Patient Centered Health Literacy

GIVING PEOPLE *THE INFORMATION* THEY NEED, *WHEN* THEY NEED IT, IN A *WAY* THEY CAN USE

Ray Ownby, MD, PhD, MBA

Ray Ownby, MD, PhD, MBA

Professor and Chair

Department of Psychiatry and Behavioral Medicine

Nova Southeastern University

and

Chief Development Officer

Enalan Communications, Inc.

Fort Lauderdale, Florida

Ray Ownby, MD, PhD, MBA

Conflicts

- Dr. Ownby has a patent pending for a device to automatically deliver appropriate health information

- He is a major stockholder in Enalan Communications, Inc., which has a trademark application pending for "Precision Health Information."™
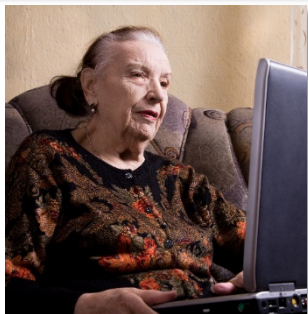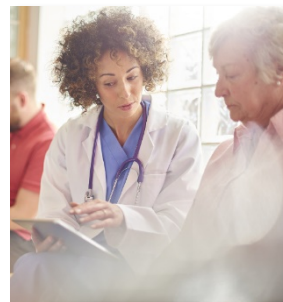
2010

Fostering Literacy for Good
Health Today
R01 HL096578

2015

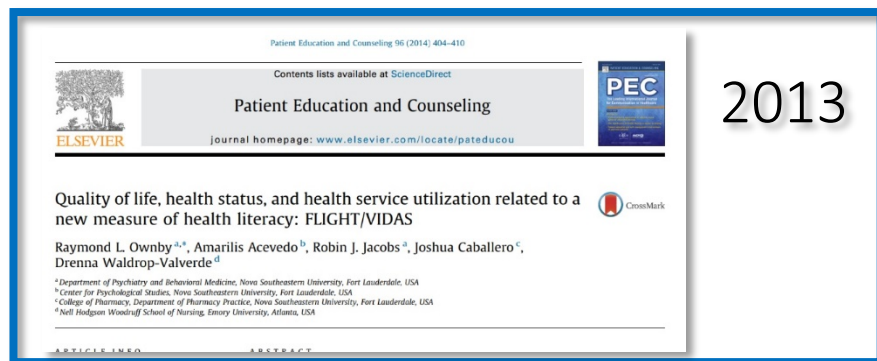Fostering Literacy for Good
Health Today (continuation)
R56 HL096578

2016

FV2: Interventions to Address
Disparities
R01 MD010368

2013

Patient Related Outcome Measures — Dovepress
open access to scientific and medical research
Open Access Full Text Article — ORIGINAL RESEARCH

Development and initial validation of a computer-administered health literacy assessment in Spanish and English: FLIGHT/VIDAS

This article was published in the following Dove Press journal:
Patient Related Outcome Measures
17 August 2013
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2013

Patient Education and Counseling 96 (2014) 404–410
Contents lists available at ScienceDirect
Patient Education and Counseling
ELSEVIER — journal homepage: www.elsevier.com/locate/pateducou
PEC

Quality of life, health status, and health service utilization related to a new measure of health literacy: FLIGHT/VIDAS

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[b] Center for Psychological Studies, Nova Southeastern University, Fort Lauderdale, USA
[c] College of Pharmacy, Department of Pharmacy Practice, Nova Southeastern University, Fort Lauderdale, USA
[d] Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, USA

2014

Patient Education and Counseling 95 (2014) 211–217
Contents lists available at ScienceDirect
Patient Education and Counseling
ELSEVIER — journal homepage: www.elsevier.com/locate/pateducou
PEC

Health Literacy
Abilities, skills and knowledge in measures of health literacy

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[d] College of Pharmacy, Department of Pharmacy Practice, Nova Southeastern University, Fort Lauderdale, USA

2015

Clinical Research and Trials

Research Article   ISSN: 2059-0377

Health literacy predicts participant understanding of orally-presented informed consent information

Raymond L Ownby[1]*, Amarilis Acevedo[2], Kenneth Goodman[3], Joshua Caballero[4] and Drenna Waldrop-Valverde[5]

[1]Department of Psychiatry and Behavioral Medicine, Nova Southeastern University, USA
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2017

JMIR RESEARCH PROTOCOLS   Ownby et al

Protocol

A Mobile App for Chronic Disease Self-Management: Protocol for a Randomized Controlled Trial

Raymond L Ownby[1], MD, PhD, MBA; Amarilis Acevedo[2], PhD; Drenna Waldrop-Valverde[3], PhD; Joshua Caballero[4], PharmD; Michael Simonson[5], PhD; Rosemary Davenport[1], MSN, ARNP-BC; Kofi Kondwani[6], PhD; Robin J Jacobs[7], PhD, MSW, MS, MPH

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2018

Patient Centered Health Literacy

GIVING PEOPLE **WHAT** THEY NEED,
WHEN THEY NEED IT,
IN A **WAY** THEY CAN USE

Company Name: Enalan Communications, Inc.
Email: rownby@enalan.com
Web: www.enalan.com

Ray Ownby, MD, PhD, MBA

Theme

Patient Centered Health Literacy Interventions: Problems and Answers

HOW DO WE GIVE PEOPLE THE *INFORMATION* THEY NEED, *WHEN* THEY NEED IT, IN A *WAY* THEY CAN USE?

Project

"FLIGHT/VIDAS"

FOSTERING **L**ITERACY FOR **G**OOD **H**EALTH **T**ODAY *AND*

VIVE **D**ESAROLLANDO **A**MPLIA **S**ALUD

Ongoing projects to create electronic health literacy measures and interventions.

Problems

- What is "health literacy?"
- How can health literacy be measured in a rigorous and efficient way?
- How does it have an impact on health?
- How can we improve it?
- Dissemination:
  - *How do we get the right information to the people who want it and need it?*

Answers

- A model of health literacy and health behavior
- A strategy for individualized assessment
- A way to create interventions that work and are cost effective
- A way to get the information to the people who want it and need it so they can use it

Problem

What is "health literacy?"

Institute of Medicine report (2004):

"The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."

Problem

What is "health literacy?"

Sørensen et al. review article:

"17 definitions and 12 conceptual models"

-- BMC Public Health 2012, **12**:80

Problem

What is "health literacy?"

How do you link concepts to measures?

Little work actually on mechanisms linking health literacy to health.

What is "health literacy?"

We need more than conceptual models.

We need one that tells us **what,** *specifically* we should measure, and **how,** *specifically,* it should be measured.

Answer

ASK Model

ASK Model

An operational model of health literacy that can be used for measurement and evaluation of health literacy interventions.

Model

Health literacy is:

Reading

Knowledge

Attitudes &

Self-Efficacy

Reading and knowledge are key in health literacy

Health literacy influences health attitudes and self-efficacy.

