Understanding Consumer/Patient Health and Health Care Decision Making Needs

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AARP

Decision making: the challenge

The task: deciding what to do to make the best use of services, drugs, and information, and technology to address one's personal needs
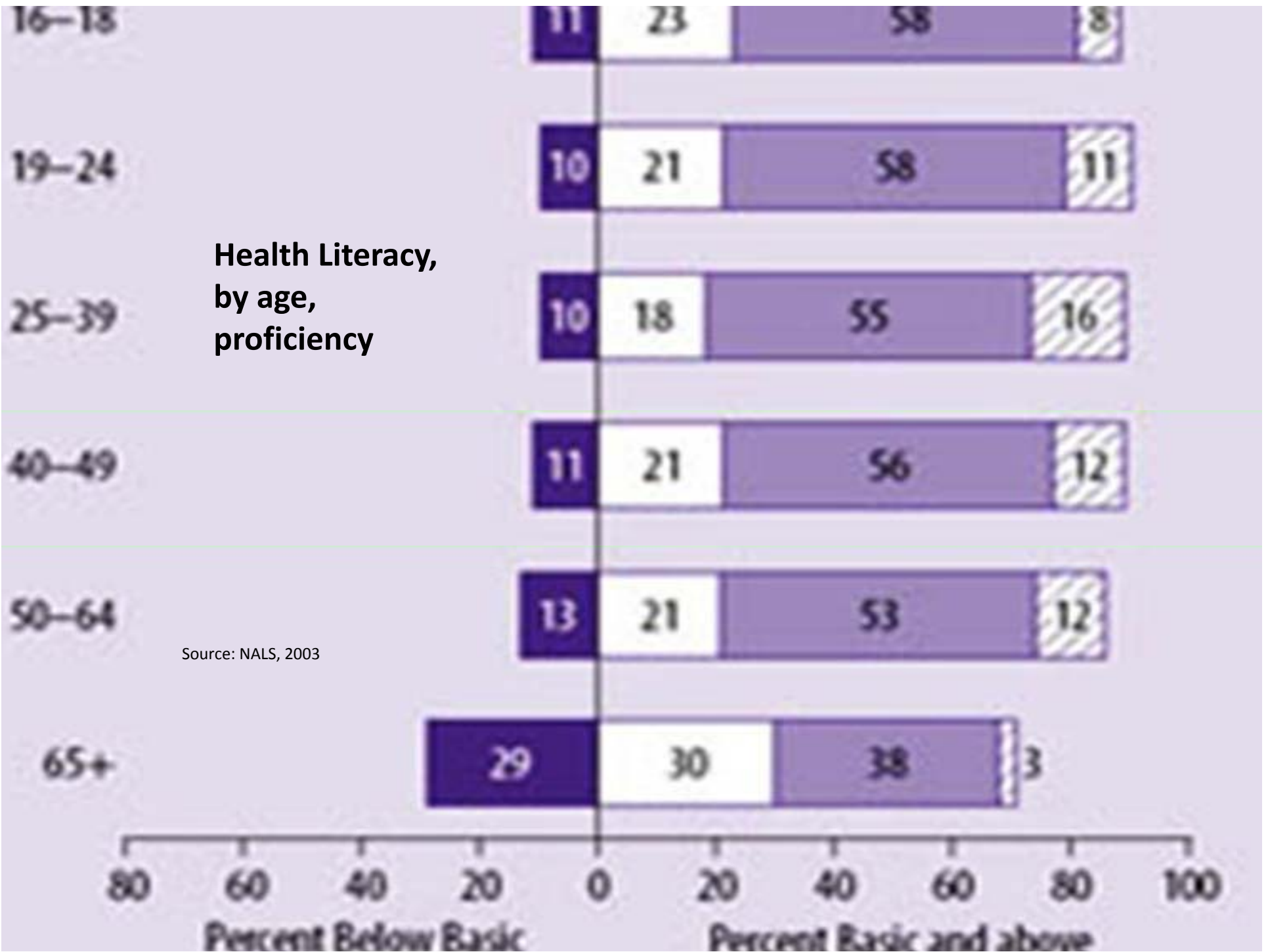
- Required skills: literacy, health literacy, numeracy,
  - Problem solving and making tradeoffs: conflicting goals and bringing together multiple factors-- most can only process 5-6 variables
  - Confidence/self-efficacy (ability to deal with health problems)

What we know about decision making (J. Hibbard)

- Decision making is a complex task: one needs to integrate multiple variables into a decision and make trade-offs
- To ease burden of trade-offs, people focus on a single factor, often undermining their own interests by ignoring important information
- People weight factors more heavily when the factor is concrete, easy to grasp
- Preferences are not stable and can be influenced (manipulated) by how information is presented
- A decision framed as a loss has a greater impact than one framed as a gain

Barriers to consumers' use of performance information

- **The public does not believe there are quality problems**
- **Many see choice as a proxy for quality**
- **Many believe more is better**
- **Performance information often not understandable— leads to belief that the information is not important**
- **Difficult for many people to process and use the information due to its complexity and heavy cognitive burden**
  - **Humans process only 5-6 variables– with > variables, likelihood of conflicting information >, forcing tradeoffs among personal preferences**

