In Search of a Digital Health Compass

My Data, My Decision, Our ePower
Moderator: John Rayner

• Panelist’s introduction
  #digitalhealthcompass #ehealthweek
• How to co-create a digital health compass ?
  – Health Data Standards
  – Digital Health Literacy
• Q&A – interaction with you all

Tell me and I forget, Show me and I may remember,
Involve me and I’ll understand
Knowledge is power

• Extensive investments in digital health technology – however low adoption of eHealth and persistent health disparities call for multidisciplinary action.

• Navigating for health online is challenging, and understanding culture, education, skills, costs, perceptions of power and role is essential.

• Citizens engaged in self-care, patients coping with persistent, chronic disease or living with an implanted device, or informal carers helping an elderly relative, a child or neighbor with illness or declining health, need a digital health compass.
Digital health: Gutenberg moment for healthcare

- Undiagnosed disease network
- Patient Centered Outcomes Research Institute (PCORI)
  - non-profit, non-government organization
  - Patient powered research networks
  - Patients share, load to apps, donate their genomic data
Objectives

• How can eHealth investments pay-off?
  – Citizens – patients, caregivers and providers come together with standards, industry and researchers to **co-create** a personal digital health compass

• Call for joint actions by health care, informatics, policy, standards, and industry
  – Broad scope of Informatics in service for health
Anne Moen

Vision – a digital health compass

- Use myData for knowledge and give me tools to participate in digital transforming society
- Patient & families, health professionals and health informatics join forces with research and policy to advance digital health literacy
- Health Data standards and API as catalysts
Examples of storing and organizing health information artifacts and spaces
Current situation

• People, patients and caregivers do not use available digital health services to meet health and wellness needs for several (good) reasons

• Few models for partnerships and information sharing between patients – professionals

• Little integration and interoperability of health data for collaboration – engagement purposes
Co-creation → tomorrow’s care

- Health care experiences & expectations
- Health & Digital Health Literacy
- Personal characteristics
  - health & wellness
- Digital literacy, eSkills
Digital Health: One size does not fit all!

Beyond socio-demographic aspects that challenge adoption of digital health technology, there is also behavior ..

- Self Achievers
- Priority Jugglers
- Direction Takers
- Balance Seekers
- Willful Endures

There is an app for YOU!
Measuring up
Health Confidence

The Health Confidence Score (HCS) is a short generic measure of person’s confidence to engage fully in their health and care.

- Knowledge
- Self-management
- Access
- Shared decision-making

Ref: Benson T, Bowman C, Potts HWW. Health Confidence Score (HCS): development and validation of a short generic questionnaire for person centred care. Submitted for publication 2015
Searching for my digital health compass

- Expert
- Empower
- Evaluate
- Equity
- Enable
- Evolve
- Educate

[Logos: EFMI, HL7, HIMSS Europe]
Moving forward

• Knowledge and expertise to us as citizens
  – resources that make sense – the relevant data
  – Engage – convenient – balance – targets

• Balance what really matters
  – Human relationships – empathy – the people
  – Complex knowledge based collaboration
  – Self-care between care – health encounter
Petra Wilson

- perspectives of patients – citizens
- confidence raising a call for action for the health systems to integrate digital health literacy interventions every step of the way
Why the Patient Needs a New Compass

**Scarcity**
- resources, HCPs, time

**Complexity**
- comorbidity, medication, environment

**Personalisation**
- retail, leisure, education

**Mobility**
- work, communication, money
What the compass should provide to the Patient

Engage me in my own health and care
- Access to relevant, timely and understandable information.

Empower me to make decision and inform others
- Ability to share information and interact on information
What are the building blocks?

- **Data**
  - Add
  - Access
  - Share
  - Control

- **Trust**
  - partners
  - System
  - Redress

- **Access**
  - Reimbursement
  - Security
  - Mobility

- **Standards**
- **Interoperability**
- **Integration**
Are we nearly there yet ????

- **Standards** .... Good progress
- **Interoperability** ....... in some contexts
- **Integration** ....... Limited

- We are missing too many opportunities to engage and empower the patient!
Robert A. Stegwee

Personal Digital Health
Personal Health Records and the capabilities they provide to citizens

- A personal health record is more than a viewer and organizer of personal health information
- It provides **treatment** support, including self management options
- It facilitates the **exchange** of health information with health care providers
- It supports healthy **lifestyle** options and the tracking of personal fitness
Adoption of Personal Health Records is very limited

- Survey among invited experts in 25 countries across 6 continents
- No individual PHR systems are reported that currently reach a million users or more
- Many PHR systems are still in a pilot phase with user numbers in the 100s or 1000s
Different strategies are being implemented, with no clear differentiation in success

- Having a strategy leads to more scale and more exchange of health information between citizen and other stakeholders in the health system

