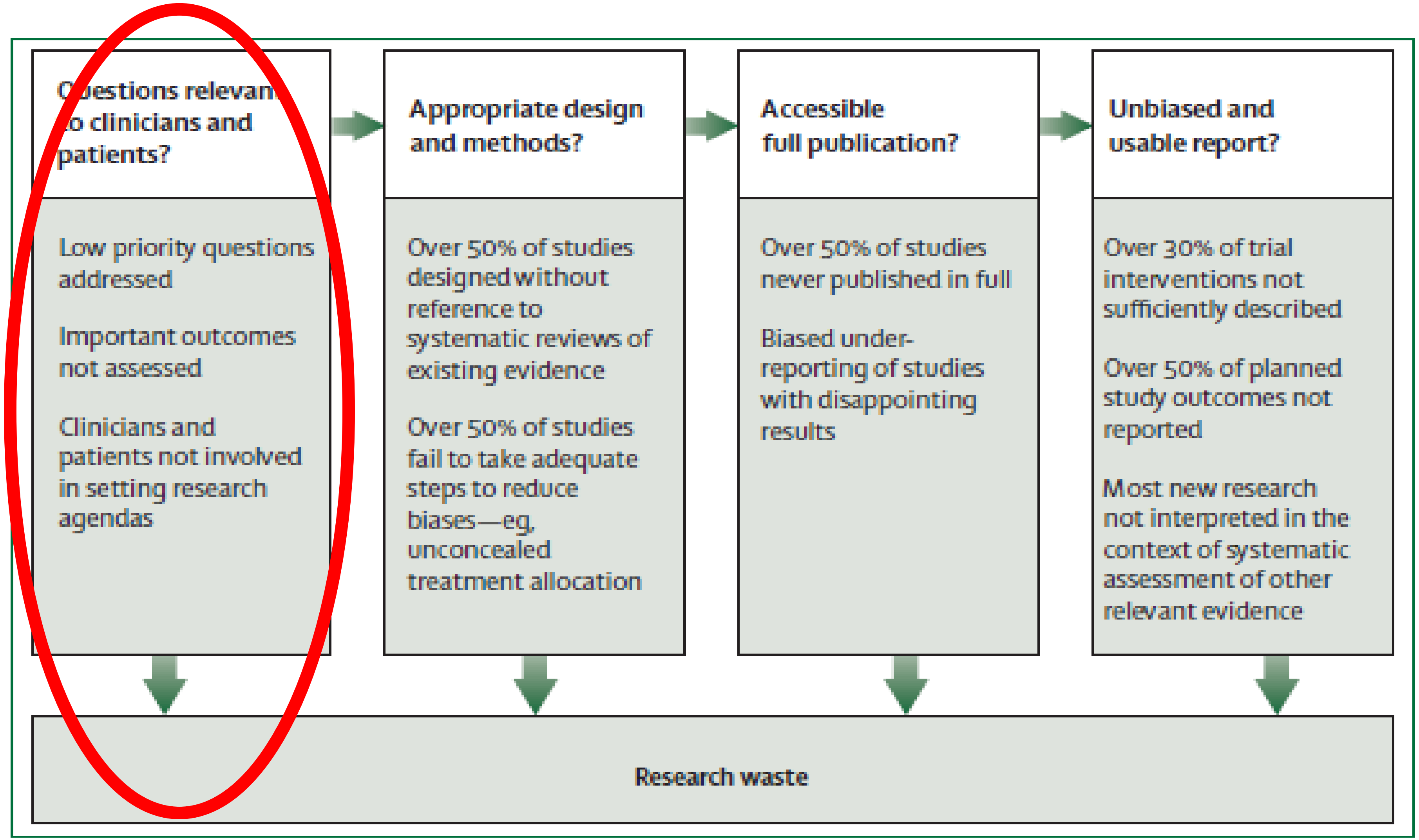
    - dissemination
    - Interconnect with other organisations they are involved in (networking)
- Ground research in reality of patient experience
- Enhance relevance, implementability, impact, legitimacy

Wasted research and noise generation



Questions relevant to clinicians and patients?

Low priority questions addressed

Important outcomes not assessed

Clinicians and patients not involved in setting research agendas

Appropriate design and methods?

Over 50% of studies designed without reference to systematic reviews of existing evidence

Over 50% of studies fail to take adequate steps to reduce biases—eg, unconcealed treatment allocation

Accessible full publication?

Over 50% of studies never published in full

Biased under-reporting of studies with disappointing results

Unbiased and usable report?

