Welcome!
Meeting Logistics

WiFi Access:
- Network Name: @Hyatt_meeting
- Access code: PCCDS2017 (case sensitive)

Bathroom Access:
- Bathrooms are located on this level

Breaks:
- Light refreshments will be served during the break in the hall

Lunch:
- Lunch will be served in the hall at 12:00 this will be an opportunity to network with colleagues.
- Abbott (one of our sponsors) will be hosting a discussion – look for the identified table

Links:
- Conference materials: https://pccds-ln.org/annual-conference
- Conference Evaluation form: https://goo.gl/forms/QsHfIXlRSIZiz1LD2
Thank You to Our Platinum Level Sponsor!

Platinum level including:
- Support for breakfast and lunch
- Patient advocate scholarship

Look for the Abbott Table at Lunch!
HLN is a leading Open Source software developer in the area of clinical decision support in various domains including immunization evaluation and forecasting, and electronic case reporting. While its major focus has historically been on public health, many of its projects involve and apply equally to other participants in the healthcare ecosystem. Increasingly, patients are accessing systems that directly use the output of HLN's CDS algorithms.

DynaMed Plus has the mission to provide the most useful information to health care professionals at the point of care. By continuously monitoring and synthesizing patient-centered evidence and guidance for point-of-care reference support DynaMed Plus can provide and maintain the most reliable level 1 knowledge artifacts for patient-centered clinical decision support. The publisher, EBSCO Health, is expanding the mission to provide the most useful support for healthcare decision-making. This includes reference centers for all healthcare professionals and patients and patient decision aids or conversation aids to facilitate shared decision making.
The PCCDS Learning Network - Thanks AHRQ!

Support from AHRQ grant 1U18H5024849-01
The PCCDS Learning Network and eGEMS partner to advance evidence on patient-centered clinical decision support

Since 2016, RTI International has led the Patient-Centered Clinical Decision Support Learning Network, which is funded by the Agency for Healthcare Research and Quality (AHRQ).

As part of that project, RTI International and AcademyHealth are partnering to launch a regular special section in AcademyHealth’s open access, peer-reviewed online journal eGEMs that will focus on Patient-Centered CDS...
Introducing the PCCDS Learning Network Resource Center

Resource Center

This Resource Center is intended to accelerate the development of patient-centered clinical decision support to help catalyze the unfolding transformation towards patient-centered health care.

This collection of CDS-related resources points to information that can be useful in driving these patient-centeredness goals and they are divided into categories which reflect sequential elements that can facilitate this transformation:

- **EVIDENCE**: Findings and evidence-based guidelines to enhance clinical care which could be implemented via PCCDS
- **STANDARDS/TOOLS**: Rules, methods or utilities that can be used for structuring or delivering PCCDS interventions
- **ARTIFACTS/REPOSITORIES**: PCCDS interventions such as tools to gather, transmit and provide feedback and guidance on patient-generated health data (Artifacts), and collections of such artifacts (Repositories)
- **INITIATIVES/LITERATURE**: Material describes development, implementation, and/or results from specific PCCDS approaches more broadly

Please help us make this a valuable tool for leveraging CDS to make health care more patient-centered by providing feedback to the Learning Network on the use and usefulness of this information. To propose an entry to the Resource Center, please complete a submission form.
Plan for the Day

- **Plenary session:**
  - Dana Lewis
  - Ken Kawamoto, MD, PhD, MHS, FACMI

- **Panel discussion:**
  - Edwin Lomotan, MD
  - Jonathan S. Wald, MD, MPH
  - William Lawrence, MD, MS
  - Blackford Middleton, MD, MPH, MSc

- **Networking lunch**

- **Moderated breakout discussions on PCCDS:**
  - For Patient Engagement
  - Measurement and Outcomes
  - User Needs and Technologies
  - For Continuous Learning
What is Patient-Centered Clinical Decision Support?
The Ingredients

Evidence +
(CER, PCOR)
Patient-Centered Clinical Decision Support (PCCDS) is:

CDS that supports individual patients and their approved care givers and/or care teams in health-related decisions and actions by leveraging information from patient centered outcomes research findings and/or patient-specific information (e.g. patient-generated health data).
What PCCDS Must Not Be...

PATIENT-CENTERED CARE

Concept by Sachin Jain, Art by Matthew Hayward © 2014 All Rights Reserved
Plenary Session
Articulating and Achieving a Compelling Vision for PCCDS
Healthcare Shift from Provider-centric to Patient-centric
Imagine the following...

Mr. Stuart:

- 60 year old male
- increased blood pressure (BP) in drug store
- sister w/ history of heart attack

- Uses evidence based risk assessment tool
- Links to vetted, personalized information
- Selects provider w/practice approach that match what he’s looking for
- Completes online profile w/info on concerns, understanding, care goals
- Scheduler matches openings w/ his e-schedule. Personalized visit prep info
Clinician Mary Smith:

- Uses huddle tool to **flag home BP monitoring guidelines**; team ‘pends’ orders
- Orders with a tablet to provide **unobtrusive documentation support**

- **Joint care plan, supported by helpful tools for** shared decision making (SDM)/ documentation/ ordering

- Evidence-based prevention **plan/orders** leverage external data

- **Personalized information tools**: lifestyle changes, prostate cancer screening

