

A Look at “Family” in Person- and Family- Centered Care: What Does it Mean?

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Roadmap for Discussion

The Challenges and Benefits of Involving Family in Person- and Family-Centered Care

A Few Recent Projects:

- A look at person- and family-centered care: what do older adults say?
- A person-family agenda-setting communication intervention
- Consumer e-health and shared access to the patient portal

Concluding Thoughts and Discussion



“I believe that of the six IOM aims for improvement-safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity “patient-centeredness” is the keystone and that, from it, the others properly devolve. To me, “patient-centered care” is care that respects each person as an individual, honoring his or her background, their families, and their choices...”

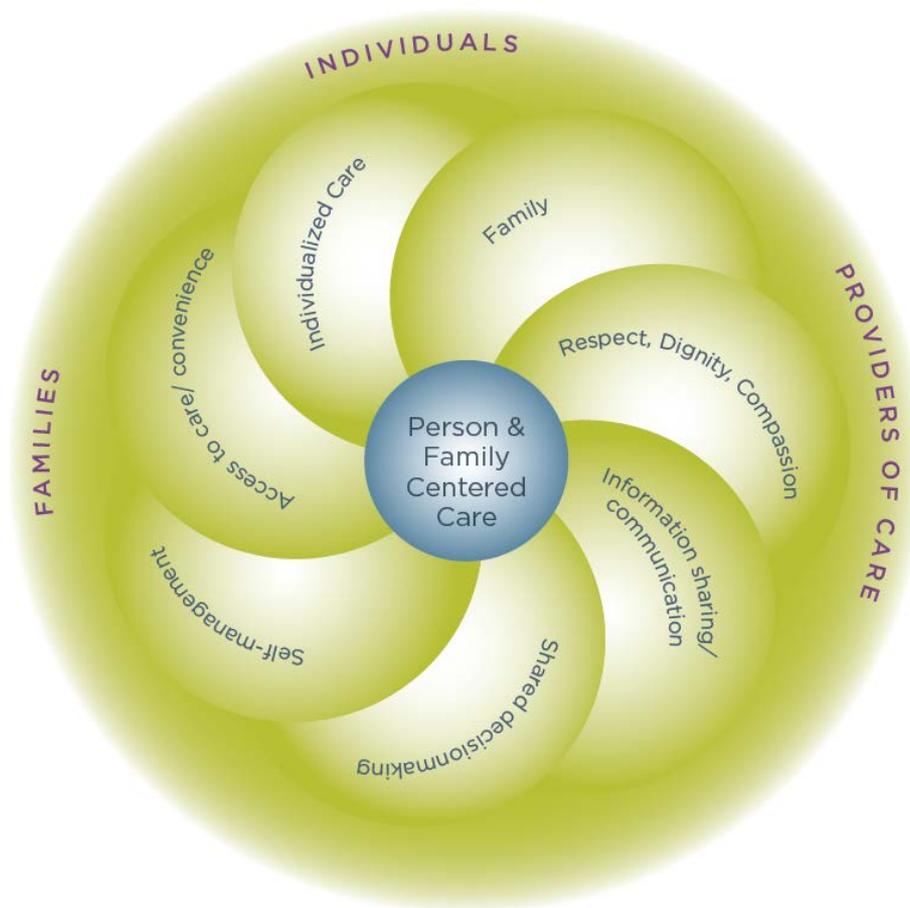
---Don Berwick, 2009

NATIONAL QUALITY STRATEGY AIMS AND PRIORITIES



PERSON-AND FAMILY-CENTERED CARE

CORE CONCEPTS TO GUIDE PERFORMANCE MEASUREMENT



a **Care Team** includes individuals and families and all healthcare and supportive services workers who interact with them.

b **Family** is defined by each individual.

1. Individualized care - I work with other members of my care team^a so that my needs, priorities, and goals for my physical, mental, spiritual, and social health guide my care.

2. Family - My family^b is supported and involved in my care as I choose.

3. Respect, dignity, and compassion are always present.

4. Information sharing/communication - There is an open sharing of information with me, my family, and all other members of my care team(s).

5. Shared decisionmaking - I am helped to understand my choices and I make decisions with my care team, to the extent I want or am able.

6. Self-management - I am prepared and supported to care for myself, to the extent I am able.

7. Access to care/convenience - I can obtain care and information and reach my care team when I need and how I prefer.

Person- and Family-Centered Care is:

An approach to the planning and delivery of care across settings and time that is centered around collaborative partnerships among individuals, their defined family, and providers of care. It supports health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values.

---NQF 2014.

From the Perspective of Family,
Is Health Care Delivery
Person- and Family- Centered?

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Person- and Family- Centered?

No

Why is Health Care Delivery Not Family Centered?

1. Misaligned reimbursement – lack of compensation for additional providers time and effort with family
2. Prevailing orientation toward patient autonomy and privacy
3. Patient-oriented information systems – (where to add information about “family caregiver;” family member information access about patient)
4. Lack of evidence of demonstrated benefits on outcomes valued by providers of care

What Do We Know About Family Involvement in Health Care Delivery?

