Shared Decision Making Learning Community Kickoff Meeting

February 13, 2025
9:00 a.m. – 10:00 a.m.

Washington State Health Care Authority

Meeting Agenda

- Welcome/Introductions
- Overview of purpose of learning community
- Introduction to Shared Decision Making
- Learning Community Charter
- Presentation Schedule
- Logistic details
- Wrap Up

Welcome and introductions

Please briefly share:

- Name
- Organization
- Interest in learning community
  - Newbie
  - Some experience
  - Expert

Overview of Purpose of Learning Community

Heather Schultz, MD, HCA

Washington State Health Care Authority

SDM Learning Community Purpose

- To provide a platform for organizations who are considering implementing SDM to learn from others who have successfully integrated SDM into practice
- To hear from experts in the field of SDM and patient decision aids to learn how PDAs can support good SDM
- To have a collaborative space to learn from peers

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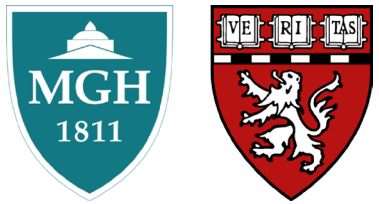

Shared Decision Making: The Pinnacle of Patient-Centered Care

Michael J. Barry, MD

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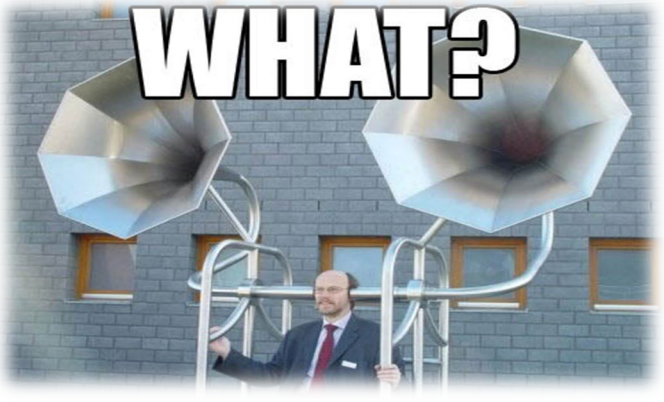
Shared Decision Making Learning Community
Washington State Health Care Authority
February 13, 2025

Informed Medical Decisions Program Vision

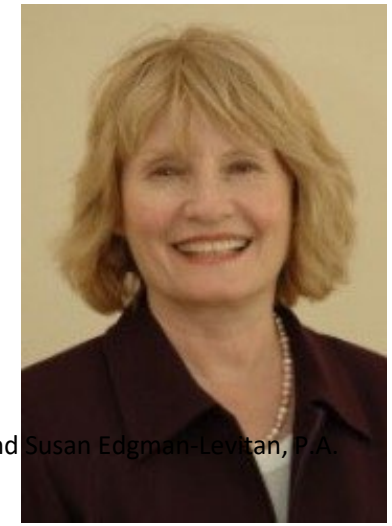
To inform and amplify the patient's voice in healthcare decisions.



Disclosure: I am a primary care physician at Massachusetts General Hospital and Professor of Medicine at Harvard Medical School, both nonprofits.

The NEW ENGLAND JOURNAL of MEDICINE

Clinicians, in turn, need to relinquish their role as the single, paternalistic authority and train to become more effective coaches or partners — learning, in other words, how to ask, **"What matters to you?"** as well as **"What is the matter?"**



Barry and Susan Edgman-Levitan, P.A.

PERSPECTIVE

SHARED DECISION MAKING

Shared Decision Making — The Pinnacle of Patient-Centered Care

Michael J. Barry, M.D., and Susan Edgman-Levitan, P.A.

Nothing about me without me.

— Valerie Billingham,
Through the Patient's Eyes,
Salzburg Seminar
Session 356, 1998

Caring and compassion were once often the only "treatment" available to clinicians. Over time, advances in medical science have provided new options that, although often improving outcomes, have inadvertently distanced physicians from their patients. The result is a health care environment in which patients and their families are often excluded from important discussions and left feeling in the dark about how their problems are being managed and how to navigate the overwhelming array of diagnostic and treatment options available to them.

