

Following the Path of the Patient

Reaching
New Heights
in Patient
Powered Care



Evaluating Technology-Enabled Patient Education

Susan C. Hull MSN, RN-BC, NEA-BC
September 7, 2017

PART 1 slides

Objectives

1. Describe advances in e-health interactive technology/tools making the vision for connected health and connected care a reality.
 2. Explore models of coproduction to bring the voice of patients and patient communities to the patient education table.
 3. Identify five lenses for evaluating m-health patient education apps.
 4. Share best practices in your settings to deepen partnership with others -- including patients, communities & HIT partners.
 5. Anticipate future trends to guide capacity building in NEAC community.
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Objective 1

Describe advances in e-health interactive technology/tools making the vision for connected health and connected care a reality.

From EHRs To Connected Health Ecosystems

Where We Are Now

Many doctors are using electronic health records.

Doctors, labs, pharmacies, and hospitals can store patients' health data electronically. This will help:

- Make your doctor visits faster
- Seamlessly coordinate your care among all your doctors
- Allow you to be in full control of all your medical data

pharmacy trusted provider hospital

2 out of 3 people would consider switching to a physician who offers access to medical records through a secure internet connection?

What can you do with access to your health record?

- Check to make sure your information is correct and complete
- Keep track of important health information (e.g., vaccination records and test results)
- Have your medical history available if you are changing doctors or visiting a specialist
- Keep track of all your medicines and dosages

HealthIT.gov

Electronic Health Records:

How they connect you and your doctors

You and your doctor can share your data more effectively and quickly with other health care providers. There are multiple benefits to YOU. For example, you can eliminate the time and hassle of taking multiple tests or exams.

Where We Are Headed

Emerging technologies offer new ways for you and your doctor to monitor and manage chronic illnesses.



You will be able to:

- Use GPS technology or real-time reminders and alerts to better prevent and treat health complications
- Send vital health data from your home to physicians' offices
- Have virtual visits and receive health coaching from providers based on clinical data transmitted



11% users who downloaded an app to help them track or manage their health⁹



Having electronic access to your medical record can help you better manage your health.

80%

Americans who have access to their health information in electronic health records use it³



65%

Americans who don't have electronic access to their health information say it's important to have it⁴

E-health tools and mobile devices can help you better manage your personal health and wellness.

17 million

Number of consumers using mobile devices to access health information in 2011⁵



27%

Adults who use the internet have tracked the following:⁶



People who are more engaged in their health actually get better health care⁷





THE VALUE OF CONSUMER ACCESS & USE OF ONLINE HEALTH RECORDS

Giving individuals easy and secure access to their health information increases patient engagement and advances person-centered health.



**INDIVIDUALS NEED ACCESS TO THEIR FULL HEALTH RECORDS
TO ADDRESS INFORMATION GAPS**

1 IN 3 INDIVIDUALS

who have seen a health care provider in the last year experienced at least one of the following gaps in information exchange.¹



Had to bring an X-ray, MRI, or other type of test result with them to the appointment.



Had to wait for test results longer than they thought reasonable.



Had to redo a test or procedure because the earlier test results were not available.



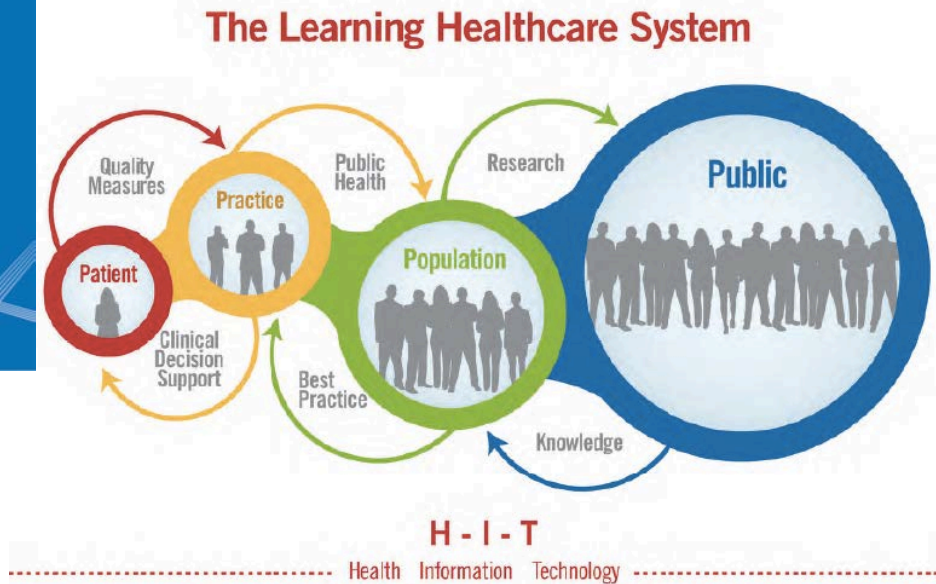
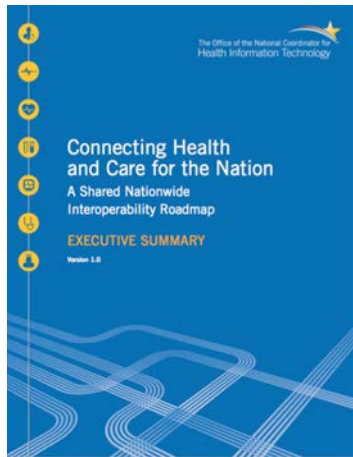
Had to provide their medical history again because their chart could not be found.



Had to tell a health care provider about their medical history because they had not gotten their records from another health care provider.

INDIVIDUALS CAN SERVE AS THE HUB OF INFORMATION EXCHANGE

Co-Creating Value with Patients, Carers and Communities

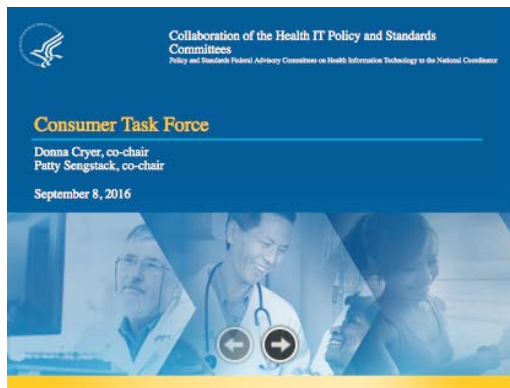


“We need a digital health information platform, data model and infrastructure that is **person-centric** rather than institutional-centric.”

Karen DeSalvo, ONC Annual Meeting, February 2, 2015

Shifting the culture, place and cost of care

Policy Advocacy: Person at the Center



Collaboration of the Health IT Policy and Standards Committees
Policy and Standards Federal Advisory Committees on Health Information Technology to the National Coordinator

Consumer Task Force

Donna Cryer, co-chair
Patty Sengstack, co-chair

September 8, 2016

The banner features a blue background with a white eagle logo at the top left. Below the header, the text is in white and yellow. At the bottom, there is a photograph of three healthcare professionals (two men and one woman) looking at a screen, with two circular arrows pointing left and right overlaid on the image.



