Connecting Americans to Their Health Care:

Empowered Consumers, Personal Health Records and Emerging Technologies

NATIONAL CONFERENCE
DECEMBER 7-8, 2006
WASHINGTON, D.C.

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2006

Involving Diverse Populations

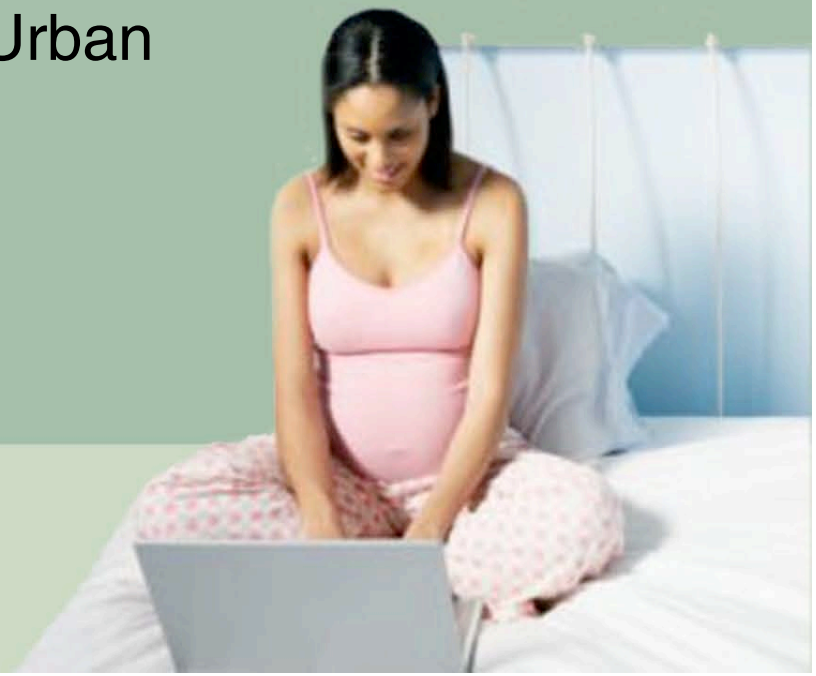
Steve Downs - Robert Wood Johnson Foundation

Francesca Gany - New York University Medical Center

M. Chris Gibbons - Johns Hopkins Urban Health Institute

Cynthia Baur - Centers for Disease Control and Prevention

Adolph Falcón - National Alliance for Hispanic Health



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Francesca Gany

New York University Medical Center

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Health IT: Promoting Access to the I through T

The Center for Immigrant Health

New York University School of Medicine

The Center for Immigrant Health NYU School of Medicine

- Founded in 1989
- Network of community members/CBOs/FBOs, providers, researchers, facilities and administrators, program and policymakers
- Mission: To facilitate linguistically, culturally, and epidemiologically sensitive health services

  To reduce health disparities
- Research, Education/Training , Program/Policy

PARTNERS

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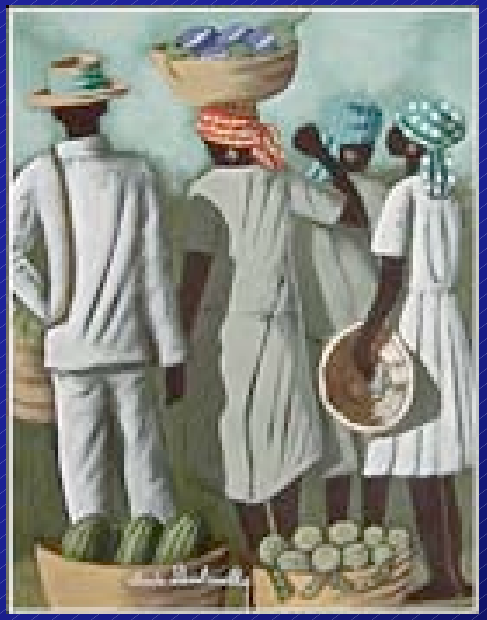
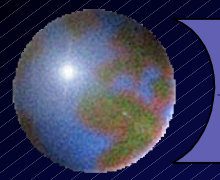
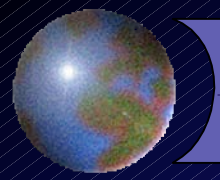
CARIBBEAN WOMEN'S HEALTH ASSOCIATION
COMMUNITY SERVICE CENTER