Over 30% of trial interventions not sufficiently described

Over 50% of planned study outcomes not reported

Most new research not interpreted in the context of systematic assessment of other relevant evidence

Research waste

Figure: Stages of waste in the production and reporting of research evidence relevant to clinicians and patients

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MIND ALSO HERE: WHOSE PERSPECTIVE: PATIENT vs PUBLIC

Specific individual centric versus common good

WHAT (QUALITY OF) SERVICE
IS
ACTUALLY PROVIDED

picker INSTITUTE


IMPROVING HEALTHCARE THROUGH THE PATIENT'S EYES

LISTENING
INFORMING
INVOLVING

Patient *relevant* outcomes ⇔ patient *preferred* outcomes

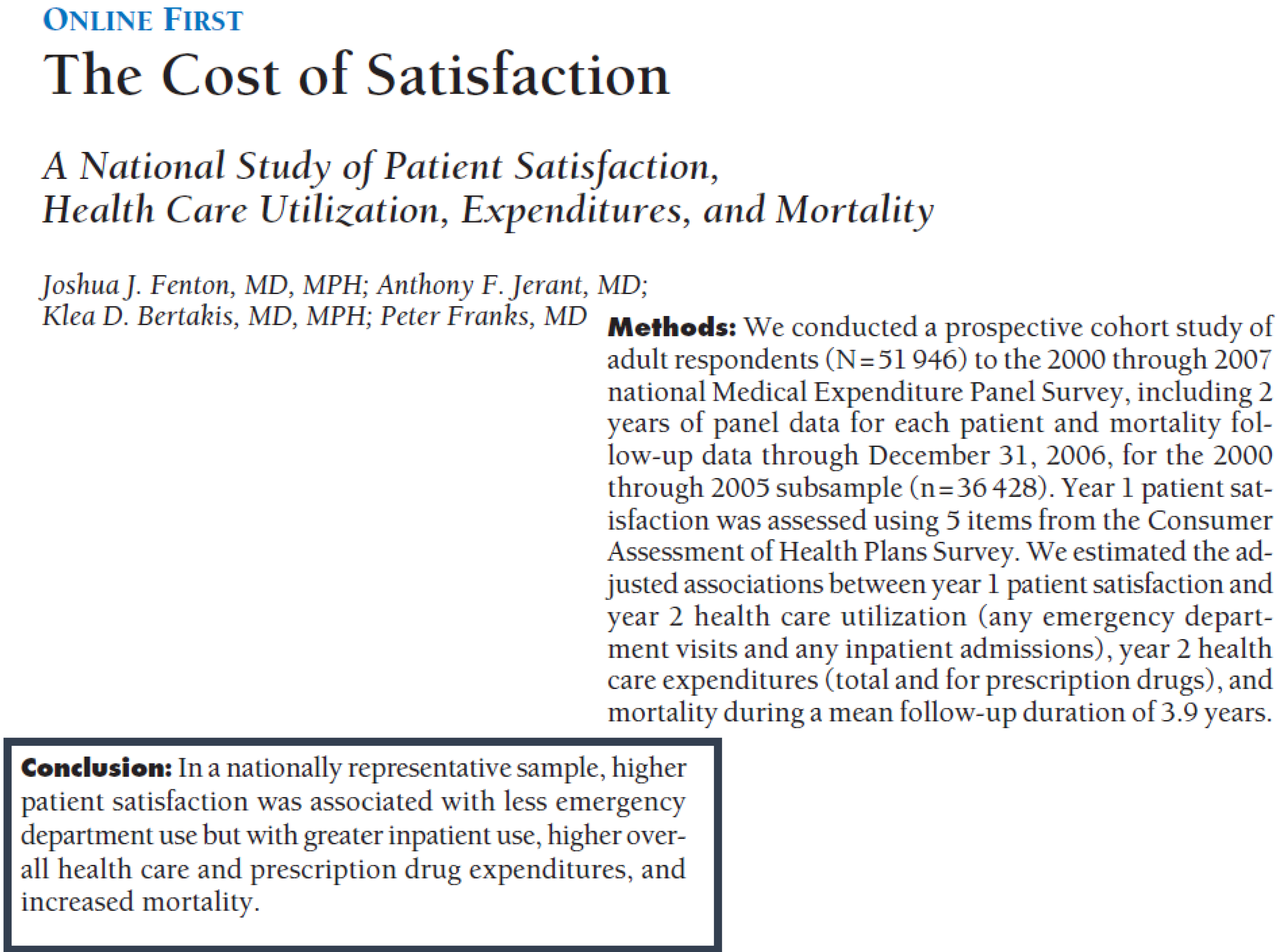
ONLINE FIRST

The Cost of Satisfaction

A National Study of Patient Satisfaction, Health Care Utilization, Expenditures, and Mortality

