‘Make it Simple, but Significant’

In Remembrance

Dr. Jane Wardle

October 30, 1950 – October 20, 2015

LITERACY AND HEALTH STATUS IN DEVELOPING COUNTRIES

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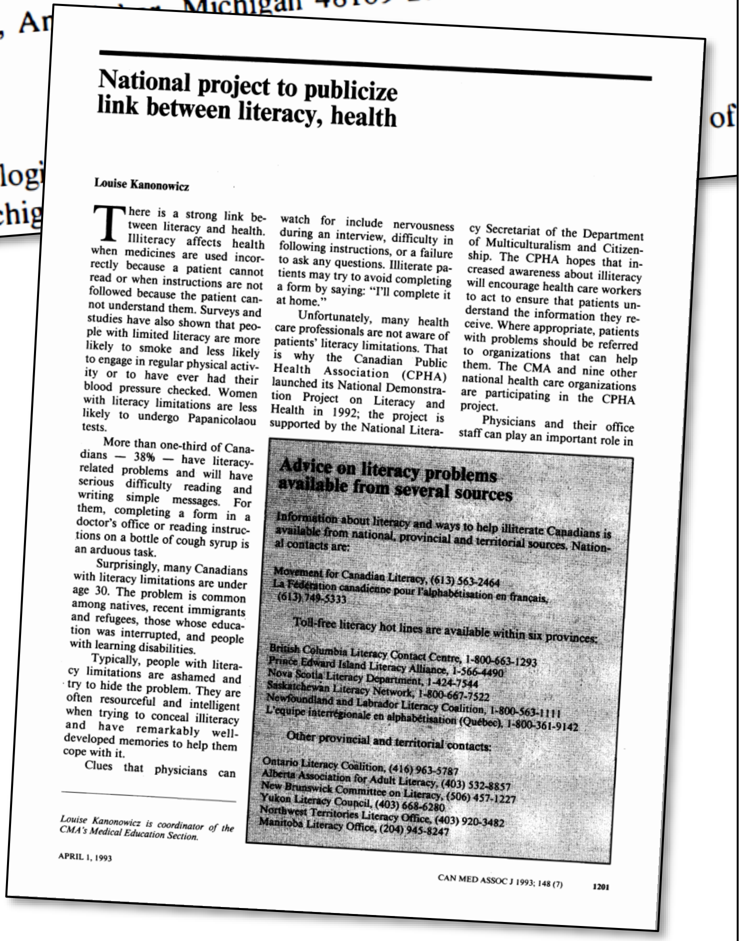


National project to publicize link between literacy, health

Louise Kanonowicz

There is a strong link between literacy and health. Illiteracy affects health when medicines are used incorrectly because a patient cannot read or when instructions are not followed because the patient cannot understand them. Surveys and studies have also shown that people with limited literacy are more likely to smoke and less likely to engage in regular physical activity or to have ever had their blood pressure checked. Women with literacy limitations are less likely to undergo Papanicolaou tests.

More than one-third of Canadians — 38% — have literacy-related problems and will have serious difficulty reading and writing simple messages. For them, completing a form in a doctor's office or reading instructions on a bottle of cough syrup is an arduous task.

Surprisingly, many Canadians with literacy limitations are under age 30. The problem is common among natives, recent immigrants and refugees, those whose education was interrupted, and people with learning disabilities.

Typically, people with literacy limitations are ashamed and try to hide the problem. They are often resourceful and intelligent when trying to conceal illiteracy and have remarkably well-developed memories to help them cope with it.

Clues that physicians can watch for include nervousness during an interview, difficulty in following instructions, or a failure to ask any questions. Illiterate patients may try to avoid completing a form by saying: "I'll complete it at home."

Unfortunately, many health care professionals are not aware of patients' literacy limitations. That is why the Canadian Public Health Association (CPHA) launched its National Demonstration Project on Literacy and Health in 1992; the project is supported by the National Literacy Secretariat of the Department of Multiculturalism and Citizenship. The CPHA hopes that increased awareness about illiteracy will encourage health care workers to act to ensure that patients understand the information they receive. Where appropriate, patients with problems should be referred to organizations that can help them. The CMA and nine other national health care organizations are participating in the CPHA project.

Physicians and their office staff can play an important role in

Advice on literacy problems available from several sources

Information about literacy and ways to help illiterate Canadians is available from national, provincial and territorial sources. National contacts are:

Movement for Canadian Literacy, (613) 563-2464
La Fédération canadienne pour l'alphabétisation en français, (613) 749-5333

Toll-free literacy hot lines are available within six provinces:

British Columbia Literacy Contact Centre, 1-800-663-1293
Prince Edward Island Literacy Alliance, 1-566-4490
Nova Scotia Literacy Department, 1-424-7544
Saskatchewan Literacy Network, 1-800-667-7522
Newfoundland and Labrador Literacy Coalition, 1-800-563-1111
L'equipe interrégionale en alphabétisation (Québec), 1-800-361-9142

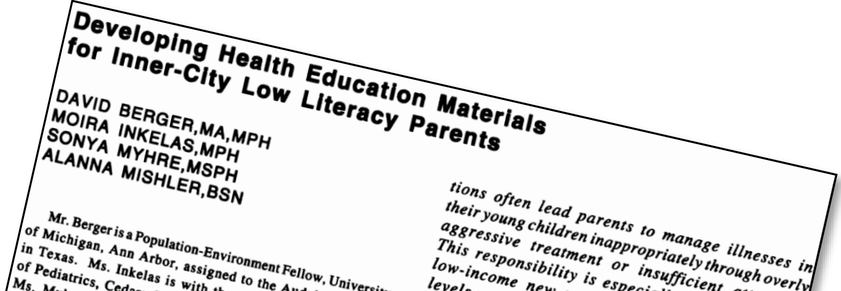
Other provincial and territorial contacts:

Ontario Literacy Coalition, (416) 963-5787
Alberta Association for Adult Literacy, (403) 532-8857
New Brunswick Committee on Literacy, (506) 457-1227
Yukon Literacy Council, (403) 668-6280
Northwest Territories Literacy Office, (403) 920-3482
Manitoba Literacy Office, (204) 945-8247

Louise Kanonowicz is coordinator of the CMA's Medical Education Section.

APRIL 1, 1993

CAN MED ASSOC J 1993; 148 (7) 1201



Developing Health Education Materials for Inner-City Low Literacy Parents

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tions often lead parents to manage illnesses in their young children inappropriately through overly aggressive treatment or insufficient attention. This responsibility is especially challenging for low-income new parents who lack the literacy levels needed to understand and use much of the existing health education literature and who are without access to health facilities and providers.

In response to a perceived need for health information directed at low-income, low-literacy parents, students from the University of Califor-

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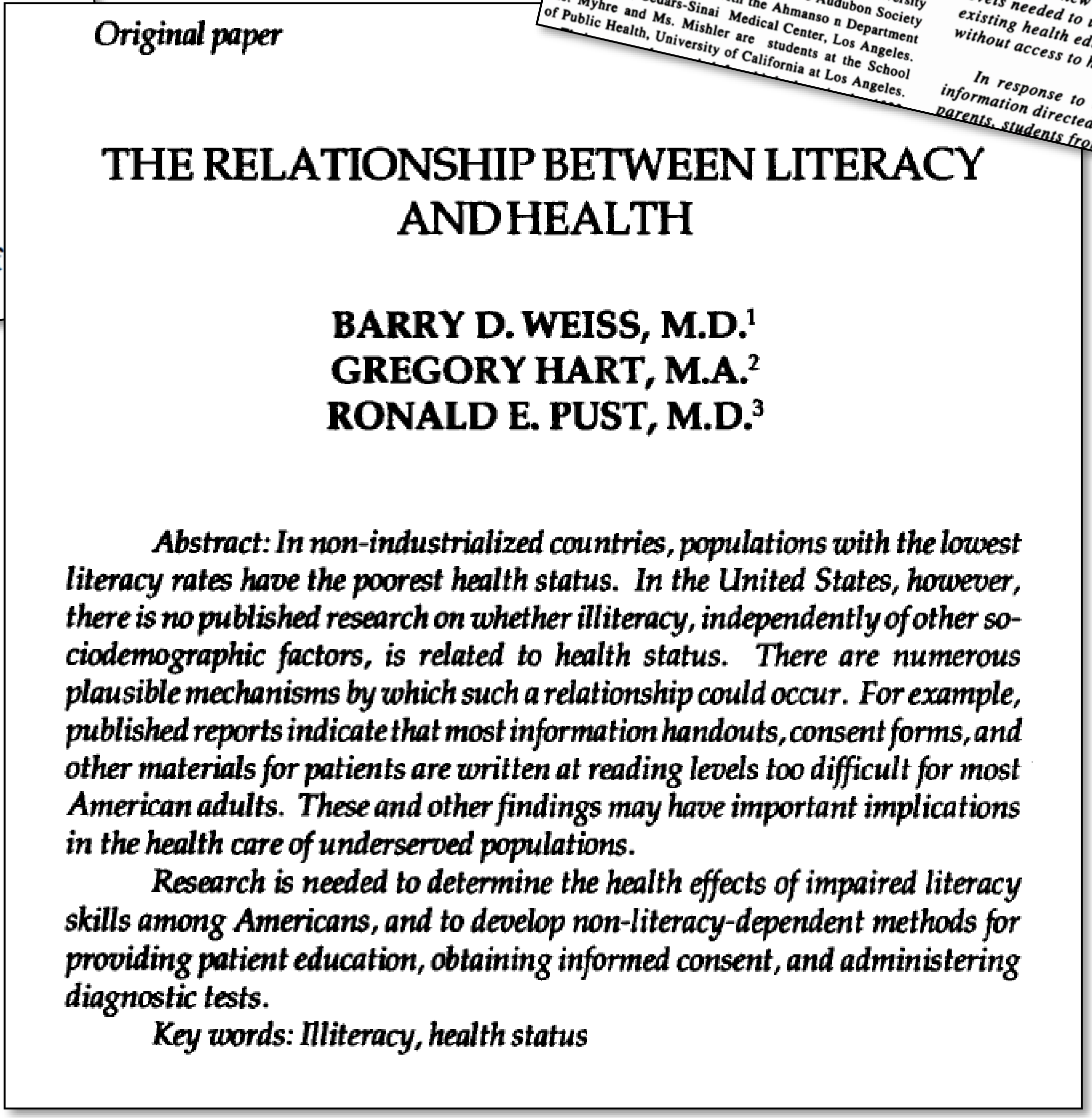


Original paper

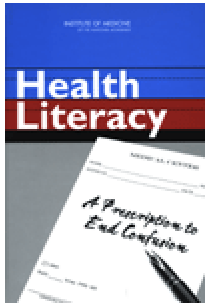
THE RELATIONSHIP BETWEEN LITERACY AND HEALTH

BARRY D. WEISS, M.D.[1]
GREGORY HART, M.A.[2]
RONALD E. PUST, M.D.[3]

Abstract: In non-industrialized countries, populations with the lowest literacy rates have the poorest health status. In the United States, however, there is no published research on whether illiteracy, independently of other sociodemographic factors, is related to health status. There are numerous plausible mechanisms by which such a relationship could occur. For example, published reports indicate that most information handouts, consent forms, and other materials for patients are written at reading levels too difficult for most American adults. These and other findings may have important implications in the health care of underserved populations.