- BP cuff/app: **records, averages, transmits** BP. **Guidance** on elevations

- Apps/tools help Mr. Stuart **develop, monitor, and adhere to** lifestyle regimens
Personalized Acute Problem Management

- Chest discomfort; *individualized symptom/history tool* suggests calling 911.
- Paramedics/Emergency Dept. *access Community Health Record*; diagnosis=heart attack (MI)

- In hospital, latest, *evidence-based, MI management protocols* executed
- *Patient-centered documentation tools, order sets*, other PCCDS approaches help *individualize care*
- *Tablet-based tools* help him *express questions/needs/input* to care plan; *understand* tests/treatments; *drive* his care
- After discharge, similar *PCCDS/SDM* approaches are used to *design and implement* a rehabilitation plan aligned with his priorities/constraints
Our Plenary Speakers

Dana Lewis, Patient Advocate, Inventor and Founder

Why I built an artificial pancreas
(and why #WeAreNotWaiting to change the rest of healthcare, too)

Kensaku (Ken) Kawamoto, MD, PhD, MHS, FACMI

Enabling Patient-Centered Decision Support at Scale through Multi-Stakeholder Collaboration: Why It’s Needed, How We Could Get There

Kensaku Kawamoto, MD, PhD, MHS, FACMI
Associate Chief medical Information Officer
Assistant Professor of biomedical informatics
University of Utah
Why I built an artificial pancreas
(and why #WeAreNotWaiting to change the rest of healthcare, too)
Getting diagnosed with a chronic disease is like being struck by lightning.
Food, hormones, sickness, stress

Insulin, exercise, sickness, stress
“Diabetes is the ultimate DIY. *It has to be* – people make up to 300 decisions daily that impact their blood glucose.”
An artificial pancreas is the closest thing to a self-driving car for diabetes.
The tools I had were not perfect....

Continuous Glucose Monitor (CGM)  Insulin Pump
Often leaving me with this:
If we can’t change existing devices…

what if we could add *new* tools?
Tackling the problem of less-audible alarms:

- Get data from device with open source code
- Display data & generate louder alarms
- Share data with loved ones
- Enter specific actions/more buttons
- Create forecast (algorithm) with data sources
- Add additional “smart” alarms with action recommendations
From reactive to predictive: an “open loop”
And it turns out....

We already had in our pockets the tools needed for an “artificial pancreas”.

@DanaMLewis
Components of an open source artificial pancreas

1. Continuous glucose monitor
2. Computer
3. Battery
4. Radio stick
5. Insulin pump
What did my HCP say?
#OpenAPS

is an open and transparent effort to make safe and effective basic Artificial Pancreas System (APS) technology widely available to reduce the burden of Type 1 diabetes.
There are now \((n=1)*396+\) people with DIY closed loops in the world.

(That’s something like 1,900,000+ hours of DIY closed loop experience.)
An even smaller pancreas:

The #OpenAPS "stack":
1. "Explorer board" rig
2. Insulin pump
3. Continuous glucose monitor (CGM)

@DanaMLewis
Interoperability:

“Hey Siri text MyArtificialPancreas
#Speaking,”
tap to edit

Here’s your message:

Message

To: MyArtificialPancreas
#Speaking.

Cancel Send

I’ll send it.

Message

To: MyArtificialPancreas
#Speaking.

Done.

@DanaMLewis
“Autosensitivity”

(what if we *didn’t* have to track daily changes in activity patterns… or remember to adjust ISF for menstrual cycle… or when sick… or when a pump site fails?)
Meet “Autotune”

(“tune” basal rates, ISF, and carb ratio)
Traditional innovation
Traditional innovation

User-driven innovation

NOT LIKE THIS

LIKE THIS

Start Here
How do we start scaling these types of efforts more broadly?
Step 1: It’s as simple as...

LISTENING
(and sharing)
OpenAPS Data Commons

Managed by: Dana Lewis
OpenAPS
Contact email: dana@openAPS.org
Project website: https://openaps.org/data-commons/
Stats: Joined by 43 members.

Members of the OpenAPS and DIY closed loop community have frequently expressed the desire to donate their DIY closed loop data for scientific research, or to perform research themselves. The OpenAPS Data Commons was created to enable a simple way to share data sets from the community, both with traditional researchers who will create traditional research studies, and with groups or individuals from the community who want to review data as part of their own research projects. The OpenAPS Data Commons will enable easy facilitation of data sharing from and with the OpenAPS community. Anyone using a DIY closed loop is welcome to donate their data to the OpenAPS Data Commons. We encourage other studies or projects (including n=1 research, or research by individuals in the community) to access this data, as long as it means the community principles for sharing results back to the community in a reasonable time frame and relatively open manner.