Health Information Barriers of Focus

- Language and Literacy
- Economic Access to Technology



NACHOS

Using Technology to Enable Health Information Exchange

RSMI

Intervention:Remote Simultaneous Medical Interpreting System(RSMI)

- Trained Simultaneous Medical Interpreters
- Remotely Located, Pooled Resource
- Spanish, Mandarin, Cantonese, Bengla, Polish, French, Haitian Creole

How Effective is RSMI?

Thanks:

- UHF
- Altman
- New York Community Trust
- Commonwealth Fund
- California Endowment

Research Questions

- Does RSMI Improve Timely Diagnosis of Depression?
- Does RSMI Facilitate Appropriate Follow-up Care?

Research Questions

- Does RSMI Improve Adherence to Screening Guidelines?
- Does RSMI Improve Outcomes for Chronic Diseases?

  Diabetes, Hypertension, and Hypercholesterolemia

Research Questions

- Does RSMI lead to fewer interpreting errors?
- Is RSMI a more efficient form of interpreting?
- Does RSMI lead to improved understanding of exit instructions

Error Analysis and Efficiency

Scripted Encounters:

- Spanish and Chinese: TB, Menopause, Diabetes, Depression
- Bengali: Breast Cancer

RSMI, Proximate Consecutive, Over-the-telephone Consecutive, Ad Hoc

Patient/Doctor Actors

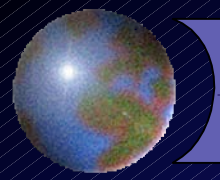
Encounters Audiotaped and Transcribed

Error Analysis Tool

- Word-by-word, and by concept
- Linguistic errors: meaningful and non-meaningful
- Medical errors: no, mild, moderate, high, and life-threatening significance
- HPI, meds/allergies, family history, diagnosis, plan, psychosocial, F/U, patient education

Error Analysis Panel

- Linguist and 3 physicians, at least 2 bilingual
- Scored separately, then discussed differences until consensus



Error Analysis

- Error rate per utterance
- Medically significant/Category
- Time
- Control for training

Spanish Error Analysis

RSMI versus non-RSMI

RSMI 30% as likely to result in potential medical error

**p<0.05

Spanish Error Analysis: Odds Ratio of a moderately significant to life-threatening error

Trained Proximate Consecutive	6.3***
Trained Remote Consecutive	7.54***
Ad Hoc(18 yrs experience)	1.71
Trained Remote Simultaneous	1.00

***p<0.001

Error Analysis Efficiency Results

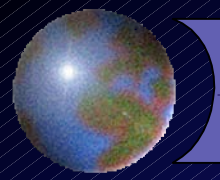
Mean time (in seconds) for each group

Mean	N	Method
1420.75	4	Distal Consecutive
1174.75	4	Proximal Consecutive
1095.00	4	Proximal Ad-Hoc
762.00	4	RSMI

Spanish Efficiency

- RSMI is 30% faster than the next fastest mode(ad hoc)
- RSMI two times faster than over-the-phone consecutive

- **Spanish encounters more accurate and efficient with RSMI**



Bengali Error Analysis

Standardized Training

Standardized Practice

One Script Across All Modes

Training: Error Examples

- Dr: The results were positive which means that you carry the gene that puts you at risk for developing breast cancer
- Int: The results were correct

- Dr: One important thing that you have going for you is the fact that the cancer has probably been caught early
- Int: One important thing is the fact that the cancer is working quickly in your body

- Dr: The doxy could hurt your heart
- Int: The doxy can give you pain

Training Matters

- 27% of errors made by untrained interpreters were of moderate or greater clinical significance vs. 8.5% of errors made by trained interpreters