Joshua J. Fenton, MD, MPH; Anthony F. Jerant, MD;
Klea D. Bertakis, MD, MPH; Peter Franks, MD

Methods: We conducted a prospective cohort study of adult respondents (N=51 946) to the 2000 through 2007 national Medical Expenditure Panel Survey, including 2 years of panel data for each patient and mortality follow-up data through December 31, 2006, for the 2000 through 2005 subsample (n=36 428). Year 1 patient satisfaction was assessed using 5 items from the Consumer Assessment of Health Plans Survey. We estimated the adjusted associations between year 1 patient satisfaction and year 2 health care utilization (any emergency department visits and any inpatient admissions), year 2 health care expenditures (total and for prescription drugs), and mortality during a mean follow-up duration of 3.9 years.



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Conclusion: In a nationally representative sample, higher patient satisfaction was associated with less emergency department use but with greater inpatient use, higher overall health care and prescription drug expenditures, and increased mortality.

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SONG

STANDARDISED OUTCOMES IN NEPHROLOGY

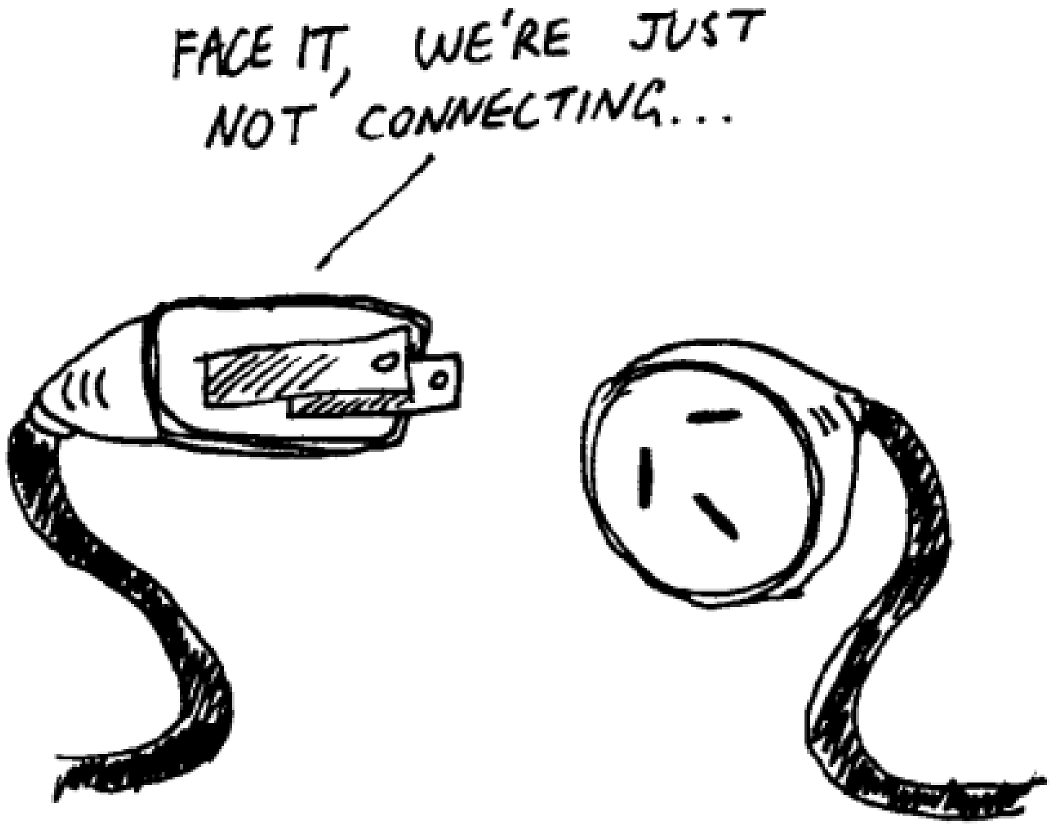
COMET INITIATIVE

Core Outcome Measures in Effectiveness Trials