Health Literacy, by age, proficiency

Source: NALS, 2003

Age	16–18	19–24	25–39	40–49	50–64	65+
	11	10	10	11	13	29
	23	21	18	21	21	30
	58	58	55	56	53	38
	8	11	16	12	12	3

Percent Below Basic | Percent Basic and above

80 60 40 20 0 20 40 60 80 100

Demands on consumers: types of decisions

- ***Choice of coverage option*** **(in the Exchanges, this will entail selecting among "metal" categories; in Medicare, this means choosing from among average of 26 MA plans plus traditional Medicare**
  - Analyze comparative cost and performance information
  - Estimate expected out-of-pocket costs
- **Provider(s) selection-usually physicians, but sometimes, hospitals, post-acute facilities**
  - Compare comparative performance information on physician/ medical practice

Types of consumer decisions, cont.

- **Selection of treatments/interventions/prescription drugs**
  - Engage in shared decision making
  - Assess risks/benefits
  - Identify preferred tx
- **Participation in development and implementation of care plan**
  - Identify personal goals
  - Actively engage: need knowledge of behaviors that help achieve goals (e.g., maintain function, improve health
  - Self-management single and co-morbid conditions
- *Engagement in self-protective behavior*
  - Assert (hand washing)
  - Question (risk/benefits, side-effects, cost)
  - Appeal (challenge coverage decisions)

Current state: consumer information does not adequately meet the need

- **Materials tend to be "one size fits all"**
  - Lack of routine screening to determine skill levels—health literacy, decision confidence, personal preferences; physical/cognitive limitations
- **Strong reliance on web-based materials**
- **Overreliance on technology** as a vehicle to provide patients access to their health data or other decision making tools may create barriers for many consumers (IOM HIT and Safety report)
  - Many have limited or no access to high-speed internet access—could exacerbate disparities ; need knowledge skills to navigate internet, proficient language, health literacy skills
- **Materials not suited to range of socio-economic or cultural needs**

Current state, cont.

- **Comprehensive information rarely available**
  - **Lack of information on quality, "cost-to me"**
  - **Quality info that is provided is not salient to individuals (unit of analysis not sufficiently granular)**
- **Evaluable formats not used**
- **Some use of frameworks to ease comprehension**
  - **CMS Compare sites**
  - **NCQA report card**
  - **Some state report cards**

How Consumers Respond to these Approaches

Chart 2

Exposure to and Use of Comparison Quality Information

Percent who say they saw information in the past year comparing quality among each of the following and used it to make health care decisions:
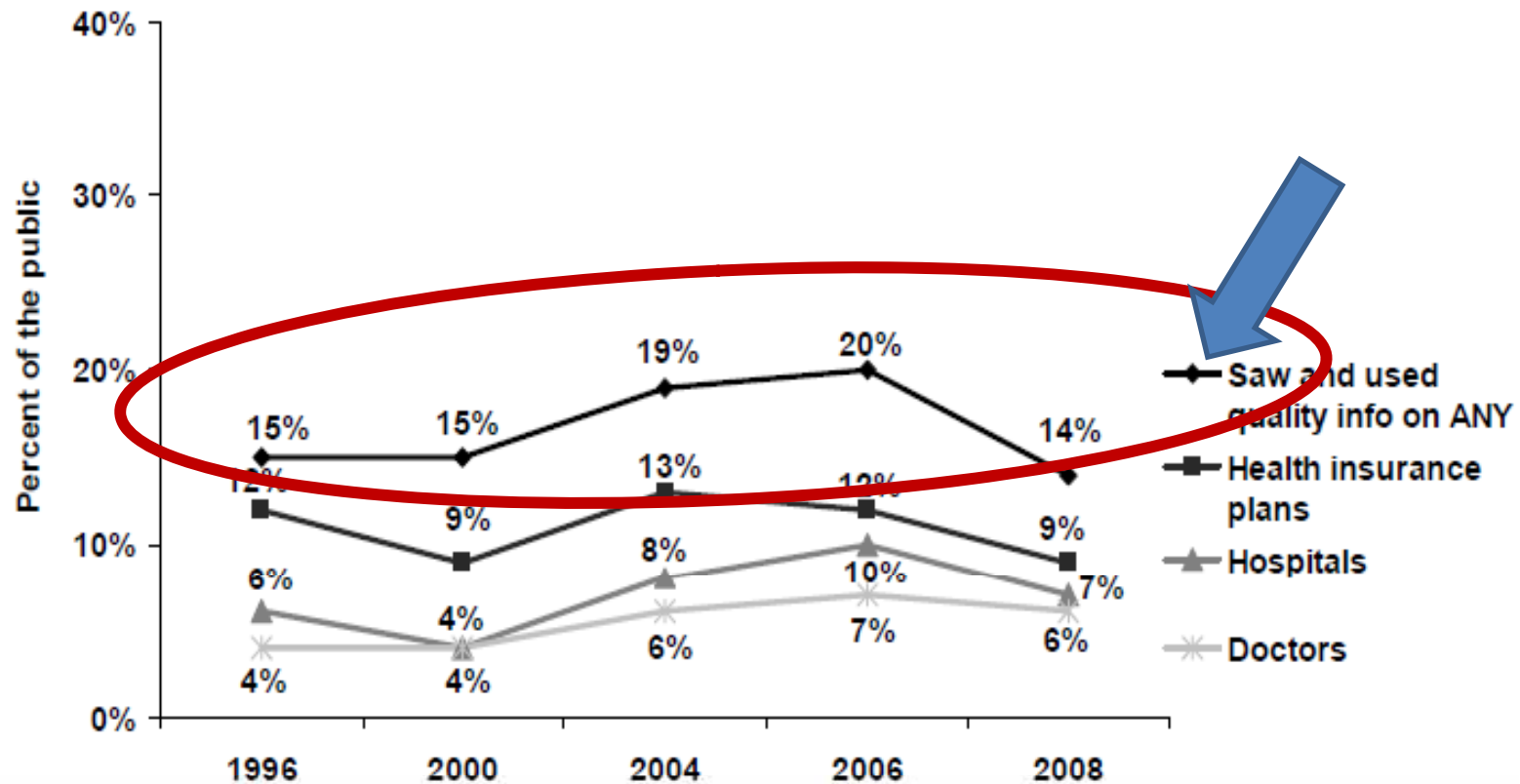
Sources: KFF 2008 Update on Consumers' Views of Patient Safety and Quality Information (Jul. 29-Aug. 6, 2008); KFF/AHRQ 2006 Update on Consumers' Views of Patient Safety and Quality Information (Aug. 3-8, 2006); KFF/AHRQ/Harvard School of Public Health National Survey on Consumers' Experiences with Patient Safety and Quality Information (Jul. 7-Sep. 5, 2004); KFF/AHRQ National Survey on Americans as Health Care Consumers: An Update on The Role of Quality Information (Jul. 31-Oct. 13, 2000); KFF/AHRQ Consumer Information Survey (Jul. 26-Sep. 5, 1996)