Health Records Apps FAQs

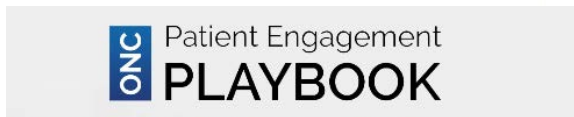


Blue Button[®] Connector

A Way to Help You Find Your Health Data

Get Started

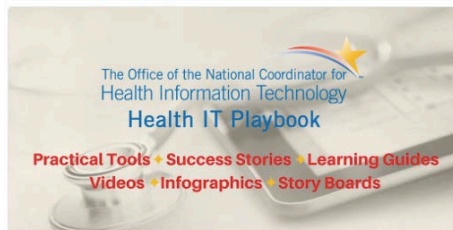
The banner has a white background. It features a blue circular icon with a white download arrow. Below the icon, the text is in blue and black. At the bottom, there is a blue button with white text.



ONC Patient Engagement PLAYBOOK

The banner has a light gray background. On the left, there is a blue square with the letters 'ONC' in white. To the right of this square, the text 'Patient Engagement' is in a smaller font, and 'PLAYBOOK' is in a larger, bold font.

ONC @ONC_HealthIT - 14h
NEW ONLINE TOOL: Expanded #HealthIT Playbook features tools, resources, best practices to help healthcare providers.
healthit.gov/playbook



The Office of the National Coordinator for Health Information Technology
Health IT Playbook

Practical Tools • Success Stories • Learning Guides
Videos • Infographics • Story Boards

The banner features a photograph of a person's hands holding a tablet. Overlaid on the image is the text 'The Office of the National Coordinator for Health Information Technology Health IT Playbook' in blue and black. Below this, there is a list of content types: 'Practical Tools • Success Stories • Learning Guides Videos • Infographics • Story Boards' in red and black.



accenture
Strategy | Consulting | Digital | Technology | Operations

Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024

Draft White Paper for a PGHD Policy Framework

Submitted: October 28, 2016
By: Accenture Federal Services

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Draft White Paper for a PGHD Policy Framework
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The cover has a blue background with a photograph of a person's hands holding a tablet. The Accenture logo is at the top left. The title is in white text. Below the title, there is a subtitle. At the bottom, there is a small text block with legal disclaimers.

Author: Accenture Federal Services

Posted: January 10, 2017

Available at: https://www.healthit.gov/sites/default/files/Draft_White_Paper_PGHD_Policy_Framework.pdf

Voices of Patients Gaining Strength

“Patients share responsibility for their own health care.”
AMA Code of Medical Ethics



“Patients can help. We can be a second set of eyes on our medical record.”
Dave DeBronkart (ePatient Dave)



Consumers Harnessing Power of Open Data

TECHNOLOGY

The Healing Power of Your Own Medical Records

By STEVE LOHR MARCH 31, 2015



Steven Keating, a doctoral student at M.I.T.'s Media Lab, collected and researched his own patient data, which led to the discovery of a brain tumor. He is shown in front of an image of radiation backscatter from his brain during therapy. Erik Jacobs for The New York Times



Mr. Keating with a 3-D-printed copy of his brain tumor. Erik Jacobs for The New York Times

<https://www.youtube.com/watch?v=-L-WFukOARU>

“Click here to download my brain tumor”
“I want to open source my health data”

health

fighting cancer through curiosity

In August, 2014, I was diagnosed with a baseball-sized IDH1 tumor (astrocytoma). I was asymptomatic until then and given three weeks before a 10-hour awake brain surgery. But the story dates back much further, to 2007 when I was merely curious about viewing my own brain in a voluntary academic scan and had accidental findings. Science and curiosity have saved my life. I am writing this with a hole in my brain, roughly 12 trillion synapses! I want to enable other patients to collect, understand, and share their data. I am a strong privacy proponent - I believe patients should have the choice and control of their own data.

For more information, to the right is a 10-minute recent talk I presented at the MIT Koch Institute [\(YouTube link here\)](#). As well, [about art-lab on my](#)

click here to download my brain tumor and more!
(ok, I know that's an odd phrase to read...but at least it's interesting?)

fighting cancer

health data

future

<http://stevenkeating.info/main.html>



NIGHTSCOUT

#WeAreNotWaiting

Nightscout (CGM in the Cloud) is an open source, DIY project that allows real time access to a CGM data via personal website, smartwatch viewers, or apps and widgets available for smartphones.

How Do You Get Your CGM in the Cloud?



Features of a Nightscout site include:

- Transfer data
- Real-time updates
- Alerts and notifications
- Share data with family/friends
- Export data to CSV/Excel
- Customizable views
- Mobile app
- Smartwatch integration
- Widgets
- API access
- Open source
- Community support



Dana Lewis and her husband Scott Leibrand invented the Do It Yourself Artificial Pancreas System (#DIYPS)

She then took it a step further, founding the #OpenAPS movement to make safe and effective basic Artificial Pancreas System technology more widely available (and sooner).



Quantified Self
self knowledge through numbers

The Quantified Self community

Quantified Self is a collaboration of users and tool makers who share an interest in self knowledge through self-tracking.

We exchange information about our personal projects, the tools we use, tips we've gleaned, lessons we've learned. We blog, meet face to face, and collaborate online. There are three main "branches" to our work.

The Quantified Self blog and community site.

Show and Tell meetings (Meetup groups) - Melbourne

Quantified Self Conferences (US and Europe)

Groups 243, **Members** 72K, Cities 126, Countries 39

Developing Trust for eHealth Data




- A consumer-lead national campaign to help patients request their electronic health data and report on experiences in the real world
- Advocates for changes that enable consumer health data download and use become the norm
- Coordinated by the National Partnership for Women and Families
- in collaboration with health, consumer, technology groups and individual advocates and experts
- First year funded by Robert Wood Johnson Foundation and individual donors
- July 4, 2015 “Data Independence Day”



Resources and Toolkits

HIPAA Fact Sheet: The P is for Portability


Key facts about patient requests for electronic health data



ACCESS

Patients have the right to electronic copies (e-copies) of their health records.


If records are kept electronically, patients or their representatives can request an e-copy of their health data. In most cases, e-copies must be given to the patient within 30 days. Patients do not need to give a reason for their request. This information helps patients manage their own health and care for loved ones.



FORMAT

Patients can request their data in specific formats, if readily producible.


Data can be in a structured format (CCDA, etc.) or read-only (PDF, etc.). Patients need structured data if they want to use a computer or mobile app to organize or analyze it. Providers are encouraged to help patients determine which electronic format best meets their needs.



DELIVERY

Providers can email patients a copy of their records.


HIPAA allows providers to send a patient's records to a mainstream email account (Gmail, etc.) at the patient's request. Providers should advise patients that traditional email may not be secure, and patients can decide to accept this risk. A patient can also request other methods, such as mobile health applications.



COST

Providers can charge certain fees for electronic copies of a patient's records.

Reasonable fees include the cost of labor to create and copy the electronic file, cost of supplies (USB drive, etc.), and postage. Fees vary by state. Providers cannot charge fees for searching for or retrieving records. Federal law does not expressly recognize per-page fees for e-copies. Patients cannot be denied their records because of an unpaid bill.