An audio interview with Dr. Barry is available at NEJM.org

In 1988, the Picker/Commonwealth Program for Patient-Centered Care (now the Picker Institute) coined the term "patient-centered care" to call attention to the need for clinicians, staff, and health care systems to shift their focus away from diseases and back to the patient and family.[1] The term was meant to stress the importance of better understanding the experience of illness and of addressing patients' needs within an increasingly complex and fragmented health care delivery system.

The Picker Institute, in partnership with patients and families, conducted a multiyear research project and ultimately identified eight characteristics of care as the most important indicators of quality and safety, from the perspective of patients: respect for the patient's values, preferences, and expressed needs; coordinated and integrated care; clear, high-quality information and education for the patient and family; physical comfort, including pain management; emotional support and alleviation of fear and anxiety; involvement of family members and friends, as appropriate; continuity, including through care-site transitions; and access to care.[2] Successfully addressing these dimensions requires enlisting patients and families as allies in designing, implementing, and evaluating care systems.

This concept was introduced in the landmark Institute of Medicine (IOM) report *Crossing the Quality Chasm*[2] as one of the fundamental approaches to improving the quality of U.S. health care. The IOM defined patient-centered care as "care that is respectful of and responsive to individual patient preferences, needs, and values" and that ensures "that patient values guide all clinical decisions." This definition highlights the importance of clinicians and patients working together to produce the best outcomes possible.

As the definition implies, the most important attribute of patient-centered care is the active engagement of patients when fateful health care decisions must be made — when an individual patient arrives at a crossroads of medical options, where the diverging paths have different and important consequences with lasting implications. Examples include decisions about major surgery, medications that must be taken for the rest of one's life, and screening and diagnostic tests that can trigger cascades of serious and stressful interventions.

For some decisions, there is one clearly superior path, and patient preferences play little or no role — a fractured hip needs repair, acute appendicitis necessitates surgery, and bacterial meningitis requires antibiotics. For most medical decisions, however, more than one reasonable path forward exists (including the option of doing nothing, when appropriate), and different paths entail different combinations of possible therapeutic effects and side effects. Decisions about therapy for early-stage breast cancer or prostate cancer, lipid-lowering medication for the primary prevention of coronary heart disease, and genetic and cancer screening tests are good examples. In such cases, patient involvement in decision making adds substantial value.

In an influential article on clinical practice guidelines, David Eddy argued that an intervention should be considered a "standard" only if there is "virtual unanimity among patients about the overall desirability . . . of the outcomes."[3] For the vast majority of decisions in which there is no intervention that meets this high bar, patients need to be involved in determining the management strategy most consistent with their preferences and values.

The process by which the optimal decision may be reached for a patient at a fateful health crossroads is called shared decision making and involves, at minimum, a clinician and the patient, although other members of the

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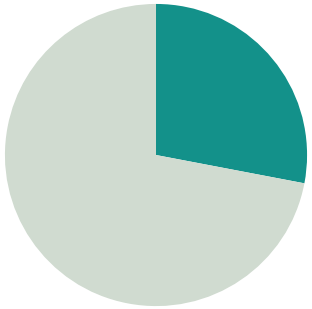
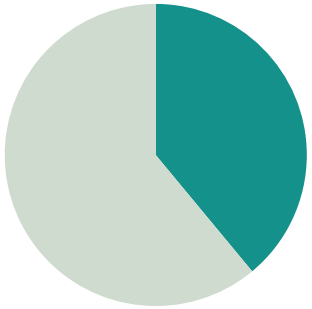
Are patients informed? Not very!