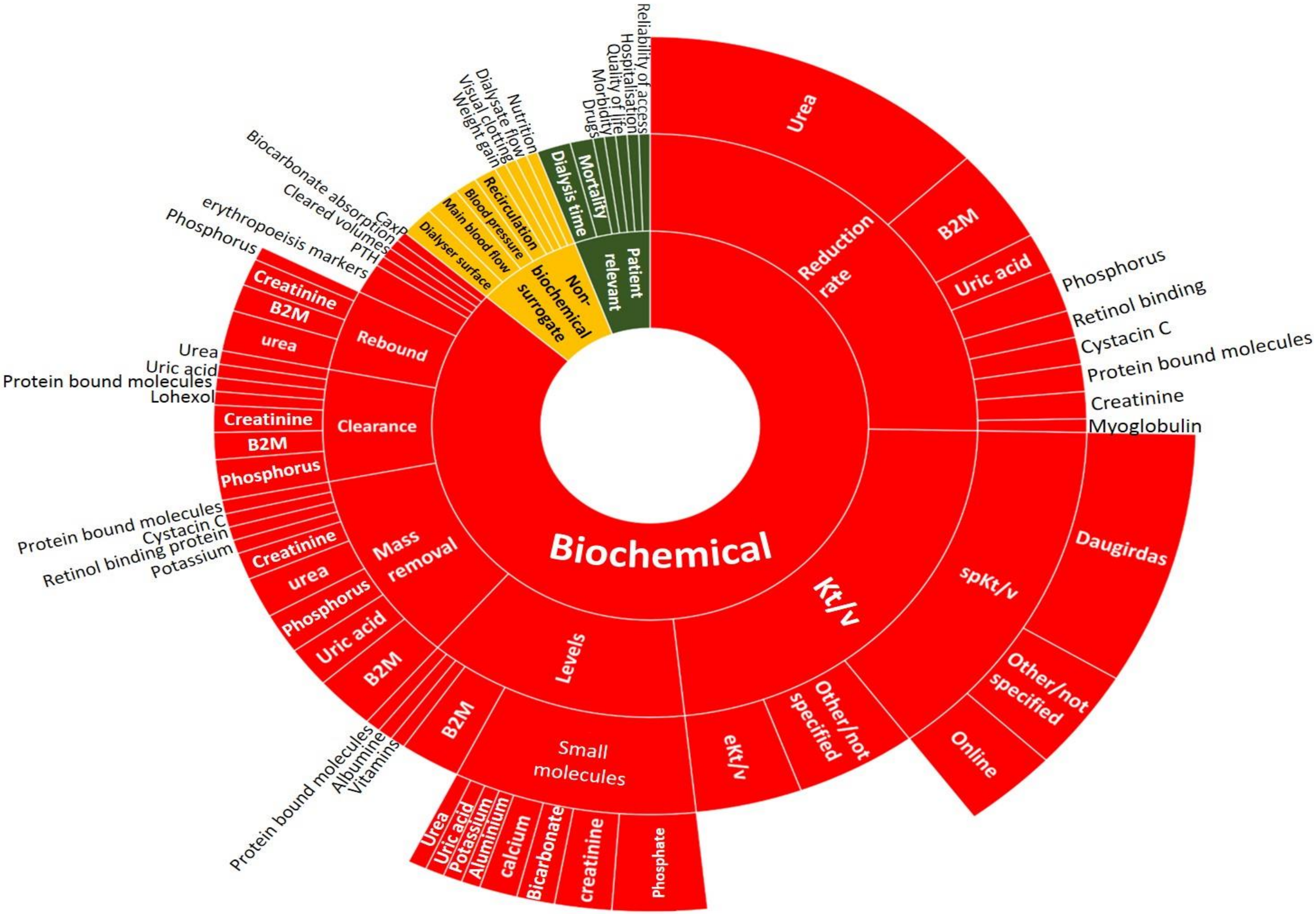
www.comet-initiative.org

Twitter: @COMETinitiative
Email: info@comet-initiative.org

Irrelevant unstandardised outcomes impede meta-analysis



Adequacy of dialysis: definitions in RCTs: a systematic review

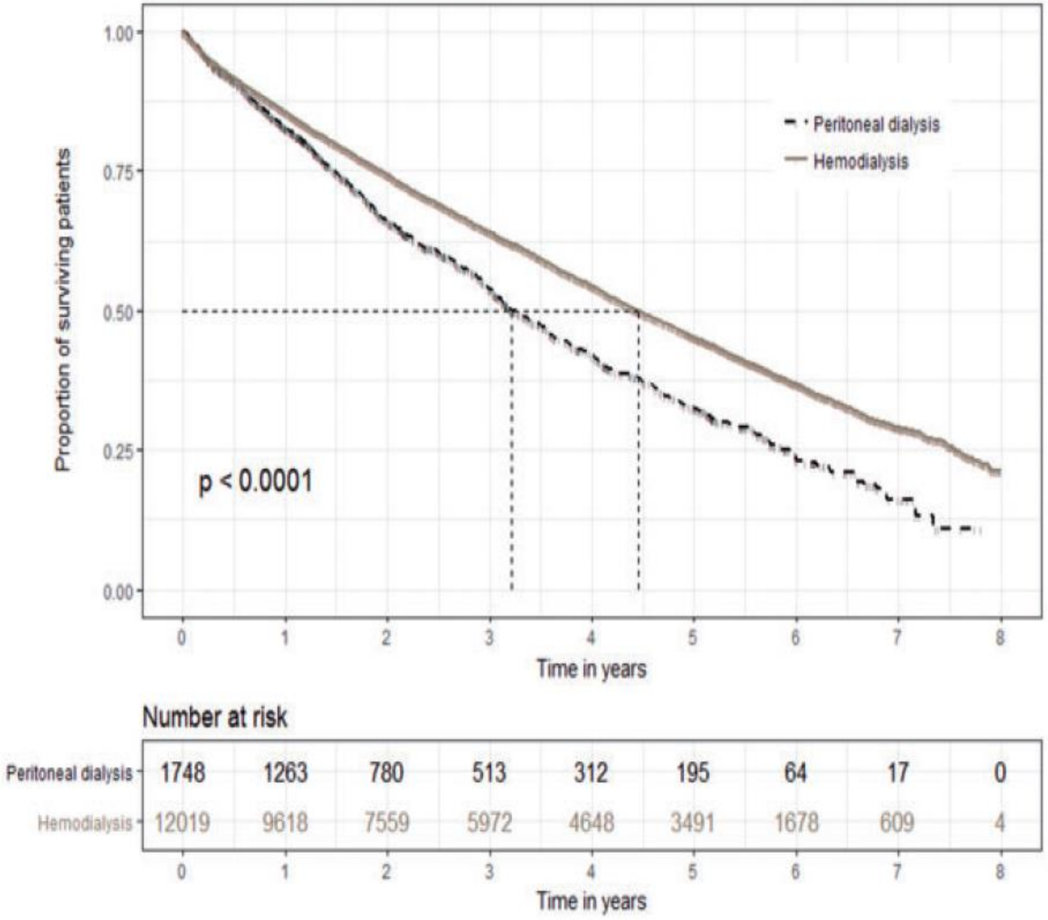


Irrelevant unstandardised outcomes lead to Babylonic misunderstanding

Survival advantage of planned haemodialysis over peritoneal dialysis: a cohort study

Alicia Thiery[1], François Séverac[2,3], Thierry Hannedouche[4,5], Cecile Couchoud[6], Van Huyen Do[3], Aurélien Tiple[7], Clémence Béchade[8], Erik-Andre Sauleau[2,3,4] and Thierry Krummel[5]
on behalf of the REIN registry