Baker, *J Gen Intern Med*. 2006 Aug; 21(8): 878–883.

Model

Individual Characteristics

Abilities

Knowledge &

Self Efficacy

Individual characteristics and abilities influence health literacy

Health literacy influences self-efficacy.

Paasche-Orlow & Wolf, Am J Health Behav, 2007

Model

Health literacy is:

Abilities

Skills

Knowledge

Contents lists available at ScienceDirect

Patient Education and Counseling

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PEC

Health Literacy

Abilities, skills and knowledge in measures of health literacy

CrossMark

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Answer

Abilities

Abilities

Basic cognitive abilities

Verbal ("Crystallized")

Visuospatial ("Fluid")

Answer

Skills

Skills are:

Reading

Math

Listening

Expressing

Reading
  Decoding
  Vocabulary
  Skilled reading
Math
  Arithmetic
  Probability
  Quantitative
reasoning

The Problem

Conceptual knowledge about health:

Facts

"It would be very helpful to have a comprehensive test of the general public's conceptual knowledge about health. . ." (p. 880)

Baker, *J Gen Intern Med*. 2006 Aug; 21(8): 878–883.

The Problem

Health literacy is:

Conceptual knowledge

Basic ideas about healthcare

FACT subscale

- Wide range of conceptual knowledge questions

Answer

Specific facts related to health and healthcare

Example:

Dra. Hernández is a nephrologist. She specializes in diseases of which part of the body?

Answer — ASK Model

Expertise that requires abilities, skills and knowledge (facts)

Problem

How is health literacy linked to health?

We need a model of how health literacy is linked to health.

Without such a model, we can't know how to create effective interventions.

We won't know what interventions work or how they work.
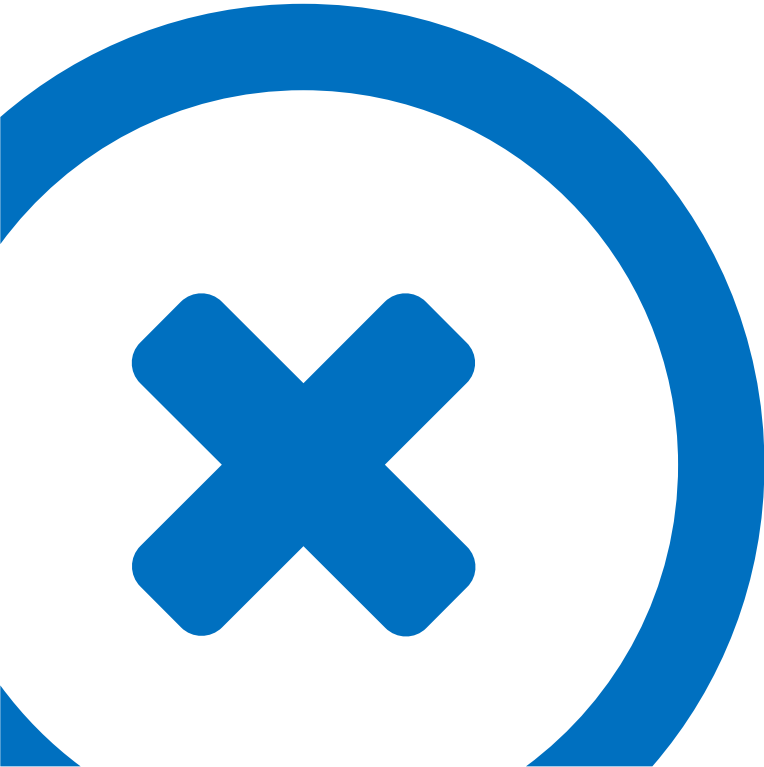
Answer

Theory of Planned Behavior

Health behavior

Attitudes

Norms

Perceived Behavioral Control

Attitudes, norms, and perceived behavioral control influence the intention to do things.

The intention to do things makes it more likely that someone will do something.

