



*Advising the Congress on Medicare issues*

# Patient engagement and health care disparities

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# Roadmap

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- Study design
- Role of communication in health care disparities
- Efforts to reduce disparities through shared decision-making and patient activation programs
- Key findings

# Shared decision-making and patient activation

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- **Shared decision-making (SDM):**
  - Gives patients specific information about condition, treatment options, and probabilities of clinical outcomes
  - Allows patients to communicate their values and the relative importance of benefits and harms
- **Patient activation:**
  - Teaches patients their roles in self-managing care, collaborating with providers, and maintaining their health, and the skills necessary to do so

# Health literacy

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- The degree to which individuals have the capacity to understand basic health information and services needed to make appropriate health decisions
- Individuals who are sicker, older, poorer and/or minorities tend to have lower health literacy

# Study design

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- Literature survey, interviews, focus groups, site visits
- Studies on use of patient engagement to reduce disparities are based on controlled experiments with small samples
- Results are limited and not generalizable, but suggestive



## Poor communication between patients and providers influences health care disparities

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- Poor communication can be a problem for all patients but especially the elderly and racial and ethnic minorities
- Challenges include lower health literacy, non-English speaking, distrust of health care system
- Hispanic and African-American patients report poorer communication with providers than Whites

## Providers may mistake poor communication with disinterest in SDM

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- Some providers believe some patients would not be interested in SDM
- AHRQ survey found Black and Hispanic patients were less likely to be asked their preferences in treatment decisions
- In one study, African-Americans reported receiving less information, less opportunity to ask questions but equal desire for SDM

Some SDM programs aim to help providers better communicate with patients

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- Teaching hospitals have integrated SDM programs into medical education
  - Massachusetts General
  - Sophie Davis Medical School
- Program at University of California San Francisco breast cancer center
  - Pre-med students provide question listing, note-taking services for cancer patients
  - Ensure physicians get questions before visit