Irrelevant unstandardised outcomes lead to incorrect information

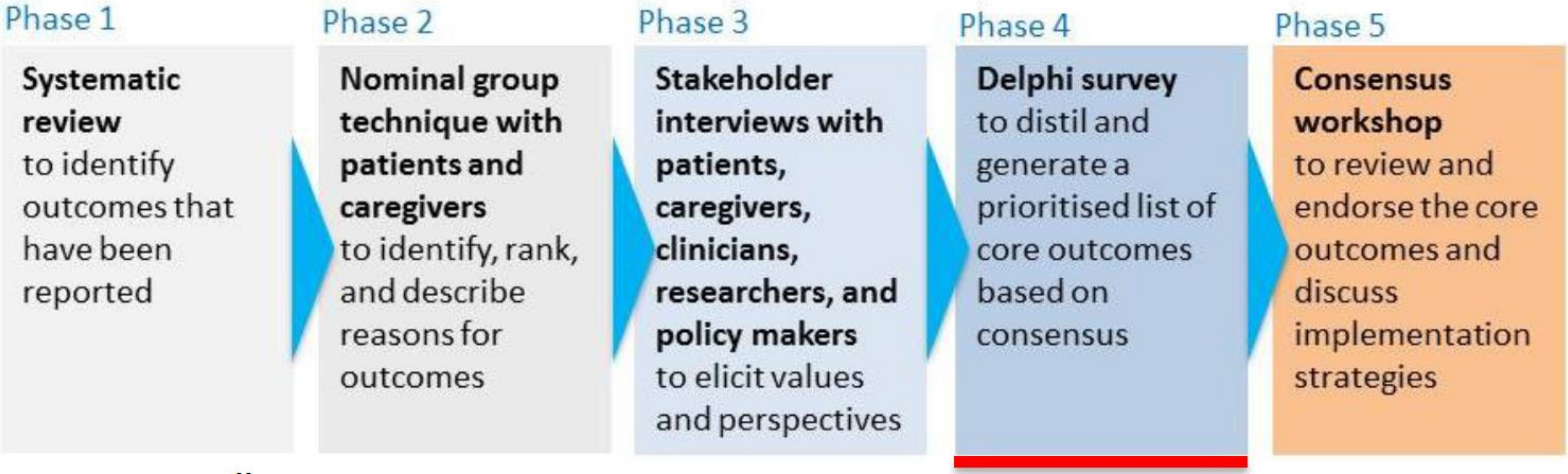


Number at risk	0	1	2	3	4	5	6	7	8
Peritoneal dialysis	1748	1263	780	513	312	195	64	17	0
Hemodialysis	12019	9618	7559	5972	4648	3491	1678	609	4

FIGURE 2: Kaplan–Meier survival curve analysis in patients receiving either PD or HD, considering censorship upon modality change.

Choosing outcomes

- **What if what is measured is not important?**
- **What if what is important is not measured?**
- **How do we make sure that all important outcomes are covered?**



Phase 1

Systematic review
to identify outcomes that have been reported

Phase 2

Nominal group technique with patients and caregivers
to identify, rank, and describe reasons for outcomes

Phase 3

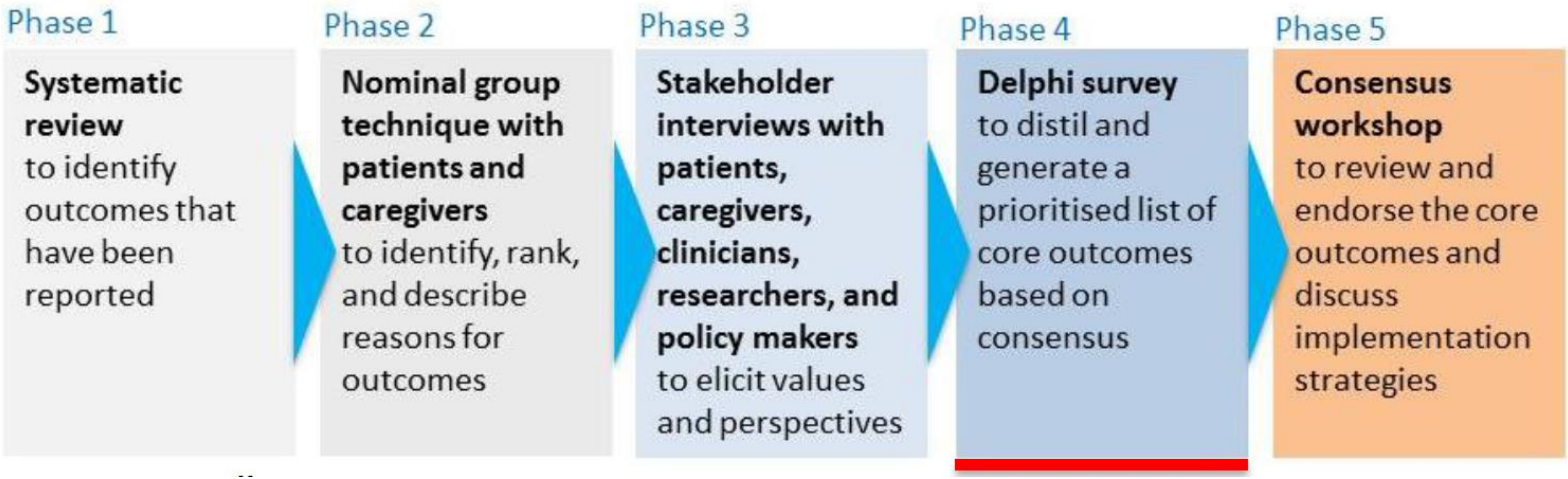
Stakeholder interviews with patients, caregivers, clinicians, researchers, and policy makers
to elicit values and perspectives

Phase 4

Delphi survey
to distil and generate a prioritised list of core outcomes based on consensus

Phase 5

Consensus workshop
to review and endorse the core outcomes and discuss implementation strategies



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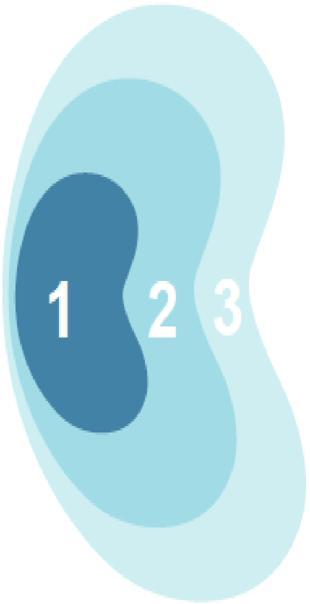
Patients involved as co-producers in research



1 CORE OUTCOMES

Critically important to all stakeholder groups. Report in all trials.