Percentage of patients undergoing hip or knee arthroplasty who answered each knowledge question correctly:



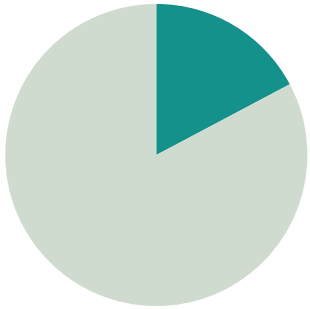
28%

How many people **get pain relief from surgery**



46%

How many people **experience surgical complication (e.g., wound infection)**



15%

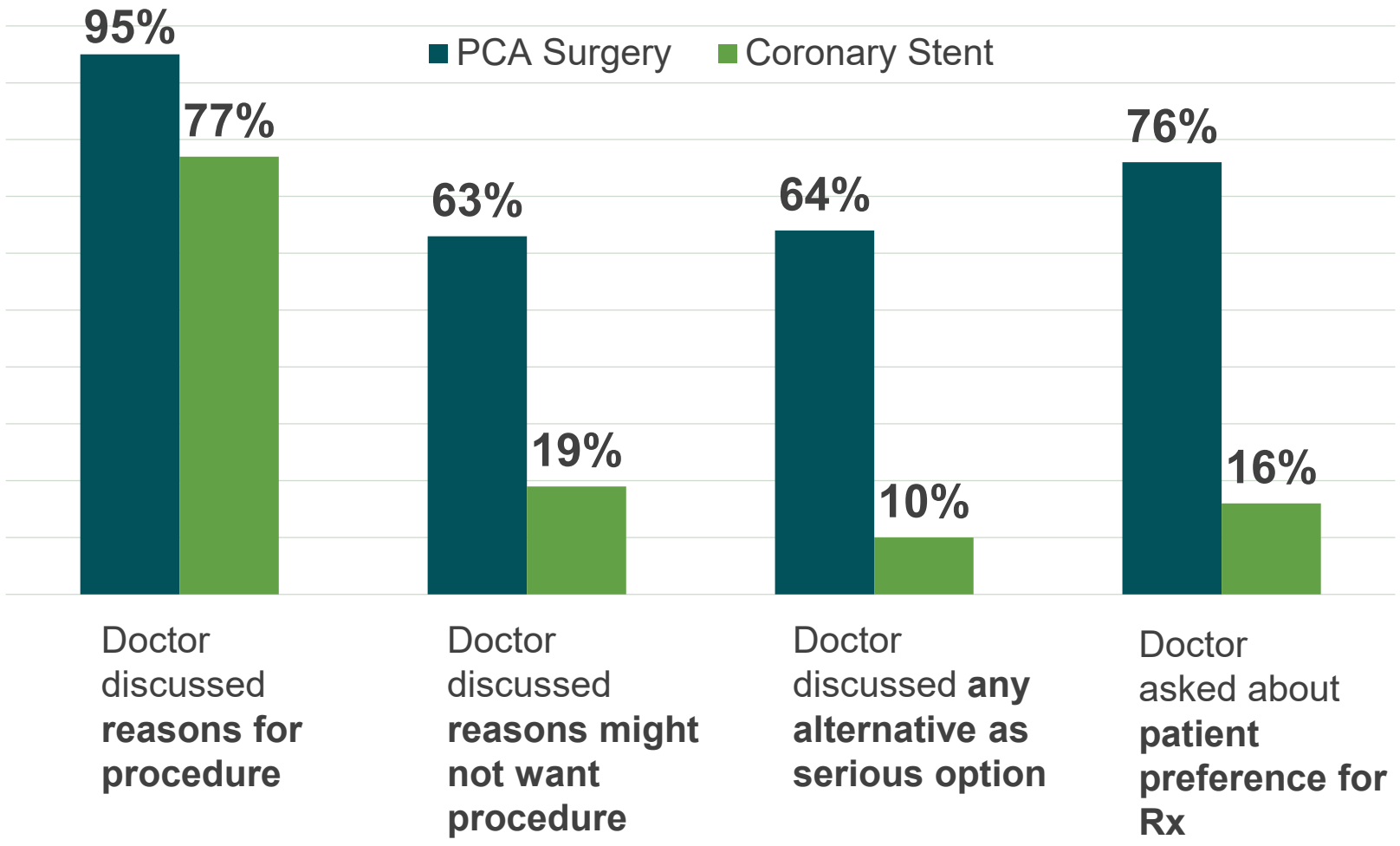
How many people will have **replacement at least 20 years**