Resources

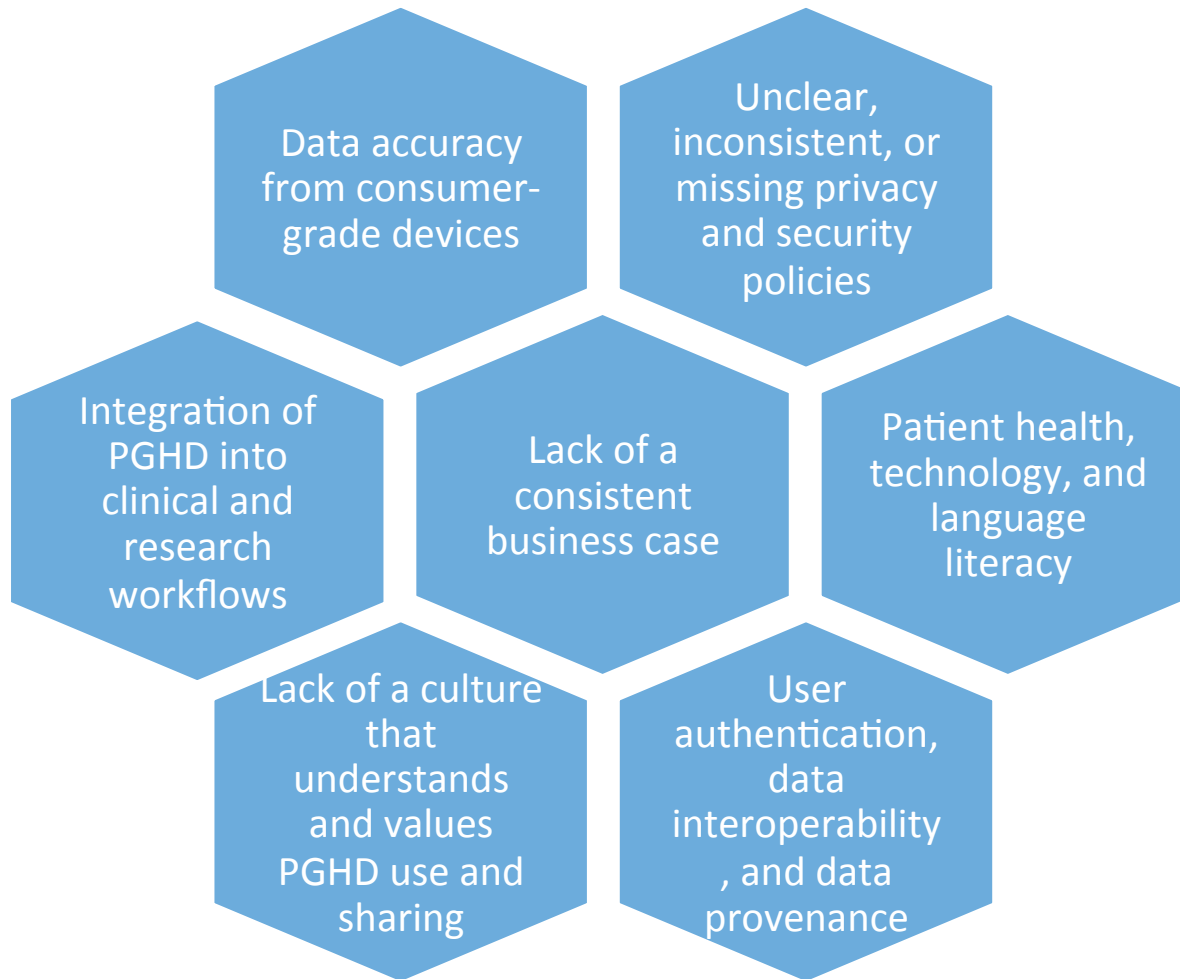
- [GetMyHealthData Results and Lessons](#) PDF
- [Right to Access Memo](#) PDF
- [Learn More About Blue Button](#) 🔊
- [Direct Basics: Q&A for Providers](#) PDF
- [Blue Button FAQs](#) 🔊
- [Learn More About Vocatus](#) 🔊
- [Permission to Email Records](#)
- [Personal Representatives](#) 🔊
- [Disclosures to Friends and Family](#) 🔊
- [Communicating with Friends and Family](#)
- [Your Health Information Privacy Rights](#) PDF
- [HIPAA Infographic](#)
- [Health Info & the Law](#)
- [Provider Resources](#)

Tracer Feedback Makes a Difference

- **Sharing Tracer experiences with high-level policymakers resulted in better public policies and more informed national dialogue about patient data access**
 - HHS Office of the National Coordinator for Health IT
 - HHS Office for Civil Rights
 - U.S. Senate and House of Representatives
 - White House Office of Science and Technology Policy



Adoption of PGHD For Research and Care



A complex web of technical and cultural challenges may impede successful capture, use, and sharing of PGHD in and across research and care delivery settings

ONC Consumer Health Data Aggregator Challenge Winners

Enable consumers to easily and electronically access and securely integrate their health data from different health care providers using a variety of different health IT systems

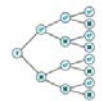
- **First Place: Patient Link Enterprises, MyLinks (\$50K)**
 - Cloud-based application using FHIR® and Direct messaging
 - Interactive platform that allows patients to download their medical records from all their health providers, transmit their records, plus link to researchers, pharmacists, care-givers, family and friends
- **Second Place: Green Circle Health (\$25K)**
 - Application uses FHIR® to import patient data into a platform
 - Integrating a comprehensive family health dashboard that includes personal and medical device data, remote monitoring, and reminders.
- **Honorable Mention: 1upHealth**



Store health data
Securely store your clinical hospital data and wearable sensor data in one place on 1upHealth.



Learn from similar users
Don't just see averages, learn from patients who have similar conditions and treatments as you



Get help deciding
1upHealth calculates quality of life after medical decisions to help choose those with better outcomes



[January 12, 2017](#)

January 12, 2017

Green Circle Health Family Health Dashboard

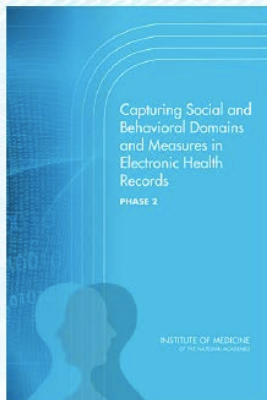


- Green Circle Health winner of ONC Phase 2 Consumer Health Data Aggregator Challenge
- Uses FHIR & APIs to import patient data into platform
- Family health dashboard: personal data, medical device data, remote monitoring, reminders
- Note use of “Dr. Mom will manage it now” recognizing role of family Chief Health Officer



Jane Sarasohn-Kahn, MA (Econ.), MHSA
Health Economist, Advisor, Trend Weaver
jane@think-health.com
www.healthpopuli.com Blog

Social Determinants of Health (SDOH)



Individual Factors

Sociodemographic

- Sexual orientation
- Race/ethnicity
- Country of origin/U.S. born or non-U.S. born
- Education
- Employment
- Financial resource strain: Food and housing insecurity