Research is needed to determine the health effects of impaired literacy skills among Americans, and to develop non-literacy-dependent methods for providing patient education, obtaining informed consent, and administering diagnostic tests.

Key words: Illiteracy, health status



Health Literacy

NORTHWESTERN UNIVERSITY

HeLP

Health Literacy & Learning Program

What a Decade...

> 500 health literacy projects funded

> $500 million investment

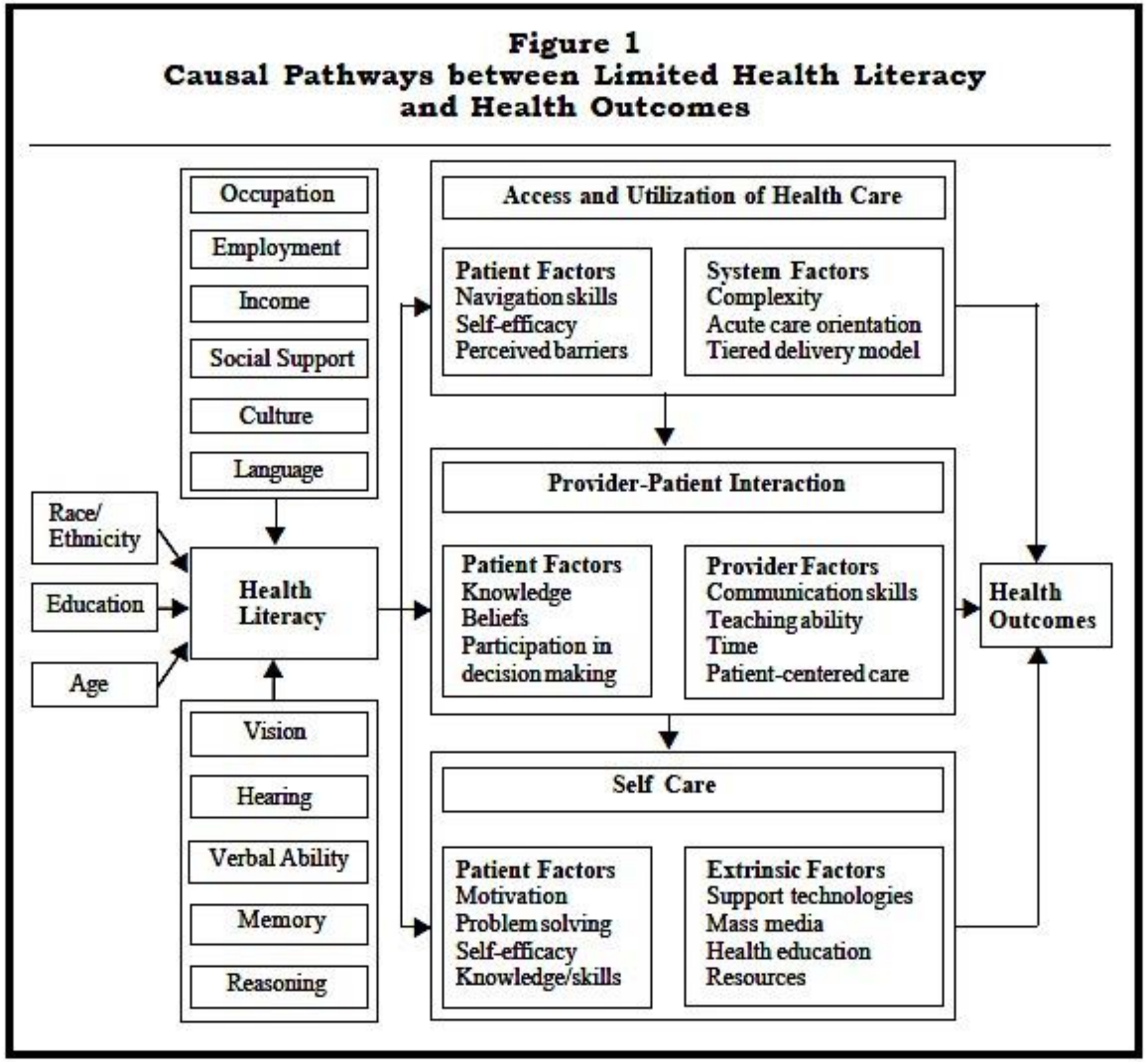
What Have We Accomplished?

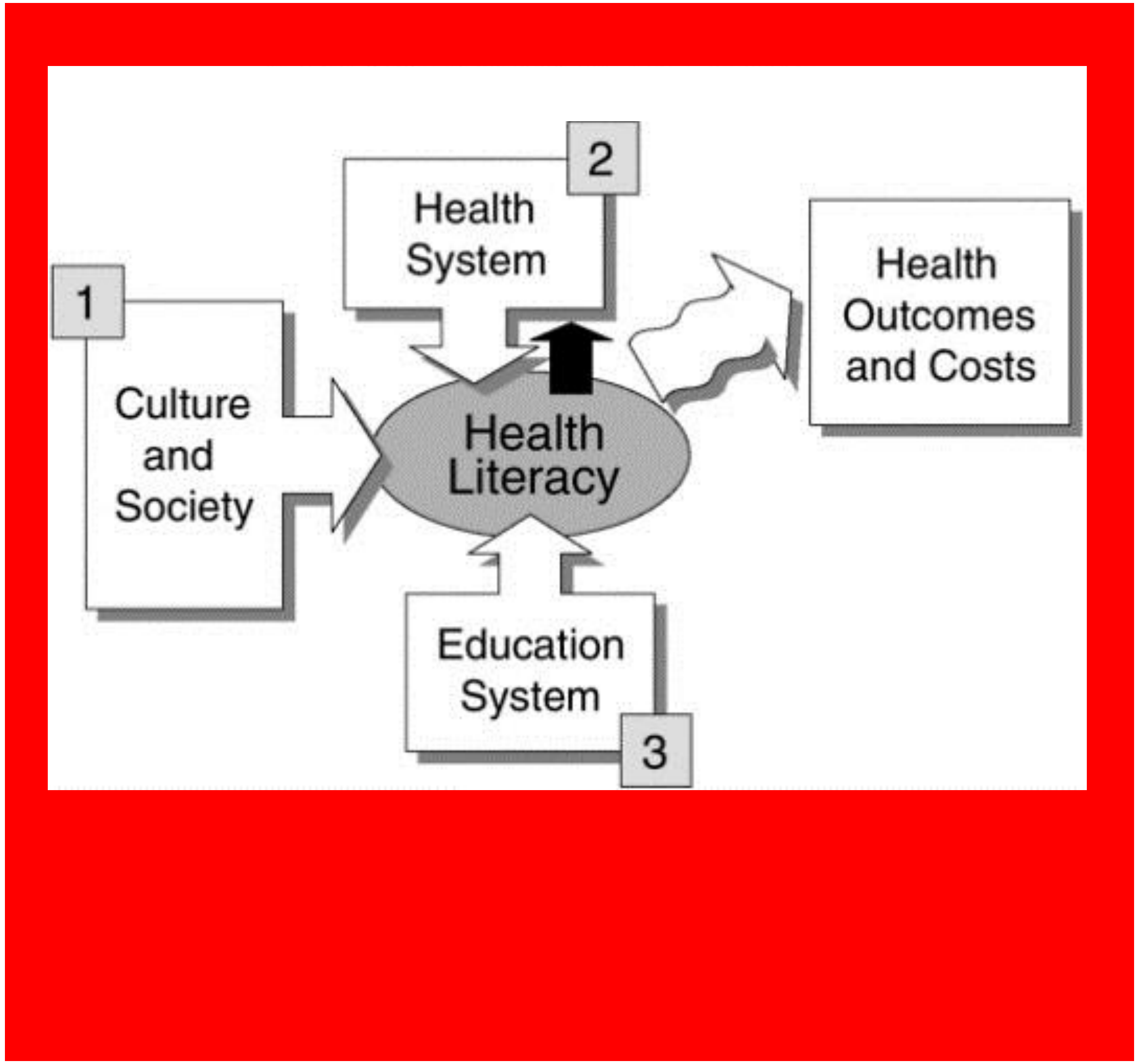
National Action Plan to Improve Health Literacy

Stagnation in...

- research
- practice
- policy

Getting Beyond Semantics





THE PITCH

for healthcare systems

- Health Literacy is Necessary for Quality, Safety, and Equity
- Cost-saving

for industry

- All of the Above
- Health Literacy can Sell Product, Foster Efficiency
- Compliance with Mandate

‘Make it Simple, but **Significant**’

A Prescription for Designing Meaningful Health Literacy Interventions

A ‘Slightly’ Complex Patient

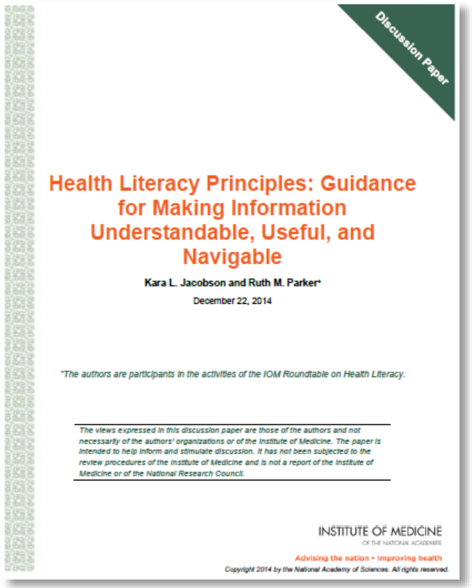
Lesson 1:

“If you don’t like what’s being said, change the conversation.”

Making it Simple

- ✓ <u>print</u> health materials
  - ☐ web, multimedia
  - ☐ numeric content
- ✓ provider counseling
- ✓ healthcare navigation

The Core Health Literacy Product



Health Literacy Principles: Guidance for Making Information Understandable, Useful, and Navigable

Kara L. Jacobson and Ruth M. Parker*

December 22, 2014

*The authors are participants in the activities of the IOM Roundtable on Health Literacy.

