Informed Medical
Decisions Program

Advancing Progress in the Development and Implementation of Effective, High-Quality Cancer Screening Workshop

Strategies to Promote Shared Decision Making

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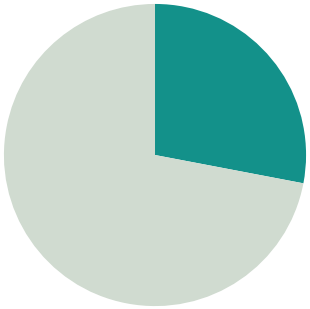
Informed Medical Decisions Program Vision

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

Disclosure: I receive grant support through Massachusetts General Hospital from Healthwise, a nonprofit patient education and decision support organization; and I am a primary care physician at Massachusetts General Hospital and Professor of Medicine at Harvard Medical School, both nonprofits.

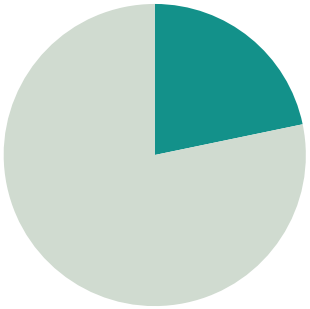
Are patients informed? Not very!

Percentage of patients undergoing cancer screening who answered each knowledge question correctly:



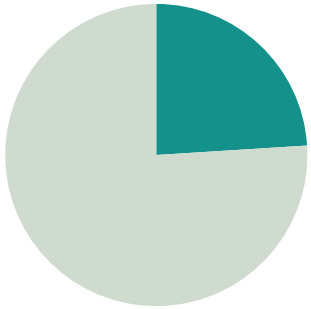
35%

Lifetime risk of dying from colorectal cancer (1-5%)



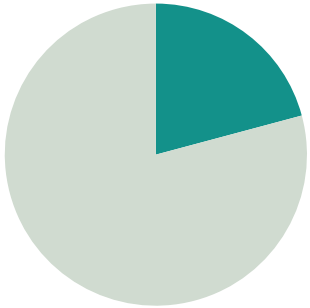
17%

When normal colonoscopy be repeated for average risk? (10 years)



24%

Probability a positive mammogram results in CA diagnosis? (1-14%)