Psychological

- Health literacy
- Stress
- Negative mood and affect: Depression and anxiety
- Psychological assets: Conscientiousness, patient engagement/activation, optimism, and self efficacy

Behavioral

- Dietary patterns
- Physical activity
- Nicotine use and exposure
- Alcohol use

Individual-Level Social Relationships and Living Conditions

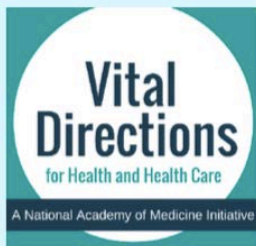
- Social connections and social isolation
- Exposure to violence

Neighborhoods/Communities

- Geocodable domains: Socioeconomic and race/ethnic characteristics



About the Vital Directions for Health and Health Care Series



This publication is part of the National Academy of Medicine's **Vital Directions for Health and Health Care Initiative**, which called on more than 100 leading researchers, scientists, and policy makers from across the United States to assess and provide expert guidance on 19 priority focus areas for U.S. health policy. The views presented in this publication and others in the series are those of the authors and do not represent formal consensus positions of the NAM, the National Academies of Sciences, Engineering, and Medicine, or the authors' organizations. Learn more: nam.edu/VitalDirections.



ABOUT THE NAM | PROGRAMS | INITIATIVES | PERSPECTIVES | NEWS | SUPPORT | MEMBER RESOURCES

Discussion Paper

Addressing Social Determinants of Health and Health Disparities: A Vital Direction for Health and Health Care

By Nancy E. Adler, David M. Cutler, Jonathan E. Fielding, Sandro Galea, M. Maria Glymour, Howard K. Koh, and David Satcher

September 19, 2016

To learn more visit iom.edu.ehrdomains2

Community Rx

Dr. Stacy Lindau's project, a University of Chicago grant funded 2012 CMMI Award



We connect health care to self care.

NowPow connects underserved populations to the existing assets of their communities—services, resources, and businesses that can help them get and stay healthy.

NowPow's roots stem from Dr. Stacy Lindau's CommunityRx project, a University of Chicago grant funded in 2012 by a Center for Medicare and Medicaid Innovation Award. CommunityRx was deployed in 33 clinical sites on Chicago's south side.

2

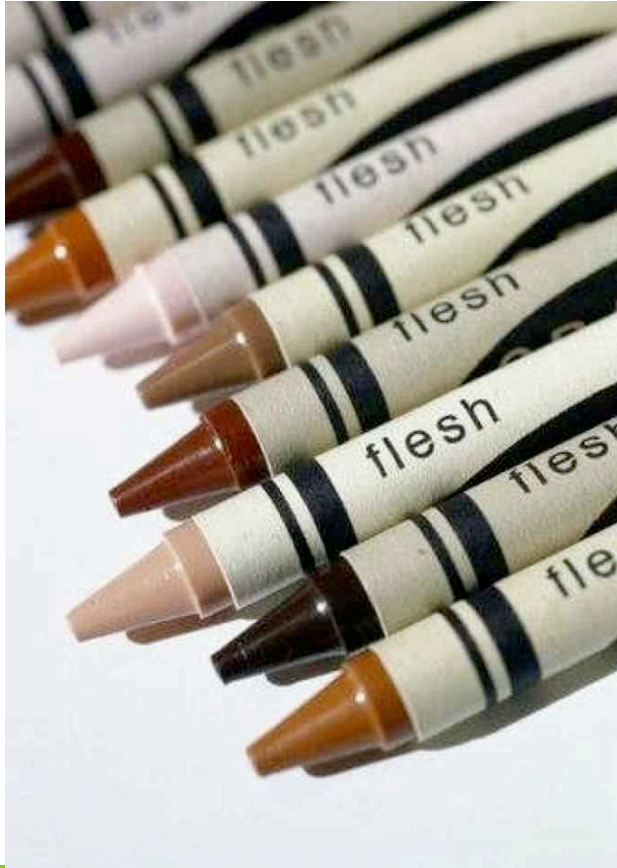


A Care Continuum Solution

NowPow is a cloud-based, mobile-enabled platform that can communicate seamlessly with Electronic Health Records (EHRs), care and case management systems, and CRMs. In addition to providing data-driven patient referrals, NowPow also tracks patient engagement and activation.



Personalizing Preference Sensitive Patient Education



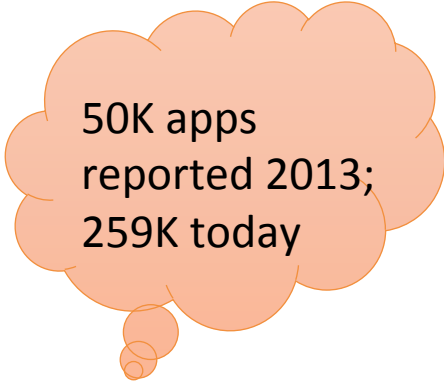
- Can mobile technologies help?
- Personalization and mass customization
- Preferences, needs and values
 - Learning styles
 - Sharing preferences
 - Carer circle identification
 - Storage and devices
 - Privacy and security

mHealth Apps

Non-Adherence to Medication Treatment

A recent IMS Institute for Healthcare Informatics report on Patient Apps for Improved Healthcare (Aiken & Gauntlett, 2013) demonstrates that the following **six disease areas** account for \$105 billion dollars annually in avoidable cost from non-adherence to medication treatment:

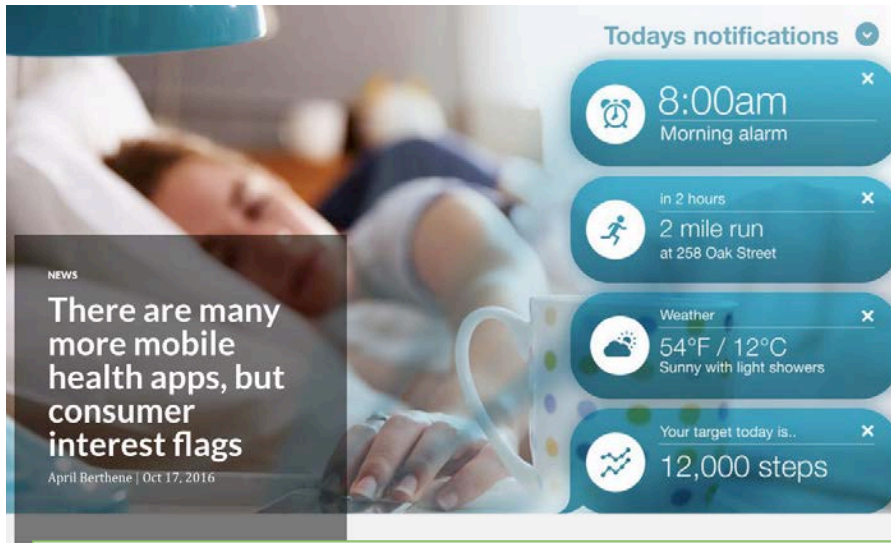
- Hypercholesterolemia, \$44B
- Diabetes, \$24.6B
- Hypertension, \$18.6B
- Osteoporosis, \$15.5B
- HIV, \$1.8B
- Congestive heart failure, \$1B



50K apps reported 2013;
259K today

IMS concludes that of the nearly 2,000 mHealth (apps) related to specific therapy areas, those dedicated to chronic conditions dominate.