The views expressed in this discussion paper are those of the authors and not necessarily of the authors' organizations or of the Institute of Medicine. The paper is intended to help inform and stimulate discussion. It has not been subjected to the review procedures of the Institute of Medicine and is not a report of the Institute of Medicine or of the National Research Council.

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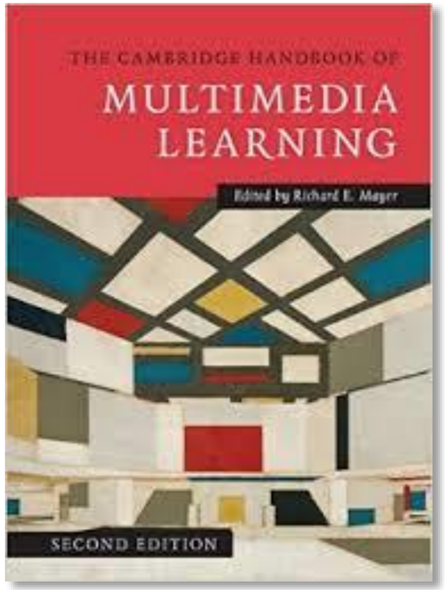
The Patient Education Materials Assessment Tool (PEMAT) and User's Guide

An Instrument To Assess the Understandability and Actionability of Print and Audiovisual Education Materials

(Version 1.0)

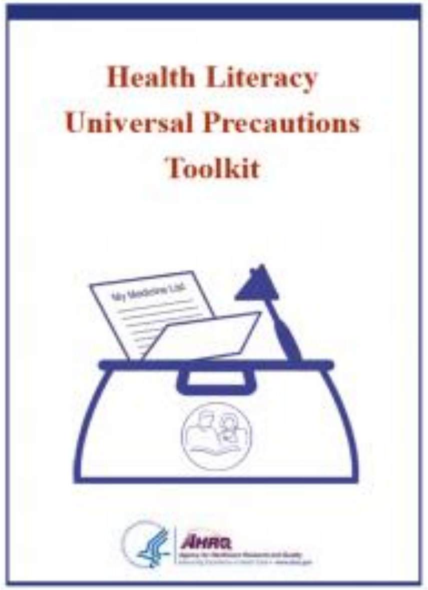


THE CAMBRIDGE HANDBOOK OF

MULTIMEDIA LEARNING

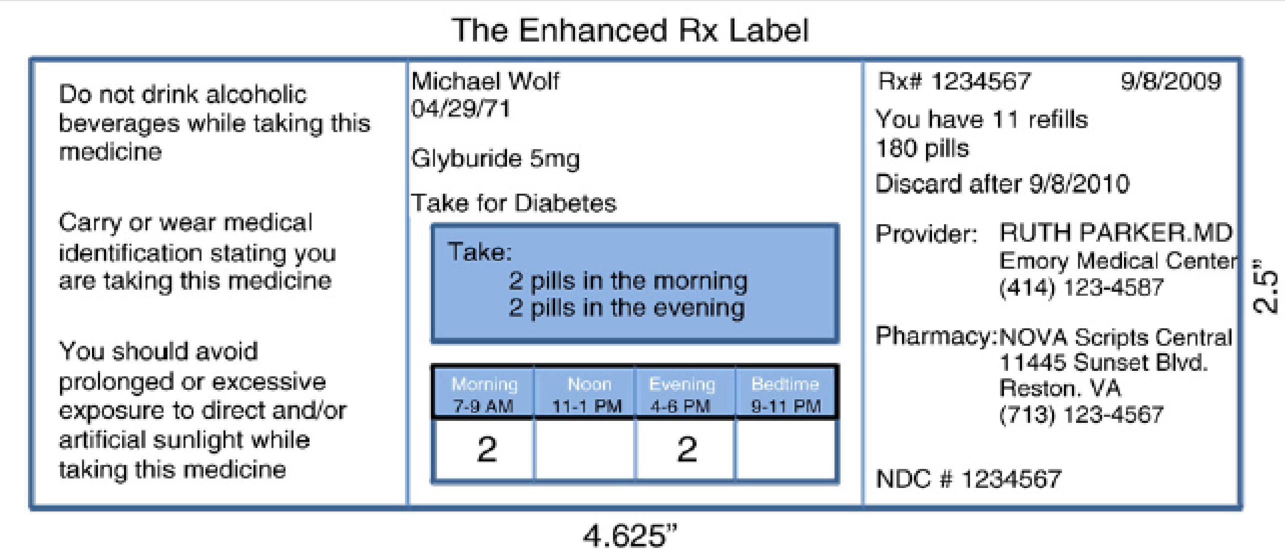
Edited by Richard E. Mayer

SECOND EDITION



Health Literacy Universal Precautions Toolkit

Universal Medication Schedule (UMS)



The Enhanced Rx Label

Do not drink alcoholic beverages while taking this medicine

Carry or wear medical identification stating you are taking this medicine

You should avoid prolonged or excessive exposure to direct and/or artificial sunlight while taking this medicine

Michael Wolf
04/29/71

Glyburide 5mg

Take for Diabetes

Take:
2 pills in the morning
2 pills in the evening

Morning 7-9 AM	Noon 11-1 PM	Evening 4-6 PM	Bedtime 9-11 PM
2		2	

Rx# 1234567 9/8/2009

You have 11 refills
180 pills

Discard after 9/8/2010

Provider: RUTH PARKER.MD
Emory Medical Center
(414) 123-4587

Pharmacy: NOVA Scripts Central
11445 Sunset Blvd.
Reston. VA
(713) 123-4567

NDC # 1234567

Take

Take

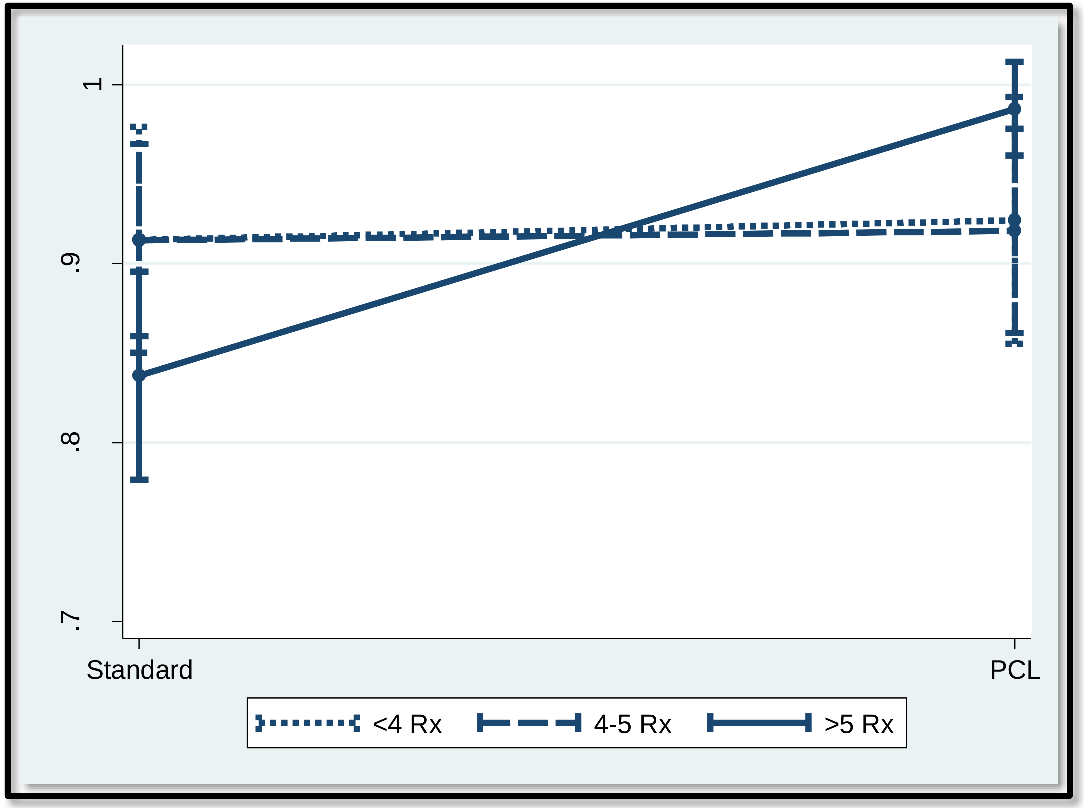
Take
1 pill at noon
1 pill in the evening

Take
1 pill in the morning
1 pill at noon
1 pill in the evening
1 pill at bedtime

6-8 am
Noon: 11-1 pm
Evening: 4-6 pm
Bedtime: 9-11 pm

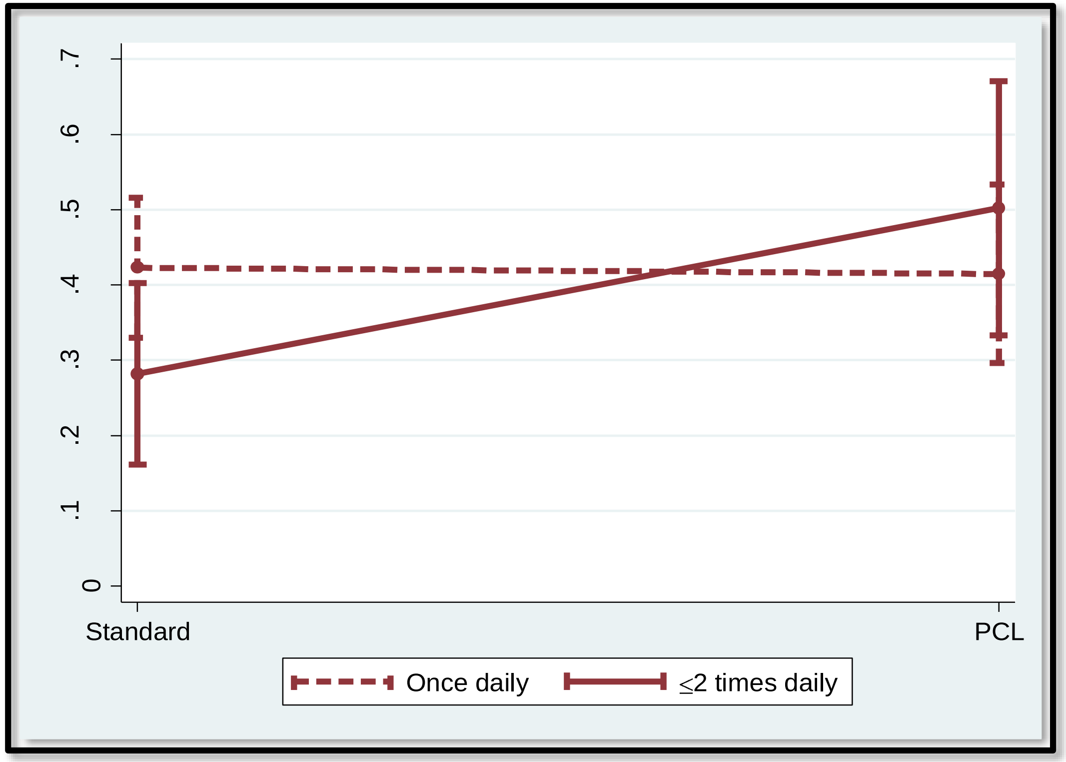
Davis et al J Gen Intern Med, 2010; Wolf et al Arch Intern Med 2011; Med Care 2011; Bailey J Gen Intern Med 2012