- Family is the main provider of long-term (*CBO 2004*) and chronic care (*IOM 2008*) in late life.
- Patients commonly choose to involve family members in routine (*Price et al, 2012; Zulman et al, 2011*) and surrogate decision-making (*Torke et al, 2014; Sessums et al 2011*)
- 4 in 10 older adults attend regular physician visits with family member or friend (*Wolff & Roter, 2008 & 2011*) whose involvement persists over time (*Wolff et al, 2012*).
- Family caregivers often assist with complex medical and nursing tasks (*Reinhard et al, "Home Alone", 2013*).
- Little is known about the impacts family in routine delivery processes due to lack of systematic process data

Study #1: A Look at Person- and Family-Centered Care Among Older Adults

- Delivering care that is person- and family-centered is particularly important but challenging in the care of older adults (*Boyd 2005; Tinetti & Reuben 2012; Giovanetti 2011*)
 - Greater heterogeneity in health, function, preferences, goals
 - Susceptible to treatment burden and harms
 - Sensory and cognitive impairments may prompt family involvement
- Existing literature describes older adults as passive and disengaged in decisions (*Levinson 2005; Zikmund-Fisher 2010; Naik 2011*), and as burdened by care (*Gallacher 2013; Eton 2013*)
- Collaborated with Cynthia Boyd in design of supplemental 2012 NHATS module (n=2,040) to assess how older adults manage health care activities, preferences for making health care decisions, experience of treatment burden

Question 1:

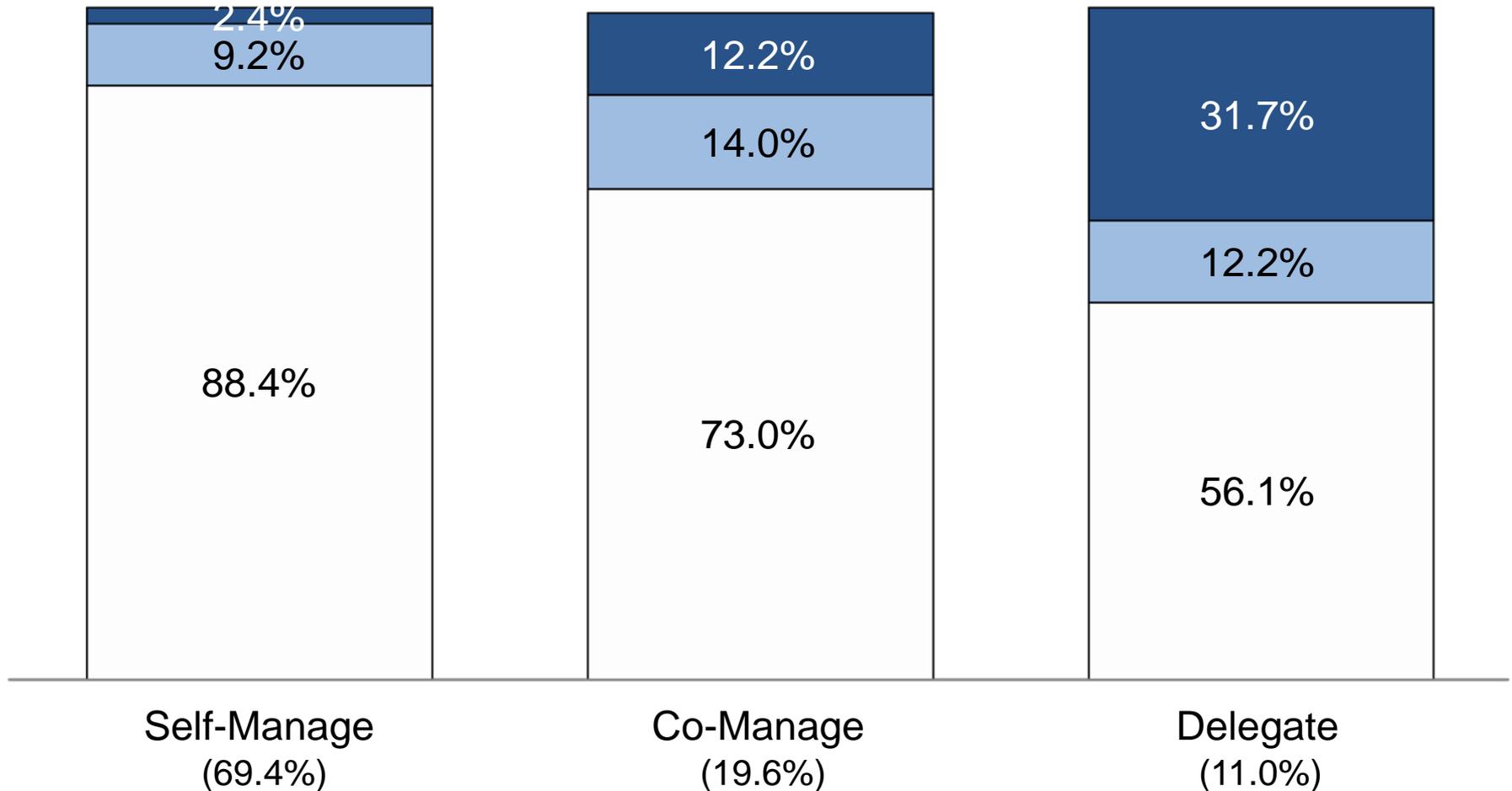
How do older adults manage their health?

“People today are asked by their doctors and other health care providers to do many things to stay healthy or treat health problems – for example, manage medicines, get tests and lab work done, watch weight and blood pressure, or have yearly exams. How do you usually handle these things?”

