2019 Patient-Centered Clinical Decision Support Learning Network Annual Meeting

October 21, 2019
Capital Hilton
Washington, DC
# Agenda for the Day

## Schedule at a Glance

<table>
<thead>
<tr>
<th>Time</th>
<th>Title</th>
<th>Session Speakers</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 AM</td>
<td>Breakfast</td>
<td></td>
<td>Breakfast and opportunity to visit sponsor tables</td>
</tr>
<tr>
<td>8:00 AM</td>
<td>Welcome/Day Plan</td>
<td>Barry H. Blumenfeld, MD, MS</td>
<td>Greetings to attendees and instructions for the day</td>
</tr>
<tr>
<td>8:05 AM</td>
<td>Patient Perspective</td>
<td>Danny van Leeuwen, RN, MPH</td>
<td>Including the patient perspective in CDS</td>
</tr>
<tr>
<td>10:00 AM</td>
<td>Break</td>
<td></td>
<td>Health IT User Experience: 3 Stories, 2 Apps, 1 Vision</td>
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<tr>
<td>10:15 AM</td>
<td>Networking, Sponsor tables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10:15 AM</td>
<td>Presentation from PFWG/Codeathon Introduction</td>
<td>Kensaku Kawamoto, MD, PhD, MHS Danny van Leeuwen, MPH, RN</td>
<td>Dr. Kawamoto and Mr. van Leeuwen present findings from the Patient-facing app working group and describe the Codeathon</td>
</tr>
<tr>
<td>11:00 AM</td>
<td>Moving PCCDS to the Point of Care</td>
<td>Clifford Goldsmith, MD Maria Michaels, MBA, PMP Kristen Miller, DrPH, CPPS</td>
<td>Panel describes their experience with bringing patient-facing CDS more available in the marketplace</td>
</tr>
<tr>
<td>12:00 PM</td>
<td>Lunch</td>
<td></td>
<td>Networking, Sponsor tables</td>
</tr>
<tr>
<td>1:00 PM</td>
<td>Participant Panel on Technical Issues in CDS</td>
<td>Brian Doughty, MSN, RN-BC Gabriella Flynn Med Brian S. Alper, MD, MSPH, FAAFP</td>
<td>A systematic approach for integrating the Palliative Care Planner app into the electronic health records usability evaluation of the mHealth App for Improving HIV Testing Behaviors in High-Risk Young Men Disruptive Innovations to Overcome Healthcare Challenges</td>
</tr>
<tr>
<td>2:00 PM</td>
<td>Creating a Better PCCDS Ecosystem</td>
<td>Jerome Osheroff, MD, FACP Barry Blumenfeld, MD, MS Blackford Middleton MD, MPH, MSc</td>
<td>Panel discussion on the future of PCCDS and how to continue implementing PCCDS</td>
</tr>
<tr>
<td>2:45 PM</td>
<td>Break</td>
<td></td>
<td>Networking, Sponsor tables</td>
</tr>
<tr>
<td>4:00 PM</td>
<td>Closing remarks and Codeathon wrap-up</td>
<td>Barry Blumenfeld, MD, MS Kensaku Kawamoto, MD, PhD, MHS</td>
<td>Dr. Blumenfeld and Dr. Kawamoto discuss follow-on activities from the conference</td>
</tr>
</tbody>
</table>

For all of the conference materials, please visit [https://pccds-ln.org/2019conference](https://pccds-ln.org/2019conference).
• Wi-Fi Code for day **pcdds2019**
• Restrooms are out the door to the right by Federal A and elevator bank
• Breakfast and lunch will be served in lobby
• Codeathon will be in New York
Acknowledgements
Funded by the Agency for Healthcare Research and Quality for its support via a Cooperative Agreement (U18 HS024849).
Project Team

Barry Blumenfeld  Beth Lasater  Laura Marcial  Joshua Richardson
Project Team

Kensaku (Ken) Kawamoto
Blackford Middleton
Jerome (Jerry) Osheroff
Danny van Leeuwen
One Person’s POV

Danny van Leeuwen, Opa, RN, MPH
Health Hats

Website and podcast: https://www.health-hats.com/pod
Support: https://www.health-hats.com/support/
Website and podcast: https://www.health-hats.com/pod
Support: https://www.health-hats.com/support/
Websites and podcast: https://www.health-hats.com/pod
Support: https://www.health-hats.com/support/
Website and podcast: https://www.health-hats.com/pod
Support: https://www.health-hats.com/support/
DANNY VAN LEEUWEN
Learn with people on the journey to best health

Website and podcast: https://www.health-hats.com/pod
Support: https://www.health-hats.com/support/
Co-Designing the Future of Healthcare with Patients & Their Families: Making Decisions Together

Sarah Krüg
Founder, Health Collaboratory
CEO, CANCER101
Executive Director, Society for Participatory Medicine
@sarahkrug1
If you could wave a magic wand and change one thing about healthcare (aside from making it free) ...what would you change?

#magicwandproject
Magic Wand Project

Focus Groups & Data

What are main issues?
Trends?

Identification of Solutions & Gaps

Health Match

Participatory Co-Design

Magic Wand Project
>10,000 Responses
BANISH THE FREE SHOW HOSPITAL GOWN
SIMPLIFY IT.
I NEED A BETTER ROADMAP.
We have developed a matchmaking platform to connect you with solutions to address issues you might be experiencing. As you navigate these resources, please take the time to tell us how effective they were by rating them. Don’t see your issue listed here, Tell us about it!

What do you need help with?

- Find a Doctor
- Cost of Care
- Manage Symptoms
- I’m Feeling Alone
- Legal issues
- I Need an Escape
- Care Partner Support
- Talking to Kids About Cancer/Child Care
- Lodging & Transportation
- Home/Care Coordination
- Work issues
- Self Image & Sexuality
Cost of Care

Below you will find resources/services specific to Cost of Care. These are general resources. To see resources specific to a particular condition, select Type of Condition below.

To see additional resources, descriptions and ratings, please join our community! Join Now

Personalize Your Search
Type of Condition
Select Condition type

What type of resources are you looking for?
- Select All
- Articles (56)
- Books (2)
- Brochures (2)
- Hotlines (1)
- Online Communities
- Mobile Apps
- Podcasts
- Videos (2)
- Live Support Groups

Sort By
Select Sort option

Narrow Down Your Search
Enter keyword or title

Search

ZERO360: Comprehensive Patient Support
by ZERO - The End of Prostate Cancer
A free, comprehensive patient support service to help patients and their families navigate insurance and financial
Read More

ASCO Answers: Clinical Trials Coverage through the Affordable Care Act
by CancerNet
Fact sheet about Clinical Trials Coverage through the Affordable Care Act
Read More

Managing Long Term Financial Concerns
by Cancer Support Community
Webinar about coping with the cost of care. Discusses financial concerns, unexpected expenses, obtaining
Read More

Patient Assistance Programs
by Good Days
Provides financial support by covering prohibitively costly co-pays for those with life-altering conditions, financial
Read More

Managing Costs of Prostate Cancer Care
I NEED A HEALTHCARE GPS.
INFORMATION OVERLOAD!
PRESCRIBE SOCIAL SUPPORT.
Participatory Co-Design

Who was involved?

- 125 Patients & Caregivers
- 22 Clinicians
- 58 Advocacy Partners
- 4 Academic Centers
- 3 Pharmaceutical/Biotech Companies
- 18 Reviewers/Content Experts
The trusted ecosystem focused on YOU, your health, and navigation of next steps.

- Solving a Problem
- How Do I Best Learn?
- Cool Technologies
- You Are How You Live
- Research & Clinical Trials
- Connect With Others
- Health Tips & Life Hacks
- Where Do I Start?
Normal cells in your body have a particular job to do and grow and divide in an orderly way. Normal cells die (called apoptosis) and new cells take their place. Cancer is when this process breaks down and those cells begin to grow and divide out of control.

There were approximately 18 million people diagnosed with cancer around the world in 2018. Lung and breast cancers are the most common cancers globally. Colorectal cancer is the third most common cancer. 9.5 million men were diagnosed with cancer in 2018, and the most common sites were lung, prostate, colon, rectum, stomach and liver. 8.5 million women were diagnosed with cancer in 2018 and the most common sites were breast, colon, rectum, lung, cervix and stomach.

A healthy lifestyle, cancer screening, early detection, and understanding any changes in your body are all imperative to your health. You can also reduce your risk of cancer by making healthy choices such as watching what you eat, limiting how much you drink, staying physically active, and not smoking.
I am recommending a few resources for you to use to learn more about your options. You can also access other educational resources in this system as well. If you have any questions, please do not hesitate to contact our office.

