Keep Your Eyes on the Prize: Health Literacy Research as a Means to an End

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Disclosures

- I work for the Agency for Healthcare Research and Quality
  - The statements in this presentation are those of the author, who is responsible for its content, and do not necessarily represent the views of AHRQ.
  - No statements in this presentation should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.
What AHRQ Does

• AHRQ invests in research to understand how to make health care safer and improve quality

• AHRQ creates materials to teach and train health care professionals and systems to improve care for their patients

• AHRQ generates measures and data used to track and improve performance and evaluate progress of the U.S. health system
Overview

• Review accomplishments and deficits in health literacy research

• Propose new research directions

• Address vulnerable populations
Polling Question

Why do you conduct health literacy research?

A. To get tenure or promotion
B. To gain prestige
C. Make a contribution to the field
D. Improve health and health care

You may select more than 1 option.
Results

- Get tenure or promotion: 42
- Prestige: 12
- Contribute to the field: 85
- Improve health & health care: 100
A society that:

- Provides everyone access to accurate, actionable health information
- Delivers person-centered health information and services
- Supports life-long learning and skills to promote good health
Researchers Put Health Literacy on the Map
Health Literacy: Growing the Field
2004 AHRQ Evidence Review

- 73 articles, 29 on interventions
- Limited literacy linked to poor health outcomes
- Effectiveness of interventions not supported – few studies, fair quality
- No studies on costs of interventions
Skills/Abilities × Difficulty/Complexity = Health Literacy
• 114 new articles: 13 on numeracy, 33 on interventions
• Possible causal pathways: knowledge, self-efficacy, and social stigma
• Low or insufficient evidence for specific design features
• Moderate evidence for combo interventions: intensive self-management & adherence
• 2 contradictory studies on cost
Enough Research on Associations

Low Health Literacy → Poor Health Outcomes
Number of Articles Assessing Readability of Written Materials

Weiss 2015
Brain Dead Research
Brain Dead Research
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3 Antidotes to Brain Dead Research

1. Conduct actionable research
2. Try new methods
3. Study systems
Actionable Research

• User-driven research: answer questions that would-be users are asking

• User-informed research: involve would-be users in design of research
Partner With Health Care Systems

- What are the operational managers’ burning questions?
- What data sets do they have and how could they improve them?
- Test feasibility of interventions
- Take advantage of natural experiments
- Learn about implementation
Partner With Communities

- Engage communities in choice of research questions, not just recruitment
- Conduct hypothesis generating as well as hypothesis testing research
- Collaborate on development of interventions
- Gain insight into how to translate research results into practice
2. Try New Methods
False Precision
Qualitative Research

Observation
Themes
Inductive

Context
Process
coding
Examples

Grounded
theory

Network
settings
test
views

Skills
Explain
causal

Culture
Focus
groups
diverse

Particular
concept
inquiry

Trustworthy
representative
interviews

Dynamic
Evidence
Change

Uncertainty
Perceptions
Research Paradigms

Quantitative
- Assumes fixed, measurable reality
- Deductive
- Independent and dependent variables
- Probabilistic sampling
- Generalizable
- Biases unknown
- Truth

Qualitative
- Assumes dynamic and negotiated reality
- Inductive
- Holistic, interdependent system
- Purposive sampling
- Trustworthy
- Biases stated
- Understanding
Alternatives to the RCT

- Positive Deviance
- Most Significant Change
- Harvesting Outcomes
- Fuzzy Set Qualitative Comparison Analysis
- Interrupted Time Series
- Step-wedge Design
## Examples of Mixed Methods

<table>
<thead>
<tr>
<th>Door-to-Balloon Time</th>
<th>Care Coordinated Demos</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Purposive sampling using national registry data</td>
<td>• Purposive sampling using admissions data</td>
</tr>
<tr>
<td>• Conducted in-depth interviews</td>
<td>• Conducted interviews and site visits</td>
</tr>
<tr>
<td>• Used constant comparative method to ID effective strategies</td>
<td>• Identified common features</td>
</tr>
<tr>
<td>• Conducted survey and regression to ID best strategies &amp; effect size</td>
<td>• Compared cost of program with savings from averted hospitalizations + natural experiment</td>
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</tbody>
</table>
Keep Your Eyes on the Prize

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Based on Koh, Berwick et al. 2013
Systems-level Research Questions

• Which system-level changes most effectively help care teams routinely confirm understanding?

• Which organizational communication strategies can help reduce the burden on individuals to coordinate their own care?

• How can information systems best engage individuals with easily understandable personalized medical record data?
Take Chances! Get Messy!
Brach et al. 2012

This graphic reflects the views of the authors of the Discussion Paper "Ten Attributes of Health Literate Health Care Organizations" and not necessarily of the authors' organizations or of the IOM. The paper has not been subjected to the review procedures of the IOM and is not a report of the IOM or of the National Research Council.
A society that:

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Vulnerable Populations

HHS Mission: To enhance and protect the health and well-being of all Americans

HHS 2016 Performance Plan: especially for those who are least able to help themselves.
• Communicate Clearly
• Follow-up with Patients
• Use Health Education Material Effectively
• Link Patients to Non-Medical Support
• Make Referrals Easy
• Now with 21 tools and companion guide!

http://ahrq.gov/qual/literacy
Which disparities should health literacy research reduce?

A. Health literacy
B. Racial and ethnic
C. Linguistic
D. A and B
E. A and C
F. All of the above

Select 1 option.
Results: Health Literacy Research Should Impact:

- Health literacy only: 40
- Racial/ethnic only: 0
- Linguistic only: 5
- Health literacy & Racial/ethnic: 2
- Health literacy & linguistic: 38
- All of the above: 15
Clear Information Decreases Group Differences in Preferences for Shared Decision Making

Langer et al. 2012
Re-Engineered Discharge Program (RED)

• Evaluated their current discharge process and re-engineered using health literacy principles

• Randomized control trial: 30% reduction in subsequent emergency visits and readmissions

• Tested only with English speakers
New **RED Toolkit** for Serving Diverse Populations

- Integrated into all RED implementation tools
- Separate tool for serving diverse populations
New **RED Toolkit** for Serving Diverse Populations

- Integrated into RED implementation tools
- Separate tool for serving diverse populations
- Added 12th component: Ascertain need for and obtain language assistance
Catch the Moving Train

• Patient engagement
Catch the Moving Train

- Patient engagement
- Shared decision-making
Catch the Moving Train

- Patient engagement
- Shared decision-making
- Complex patients
Research Impact: RE-AIM

- **Reach** into the target population
- **Effectiveness or efficacy**
- **Adoption** by target settings, institutions and staff
- **Implementation** - consistency and cost of delivery of intervention
- **Maintenance** of intervention effects in individuals and settings over time.
What Potential Adopters Want to Know

- Does the innovation fit?
- **Should** we do it here?
- **Can** we do it here?
- **How** will we do it here?

Brach et al. 2008
Research Translation

- Report Context
  - Consolidated Framework for Implementation Research (CFIR)
- Build translation activities into grants

- Beyond the peer-reviewed article
  - Create tools & guides
  - Write trade press articles
  - Train others, leverage opinion leaders, groom champions
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Ask Me 3 for Health Literacy Researchers

• Will my findings provide information on what to do to increase health equity?
• Will my findings provide information on how to do it?
• Will it provide information about why its important to do it?
Win Hearts and Minds