- Mostly independently (self-manage)
- Together with family members/close friends (co-manage)
- Mostly managed by others/it varies (delegate)

Characteristics of Community-Dwelling Older Adults by How They Manage Health Care Activities

□ No Impairment □ Possible Dementia ■ Probable Dementia



Source: Wolff & Boyd, forthcoming, *Journal of General Internal Medicine*

Question 2:

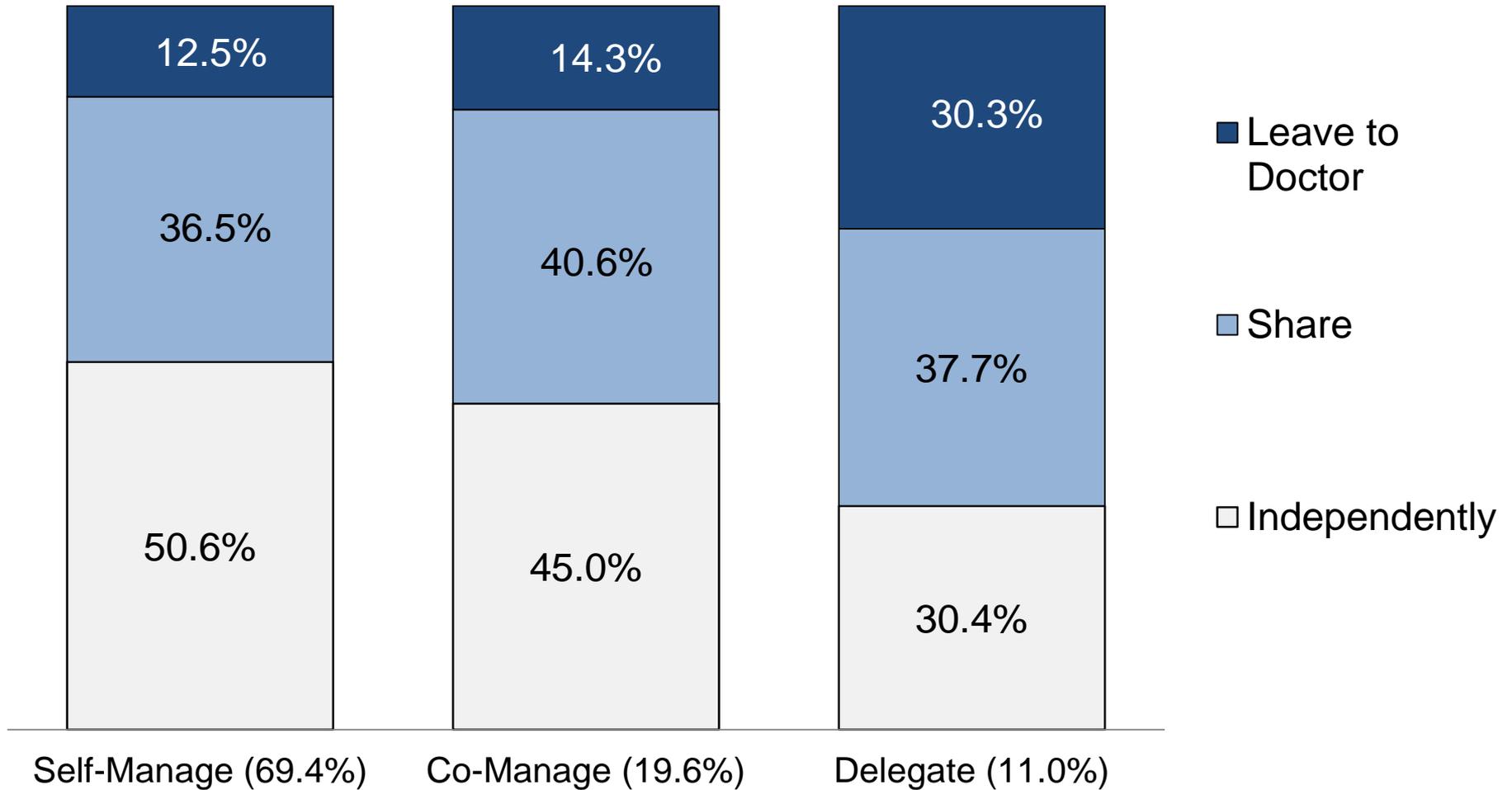
How do older adults prefer to make health care decisions?

“People today are faced with many decisions about their health care, for example...We want to know how you prefer to have doctors and family/close friends help with decisions. Thinking about your doctors, do you prefer to...”