**WAR ON CANCER**
Description: A resource that guides the patient through their cancer journey and follow up care, enabling the patient to document experiences in a way that complements objective healthcare data gathered during the care process and make informed decisions.
www.waroncancer.org

**CANCER101 PLANNER**
Description: A resource that guides the patient through their cancer journey and follow up care, enabling the patient to document experiences in a way that complements objective healthcare data gathered during the care process and make informed decisions.
www.cancer101.org

**CANCER SURVIVAL BIBLE**
Description: A resource that guides the patient through their cancer journey and follow up care, enabling the patient to document experiences in a way that complements objective healthcare data gathered during the care process and make informed decisions.
www.csb.org

Clinician can “prescribe” resources
Would’ve, Should’ve, Could’ve...

We work with hundreds of thousands of patients each year and often they share their stories. What do I wish I had known? What would I have done differently? Here we have compiled the top tips based on the stories of patients, care partners and healthcare professionals. Do you have a tip or life hack based on your health experience?

Please share with us!

- Ten Things Every Patient Needs to Know
- Top 10 Tips to Avoid Medical Errors
- Top 10 Tips to Manage Costs of Care
- What to do During Visit With Your Doctor
- Do You Know Your Healthcare Team?
- Our Love/Hate Relationship with Technology
Circle of Care
Do you Know the Members of Your Health Care Team?
Tensions

Legacy “Best Practices”  What Patients/Caregivers Want
CANCER101 (C101) Overview

Our Mission

To empower, inform and engage patients and their caregivers to take control over their diagnosis, navigate the cancer journey, and partner with their healthcare team to make informed decisions.

Who We Are

To fulfill its mission, C101, founded in 2002:
- Meets the cancer patient and caregiver on the front line and turns a chaotic experience into a calm and organized plan of attack
- Provides innovative tools and resources patients and caregivers need to manage chronic condition in partnership with the healthcare team, allowing them to document their day to day life experiences
- Creates a comprehensive roadmap for patients by filtering “garbage from gold”, aggregating best practice content through partnerships with other organizations in order to avoid “recreating the wheel”, and creating new content to address unmet needs
- Personalization of the patient experience...one patient at a time through tailored education based on personal profile

CANCER101 has been Featured:

The New York Times  abc Good Morning America  NYSE  abc NEWS  The White House  Biden Cancer Initiative
Overview

CANCER101 guides patients through the cancer journey by:

- Igniting a **participatory relationship** between patient, caregiver and clinician at the point of care, encouraging partnership that converges a patient’s **day to day life expertise with a clinician’s medical expertise**
- Providing information to **support decision making**
- Deploying tools to track and manage symptoms and medications
- Arming patients with a platform to keep it all organized
- Facilitating **coordinated cancer management** between patients, caregivers and the medical community
- Enabling patients to document **experiences** in a way that complements objective healthcare data gathered during the care process

Touch Points

Reach 100,000 patients/ caregivers annually
300,000 requests for planners

CANCER101’s Reach

We partner with > 1200 cancer centers and community oncology practices to disseminate tools in 50 states & Canada with requests from over 40 countries.
To Tech or Not to Tech: That is the Question

table of contents

Introduction
Acknowledgments
A Note to the Reader
How to use the CANCER101 Planner and Four Important Things You Need to Know
Help Other Survivors
1. myCANCER101 – Personalize Your Planner
2. Calendar Planner and Notes
3. Address Book
4. Medical History & Appointment Tracker
5. Symptoms Tracker
6. Medical Bills and Insurance Tracker
7. Questions to Ask Your Doctors by Cancer.Net
8. What is a Clinical Trial? by the Coalition of Cancer Cooperative Groups
9. National Cancer Resources
10. Dictionary of Cancer Terms by National Cancer Institute
The Metamorphosis

How Might We...

- Redesign the Toolkit so that it’s supportive, motivational, organizational, AND educational?
- Leverage technology so that we can personalize the educational journey in a meaningful way?
- Build a relationship with the “whole person” diagnosed and their family through engaging techniques beyond initial interface?
- Personalize how we measure impact?
• 101 Patients & Caregivers
• Information & Graphic Designers, Health Literacy & Patient Education Experts
• HCPs
• Other Disciplines
Point of Care Connections

1. myCANCER101
   Get Informed.

2. myNavigator
   Take Control. Navigating your Care.

3. myToolbox
   Stay Organized.

4. Questions to Ask The Doctor

5. Clinical Trials
   What are my options?

6. Medicine & Symptom Tracker
   Mind your Medications.

7. Managing Costs of Care
   How do I pay for treatment?

8. Mind, Body & Connections
   Wellness101.

9. C101 Lifesavers
   Caring for the Caregiver.

10. Resources
    Dictionary of Terms & Support.

Clinician Prescribes C101 Planner

With permission from patient, survey data can be aggregated and shared with clinician

Patient & Caregiver
Learn, Engage, Share Decisions, Track Partner

Patient completes survey on condition and how planner helped improve journey
myCANCER101
Where Do I Start?

myNAVIGATOR
Take Control, Navigating Your Care.
myTOOLBOX
Stay Organized.

LIFE IS A BLANK CANVAS
AND AS THE PAINTER
THAT HOLDS THE BRUSH,
WE ARE ALL ARTISTS OF
THE PATH AHEAD.

QUESTIONS TO ASK YOUR
HEALTHCARE TEAM
CLINICAL TRIALS
What Are My Options?

MEDICINE & SYMPTOM TRACKER
Mind Your Meds.
C101 LIFESAVERS
Caring for the Care/Support Partner.

RESOURCES
Dictionary of Terms and Support.
A Dose of Sunshine

To address the ripple effects of cancer for the patient and family during treatment our goal is to create a program where the patient and family will receive a subscription box each month to help motivate, educate and keep them engaged. Monthly packages will consist of health and wellness samples, educational tips around various dimensions of life, life hacks and stories around readjustment.
Tensions

Legacy
“Best Practices”

What Patients/Caregivers Want
Key Takeaway #1

What matters most to patients and their families?

“Back to Basics” Approach to Innovation
ASK ME WHAT I THINK BEFORE YOU BUILD IT AND THEN LET ME HELP YOU BUILD IT...
Where do we go today?

- Patient Influencers
- Patient Advocacy Organizations
- Expert Patients
- Social Listening-Open Forums
- Online Communities-Closed
- Patient Family Advisory Councils

Are we reaching the average patient/caregiver affected by a condition?

RAW and unfiltered perspectives are often overlooked in healthcare
The Issues Today

- Who represents the voice of patient today?
- Alignment-right patient for right project
- Lack of diversity
- Variation in compensation
- Training & support
Challenges--What Patients Said...

- Not able to understand agreements or terms...
- Not enough time to prepare
- Negotiation process for payment or scope of...
- Not enough information or insight provided...
- Inconsistency in payment across different...
- Burden of administrative requirements: too...
- Not sure what is expected me or expectations...
- Insincere interest or lack of respect for...
- Not enough resources for participation (travel,...

Percentage of Patients
The Good, The Bad & the Ugly-
What Patients Said...

Positive Experiences

▪ “Was recognized as a patient and got to sit in the front row with dedicated chairs for patients.”

▪ “Preparation is key, providing the context for the work, the desired outcomes of the partnership and the expectations for result in high value partnerships.”

▪ “Intelligent people sitting and talking to me as if I were a consultant”

▪ “Training, support, inclusion, celebratory & all participants excited to be involved”
The Good, The Bad & the Ugly—What Patients Said...

NOT so Positive Experiences

- “I didn’t get to sit with everyone else. Kind of felt like I had to sit with other patients and felt a bit excluded.”

- “All other members at the table paid (often handsomely) and no one even thought to see that the patient voice was at least as important as other board members.”

- “Being ignored or requested to share but then cut off by someone else or running out of time.”

- “Token patient/caregiver who is not considered an equal to others who are participating.”

- “...Not clear about why they are engaging patients and families, which makes setting expectations difficult. Organizations that focus solely on sharing patient stories miss the opportunity for co design.”
Co-designing the Future of Healthcare for Patients WITH Patients

>18,000 Patients & Care Partners

Patient/Family Education

Technology

Concepts & Strategies

Research & Clinical Trial Design

Services/Processes/Policies

Retrospective Assessments

The Patient Shark Tank® is a platform created to integrate the voice of the patient, caregiver (and even clinician) voice in the design, development and/or continuous improvement of innovations.
Patient Shark Tank®

>840 innovations

Virtual build underway to engage patients/caregivers remotely

Training & Coaching

Feedback Loops.

