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Shared Decision Making in Neurocritical Care: Barriers and Facilitators

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In Medicine, including in the NeuroICU, decisions are often difficult – no right or wrong.

"I have diabetes. Should I take insulin or pills?"

Without a hemicraniectomy, this Stroke patient will die. The procedure will save the patient's life, but will leave the patient permanently disabled. Should we offer / do it?

Difficult decisions

Value laden decisions

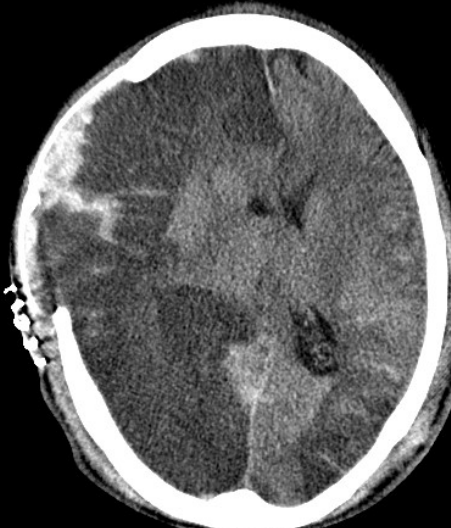
"I have Breast cancer. Should I have a mastectomy or choose breast-conserving surgery?"

"My wife is on a ventilator and needs a tracheostomy/feeding tube. I'm not sure she would want that."

I will use the example of the Neuro-Intensive Care unit (NeuroICU) to explain the concept of Shared Decision Making.

In the NeuroICU, outcome prognostication may be particularly difficult.

- Sudden
- Heterogeneous
- Biased providers
- Prognosis is unknown
- Communication breakdown



Critically-ill NeuroICU patients are too ill to make their own decisions.

Too ill, very suddenly

- Confused
- Sedated (to tolerate ventilator)
- Comatose

Brain injury

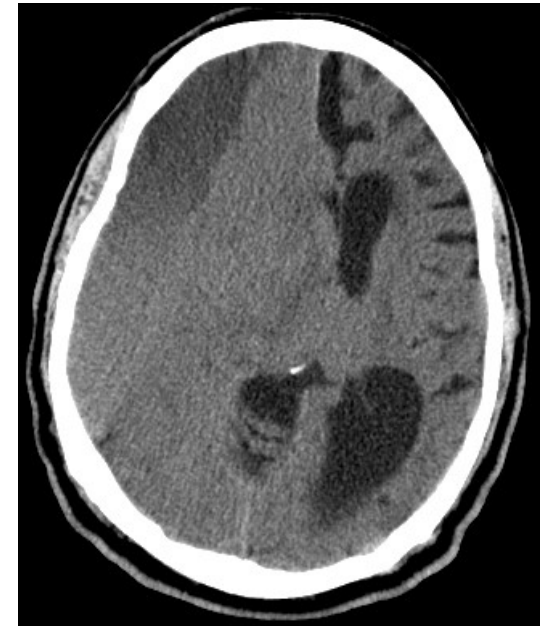
- Leaves them without decision-making capacity
- For weeks/months/life

?Brain surgery/hemicraniectomy?

Most survive first 7-10 days

- What's next? Prognosis?
- Tracheostomy or not?
- Feeding tube or not?
- Rehab ? Nursing home?
- Or comfort care / hospice?

**"Goals-of-Care"
Decisions**




Self-fulfilling prophecies are ever present in the NeuroICU.

Withdrawal of support in intracerebral hemorrhage may lead to self-fulfilling prophecies

K.J. Becker, MD; A.B. Baxter, MD; W.A. Cohen, MD; H.M. Bybee, MD; D.W. Newell, MD; H.R. Winn, MD

Clinical Nihilism in Neuroemergencies

Claude Hemphill III, MD, MAS^{a,b,c,*}, Douglas B. White, MD, MAS^{d,e,f}
Emerg Med Clin N Am 27 (2009) 27–37

 neurocritical care society Neurocrit Care (2013) 19:347–363
DOI 10.1007/s12028-013-9925-z