Join OpenAPS Data Commons

This project requests the following permissions from members that join it:

- **Permission to send messages:** Messages are received as emails, but the project does not receive access to the member’s email address.
- **Access to these data sources:**
  - Data selfie
  - Nightscout Data Transfer
- **Permission to return data:** Data from any associated project research surveys (such as an engagement score or other QOL data gathered)

Join OpenAPS Data Commons
But be aware of the barriers:

- Funding is usually for traditional researchers
- Top-down research may miss the mark
- Be aligned on true goals and impact of research
Step 3: To be determined...
#WeAreNotWaiting

@DanaMLewis | dana@OpenAPS.org | www.OpenAPS.org
Enabling Patient-Centered Decision Support at Scale through Multi-Stakeholder Collaboration: Why It’s Needed, How We Could Get There

Kensaku Kawamoto, MD, PhD, MHS, FACMI
Associate Chief medical Information Officer
Assistant Professor of biomedical informatics
University of Utah
Disclosures

- In the past year, I have been a consultant or sponsored researcher on CDS for:
  - Office of the National Coordinator for Health IT*
  - Hitachi
  - McKesson InterQual

*Via ESAC, A+ Government Solutions, Hausam Consulting
Perspectives

▪ Health System
  – Associate CMIO leading enterprise CDS and Interoperable Apps and Services (IAPPS) initiatives
  – Co-architect of enterprise value management solution*

▪ Standards Developer and Implementer
  – Co-chair, HL7 CDS Work Group
  – Founder, OpenCDS (www.opencds.org)
  – Member, U.S. Health IT Advisory Committee

Large Untapped Potential for PC-CDS: Patients and Others Who are Not the “Usual Suspects”

- Patients are enormous untapped resources with great talent and unmatched motivation

- Other potential contributors:
  - Other institutions
  - A variety of companies (not just primary IT vendor)
  - Game designers
  - Students
  - etc.
Vision

- Patients have PC-CDS seamlessly integrated into their daily lives for managing their conditions and optimizing their health.
- Providers have PC-CDS seamlessly integrated into their clinical workflows.
- Comprehensive and available to everyone.
- Connected and consistent across users.
- Driven by a diverse group of stakeholders.
Key Enabler 1: Pay-for-Value

- If PC-CDS can be shown to improve health at lower cost, there will be strong incentives for deployment
Key Enabler 2: Standards Adoption

- Data interchange: **HL7 FHIR US Core Profile**
- Integration of CDS with EHR: **CDS Hooks**
- Integration of apps within EHR: **SMART on FHIR**

- Still much more to be done, but strong EHR vendor adoption = a game changer
Sample EHR-Integrated Patient FHIR App

### Medications

<table>
<thead>
<tr>
<th>Active</th>
<th>Past</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>Dose</th>
<th>Frequency</th>
<th>Days</th>
<th>Month</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>ZILOPRIM (allopurinol) 100 MG tablet</td>
<td></td>
<td>3/day</td>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>ADDERALL XR (amphetamine-dextroamphetamine) 15 MG 24 hr capsule</td>
<td></td>
<td>1/day</td>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>LIPIST (atorvastatin) 80 MG tablet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACCUTANE (ISOTretinoin) 30 MG capsule</td>
<td></td>
<td>2/day</td>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>

Reminders:
- ZILOPRIM: 07:00 AM, 12:00 PM, 06:30 AM
- ADDERALL XR: 07:00 AM
- LIPIST: 06:30 PM
- ACCUTANE: 07:00 AM, 06:30 PM
Sample EHR-Integrated SMART on FHIR App

![Bilirubin App](image)

- **Gest. Age (auto-calculated)**: 38 wks+, 35-37 wks, < 35 wks
- **Direct Coombs** (risk factor; auto-calculated): Pos. (09/28/16), Neg., Unknown
- **Other risk factors** (not auto-calculated): Isoimmune hemolytic disease, G6PD deficiency, asphyxia, sig. lethargy, temp. instability, sepsis, acidosis
  - Present, Not Present
- **Albumin < 3.0 g/L** (risk factor for phototherapy only; auto-calculated): Yes (2.9, 09/28/16), No, None on record
- **Consider Exchange Transfusion**: Rationale: Patient's latest bilirubin level of 17.1 mg/dL at 46.57 hrs is above treatment threshold for exchange transfusion (16.98) given gestational age >= 35 wks and < 38 wks with risk factors for exchange transfusion.

**Bilirubin Measurements**

<table>
<thead>
<tr>
<th>Age (Hrs)</th>
<th>Result</th>
<th>Date/Time</th>
<th>Test Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.25</td>
<td>8.1</td>
<td>09/26/16 16:24</td>
<td>Total</td>
</tr>
<tr>
<td>23.38</td>
<td>10.5</td>
<td>09/27/16 03:32</td>
<td>Transcutaneous</td>
</tr>
<tr>
<td>30.68</td>
<td>12.2</td>
<td>09/27/16 10:50</td>
<td>Total</td>
</tr>
<tr>
<td>36.9</td>
<td>14.8</td>
<td>09/27/16 17:03</td>
<td>Total</td>
</tr>
<tr>
<td>46.57</td>
<td>17.1</td>
<td>09/28/16 02:43</td>
<td>Total</td>
</tr>
</tbody>
</table>

**Albumin Measurements**

<table>
<thead>
<tr>
<th>Age (Hrs)</th>
<th>Result</th>
<th>Date/Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>43.85</td>
<td>2.9</td>
<td>09/28/16 00:00</td>
</tr>
</tbody>
</table>

*Bold = patient-specific threshold.


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Sample EHR-Integrated CDS Hooks Advice

Maximum morphine equivalent daily dose (MEDD) is **465** mg/day (PRN meds assumed to be taken at maximum allowed frequency). Taper to < 50.