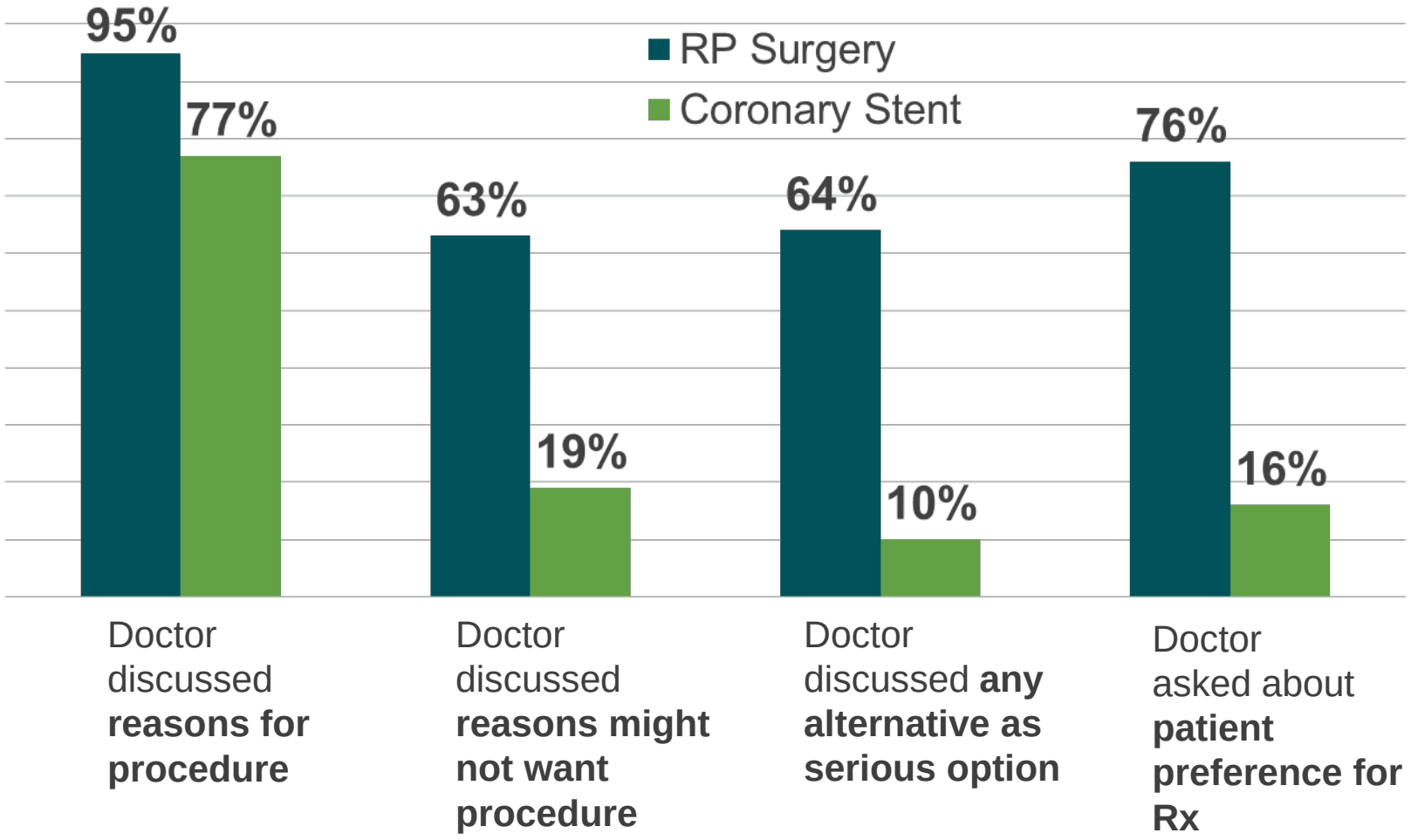


20%

Probability an elevated PSA results in a CA diagnosis? (1-14%)

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.

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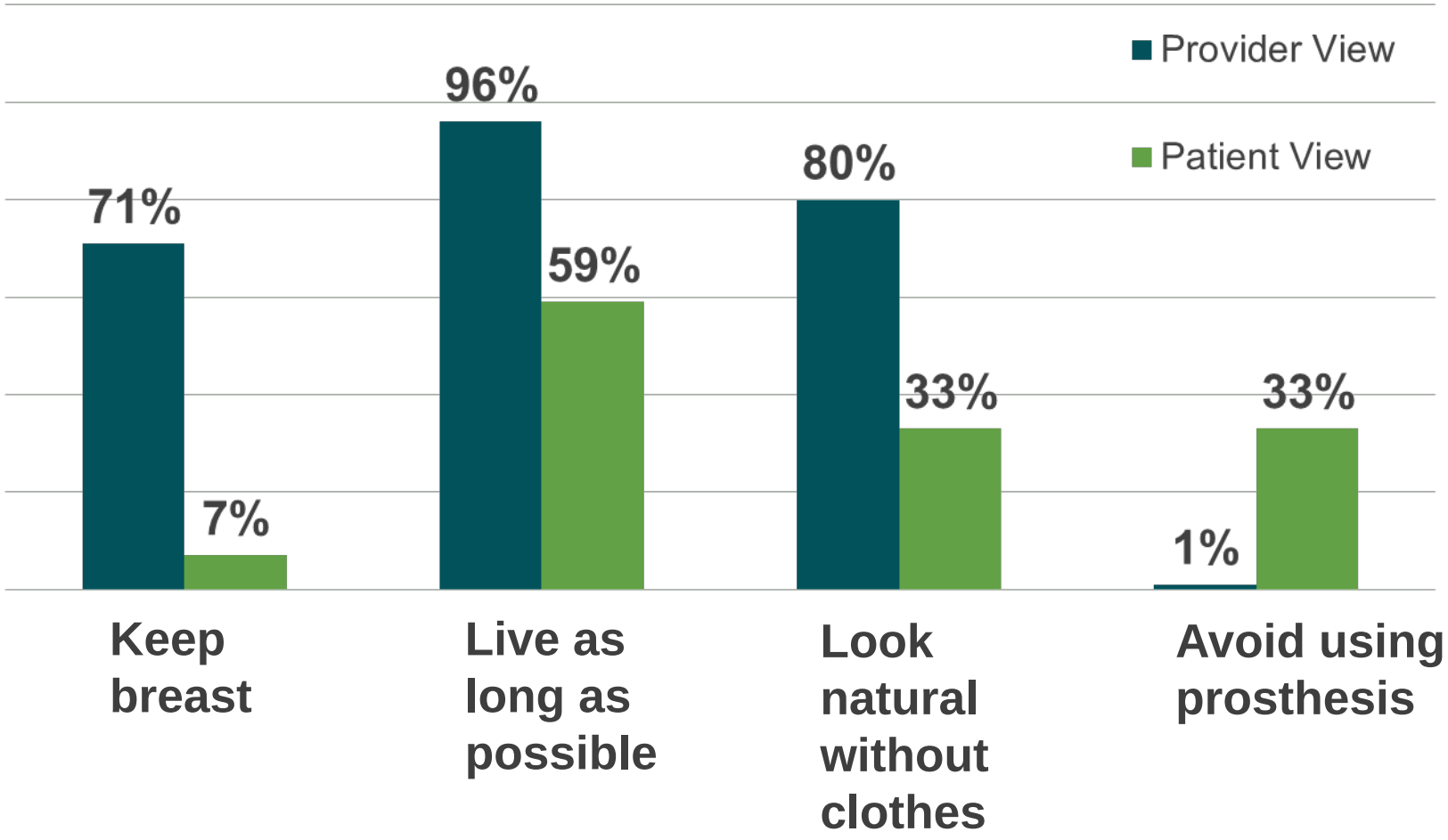
Top four goals and concerns for breast cancer decisions