- Vocabulary precision rate .69 for trained vs. 0.34 for the untrained

Study Design

- Randomized Control for Discordant(Spanish-English, Mandarin-English, Cantonese-English)
  - RSMI
  - Usual and Customary
  - Language Concordant Encounters: English-English, Spanish-Spanish, Chinese-Chinese

Immigrants at Risk: Language and Influenza Vaccination

- 462 patients were enrolled in the study between November 2003 and July 2004
- 102 were at the highest risk of complications from influenza (chronic medical condition, age, or pregnancy)
- Only 10 patients in this group were referred for vaccination
  - 9 received vaccination
- 54 patients aged 50 to 64 years without underlying medical conditions composed a second group who were eligible
  - 4 in this group were referred for and received flu vaccination

- ***None of the Cantonese or Mandarin-speaking patients in either group received vaccination.***

CLEAN

- RSMI associated with a higher referral rate for screening colonoscopy (OR of 1.7) compared with U&C
- Physicians in "language concordant" encounters had lower rates of referrals for screening colonoscopy than language discordant

Instructions Given

- Audiotape analyses of 214 ER Spanish language encounters Spanish language concordant, RSMI, U&C
- Trained RSMI

  mean # instructions per encounter: 14.29,std dv 6.9 equal to Spanish language concordant

  (14.33, std dev 6.33)
- Usual and customary interpreting

  significantly fewer instructions: mean # 11.9, std dev 6.17

Patient Satisfaction/Understanding Perception

- ER and Clinic Combined
- First Visits
- Language Concordant(E-E,Sp-Sp, M-M, Ca-Ca), RSMI, Usual and Customary

Understanding

	MD Understands			Pt Underst Explan			Pt Under Instructions		
	LC	RS MI	UC	LC	RS MI	UC	LC	RS MI	UC
VW	69%	49%	35%	59%	39%	34%	63%	38%	32%
W	33%	49%	55%	33%	52%	50%	33%	54%	59%
NW	2%	2%	10%	4%	9%	15%	3%	8%	9%

Satisfaction

- How would you rate the MD overall?

	LC	RSMI	UC
Ex	63%	56%	49%
Gd	32%	40%	44%
Fa	4%	4%	4%

- How satisfied with care overall?

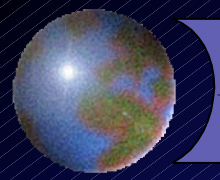
	LC	RSMI	UC
Very	57%	57%	47%
Swht	38%	40%	48%
SwtDis	4%	3%	5%

How well did the method protect your privacy?

	RSMI	U&C
Very Well	49%	40%
Well	44%	49%
Not Well	7%	10%
Poor	0%	1%

No Difference

- How well did the interpreter understand you?
- Did the interpreter listen carefully(yes/no)?
- Did the interpreter treat you with respect?(trend)
- How well did the interpreter interpret?(trend)



Virtual Community for Immigrants with Cancer

Project Overview

- Online support group (OSG) to provide
  - informational,
  - emotional, and
  - social network support to immigrants with cancer
- Service + Research
- Funded by Langeloth Foundation

Participants

- Spanish-speaking immigrants
- Newly diagnosed with breast cancer
- 48 participants in OSG, 24 in control group
- No computer/Internet experience necessary
  - Training on computers and Internet, if necessary
  - Provision of computers and Internet access, if necessary

VCIC Online Support Groups

- 8 participants in each group
- Series of 30 weekly online chat sessions
- Led by trained facilitators
- Periodic informational online sessions

Recruitment of Participants

- Key community stakeholders, including volunteer survivors, have aided tremendously
- 80% of potential participants approached enrolled
- Reasons for declining have included
  - not having a stable place to live
  - not having a telephone at home for internet access
  - family issues, such as family member death/illness

Who is Chatting?