39%

How many people **return to normal activity**

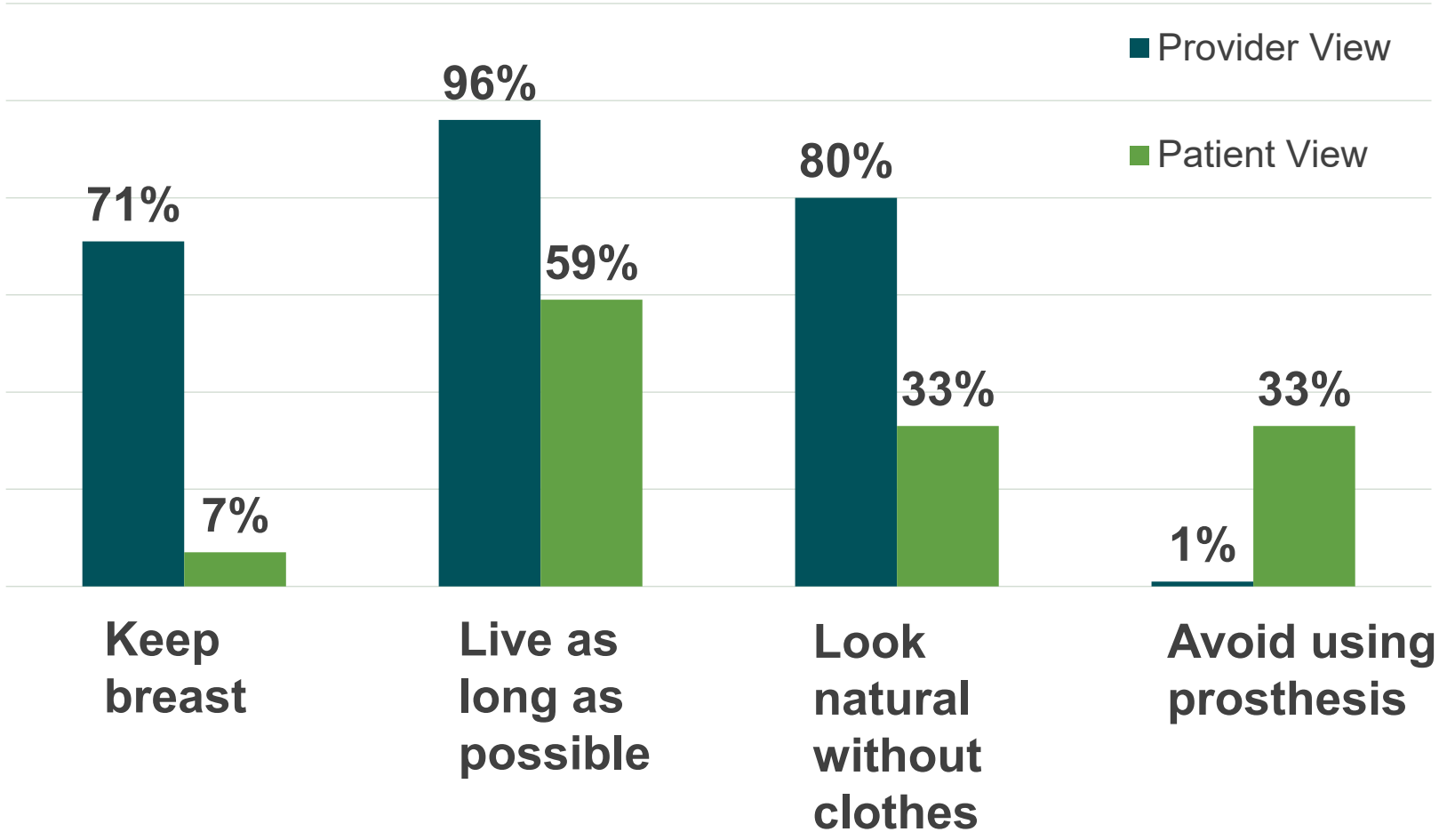
Fagerlin A, et al. (2010). *Med Decis Making.* 30(5 Suppl): 35S-52S.

Are patients involved? It depends!



Fowler FJ, et al. (2012). *JGIM.* 27(8): 911-16.