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

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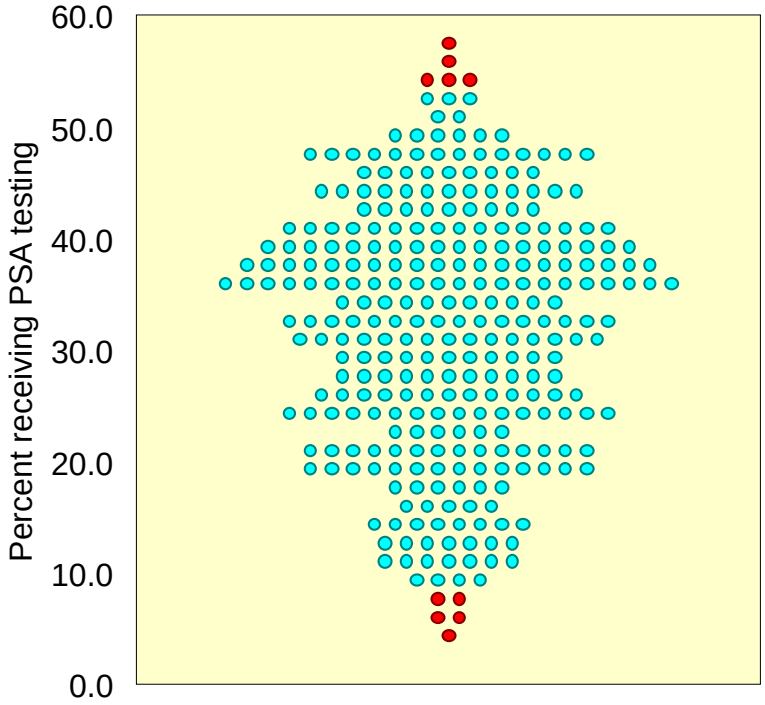
The silent misdiagnosis

“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.

PSA Screening: Medicare Beneficiaries 75 and Under

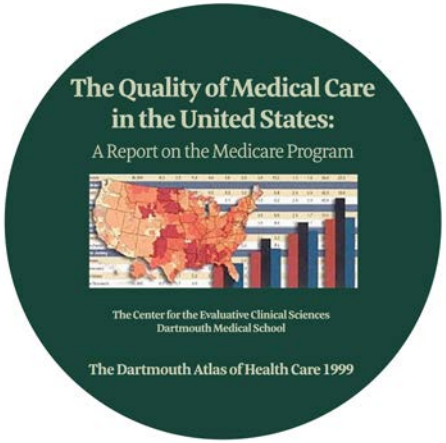


Miami, FL	58.4%
Wilmington, NC	55.8%
Sun City, AZ	55.1%
Paterson, NJ	53.7%
McAllen, TX	53.5%
Binghamton, NY	7.2%
Minot, ND	7.2%
Burlington, VT	6.8%
Mason City, IA	5.8%
Lebanon, NH	3.6%

From the Dartmouth Atlas of Health Care. Each blue dot represents the rate of PSA testing in one of 306 hospital referral regions in the U.S. Red dots indicate the regions with the 5 lowest and 5 highest rates

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

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.