Certification & Standards

Co-Designed Scorecard

Health Literacy. Connectivity. Motivation to use/apply. Data
Patients/Caregivers utilize standard 12-part scorecard co-designed with patients/caregivers to assess intervention but also reflect personal perspective.
Patient Shark Tank® Models

- The Traditional Model
- The Bi-Directional
- The Deep Dive
- Co-Design
- Traveling Co-Design Lab
- Pathway Mapping
The Traditional Model

- Organization has a series of cancer digital and paper based innovations they are launching
- Five innovations are presented to Patient Shark Tank® as prototypes
- Patients/caregivers use abbreviated version of scorecard to assess resources reflecting on individual health experiences
- Scoring and feedback is aggregated and provided to organization in form of a report, which organization uses to enhance prototypes
- Organization presents next version of resources to patient/caregivers prior to launch obtaining additional insights, some of which are incorporated into v2
- Clinicians are also brought into conversation to determine how innovations fit into workflow and how data aggregated by patient may be acted upon by clinician
The Deep Dive

- **Landscape Assessment**: What’s out there? What’s working? What’s not? What do patients/caregivers like and not like about some of these other innovations? Where is there true unmet need?
  - Prior to building an app, 40 patients/caregivers review 10 other apps that have been pre-selected by organization
  - Patients/caregivers use scorecard to assess different apps, conduct a comparative assessment, and also provide specific feedback based on questions that organization wants to learn to determine unmet need. Perspectives are consolidated in a report that will allow organization to understand unmet needs and avoid pitfalls of building an app that no one uses

- **Health Literacy & Readability**: How easy and intuitive is this innovation to navigate and understand on my own without any additional help from others?
  - To ensure that a new website, meets health literacy and readability needs, an organization requests a thorough review by 50 patients and caregivers. Feedback on readability is assessed with any words that aren’t understood highlighted.
The Patient Shark Tank® Goes to Harvard Medical School: A Year Long Co-Design Program

- Innovation Accelerator Program
- Patient and Caregiver perspectives embedded into year-long curriculum to ensure needs, barriers, preferences, concerns, and values well understood allowing for unmet needs to serve as the foundation to concepts, ideas, and eventually innovations
- Patients served as partners on cross-functional teams focused on tackling key issues in healthcare
- Continuing education was woven into curriculum
- Concepts were pitched to different set of patients/caregivers on Patient Shark Tank
- Innovators went back to drawing board incorporating feedback from Patient Shark Tank
- Innovators pitched prototypes to Patient Shark Tank®
- Feedback incorporated into final innovations that were then tested by Patient Shark Tank®
Key Takeaway #2

Leverage RAW & Diverse Perspectives
DON’T JUST GIVE ME THE DATA. GIVE ME THE TOOLS AND RESOURCES TO UNDERSTAND THE DATA.
Factors that Impact Decision-Making

- Environment
- Emotions
- Comprehension
- History
The words we use matter...

If we follow the ripple effect of our words to understand the emotions and/or behaviors they might potentially trigger, would it force us to pause, think and perhaps communicate differently?
Patient Engagement

“Last I checked, engagement was a formal agreement to get married. How does that apply to healthcare??”

“It’s a paternalistic term. If I don’t want to track my symptoms using your app and don’t want a weekly call, does it make me non-engaged? I don’t always want to be reminded that I am sick but I’m managing my health to the best of my ability, while managing life. Why does it have to be one size fits all?”
Patient-Centric

“This seems fairly new and I hear it all the time now. What were you focused on before you became patient-centric? It makes me wonder if this is just marketing buzz. Also, if the goal is partnership (and maybe on even terms), shouldn’t I be part of the circle instead of in the middle?”
Patient Journey

“A 6 day trip to an exotic place that I’ve happily planned with an origin and destination is a journey. The multiple sclerosis I have or the cancer my husband got a few years ago—that’s not a journey!”

#wordsdomatter
How Do You Prefer to Learn?
<table>
<thead>
<tr>
<th><strong>Visual Learners</strong> see color, size and shape</th>
<th><strong>Auditory Learners</strong> prefer details, vocal presentations and audiotapes</th>
<th><strong>Kinesthetic Learners</strong> prefer to put their hands on and touch something</th>
<th><strong>Linguistic Learners</strong> want to consume information through words</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual</td>
<td>Auditory</td>
<td>Kinesthetic</td>
<td>Linguistic</td>
</tr>
<tr>
<td>See it</td>
<td>Hear it</td>
<td>Touch it/Do it</td>
<td>Read/write it</td>
</tr>
<tr>
<td><strong>Visual</strong> Learners see color, size and shape</td>
<td><strong>Auditory</strong> Learners prefer details, vocal presentations and audiotapes</td>
<td><strong>Kinesthetic</strong> Learners prefer to put their hands on and touch something</td>
<td><strong>Linguistic</strong> Learners want to consume information through words</td>
</tr>
<tr>
<td>Create diagrams of what they hear. Prefer pictures, illustrations &amp; visual cues</td>
<td>They pay attention to speaker’s voice – tone, energy, pitch</td>
<td>Like to participate in groups and moving about doing several different activities</td>
<td>Enjoy reading, take exhaustive notes &amp; even “rewrite their notes”</td>
</tr>
<tr>
<td>Run movies in their minds and like to read</td>
<td>Play tape recorder in their minds</td>
<td>The re-live the sensation or the feeling they experienced</td>
<td>They are often addicted to internet, lists, quotations, words, and POWERPOINT!</td>
</tr>
</tbody>
</table>
LEARNING PREFERENCE BAROMETER

How do you prefer to receive information? How do you prefer to learn? Receiving information in a manner that you best understand can help you cut through the clutter as you navigate healthcare. Please answer a few short questions to determine what type of learner you are.

**Are you a** Visual Learner? Auditory? Linguistic? Kinesthetic?

Let's Get Started
Learning Preference Barometer
Please answer a few questions to help us determine your learning preferences.

2. When you are searching the internet, you prefer websites that have:

- Interesting design and visuals
- Audio channels where I can listen to interviews or music
- Written descriptions, lists and explanations that I can easily print
- Page that are interactive, where I can click on different sections and try various things
Thank you for your responses.

Many of us have more than one way that we prefer to receive information and this may change over time. Based on your responses, your preferred learning method is Linguistic.

Your secondary learning method is Auditory.

Be sure to share your learning preference with your doctors and healthcare team!

Learn more about the Preferences by clicking on them.
Science of patient engagement framework is backbone of P2L created to distinguish and define the various phases of educating/engaging the patient/caregiver to allow us to align the right resource with the right patient at the right time.

Each resource tagged with phase in the MPC to allow us to identify trends in engagement based on journey phase and gaps that may exist, including those between the patient and clinician.

Objective of MPC is to provide the healthcare community with a standard method of defining engagement method and creating scales to measure the impact of patient/caregiver educational/support interventions.
Key Takeaway #3

Personalization.

**Context is everything.**

Right resource at the right time.
HOW DO I KNOW WHO I CAN TRUST?
A Word About Trust & Data

• How is data being collected, protected, stored, shared?

• How is de-identified data being used?

• What are underlying motivations of organization?

• As the amount of available health data increases so does the hesitancy for patients to share that information due to privacy/security issues and data breaches

• 75% of respondents say they won’t buy a product from a company – no matter how great the product – if they don’t trust company to protect their data, while 60% ranked a potential war less concerning than cybersecurity-IBM Survey
"It's Time For a Code of Ethics in Patient Education"
Healthcare Confessions™

>5,000 anonymous stories collected.
Key Takeaway #4

Building
TRUST
is an invaluable currency
Learn with people on the journey to best health.
Art & Science of Patient Story
“Stories are Data with a Soul”

Life Impact Factor
Emotional Journey Barometer
Patient Doctor Tango Score
Key Takeaway #5

Recognize the whole person, not just the patient and their disease
If I could wave a magic wand...
What matters most to patients and their families?

“Back to Basics” Approach to Innovation
Leverage RAW & Diverse Perspectives
Personalization.

Context is everything.