- Government led initiatives have the best track record in realizing exchange, often realized within a government led health system

- Apparently the consumer market lifestyle focus of tech companies is not perceived as a contribution to the PHR initiatives in different countries
Leadership and commitment of providers are key to success of Personal Health Records

- Top three barriers to success of Personal Health Records adoption mentioned:
  
  1. Leadership
  2. Incentives for providers
  3. Standards for information exchange

Legislation and Citizen interest are not identified as key barriers
A vision on the role of personal health information for future delivery of health care

- Personal experience is key in understanding
  - The perceived impact on a person’s life
  - The progression of a disease for an individual patient
  - The outcome of different treatment options
  - In relation to individual lifestyle choices

- Tools for capturing, analysing, and relating all this data are becoming available – with the person at the centre!

First hand experts are those people who are suffering from cognitive impairments and who are willing to share with us the effects of the disease on their lives. They are the ones who can tell us the real story behind the effects of this disease and its diagnosis, from their own perspective.

www.cottonwoolinmyhead.org
Ed Hammond

HL7 FHIR

(Fast Healthcare Interoperability Resources and standards)

- New initiative in standards seeking to liberate data for population health and precision medicine in the learning health system.

- Give an example of recent development.
The compass is shifting

- Sick care to Health
- Provider focus to patient focus
- Proprietary to shared
- Competition to collaborative
- Licensed to free
- Site specific to mobile
- National to global
Drivers

- Population Health
- Precision Medicine
- Data Sharing
- Learning Health
- Big Data
- New Media
- Mobile/wearable devices
- Health Analytics
- Translational Medicine

Interoperability

Dr. Karen DeSalvo, U.S. National Coordinator for Health IT pointed to HL7’s Fast Healthcare Interoperability Resources (FHIR) as an open health data standard that offers a promising approach to meet the demand for semantic interoperability and minimizing the need for metadata translation services. The challenge now “is how to bring that information together to make it usable and actionable for everybody who wants it.”
FHIR is FREE!!

F – Fast (design & implement)

H – Healthcare

I – Interoperable

R – Resources (Building blocks)
What is FHIR?

• Based on a set of modular components - “Resources”
  – Resources refer to each other using URLs
  – Small discrete units of exchange with defined behaviour and meaning
  – Have known identity and behaviour
  – Extensions permit adding data not part of core

• Resources are combined into “Profiles” to solve clinical and administrative problems in a practical way.
  – Parties exchanging data define the specific way they want to use resources and their relations using Profiles.
  – Profiles are the framework for defining services.
What is FHIR?

• Exchange resources between systems
  – Using a RESTful API (e.g. web approach)
  – As a Bundle of resources (messages, documents)

• Positives
  – Service driven
  – Modify components with changing need
  – Portability of components by moving program code with the data
To: William E Hammond
From: Donna Marie Tuccero, MD
Received: 3/23/2016 2:02 PM EDT

Noticed a few pulses in the 50's. Why not check a couple BPs along with that, see if there is room to dial your meds back a bit.

Reply  Delete

Back to the Message List
<table>
<thead>
<tr>
<th>Digital Health Compass</th>
<th>FHIR®</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Empower</strong></td>
<td>Service directed, Data Sharing, Patient Reporting Outcome</td>
</tr>
<tr>
<td><strong>Evolve</strong></td>
<td>Continual evolution through controlled versions, maturity levels</td>
</tr>
<tr>
<td><strong>Evaluate</strong></td>
<td>Standards for trial use, pilot studies, Argonaut</td>
</tr>
<tr>
<td><strong>Educate</strong></td>
<td>Tutorials, connectathons, application symposia, Learning Health</td>
</tr>
<tr>
<td><strong>Equity</strong></td>
<td>All stakeholders complete flexibility, mobile health, wearable sensors</td>
</tr>
<tr>
<td><strong>Enable</strong></td>
<td>Interoperability, push and pull, current directives, bidirectional data exchange</td>
</tr>
<tr>
<td><strong>Engage</strong></td>
<td>Persons, sites, communities, regions, countries, professional, patients</td>
</tr>
<tr>
<td><strong>Expert</strong></td>
<td>Easy to use</td>
</tr>
</tbody>
</table>
Christian Lovis

• Access to knowledge and research strategies that alleviate health disparities

• Set knowledge free!

• Make it matter for us!
In 1455, Gutenberg completed copies of a beautifully executed folio Bible (Biblia Sacra), with 42 lines on each page. Copies sold for 30 florins each,[23] which was roughly three years' wages for an average clerk. Nonetheless, it was significantly cheaper than a manuscript Bible that could take a single scribe over a year to prepare. After printing, some copies were rubricated or hand-illuminated in the same elegant way as manuscript Bibles from the same period.