However, according to the IMS study, the focus of these apps is not related to leading causes of mortality or non-adherence.



- 53% say their health apps generated fewer than 5,000 downloads
- 23% say their app generated between 5,000 and 50,000 downloads
- only 24% of health apps registered more than 50,000 downloads
- 56% developing apps aimed at chronically ill consumers
- 33% are aimed at consumers interested in health and fitness

58% of healthcare publisher use an application program interface (API)

- Apples HealthKit is the most popular API
- With the users permission, this API lets other parties feed information to Apples health app, which comes pre-loaded on iPhones.
- The Health apps allows consumers to look at their data from multiple health apps in one place.

100,000 new mobile health apps developed in 2016

57% increase over 2015.

259,000 health apps globally available to consumers

Study by Research to Guidance, health research group

Objective 2

Explore models of coproduction and design thinking to bring the voice of patients and patient communities to the patient education table.

Coproduction

Downloaded from <http://qualitysafety.bmj.com/> on October 6, 2016 - Published by group.bmj.com
BMJ Quality & Safety Online First, published on 16 September 2015 as 10.1136/bmjqs-2015-004315
ORIGINAL RESEARCH



OPEN ACCESS

Coproduction of healthcare service

Maren Batalden,¹ Paul Batalden,² Peter Margolis,³ Michael Seid,³
Gail Armstrong,⁴ Lisa Opipari-Arrigan,³ Hans Hartung⁵

- National Health Service (NHS) campaign, Co-Creating Health Initiative promoted self-management
- Clinic's experience with shared medical appointments
- Co-creating health in facilitated learning network of patients with chronic disease



Sarah Myers @myers3411 · Sep 30

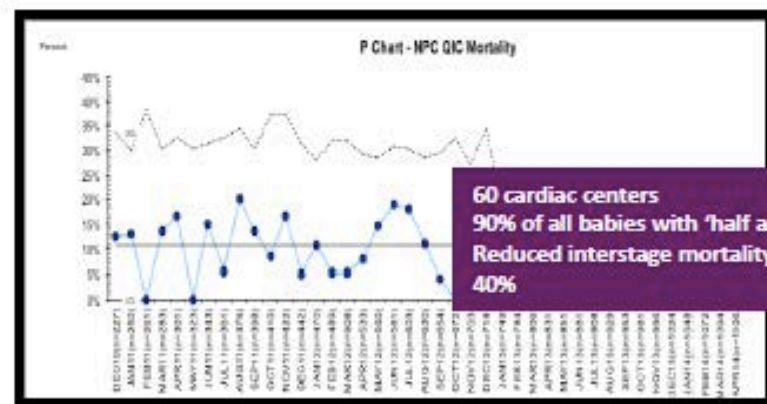
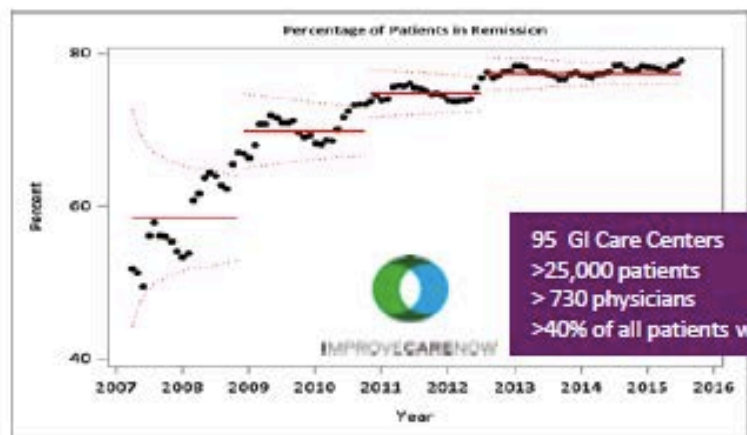
Bursting with pride for our community today. We have a large extended "family" & many wise muses who should be very proud of their role too.



Drucker Institute @DruckerInst

ANNOUNCING: The 2016 WINNER of #TheDruckerPrize is @ImproveCareNow. Our heartiest congratulations!
bit.ly/2dwVdXv