Azjen, 1991
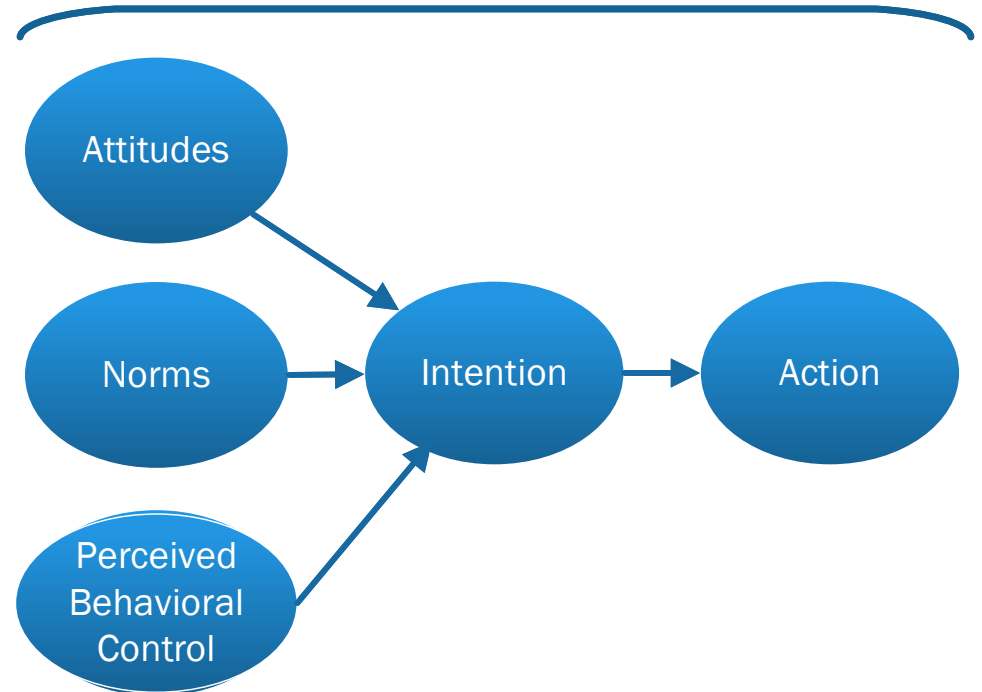
Answer
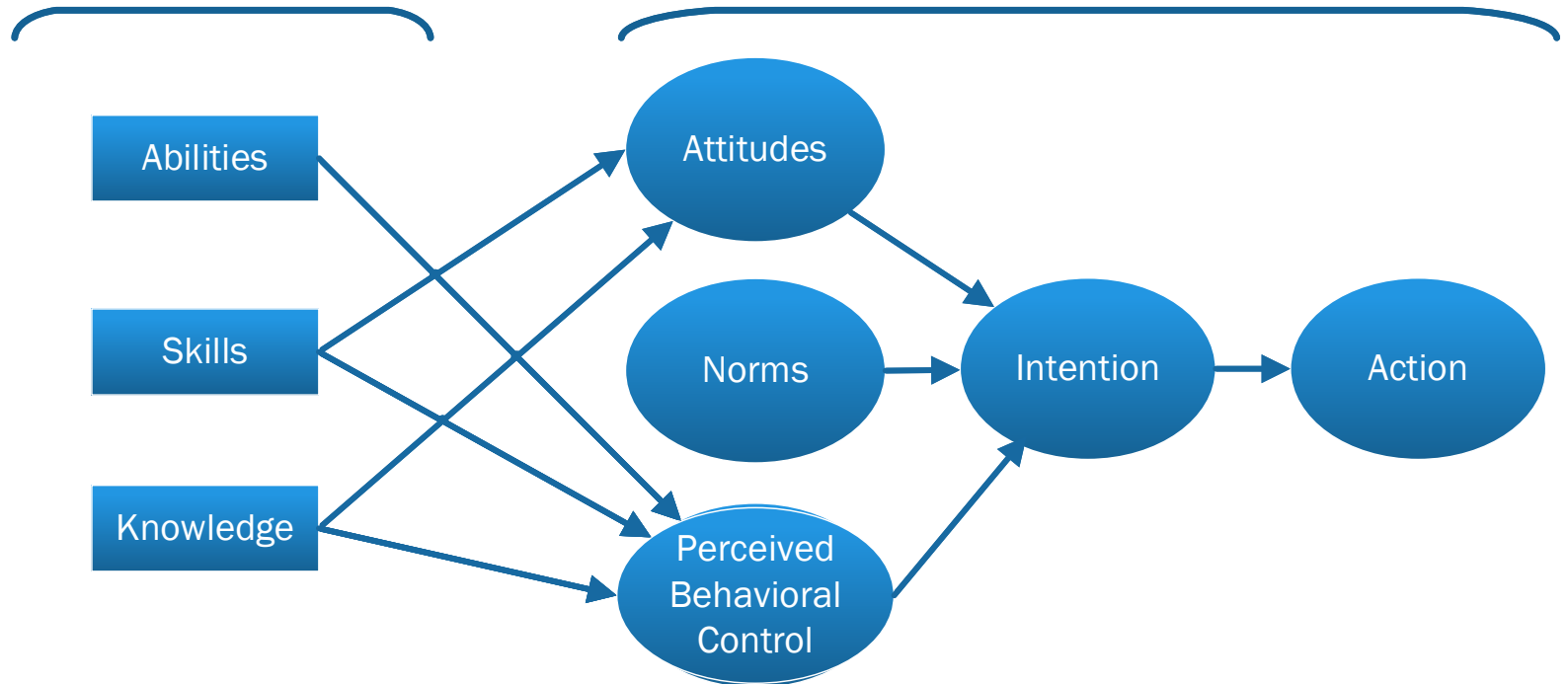
Theory of Planned Behavior
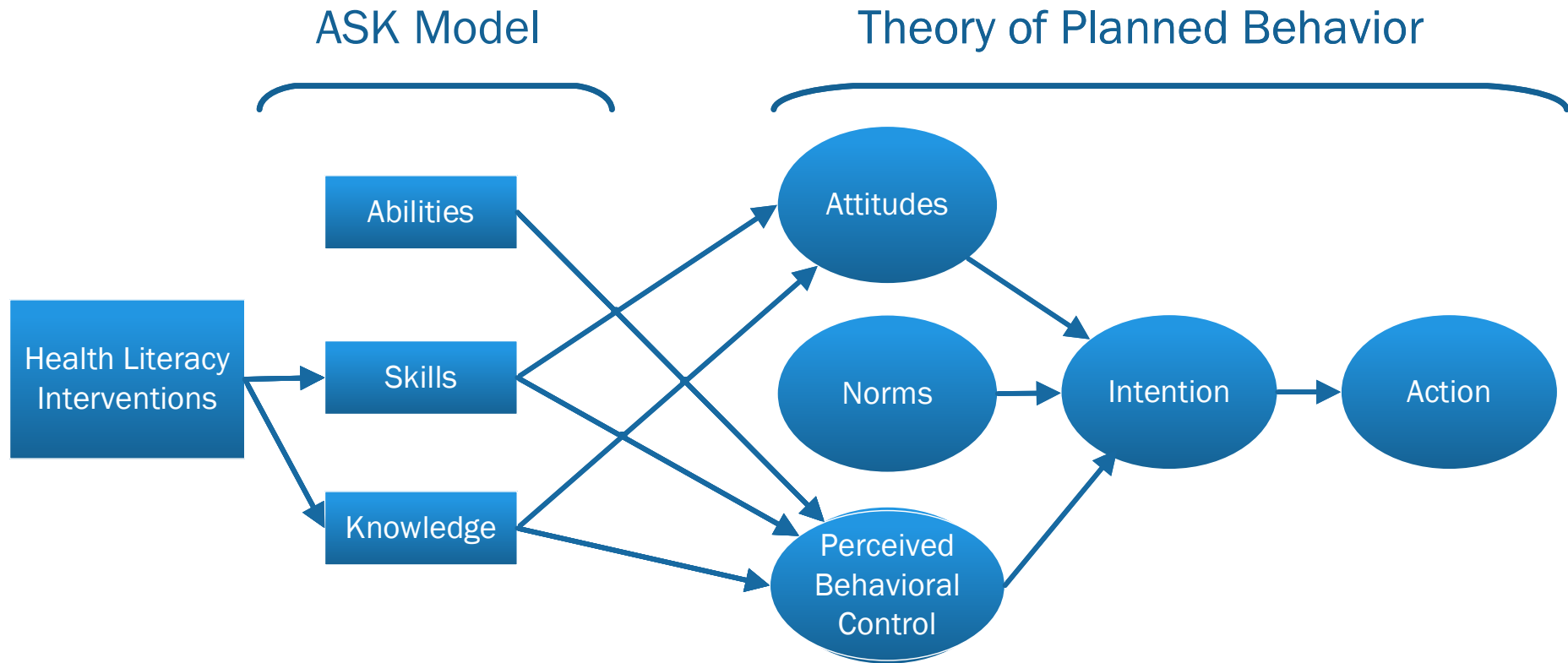
Problem

Little Good Research on Outcomes

However, we have little or no hard evidence to show which, if any, . . . interventions truly make a difference in changing the negative outcomes associated with limited health literacy.

Weiss, Health Communication, 2015, p. 1173

Addressing the Problem

Even if we had good research, we have to face another problem:

Scalability

Problem

How Can We Address the Problem?

The scope of the problem is enormous.

Scope

Who needs help?

59,000,000 Medicare Beneficiaries

CMS, July, 2018

21,000,000 Need Help

NAAL, 2003

The Problem

21,000,000 Need Help

Cost?

NAAL, 2003

$ 50 - $ 150 to $ 712 pp (NHS)

E.E. Bartlett / Patient Educ. Couns. 26 (1995) 87-91

Total Cost:

$3,150,000,000

Problem

A billion here, a billion there, and *pretty soon you're talking about real money.*

-- Everett Dirksen

Addressing the Problem

We need a way to address the problem of low health literacy on a large scale.