<table>
<thead>
<tr>
<th>Active Opioid Rx</th>
<th>Max MEDD</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ New ] Acetaminophen 325 MG / Hydrocodone Bitartrate 10 MG Oral Tablet</td>
<td>80 mg</td>
</tr>
<tr>
<td>&gt; Sig: 1 tablet Oral Every 4 hours as needed</td>
<td></td>
</tr>
<tr>
<td>&gt; Daily dose: Hydrocodone Oral Tablet 6/d * 1 tablet * 10 mg = 60 mg. Morphine equivalence: 1x.</td>
<td></td>
</tr>
<tr>
<td>72 HR Fentanyl 0.1 MG/HR Transdermal System</td>
<td>240 mg</td>
</tr>
<tr>
<td>&gt; Sig: Apply 1 patch to the skin Every 72 hours</td>
<td></td>
</tr>
<tr>
<td>&gt; Prescriber: Michael Flynn, MD (Internal Medicine/Pediatrics). Rx date: 2017-04-19.</td>
<td></td>
</tr>
<tr>
<td>&gt; Dispense: 15 patches. Refills: 0. Expected supply duration: through 2017-08-02.</td>
<td></td>
</tr>
<tr>
<td>&gt; Daily dose: Fentanyl patch: 1 * 0.1 mg/hr = 0.1 mg/hr. Morphine equivalence: 2400x.</td>
<td></td>
</tr>
<tr>
<td>Acetaminophen 325 MG / Oxycodone Hydrochloride 5 MG Oral Tablet</td>
<td>30 mg</td>
</tr>
<tr>
<td>&gt; Sig: Take 1 tablet daily as needed for pain</td>
<td></td>
</tr>
<tr>
<td>&gt; Prescriber: Michael Flynn, MD (Internal Medicine/Pediatrics). Rx date: 2017-05-04.</td>
<td></td>
</tr>
<tr>
<td>&gt; Daily dose: Oxycodone Oral Tablet 4d * 1 tablet * 5 mg = 20 mg. Morphine equivalence: 1.5x.</td>
<td></td>
</tr>
<tr>
<td>Oxycodone Hydrochloride 10 MG Oral Tablet</td>
<td>90 mg</td>
</tr>
<tr>
<td>&gt; Sig: Take 1 tablet by mouth Every 4 hours as needed for pain</td>
<td></td>
</tr>
<tr>
<td>&gt; Prescriber: Michael Flynn, MD (Internal Medicine/Pediatrics). Rx date: 2017-05-04.</td>
<td></td>
</tr>
<tr>
<td>&gt; Daily dose: Oxycodone Oral Tablet 6d * 10 mg = 60 mg. Morphine equivalence: 1.5x.</td>
<td></td>
</tr>
<tr>
<td>Oxycodone Hydrochloride 5 MG Oral Tablet</td>
<td>45 mg</td>
</tr>
<tr>
<td>&gt; Sig: Take 1 tablet by mouth Every 4 hours as needed for pain</td>
<td></td>
</tr>
<tr>
<td>&gt; Prescriber: Michael Flynn, MD (Internal Medicine/Pediatrics). Rx date: 2017-05-04.</td>
<td></td>
</tr>
<tr>
<td>&gt; Daily dose: Oxycodone Oral Tablet 6d * 5 mg = 30 mg. Morphine equivalence: 1.5x.</td>
<td></td>
</tr>
</tbody>
</table>

Total: **465 mg**

**CDC opioid recommendation #5**

MME conversion table

Source: CDC

---

<table>
<thead>
<tr>
<th>Acknowledge Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will reduce dosage</td>
</tr>
<tr>
<td>Risk outweighed by benefit; snooze 3 mo</td>
</tr>
<tr>
<td>Acute pain; snooze 1mo</td>
</tr>
<tr>
<td>N/A — see comment; snooze 3 mo</td>
</tr>
</tbody>
</table>
Objective 5. Organizations **must provide an API (e.g., FHIR) that patients can use** to access their health information

*Providers may not prohibit patients from using any application, including third-party applications, which meet the technical specifications of the API*

How Could This Work?

▪ Broad awareness
▪ Broad training
▪ Broad opportunity identification
▪ Broad solution creation, supported by “usual suspects” (e.g., to extend EHR FHIR API)
▪ (n=1) * X and other pilot implementation
▪ ROI validation
▪ Traditional scaling mechanisms
What Do We Need to Do?

- Broad awareness  
  Dissemination via PC-CDS LN

- Broad training  
  Leveraging existing training resources, e.g., HSPC

- Broad opportunity identification  
  Via PC-CDS LN

- Broad solution creation, supported by “usual suspects” (e.g., to extend EHR FHIR API)  
  (n=1) * X and other pilot implementation  
  LN + HSPC?

- ROI validation  
  Partner with academics, coordinated w/PC-CDS LN

- Traditional scaling mechanisms  
  Align with financial Incentives (incl. grants), spread via PC-CDS LN
Thank You!

Kensaku Kawamoto, MD, PhD, MHS, FACMI
Associate Chief Medical Information Officer
Assistant Professor of Biomedical Informatics
University of Utah

kensaku.kawamoto@utah.edu
Discussion: Refining the Vision, and Getting There

- Thoughts about PCCDS Future State vision?
  - JIT information/tools support person-centered health journey
- What does the ‘big win’ from vision look like for you?
- What are you doing to get there? Progress? Barriers?
- What information/collaboration/tooling/etc. would help?
- What can the LN do to accelerate individual/joint progress?
  - Web/Resource Center, webinars, Annual Conference, etc.