The network model delivers results

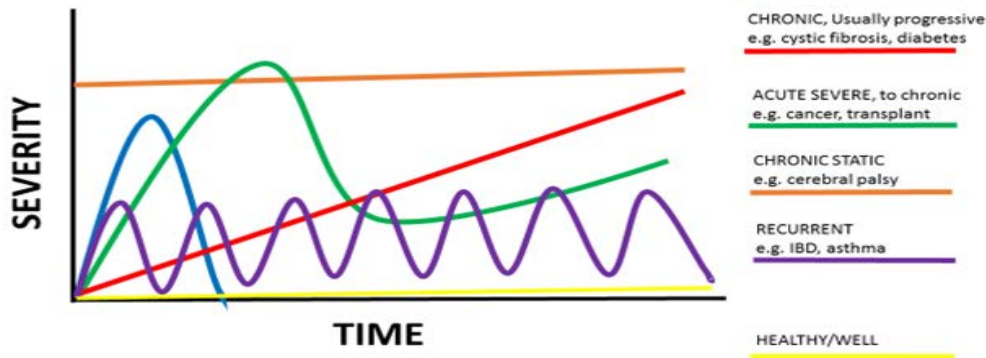


Coproducing Health

4XAim Challenges

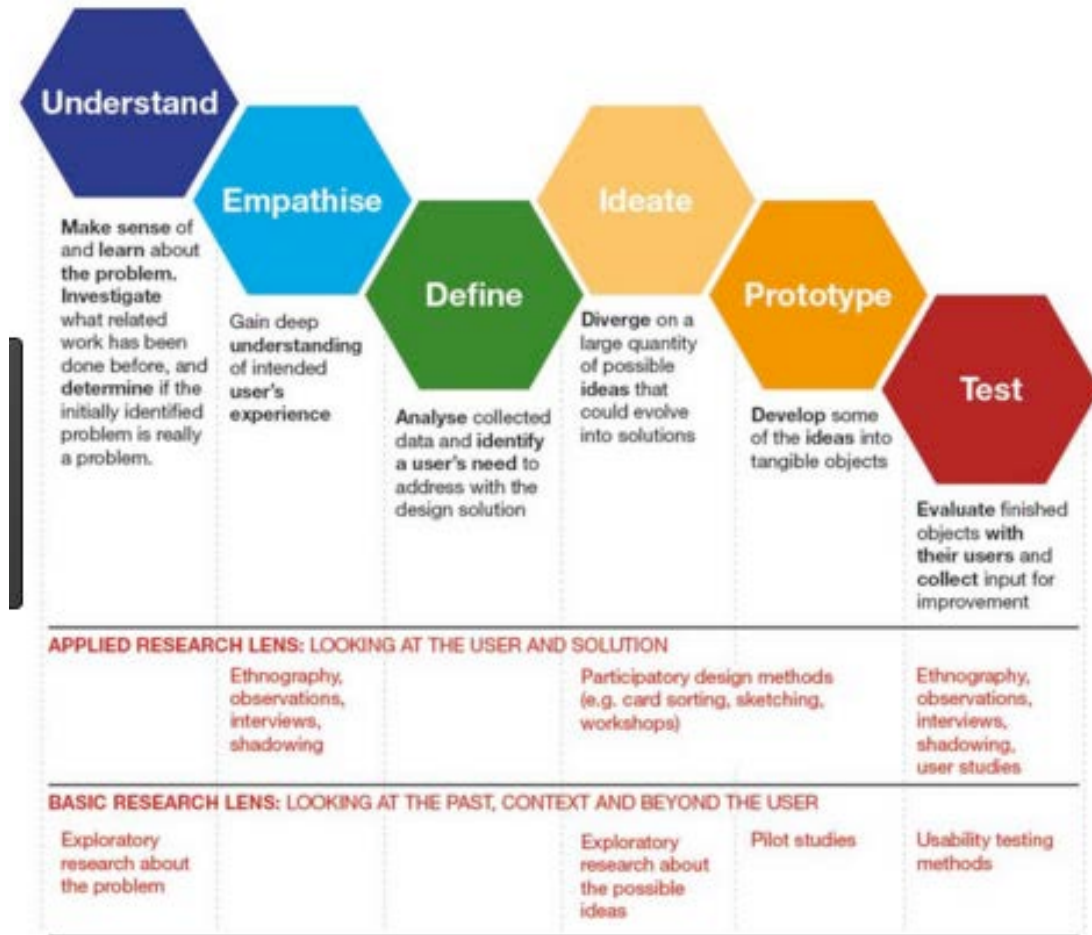
Following the PATH OF THE PATIENT

Measuring & Improving the Healthcare "Value Equation"



1. Diversity among patients
2. Power and responsibility
3. Letting the pendulum swing too far
4. Contextualizing standardization
5. A resistant healthcare culture

Design Thinking

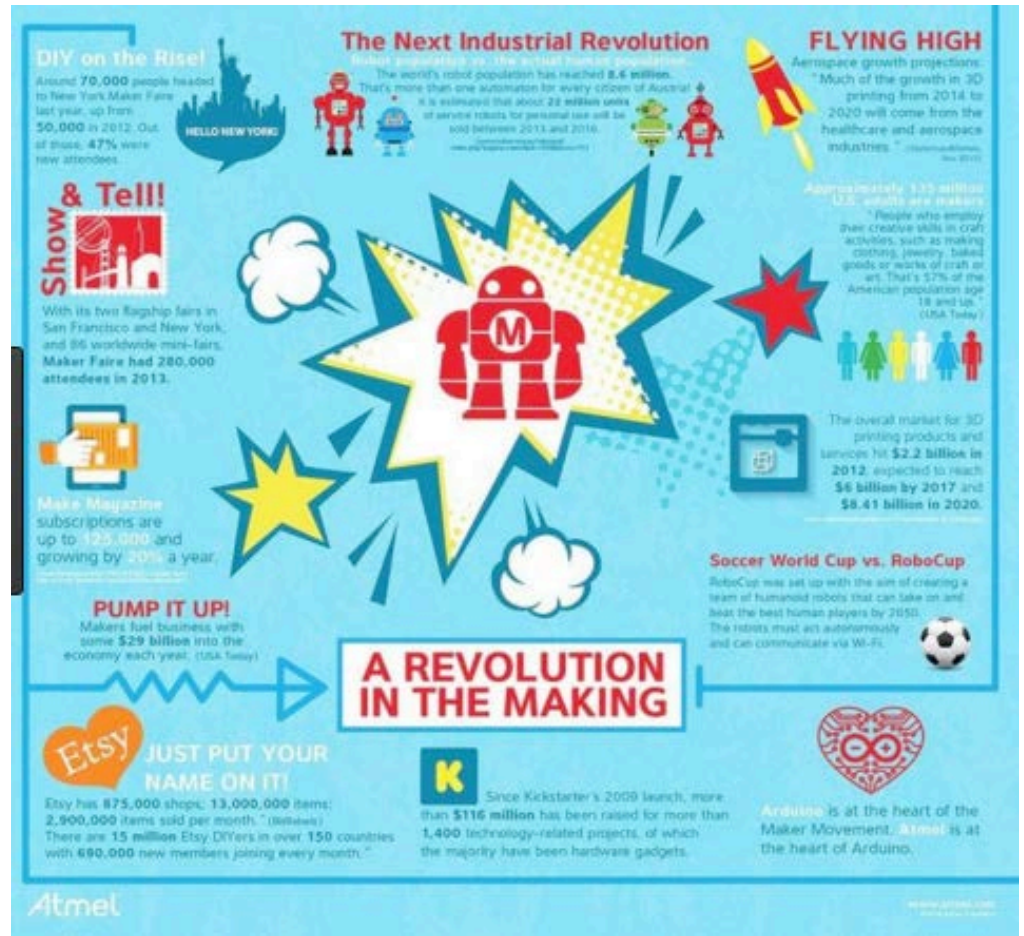
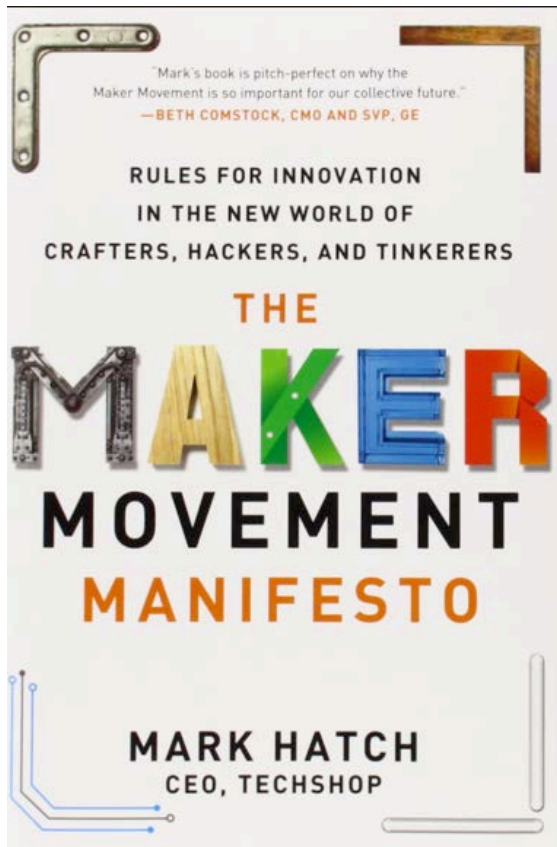