Right Resource at the Right Time
#4

Building

TRUST

is an invaluable currency
Focus on the whole person, not just the patient and their disease
Questions

sarahkrug@cancer101.org

@sarahkrug1
Health IT User Experience:

3 stories
2 apps
1 vision

Ted Melnick, MD, MHS
Assistant Professor of Emergency Medicine
Program Director, Yale/VA ACGME Clinical Informatics Fellowship
Principal Investigator, EMBED Trial Network

October 21, 2019
Disclosures

- The work presented here has been supported by:
  - The Agency for Healthcare Research and Quality
    - Award Number K08HS021271
  - The National Institute on Drug Abuse
    - Award Numbers: UG3DA047003 & UH3DA047003
  - National Institutes of Health (NIH) Health Care Systems Research Collaboratory by the NIH Common Fund through cooperative agreement U24AT009676 from the Office of Strategic Coordination within the Office of the NIH Director

- The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or the Agency for Healthcare Research and Quality.
Story #1: Computers in the Exam Room & the Patient Experience
Story #2: The Desktop Computer & Usability in Healthcare
World War II era radar with cathode ray tube
Flexibility – Usability Tradeoff
Design Thinking

- Brown. *HBR* 2008
- Gibbons. [https://www.nngroup.com/articles/design-thinking/](https://www.nngroup.com/articles/design-thinking/)
### Academic vs Pragmatic Usability Testing

<table>
<thead>
<tr>
<th>Academic usability</th>
<th>Pragmatic usability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Objectives</strong></td>
<td></td>
</tr>
<tr>
<td>• Publication and dissemination</td>
<td>• Rapid iterative design</td>
</tr>
<tr>
<td>• Rigor &amp; reproducibility</td>
<td>• Speed &amp; cost-effectiveness</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td></td>
</tr>
<tr>
<td>High-fidelity, representative testing environment and tasks</td>
<td>Convenience over fidelity</td>
</tr>
<tr>
<td><strong>Number of participants</strong></td>
<td></td>
</tr>
<tr>
<td>• 15+</td>
<td>• &lt;10, (typically &gt;4)</td>
</tr>
<tr>
<td>• Priority: representative users</td>
<td>• Priority: convenience &amp; within time constraints</td>
</tr>
<tr>
<td><strong>Data capture &amp; analysis</strong></td>
<td></td>
</tr>
<tr>
<td>• Full data capture for detailed analysis</td>
<td>• Close to real-time analysis</td>
</tr>
<tr>
<td>• Quantitative emphasis</td>
<td>• Concise, structured summary</td>
</tr>
<tr>
<td><strong>Termination criteria</strong></td>
<td></td>
</tr>
<tr>
<td>Based on data saturation</td>
<td>Based on consensus, cost, and time constraints</td>
</tr>
</tbody>
</table>

Mann. *JMIR Human Factors 2018*
Story #3: Diffusion of Innovations (and evidence-based medicine)
Ether vs Anti-Sepsis vs Handwashing


Lister. Lancet. 1867
Diffusion of Innovations

- Rogers. *Diffusion of Innovations* 1962
- Gladwell. *Tipping Point* 2000
- Dearing & Cox. *Health Affairs* Feb 2018
Parameters of a typical diffusion study

- Rogers. *Diffusion of Innovations* 1962
- Gladwell. *Tipping Point* 2000
- Dearing & Cox. *Health Affairs* Feb 2018
App #1: Concussion or Brain Bleed
Understanding Overuse Of CT For Minor Head Injury In The ED: A Triangulated Qualitative Study

Sir Luke Fildes’ *The Doctor*, 1887

Acad Emerg Med. 2015;22(12):1474-83
## The Canadian CT Head Rule

<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Sensitivity for intervention</th>
<th>Sensitivity for injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Derivation</td>
<td>3121</td>
<td>100%</td>
<td>98%</td>
</tr>
<tr>
<td>Validation</td>
<td>1822</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Implementation</td>
<td>4531 (897)</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>External validation</td>
<td>431</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

## Implementation Imaging Rates

<table>
<thead>
<tr>
<th>Decision Rule</th>
<th>N</th>
<th>Pre-implementation</th>
<th>Post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>C-Spine</td>
<td>11,824</td>
<td>62%</td>
<td>53%</td>
</tr>
<tr>
<td>Head</td>
<td>4,531</td>
<td>63-68%</td>
<td>74-76%</td>
</tr>
</tbody>
</table>

Objective & Methods

▪ To identify factors that promote or inhibit appropriate use of CT in ED patients with minor head injury.

▪ Urban Level I Trauma Center ED
  ▪ Satellite Community ED

▪ Patient Focus Groups: 4 groups, 22 subjects
  ▪ Provider Focus Groups: 3 groups, 22 subjects
  ▪ Cognitive task Analysis: 4 SMEs

▪ Iterative Qualitative Analysis: Constant Comparative Method
“Every patient has a different stomach for uncertainty. Right? What I would love is a way to screen... If I could just figure out who can tolerate ambiguity and who cannot tolerate ambiguity and uncertainty and then have a tailored way to explain it to them, that would be ideal. But you can’t.”
"To cover his ass. Before this, years ago, before Sonny Bono died and hit his head and there was a Kennedy who hit his head. These were celebrities. Now they just run them through. They are so paranoid. CAT 'em. CAT 'em. CAT 'em. CAT 'em. CAT 'em."
“For me personally, you could have the head of the medical school come and tell me that there’s no risk in terms of waiting on the CAT scan, and I would just say, ‘Look it’s not your daughter.’ ... I would just say ‘No, let’s risk it.’ Because it’s a short-term risk that she’s not going to wake up ... A long-term risk of cancer just doesn’t do it... I have a very consumer-driven approach to medicine—that I am buying a product.”
Is a picture worth 1000 words?
“Give it the time it takes to make me feel better”
Patient-Centered Decision Support

- **Back to the Bedside: Developing a Bedside Aid** for Concussion and Brain Injury Decisions in the Emergency Department. *EGEMS* 2015

- **Formative Usability Evaluation** of Integrated Clinical Decision Support With a Patient Decision Aid for Minor Head Injury in the Emergency Department. *J Med Internet Res* 2017

- Tablet-Based Patient-Centered Decision Support for Minor Head Injury in the Emergency Department: **Pilot Study**. *JMIR Mhealth Uhealth* 2017
Conceptualization of the workflow and potential pathways for the Concussion or Brain Bleed application

CONCUSSION OR BRAIN BLEED?

INJURY EVALUATOR

RISK VISUALIZATION
- HIGH RISK
- MEDIUM RISK
- LOW RISK

RISK DISCUSSION
- Evidence DOES support getting a CT
- "You can't see concussion on CT?"

CONSIDERATIONS
- CLAUSTROPHOBIA
- RADIATION
- TIME
- COST
- SYMPTOMS
- DANGER
- DURATION
- HOW TO HEAL
- FOLLOW-UP

Email or text handout to patient
Review decision and prepare EHR note
Concussion or Brain Bleed?

Let’s talk about how we tell the difference

IMPORTANT NOTE

This decision tool is designed for use with people who...
- DO NOT have a bleeding disorder
- DO NOT use a prescription strength blood thinner like coumadin
- DID NOT have a seizure after their injury
YOUR INJURY IS LOW RISK.

This means that the current risk of finding a brain bleed on CT scan for 100 people like you is...

- 97 people will not have a finding of brain bleed on CT scan
- 3 people will have a brain injury seen on CT scan which may or may not be a brain bleed
- 1 person would have their care plan changed (e.g. staying in the hospital longer)
- 0 people will have a finding that requires surgery or some other invasive procedure
With a **LOW RISK** injury, the best evidence **DOES NOT** support getting a CT scan for your injury.

What you likely have is a concussion.

A concussion can happen when the brain moves around in the skull.

**A concussion is not a brain bleed and you cannot see a concussion.**

Concussions do **not** show up on CT scan. Brain bleeds do.

Are you surprised that you can’t see concussion on CT scan?

How comfortable do you feel not getting a CT scan?

What are you most concerned about?
Pilot Study Results

▪ 41 patient convenience sample with 29 clinicians
▪ Patient knowledge increased before and after app use
  – 1.4 more questions correct out of 9: pre-encounter, 3.3 vs post-encounter, 4.7; 95% CI 0.8-2.0
▪ 7 (17%) patients received a head CT in the ED
▪ RCT of app underway at Mayo Clinic, PI Neha Raukar

*JMIR Mhealth Uhealth* 2017
App #2: EMBED

EMBED:
PRAGMATIC TRIAL OF USER-CENTERED CLINICAL DECISION SUPPORT TO IMPLEMENT EMERGENCY DEPARTMENT-INITIATED BUPRENORPHINE FOR OPIOID USE DISORDER
Background: OUD

- Opioid use disorder (OUD): Dependence on opioids or heroin
- 3 million Americans have or have had OUD
- 47,000 deaths in 2017 (5.9x higher than 1999)

Source: Centers for Disease Control and Prevention, National Center for Health Statistics. Multiple Cause of Death 1999-2017 on CDC WONDER Online Database, released December, 2018
Background: MOUD

- Emergency department (ED)
  - 420,000 visits in 2011
  - Vulnerable time
  - ED-initiated buprenorphine with referral for ongoing MOUD doubles rate of engagement in addiction treatment
  - Large survival benefit
  - 12 months after ED visit, 1/3 on treatment

- How can we EMBED this life-saving treatment into routine emergency care?

LaRochelle. *Annals of IM* 2018

Williams. *AJDAA* 2018
User Centered Design: To simplify the process from a complicated algorithm...