Problem

A first step is identifying people with limited health literacy.

Effective and efficient strategies for assessment can do this.

But what about the "deficit assessment model?"

Aren't we supposed to abandon it?

Problem

Can we assess individuals' health literacy?

Educators who talk about abandoning the "deficit assessment model" do not advocate abandoning all assessment.

Problem

The Balanced Assessment Model

Rather, they talk about linking assessment to understanding a person's strengths and building on them instead of using assessment to categorize people.

Classroom assessment for student learning, 2nd ed. (2012). Chappuis et al.

Problem

The Balanced Assessment Model

Balanced assessment allows us to determine what people want to learn and use an estimate of their health literacy to decide the best way to present the information to them.

Answer

Abandoning all assessment is throwing the baby out with the bathwater.

Answer

FLIGHT/VIDAS

Health literacy is:

- Abilities

- Skills

- Knowledge

A health literacy measure that incorporates a wide variety of skills and tasks.

Assesses skills and knowledge related to health.

Computer administered with automated scoring.

See: www.flightvidas.org

Problem

The nurse

Problem

"So what if I give patients this test?"

"What will I know?"

Problem

Epiphany

Answer

Linking Health Literacy to Interventions

We developed a way to determine a person's level of health literacy in a way that would help people link it to instructional strategies.

Assessing health literacy as below basic, basic, intermediate, or proficient.

National Assessment of Adult Literacy, Kutner et al, 2006

Strategy

Linking Health Literacy to Interventions

- Predictive model using performance on FV health literacy items and personal characteristics.

- High degree of accuracy for below basic and basic vs intermediate and proficient (> 90%).

- Easily integrated into electronic health records for use by clinicians.

- Can be used for tailoring automated interventions

FV Sample by Health Literacy Group

Level of Health Literacy
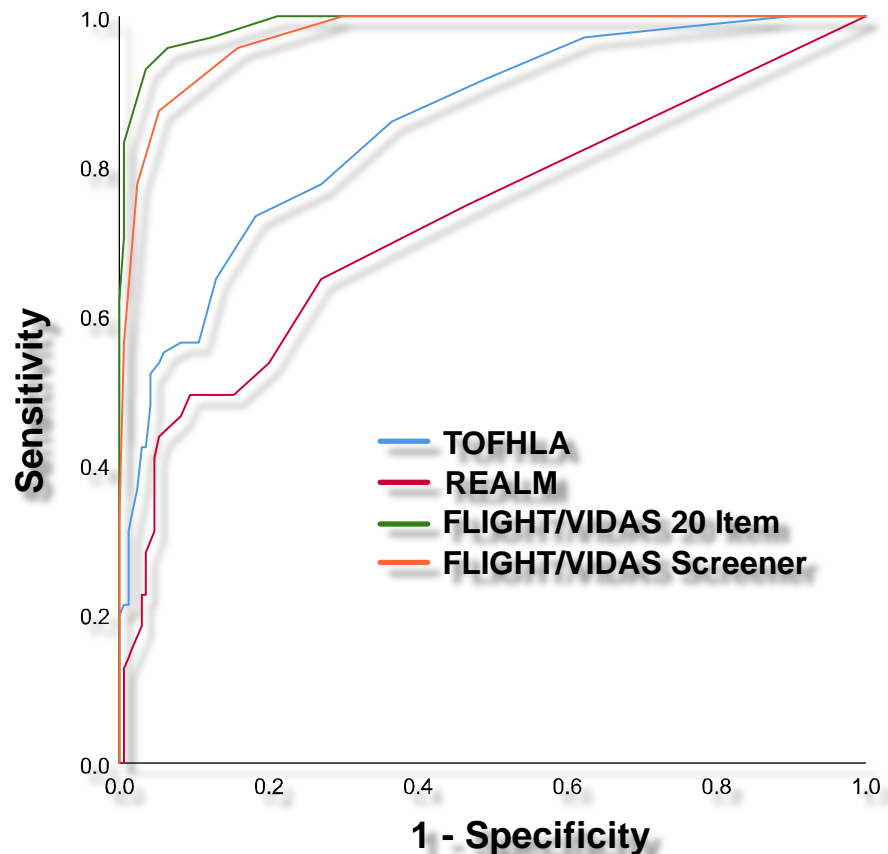
- Below Basic
- Basic
- Intermediate
- Proficient

Pie chart:
- Below Basic — 12%
- Basic — 27%
- Proficient — 31%
- Intermediate — 30%
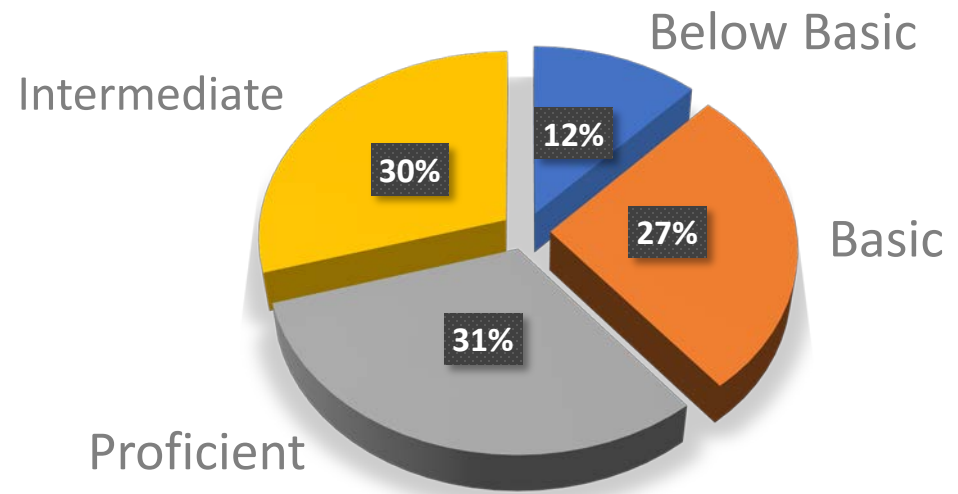
Strategy

Receiver Operating Characteristic Curve

Comparing Accuracy:

Identifying Persons with Basic and Below Basic Skills

The Next Step

So we have this method, what do we do with it?
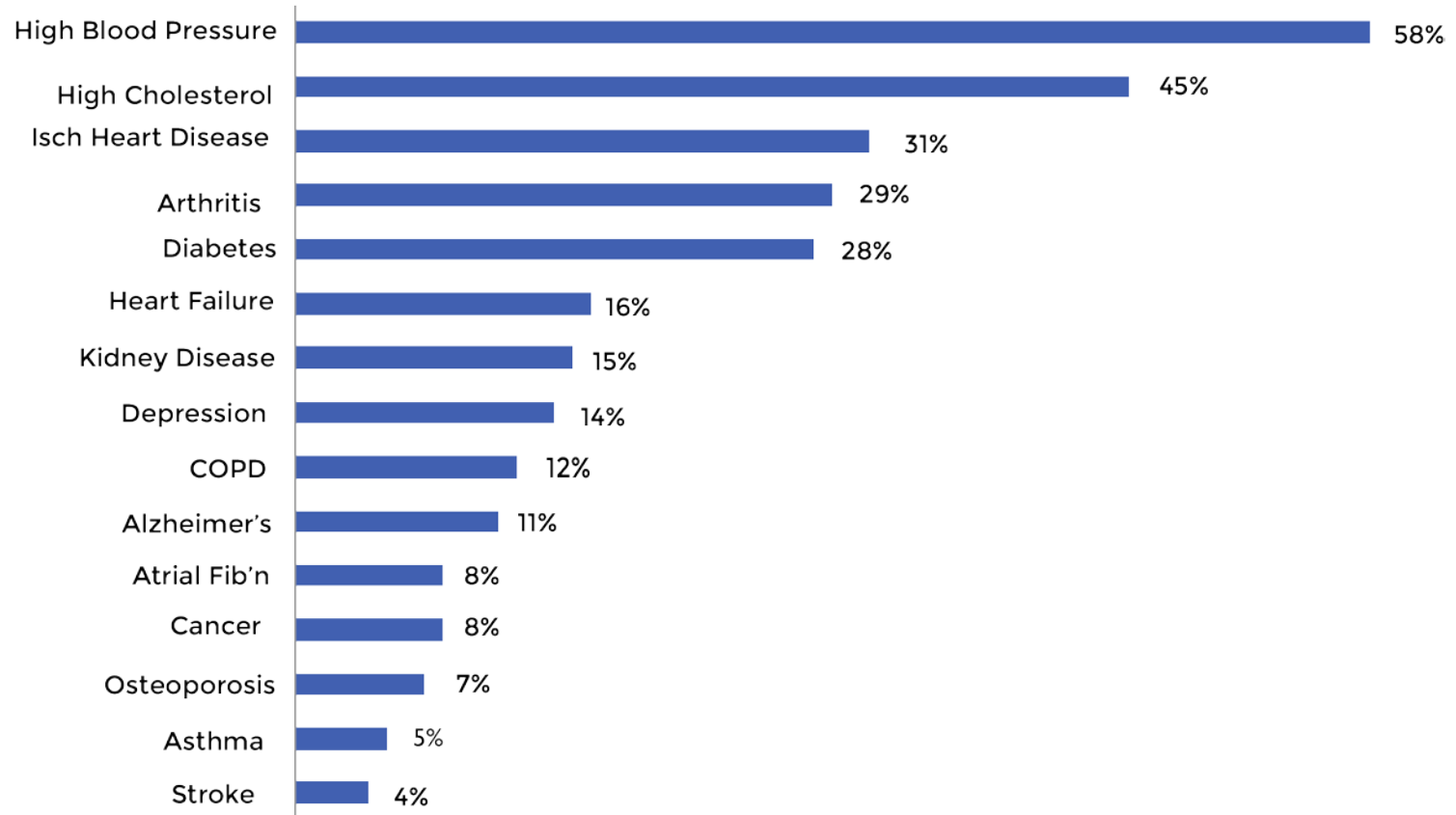
Answer Multimorbidity

- The most common chronic condition is ***multimorbidity.***

- Most older persons in the US have ***more than one chronic condition.***

- ***Multiple chronic conditions (MCC)***

Figure: After RAND Corporation, 2017

Percentage of Medicare Beneficiaries with Selected Chronic Conditions

- High Blood Pressure — 58%
- High Cholesterol — 45%
- Isch Heart Disease — 31%
- Arthritis — 29%
- Diabetes — 28%
- Heart Failure — 16%
- Kidney Disease — 15%
- Depression — 14%
- COPD — 12%
- Alzheimer's — 11%
- Atrial Fib'n — 8%
- Cancer — 8%
- Osteoporosis — 7%
- Asthma — 5%
- Stroke — 4%

Problem

Where should we start?

- 71% of all healthcare spending on people with more than one chronic condition
  - *2010 CDC expenditures chartbook*

- 93% of fee-for-service Medicare expenditures
  - *CMS 2012 chartbook*

Answer

Where should we start?

- *"Even the highest quality provision of care to individuals with MCC alone will not guarantee improved health outcomes for this population. Individuals must be informed, motivated, and involved as partners in their own care."*
  - *HHS strategic framework 2010*

Answer Multimorbidity

Priorities to Address MCC

- "Maximize the use of proven self-care management . . . " approaches.

HHS strategic framework 2010

Answer

CDSM programs

- Brady TJ, et al. *Preventing Chronic Disease.* 2013;10:1-14.

- Foster G et al. *Cochrane Database of Systematic Reviews.* 2007;(4):CD005108.

- Warsi A et al., *Archives of Internal Medicine.* 2004;164(5):1641-49.

Answer

Intervening

Electronic

- McCabe C et al. *Cochrane Database of Systematic Reviews.* 2017;(5):CD011425.

- Jones KR, Lekhak N, Kaewluang N. *Worldviews on Evidence-Based Nursing.* 2014;11(2):81-88.

- McDermott MS, While AE. *Patient Education and Counseling.* 2013;92(1):13-22.

Answer

Intervening

Chronic Disease Self-Management Programs

- In-person delivery
- Professional and peer educators
- Widely used
- Not available to everyone

Answer

Healthcare as a Cottage Industry

- If we can download any music we want,
- Buy a car online,

- *Why are we relying on outdated strategies to give patients access to the healthcare information they need and want and in a form they can understand and use?*