Disproportionate Benefits



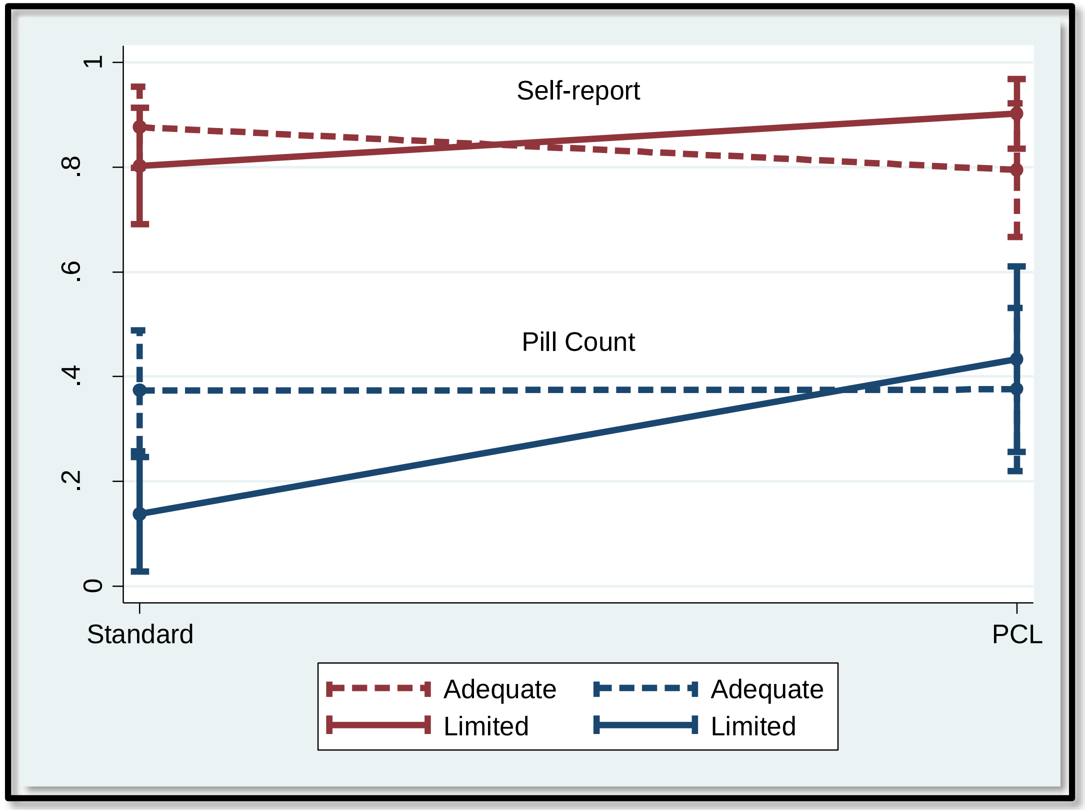
Fewer medication errors with more complex Rx regimens

Disproportionate Benefits



Greater adherence to multi-daily dosing Rx regimens

Disproportionate Benefits



Greater adherence among lower literate adults

Eur J Clin Pharmacol (2012) 68:777–782
DOI 10.1007/s00228-011-1169-2

PHARMACOEPIDEMIOLOGY AND PRESCRIPTION

What's in a label? An exploratory study of patient-centered drug instructions

Laura J. Sahm · M. S. Wolf · L. M. Curtis · R. Behan ·
M. Brennan · H

Received: 25 May

Abstract

ORIGINAL INVESTIGATION

Improving Prescription Drug Warnings to Promote Patient Comprehension

Michael S. Wolf, PhD, MPH; Terry C. Davis, PhD; Patrick F. Bass, MD, MPH;
Laura M. Curtis, MS; Lee A. Lindquist, MD, MPH; Jennifer A. Webb, MA;
Mary V. Bocchini, BS; Stacy Cooper Bailey, MPH; Ruth M. Parker, MD

Background: Prior studies have documented a high prevalence of patients who misunderstand prescription drug warning labels, placing them at risk for medication error. We evaluated whether the use of "enhanced print" drug warnings could improve patient comprehension beyond a current standard.

Methods: An evaluation of enhanced print warning labels was conducted at 2 academic and 2 community health primary care clinics in Chicago, Illinois, and Shreveport, Louisiana. In total, 500 adult patients were consecutively recruited and assigned to receive (1) current standard drug warning labels on prescription containers (standard), (2) drug warnings with text rewritten in plain language (simplified text), or (3) plain language and icons developed with patient feedback (simplified text + icon). The primary outcome was correct interpretation of 9 drug warning labels as determined by a blinded panel review of patients' verbatim responses.

Results: Overall rates of correct interpretation of drug warnings varied among standard, simplified text, and simplified text + icon labels (80.3%, 90.6%, and 92.1%, respectively; $P < .001$). Warnings with simplified text and simplified text + icons were more likely to be correctly interpreted compared with standard labels (simplified text –adjusted odds ratio [AOR] = 2.64; 95% confidence interval [CI], 2.00-3.49; simplified text + icons – AOR = 3.26; 95% CI, 2.46-4.32). Patients' ability to correctly interpret labels was not significantly different with the inclusion of icons (simplified text + icons – AOR = 1.23; 95% CI, 0.90-1.67; $P = .20$). Low literacy was also an independent predictor of misinterpretation (AOR, 0.65; 95% CI, 0.44-0.94). Patients with marginal and low literacy were better able to correctly interpret warning labels with simplified text + icons compared with labels with simplified text only (marginal literacy – AOR = 2.59; 95% CI, 1.24-5.44; $P = .01$; low literacy – AOR = 3.22; 95% CI, 1.39-7.50; $P = .006$).

Conclusions: Simple, explicit language on warning labels can increase patient understanding; the addition of appropriate icons is particularly useful for adults with lower literacy skills. Evidence-based standards are needed to promote patient-centered prescription labeling practices.

Arch Intern Med. 2010;170(1):50-56

Author Affiliations: Health Literacy and Learning Program, Division of General Internal Medicine, Feinberg School of Medicine, Chicago (Drs Wolf and Lindquist and Mss Curtis, Webb, and Bailey), and Department of Learning Sciences, School of Education and Social Policy (Dr Wolf), Northwestern University, Evanston, Illinois; Department of Medicine–Pediatrics, Louisiana State University Health Sciences Center at Shreveport (Drs Davis and Bass and Ms Bocchini); and Department of General Medicine, Emory University School of Medicine, Atlanta, Georgia (Dr Parker).

A CURRENT AND WELL-PUBLICIZED body of research has focused on the ability of patients to read, understand, and demonstrate instructions on prescription medication container labels.[1-4] In particular, recent studies[3,4] have documented a high prevalence of patients who misinterpret seemingly simple auxiliary warnings and instructions provided on the labels of medication containers. More than half of adults (54%) misunderstood 1 or more common prescription warnings and precautions. Older patients and those with limited literacy skills had the greatest difficulty interpreting the text messages and icons used on the labels. Two Institute of Medicine (IOM) reports, *Preventing Medication Error* (2006)[5] and *Standardizing Medication Labels* (2008),[6] have concluded that drug labeling itself is not patient centered and is a root cause of a large proportion of medication errors.

The US Food and Drug Administration (FDA), along with numerous medical, pharmacy, and public health organizations, is directing greater attention to the quality of prescription drug labeling.[6-10] More than a decade ago, the Keystone Dialogue was initiated by the Department of Health and Human Services and the IOM and FDA to develop an action plan for improving medication labeling.[11] One of the recommendations was to involve consumers in the development of prescription drug information, including drug warning labels, to gain assurances that content would be properly understood by patients across

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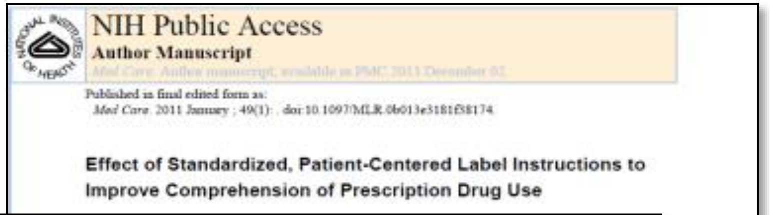

Published in final edited form as:
Med Care. 2011 January ; 49(1): . doi:10.1097/MLR.0b013e3181f38174.

Effect of Standardized, Patient-Centered Label Instructions to Improve Comprehension of Prescription Drug Use

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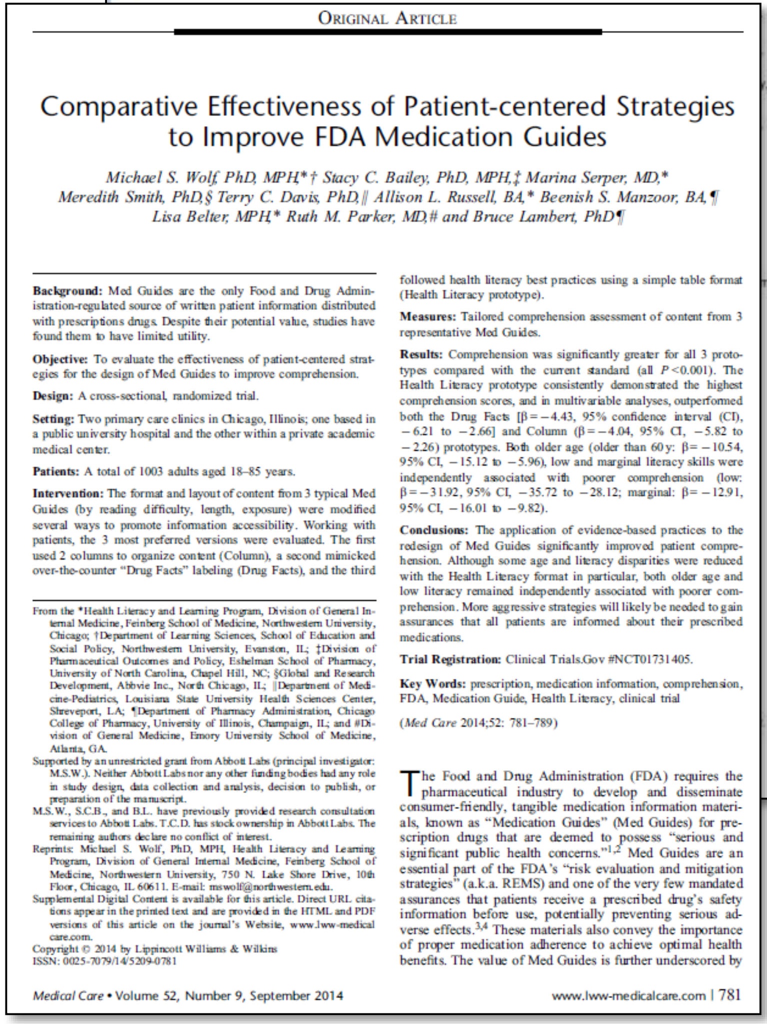

ORIGINAL ARTICLE

Comparative Effectiveness of Patient-centered Strategies to Improve FDA Medication Guides

Michael S. Wolf, PhD, MPH,[†] Stacy C. Bailey, PhD, MPH,[‡] Marina Serper, MD,[*]*
Meredith Smith, PhD,[§] Terry C. Davis, PhD,[||] Allison L. Russell, BA,[*] Beenish S. Manzoor, BA,[¶]
Lisa Belter, MPH,[*] Ruth M. Parker, MD,[#] and Bruce Lambert, PhD[¶]

Background: Med Guides are the only Food and Drug Administration-regulated source of written patient information distributed with prescriptions drugs. Despite their potential value, studies have found them to have limited utility.