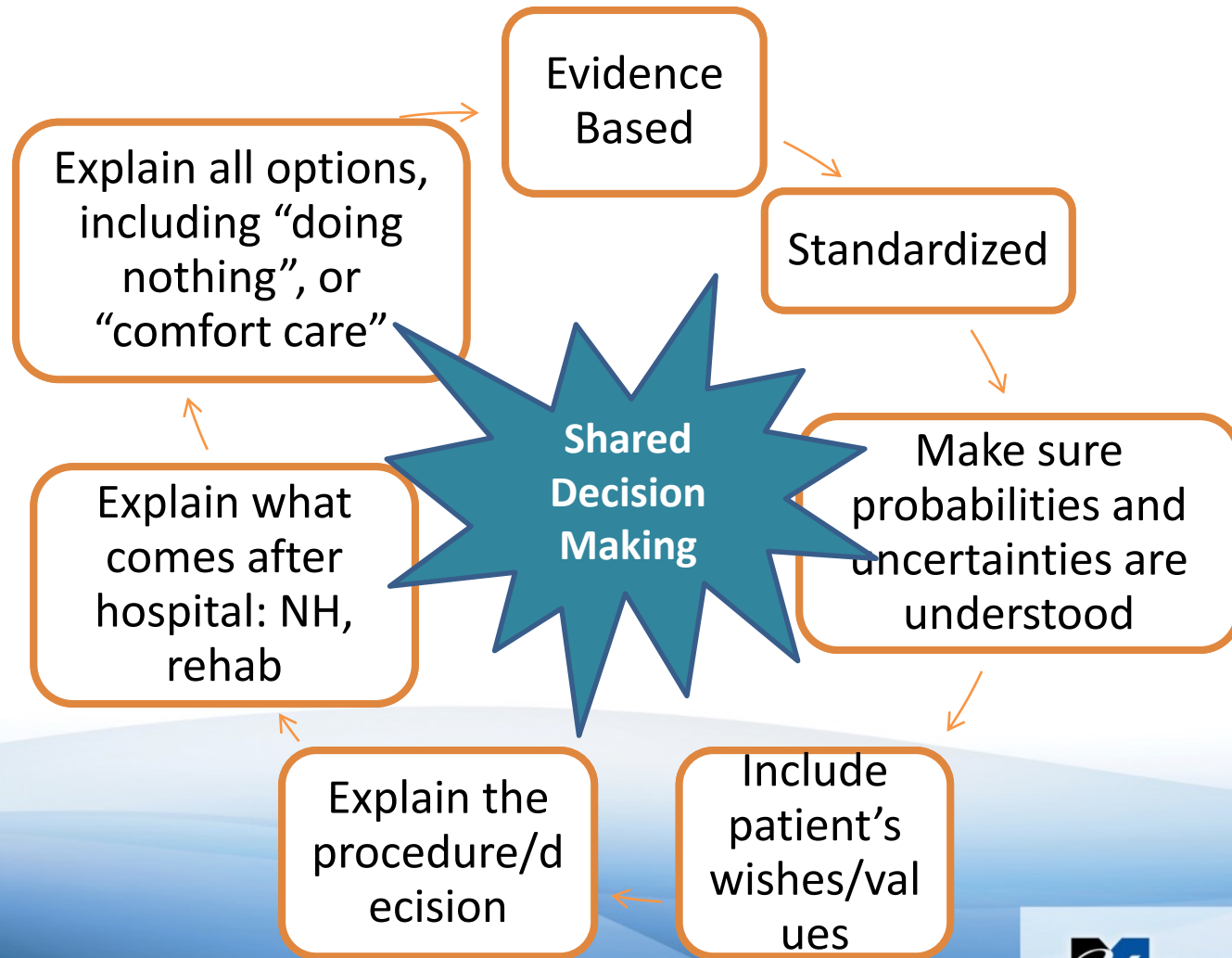
ORIGINAL ARTICLE

Self-Fulfilling Prophecies Through Withdrawal of Care: Do They Exist in Traumatic Brain Injury, Too?

Saef Izzy · Rebecca Compton · Raphael Carandang ·
Wiley Hall · Susanne Muehlschlegel

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“What would be the best possible way to present care options to families?”



What the heck is Shared Decision Making (SDM)?