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 evidence about decision aids

2017 Cochrane Review "Decision aids for people facing health treatment or screening decisions" 2017

- Search through 2015
- 105 trials of pDA versus usual care/other interventions
- 31,043 participants

Stacey D, et al. (2017). *Cochrane Database Syst Rev*. 2017 Apr 12;4:CD001431. doi: 10.1002/14651858.CD001431.pub5.

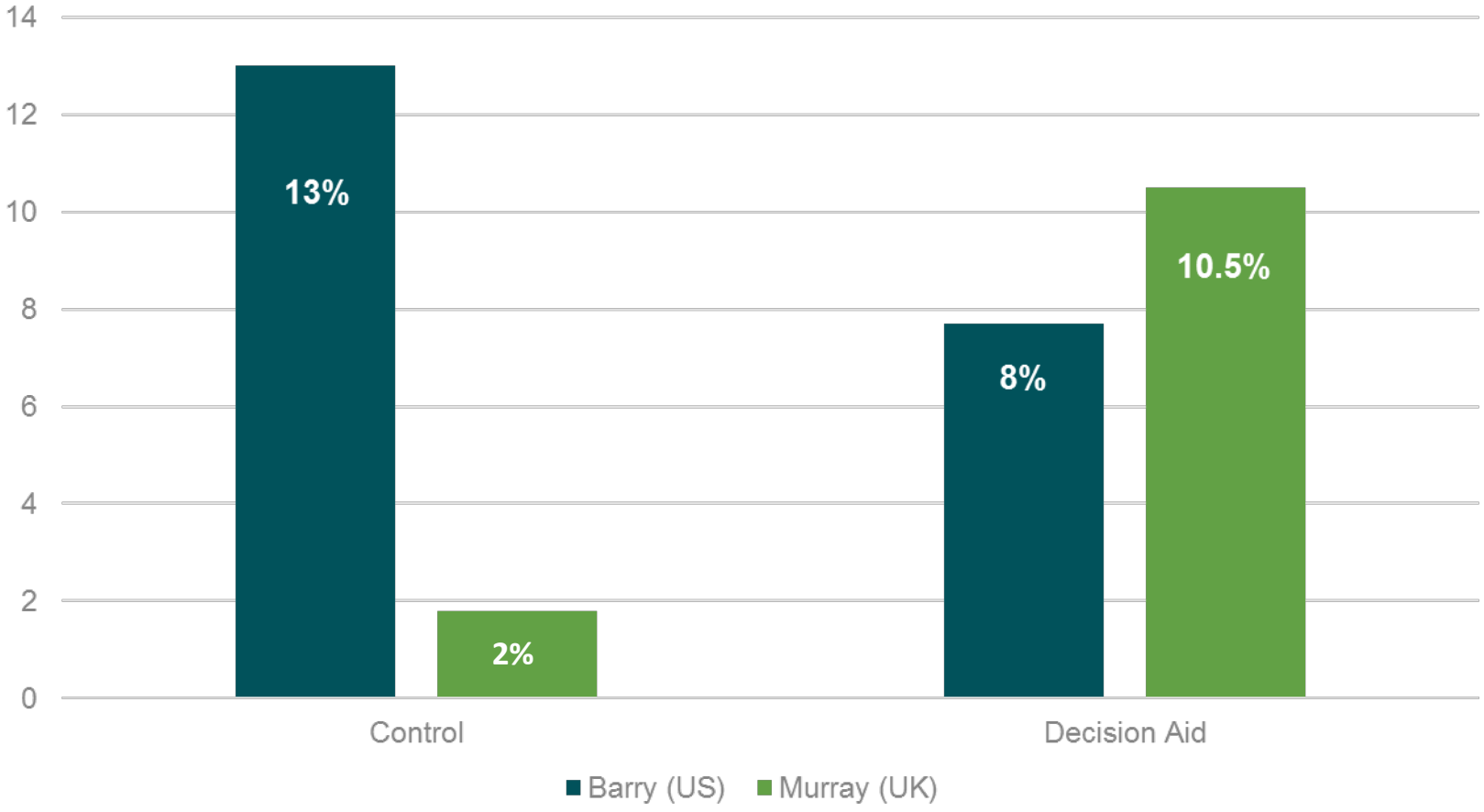
Decision aids increase:

- Patient knowledge
- Patient involvement
- Proportion of patients with accurate risk perceptions
- Consistency between patient decisions and patient values

Decision aids **decrease:**

- Feeling uninformed or unclear about personal values
- Proportion of patients who remain undecided
- Major elective surgery

Effect of the same decision aid on BPH Surgery



Barry MJ, et al. (1997). *Dis Management Clin Outcomes*. 1: 5-14.