- Mean age is 46.8 years (range 22-84 years)
- Hail from several Latin American countries
- Top two countries: Dominican Republic (25.5%)
  Colombia (18.2%)
- Mean number of years in the U.S. is 16.7 (range 0.25-43) years
- 40.7% have not completed high school
- 32.7% employed outside their homes
- 11.3% do not have health insurance

Chat-Sessions Themes

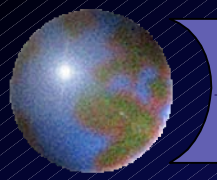
- Chat-sessions themes have been varied, including:
  - Faith
  - Family, including lack of family in the U.S.
  - Financial/insurance issues
  - Health Information
  - Breast reconstruction
  - Pain

Dropping Out of VCIC

- Dropout rate to date has been 13%
- Reasons have included
  - participant's death
  - eviction from apartment
  - disconnection of telephone
  - too tired to participate
  - work schedule changes
  - return to home country

Research

- Feasibility, Acceptance, and Effectiveness
- What percentage of immigrants with cancer can be recruited and retained for online support groups?
- How effective are online support groups in enabling emotional well-being for immigrants with cancer?



Feedback from Participants

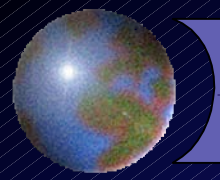
"…El hecho de no vernos las caras, el que no haya contacto físico, facilita el que podamos tener mas libertad para expresarnos y aconsejarnos. Esto también nos `permite abrirnos mas emocionalmente al comunicarnos. Yo me atrevería a decir que el simple hecho de usar la computadora nos provee o nos ayuda a sentirnos mas importantes, con un tipo de valor y poder distinto. Definitivamente puedo decir sin lugar a dudas que el haber aceptado integrarme a participar en el programa de CAVIC ha sido una de las mejores cosas que me han podido pasar en estos últimos tiempos…"

"… The fact that we can't see each other's faces, that there is not physical contact, allows us to have more freedom to express ourselves and give each other advice. This also permits us to open ourselves up emotionally when we are communicating. I would venture to say that the simple act of using the computer provides us with and helps us to acquire a new and different type of security, with a distinct type of bravery and power. Definitely, I can say, without a doubt, that having chosen to integrate myself or participate in CAVIC has been one of the best things that has happened to me in the past few years."

"Bueno, yo les doy la gracias al programa CAVIC. Pues me relaje bastante, pude en el limpiar mi cuerpo y mi mente de tantos confusión y gracias a Lauren pude cambiar de medico... Pues ellos se dedicaron a ayudarnos a todas nosotras a sacarnos una o dos horas de esa rutina que una como madre experimenta aunque fuera una vez a la semana, me sentí y muy agradecida con todos los ayudos tanto del programa CAVIC como de todos los compañeros que conocí y espero que seguir siendo mis amigas por siempre."

"Well, I give my thanks to the VCIC program.
I was able to relax a lot, I could clear out my body and mind of so much confusion, and thanks to Lauren,
I could change my doctor. They dedicated themselves to all of us, to take us away one or two hours a week, from this routine that one experiences as a mother.
Although it was only once a week,
I felt so grateful for all of the help, from both the program as well as all of my companeras that I met, and I hope will continue to be my friends forever."

"Mi comentario se basa en lo agradecida y satisfecha quede con las personas que de una manera o otra me han ayudado con su apoyo, charla, compresión y paciencia durante este estudio de CAVIC. Fueron de mucho valor los comentarios y las experiencias que compartimos unas con otras. Los mas Hermosa de todo es haber las conocido a todas aunque fuera por el internet. Mil gracias por la compu y que Dios bendiga a todo el que aporto su granito de arena. Les quiero mucho. "



"My comments address how grateful and satisfied I am with the people, who in some way or another, have helped me with their support, words, understanding and patience during this VCIC study. Their commentary was very valuable, as were the experiences that we shared with one another. The most beautiful of all is having met each one of you all, although it was through the Internet. Thanks a million for the computer and may God bless each person who gave of themselves to this. I love you all very much."