Objective: To evaluate the effectiveness of patient-centered strategies for the design of Med Guides to improve comprehension.

Design: A cross-sectional, randomized trial.

Setting: Two primary care clinics in Chicago, Illinois; one based in a public university hospital and the other within a private academic medical center.

Patients: A total of 1003 adults aged 18–85 years.

Intervention: The format and layout of content from 3 typical Med Guides (by reading difficulty, length, exposure) were modified several ways to promote information accessibility. Working with patients, the 3 most preferred versions were evaluated. The first used 2 columns to organize content (Column), a second mimicked over-the-counter "Drug Facts" labeling (Drug Facts), and the third followed health literacy best practices using a simple table format (Health Literacy prototype).

Measures: Tailored comprehension assessment of content from 3 representative Med Guides.

Results: Comprehension was significantly greater for all 3 prototypes compared with the current standard (all $P < 0.001$). The Health Literacy prototype consistently demonstrated the highest comprehension scores, and in multivariable analyses, outperformed both the Drug Facts [$\beta = -4.43$, 95% confidence interval (CI), -6.21 to -2.66] and Column ($\beta = -4.04$, 95% CI, -5.82 to -2.26) prototypes. Both older age (older than 60 y: $\beta = -10.54$, 95% CI, -15.12 to -5.96), low and marginal literacy skills were independently associated with poorer comprehension (low: $\beta = -31.92$, 95% CI, -35.72 to -28.12; marginal: $\beta = -12.91$, 95% CI, -16.01 to -9.82).

Conclusions: The application of evidence-based practices to the redesign of Med Guides significantly improved patient comprehension. Although some age and literacy disparities were reduced with the Health Literacy format in particular, both older age and low literacy remained independently associated with poorer comprehension. More aggressive strategies will likely be needed to gain assurances that all patients are informed about their prescribed medications.

Trial Registration: Clinical Trials.Gov #NCT01731405.

Key Words: prescription, medication information, comprehension, FDA, Medication Guide, Health Literacy, clinical trial

(*Med Care* 2014;52: 781–789)

The Food and Drug Administration (FDA) requires the pharmaceutical industry to develop and disseminate consumer-friendly, tangible medication information materials, known as "Medication Guides" (Med Guides) for prescription drugs that are deemed to possess "serious and significant public health concerns."[1,2] Med Guides are an essential part of the FDA's "risk evaluation and mitigation strategies" (a.k.a. REMS) and one of the very few mandated assurances that patients receive a prescribed drug's safety information before use, potentially preventing serious adverse effects.[3,4] These materials also convey the importance of proper medication adherence to achieve optimal health benefits. The value of Med Guides is further underscored by

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M.S.W., S.C.B., and B.L. have previously provided research consultation services to Abbott Labs. T.C.D. has stock ownership in Abbott Labs. The remaining authors declare no conflict of interest.

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Lesson 2:

"You are the product. You feeling something."

Making it Significant

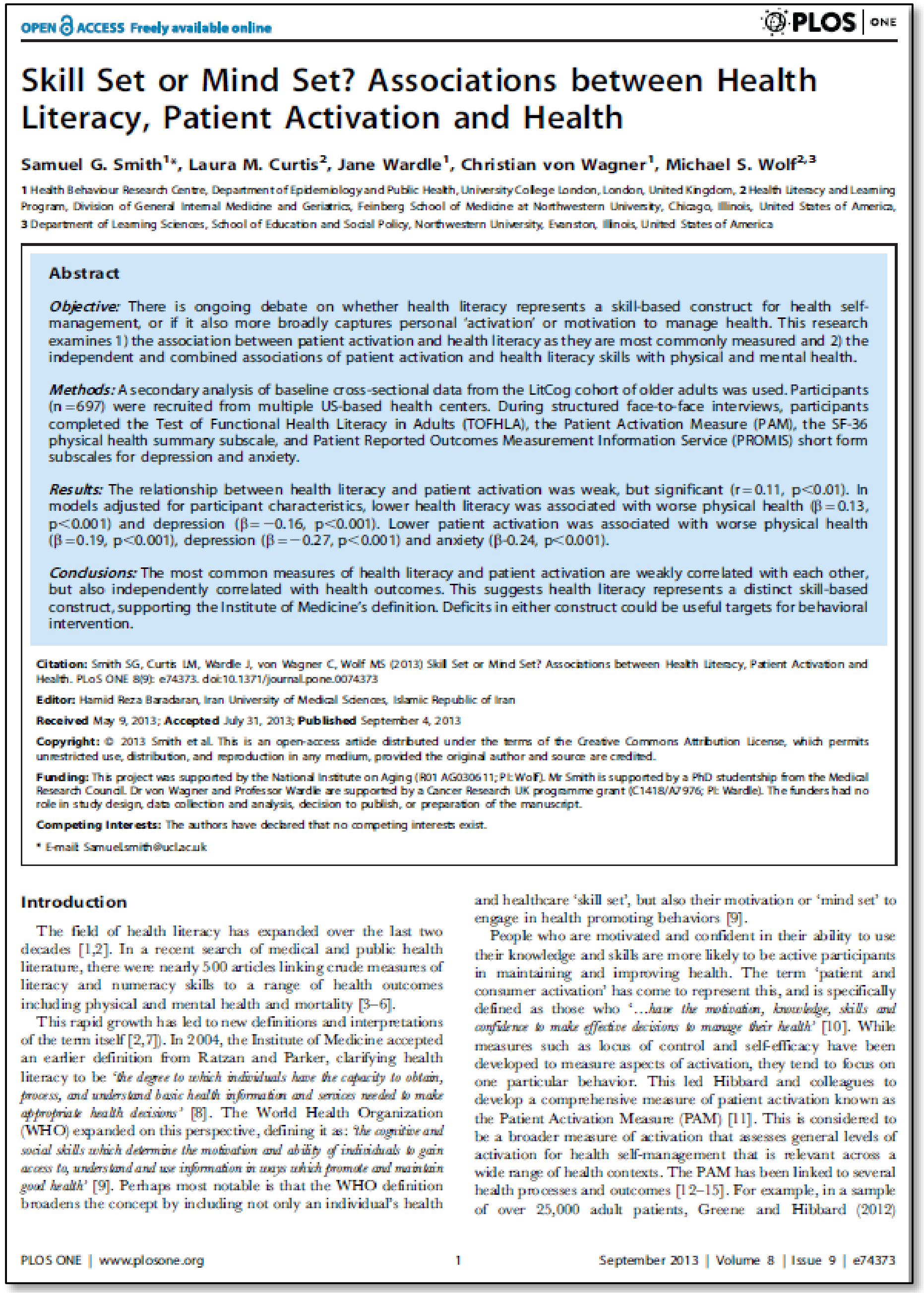
☐ improve self-efficacy, activation

☐ demonstrate behavior change

☐ achieve optimal health outcomes

Skill Set or Mind Set?

- Improving health literacy alone is insufficient for meaningful behavior change
- Addressing motivational, emotional aspects equally important



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PLOS | ONE

Skill Set or Mind Set? Associations between Health Literacy, Patient Activation and Health

Samuel G. Smith[1]*, Laura M. Curtis[2], Jane Wardle[1], Christian von Wagner[1], Michael S. Wolf[2,3]

1 Health Behaviour Research Centre, Department of Epidemiology and Public Health, University College London, London, United Kingdom, 2 Health Literacy and Learning Program, Division of General Internal Medicine and Geriatrics, Feinberg School of Medicine at Northwestern University, Chicago, Illinois, United States of America, 3 Department of Learning Sciences, School of Education and Social Policy, Northwestern University, Evanston, Illinois, United States of America

Abstract

Objective: There is ongoing debate on whether health literacy represents a skill-based construct for health self-management, or if it also more broadly captures personal 'activation' or motivation to manage health. This research examines 1) the association between patient activation and health literacy as they are most commonly measured and 2) the independent and combined associations of patient activation and health literacy skills with physical and mental health.

Methods: A secondary analysis of baseline cross-sectional data from the LitCog cohort of older adults was used. Participants ($n = 697$) were recruited from multiple US-based health centers. During structured face-to-face interviews, participants completed the Test of Functional Health Literacy in Adults (TOFHLA), the Patient Activation Measure (PAM), the SF-36 physical health summary subscale, and Patient Reported Outcomes Measurement Information Service (PROMIS) short form subscales for depression and anxiety.

Results: The relationship between health literacy and patient activation was weak, but significant ($r = 0.11$, $p < 0.01$). In models adjusted for participant characteristics, lower health literacy was associated with worse physical health ($\beta = 0.13$, $p < 0.001$) and depression ($\beta = -0.16$, $p < 0.001$). Lower patient activation was associated with worse physical health ($\beta = 0.19$, $p < 0.001$), depression ($\beta = -0.27$, $p < 0.001$) and anxiety (β-0.24, $p < 0.001$).

Conclusions: The most common measures of health literacy and patient activation are weakly correlated with each other, but also independently correlated with health outcomes. This suggests health literacy represents a distinct skill-based construct, supporting the Institute of Medicine's definition. Deficits in either construct could be useful targets for behavioral intervention.

Citation: Smith SG, Curtis LM, Wardle J, von Wagner C, Wolf MS (2013) Skill Set or Mind Set? Associations between Health Literacy, Patient Activation and Health. PLoS ONE 8(9): e74373. doi:10.1371/journal.pone.0074373

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Competing Interests: The authors have declared that no competing interests exist.