2 MIDDLE TIER

Critically important to some stakeholder groups. Report in some trials.

3 OUTER TIER

Important to some or all stakeholder groups. Consider for trials.

Figure 1a. Conceptual schema of a core outcome set (adapted from OMERACT)

1 **FATIGUE**
CARDIOVASCULAR DISEASE
VASCULAR ACCESS
MORTALITY

2 Ability to travel
Ability to work
Anaemia
Blood pressure
Depression
Dialysis adequacy
Dialysis-free time
Drop in blood pressure
Hospitalisation
Impact on family/ friends
Infection/Immunity
Mobility
Pain
Potassium
Target weight
Washed out after dialysis

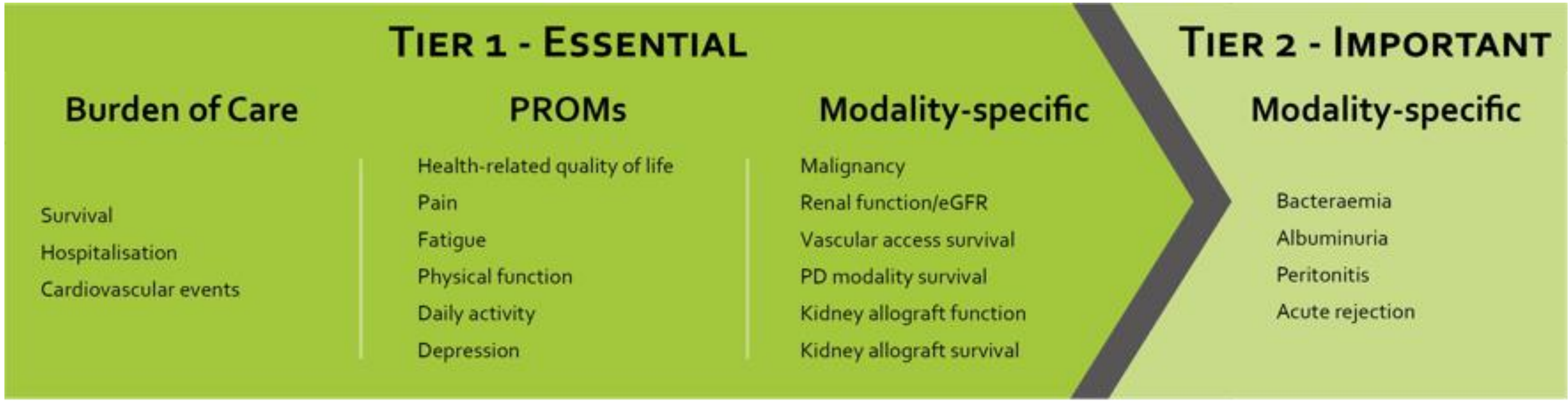
3 Anxiety/stress
Bone health
Calcium
Cognition
Cramps
Financial impact
Food enjoyment
Itching
Nausea/vomiting
Parathyroid hormone
Phosphate
Restless legs syndrome
Sexual function
Sleep

These are the outcomes of the CKD Standard Set

⬜ Not measured
🟩 Measured

				Patients				
	Domains		Subdomains	Pre-RRT	HD	PD	Tx	CC
Outcomes	Burden of care	Tier- 1 Essential	Survival	🟩	🟩	🟩	🟩	🟩
			Hospitalization	🟩	🟩	🟩	🟩	🟩
			Cardiovascular events	🟩	🟩	🟩	🟩	🟩
	Health & Wellbeing		HRQoL	🟩	🟩	🟩	🟩	🟩
			Pain	🟩	🟩	🟩	🟩	🟩
			Fatigue	🟩	🟩	🟩	🟩	🟩
			Physical function	🟩	🟩	🟩	🟩	🟩
			Depression	🟩	🟩	🟩	🟩	🟩
			Daily activity	🟩	🟩	🟩	🟩	🟩
	Treatment specific		Renal function / eGFR	🟩	⬜	⬜	⬜	🟩
			Vascular access survival	⬜	🟩	⬜	⬜	⬜
			PD modality survival	⬜	⬜	🟩	⬜	⬜
			Malignancy	⬜	⬜	⬜	🟩	⬜
			Kidney allograft function	⬜	⬜	⬜	🟩	⬜
			Kidney allograft survival	⬜	⬜	⬜	🟩	⬜
		Tier- 2 Important	Acute rejection	⬜	⬜	⬜	🟩	⬜
			Albuminuria	🟩	⬜	⬜	🟩	🟩
			Bacteraemia	⬜	🟩	🟩	🟩	⬜
			Peritonitis	⬜	⬜	🟩	⬜	⬜