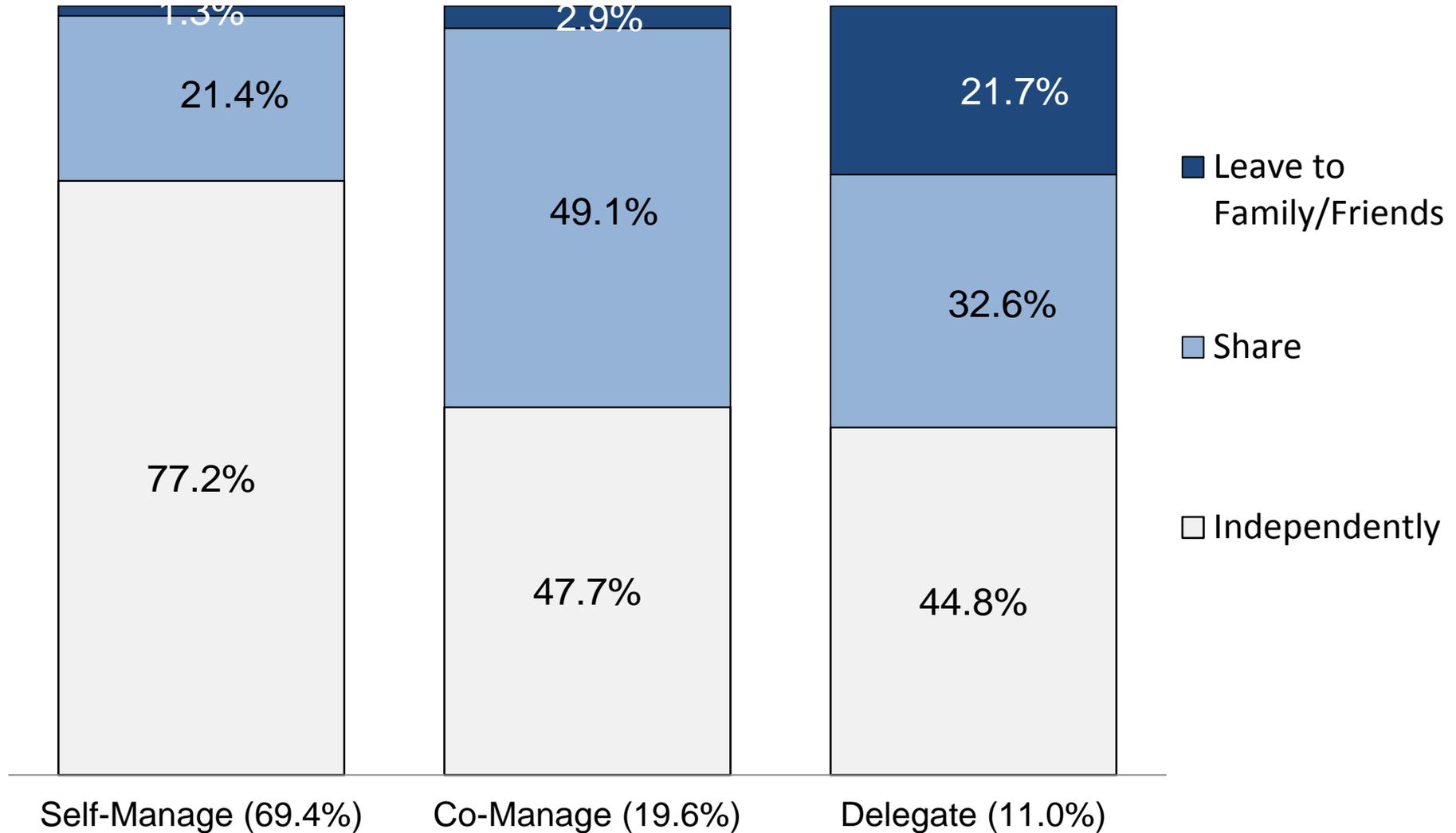
- Make decisions without much advice (independent)
- Get their advice and then make decisions (independent)
- Make decisions together (share)
- Leave decisions up to them

Older Adults and Decision-Making Preferences

How They Engage With Doctors



Older Adults and Decision-Making Preferences How They Engage With Family/Close Friends



Source: Wolff & Boyd, forthcoming, *Journal of General Internal Medicine*

Question 3:

What are older adults' experiences with care?

Experience of Treatment Burden

“The things that you are asked to do to stay healthy are
“sometimes or often (versus “never” or “rarely”)

	Self-Manage	Co-Manage	Delegate
Experience of Treatment Burden	34.3%	41.7%	54.0%
Hard for you?	21.9%	30.8%	25.4%
Hard for family or close friends?	0.0%	20.1%	28.0%
Get delayed or not get done?	22.6%	20.1%	22.9%
Doctors/other providers ask you to do too much?	12.1%	12.9%	13.1%

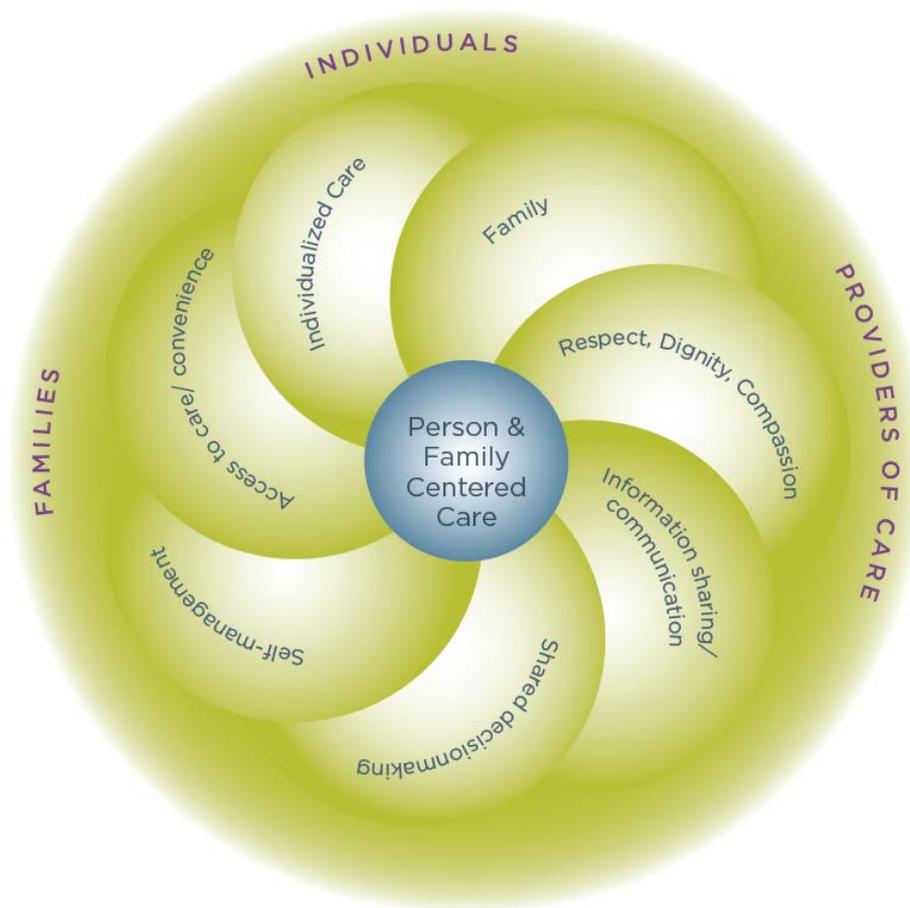
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Study #2: A Person-Family Agenda-Setting Intervention to Improve Primary Care Communication