From: <http://healthypeople2020.gov>

SDM a priority by Obama administration
Healthy People 2020

Home About Healthy People **2020 Topics & Objectives** Data Learn Implement Get Involved Leading Health Indicators

Home > 2020 Topics & Objectives > Health Communication and Health Information Technology

Health Communication and Health Information Technology

Print E-mail Share

Overview **Objectives** Interventions & Resources National Snapshot National Data

- [Redacted]
- [Redacted]
- Building social support networks.
- Facilitating the meaningful use of health IT
- Enabling quick and informed action to health risks
- Increasing health literacy skills.
- Provide new connections to hard-to-reach populations
- Provide sound principles for design of interventions
- Increasing Internet and mobile access.



What the heck is Shared Decision Making (SDM)?

From: <http://www.informedmedicaldecisions.org>

SDM a priority by Obama administration
Healthy People 2020

SDM

is a **collaborative** process that allows patients and their providers to make health care decisions together, taking into account the **best scientific evidence** available, as well as the **patient's values and preferences**.

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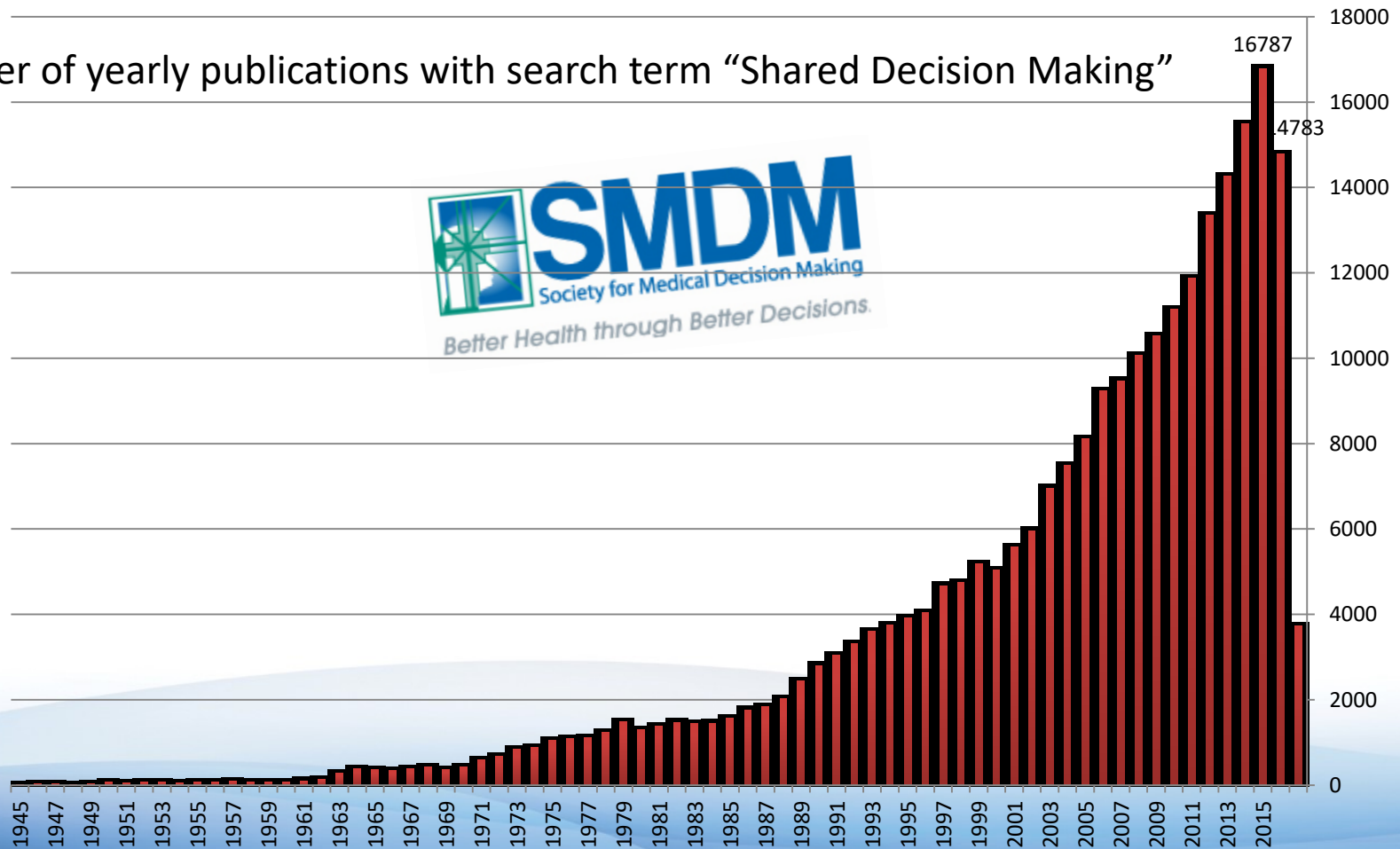
SDM