The two-tier implementation model will help to guide implementation and reporting of patient-centred outcome



TIER 1 - ESSENTIAL

Burden of Care
- Survival
- Hospitalisation
- Cardiovascular events

PROMs
- Health-related quality of life
- Pain
- Fatigue
- Physical function
- Daily activity
- Depression

Modality-specific
- Malignancy
- Renal function/eGFR
- Vascular access survival
- PD modality survival
- Kidney allograft function
- Kidney allograft survival

TIER 2 - IMPORTANT

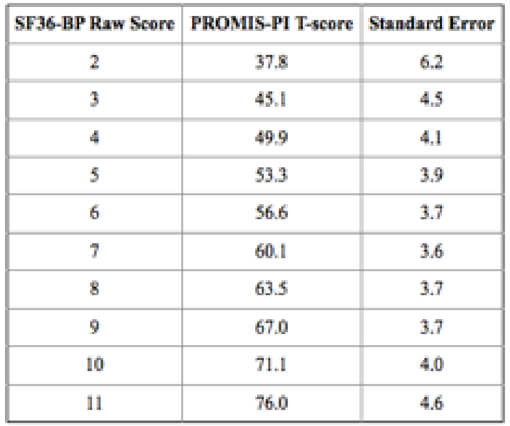
Modality-specific
- Bacteraemia
- Albuminuria
- Peritonitis
- Acute rejection

Health & Wellbeing

Outcome domain	Definition and response options	Timing	Data Source
HRQOL **Pain** **Fatigue** **Physical activity** **Depression** **Daily activity** Pre-RRT, HD, PD, Tx, CC	SF-36 V2.0 Or RAND-36 Or PROMIS Global Health with PROMIS-29	HD, PD, CC 6 monthly Pre-RRT, Tx annually	Patient

SF-36/RAND-36/PROMIS:

- Generic health survey that can be used across age (18 and older), disease and treatment group, as opposed to a disease-specific health survey, which focuses on a particular condition or disease
- Provide scores for individual health domains and two summary scores for overall physical and mental component
- Cross-walk table allows to places to instruments on the same metrics (scale)



SF36-BP Raw Score	PROMIS-PI T-score	Standard Error
2	37.8	6.2
3	45.1	4.5
4	49.9	4.1
5	53.3	3.9
6	56.6	3.7
7	60.1	3.6
8	63.5	3.7
9	67.0	3.7
10	71.1	4.0
11	76.0	4.6

Cross-walk table match each possible score on SF-36 Bodily Pain to a PROMIS Pain Interference score

How Data-Driven Decisions **REALLY** work

http://dilbert.com/strips/comic/2007-05-16/

Patient centered care dilemmas

Patient centered care dilemmas

- **Do I listen to the patient or to the lungs of the patient?**

(and how does that impact on my KPI?)

Patient centered care dilemmas

- Do listen to the patient or to the lungs of the patient?
- **While you register what you are doing, you do not do what you are registering**

(or why am I spending so much time on putting the administration right while I should be administering care to patients)

Patient centered care dilemmas

- Do listen to the patient or to the lungs of the patient?
- While you register what you are doing, you do not do what you are registering
- **As a nephrologist, I am not the psychologist nor the pastoral worker or household help, or am I?**

(or should I spend my precious time and expertise in trying to answer existential or down to earth practical problems, this is not efficient, is it?

Or: Am I technician repairing something or a healer?

Patient centered care dilemmas

- Do listen to the patient or to the lungs of the patient?
- While you register what you are doing, you do not do what you are registering
- As a nephrologist, I am not the psychologist nor the pastoral worker or household help, or am I?
- **Do no harm or Do what is best for your patient?**

(or should we keep the patient hostage to keep him safe?

INTERNATIONAL SOCIETY FOR PERITONEAL DIALYSIS

EuroPD

EUROPD meeting Ljubljana 2019

ISPD EuroPD 2020 2-5 May

SEC, GLASGOW, SCOTLAND

www.ISPD-EUROPD2020.com

info@ISPD-EUROPD2020.com