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M. Chris Gibbons

Johns Hopkins Urban Health Institute

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Improving Disparities with eHealth Opportunities & Observations

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The potential of eHealth Solutions

- Far beyond EMR, EPR and CPOE
- On the brink of a transition from a service and technology to an information society

The potential of eHealth Solutions

- The advent of ubiquitous computing, pervasive computing, RFID, Mesh networks and WiMax and nanotechnology will usher in an era of unprecedented connectivity and communication between humans (H2H) and things (H2T) and between things (T2T)

The potential of eHealth Solutions

- Human to Human (H2H) connectivity will enable providers and healthcare systems to stay in audio and visual contact as needed, whoever you are, where ever you live.

The potential of eHealth Solutions

- Human to Thing (H2T) connectivity will enable both providers and patients to know about the health status of individuals and populations at any time, in real time

The potential of eHealth Solutions

- Thing to Thing (T2T) connectivity in the absence of human involvement will mean the development of “intelligent devices” that can make decisions and do things independent of the “human element”
  - » Smart Jackets
  - » Insulin phones

The potential of eHealth Solutions

- In this world
  - » Clinicians know and understand how all social, environmental and biological factors collectively contribute to ill health
  - » Health risks are managed before they become diseases and before patients ever need to go to the hospital

The potential of eHealth Solutions

- In this world
  - » healthcare is proactive not reactive
  - » Patients don’t delay seeking care
  - » Medical errors rarely made

The potential of eHealth Solutions

- Over time, there exists real potential to make significant impact towards the goal of reducing and eliminating disparities in health care access, utilization and outcomes.

Realizing the Potential

- Who's online?
- How are they getting online?
- What are they doing online?
- What difference does it make to health?

Who's online?

- Computer ownership and internet use is strongly influenced by household income.
- African Americans are less likely than Whites to own a computer or be online at all income and educational levels

How are they getting online?

- Home broadband use has rapidly increased among Whites and African Americans since 2002
- The *gap* in utilization has *increased* from 4% to 19%
- Differences persist at all income and educational levels

What are they doing online?

- African-Americans *less* likely the Whites to
  - use email
  - Take online courses
  - News/sports/weather
  - Purchase clothes, books or PC.s
  - Obtain information on products
  - Use the internet every day
  - Use it to stay connected with family

What are they doing online?

- African-Americans *more* likely the Whites to
  - Seek religious information
  - Seek health information
  - Major life issues (place to live)
  - Download music
  - Respond to online advertising
  - Make certain online purchases (music, video)

What are they doing online?

- African-Americans *equally* likely as Whites to
  - Seek a job
  - Watch TV, movies
  - Listen to the radio

What difference does it make?

- Despite improvements, disparities exist in
  - Extent of use
  - Knowledge about computer/internet use
  - Quality of technical connections
  - Quality of social support

What difference does it make?

- Differences in information services vs. information goods
- Differences in utilization must be viewed within a cultural context

What difference does it make?

- Ability of AA to benefit may lag behind that of whites if the broadband gap is not reversed
- Should not expect *a priori* equivalence in outcomes by race or maximal efficacy across races

What difference does it make?

- Without dedicated investments in understanding the perspectives of minorities towards Health Information Technologies we risk building systems that remain largely ineffective for significant and growing proportions of our society. This will limit the value of our investments and risk increasing rather than decreasing the health gap.

A final word

The challenges may seem insurmountable,
but the pay off is priceless!