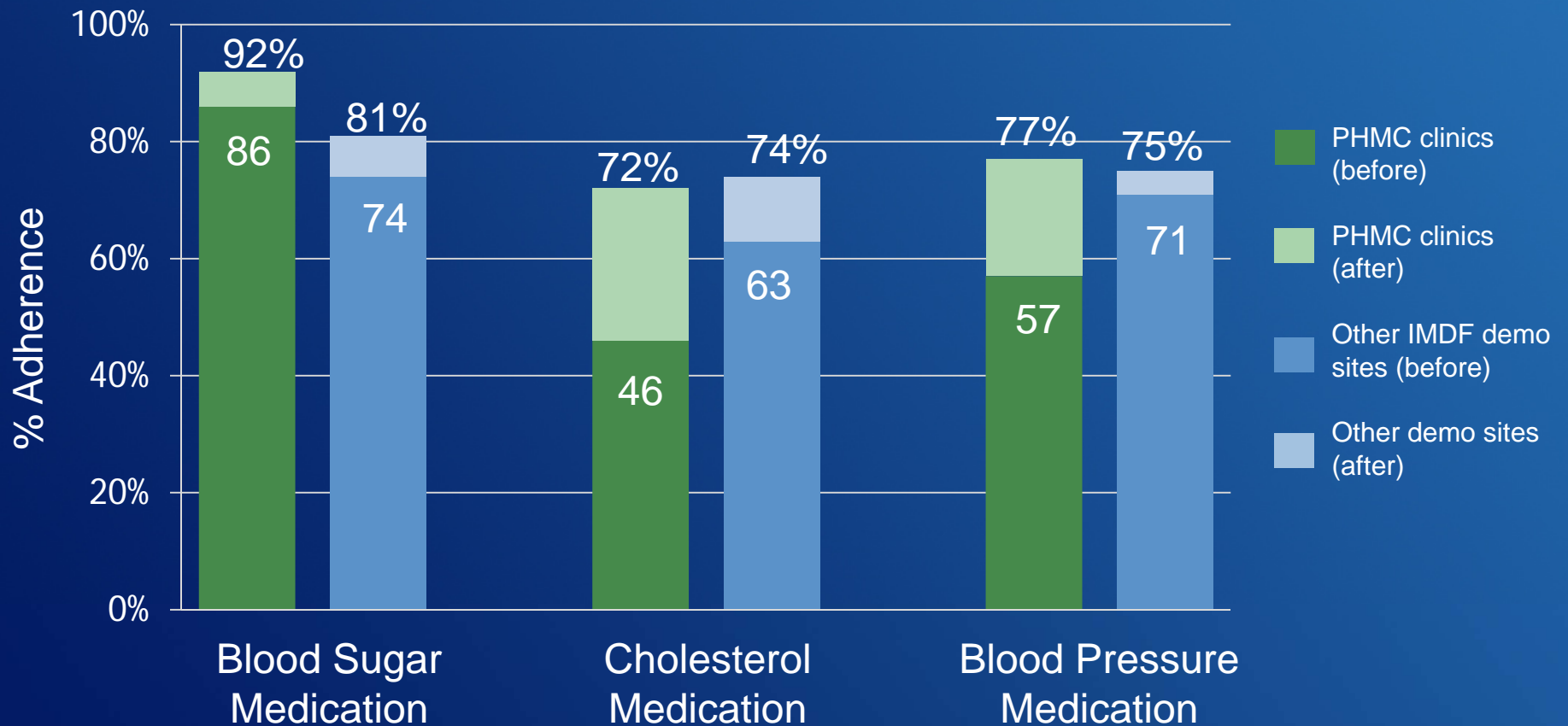


## SDM programs for patients with low health literacy may need different techniques

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- Audiovisual decision aids have been most effective
  - Patients with CAD
  - Advanced care planning videos
- Watching videos in groups
  - Massachusetts clinics
  - Philadelphia clinics

# Limited data suggest that minority groups may benefit most from SDM



Source: Rothman, N. and M. Clark. 2012. Patient provider decision sharing: Better decisions together. Presentation to American Public Health Association.

# Patient activation is more general than SDM

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- Theoretical framework:
  - More confident patients are more equipped to participate actively in their care
  - Better communication with health providers is associated with healthy behaviors and medication adherence
  - More active and adherent patients should have better health outcomes
- Evidence is limited, but suggestive
- Unlike SDM, which is condition-specific, patient activation focuses improving the patient-provider communication by teaching patients to ask strategic questions

# Patient activation may be a tool to reduce disparities

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- Patients often do not realize that there are decisions to be made, or that they are allowed to ask questions
- Minority patients tend to have lower levels of activation than White patients

# Patient activation demonstrations target low-income populations

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- Right Question Project
  - Non-profit organization that teaches individuals in underserved communities to advocate for themselves
- Intervention
  - Define the word “decision” generally, and demonstrate how asking strategic questions can lead to better decisions
  - Then help patients choose a focus for the current visit, brainstorm and prioritize questions
  - Strategize about how to self-manage after appointment
  - Intervention takes about ten minutes on average to administer



# Patient activation interventions are flexible

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- At Sophie Davis Medical School demonstration, students lead training
  - In waiting room before clinic visit
  - Ten-minute interaction
- Massachusetts's Medicaid managed care uses community health workers to periodically follow up with patients
  - Collect clinical and self-management data
  - Complete home visits and phone contacts

# Minority patients' self-management behaviors have improved in demonstration projects

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- Limited results in primary care
  - More likely to keep appointments, ask questions of clinicians, and take medications
  - Fewer emergency department visits
- Mental health patients participate more in treatment

# Key findings

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- Some SDM programs help providers to better communicate with patients
- Audiovisual decision aids and group meetings can help beneficiaries with low health literacy participate in SDM
- Limited data suggest minority groups benefit most from SDM
- Patient activation seems to improve patients' willingness and ability to manage their care and better communicate with their providers

# Future work

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- What next steps on SDM do Commissioners want to pursue?
- Possible topics:
  - Should we look further into the requirements and quality metrics for ACOs and medical homes regarding patient engagement?
  - What programs are being tested to elicit patient preferences on advance care planning?
  - Other topics?