ED-Initiated Buprenorphine

Diagnosis of Moderate to Severe Opioid Use Disorder
Assess for opioid type and last use
Patients taking methadone may have withdrawal reactions to buprenorphine up to 72 hours after last use
Consider consultation before starting buprenorphine in these patients

COWS

(0-7) none - mild withdrawal
(>8) mild - severe withdrawal

Dosing: None in ED
Waivered provider able to prescribe buprenorphine?

YES
Unobserved buprenorphine induction and referral for ongoing treatment

NO
Referral for ongoing treatment

Prescription
16mg dosing for each day until appointment for ongoing treatment

Dosing: 4-8mg SL*
Observe for 45-60 min
No adverse reaction
If initial dose 4mg SL repeat 4mg SL for total 8mg
Observe **
Waivered provider able to prescribe buprenorphine?

YES

NO
Consider return to the ED for 2 days of 16mg dosing (72-hour rule)***
Referral for ongoing treatment

Notes:
*Clinical Opioid Withdrawal Scale (COWS) ≥ 13 (Moderate-Severe) consider starting with 8 mg buprenorphine or buprenorphine/naloxone SL
** Patient remains in moderate withdrawal may consider adding additional 4mg and observation for 60 minutes
***Consider high dosing in consultation with an Addiction Medicine Specialist
Warm hand-offs with specific time & date to opioid treatment providers/programs within 24-72 hours whenever possible
All patients should be educated regarding dangers of benzodiazepine and alcohol co-use
Ancillary medication treatments with buprenorphine induction are not needed
...to a simple, automated application
Clinicians continue in their current Epic workflow
Clicking the ‘EMBED’ button in the patient’s chart launches the app.
App offers care pathways & patient assessment tools with the flexibility to use just the parts you need.
Launching a care pathway automatically generates the appropriate documentation, orders, and referral in Epic.
After signing the orders, the clinician continues to use Epic
## Pilot Study Preliminary Results

<table>
<thead>
<tr>
<th></th>
<th>Pre-Intervention Apr-Aug 2018 N (%)</th>
<th>Post-intervention Apr-Aug 2019 N (%)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phenotype positive patients</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>289</td>
<td>304</td>
<td></td>
</tr>
<tr>
<td><strong>BUP Initiation in the ED</strong></td>
<td>11 (3.8%)</td>
<td>24 (7.9%)</td>
<td>0.035</td>
</tr>
<tr>
<td><strong>Referral for ongoing MOUD</strong></td>
<td>53 (18.3%)</td>
<td>53 (17.4%)</td>
<td>0.77</td>
</tr>
<tr>
<td><strong>Naloxone Prescription</strong></td>
<td>10 (3.5%)</td>
<td>40 (13.2%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td><strong>X-waivered Attending Physicians</strong></td>
<td>34/52 (65.4%)</td>
<td>38/53 (73.1 %)</td>
<td></td>
</tr>
</tbody>
</table>
EMBED: Intervention & Outcomes

• **Setting**: 20 Emergency Departments (EDs) across 5 healthcare systems

• **Intervention**: The intervention consists of a user-friendly, integrated IT intervention to support:

• **Primary Outcome**: Initiation of BUP in the ED (administered and/or prescribed)
EMBED Teams, People & Sites

1. **YALE (Epic)**
   - PILOT: YNHH-YSC
   - INTERVENTION:
     - SRC - Meir Dashevsky, MD
     - GH - Christopher Davidson, MD
   - CONTROL:
     - BPT - Lisa Sander, MD
     - L&M

2. **UNC (Epic)**
   - Intervention: Rex, Nash
   - Control: Main, Chatham, Johnston-Smithfield
   - PI: Timothy Platts-Mills, MD, MSc
   - Co-PI: Mehul Patel, MS, PhD
   - IT: Edmund Finerty
   - Data: Bill Korey Ross, Emily Pfaff

3. **UAB (Cerner)**
   - Intervention: Gardendale
   - Control: Main Campus, Highlands
   - Site PI: Erik P. Hess, MD, MSc
   - IT, Data - Carolyn Williams

4. **COLORADO (Epic)**
   - Intervention: UC Hospital AMC, Poudre Valley + Med Center of Rockies cluster
   - Control: Memorial Central
   - PI: Jason Hoppe, MD
   - IT, Data - Sean Michael, MD
   - Proj Coord – Cheryl Napier

5. **BAYSTATE (Cerner)**
   - Intervention: Main Campus- Baystate Springfield; Baystate Wing; Baystate Mary Lane
   - Control: Baystate Franklin; Baystate Noble
   - Site PI: William Soares MD
   - Data – Haiping Li
   - IT - Tech Spring Christian Lagier

DATA TEAM (Yale)
- James Dziura, PhD, MPH
- Charles Lu
- Fangyong Li, MPH, MS
- Liliya Katsoyich – PM
- Haseena Rajeevan, PhD
- Fan Li, MS, PhD
- David Chartash, PhD
- Molly Jefferey, PhD – Co-PI at Mayo Clinic

LEADERSHIP/MANAGEMENT TEAM
- Ted Melnick, MD, MHS - PI
- Gail D’Onofrio, MD, MS – Co-PI
- Bidisha Nath – Project Manager

GRANTS TEAM/Dept of EM
- Theresa Odyniec - Budget, Finance
- Ann Criscuolo, Admin
- Shara Martel, Project Manager

IT TEAM (Yale)
- Cynthia Brandt, MD, MPH
- Allen Hsiao, MD – CMIO
- Yauheni Solad, MD, MHS
- Hyung Paek, MD
- YNHH-Epic Analysts
  - Nancy Rutski
  - Cheryl Brophy
  - Kristina Folio
  - Michelle DeWitt

Summer Medical Students
- Wesley Holland, MS2, YSM
- Jodi Mao, MS3, EVMS
- Osama Ahme, MS3, YSM

DESIGN TEAM
- Mathew Maleska, MBA
- Jessica Ray, PhD

SYSTEMS

2019
One Vision: To accelerate the improvement of the Health IT user experience
## Healthcare Usability Maturity Model

### UNRECOGNIZED
- Lack of awareness of usability.
- No practices, policies or resources.

### PRELIMINARY
- Sporadic inclusion of usability.
- Very limited resources.

### IMPLEMENTED
- Recognized value of usability.
- Small team responsible for usability.

### INTEGRATED
- All benchmarks of usability implemented.
- Dedicated user experience team.

### STRATEGIC
- Business benefit well understood.
- Usability mandated.
- Budget and people part of each year’s results.
- Budget used strategically throughout the organization.

HIMSS Usability Task Force 2011
System Usability Scale (SUS) Score

Thank you.

Questions?

email: edward.melnick@yale.edu

Twitter: @Ted_Melnick
Annual Meeting: Patient-Facing CDS Working Group (PFWG)

Monday, October 21, 2019
Background - Charge

Focus on development and implementation of standards-based patient-facing CDS applications

- The specification and creation of a **prototype application** in the pain management domain
- The development of a set of **human-centered usability design guidelines** for patient-facing PCCDS applications
- **Recommendations for actionable steps** that interested stakeholders could take to advance from prototype to use by patients, caregivers, and direct care clinicians
Background - Participants

- Academics/Researchers
- App Developers
- EHR Vendors
- Direct Care Clinicians
- Policy Makers
- Patients
Objectives

- **Describe** background for the PFWG
- **Demonstrate** CDS-app prototype
- **Contrast** CDS expert features with patient expert needs
- **Distill** Minimum Viable Product (MVP)
- **Explore** lessons learned about citizen expert engagement
Patient-facing CDS Prototype
Demo App Objectives and Approach

▪ Objectives
  – Provide demo of SMART on FHIR approach to patient-facing app
  – Leveraging EHR PHR login

▪ Approach
  – Start with provider-facing SMART on FHIR app for opioids developed with prior CDC/ONC/AHRQ support
  – Connect with Epic PHR login
  – Develop sandbox environment
App Development: Authorization, User Authentication and Launch

Display App Launch Page → Launch Page → User Clicks “Launch” → App attempts to authorize → Displayed: EHR Login Screen

Return to app with “access_denied” state

cancelled

Displayed: EHR Login Screen → Login successful?

yes → Obtain access_token

no → Show Login Denied page

Obtained access_token?

yes → Retrieve FHIR Resources → Display Results

no → Show Denied Page
CDS Experts Listing Problems and Potential Solutions
### Problems and Potential Solutions - Example