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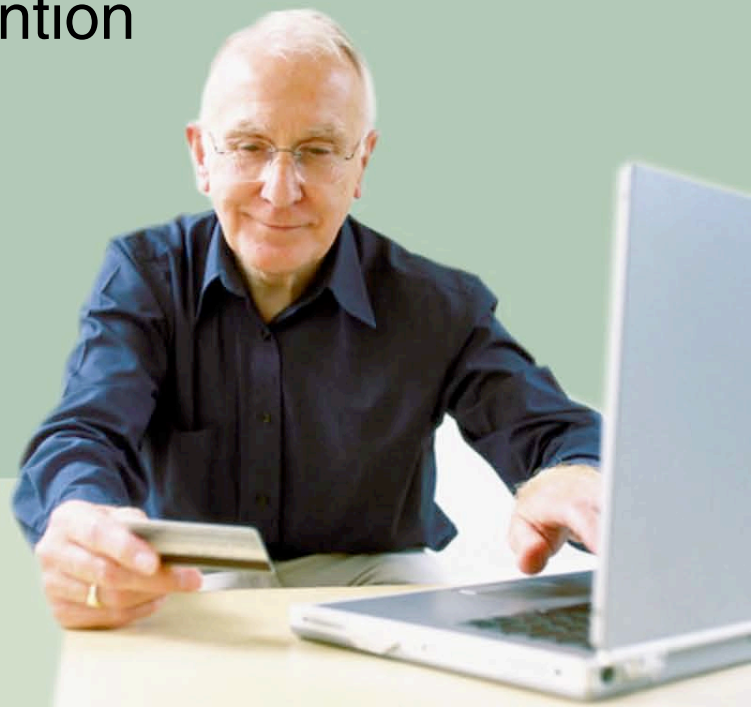
Cynthia Baur

Centers for Disease Control and Prevention



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Personal Health Records, Health Literacy and Diverse Populations

Cynthia Baur, Ph.D.
Centers for Disease Control and Prevention
U.S. Department of Health and Human Services
December 7, 2006

What is Health Literacy?

- Health literacy is the degree to which individuals have the capacity to *obtain, process,* and *understand* basic health information and services needed to make appropriate health decisions.
- Key concepts:
  - Obtain -- Understand
  - Process -- Decide

Why is Health Literacy Important?

Health literacy is important because it affects people's ability to:

- Navigate the healthcare system, including locating providers and services and filling out forms
- Share personal and health information with providers
- Engage in self-care and chronic disease management
- Adopt health-promoting behaviors, such as exercising and eating a healthy diet
- Act on health-related news and announcements

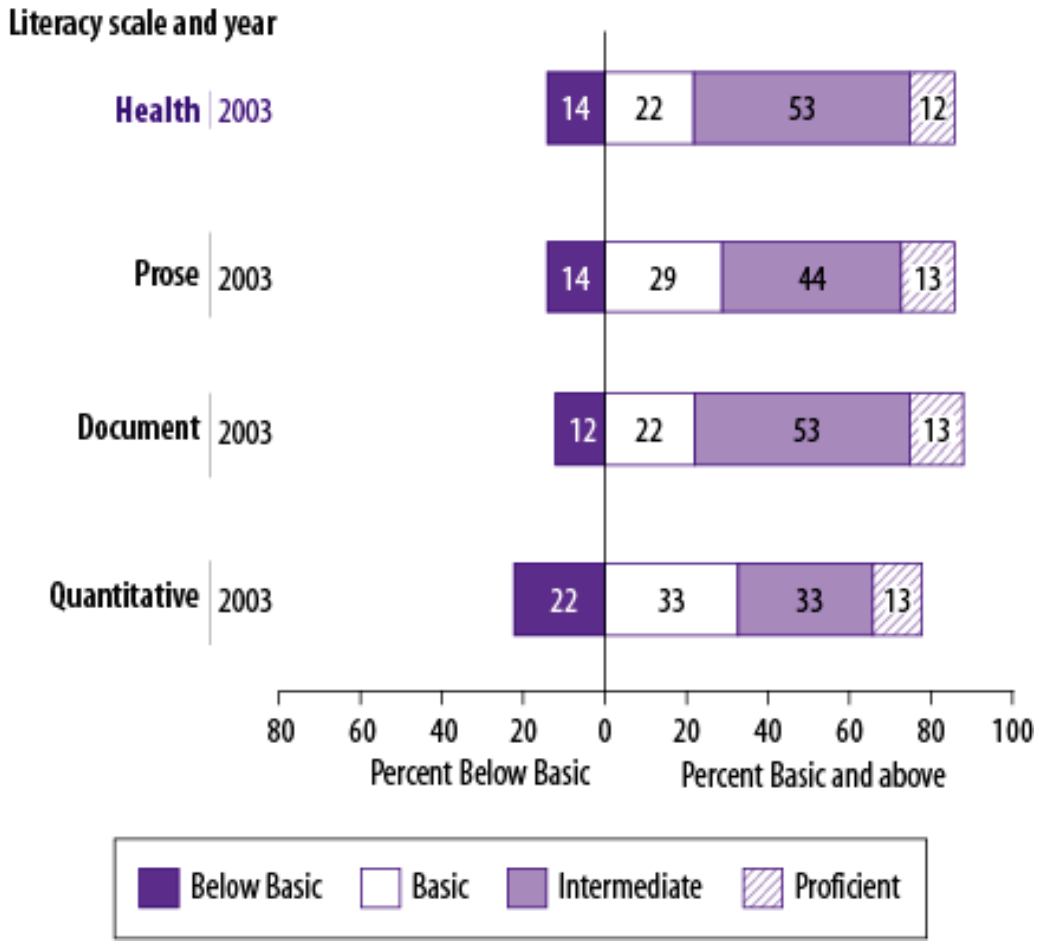
These intermediate outcomes impact:

- Health outcomes
- Healthcare costs
- Quality of care

Health Literacy in the Adult Population

- Measured by the 2003 National Assessment of Adult Literacy (NAAL)
- Nationally representative sample of more than 19,000 adults
- Health literacy component within the general literacy study
- Assessed English-speaking adults' ability to use and understand print health information

Percentage of Adults in Each Literacy Level: 2003



Who is Most Likely to Have the Lowest Health Literacy Skills?

- Racial and ethnic minorities, except Asian/Pacific Islanders
- Persons who spoke languages other than English before starting school
- Persons 65 and older
- Persons who did not complete high school
- Persons living below the poverty level
- Persons who do not use the Internet for health information

Below Basic Health Literacy and Health Information Choices

- 30 million adults in below basic health literacy category
  - 37% or 11 million no information from newspapers
  - 41% or 12 million no information from magazines
  - 41% or 12 million no information from books or brochures
  - 80% or 24 million no information from the Internet

What is the Relevance of these Data for PHRs?

- Adults with limited health literacy skills
  - are not accustomed to using the Internet as a health resource
  - prefer mass media or interpersonal sources of health information
  - will be unable to handle many of the multiple and complex tasks in PHRs

Examples of PHR Tasks

- Navigating Web sites and other applications
- Seeking out information
- Entering data
- Comparing two or more pieces of information
- Reading charts and graphs
- Writing messages
- Analyzing reports
- Reading textual information

Vision of PHRs for All

- All types of consumers are included in the design of and have meaningful access to evidence-based PHRs with strong privacy and security protections
  - Extensive consumer research is essential
- Diverse consumers have the skills and support to evaluate, choose and use PHRs
  - Improved health literacy is essential

Vision (cont.)

- Healthcare systems use the full range of e-health tools to engage and support consumers
  - Segmentation of PHR markets is essential
- Public policies and programs support sustainable development and dissemination of appropriate e-health tools, including communities served by safety net providers
  - Supporting safety net providers is essential

Vision (cont.)

- Alliances and partnerships facilitate access to and use of PHRs, consistent with the perspectives of each consumer group
  - Easy access through trusted sources is essential
- Appropriate funding and incentives exist in public policy and the market to enable sustainable business models for PHRs with demonstrated effectiveness
  - Sustainability of products is essential

Report on Diversity and e-health

- Expanding the Reach and Impact of Consumer e-health Tools
- U.S. Department of Health and Human Services
- Available online at www.health.gov/communication

Contact Information

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- Division, Health Communication and Marketing
- 404-498-6411
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