- Patient participation is a prerequisite to person-centered care BUT - not all patients want or are able to participate actively in their care (*Price et al, 2012; AGS Guidelines, 2012; Kiesler, PEC 2006*)
- Pre-visit agenda-setting strategies widely studied; increase participation & satisfaction (*Kinnersley, BMJ 2008; Haywood, PEC 2006*)
- Patients (*Smith et al, 2009; Price et al, 2012*) and providers (*Schwartzberg et al, 2007*) strongly endorse involving family to bridge communication needs of patients with low health literacy.
- Family companions are often present and involved during face-to-face medical visits but not always helpful to communication (*Clayman et al, 2005; Wolff & Roter 2012*)

Patient-Companion Agenda-Setting Intervention

Objectives:

1. Elicit and prioritize patients' treatment goals:
Symptom Checklist: 23 “common patient concerns” distributed across physical, mental, & social role function topics, focus on geriatric issues appropriate for primary care; not prescriptive as to process for completion
2. Introduce concept of companion role during the visit:
Companion Role Checklist: Patient to identify how companion can best help them during the visit

Study Sample n=32

(n=17 Checklist; n=15 Usual Care)

Patient age; mean (range)	82 (65-99)
Lives alone (%)	61%
Low health literacy (1-item screener)	34%
Self rated health	
Excellent / Very Good	28%
Good	31%
Fair / Poor	41%
<hr/>	
Companion Relationship	
Spouse	31%
Adult Child	53%
Other	16%
Companion age; mean (range)	63 (35-81)
Companion female (%)	69%
Employed for pay	45%



Thank you for talking with us today.

We have developed a checklist for patients who attend medical visits with a family member or friend. The checklist was designed to help patients and their family member or friend communicate more effectively with their doctor.

We want to ask for your opinion about the checklist. We are interested in learning how we can make the checklist better. Before we ask for your opinions, we would like to ask the two of you to complete the checklist.

You will each be asked to review, and then discuss a list of common patient concerns. Afterward, the two of you will be asked to discuss how to work together to get the answers or information you need during a doctor's visit.

Thank you for participating in this study!

Instructions:

The next page lists some common patient concerns. Use the following three steps to work together to review and discuss this list of concerns.

1. First, the **patient** should identify their level of concern for each topic. The patient may work independently, or the companion may read the list and record the patient's answer. If the patient is unable to respond then the companion may report what they think the patient would say if he or she was able to state their level of concern.
2. Next, the **companion** should identify their level of concern for each topic in regard to the patient's health. It is fine if the companion's concerns are different than those of the patient.
3. **Together** decide which identified concern or concerns are most important to discuss with the doctor. Use the right column to check at least three topics to discuss with your doctor today.

It is important to remember that doctors are used to talking about **all** kinds of health and personal matters, including topics that may be sensitive, like memory problems or depression. Talking honestly with your doctor about your concerns is the first step in an effective partnership.

Common Concerns	Level of Concern			Discuss with Doctor
	Not at All	A Little	A Lot	
Shortness of breath	①	2	3	/
Pain *	①	2	3	/
Falling or fear of falling	1	2	3	
Dizziness or balance	①	2	3	/
Hearing or vision	1	2	3	
Trouble with sleep	1	2	3	
Lack of energy	1	2	3	
Incontinence or bladder problems	1	2	3	/
Constipation or bowel problems *	①	2	3	/
Poor appetite or weight loss	①	2	3	
Concerns about driving	1	②	3	
Stress or worry	1	②	3	/
Feeling sad or blue	1	②	3	
Trouble concentrating or remembering	1	2	3	
Smoking or alcohol use	1	②	3	/
Medication issues or side effects *	①	2	3	/

The Older Patient-Family-Physician Partnership

99 yo man and 59 yo daughter

Doctor: *So what's new?*

Patient: *Well, as far as I know, I've got to ask you that.*

Companion: *Yeah, tell him, didn't you fall last week?*

Patient: *Oh yeah, I fell last week and...*

The Older Patient-Family-Physician Partnership

86 yo woman and 52 yo daughter

Doctor: *How have you been feeling?*

Patient: *Not too good.*

Doctor: *Tell me about it.*

Patient: *Well for one thing the Sinemet didn't pan out right.*

Doctor: *Didn't help you?*

Patient: *It didn't help me I don't think at all.*

Doctor: *Okay.*

Patient: *And then I've been having a couple of other problems with pain and numbness in the hands and that's all I can think of right now.*