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How Consumers Respond
to these Approaches

- **Fewer than half of adults in the following groups look online for health information (Pew 2/11): African Americans, Latinos, adults living with a disability, adults 65+, adults with a high school education or less, adults living in household with incomes of $30,000 or less.**

- **Volume of calls to Help lines (e.g., Medicare Rights Center) demonstrates need for easy-to-use resources to assist older adults in comparing plans in Medicare**

Opportunities for Improvement

- **Consider target audience's skill levels**
- **Offer information that consumers find *relevant* and *actionable***
  - information about finding "good" physicians, other clinicians , institutions
  - information about "patients like me"
  - Information on "cost to me"
- **Integrate information** about physicians, hospitals, and other health plan providers at useful ("teachable") moment
- **Improve communications between patients and health professionals**
  - PHRs/EHRs
    - encourage engagement via access to one's personal information
    - "People pay more attention to and become more engaged in their health and medical care when they have easy online access to their health information (IOM, Health IT and Patient Safety)

  Caveat: computer-mediated interactions between people more prone to misinterpretation and misunderstanding than interactions conducted face-to-face (IOM)

Opportunities for improvement

- **Make information "evaluable"**
  - **Lower cognitive burden, reduce complexity**
  - **Rank order comparisons**
  - **Use symbols**
  - **Use composites with "drill downs" for details**
- **Create a consistent framework to communicate about quality (Hibbard)**
- **Narratives**
- **Plain English, no jargon, short sentences white space, large font (13 pt)**

Opportunities for improvement

- **Use multiple approaches to convey information—face-to-face, electronic, web**
- **Reduce number of "me-too" choices**
- **Feature quality information as prominently as other aspects of plan performance, such as premium levels**
- **Enable "at glance" interpretation (evaluability)**

Opportunities for improvement

- **Make consumers aware** of the availability of the information
- **Summarize** key points
- Identify sources of **additional help**/information

Opportunities for improvement

- **Guard against manipulation**: how information is presented is as important as what it conveys

- **Negative framing?** (protecting self vs. seeing high quality)

Other strategies

- **Include features to enable intermediaries—e.g., family members, brokers, Navigators, media—to extract or print out information to help consumers who want help**
- **Include users in the design of health insurance exchange websites and test the design to ensure its usefulness and navigability to consumers**

Key Features for CHECKBOOK'S Health Plan Comparison Tool

- **Best estimate of likely costs—premium plus out-of-pocket—under each plan for the user's age and family characteristics—using actuarial data.**
  - Not just a description of benefits and coverage.
  - Not just a calculation of out-of-pocket costs for known future expenses (which ignores the need to *insure* against unexpected injuries and diseases).
- **Estimates of user's possible costs in a very good year and a very bad year, and probabilities of each—and maximum out-of-pocket cost.**

State Health Insurance Exchange Websites:

A Review, Discussion and Recommendations for Providing Consumers Information about Quality and Performance