Top four goals and concerns for breast cancer decisions



Sepucha K, et al. (2008). *Patient Educ Couns.* 73: 504-10.

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The silent misdiagnosis

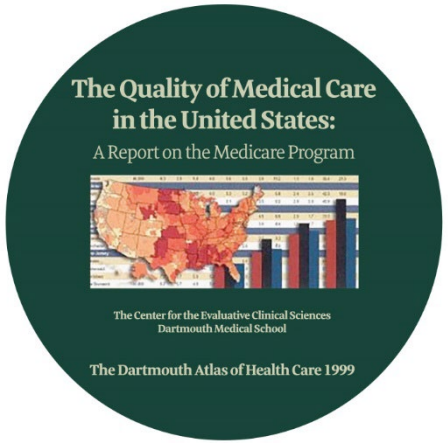
> **"Many doctors aspire to excellence in diagnosing disease. Far fewer, unfortunately, aspire to the same standards of excellence in diagnosing what patients want."**

Al Mulley, Chris Trimble, Glyn Elwyn

Mulley A, et al. (2012). Patients' preferences matter: Stop the silent misdiagnosis. London: The King's Fund.

Forces sustaining unwanted practice variation

Patients:
Making decisions in the face of avoidable ignorance



Clinicians:
Less than optimal "diagnosis" of patients' preferences

Poor Decision Quality
Unwanted Practice Variation

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A word on taxonomy

Effective Care

- Strong evidence base supports care
- Benefit-to-harm ratio high
- All with need should receive

A word on taxonomy

Preference-Sensitive Care

- Evidence supports different approaches
- Treatment/testing options involve trade-offs
- Personal values, preferences should drive decisions

Shared decision making model

Key characteristics:

- At least two participants (clinician & patient) are involved
- Both parties share information
- Both parties take steps to build a consensus about the preferred treatment
- An agreement is reached on the treatment to implement

Charles C, et al. (1997). *Soc Sci Med*. 44(5): 681-92.

NQF Definition of Shared Decision Making

Shared decision making (SDM) is a process of communication in which clinicians and patients work together to make optimal healthcare decisions that align with what matters most to patients. SDM requires three components:

- clear, accurate, and unbiased medical evidence about reasonable alternatives—including no intervention—and the risks and benefits of each;
- clinician expertise in communicating and tailoring that evidence for individual patients; and
- patient values, goals, informed preferences, and concerns, which may include treatment burdens.

http://www.qualityforum.org/Publications/2017/10/NQP_Shared_Decision_Making_Action_Brief.aspx

Patient decision aids can help

- Tools designed to help people participate in decision-making
- Provide information on the options
- Help patients clarify and communicate the values they associate with different features of the options

The Ottawa Hospital A to Z Inventory of Decision Aids

- Inventory of publicly available decision aids
- Decision aids are rated according to the IPDAS criteria
- Lists of developers
- Implementation toolkits

The Ottawa Hospital | L'Hôpital d'Ottawa

Inspired by research. Driven by compassion. Inspiré par la recherche. Guidé par la compassion.

https://decisionaid.ohri.ca/azinvent.php

The evidence about decision aids

Cochrane Review “Decision aids for people facing health treatment or screening decisions” first published in 2003

- Just updated in 2024!
- 209 trials of pDA versus usual care/other interventions (104 added since 2017 update)
- 107,698 participants