Murray E, et al. (2001). *BMJ.* 323(7311): 490-3.

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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
- And finally, over 12 months:
  - 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

Sources of patient decision aids

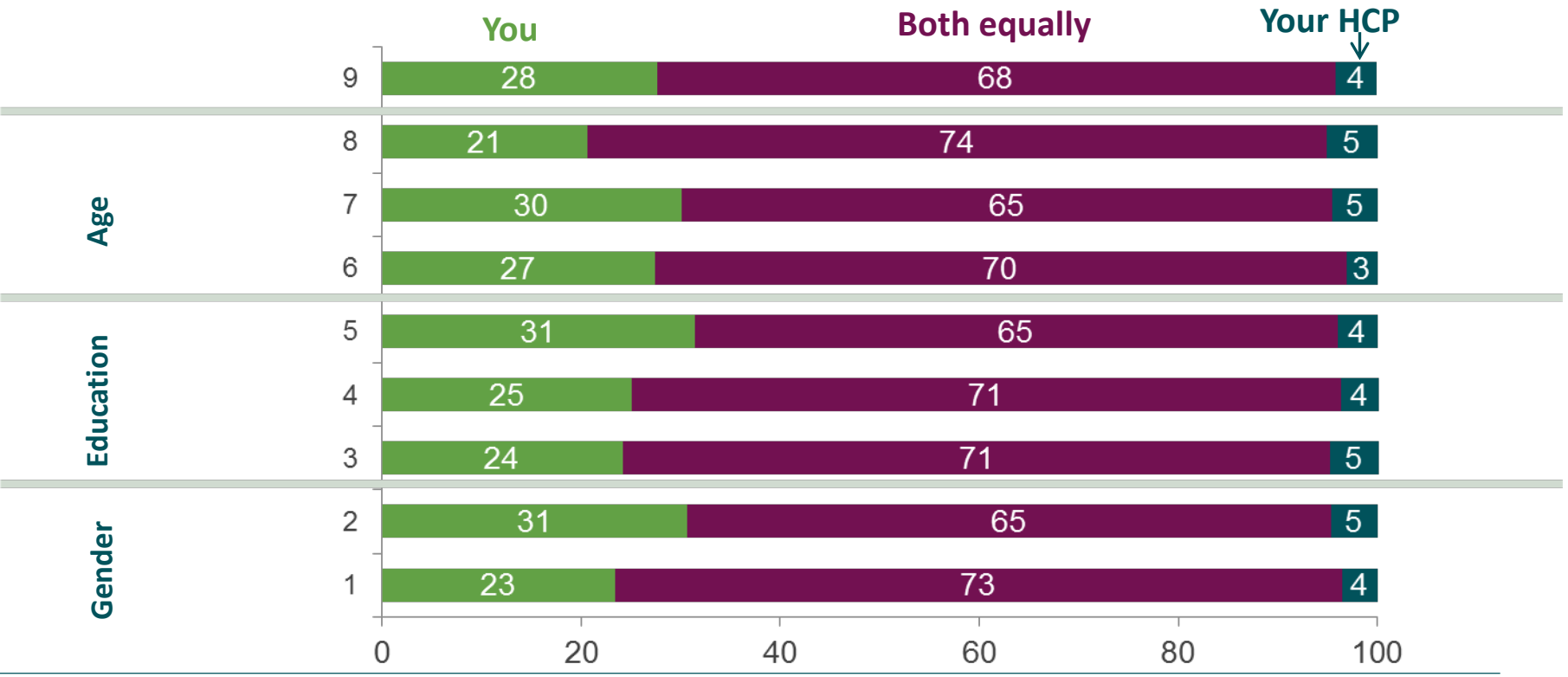
- The Ottawa Hospital A to Z Inventory of Decision Aids
- Developers
  - Healthwise
  - Health Dialog (Rite Aid)
  - Emmi (Walters Kluwer)
  - Option Grid Collaborative (now EBSCO)
  - AHRQ
  - Mayo Clinic
  - Ottawa Patient Decision Aids Research Group
  - Wisercare (Elsevier)

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

Decision role preferences by demographic group



N=4207

Wexler RM, et al (2015). Int J Person Centered Medicine 2015;5:105)