<table>
<thead>
<tr>
<th>Problem</th>
<th>Potential Solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing, communicate care plan efficiently to others</td>
<td>Source of truth for care plan</td>
</tr>
<tr>
<td>With information on past and present and verification steps</td>
<td>Example: living with sickle cell, when you have pain and a pain management plan, in the ED you are not treated as a drug seeker but can refer to care plan (pain plan)</td>
</tr>
<tr>
<td>Difficulty managing, making, remembering appointments</td>
<td>Appointment reminders, Self-scheduling</td>
</tr>
<tr>
<td>Maintaining contact between visits</td>
<td>Better management of combined human and non-human information needs and availability</td>
</tr>
<tr>
<td>Both FAQ and direct</td>
<td></td>
</tr>
<tr>
<td>Unfamiliar with medical condition</td>
<td>Training or education materials/modules</td>
</tr>
<tr>
<td>Need for contextual or personalized intervention or information peer and professional</td>
<td>Location-based or contextual prompts from app to connect with coach/agent</td>
</tr>
<tr>
<td>Examples: in the case of pain recurrence or patient stored notes in prep for visits</td>
<td></td>
</tr>
<tr>
<td>Behavior change difficult to manage without clear reward</td>
<td>Need incentives to help manage pain</td>
</tr>
<tr>
<td>Example: reward or gamify achievements like successful pain management</td>
<td>Low cost accessible testing to verify</td>
</tr>
</tbody>
</table>
Patient expert perspective (1 of 2)

- Everyone, including me, knows and accepts my **health goals** and **care plans**
  - Must capture personal data and goals including limitations (e.g., hypersensitivity) and expectations (e.g., efficacy)
- I know my **care team** and we all know how to reach each other. I know where to go for answers to my questions when I have them.
  - Communication must be bidirectional and well supported
Patient expert perspective (2 of 2)

- My doctors, caregivers, and I make decisions about my **care plan** together as I am able
  - Must be goal alignment and it must be ongoing

- My **care plan** makes sense to me and I can do it.
  - Must be care coordination and it must be clear that the patient is the final arbiter whenever possible, but this is a weighty job/role

- My **care plan** is coordinated, tracked, and prioritized
  - Must be trust, assume compliant first
Putting it all together – Themes

- **Plan:** Set goals (both personal and clinical) and associated integrated care plan based on circumstances, preferences, values, and shared decision making
- **Communicate:** Enable seamless multidirectional communication between medical and lay teams
- **Adjust:** Record, manage, track, evaluate and prioritize to adjust integrated care plan and personal and clinical outcomes
- **Support:** Engage medical, peer, and community support for the integrated care plan
Minimum Viable Product

- **Central pain management care plan**
  - Hosted by trusted entity

- **Patient-centered**
  - Patients can edit/correct, comment, set goals, track progress, document history, etc.

- **Verifiable**
  - Verified MD login or SMART on FHIR connection
  - Clear which aspects have sign off by MD

- **Useful**
  - Pre-set plan templates with educational resources
  - Can be copied into EHR
Lessons Learned

- Focus on an **Integrated Care Plan**
- Must include the voice of **people at the center of care** (patients, caregivers, direct care clinicians) from planning to dissemination
- Evangelize and spread **what’s working**
- Don’t underestimate:
  - The **lag** of technology to meet the need
  - The impact of **misaligned incentives**
  - The parable of the **blind people and the elephant**
What’s Next?

▪ Continue this conversation!
▪ Ensure seats at the table for people at the center – realize user-centered design
▪ Advocate for MVP progress
▪ Align with related initiatives
▪ Spread the word about what works
Moving PCCDS to the Point of Care
Towards Computable Guidelines and Beyond

Maria Michaels
Public Health Advisor for the Deputy Director of Public Health Science and Surveillance Centers for Disease Control and Prevention
Why do we need computable guidelines?
The Data Lifecycle & Impacts to the Public’s Health

Delivering actionable knowledge

Updating scientific evidence

Knowledge

Analyzing data to advance evidence

Information

Data Science
Analytics
Data Linkages
Data Visualization

DATA

Point of Care
Emergency Response
Public Health Departments
Community Services

ACTION

Health Impacts & Outcomes

EHRs
Registries
Public Health Info Systems
Community Info Systems
PEOPLE (Patient-Reported)

Guidelines
Recommendations
Guidance
Public Health Policies or Mandates

UPDATING
SCIENTIFIC
EVIDENCE

INFORMATION

2019
Today’s Guideline Development and Implementation

Develop guidelines

- Research Results
- Literature Review
- Meta-analysis

Interpret guidelines

- Guideline released
- Clinicians hear about guideline
- Additional/conflicting guidelines?
- Convene internal clinical workgroup
- Determine which guideline (and which part(s)) to implement
- Adjust CDS as needed
- Test within workflow with actual users
- Multiple system tests
- Implement CDS tool in test system
- Review existing CDS tools
- Conduct workflow analysis

- Release CDS tool into production system
- Monitor CDS tool for issues & monitor for updates to guidelines
- Issue & update

Performed by up to 96% of ~5500 hospitals
Performed by up to 86% of ~355,000 clinics

https://dashboard.healthit.gov/quickstats/quickstats.php

Implement guidelines
How can we achieve computable guidelines?
Multi-stakeholder CDC Kaizen Event

- “Adapting Clinical Guidelines for the Digital Age Meeting” – Feb 5-9, 2018
- Incorporates all relevant perspectives in both a strategic and tactical method FROM THE BEGINNING
- Achieves big changes in short order (i.e., weeks instead of years)
- Provides transparency among participants, which contributes to high level of buy-in & better understanding of the challenges from each perspective
Participating Stakeholder Groups

- Guideline authors
- Health IT developers
- Communicators
- Clinicians
- Patients / Patient Advocates
- Medical Societies
- Public Health Organizations
- Evaluation experts

- Standards experts
- Clinical decision support developers
- Clinical quality measure developers
- Policy or technical support for implementation
CDC Kaizen Event: Scope & Value Streams

**SCOPE:**
- **START:** Guidelines Creation
- **END:** Evaluation

**VALUE STREAMS (Focus Areas):**
- Guidelines Creation
- Informatics
- Dissemination and Communication
- Translation and Implementation
- Evaluation
Adapting Clinical Guidelines for the Digital Age

**Problem:** Long Lag Time, Inconsistencies, and Inaccuracies in Translation

leads to an average of 17 years for scientific evidence to apply in patient care

**Reason:** Playing the “Telephone Game”

Multiple translations of guidelines add complexity, opportunity for error, and variation across sites/providers

**Solution:** Developing Tools and Guidelines Together

Can help evidence apply to patient care more easily, quickly, accurately, and consistently

https://www.cdc.gov/ddphss/clinical-guidelines/index.html
How can we develop and implement computable guidelines at scale?
Adapting Clinical Guidelines for the Digital Age: Redesigning Guideline Development and Implementation

CURRENT STATE

Guidelines
Informatics
Implementation
Evaluation (maybe)

Patient Care
CDS

10s-100s of translations
100s-1000s of translations

Inconsistent (or nonexistent) feedback loop

CQMs

PROPOSED FUTURE STATE

Guidelines
Informatics
Implementation
Evaluation (including Patient)

Local Implementation

Concurrent guideline development and translation & upfront planning

Consistent feedback loop

Patient Care

Guidelines, CDS, & CQMs

https://www.cdc.gov/ddphss/clinical-guidelines/index.html
<table>
<thead>
<tr>
<th>Knowledge Level</th>
<th>Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>L1</td>
<td>Narrative</td>
<td>Guideline for a specific disease that is written in the format of a peer-reviewed journal article</td>
</tr>
<tr>
<td>L2</td>
<td>Semi-structured</td>
<td>Flow diagram, decision tree, or other similar format that describes recommendations for implementation <em>(HUMAN READABLE)</em></td>
</tr>
<tr>
<td>L3</td>
<td>Structured</td>
<td>Standards-compliant specification encoding logic with data model(s), terminology/code sets, value sets that is ready to be implemented <em>(COMPUTER/MACHINE READABLE)</em></td>
</tr>
<tr>
<td>L4</td>
<td>Executable</td>
<td>CDS implemented and used in a local execution environment (e.g., CDS that is live in an electronic health record (EHR) production system) or available via web services</td>
</tr>
</tbody>
</table>

Adapted from: Boxwala, AA, et al.. A multi-layered framework for disseminating knowledge for computer-based decision support. *J Am Med Inform Assoc* 2011(18) i132-i139.
Implementation Guide: FHIR Clinical Guidelines

Clinical Practice Guidelines - CI build (v0.1.0). See the Directory of published versions

1.0.0 FHIR Clinical Guidelines

This Implementation is organized with the following sections, accessible via the menu bar at the top of every page:

- **Home**: The home page provides summary and background information
- **Profiles**: Index of all profiles
- **Artifacts**: Index of all artifacts (e.g. activity and plan definitions)
- **Terminology**: Index of all terminology (e.g. code systems and value sets)
- **Examples**: Index of examples
- **Extensions**: Index of extensions
- **Documentation**: Index of specification documentation

