

A patient's perspective on treatment decision making and outcomes

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DISCLOSURE SLIDE

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No conflicts of interests

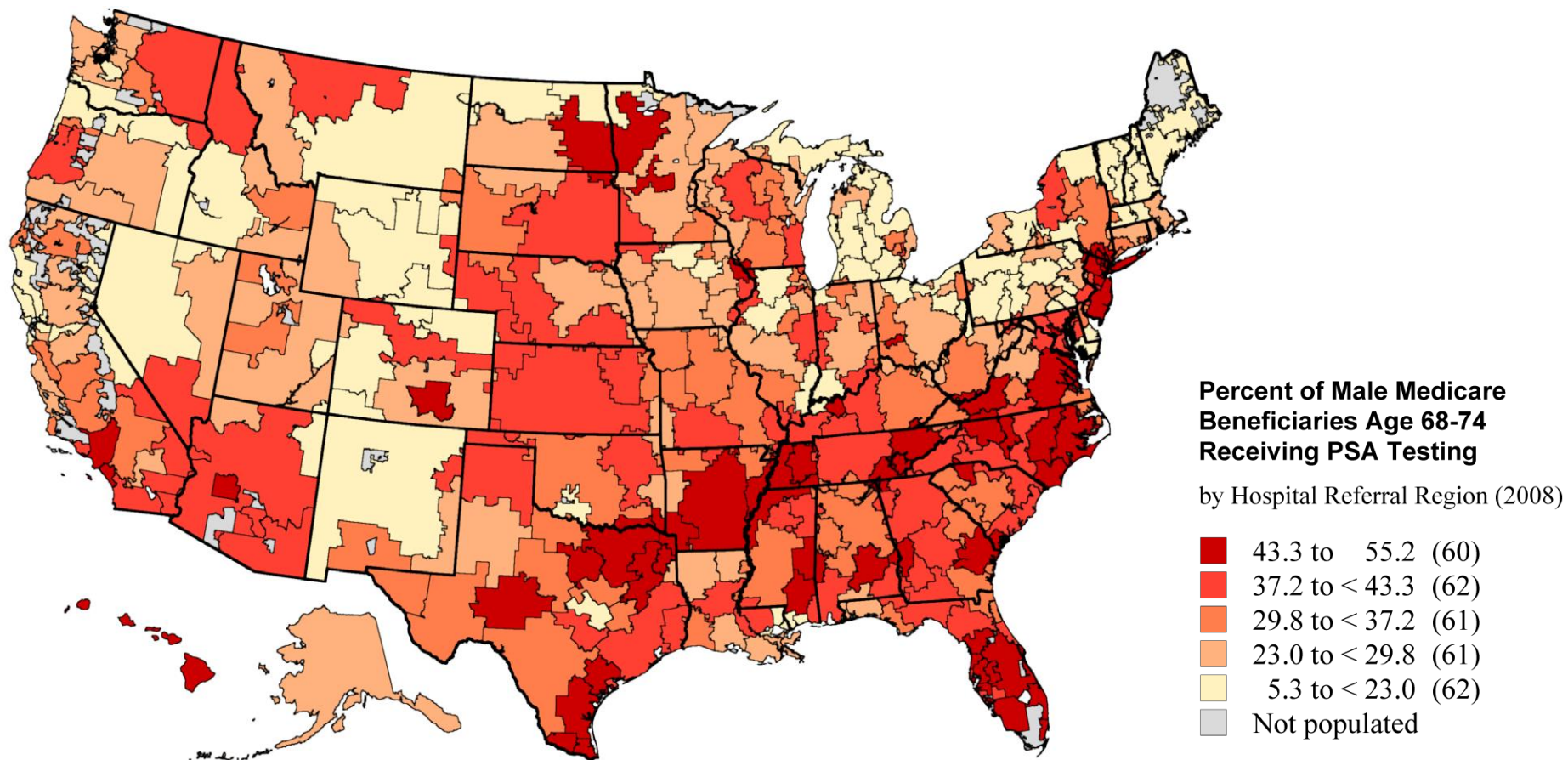
Patient-centered care:

- Patient empowerment
 - Personalized medicine
 - Shared Decision Making
 - Patient Reported Outcome Measures (PROMS)
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- ≠ Clinician centered
 - ≠ Paternalistic approach

Three reasons for more patient centered care:

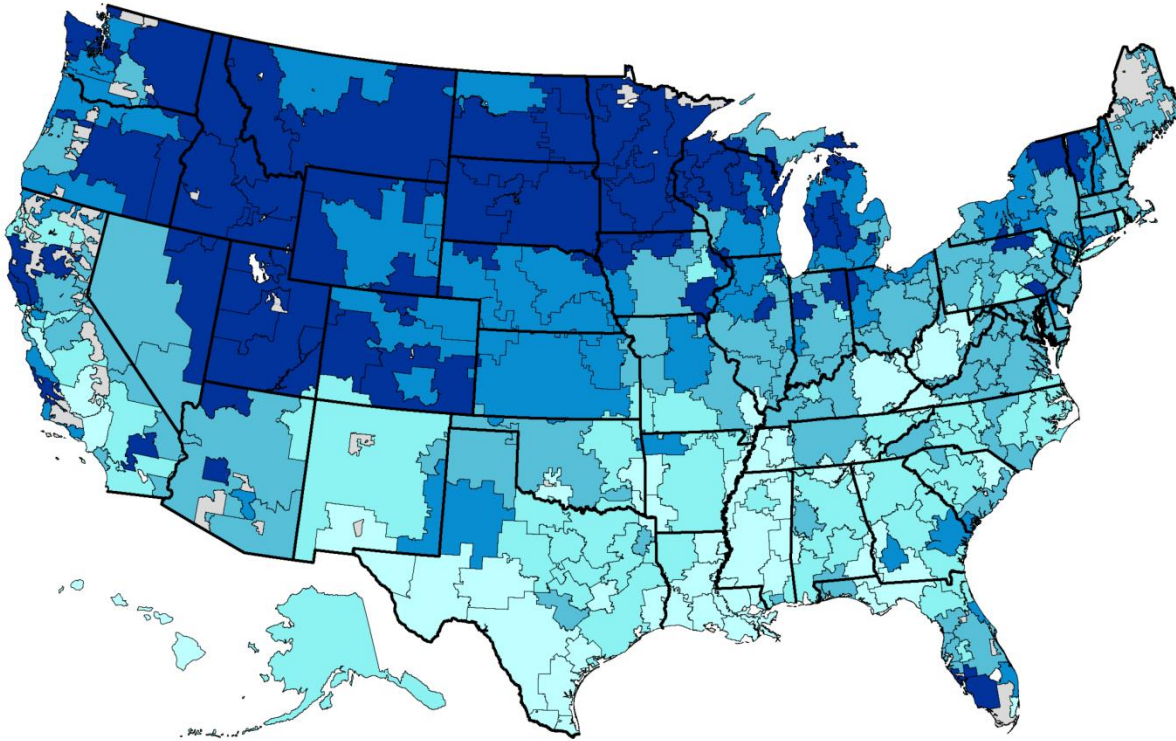
- Unwarranted practice variation
- Moral imperative and patient's autonomy
- Scientific and technological progress

Unwarranted practice variation



Percent of male Medicare beneficiaries age 68-74 receiving prostate-specific antigen (PSA) testing among hospital referral regions (2008)

Unwarranted practice variation

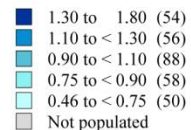


Hip replacement
among hospital
referral regions,
2005-06

Variation: 1.2 per 1000
to 6.7 per 1000

If practice variation, then not one
best decision: “preference
sensitive” decisions

by Hospital Referral Region (2005-06)



*A Dartmouth Atlas
Surgery Report,
Fisher et al. 2010*

Moral imperative:

- Engaging patients in their care is central to respect for persons
- Respects patient's autonomy

“Nothing about me without me”

→ Patient empowerment: helping patients to actively search for information and participate in decisions about their care

Scientific and technological progress

- Personalized medicine:
 - Individual focus on patients based on systems biology
 - P4: predictive, personalized, preventive, participatory
- Advances in information technology:
 - Availability of information on the internet
 - Electronic Patient Record.

Shared Decision Making

- Is about sharing the decision between clinicians and patients:
 - Using the best available evidence about e.g. treatment outcomes and risks of treatment
 - Taking into account the preferences of the patient
- Using Patient Reported Outcomes (PROMS)
 - In addition to biological measures and physical examination also
 - Measures of symptom experience, quality of life, functioning, values and preferences etc.

Obstacles:

- Practical:
 - not embedded in usual care, takes time, different skills
- Different ways of measuring outcomes:
 - Also outside the hospital and over extended periods of time, comparing with group of patients etc.
- Different perspectives on:
 - Involvement of patient in decision making process
 - On evaluation of the evidence, of pros and cons of treatment options

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Shared Decision Making and treatment of stage 1 NSCLC

- Brom, Hopmans, Pasman, Timmermans, Widdershoven, Onwuteka-Philipsen: Congruence between patients' preferred and perceived participation in medical decision making. BMC Medical Informatics and Decision Making 2014;14:25
- Hopmans, Damman, Senan, Hartemink, Smit, Timmermans: A patient perspective on shared decision making in stage 1 non-small cell lung cancer: A mixed methods study. BMC Cancer 2015;15:959
- Hopmans, Zwaan, Senan, Van der Wulp, Damman, Hartemink, Smit, Timmermans: Differences between pulmonologists, thoracic surgeons and radiation oncologists in deciding on the treatment of stage 1 non-small cell lung cancer: A binary choice experiment. Radiotherapy and Oncology 2015; 115(3):361-366
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- Hopmans, Damman, Timmermans, Haasbeek, Slotman, Senan. Communicating cancer treatment information using the Web: Utilizing the patient's perspective in website development. BMC Medical Informatics and Decision Making 2014;14:116