Phoenix Children's Journey Board



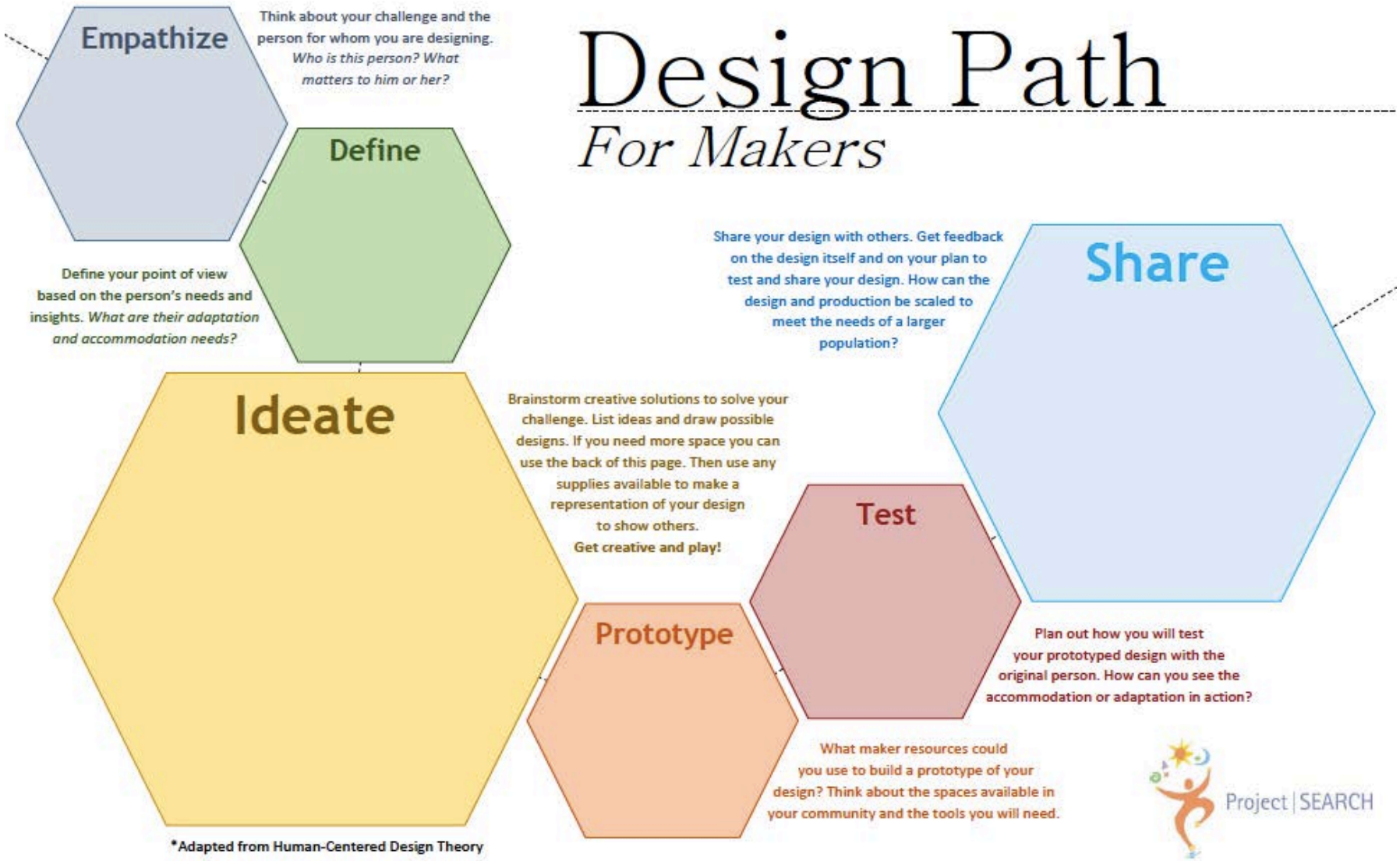
<http://www.phoenixchildrens.org/patients-visitors/during-your-stay/journey-board>

Maker Movement



Design Path

For Makers



Objective 3

Identify five lenses for evaluating m-health patient education apps.

Technology-enabled Patient Education Evaluation

Five Lenses

1. Traditional m-Health evaluation
2. Co-Production
3. Health Literacy
4. Interoperability and Usability
5. Connected Care – Connected Health

Others you have experience with?

Lens 1: Traditional mHealth Evaluation

happtique™
Curated App Boutique

Q 0 SIGN IN / REGISTER

CONDITION FITNESS FOOD LIFESTYLE WELLNESS

The Search for Health Apps Made Easy

Helping you mobilize your health and wellbeing

Start browsing our curated library of apps now!

BROWSE APPS

Let us help you find the best apps to achieve your goals.

CURATE APPS

Curated & Rated by Professionals

Happtique is an intelligence driven curated app boutique that makes it easy for you to discover, download, and manage your apps for a balanced lifestyle. Happtique provides professional reviews and personalized recommendations to help you find the right app for you.

A Operability

During our evaluation of this app, we were able to download, install, and launch this app without any issues.

A+ Functionality

This app has a full range of functionality to help you achieve your goals. There are a range of guided 'quests' you can choose from, each with daily tasks to help you get one step closer to your goal. We also liked that you could recruit friends and family to help you on your journey.

C Usability










Despite there being an orientation experience when you first open the app, it still took some time to learn how to effectively use and navigate through the app.

C+ Consumer Appeal

Despite receiving rave reviews from users, SuperBetter has not gained much popularity in the iTunes store. Also, the developer has not updated the app in over a year.

B+ Privacy & Security

Happtique – Curated Apps, Anxiety

 <p>Consumer App... C- Functionality C Operability A Usability C Privacy & Secur... A-</p> <p>AnxietyCoach Take Control of Your Anxiety</p>	 <p>Consumer App... C- Functionality C Operability A Usability A+ Privacy & Secur... A</p> <p>Anxiety Mint Get Rid of That Anxiety</p>	 <p>Consumer App... C+ Functionality B Operability A Usability B Privacy & Secur... C+</p> <p>Cognitive Diary CBT Self-Help Help With Mind Over Matter</p>
 <p>Consumer App... C+ Functionality C+ Operability A Usability C Privacy & Secur... A+</p> <p>DBSA Wellness Tracker Stay On Top of Your Mental He..</p>	 <p>Consumer App... C Functionality A- Operability A Usability B- Privacy & Secur... A</p> <p>MeQuilibrium Improve Your Mental Strength</p>	 <p>Consumer App... C Functionality A+ Operability A Usability A Privacy & Secur... A</p> <p>MyStrength Take Control of Your Mental H...</p>
 <p>Consumer App... C- Functionality C+ Operability A Usability C+ Privacy & Secur... A-</p> <p>Self Help for Anxiety Manager Help Yourself Today</p>	 <p>Consumer App... C+ Functionality A+ Operability A Usability C Privacy & Secur... B+</p> <p>Superbetter Tackle Your Real Life Challeng...</p>	 <p>Consumer App... C- Functionality C+ Operability A Usability B+ Privacy & Secur... A+</p> <p>T2 Mood Tracker Now You Can Track a Wide Ra...</p>

<http://www.happtique.com/subcategory/ANXIETY>

App Evaluation – ACUT Scores, A, B, C

DIMENSIONS THAT MAKE THE CUT:

- **Operability** - Ensures that the app downloads, installs, and runs appropriately and consistently, and connects with any and all peripheral devices, networks, and third party applications without error or failure.
- **Privacy & Security** - Investigates over 124 app behaviors across five key areas of mobile app privacy and security: (a) Accesses hardware functions (i.e. Bluetooth, camera, etc.), (b) Accesses external storage or cloud servers, (c) Sends data to social networks, Accesses data functions from device (i.e. Address book, SMS messages, Calendar, Location, etc.), (d) Data Encryption/Sensitive Data (i.e. PII, sensitive data), (e) Uses Adware.