48 substantially complete copies are known to survive, including two at the British Library that can be viewed and compared online.[24] The text lacks modern features such as pagination, indentations, and paragraph breaks.

An undated 36-line edition of the Bible was printed, probably in Bamberg in 1458–1460, possibly by Gutenberg. A large part of it was shown to have been set from a copy of Gutenberg's Bible, thus disproving earlier speculation that it may have been the earlier of the two.[25]
June 1997, Medline **free and open access** during public ceremony by VP Al Gore
Information tsunami

~4’000 papers indexed/day
The Big Data era

A new style of IT emerging

Every 60 seconds

98,000+ tweets
695,000 status updates
11 million instant messages
698,445 Google searches
168 million+ emails sent
1,820TB of data created
217 new mobile web users

Central dogma of molecular biology

From Wikipedia, the free encyclopedia
(Redirected from Central dogma)

The central dogma of molecular biology is an explanation of the flow of genetic information within a biological system. It was first stated by Francis Crick in 1958[1] and re-stated in a Nature paper published in 1970.[2]

The central dogma of molecular biology deals with the detailed residue-by-residue transfer of sequential information. It states that such information cannot be transferred back from protein to either protein or nucleic acid.

The central dogma has also been described as "DNA makes RNA and RNA makes protein,[3] a positive statement which was originally termed the sequence hypothesis by Crick. However, this simplification does not make it clear that the central dogma as stated by Crick does not preclude the reverse flow of information from RNA to DNA, only ruling out the flow from protein to RNA or DNA.

Crick had misspelled the term "dogma" in error; his proposal had nothing to do with the lexicological meaning of "dogma". He subsequently documented this error in his autobiography.

The dogma is a framework for understanding the transfer of sequence information between sequential information-carrying biopolymers, in the most common or general case, in living organisms. There are 3 major classes of such biopolymers: DNA and RNA (both nucleic acids), and protein. There are 3×3 = 9 conceivable direct transfers of information that can occur between these. The dogma classes these into 3 groups of 3: 3 general transfers (believed to occur normally in most cells), 3 special transfers (known to occur, but only under specific conditions in case of some viruses or in a laboratory), and 3 unknown transfers (believed never to occur). The general transfers describe the normal flow of biological information. DNA can be copied to DNA (DNA replication), DNA information can be copied into mRNA (transcription), and proteins can be synthesized using the information in mRNA as a template (translation).[3]
Parental olfactory experience influences behavior and neural structure in subsequent generations

Brian G Dias1,2 & Kerry J Ressler1,3

Using olfactory molecular specificity, we examined the inheritance of parental traumatic exposure, a phenomenon that has been frequently observed, but not understood. We subjected F0 mice to odor fear conditioning before conception and found that subsequently conceived F1 and F2 generations had an increased behavioral sensitivity to the F0-conditioned odor, but not to other odors. When an odor (acetophenone) that activates a known odorant receptor (Olf151) was used to condition F0 mice, the behavioral sensitivity of the F1 and F2 generations to acetophenone was complemented by an enhanced neuroanatomical representation of the Olf151 pathway. Bisulfite sequencing of sperm DNA from conditioned F0 males and F1 naive offspring revealed CpG hypomethylation in the Olf151 gene. In addition, in vitro fertilization, F2 inheritance and cross-fostering revealed that these transgenerational effects are inherited via parental gametes. Our findings provide a framework for addressing how environmental information may be inherited transgenerationally at behavioral, neuroanatomical and epigenetic levels.

Responding to environmental stimuli is crucial to the survival of organisms and often manifests as alterations in the structure and function of the nervous system. When and how information from the environment differences in methylation that may mark the specific olfactory receptor gene for enhanced transcription in the subsequent generation. Finally, using in vitro fertilization (IVF), F2 and cross-fostering stud.
In the early 1980s, a fifth component was added to these four "classic" bases, called methyl-cytosine (mC), which is derived from cytosine. Then, in the late 1990s, mC was recognized as the main cause of epigenetic mechanisms. Meaning, it can switch genes on or off depending on the physiological needs of each tissue.

In recent years, researchers have studied this fifth DNA base in more detail because it seems alterations in the mC base contribute to the development of many human diseases, including cancer.

Now, according to new findings published in the journal Cell, a sixth possible DNA base may also exist. Called methyl-adenine (mA), this potential DNA base may also help determine the epigenome and would therefore be key in the life of the cells.
Correlation does not imply causation.

Figure 1. Correlation between Countries’ Annual Per Capita Chocolate Consumption and the Number of Nobel Laureates per 10 Million Population.
New competences
Catherine Chronaki

*My Data - My Decision – our ePower*

patient engagement, *myHealthData*, tailored, adaptive and actionable health experience for individuals, families and communities.
My Data ...
Know the effects of medication you take or not...