Study SDM and stage 1 NSCLC

- Review (44 studies)
- Interviews with patients (N=11) and survey (N=76)
- Survey among pulmonologists (N=73), thoracic surgeons (N=17), radiation oncologists (N=36)
- Analysis of information for patients about treatment
- Development patient information and decision aid

Different perspectives on involvement:

- Clinicians versus patients
- Patients

Different perspectives on involvement:

- Clinicians versus patients:
 - Clinicians underestimate need for information and patient's wish to be involved in treatment decision
 - In general: 40% of patients prefer more involvement than experienced
 - Treatment stage 1 NSCLC: 71% reported having had no choice

Different perspectives on involvement:

- Patients:
 - Patients vary in preferences and some prefer a less active role,
 - i.e. older patients, lower educated patients, cancer patients
 - Clinical guidance by clinician in treatment choice was felt as more important than an active role in the decision process.
 - But more variation in preference for active role

Different perspectives on preferred treatment

- Clinicians
- Clinicians versus patients

Different perspectives on preferred treatment: clinicians

- Consider surgery and SABR to be equal treatment options:
 - Pulmonologist (N=73): 49%
 - Thoracic surgeons (N=17): 18%
 - Radiation oncologists (N=36): 83%
- Evaluation of 16 patient cases SABR recommended:
 - Pulmonologist (N=73): 8.6 cases
 - Thoracic surgeons (N=17): 6.2 cases
 - Radiation oncologists (N= 36): 9.9 cases

SABR recommended for stage 1 NSCLC:

- Case 3: Elderly patient without comorbidities, WHO-PS ≤ 1 , preference for SABR
 - Pulmonologist (N=73): 40%
 - Thoracic surgeons (N=17): 29%
 - Radiation oncologists (N=36): 64%
- Case 10: 40 year old patient, WHO-PS 2, COPD GOLD score II, no comorbidities, preference surgery
 - Pulmonologist (N=73): 40%
 - Thoracic surgeons (N=17): 12%
 - Radiation oncologists (N= 36): 25%

Different perspectives on preferred treatment

- Differences in evaluation of the evidence:
 - Clinicians:
 - Differences in evaluation of the evidence
 - Clinicians versus patients:
 - Patients decision may deviate from the guideline after being informed (PROMS) → conflicting values and preferences
 - Poor understanding by patients of evidence: overestimation of benefits, underestimation of risks; poor health literacy

Hofman, Del Mar; Patients' expectations of the benefits and harms of treatments, screening and tests: a systematic review. JAMA Intern Med 2015;175(2):274-286

... perceive and understand risks differently

- Prenatal screening, the risk on child with Down Syndrome

“I think my chance is **1 out of 400, about 25%**” “.. I think it was **1 in 250.000** or something... Well, I think it is **reasonably small.....**”

» Timmermans et al., in prep.

- Risk on heart disease

“Well, I mean, if your cholesterol is OK it means that there's no more risk of cardiovascular disease, isn't that right? You may say, it's one in a hundred. But what if I'm that one? One in a hundred means nothing to me. **It's always fifty-fifty in a way...**”

» Van Steenkiste, Van der Weijden, Timmermans et al. PEC, 2007

Steps in Shared Decision Making

- Define problem
 - Present options (option awareness)
 - Discuss benefits and harms of options
 - Ask patient about concerns, expectations, preferences
 - Explore patient's preference for involvement in treatment decision
 - Decide together about preferred treatment
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- Differences among clinicians and between clinicians and patients**
- Differences among patients and between clinicians and patients**

Stiggelbout, Van der Weijden, De Wit, Frosch et al. Shared Decision Making: really putting patients at the centre of health care. BMJ 2012;344

Stiggelbout, Pieterse, De Haes. Shared Decision Making: concepts, evidence and practice. Pat Education and Counseling 2015; 98:1172-1179

Summary

- Patient centered care and Shared decision making:
 - Practice variation
 - Moral imperative
 - Scientific and technological developments
- Some obstacles for Shared Decision Making:
 - Different perspective on involvement of patient in decision making process
 - Differences in evaluation of the evidence, of pros and cons of treatment options

Differences among clinicians, among patients, between patients and clinicians.

Wilt u meer algemene informatie over de behandelopties?

[Behandelopties >>](#)

Voor wie is deze keuzehulp bedoeld?

Deze keuzehulp is bedoeld voor mensen met een vroeg stadium niet-kleincellige longkanker. Een vroeg stadium longkanker is over het algemeen goed te behandelen, door ofwel een operatie ofwel een gerichte bestraling, ook wel stereotactische bestraling genoemd.

Er moet een keuze gemaakt worden voor één van beide behandelingen. Als u in aanmerking komt voor beide behandelopties dan is het belangrijk om goed na te denken over uw keuze. Deze keuzehulp kan u daarbij helpen.

[Meer informatie >>](#)

Toelichting keuzehulp door longarts