honors both the provider's expert knowledge and the patient's right to be fully informed of all care options and the potential harms and benefits.

This process provides patients with the support they need to make the best individualized care decisions, while allowing providers to feel confident in the care they prescribe.

Sounds easy – let's do it!

Number of yearly publications with search term "Shared Decision Making"



American College of Crit Care Med and American Thoracic Society call for increased SDM in the ICU:



Crit Care Med Jan 2016

Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement

Alexander A. Kon, MD, FCCM^{1,2}; Judy E. Davidson, DNP, RN, FCCM³;
Wynne Morrison, MD, MBE, FCCM⁴; Marion Danis, MD, FCCM⁵; Douglas B. White, MD, MAS⁶

This recently published viewpoint article in JAMA discusses certification of SDM tools.

This Issue

Views **3,236** | Citations **0** |  **498**

Viewpoint

April 4, 2017

Prime Time for Shared Decision Making

Erica S. Spatz, MD, MHS^{1,2}; Harlan M. Krumholz, MD, SM^{1,2}; Benjamin W. Moulton, JD, MPH³

» [Author Affiliations](#)

JAMA. 2017;317(13):1309-1310. doi:10.1001/jama.2017.0616

The International Patient Decision Aid Standards (IPDAS) provide an evidence-informed framework with set quality criteria.

International Patient Decision Aid Standards (IPDAS)
Collaboration

Research

BMJ

[BMJ](#). 2006 Aug 26;333(7565):417. Epub 2006 Aug 14.

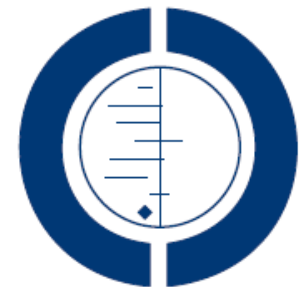
Developing a quality criteria framework for patient decision aids: online international Delphi consensus process

Glyn Elwyn, Annette O'Connor, Dawn Stacey, Robert Volk, Adrian Edwards, Angela Coulter, Richard Thomson, Alexandra Barratt, Michael Barry, Steven Bernstein, Phyllis Butow, Aileen Clarke, Vikki Entwistle, Deb Feldman-Stewart, Margaret Holmes-Rovner, Hilary Llewellyn-Thomas, Nora Mounjid, Al Mulley, Cornelia Ruland, Karen Sepucha, Alan Sykes, Tim Whelan, on behalf of the International Patient Decision Aids Standards (IPDAS) Collaboration

Decision aids for people facing health treatment or screening decisions (Review)

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

Cochrane Review: updated 2014:
Includes 115 studies involving 34,444 participants.
Evaluate which decision aids meet IPDAS criteria.



THE COCHRANE
COLLABORATION®

The current IPDAS Checklist consists of 12 Quality Dimensions.

- 1) Using A Systematic Development Process
- 2) Providing Information About Options
- 3) Presenting Probabilities
- 4) Clarifying And Expressing Values
- 5) Using Personal Stories
- 6) Guiding / Coaching In Deliberation And Communication
- 7) Disclosing Conflicts Of Interest
- 8) Delivering Decision Aids On The Internet
- 9) Balancing The Presentation of Information and Options
- 10) Addressing Health Literacy
- 11) Basing Information On Comprehensive, Critically Appraised, And Up-To-Date Syntheses Of The Scientific Evidence
- 12) Establishing The Effectiveness

The Ottawa Research Institute Decision Aid Library hosts 666 (+) decision aids.