Doctor: *I know you went to the hospital once.*

Patient: *Oh yeah.*

Doctor: *I think you sort of passed out.*

Patient: *Oh yeah. You'll have to get her (companion) to tell you about it.*

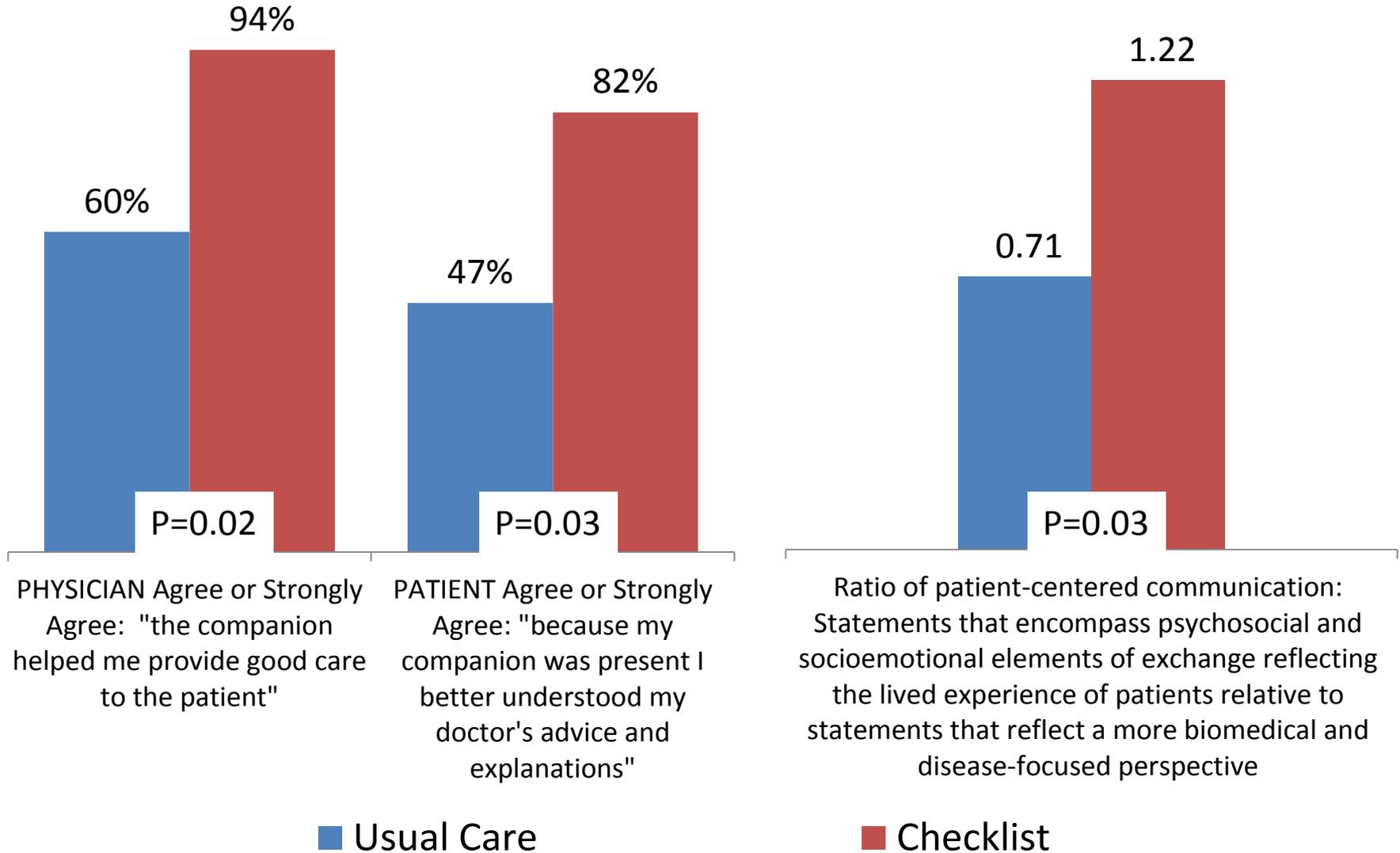
Acceptability of Checklist

	Patient	Companion
Amount of time to complete it was “Just Right”	100%	77%
Post-visit survey responses (Agree/Strongly Agree)		
Easy to complete	88%	88%
Useful	94%	88%
Improved understanding of concerns	82%	75%
Reminder to discuss concerns with doctor	94%	69%
Improved discussions with the doctor	88%	81%
Improved sense of control	88%	56%
Recommend to other patients	100%	100%
Would do it again	94%	100%

Group Differences in Medical Visit Communication

Perceived Communication
(from post-visit surveys)

Actual Communication
(from visit audiotapes)



Source: Wolff et. al., *Journal of the American Geriatrics Society*, 2014.