* E-mail: Samuel.smith@ucl.ac.uk

Introduction

The field of health literacy has expanded over the last two decades [1,2]. In a recent search of medical and public health literature, there were nearly 500 articles linking crude measures of literacy and numeracy skills to a range of health outcomes including physical and mental health and mortality [3–6].

This rapid growth has led to new definitions and interpretations of the term itself [2,7]). In 2004, the Institute of Medicine accepted an earlier definition from Ratzan and Parker, clarifying health literacy to be *'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions'* [8]. The World Health Organization (WHO) expanded on this perspective, defining it as: *'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health'* [9]. Perhaps most notable is that the WHO definition broadens the concept by including not only an individual's health and healthcare 'skill set', but also their motivation or 'mind set' to engage in health promoting behaviors [9].

People who are motivated and confident in their ability to use their knowledge and skills are more likely to be active participants in maintaining and improving health. The term 'patient and consumer activation' has come to represent this, and is specifically defined as those who '…*have the motivation, knowledge, skills and confidence to make effective decisions to manage their health'* [10]. While measures such as locus of control and self-efficacy have been developed to measure aspects of activation, they tend to focus on one particular behavior. This led Hibbard and colleagues to develop a comprehensive measure of patient activation known as the Patient Activation Measure (PAM) [11]. This is considered to be a broader measure of activation that assesses general levels of activation for health self-management that is relevant across a wide range of health contexts. The PAM has been linked to several health processes and outcomes [12–15]. For example, in a sample of over 25,000 adult patients, Greene and Hibbard (2012)

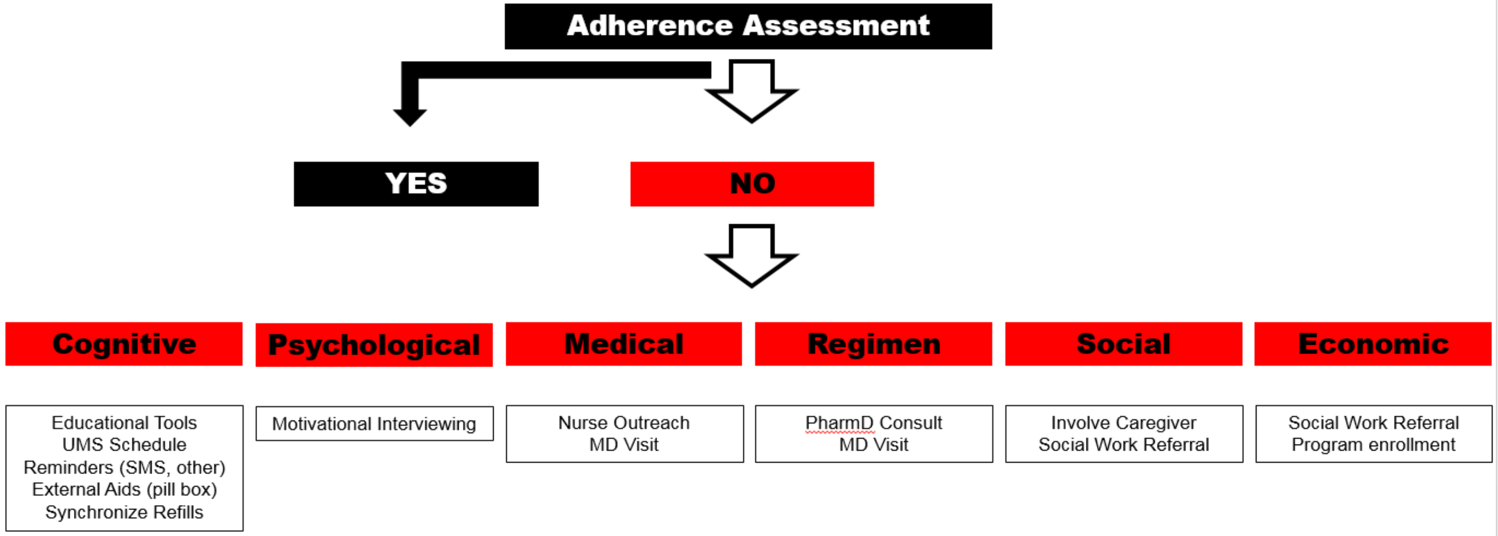
Lesson 3:

"When a man walks into a room, he brings his whole life with him. He has a million reasons for being anywhere. Just ask him."

Better, Smarter Patient Engagement

- Map patient concerns, problems in order to apply appropriate solutions

- This requires more data, and more time



Adherence Assessment

YES

NO

Cognitive
Educational Tools
UMS Schedule
Reminders (SMS, other)
External Aids (pill box)
Synchronize Refills

Psychological
Motivational Interviewing

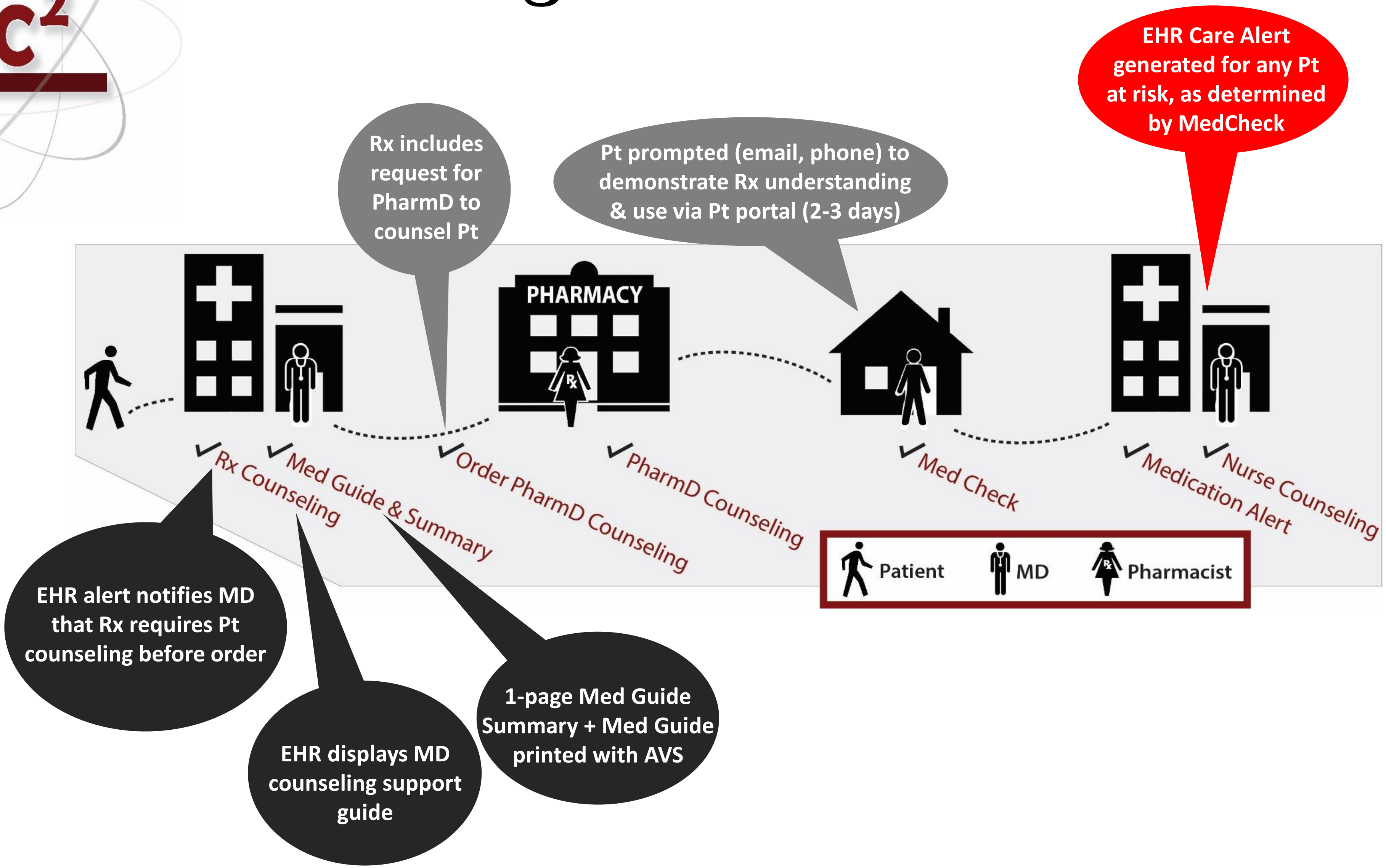
Medical
Nurse Outreach
MD Visit

Regimen
PharmD Consult
MD Visit

Social
Involve Caregiver
Social Work Referral

Economic
Social Work Referral
Program enrollment

Extending Encounters



Lesson 4:

“Is that what you want, or is that what people expect of you?”

Inviting Patients to the Conversation

McCaffery et al. BMC Medical Informatics and Decision Making 2013, **13**(Suppl 2):S10
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BMC
Medical Informatics & Decision Making

REVIEW **Open Access**

Addressing health literacy in patient decision aids

Kirsten J McCaffery[1*], Margaret Holmes-Rovner[2], Sian K Smith[3], David Rovner[2], Don Nutbeam[4], Marla L Clayman[5], Karen Kelly-Blake[2], Michael S Wolf[5], Stacey L Sheridan[6]

From The International Patient Decision Aid Standards (IPDAS) Collaboration s Quality Dimensions: Theoretical Rationales, Current Evidence, and Emerging Issues
Rockville, MD, USA. 13 September 2012

Abstract

Background: Effective use of a patient decision aid (PtDA) can be affected by the user's health literacy and the PtDA's characteristics. Systematic reviews of the relevant literature can guide PtDA developers to attend to the health literacy needs of patients. The reviews reported here aimed to assess:
1. a) the effects of health literacy / numeracy on selected decision-making outcomes, and b) the effects of interventions designed to mitigate the influence of lower health literacy on decision-making outcomes, and
2. the extent to which existing PtDAs a) account for health literacy, and b) are tested in lower health literacy populations.

Methods: We reviewed literature for evidence relevant to these two aims. When high-quality systematic reviews existed, we summarized their evidence. When reviews were unavailable, we conducted our own systematic reviews.