Answer Intervening

Electronic Interventions

Electronic Interventions

Automated Tailoring to Patient Need Teach and Reteach to Ensure Learning

Create Once, Repeat Many Times

Web-based Dissemination

Accessible When and Where the Patient Wants

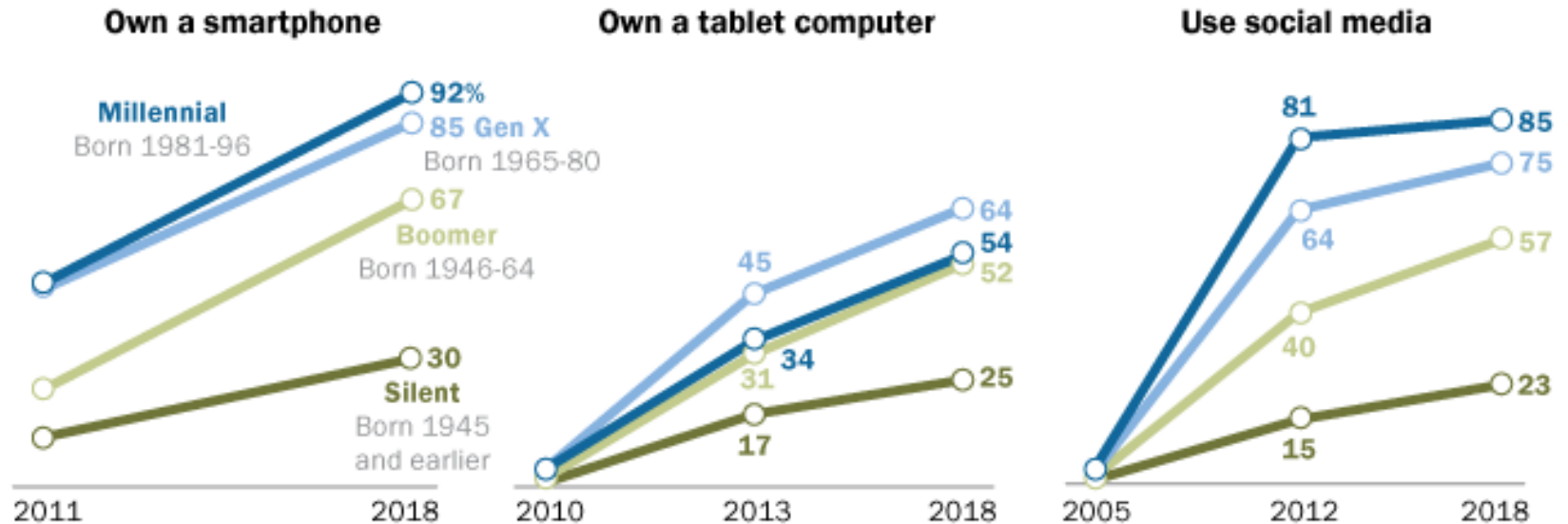Multimedia Learning

Cost Effective

BMC Medical Informatics and Decision Making, 2013 **13**:29

Answer — Intervening

Millennials lead on some technology adoption measures, but Boomers and Gen Xers are also heavy adopters

% of U.S. adults in each generation who say they ...

Own a smartphone — Own a tablet computer — Use social media

Own a smartphone:
- Millennial (Born 1981-96): 92%
- Gen X (Born 1965-80): 85
- Boomer (Born 1946-64): 67
- Silent (Born 1945 and earlier): 30
- 2011 — 2018

Own a tablet computer:
- 64
- 54
- 52
- 45
- 34
- 31
- 25
- 17
- 2010 — 2013 — 2018

Use social media:
- 85
- 81
- 75
- 64
- 57
- 40
- 23
- 15
- 2005 — 2012 — 2018

Source: Survey conducted Jan. 3-10, 2018. Trend data are from previous Pew Research Center surveys.

PEW RESEARCH CENTER

Answer

Computer-delivered, individually-tailored information for adherence in patients with HIV infection

Neurobehavioral HIV Medicine 2012, 4, 113—121

HIV Information and Race Over Time

Legend: Whites (blue), Blacks (green)

X-axis: Before Intervention, Immediately After Intervention, One Month After Intervention

Y-axis: Mean LifeWindows Information Scale (26.00–32.00)

Answer

Self-Management

FLIGHT/VIDAS 2 Interventions

FLIGHT/VIDAS 2

📄 **Protocol**

A Mobile App for Chronic Disease Self-Management: Protocol for a Randomized Controlled Trial

Raymond L Ownby[1], MD, PhD, MBA (iD) ; Amarilis Acevedo[2], PhD (iD) ;

Drenna Waldrop-Valverde[3], PhD (iD) ; Joshua Caballero[4], PharmD (iD) ; Michael Simonson[5], PhD (iD) ;

Rosemary Davenport[1], MSN, ARNP-BC (iD) ; Kofi Kondwani[6], PhD (iD) ;

Robin J Jacobs[7], PhD, MSW, MS, MPH (iD)

Answer

FLIGHT/VIDAS 2
Interventions

FLIGHT/VIDAS 2

Computer Delivered

Cognitive Load Theory

Automated Tailoring

Personalized Assessment and Information

Multimedia Instruction

Answer

Tailored Information

Tailored Information

Tailored information is made more relevant to the person receiving it

Tailoring to personal characteristics, using the person's name, or to their expressed interests or needs

People are more likely to act on information that is tailored to them.

Noar et al., *Psych Bulletin,* 2007.

www.enalan.com

Answer

Precision Health Information

**Precision Health Information**

Giving people the information they need, when they want it, and in a way that they can use.

Find out what the patient knows and doesn't know, then explain it.

Web-based delivery allows the patient to access the information at a time and place convenient to them, not the system.

Deliver it in multimedia format, tailored to the person's interests, and at a level of difficulty that matches their ability to understand it.
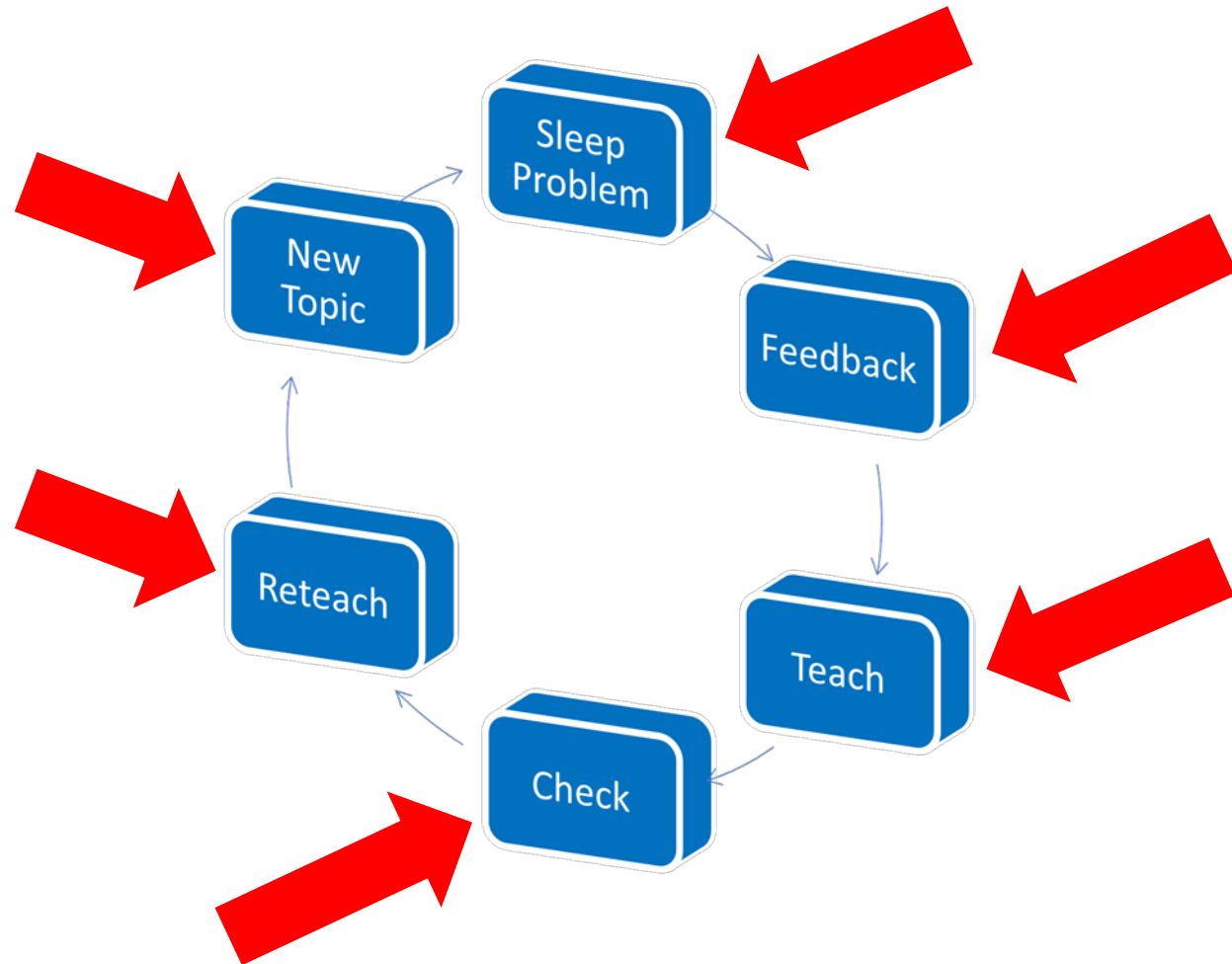
Answer