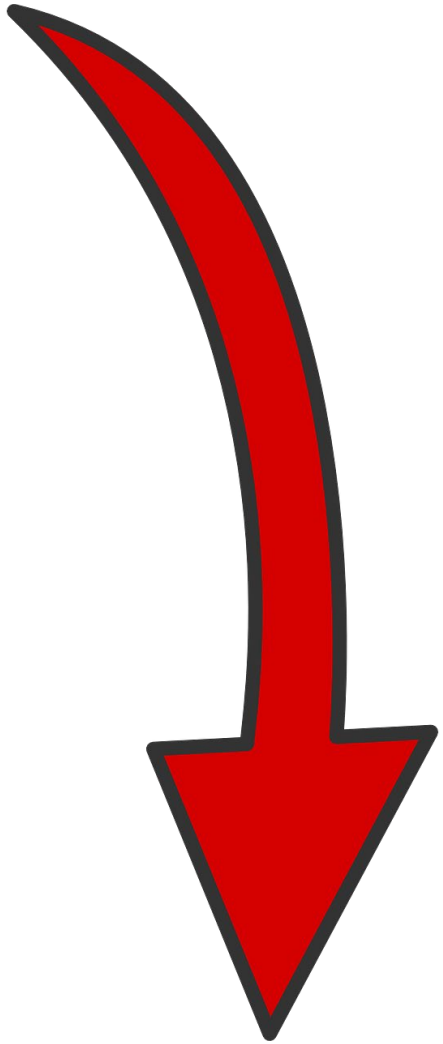
StaceyD, et al. Decision aids for people facing health treatment or screening decisions . Cochrane Database of Systematic Reviews 2024, Issue 1 . Art. No.: CD001431 . DOI: 10.1002/14651858.CD001431.pub6.

Decision aids increase:

- Patient knowledge
- Patient involvement in decision making
- Accuracy of risk perceptions
- Congruence between informed values and care choices

Decision aids **decrease:**

- Decisional conflict related to feeling uninformed
- Indecision about personal values
- Proportion of patients who remain undecided
- Surgery vs conservative option - HR 0.89 (0.83, 0.96)



Hip and knee decision aids at Group Health

- Introduced DAs for hip/knee arthroplasty candidates in 2009
- Over 6 months:
  - 38% fewer knee replacements
  - 26% fewer hip replacements
  - 12-21% lower costs

Arterburn D, et al. (2012). *Health Aff (Millwood).* 31(9): 2094-104.

Hip and knee DAs among African Americans

- RCT of THR/TKR DAs among African Americans with severe OA at 3 VA clinics
- Over 3 months:
  - Increased willingness to undergo joint replacement
- Over 12 months:
  - More referrals to orthopedics; higher attendance
  - undergo joint replacement
- And finally:
  - Higher receipt of total knee replacements

Ibrahim SA, et al. (2013) *Arthritis Rheum.* 65(5): 1253-61.

Ibrahim SA, et al. (2017) *JAMA Surg* 152(1):e164225

Everybody's doing SDM …

Science AAAS

REPORT

Shared decision-making drives collective movement in wild baboons

Ariana Strandburg-Peshkin[1,*,†], Damien R. Farine[2,3,4,*,†], Iain D. Couzin[1,5,6], Margaret C. Crofoot[2,3,*]

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† These authors contributed equally to this work.

Science 19 Jun 2015:
Vol. 348, Issue 6241, pp. 1358-1361
DOI: 10.1126/science.aaa5099

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Thank you

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SDM Learning Community Charter – Group Discussion

Sarah Pearson, HCA

Washington State Health Care Authority

Prioritization of Presentation Topics – Group Discussion

Sarah Pearson, HCA

Washington State Health Care Authority

Proposed schedule

- May 2025 – Patient experience or why is SDM important?
- August 2025 – Implementing SDM into practice
- November 2025 – Using Patient Decision Aids to support good SDM
- February 2026 – Other?

SDM Learning Community Meeting Logistics

Sarah Pearson, HCA

Washington State Health Care Authority

Meeting logistics

- Meeting cadence – Quarterly
  - February, May, August, November
- Time – one hour (is this enough time or do we want to consider 90 mins)
- Next meeting options
  - May 5 – 9-10 a.m.
  - May 8 – 8:00 – 9:00 a.m.
  - May 13 – 9:00 – 10:00 a.m.
- Other?

Questions

Resources

- Washington State Shared Decision Making website
- Current certified Patient Decision Aids
- SDM Online Skills Course for Providers
- National Quality Partners SDM in Healthcare Playbook
- Bree Collaborative SDM Report and Recommendations for Adoption of SDM

Wrap Up

Next Meeting

- May 2025 (date TBD)
- Time: TBD
- Proposed agenda items:
  - Patient experiences with SDM
    - Please reach out to HCA if you have examples you would like to share