Results: Aim 1: In an existing systematic review of PtDA trials, lower health literacy was associated with lower patient health knowledge (14 of 16 eligible studies). Fourteen studies reported practical design strategies to improve knowledge for lower health literacy patients. In our own systematic review, no studies reported on values clarity *per se*, but in 2 lower health literacy was related to higher decisional uncertainty and regret. Lower health literacy was associated with less desire for involvement in 3 studies, less question-asking in 2, and less patient-centered communication in 4 studies; its effects on other measures of patient involvement were mixed. Only one study assessed the effects of a health literacy intervention on outcomes; it showed that using video to improve the salience of health states reduced decisional uncertainty. Aim 2: In our review of 97 trials, only 3 PtDAs overtly addressed the needs of lower health literacy users. In 90% of trials, user health literacy and readability of the PtDA were not reported. However, increases in knowledge and informed choice were reported in those studies in which health literacy needs were addressed.

Conclusion: Lower health literacy affects key decision-making outcomes, but few existing PtDAs have addressed the needs of lower health literacy users. The specific effects of PtDAs designed to mitigate the influence of low health literacy are unknown. More attention to the needs of patients with lower health literacy is indicated, to ensure that PtDAs are appropriate for lower as well as higher health literacy patients.

Background

A person's health literacy status affects their ability to utilise health information and services, and their health outcomes [1]. It is therefore an important potential consideration in patient decision aid (PtDA) development and shared decision making [2,3]. There has been no systematic examination of the effects of health literacy on outcomes relevant to PtDA development or of interventions that might mitigate potential adverse effects of low health literacy in the decision-making context.

Health literacy can be conceptualized in different ways. A simple and common definition is *"the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"* [4,5]. However, broader definitions are gaining popularity and encompass a wider range of cognitive and social

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RESEARCH

A decision aid to support informed choices about bowel cancer screening among adults with low education: randomised controlled trial

ian K Smith, postdoctoral research fellow,[1] Lyndal Trevena, associate professor,[1] Judy M Simpson, professor f biostatistics,[2] Alexandra Barratt, associate professor in epidemiology,[1] Don Nutbeam, professor of public ealth,[3] Kirsten J McCaffery, senior research fellow[1]

BSTRACT

bjective To determine whether a decision aid designed r adults with low education and literacy can support nformed choice and involvement in decisions about creening for bowel cancer.

esign Randomised controlled trial.

etting Areas in New South Wales, Australia identified as ocioeconomically disadvantaged (low education ttainment, high unemployment, and unskilled ccupations).

articipants 572 adults aged between 55 and 64 with low ducational attainment, eligible for bowel cancer creening.

ntervention Patient decision aid comprising a paper ased interactive booklet (with and without a question rompt list) and a DVD, presenting quantitative risk nformation on the possible outcomes of screening using aecal occult blood testing compared with no testing. The ontrol group received standard information developed r the Australian national bowel screening programme. ll materials and a faecal occult blood test kit were posted irectly to people's homes.

ain outcome measures Informed choice (adequate nowledge and consistency between attitudes and creening behaviour) and preferences for involvement in creening decisions.

esults Participants who received the decision aid howed higher levels of knowledge than the controls; the ean score (maximum score 12) for the decision aid roup was 6.50 (95% confidence interval 6.15 to 6.84) nd for the control group was 4.10 (3.85 to 4.36; <0.001). Attitudes towards screening were less positive the decision aid group, with 51% of the participants xpressing favourable attitudes compared with 65% of articipants in the control group (14% difference, 95% onfidence interval 5% to 23%; P=0.002). The articipation rate for screening was reduced in the ecision aid group: completion of faecal occult blood esting was 59% *v* 75% in the control group (16% ifference, 8% to 24%; P=0.001). The decision aid creased the proportion of participants who made an nformed choice, from 12% in the control group to 34% in the decision aid group (22% difference, 15% to 29%; P<0.001). More participants in the decision aid group had no decisional conflict about the screening decision compared with the controls (51% *v* 38%; P=0.02). The groups did not differ for general anxiety or worry about bowel cancer.

Conclusions Tailored decision support information can be effective in supporting informed choices and greater involvement in decisions about faecal occult blood testing among adults with low levels of education, without increasing anxiety or worry about developing bowel cancer. Using a decision aid to make an informed choice may, however, lead to lower uptake of screening.

Trial registration ClinicalTrials.gov NCT00765869 and Australian New Zealand Clinical Trials Registry 12608000011381.

INTRODUCTION

Engaging patients in decisions about their health care is promoted by leading health organisations,[1-3] with growing importance placed on providing patients with the best available evidence and encouraging them to express their preferences in the decision making process.[4,5] This has led to a demand for tools to facilitate patients' involvement in decision making about their health care. Patient decision aids are interventions designed to help people make informed decisions about their health by providing information on the options and possible outcomes relevant to their own health. Typically decision aids contain numerical and graphical risk information about the possible outcomes of each choice, and exercises to help people arrive at decisions that reflect their personal values and preferences.[6] Cochrane reviews suggest that, compared with usual care, decision aids improve knowledge about clinical options, create more realistic expectations about outcomes, and increase active involvement in the decision making process.[7]

However, despite a substantial increase in the availability of decision aids (over 270 are currently listed on the Cochrane decision aid registry at www.decisionaid.ca/AZlist.html), few attempts have been made to

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Lesson 5:

"Well, technology is a glittering lure. But there's the rare occasion when the public can be engaged on a level beyond flash, if they have a sentimental bond with the product."

Review

The availability, functionality, and quality of mobile applications supporting medication self-management

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ABSTRACT
Objective To systematically review mobile
currently available to patients to support out
medication self-management.
Methods Three online stores were searche
2013 using nine distinct search terms. Appli
selected if they supported general outpatient
self-management for adults; they were exclu
focused on only one medication or condition
only a medication list or reference, only orde
were written in a non-English language, or v
local pharmacy/hospital patients only. A mul
review process was utilized by two independ
reviewers to identify eligible applications. A
form was used to abstract data. User review
compiled from a subsample of applications
qualitatively coded to identify common critic
Results 14 893 applications were initially
After the multi-step review process, 424 app
were deemed eligible for inclusion by review
(κ=0.85). On average, applications were rat
(out of 5) from 107 reviews. Almost all prov
medication reminders (91.0%), half enabled
create a medication history or log (51.5%),
could email the log to a third party. Few hel
organize their regimen (6.2%), check for dru
interactions (2.8%), or identify pills (4.0%).
(N=1091) from the subsample of 26 applica
revealed common criticisms, including techni
malfunctions, poor compatibility with certain
medications, and absence of desired feature
Conclusions Hundreds of applications exis
marketplace to support medication self-mana
However, their quality, content, and function
highly variable. Research is needed to deterr
capabilities, evaluate utility, and determine c
benefit.

INTRODUCTION

More than 90% of US adults own a cell
the majority of these adults (56%) rep
smartphone.[1] The rise and widespread
this technology has created new avenu
municating and searching for health i
delivering health messages and provi
needed support for health behaviors.[2]
more than half of smartphone ow
report using their mobile phones to
medical information and nearly one in
phone users report downloading a mob
tion to help manage their health.[3]

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Smith SG, et al. J Am Med Inform Assoc 2015;22:888–895. doi:10.1093/jamia/ocv025, Research and Applications

RESEARCH AND APPLICATIONS

Disparities in registration and use of an online patient portal among older adults: findings from the LitCog cohort

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Michael S Wolf[1,3], Mita Sanghavi Goel[1]

ABSTRACT

Objective To document disparities in registration and use of an online patient portal among older adults.
Materials and methods Data from 534 older adults were linked with information from the Northwestern Medicine Electronic Data Warehouse on patient portal registration and use of functions (secure messaging, prescription reauthorizations, checking test results, and monitoring vital statistics). Age, gender, race, education, self-reported chronic conditions, and the Newest Vital Sign health literacy measure were available from cohort data.
Results Most patients (93.4%) had a patient portal access code generated for them, and among these 57.5% registered their accounts. In multivariable analyses, White patients ($P < .001$) and college graduates were more likely to have registered their patient portal ($P = .015$). Patients with marginal ($P = .034$) or adequate ($P < .001$) health literacy were also more likely to have registered their patient portal. Among those registering their accounts, most had messaged their physician (90%), checked a test result (96%), and ordered a reauthorization (55%), but few monitored their vital statistics (11%). Adequate health literacy patients were more likely to have used the messaging function ($P = .003$) and White patients were more likely to have accessed test results ($P = .004$). Higher education was consistently associated with prescription reauthorization requests (all $P < .05$).
Discussion Among older American adults, there are stark health literacy, educational, and racial disparities in the registration, and subsequent use of an online patient portal. These population sub-group differences may exacerbate existing health disparities.
Conclusions If patient portals are implemented, intervention strategies are needed to monitor and reduce disparities in their use.

Keywords: patient portal, disparities, health literacy, race, education

BACKGROUND AND SIGNIFICANCE

The adoption of electronic health records (EHRs) by hospitals and providers in the United States is rising.[1] This trend is likely to continue following the Health Information Technology for Economic and Clinical Health act, which authorized incentive payments to increase provider adoption and meaningful use of EHRs.[2] Patient portals are secure websites for patients, typically maintained by provider practices, that offer access to a variety of functions linked to a physician's EHRs.[3] Most patient portals offer similar basic functions, including the ability to view protected health information (e.g., lab results, medication lists, immunizations), refill prescription medications, schedule appointments, and send secure messages to providers.[4] Evidence from randomized trials suggests patient portals can improve health outcomes and patient satisfaction,[5–8] but data have been inconsistent.[4]

Federal incentives for health systems and providers may not translate to increased, equitable adoption of patient portals by patients. Reports suggest ∼30–70% of eligible patients accept the offer of a patient portal.[9–12] The differential acceptance of this technology between population sub-groups may exacerbate disparities in health outcomes. Initial reports suggest low levels of use among socio-demographic sub-groups such as racial and ethnic minorities,[11,12] those with less education,[4,12] and older patients.[11,13,14] It is important to document these disparities as a first step toward preventing downstream effects on health and health care.

Older patients may be a particularly important group to study, as they are more likely to have chronic conditions, a factor which has been shown to increase uptake of patient portals.[4] However, the usability of patient portals is a significant barrier,[9,15–18] and this may be a particular problem for older adults less familiar with information technology. National data suggests older adults are less likely to make use of online health information, including treatment and quality comparison tools, and advice about chronic conditions and disease prevention.[19] Older adults are likely to be the most frequent users of healthcare, but objective portal usage data among this population group are lacking.