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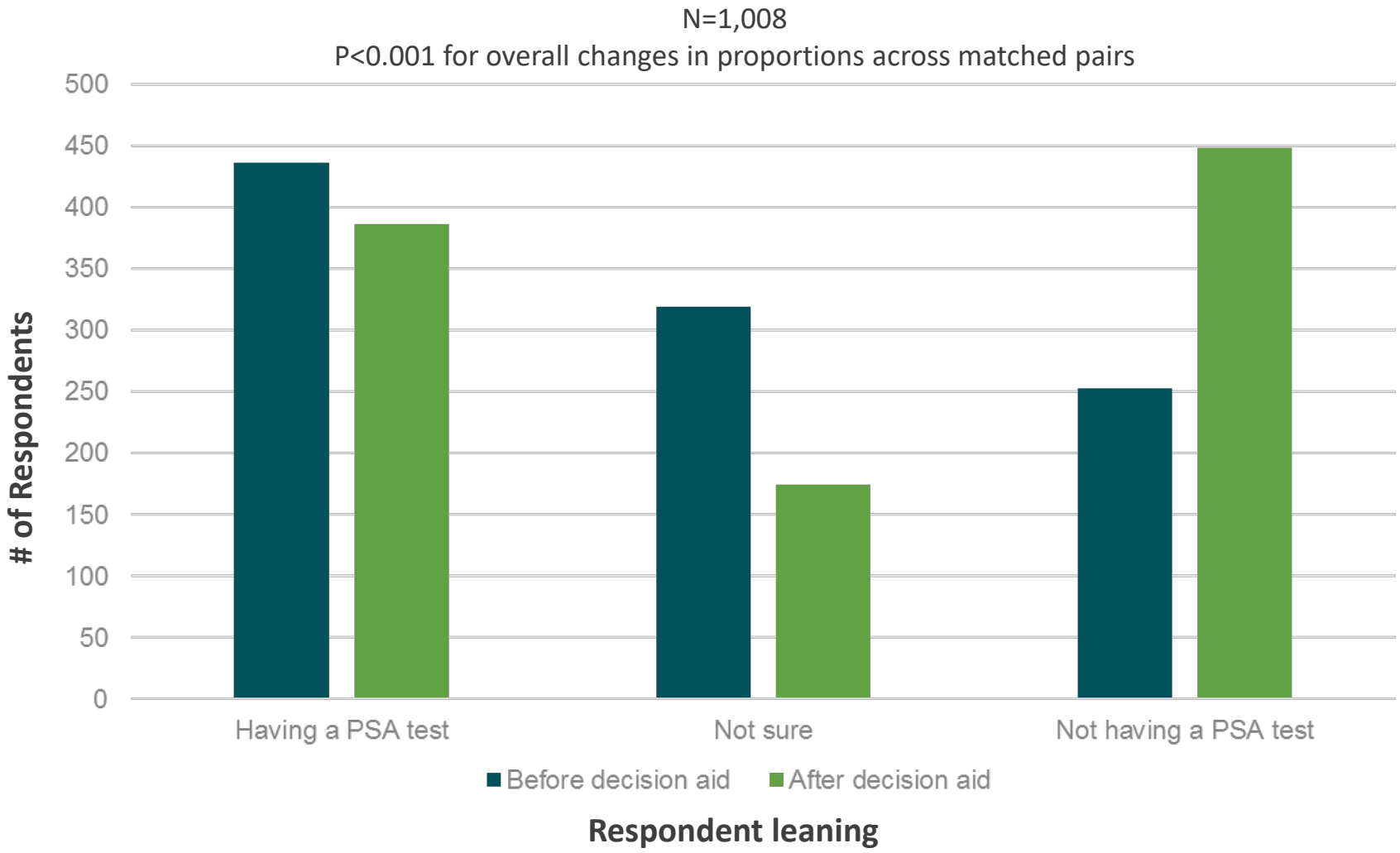
PSA test leanings after a pDA



Barry MJ, et al. (2015). *Am J Prev Med.* 49(4): 520-5.

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Aligning incentives and removing barriers to SDM

Approaches:

- Clinician and patient training
- Integration into the EMR workflow
- Incentivize clinicians/health systems
  - CMS payment for procedures
  - Decision quality measurement
- Incentivize patients
  - Value-based insurance design

The goal is to change the clinical paradigm from "what's the matter" to "what matters to you."

– Susan Edgman-Levitan,
Executive Director, John D. Stoeckle Center
for Primary Care Innovation, MGH

Science AAAS

REPORT

Shared decision-making drives collective movement in wild baboons

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Thank you

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