DIMENSIONS THAT MAKE THE GRADE:

- **Consumer Appeal** - Examines the current user/consumer ratings based on experience with the app. We also examine and report any feedback regarding the app's appeal from other sources including professionals such as health coaches and physicians.
- **Functionality** - Identifies and evaluates the basic functions of the app relative to its intended purpose including general design, onboarding, and relevance for a user in achieving app related goals.
- **Usability** - Evaluates the user's overall interactive burden with the app, including the ease of use, how quickly the user can master the primary features of the app, as well as how well they can overcome errors.

The ACUT scores are represented by letters A, B, and C

- Dimensions with an A grade (A+, A, or A-) are considered "excellent" and rank in the top segment of our App scores;
 - Dimensions represented by a B grade (B+, B, and B-) are considered "good" and rank in the upper-middle segment of our App scores;
 - Dimensions that have scored a C grade (C+, C, or C-) are considered "fair" and rank in the lower-middle segment of our App scores;
-



One Example: Super Better



Superbetter

SuperBetter, LLC
Tackle Your Real Life Challenges

Categories:

- CONDITION / Anxiety
- CONDITION / Depression
- LIFESTYLE / Energy & Productivity
- LIFESTYLE / Happiness & Humor

App Overview

We believe SuperBetter can help you reach your goals and overcome your challenges, no matter what they might be, in a fun and gamified experience. Embark on daily quests that will put you one step closer to reaching your goals, and battle the bad guys along the way. Earn badges as you complete your daily tasks and level up. You can invite friends and families to be your allies to help you along your journey.

Privacy and Security, for example

- **Based on our APS scanning of the SuperBetter app for iOS:**
 - We observed several app behaviors of which the user should be aware.
 - SuperBetter accesses several hardware and data functions on the device, such as the UDID, which can reveal personal information about the user.
 - The app also connects to social media networks, which can allow it to pull personal data from your online profiles such as post information, phone numbers, or email addresses.
 - It also sends data unencrypted, which can expose it to an attacker while the data is in transit.
 - On a positive note, the app uses security frameworks in the design and coding of the app, which may help prevent common attacks and risks to the user's personal information.
-

Lens 2: CoProduction

- PAM – Patient Activation Measure (10 item Scale)
- Self Efficacy – For Managing Chronic Disease (6 item Scale)
- CollaboRATE (3 item Scale)
- PCM 10Q Talking Mats (10 item scale)

The Four Levels of Patient Activation

LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4
<p>Predisposed to be passive</p> <p>Patients lack the confidence to play an active role in their health.</p> <p><i>'My doctor is in charge of my health.'</i></p> <p>GENERAL POPULATION: 10-15%</p> <p>Source: Insignia Health</p>	<p>Building knowledge and confidence</p> <p>Patients have some knowledge but large gaps remain. They can set simple goals.</p> <p><i>'I could be doing more.'</i></p> <p>20-25%</p>	<p>Taking action</p> <p>Patients have the key facts and are building skills. They are goal-oriented.</p> <p><i>'I'm part of my healthcare team.'</i></p> <p>25-30%</p>	<p>Maintaining behaviors, pushing further</p> <p>Patients have adopted new behaviors but may struggle in times of stress or change. Healthy lifestyle is a key focus.</p> <p><i>'I'm my own advocate.'</i></p> <p>20-25%</p>



Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

- How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do? not at all confident | 1 2 3 4 5 6 7 8 9 10 | totally confident
- How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do? not at all confident | 1 2 3 4 5 6 7 8 9 10 | totally confident
- How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do? not at all confident | 1 2 3 4 5 6 7 8 9 10 | totally confident
- How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do? not at all confident | 1 2 3 4 5 6 7 8 9 10 | totally confident
- How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor? not at all confident | 1 2 3 4 5 6 7 8 9 10 | totally confident
- How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life? not at all confident | 1 2 3 4 5 6 7 8 9 10 | totally confident

Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the six items. If more than two items are missing, do not score the scale. Higher number indicates higher self-efficacy.

PCM 10Q

TalkingMats



Please tick, circle or mark the scale.

How was the therapist at..

1... making you feel at ease?
(being friendly and warm towards you)

poor

fair

good

very good

excellent

does not apply

SDOH key factor in capacity for CoProduction



Published first in July 2016, this toolkit will be updated annually. Social needs programs and research are constantly evolving, so we welcome your feedback, ideas, and suggestions of questions to add to our library – please email us at screening-toolkit@healthleadsusa.org.

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**SOCIAL
NEEDS DOMAIN**

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**KEYS TO A GREAT
SCREENING TOOL**

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**RECOMMENDED
SCREENING TOOL**

Page 7



**SCREENING
QUESTIONS LIBRARY**

Pages 8 - 21

Sources & Additional Options

- [University of Wisconsin County Health Rankings](#)
- [New England Healthcare Institute](#)

screening-toolkit@healthleadsusa.org

Essential Social Need Domains

Representing the most common social needs impacting the health of patients today, these domains are based on findings from IOM, CMS, and Health Leads' two decades of experience implementing social needs programs. We recommend all healthcare systems include these domains in a screening tool for social determinants of health.



SOCIAL NEED DOMAIN	EXAMPLES
Food Insecurity	Limited or uncertain access to adequate & nutritious food
Housing Instability	Homelessness, unsafe housing quality, inability to pay mortgage/rent, frequent housing disruptions, eviction
Utility Needs	Difficulty paying utility bills, shut off notices, discounted phone
Financial Resource Strain ²	Public cash benefits, charity emergency funds, financial literacy, medication under-use due to cost, benefit denial
Transportation	Difficulty accessing/affording transportation (medical or public)
Exposure To Violence ³	Intimate partner violence, elder abuse, community violence
Socio-Demographic Information	Race & ethnicity, educational attainment, family income level, immigration status, languages spoken

- ² Questions about financial resource strain often produce a high false positive rate; review these questions carefully.
- ³ These categories will likely require a more highly skilled workforce than other types of social needs

Every Question rated on 3 dimensions

1. Clinically Validated:

Does the question come from a clinically validated instrument?

-  Question comes from clinically validated instrument
-  Question has not yet been clinically validated




3. Grade Level:

Is the question readable for low literacy populations?

- 5th** Written at a fifth grade level, which most adult populations will understand
- 9th** Written at a ninth grade level, some adults may not understand the question

2. Precision:

Are you looking to get a general understanding of social need prevalence in this domain, or a more specific focus?

-  Broad question, some patients may incorrectly be flagged as having social needs
-  Balanced question
-  Narrow question, some patients with social needs may be missed