Health literacy is an additional risk factor that may explain lower uptake and use of patient portals. The Institute of Medicine defines the construct as the "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[20] A study of diabetic patients reported no relationship between self-reported health literacy and accessing a patient portal,[21] although a larger and more comprehensive report linked low self-reported health literacy with lower levels of patient portal registration, logins, and use of patient portal functions.[22] However, people are typically poor judges of their own abilities,[23] and self-report literacy measures do not assess the same latent construct as objective health literacy assessments.[24] This is supported

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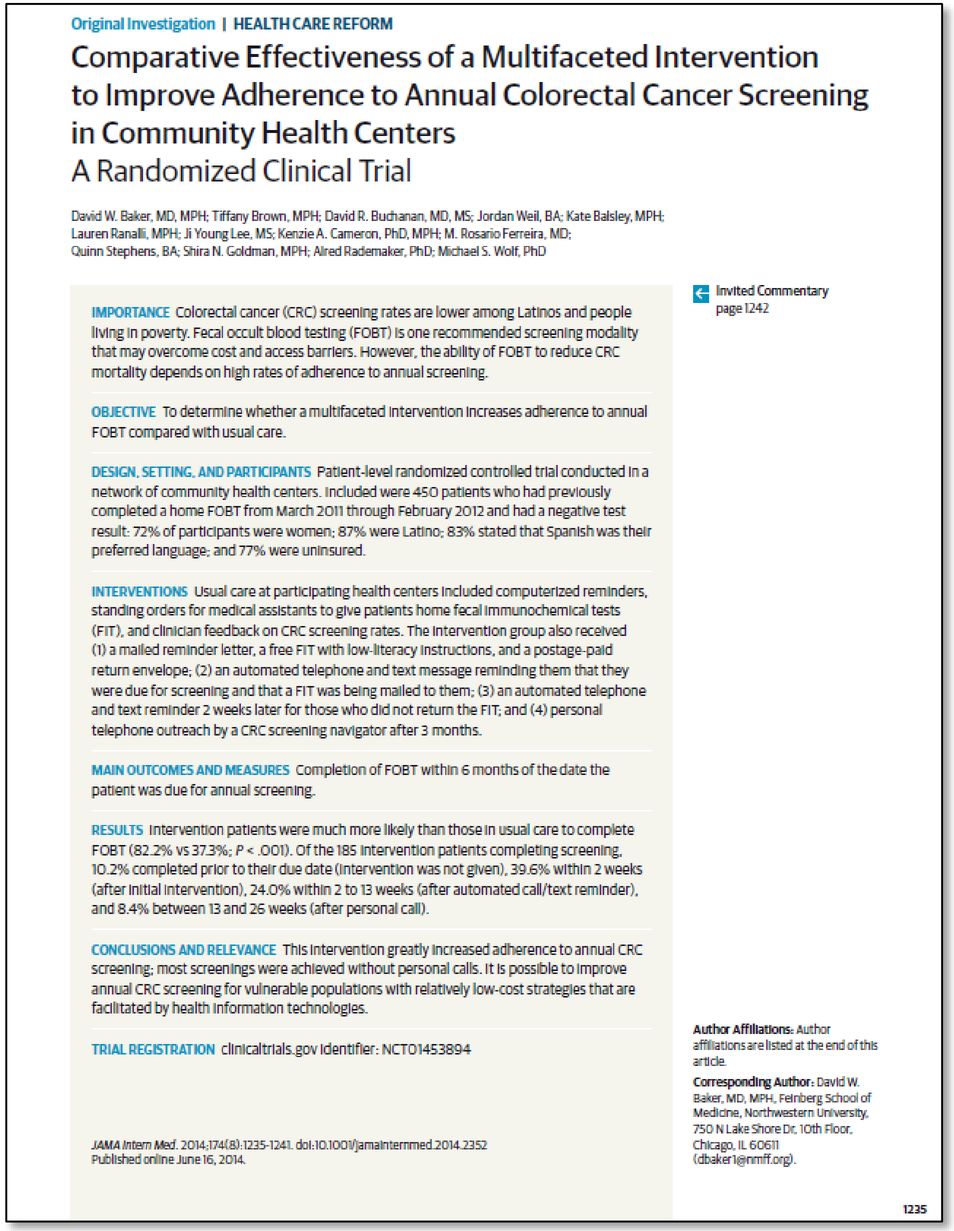

Original Investigation | HEALTH CARE REFORM

Comparative Effectiveness of a Multifaceted Intervention to Improve Adherence to Annual Colorectal Cancer Screening in Community Health Centers

A Randomized Clinical Trial

David W. Baker, MD, MPH; Tiffany Brown, MPH; David R. Buchanan, MD, MS; Jordan Weil, BA; Kate Balsley, MPH;
Lauren Ranalli, MPH; Ji Young Lee, MS; Kenzie A. Cameron, PhD, MPH; M. Rosario Ferreira, MD;
Quinn Stephens, BA; Shira N. Goldman, MPH; Alred Rademaker, PhD; Michael S. Wolf, PhD

Invited Commentary
page 1242

IMPORTANCE Colorectal cancer (CRC) screening rates are lower among Latinos and people living in poverty. Fecal occult blood testing (FOBT) is one recommended screening modality that may overcome cost and access barriers. However, the ability of FOBT to reduce CRC mortality depends on high rates of adherence to annual screening.

OBJECTIVE To determine whether a multifaceted intervention increases adherence to annual FOBT compared with usual care.

DESIGN, SETTING, AND PARTICIPANTS Patient-level randomized controlled trial conducted in a network of community health centers. Included were 450 patients who had previously completed a home FOBT from March 2011 through February 2012 and had a negative test result: 72% of participants were women; 87% were Latino; 83% stated that Spanish was their preferred language; and 77% were uninsured.

INTERVENTIONS Usual care at participating health centers included computerized reminders, standing orders for medical assistants to give patients home fecal immunochemical tests (FIT), and clinician feedback on CRC screening rates. The intervention group also received (1) a mailed reminder letter, a free FIT with low-literacy instructions, and a postage-paid return envelope; (2) an automated telephone and text message reminding them that they were due for screening and that a FIT was being mailed to them; (3) an automated telephone and text reminder 2 weeks later for those who did not return the FIT; and (4) personal telephone outreach by a CRC screening navigator after 3 months.

MAIN OUTCOMES AND MEASURES Completion of FOBT within 6 months of the date the patient was due for annual screening.

RESULTS Intervention patients were much more likely than those in usual care to complete FOBT (82.2% vs 37.3%; $P < .001$). Of the 185 intervention patients completing screening, 10.2% completed prior to their due date (intervention was not given), 39.6% within 2 weeks (after initial intervention), 24.0% within 2 to 13 weeks (after automated call/text reminder), and 8.4% between 13 and 26 weeks (after personal call).

CONCLUSIONS AND RELEVANCE This intervention greatly increased adherence to annual CRC screening; most screenings were achieved without personal calls. It is possible to improve annual CRC screening for vulnerable populations with relatively low-cost strategies that are facilitated by health information technologies.

TRIAL REGISTRATION clinicaltrials.gov Identifier: NCT01453894

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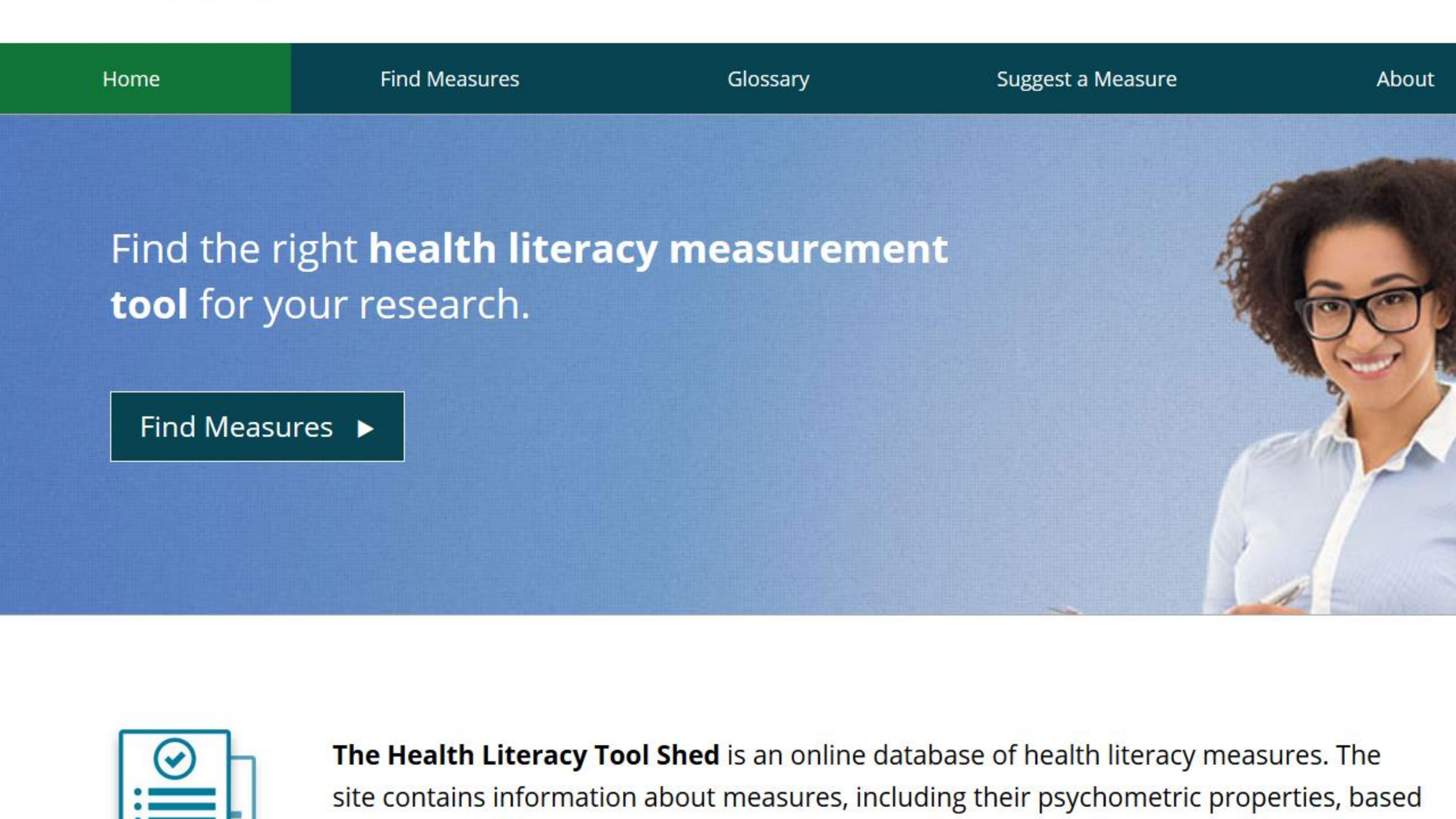
Lesson 2:

“I keep going to a lot of places and ending up somewhere I’ve already been.”

Let's Build Our Portfolio for 'Clients'

- Consolidate evidence
- Fill knowledge gaps
- Reduce variability
- Demonstrate value



Find the right **health literacy measurement tool** for your research.

The Health Literacy Tool Shed is an online database of health literacy measures. The site contains information about measures, including their psychometric properties, based

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