What would it take to make engaging in this Learning Network-mediated work a priority for you in your day job?
Break
Environment of Openness Panel
Environment of Openness: A Multi-Perspective Discussion on Patient-Centered CDS

Moderator: Joshua Richardson, PhD, MS, MLIS RTI International

October 3, 2017
Panelists

- Edwin Lomotan, MD - Chief of Clinical Informatics for the Health IT Division in the Center for Evidence and Practice Improvement at AHRQ

- Jonathan S. Wald, MD, MPH – Program Director for Digital Health and Clinical Informatics at RTI International and past President at the Society for Participatory Medicine

- William Lawrence, MD, MS – Associate Director, Science, Clinical Effectiveness and Decision Science, at the Patient-Centered Outcomes Research Institute (PCORI)

- Blackford Middleton, MD, MPH, MSc - Chief Informatics and Innovation Officer at Apervita, Inc; Instructor, Harvard T.H. Chan School of Public Health; and Co-Chair of the Learning Network
CDS Can Support Precision and Personalized Medicine

Electronic Medical Record-Integrated Pharmacogenomics and Related Clinical Decision Support Concepts

PJ Caraballo¹,², SJ Bielinski³, JL St. Sauver³,⁴ and RM Weinshilboum⁵,⁶

Advances in pharmacogenomics (PGx) have the potential to transform healthcare by allowing precision medicine to become a reality. However, PGx knowledge is new, complex, and evolving, and relying on the cognition of clinicians alone is insufficient for clinical implementation. Integrating clinical decision support (CDS) tools in the electronic health record (EHR) is critical for translating PGx into clinical practice. Herein, we review current strategies to implement PGx using EHR-CDS functionalities.

The overall positive impact of modern medication management on multiple medical conditions is undeniable. However, current prescribing practices are still significantly limited with regard to predicting the efficacy and safety of a given medication for an individual patient. Adverse drug reactions (ADRs) are responsible requires medication management to prevent significant complications. Before 1990, only two drug classes were available for treating this disease; today, up to 12 classes of drug are available, each with diverse pharmacology and therapeutic effects. Current clinical guidelines for the treatment of type 2 diabetes mellitus pro-

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CDS Can Support Precision and Personalized Medicine

The Role of Informatics in Patient-Centered Care and Personalized Medicine

Matthew G. Hanna, MD and Liron Pantanowitz, MD

The practice of cytopathology has dramatically changed due to advances in genomics and technology laboratories have accordingly become increasingly dependent on pathology informatics to address the growing demands of precision medicine. Pathology informatics deals with information technology and its impact on workflow processes and staff who interact with these tools. The role that laboratory information systems, electronic medical records, and digital imaging play in personalized medicine. The value of integrated diagnostic reports, clinical decision support, and electronic queries to better evaluate cytology samples destined for molecular testing is discussed. Image analysis and quantitative measurements in cytology is addressed, as well as the role of bioinformatics from next-generation sequencing. This article also highlights the barriers to the widespread utilization of these technologies due to regulatory obstacles, limited commercial solutions, poor interoperability between systems, and cost. The role of pathology informatics in cancer care is described.

KEY WORDS: cytopathology, genomic; informatics; information technology; molecular; personalized medicine.

INTRODUCTION

Pathology informatics involves the acquisition, storage, use, and management of data in the pathology laboratory. Informatics pertains not only to information technology (IT), but also deals with individuals and workflow

Integrating Preferences to Promote Patient-Centered Decision-making

Personalised Multi-Criterial Online Decision Support for Siblings Considering Stem Cell Donation: An Interactive Aid

Mette Kjer KALTOFT,1 Glenn SALKELD,2 Jack DOWIE

1OUH Svendborg Hospital, 2University of Southern Denmark, 3University of Sydney, 4London School of Hygiene and Tropical Medicine

Abstract. Person-centred decision support combines the best available information on the considerations that matter to the individual, with the importance the person attaches to those considerations. Nurses and other health professionals can benefit from being able to draw on this support within a clinical conversation. A case study and storyline on four siblings facing a transplant coordinator’s call to donate stem cells to their brother [1] is “translated” and used to demonstrate how an interactive multi-criteria aid can be developed for each within a conversational mode. The personalized dialogue and decision aid are accessible online for interaction. Each sibling’s decision exemplifies the communication including physical and psychosocial complexities within any decision cascade from call-to-call.

Estimating Preferences for Complex Health Technologies: Lessons Learned and Implications for Personalized Medicine

Deborah A. Marshall, PhD1, Juan Marcos Gonzalez, PhD1, Karen V. MacDonald, MPH1, F. Reed Johnson, PhD2

1Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada; 2Research Triangle Institute, Durham, NC, USA; 3Duke Clinical Research Institute, Duke University, Durham, NC, USA

ABSTRACT

We examine key study design challenges of using stated-preference methods to estimate the value of whole-genome sequencing (WGS) as a specific example of genomic testing. Assessing the value of WGS is complex because WGS provides multiple findings, some of which can be incidental in nature and unrelated to the specific health concerns that motivated the test. In addition, WGS results can include actionable findings (variants considered to be clinically useful and can be acted on), findings for which evidence for best clinical action is not available (variants considered clinically valid but do not meet as high a standard for clinical usefulness), and findings of unknown significance. We consider these key challenges encountered in designing our national study on the value of WGS—layers of uncertainty.