- **Approach**: Describes the overall approach taken to representing computable guideline content
- **Terminology**: Describes expectations for terminology defined as part of computable guideline content
- **Profiles**: Describes expectations for profiles defined as part of computable guideline content
- **Libraries**: Describes expectations for the use of libraries as part of computable guideline content
- **Recommendations**: Describes how recommendations are structured and distributed
- **Care Planning**: Describes expectations for the use dynamic care planning with computable guideline content

- **Downloads**: Downloads for the specification
- **Checklists**: Checklists provided for moving guideline content from L1-L4
- **Version History**: Index of all versions of this implementation guide


“CPG-on-FHIR”

Balloted at HL7, a health IT standards development organization

Establishes a standard way to represent the information in clinical guideline recommendations so it can more readily be translated into clinical decision support internationally
Complete Feedback Loop

CLINICAL DECISION SUPPORT

CLINICAL QUALITY MEASUREMENT

DO

STUDY

PLAN

ACT

CLINICAL GUIDELINES DEVELOPMENT

DESIRED HEALTH ACTIONS & OUTCOMES

2019
For questions or more information on this presentation please contact:

Maria Michaels, maria.michaels@cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention
Patients as Partners in CDS - Process Improvement

Technology-accelerated Collaborative Framework Using Rare Disease as an Example

Clifford Goldsmith, MD
US CMO and National Director, Providers
Microsoft Corporation
Innovations don’t just take root in Healthcare

“Many of these devices help solve the problem of what gift to give a loved one during the holidays. But few of these devices solve major health problems.”

Forbes
Quality X Engagement = Excellence

- Transparency
- Crowd-sourcing
- Collaboration
- Augmented Intelligence
Co-Design

**Clinician, Admin, Support Staff, Patients**

**Leadership Culture**
- Sets targets, ROI

**Context and Opportunities**

**System Convening**

**Virtual Participant Ideation**

**Synthesis**

**Iterate candidate solutions**

**Leadership, QI Team, Analysts, IT**

**Prototyping and Execution**
The Five I’s

- Initiate
- Ideate
- Iterate
- Implement
- Interoperate
Initiate

- Top Down and Bottom Up
- Create Culture of Growth Mindset
- AI and Analysts - Data Scientists and QI - Set Target ROI
- Identify Target Scenarios
- Develop Hypothetical Outcomes
- Link to Best Practices, Evidence, etc.
“Culture eats strategy for breakfast.”

Peter Drucker
Evolving Will Take Time

Digital transformation in Health can't take root without cultural transformation

Learn and iterate
Create meaning
Make it real
Activate

2019
Ideate and Iterate

- Confirm Desired Outcome and Success Criteria
- Ideate New Digital Process / Digital Experiences and Journeys
- Bottom Up
- Everyone Collaborates
- Iterate Around a Framework of the Patient Journey
- QI Department Provides Care and Feeding for the Process
An approach that makes complexity more manageable

*Build Around the Patient Journey*

![Patient Journey Diagram](image-url)
Ending the Diagnostic Odyssey of Rare Diseases

Patient-Specific Activities

- Provider Encounter
- Encounter Closing
- Post Encounter Activities

EHR ML Agent

Populations at Risk, Awareness

Foundation

Provider Finder Visit Mgr.

Pre-Visit Checklist

Daily Care Team Huddle

Patient Nurse Bot

Check-in

Pre-Encounter Activities

Monitor Between Visits

Facial Recognition

Patient Coordinator Bot

Social

MD Bot

Nurse Bot

Population Health
Implement

- Develop and Deploy New Digital Tools and Experiences
- Common Understanding
- Buy In
- Automates Clear Diagrams, Training Materials
- Measures Outcomes

In the end, this is all about people and processes.
Interoperate

✓ Cross Target synergies to avoid inefficiencies using a common, cloud-based QI process repository

✓ Cross Organization collaboration for best practices using a common, cloud-based repository
Follow-up:

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Microsoft Corporation

clifgold@Microsoft.com

Cell 617-823-8328
Harnessing Human Factors in Patient-Centered CDS

Kristen Miller, DrPH, CPPS
Scientific Director, National Center for Human Factors in Healthcare, MedStar Institute for Innovation
Associate Professor of Emergency Medicine, Georgetown University School of Medicine
Affiliate Faculty, Innovation Center for Biomedical Informatics, Georgetown Medical Center
Does Current Health IT Support Patient Care?

**Problem List**

**Ongoing**
- Anxiety
- Benign essential hypertension
- Bladder cancer
- CVA (cerebral vascular accident)
- Depression
- DM - Diabetes mellitus
- Hand tingling
- Hematuria
- HTN - Hypertension
- Hyperlipidemia
- Incontinence
- UTI - Urinary tract infection
- Wears glasses

**Problem List**

**Ongoing**
- Abdominal aortic aneurysm
- Chronic renal failure
- Depression
- Dizziness
- Hearing loss
- Hypertension
- Lymphoma
- None reported
- Peripheral neuropathy
Rollin J (Terry) Fairbanks, MD MS @TerryFairbanks · 10 Jun 2018
My #EHR is not helping me represent myself very well today as a clinician who knows my patient. #EHRbugList

Social History
Smoking Status - 06/10/2018
Unknown if ever smoked

Smoking Status
Tobacco Use: Never Used (06/10/18)

Lab Results

Other Labs
4. When I ordered US for both legs, they had to get scheduled separately, so my pt had to come back to the hospital 2x to get them done! obvi my error, but why couldn't it default to "bilateral" when I ordered? Isn't EHR supposed to help improve human deficiencies?

#EHRbuglist
Does Current Health IT Support Patient Care?
Optimizing Health IT as a Tool for Patient-Provider Interaction

Essential for:
- Following evidence-based practice for optimal and accurate diagnosis and clinical management
- Establishing a meaningful patient-provider relationship
- Facilitating education and counseling patients

Advancing Clinical Knowledge at the Point of Care

- Right Data
- Usability
- Right Design
Right Data
Signal Detection Theory

noise

signal
Signal Detection Theory

Missed Alarm  criterion  False Alarm

noise  signal
Case Study No. 1: Spinal Cord Compression

Acute spinal cord compression (SCC) is a triple threat:

▪ Rare
▪ Difficult to diagnose
▪ Likely to result in devastating, irreversible neurological outcomes if not treated in a timely manner

MedStar SCC Task Force:

▪ No delay diagnosis
▪ No delay imaging
▪ No delay definitive care
Data: 27,440 ED encounters [8/16 – 9/18] with SCC alerts
- 395 out of 27,440 (1.4%) had a MRI_STAT ordered.
- 392 features per ED encounter.

Assumption: MRI_STAT orders indicate a high perceived likelihood of SCC by the EM physician.

Model Inputs: SCC alert and chief complaint (free-text).

Analysis: Random forest and logistic regression used to predict if MRI_STAT would be ordered. 10 cross-fold validation applied. Cost matrix used to reduce the number of false negatives.
Applying Signal Detection Theory

<table>
<thead>
<tr>
<th>SCC Detection Tool Tool +</th>
<th>Cord Compression +</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Hit</strong></td>
</tr>
<tr>
<td></td>
<td>True Positive (TP)</td>
</tr>
<tr>
<td>SCC Detection Tool Tool -</td>
<td>Cord Compression -</td>
</tr>
<tr>
<td></td>
<td><strong>False Alarm</strong></td>
</tr>
<tr>
<td></td>
<td>False Positive (FP)</td>
</tr>
<tr>
<td></td>
<td><strong>Miss</strong></td>
</tr>
<tr>
<td></td>
<td>False Negative (FN)</td>
</tr>
<tr>
<td></td>
<td><strong>Correct Reject</strong></td>
</tr>
<tr>
<td></td>
<td>True Negative (TN)</td>
</tr>
</tbody>
</table>
## Machine Learning Results

### Random Forest

<table>
<thead>
<tr>
<th>Cost</th>
<th>1</th>
<th>10</th>
<th>100</th>
<th>10^3</th>
<th>10^4</th>
<th>2x10^4</th>
<th>5x10^4</th>
</tr>
</thead>
<tbody>
<tr>
<td>TP</td>
<td>28</td>
<td>28</td>
<td>29</td>
<td>47</td>
<td>338</td>
<td>387</td>
<td>395</td>
</tr>
<tr>
<td>FP</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>194</td>
<td>15,937</td>
<td>23512</td>
<td>26971</td>
</tr>
<tr>
<td>FN</td>
<td>367</td>
<td>367</td>
<td>366</td>
<td>348</td>
<td>57</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>AUC</td>
<td>.741</td>
<td>.741</td>
<td>.757</td>
<td>.758</td>
<td>.733</td>
<td>.721</td>
<td>.703</td>
</tr>
</tbody>
</table>