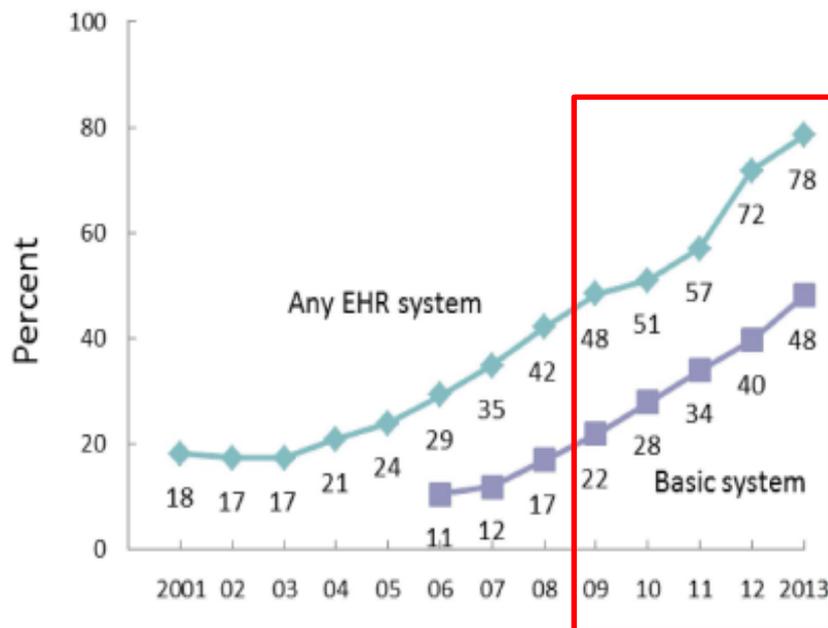
Study #3: Shared Access to the “Patient Portal”



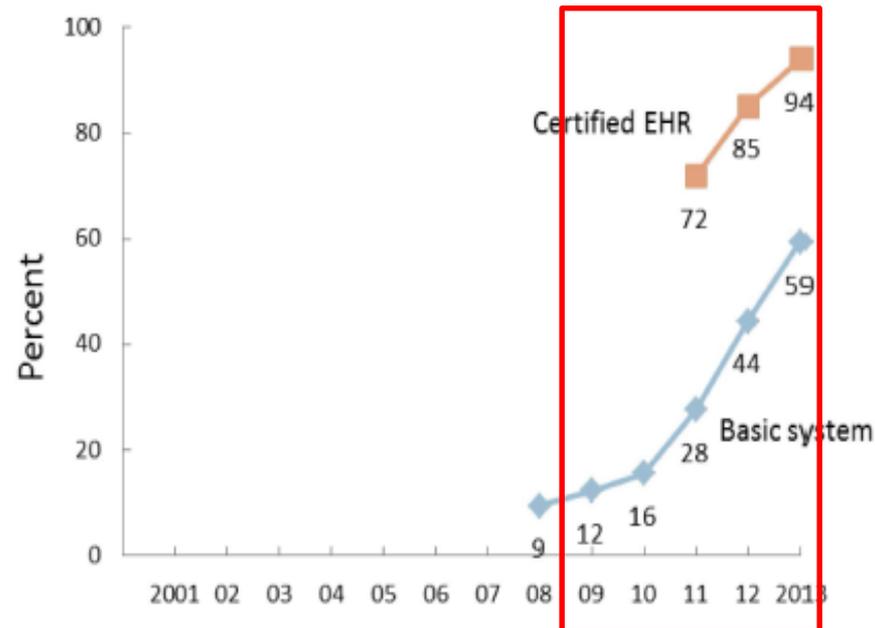
HealthIT.gov Definition of a Patient Portal: “a secure online Website that gives patients convenient 24-hour access to Personal health information from anywhere with an Internet Connection. Using a secure username and password, patients can view health information. Some patient portals also allow patients to perform health activities such as secure messaging, prescription refills, and update contact information”.

Adoption of EHRs Among Office-Based Physicians and Non-Federal Acute Care Hospitals