We conceptualized the decisions to acquire WGS information as a series of sequential choices that are resolved separately. To determine the value of WGS information at the initial decision to undergo WGS, we used contingent valuation questions, and to elicit respondent preferences for reducing risks of health problems and the consequences of taking the steps to reduce these risks, we used a discrete-choice experiment. We conclude by considering the implications for evaluating the value of other complex health technologies that involve multiple forms of uncertainty.


Leveraging New Methods, Technologies, and Data to Promote Patient-Centered Decisions

Behavioral informatics: Dynamical models for measuring and assessing behaviors for precision interventions.


Questions to Consider

• What does PCCDS mean to you?
• What would successful PCCDS look like?
• What research questions do AHRQ, PCORI or other agencies want to answer that PCCDS can address?
• What hurdles are each of you having to leap, or would have to leap, to promote PCCDS?
• How would success be measured?
• How can the PCCDS Learning Network help you?
Patient-Centered CDS Panel: Background from AHRQ

Edwin Lomotan, MD
Agency for Healthcare Research and Quality

October 3, 2017
AHRQ CDS Activities in Context

- Long history of AHRQ investment in clinical decision support
  - Investigator-initiated research
  - Demonstration contracts
  - Foundational work on data models to support both CDS and electronic clinical quality measurement

- New initiative in 2016
  - Based on legislative requirements from the Patient Protection and Affordable Care Act
  - Focuses on working with stakeholders, including patients, developers of CDS, and many others to accelerate the movement of evidence into practice through CDS
AHRQ’s Clinical Decision Support Initiative

Advancing evidence into practice through CDS and making CDS more shareable, standards-based, and publicly-available

Four components:

1. Engaging a stakeholder community

2. Creating prototype infrastructure for sharing CDS and developing CDS

3. Advancing CDS through demonstration and dissemination research

4. Evaluating the overall initiative
CDS Connect Lifecycle

CDS Community

Artifact is improved for the CDS community to use

Identifies need for a new CDS tool (known as an artifact)

Implement in health IT system and collect feedback

Source(s)
Clinical practice guidelines
Peer reviewed articles
Local best practices
CQM(s)

Publish artifact in CDS Connect

Build the CDS artifact using CDS authoring

CDS Connect lifecycle
AHRQ Resources

AHRQ CDS initiative:  http://cds.ahrq.gov

Funding opportunities: 
http://www.ahrq.gov/funding/fund-opps/index.html

For more information: 
ClinicalDecisionSupport@ahrq.hhs.gov

Email:  Edwin.Lomotan@ahrq.hhs.gov

Thank you for participating!!
Patient-Centered CDS Panel: Patient/Provider Perspective

Jonathan S. Wald, MD, MPH
Director, Digital Health and Clinical Informatics
RTI International

October 3, 2017
Type 2 Diabetes – a Lifestyle Disease

Diabetes Self-management Education and Support for Adults With Type 2 Diabetes: Algorithm of Care

ADA Standards of Medical Care in Diabetes recommends all patients be assessed and referred for:

- **Nutrition**
  - Registered dietitian for medical nutrition therapy

- **Education**
  - Diabetes self-management education and support

- **Emotional Health**
  - Mental health professional, if needed

### Four critical times to assess, provide, and adjust diabetes self-management education and support

1. **At diagnosis**
2. **Annual** assessment of education, nutrition, and emotional needs
3. **When new complicating factors influence self-management**
4. **When transitions in care occur**

#### When primary care provider or specialist should consider referral:

- Newly diagnosed. All newly diagnosed individuals with type 2 diabetes should receive DSME/S
- Ensure that both nutrition and emotional health are appropriately addressed in education or make separate referrals
- Needs review of knowledge, skills, and behaviors
- Long-standing diabetes with limited prior education
- Change in medication, activity, or nutritional intake
- HbA1c out of target
- Maintain positive health outcomes
- Unexplained hypoglycemia or hyperglycemia
- Planning pregnancy or pregnant
- For support to attain and sustain behavior change(s)
- Weight or other nutrition concerns
- Health conditions such as renal disease and stroke, need for steroid or complicated medication regimen
- Physical limitations such as visual impairment, dexterity issues, movement restrictions
- Emotional factors such as anxiety and clinical depression
- Basic living needs such as access to food, financial limitations
- Living situation such as inpatient or outpatient rehabilitation or now living alone
- Medical care team
- Insurance coverage that results in treatment change
- Age-related changes affecting cognition, self-care, etc.

Margaret A. Powers et al. Dia Care 2015;38:1372-1382
## Diabetes Self-management Education and Support Algorithm: Action Steps

### Four critical times to assess, provide, and adjust diabetes self-management education and support

<table>
<thead>
<tr>
<th>At diagnosis</th>
<th>Annual assessment of education, nutrition, and emotional needs</th>
<th>When new complicating factors influence self-management</th>
<th>When transitions in care occur</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question and provide emotional support regarding diagnosis</td>
<td>Review problem-solving skills</td>
<td>Identify presence of factors that affect diabetes self-management and attain treatment and behavioral goals</td>
<td>Develop diabetes transition plan</td>
</tr>
<tr>
<td>Provide overview of treatment and treatment goals</td>
<td>Identify strengths and challenges of living with diabetes</td>
<td>Discuss effect of complications and successes with treatment and self-management</td>
<td>Communicate transition plan to new health care team members</td>
</tr>
<tr>
<td>Teach survival skills to address immediate requirements (safe use of medication, hypoglycemia treatment if needed, introduction of eating guidelines)</td>
<td></td>
<td></td>
<td>Establish DSME/S regular follow-up care</td>
</tr>
<tr>
<td>Identify and discuss resources for education and ongoing support</td>
<td>Make referral for DSME/S and MNT</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Primary care provider/endocrinologist/clinical care team: areas of focus and action steps