- Information integration can help patients and care givers to improve treatment effectiveness, quality of life.
- Integration with scales, glucose meters, blood pressure... All in one patient’s 360 view.
- Standards like HL7 FHIR can be the catalyst in this live integration enabling participatory medicine.
My Decision ..
Enhanced tailored medication information for you!

Imagine yourself in a pharmacy for over the counter medicine:
Walk down the corridor
Your medication app suggestions are based on your health and wellness data scanning the box.

Response to questions:
- is it the right medication?
- Characteristics are highlighted for the patient (e.g. considering allergies, preconditions, etc).
- Comparison among medication products
Find out what your DNA says about you and your family.

- Learn what percent of your DNA is from populations around the world
- Contact your DNA relatives across continents or across the street
- Build your family tree and enhance your experience with relatives

order now $99
Our ePower...
Together, we can beat heart disease. Here's how:

**Answer simple questions, whenever and wherever you want.**
Details about your health and habits are key to helping us understand heart disease and save lives. You can help fight heart disease on your phone, tablet, or computer anytime.

**It doesn't take long, and it's easy to stop and pick up later.**
The initial survey set takes 30-60 minutes to complete, but you don't need to do them all at once. After that, we try to keep things easy for you and only check in every 6 months.

**Organize health data all in one place, and keep it super safe.**
You can connect your medical records and health devices (Fitbit and others) and we'll organize the info for you. Our security is top-notch and we'll keep your information private.

I'm in! Lets fight some heart disease ➔

I want to help another way
Welcome to the team—let's fight some heart disease!

Being a hero isn't always glamorous, and since information is our main weapon against heart disease, we need to collect some to get you baselined. Here's what we need for you to officially get your stripes.

Your eVisit has 5 sections. You don’t have to finish everything all at once.

Sound good? Let's get started!
EVENYONE’S PERSONAL HEALTH SERVICE

The expertise to keep you healthy.
Doctors at your fingertips when you need them.

APP STORE    GOOGLE PLAY

HOW IT WORKS
Health eHeart Alliance

- Patient-Powered Research Network for preventing and managing cardiovascular disease
- Patient-led Steering Committee
  - Patient engagement in the design, conduct and oversight of results dissemination for cardiovascular-focused research.
- Supported by
  - Health eHeart Study, platform for data collection, study management
  - Coalition of heart-related advocacy groups including the American Heart Association, Mended Hearts, StopAfib.org, and Sudden Arrhythmia Death Syndromes Foundation.

“Pioneer new ways to empower patients in improving research, care and quality of life for heart patients.”
Eric Topol on change…

<table>
<thead>
<tr>
<th>Old Medicine</th>
<th>New Medicine</th>
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<tbody>
<tr>
<td>Population-Based</td>
<td>Individualized</td>
</tr>
<tr>
<td>One-Off, Doctor’s Office</td>
<td>Real-Time Streaming, Real World</td>
</tr>
<tr>
<td>Doctor Ordered Data</td>
<td>Patient Generated Data</td>
</tr>
<tr>
<td>Doctor’s Notes, Unshared</td>
<td>Our Notes, Patient Edited</td>
</tr>
<tr>
<td>Information Owned by Doctors and Hospitals</td>
<td>Information Owned by Rightful Owner</td>
</tr>
<tr>
<td>Expensive, Big-Ticket Tech</td>
<td>Cheap Chips, Moore’s Law</td>
</tr>
<tr>
<td>Data Limited</td>
<td>Panoromic</td>
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</tbody>
</table>
Maybe we should just ...

*Liberate* the data
Shaping a new standards culture for large scale eHealth deployment

- Think of a **global eHealth ecosystem** where:
  - people (digital natives and immigrants) enjoy timely safe and informed health, anywhere around the globe
  - interoperability assets fuel creativity, entrepreneurship, and innovation

- where **eStandards**:  
  - nurture large-scale eHealth deployments to strengthen Europe’s voice and impact locally on its citizens and globally on the world  
  - enable co-creation in interoperability where trusted dialogs on health, costs, and plans meet great expectations.
The case for formal standards in large scale eHealth deployment

- **Health System** – government and regulators
  - Rules to abide by for sustaining and innovating the health system
  - Public health reporting and analysis
  - Communication and coordination across health systems

- **Workforce**
  - Communication and coordination of care
  - Dissemination and availability of knowledge (CDSS)

- **Citizens**
  - Active involvement in health maintenance and decisions
  - Navigating the health system (or systems) they are involved in

- **eHealth Market**
  - Creating opportunities for new health and IT services

**Recommendations:**

#3 enable flow and mixed use of health data...

#4 provide clarity and guidance on the regulatory framework..

#8 support development & use of open-access tools across the standards lifecycle

Join us to build the future for eStandards!
Search for a digital health compass

Expert
Empower
Equity
Evolve
Enable
Evaluate
Engage
Educate