<https://decisionaid.ohri.ca/>

Examples:

Atrial Fibrillation: Which Anticoagulant Should I Take to Prevent Stroke?

A Decision Aid to Prepare Patients And Their Families For Shared Decision-Making About Cardio-Pulmonary Resuscitation (CPR)

Decision Aids have been shown to have important effects on decisions and decision-making.

• **Knowledge**

- DAs improved knowledge of options and outcomes; lead to more realistic expectations

• **Decision processes**

- DAs help match their values to their choices; reduce decisional conflict and passivity; help the undecided to decide

• **Adherence to treatment**

- DAs do not improve adherence to medication

• **Treatment decisions**

- Impact on treatment choice is modest and variable

• **Impact on major elective surgeries**

- Reduction in the choice of major elective surgery in the DA group, compared to usual care
- No effect on minor elective surgeries

From: Stacey et al, Cochrane Review Decision aids, 2014;
Col: Chapter 17: Shared Decision Making, from Communicating Risks and Benefits: An Evidence-Based User's Guide (FDA)

There are some barriers to SDM making it difficult to implement decision aids into health care settings.

Patient barriers

- Unaware that there is a decision to make
- Believing that clinicians prescribe the only available treatment
- Discomfort, inexperience with SDM
- Preconceptions about care

Physician barriers

- Concerns about time
- Lack of training
- Pessimism about pt's ability to assume a more active role
- Believing it's not applicable to their patients
- Clinical situation
- Clinical care pattern
- Difficulty reconciling patient preferences
- Concerns that DA could bias patients to choose less expensive options

Decision aid development activities at UMASS

Example: Goals of Care Decision in Critically-ill TBI patients

NIH/NICHD 5K23HD080971 (PI Muehlschlegel)
Mentors: Mazor, Goldberg, Col (UNE) Shutter (UPMC)



Eunice Kennedy Shriver National Institute
of Child Health and Human Development
Health research throughout the lifespan

In TBI, “Goals-of-Care” decisions may be better supported using Shared Decision Making.

In order to create a decision aid for “Goals-of-Care” decisions for surrogate decision-makers, we move through stages:

First Stage

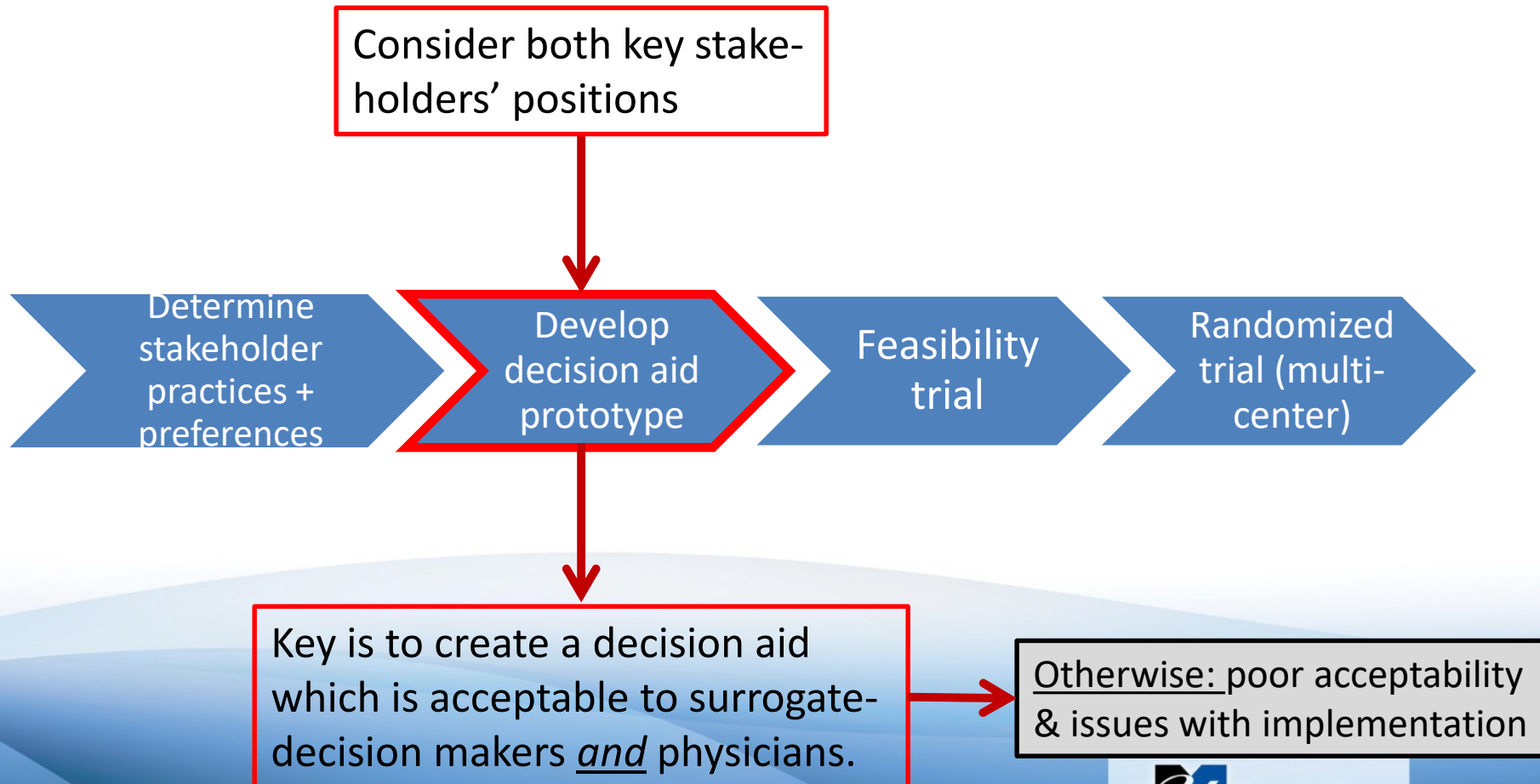


Qualitative study of surrogate decision-makers and physicians caring for **critically ill TBI patients**

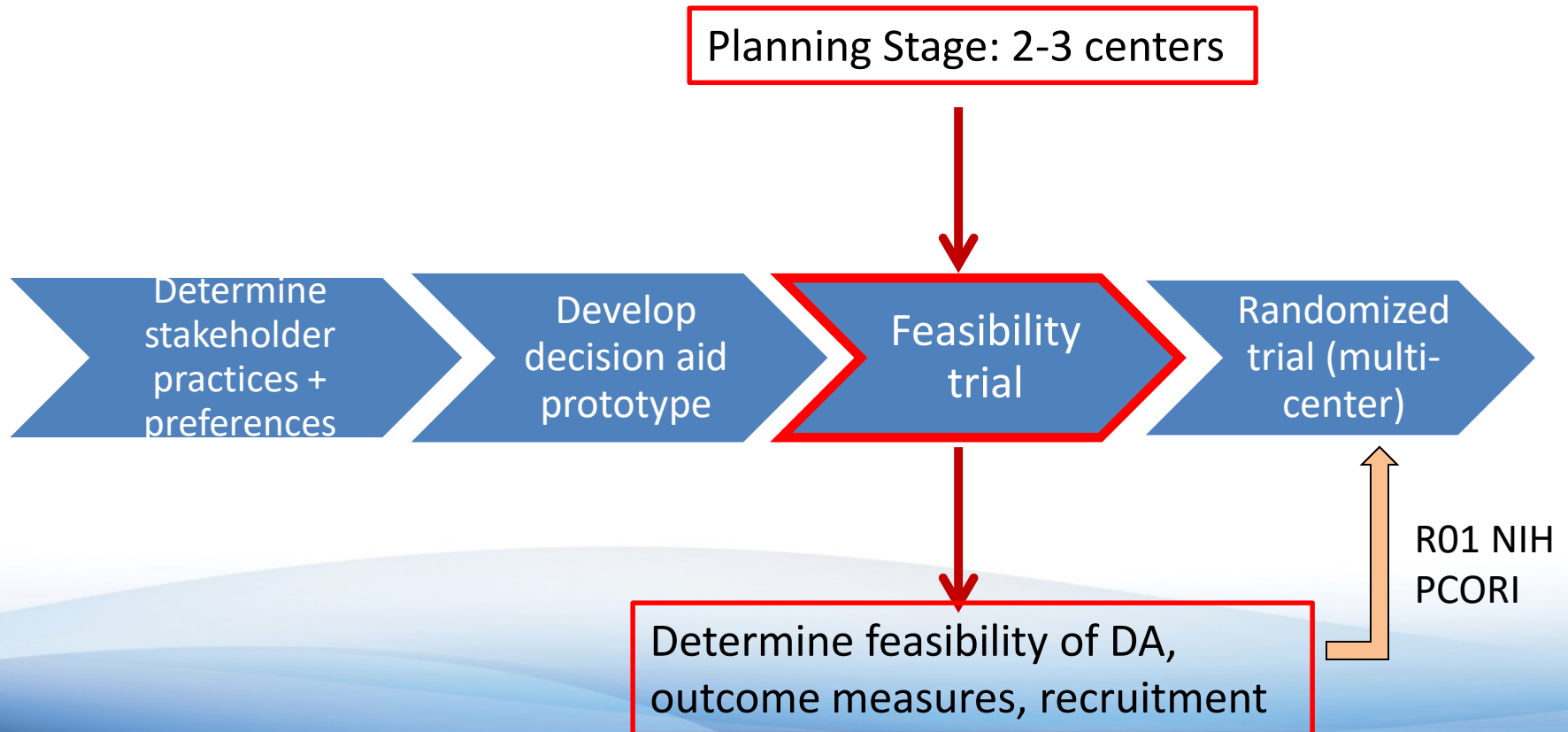
For methods and results, please view our posters this afternoon.