### Logistic Regression

<table>
<thead>
<tr>
<th>Cost</th>
<th>1</th>
<th>10</th>
<th>100</th>
<th>10^3</th>
<th>10^4</th>
</tr>
</thead>
<tbody>
<tr>
<td>TP</td>
<td>18</td>
<td>103</td>
<td>222</td>
<td>270</td>
<td>395</td>
</tr>
<tr>
<td>FP</td>
<td>50</td>
<td>893</td>
<td>5316</td>
<td>8962</td>
<td>27044</td>
</tr>
<tr>
<td>FN</td>
<td>377</td>
<td>292</td>
<td>173</td>
<td>125</td>
<td>0</td>
</tr>
<tr>
<td>AUC</td>
<td>.762</td>
<td>.761</td>
<td>.749</td>
<td>.735</td>
<td>.5</td>
</tr>
</tbody>
</table>
Right Design
Case Study No. 2: Medication Alerts

Pregnancy/Lactation Alert

Patient reported she is breastfeeding. Documented on Nursing Profile, 06/15/15 11:49

Please consider this information and amend your orders, as needed. The hospital formulary includes information on the pregnancy/breastfeeding category of individual medications.
<table>
<thead>
<tr>
<th>Human Factors Principle</th>
<th>Summary of Principle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alarm Philosophy</td>
<td>Logic used to clarify alert priority levels, catalogued and available. Should capture user acknowledgement and response</td>
</tr>
<tr>
<td>False Alarms</td>
<td>Up to date, accurate, and intelligently calibrated alarms to reduce irrelevant alarm triggers</td>
</tr>
<tr>
<td>Placement</td>
<td>Optimized alert visibility through deliberate screen placement (close proximity to current task)</td>
</tr>
<tr>
<td>Visibility</td>
<td>Overall screen-size of the alert (target size), luminance, background contrast, and lettering characteristics.</td>
</tr>
<tr>
<td>Prioritization</td>
<td>Match appearance of the warning to the level of hazard associated with the clinical implications of the alert. To address color-blind users’ needs, signal words and shapes can be used to communicate the priority and level of hazard</td>
</tr>
<tr>
<td>Color</td>
<td>Used to indicate severity, type of alert, or required response. Using more than 10 colors could make it difficult for users to remember what each color indicates.</td>
</tr>
<tr>
<td>Learnability/Confusability</td>
<td>User ability to learn and distinguish between different types of visual alerts. Fewer shared features make alerts appear more distinct, making it easier for users to recognize and remember different alert types.</td>
</tr>
<tr>
<td>Textual Information</td>
<td>Effective text content should contain: (1) signal word to indicate alert severity, (2) statement of the nature of the hazard, (3) instruction statement with recommended actions, (4) a consequence statement indicating the potential patient harm. Numbers (2) and (3) are the most important components.</td>
</tr>
<tr>
<td>Habituation</td>
<td>Habituation predicts that repeated exposure to an alert that does not require that a meaningful response will result in a decrease, and eventual elimination, of responding to the alert. Draws on principles of alarm philosophy, false alarm rate, and visual distinction</td>
</tr>
<tr>
<td>Mental Model</td>
<td>Represents the understanding individuals have about a particular topic. Given that mental models govern users’ behavior, alerting systems should adequately support pervading mental models</td>
</tr>
<tr>
<td>Proximity of Displayed Task</td>
<td>Tools for decision-making should be integrated into the body of the alert or found within close temporal and spatial proximity to the alert.</td>
</tr>
<tr>
<td>Components</td>
<td></td>
</tr>
</tbody>
</table>
I-MeDeSA Instrument (Zachariah, et al)

- Instrument for evaluating the Human-Factor Principles in Medication-Related Decision Support Alerts (I-MeDeSA)
  - Developed and validated to allow EHR designers to examine the compliance of alerts with human factors principles

- I-MeDeSA scores alerts on the following nine human factors principles:
  - Alarm philosophy, placement, visibility, prioritization, color learnability and confusability, text-based information, proximity of task components being displayed, and corrective actions.

- Each principle exists as a construct of individual questions that are scored.
  - There are a total of 26 questions (or items) across nine constructs. Each item receives a score of ‘1’ if the item characteristic is present and a score of ‘0’ if it is absent.
Example: Good Design
The Special Population Warning scored the highest (19/26)

Example: Poor Design
The Pregnancy/Lactation Alert scored the lowest (8/26)
Redesign

Why/ Risk/ Action Framework

- Why the alert was triggered
- The risk to the patient
- Recommended actions
- Uses the signal word Warning
- Allows corrective action other than acknowledgement of having seen the alert
- Color and icon (alarm philosophy)
- “Opt-out”
Usability
Case Study No. 3: Cardiac Risk

- Cardiovascular disease remains the leading cause of death in the US.
- The AHA/ACC recommend use of the Atherosclerotic Cardiovascular Disease (ASCVD) risk estimator: evaluates 10-year and lifetime risk for ASCVD.
- Variables include:
  - Age and Race
  - Cholesterol levels (HDL, LDL)
  - Blood pressure
  - Use of statin therapy
  - Antihypertensive medication
  - Use of aspirin therapy
  - Smoking status
  - Diabetes status
Workflow Analysis: Methods and Results

- Stakeholder Interviews
  - 6 Cardiologists, 7 Primary Care Physicians, 4 Care Navigators

- Clinical observations
  - 30 hours = 34 observed patient visits

- Data Analysis
  - “Work-as-imagined” versus “Work-as-done”

3 Main Uses
- To educate patients about managing cardiovascular risk.
- To aide in clinical decision making about whether or not to prescribe a statin.
- To identify, in borderline cases, whether or not a patient is at risk of cardiovascular disease.
### ASCVD Risk Estimator

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Value</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systolic Blood Pressure (mm Hg)</td>
<td>125</td>
<td></td>
</tr>
<tr>
<td>Diastolic Blood Pressure (mm Hg)</td>
<td>78</td>
<td></td>
</tr>
<tr>
<td>Total Cholesterol (mg/dL)</td>
<td>212</td>
<td></td>
</tr>
<tr>
<td>HDL Cholesterol (mg/dL)</td>
<td>39</td>
<td></td>
</tr>
<tr>
<td>LDL Cholesterol (mg/dL)</td>
<td>154</td>
<td></td>
</tr>
<tr>
<td>Hypertension Treatment</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Statin</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Aspirin Therapy</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>History of Diabetes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Smoker</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>47</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>African American</td>
<td></td>
</tr>
</tbody>
</table>

**Risk Calculation:** 5.4%

**Risk Category:** Borderline Risk

**Quick Links:**
- Clinical Guidelines
- ASCVD Risk Educator
## ASCVD Risk Educator

(Any changes entered here will not be added to the Medical Record)

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systolic Blood Pressure (mm Hg)</td>
<td>150</td>
</tr>
<tr>
<td>Diastolic Blood Pressure (mm Hg)</td>
<td>80</td>
</tr>
<tr>
<td>Total Cholesterol (mg/dL)</td>
<td>210</td>
</tr>
<tr>
<td>HDL Cholesterol (mg/dL)</td>
<td>45</td>
</tr>
<tr>
<td>LDL Cholesterol (mg/dL)</td>
<td>160</td>
</tr>
</tbody>
</table>

### Risk of having heart attack or stroke within 10 years

- **You are here**
- **15.5%**
- **High Risk**

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>On Hypertension Treatment?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>History of Diabetes?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Current Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Race</td>
<td>White</td>
<td>African American</td>
</tr>
<tr>
<td>On a Statin?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Smoker?</td>
<td>Yes</td>
<td>Former</td>
</tr>
<tr>
<td>On Aspirin Therapy?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
Usability Testing

- **Formative Usability Testing**
  - 8 Cardiologists, 7 Primary Care Physicians

- **Areas of Interest for our Prototype**
  - Display
  - General Content
  - Functionality
Take-Away Points

- Challenges to optimize patient-centered CDS exist from both data analytics and informatics perspectives.
- Effective solutions must satisfy a number of constraints arising from clinical needs, social interactions, cognitive limitations, and healthcare policy.
- Solutions must be designed with appropriate considerations of the actual work environment, and must compensate for known human abilities, limitations, and baseline human error rates while considering demands of the complex healthcare environment.
Lunch

- Served in lobby area outside room
- Networking opportunity
- Visit the Codeathon happening in New York room
- Reconvene at 1:00
PCCDS-LN Contact Information

For updates on future events and activities of the PCCDS Learning Network please check out our website at

www.pccds-ln.org

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– Beth Lasater, MSPH (boverman@rti.org)