- Answer questions and provide emotional support regarding diagnosis
- Provide overview of treatment and treatment goals
- Teach survival skills to address immediate requirements (safe use of medication, hypoglycemia treatment if needed, introduction of eating guidelines)
- Identify and discuss resources for education and ongoing support
- Make referral for DSME/S and MNT

### Diabetes education: areas of focus and action steps

- Assess cultural influences, health beliefs, current knowledge, physical limitations, family support, financial status, medical history, literacy, numeracy to determine content to provide and how:
  - Medications—choices, action, titration, side effects
  - Monitoring blood glucose—when to test, interpreting and using glucose pattern management for feedback
  - Physical activity—safety, short-term vs. long-term goals/recommendations
  - Preventing, detecting, and treating acute and chronic complications
  - Nutrition—food plan, planning meals, purchasing food, preparing meals, portioning food
  - Risk reduction—smoking cessation, foot care
  - Developing personal strategies to address psychosocial issues and concerns
  - Developing personal strategies to promote health and behavior change

- Review and reinforce treatment goals and self-management needs
- Emphasize preventing complications and promoting quality of life
- Discuss how to adapt diabetes treatment and self-management to new life situations and competing demands
- Support efforts to sustain initial behavior changes and cope with the ongoing burden of diabetes

- Provide support for the provision of self-care skills in an effort to delay progression of the disease and prevent new complications
- Provide/refer for emotional support for diabetes-related distress and depression
- Develop and support personal strategies for behavior change and healthy coping
- Develop personal strategies to accommodate sensory or physical limitation(s), adapting to new self-management demands, and promote health and behavior change

- Identify needed adaptations in diabetes self-management
- Provide support for independent self-management skills and self-efficacy
- Identify level of significant other involvement and facilitate education and support
- Assist with facing challenges affecting usual level of activity, ability to function, health beliefs, and feelings of well-being
- Maximize quality of life and emotional support for the patient (and family members)
- Provide education for others now involved in care
- Establish communication and follow-up plans with the provider, family, and others

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**Margaret A. Powers et al. Dia Care 2015;38:1372-1382**
Type 2 Diabetes – *Lifestyle Management*
Type 1 Diabetes is the ONLY disease I know of where patients and their caregivers are making dosing decisions for a drug that could kill you - and they are making these decisions 24/7/365.

David Panzirer
Lots of Data
Type 1 Diabetes - Lots to Manage

- How to Give Your Loved One an Insulin Injection
- How to Test Blood Sugar
- Insurance: Navigating Denials
- Hospital Stay: What to Expect When Expecting a Hospital Stay with Type 1
- Hyperglycemia and How to Treat It
- Give Yourself a Foot Exam to Prevent Diabetes-Related Complications
- Ketones – The 6 Must-Knows
- Hypoglycemia and How to Treat It
- Insulin Delivery
- Clinical Trials and the Type 1 Diabetes Cure

TrialNet
Type 1 Diabetes TrialNet
## Viewing CDS from a *Patient Perspective*

<table>
<thead>
<tr>
<th>CDS for my... Provider / EHR context</th>
<th>CDS for me: Patient / Apps context</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mediated by: Clinician</td>
<td>Mediated by: Patient</td>
</tr>
<tr>
<td>Supports professional clinical care decisions</td>
<td>Supports patient self-management; Feeds into care decisions</td>
</tr>
<tr>
<td>Transparent to clinician; others (?)</td>
<td>Transparent to patient; others (?)</td>
</tr>
<tr>
<td>Brings patient data &amp; judgment to professionals</td>
<td>Brings clinical data &amp; judgment to the patient</td>
</tr>
<tr>
<td>Varies from simple to complex</td>
<td>Varies from simple to complex</td>
</tr>
</tbody>
</table>
Patient-Centered CDS Panel

William Lawrence  
Associate Director, Clinical Effectiveness and Decision Science  
Patient-Centered Outcomes Research Institute (PCORI)

October 3, 2017
PCORI’s Mission

PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.
“The purpose of the Institute is to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis...

... and the dissemination of research findings with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services…”

-from PCORI’s authorizing legislation
Our National Research Priorities

- Assessment of Prevention, Diagnosis, and Treatment Options
- Improving Healthcare Systems
- Communication and Dissemination Research
- Addressing Disparities
- Accelerating PCOR and Methodological Research
Engagement as a Path to Useful, High-Quality Research

- Topic Selection and Research Prioritization
- Proposal Review; Design and Conduct of Research
- Evaluation
- Dissemination and Implementation of Results
How Will Treating My Early-Stage Prostate Cancer Affect My Quality of Life?

Early-stage prostate cancer can be treated in different ways. The three main ways are active surveillance, surgery, and radiotherapy. Active surveillance means having your prostate checked every few months to make sure the cancer is not spreading. Surgery would take out the prostate, and radiotherapy uses high-energy rays to kill cancer cells in the prostate.

Two recent PCORI-funded studies compare the effects of these choices on the quality of life for men with early stage prostate cancer. These studies looked at three effects treatment might have on a man’s quality of life. These are problems having sex, urinary problems, and bowel problems.