Posters 54 and 65

These findings inform our pilot decision aid for goals-of-care discussions



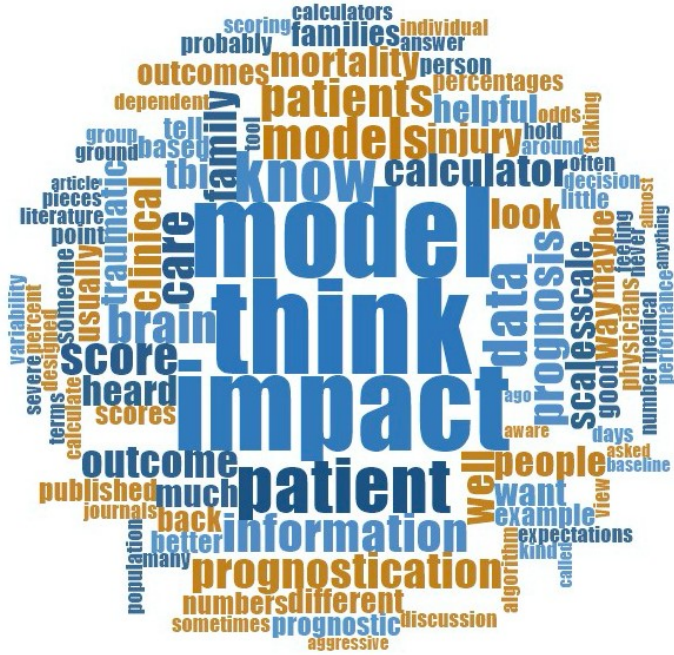
These findings inform our pilot decision aid for goals-of-care discussions





**"You want to speak to the head of the household?
There is no head of the household. My parents
are into shared decision making."**

From:
www.Cartoonstock.com



UMASS Neurocritical Care Research Lab

- Wiley Hall, MD
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- Marcey Osgood, DO
- Thomas Quinn, BS (UMMS 2019)
- Jesse Moskowitz, BS (UMMS 2018)
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- Nananda Col, MD, MPH, MPS (UNE)
- Lori Shutter, MD (UPMC)

 #SMuehlschMD

Collaborators

- Bengisu Tulu, PhD (WPI)
- Angelos Koliass, MD (U of Cambridge, UK)



UNIVERSITY OF CAMBRIDGE

Thank you.

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