Content of the Modules

- Introduction and overview
- Adherence
- Stress
- Mood
- Sleep

- Pain
- Memory
- Fatigue
- Shortness of breath
- Anger

Answer

Rigorous Development Process

- Qualitative study
- Team development
- Usability testing in multiple rounds
- Feedback from potential users

- Creation of modules at three levels of difficulty

Answer

Testing process

- 10 modules, each at 3rd, 6th, or 8th grade reading difficulty

- All participants screened for 8th grade or lower health literacy

- Random assignment to grade level

- Baseline and follow-up assessments

- Quantitative and qualitative assessment of changes in patient attitudes and behaviors

- Ongoing

- ClinicalTrials.gov, NCT02922439
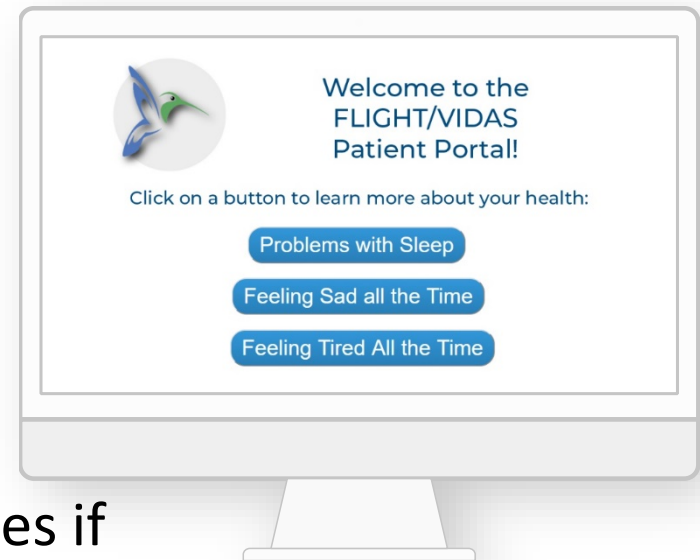
Answer

FV2 Mobile App
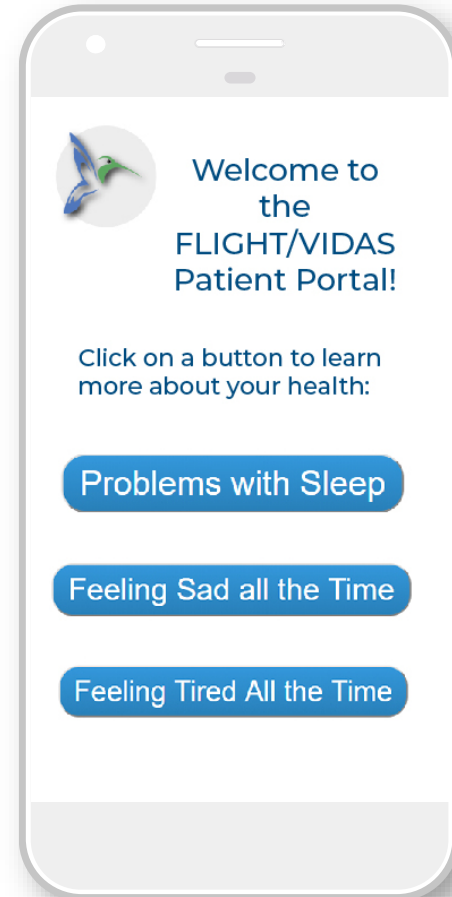
- Ten areas for chronic disease self-management

- States purpose, assesses needs, provides information

- Checks understanding and reteaches if needed (cf. teach back)

Answer

FV2 Mobile App

- Ten areas for chronic disease self-management

- States purpose, assesses needs, provides information

- Checks understanding and reteaches if needed (cf. teach back)

Welcome to the
FLIGHT/VIDAS
Patient Portal!

Click on a button to learn more about your health:

Problems with Sleep

Feeling Sad all the Time

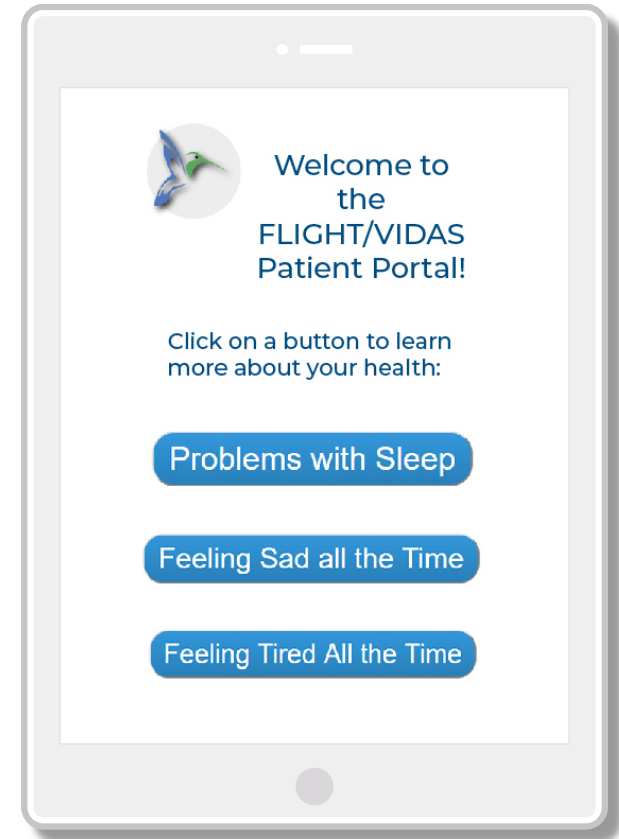Feeling Tired All the Time

Answer

FV2 Mobile App

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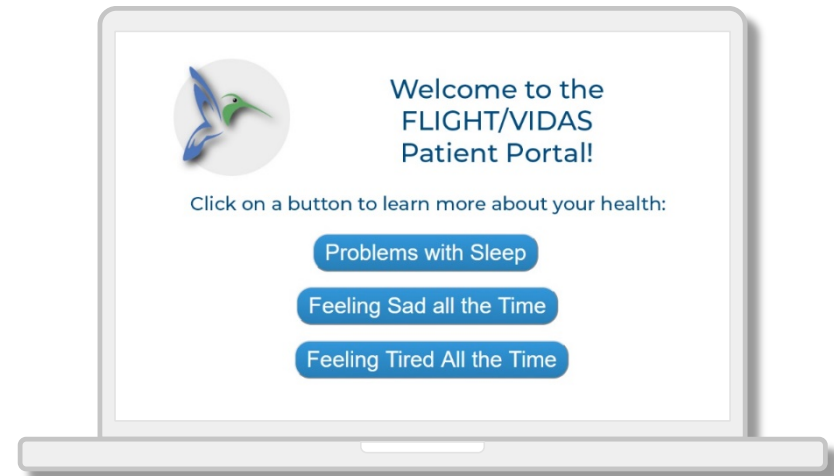Feeling Tired All the Time

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Answer

Welcome to the
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Patient Portal!

Click on a button to learn more about your health:

Problems with Sleep

Feeling Sad all the Time

Feeling Tired All the Time

Answer

Before:

You should make all this stuff about health so people can understand it.

Then put it in an app or something so people can download it on their phones.

**Answer**

Initial patient reaction

After:

This is great! Every one of these things was about me.

Transforming Health Literacy Interventions: Challenges

- To move from a cottage industry of individual practitioners to efficient use of the tools we have to improve patients' lives

- This includes effective and efficient use of information technologies to help patients improve their lives

Problem
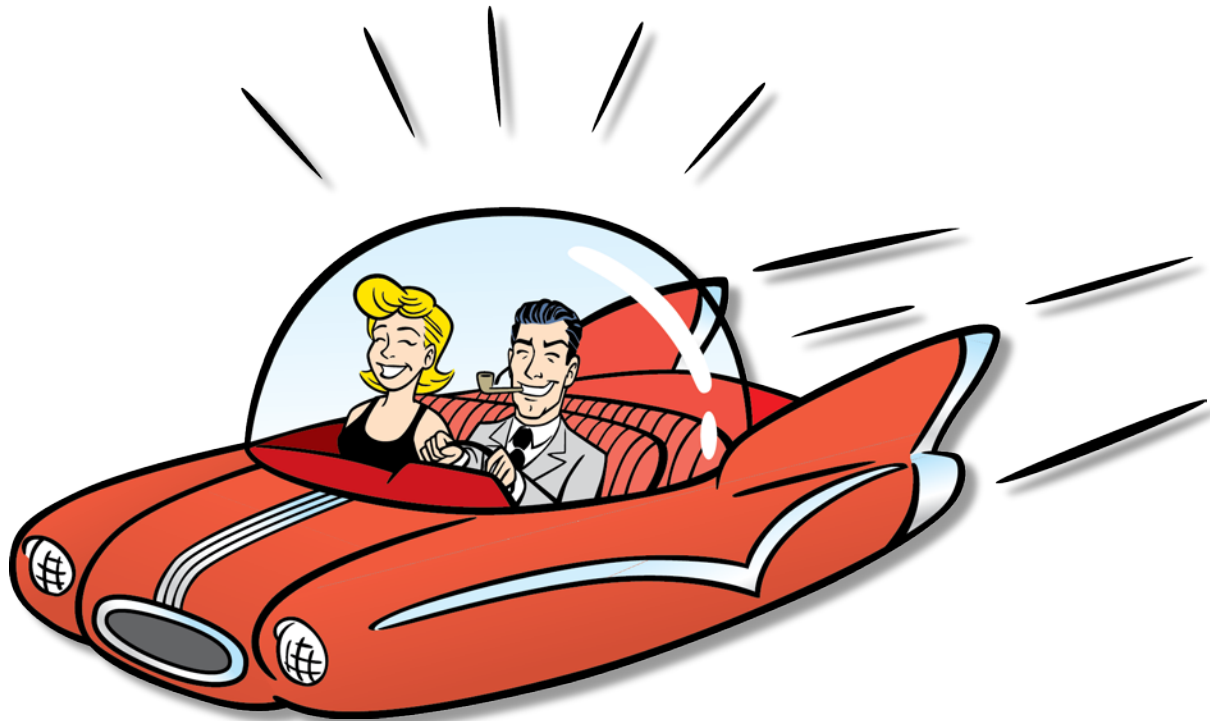
Problem

"**Build a better mousetrap,** and the world will beat a path to your door" is a phrase attributed to Ralph Waldo Emerson in the late nineteenth century

-- *Wikipedia*

BRAND CAMP   by Tom Fishburne

A BETTER MOUSETRAP

NOW 5% BETTER

NOW THAT WE'VE BUILT IT, LET'S SIT TIGHT AND WAIT FOR THE WORLD TO BEAT A PATH TO OUR DOOR.

© 2011   MARKETOONIST.COM

Nobody has called . . .

Problem

Current Healthcare: Transforming It

- *The country's on fire about the opportunity to bend healthcare trends by understanding and addressing social determinants.*

- *Perhaps most important is how **technology can democratize access to great care**.*

  - Karen DeSalvo, Dell Medical School, UT Austin
  - Former National Coordinator for Health IT
    - https://healthtechmagazine.net/article/2018/10/qa-dell-medical-schools-dr-karen-desalvo-calls-patient-care-revolution

Answer

Future Development

Web, Apple, Google

Inclusion in EHR Patient Education Modules

Promote Use on Patient Education and Health Websites

E-learning Tools

- PowerPoint style interface
- Many effects and interactions are built in do not require coding
- Publish to the web
- Publish to Apple Store and/or Google Play
- Easily integrated into electronic health records
- Create videos that can easily be uploaded to YouTube.

Authoring Tools

- Adobe Captivate
- Articulate Storyline
- Adapt
- iSpring
- Lectoris
- Camtasia

Conclusion

An essential part of empowering our patients is empowering ourselves to use these new and powerful tools.

That is how we can give them the information they need and want, when they want it, and in a form they can use.

Support

We acknowledge support from the follo

K23 AG19745 National Institute on Aging

R21086491 National Institute on Mental Health

RO1HL096578 National Heart, Lung, and Blood Institute

R56 HL096578 National Heart, Lung, and Blood Institute

RO1MD010368 National Institute on Minority Health and Health Disparities

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Thank you

Fort Lauderdale

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Thank you

Thank you

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