Here’s what the new research says:

The different ways of treating early-stage prostate cancer (active surveillance, radiotherapy, or surgery) affect men differently. Men who have surgery or radiotherapy have more sexual, urinary, and bowel problems in the first year compared with men who were treated with active surveillance. After 2 to 3 years, most symptoms improve, but there may still be differences.

Surgery

Men who had surgery to remove the prostate (called a total prostatectomy) were:
• more likely to have problems with sex
• more likely to leak urine

Radiation

Men who had radiation to kill cancer cells in the prostate were:
• more likely to feel burning when peeing, more likely to feel that their pee won’t come out. or a
Closing Thoughts

- Keep the patient as the focus
- Engagement in care as well as research
- Getting the evidence to people who need it
- How does the CDS help people make better decisions about care?
Patient-Centered CDS Panel

Blackford Middleton, MD, MPH, MSc
PCCDS Learning Network Steering Committee Co-Chair
Chief Informatics and Innovation Officer at Apervita, Inc.

October 3, 2017
What Does Patient-Centered CDS Mean to Me?

- It’s all about the patient

- 5 Essential patient **data dimensions** are used to personalize the CDS – from the nano to the macro
  - Genomic/proteomic: Gene variants
  - Signs: Clinical observations and assessments (e.g. lab data)
  - Symptoms: pain, fatigue, mental status, etc.
  - Social context: social network, patient activation
  - Community Context: community supports, hazards, environment

- Essential patient **preferences (utilities)** are used to personalize the CDS – from the intrinsic to the extrinsic
  - Personal belief structures and values (we should have ice cream for all)
  - Personal preferences (I like strawberry)
  - Personal utilities (quantified values) (I’ll have 2 scoops)
What is the PCCDS Ecosystem?

- ALL of the players in the full spectrum of the lifecycle from knowledge creation to implementation as CDS.
  - **Investigators** -> published PCOR findings
  - **Knowledge Curators (Public and Private)**: PCOR findings -> computable knowledge artifacts
    - Critical components: Open access or other IP arrangements, Standards Development Organizations (SDOs), Legal framework
    - Technology developers: new computational methods (XMLs, APIs, web services, SMART on FHIR, containerization, etc.)
  - **CDS Implementers**: Computable knowledge -> implemented CDS
    - EHR Vendors
    - CDS Vendors
How do We Reduce *Friction* in the PCCDS Ecosystem?

Sittig DF, Wright A, Ash JS, Turechek ZD, Middleton B. unpublished manuscript
What is the Approach We are Taking at Apervita?

At Apervita, we believe in...
Open, industry-scale collaboration platform for health analytics & data
Learning Network Desiderata from a Vendor’s POV

- Transitioning toward a post-EMR world of externalized cognitive decision-support services
- Knowledge repositories (public and private)
  - Access to essential building blocks (terminologies/ontologies, metadata; public or private)
  - Filled with high quality, validated/vetted, curated knowledge artifacts
  - Clear knowledge management lifecycle specifications
  - Standardized knowledge representation formalism
- Standardized clinical integration (implementation) methods
  - Cardinal CDS Types
  - Standard workflow insertion points
  - Standard feedback loop(s)
- A business model for QI driving CDS effective utilization
Support from AHRQ grant 1U18H5024849-01
Patient-Centered Clinical Decision Support (PCCDS) Analytic Framework for Action (AFA) to Improve Healthcare Delivery and Outcomes
WELCOME BACK...
Words to Live By...

- Seek to understand
- We all have something to learn and something to contribute
- Respect the person, challenge the idea
- Have fun!
Current State - Choose a Domain

PCCDS for..

- Patient Engagement
- Measurement and Outcomes

- User Needs and Technologies
- Continuous Learning
In groups of 4-5 people:

- On a piece of flipchart paper, draw a vehicle that represents the current state of your domain.

- Be prepared to share the following with your peers:
  - Why did you choose that vehicle?
  - What about it particularly reflects the current state of your domain?
  - What additional characteristics does your vehicle have?
Current State Report Out
Future State - Choose a Domain

PCCDS for..

▪ Patient Engagement  ▪ User Needs and Technologies

▪ Measurement and Outcomes  ▪ Continuous Learning
PCCDS - Future State – Part I

• Again, in small groups of 4-5 people:

• Now draw a vehicle that represents the FUTURE state of your domain.

• Be prepared to share the following with your peers:
  – Why did you choose that vehicle?
  – What about it particularly reflects the future state of your domain?
  – What additional characteristics does your vehicle have?
• Individually, on the corresponding colored Post-Its, write down what would need to be true/in place for each audience in order to make the future state possible.

• Work backwards from 3 years from now.

• Use marker

• Only one idea per Post-it
Future State Report Out
To be completed day of conference (for wrap up)
Well Done...

Thank You!
For updates on future events and activities of the PCCDS-LN please check out our website at www.pccds-ln.org

Project Team Contact Information:
- Principal Investigator: Barry Blumenfeld, MD, MS (bhb@rti.org)
- Joshua Richardson, PhD, MS, MLIS (jrichardson@rti.org)
- Laura Marcial, PhD (lmarcial@rti.org)
- Beth Lasater, MSPH (boverman@rti.org)

Links:
- Conference materials: https://pccds-ln.org/annual-conference
- Conference evaluation form: https://goo.gl/forms/QsHfIXlRSIZiz1LD2