Office-Based Physicians

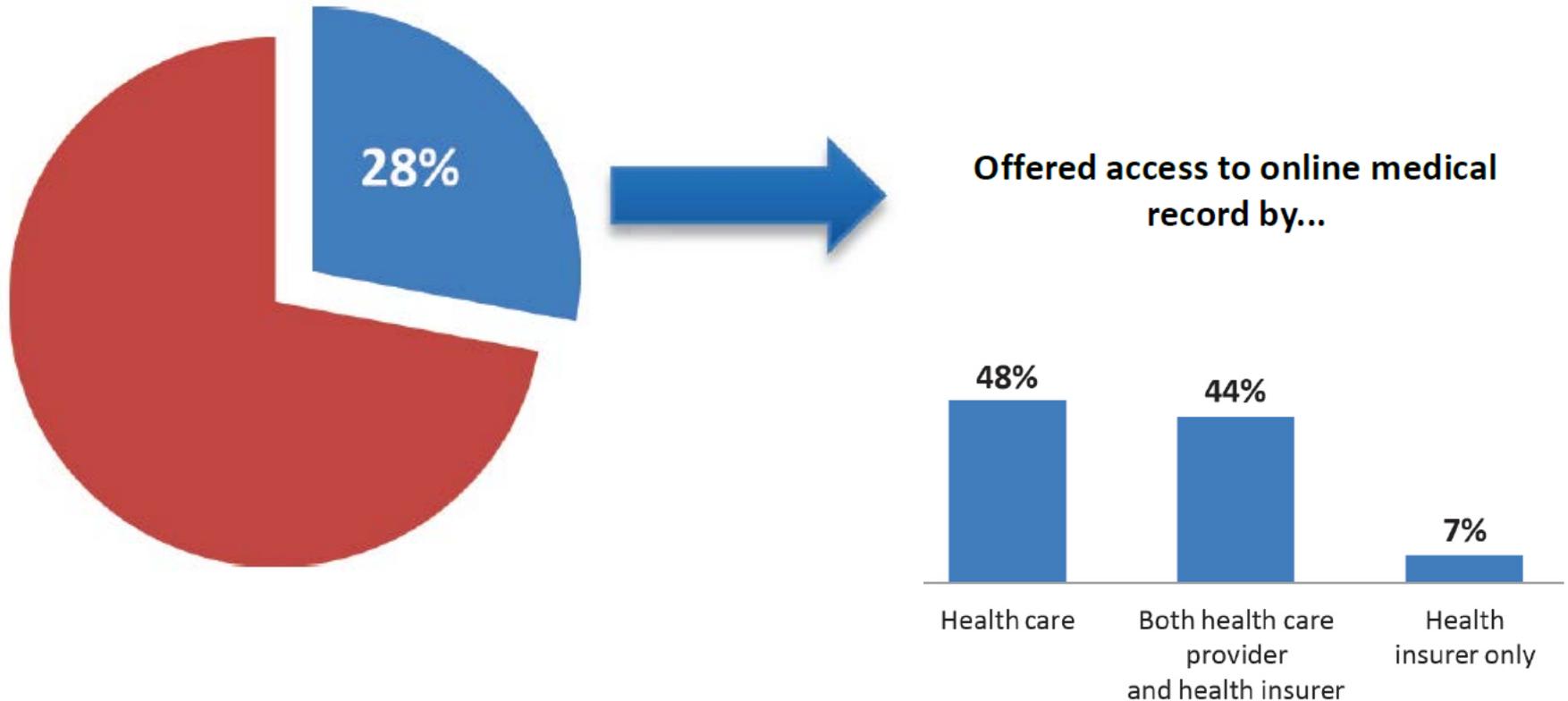


Non-Federal Acute Care Hospitals



Source: October 2014 Report to Congress Prepared by the ONC, HHS
http://www.healthit.gov/sites/default/files/rtc_adoption_and_exchange9302014.pdf

Individuals Offered Online Access to Their Medical Record in 2013 (n=2,063)



SOURCE: 2013 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange.

Challenges to Engaging Patients and Families Through the “Patient Portal”

1. HHS/ONC provides oversight but responsibility for adoption and use lies with providers and patients.
2. HIT is not broadly accessible. People who are older, less educated, sicker, and with few financial resources and less technology experience are less able to access (*e.g. Greysen 2014*) and use (*e.g., Osborn 2013; Taha 2013*) it.
3. Providers are ambivalent about engaging patients in health information technology. Concerns over privacy & security/risk management are front and central.
4. Best practices for credentialing and registering individuals other than a patient (*e.g. personal representatives, family, or friends*) do not now exist.

A First Look at “Shared Access” at A Large Integrated Health System

- Geisinger Health System: integrated health system providing care to 2.6 million patients in Central Pennsylvania
- Implemented electronic health record in 1996; patient portal in 2001; shared “proxy” access in 2003.
- Geisinger Innovations (Jon Darer and group) participated in trial of “OpenNotes” to provide patients access to their doctor notes (*Delbanco, 2012*) . More than 1 in 5 patients reported sharing notes with family members.
- Trial under way to examine impact of making doctor notes through MyGeisinger available through “Shared Access”

How Common Is Shared Access?

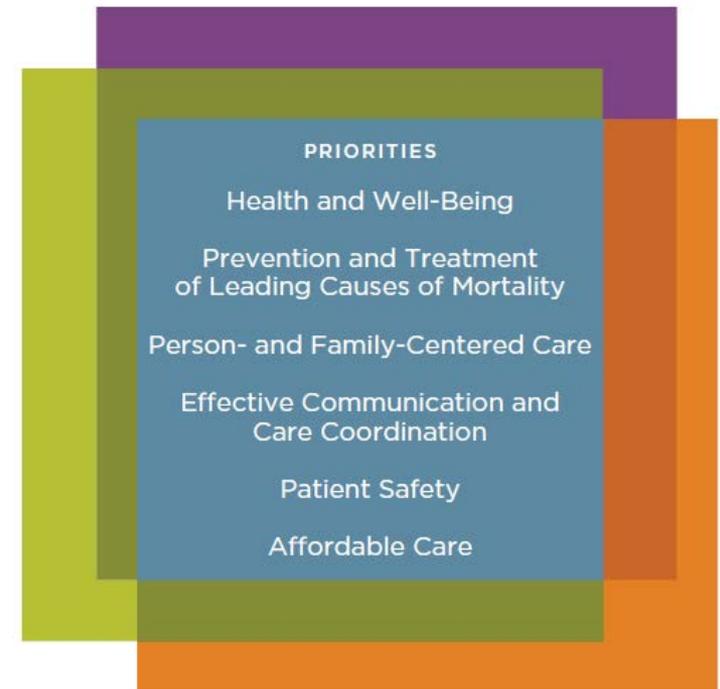
How Common Is Shared Access?

Not Common

856 of ~240,000 (0.4%) Registered Patient Portal
Users Registered for Shared Access

Summary & Implications

- Family is a core element of Person- and Family-Centered care.
- Some patients, desire or require family when sharing information with providers of care, making health care decisions, and managing their health.
- Health system processes to recognize, engage, and support families are often notably absent.
- Family is a natural partner in health system efforts that seek to attain higher quality, higher performing health system



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“There are only four kinds of people in the world - those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers”

- Rosalynn Carter

