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

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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.

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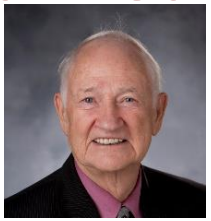

Digital health: Gutenberg moment for healthcare

- 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**

pcornet The National Patient-Centered Clinical Research Network

UDN Undiagnosed Diseases Network

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23andMe

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

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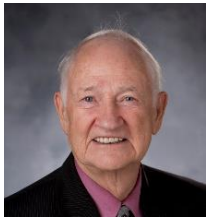
Panelists

Anne Moen



Ed Hammond

Petra Wilson

Christian Lovis

Robert Stegwee

Catherine Chronaki

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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

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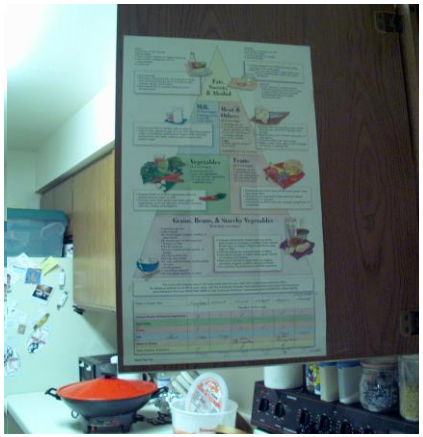
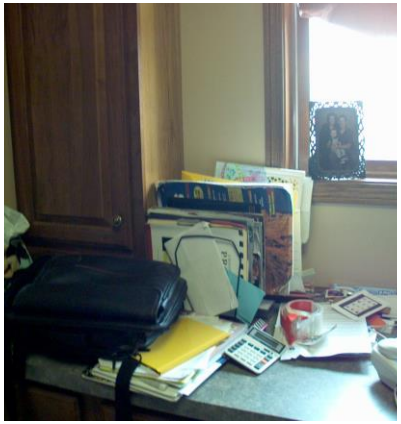
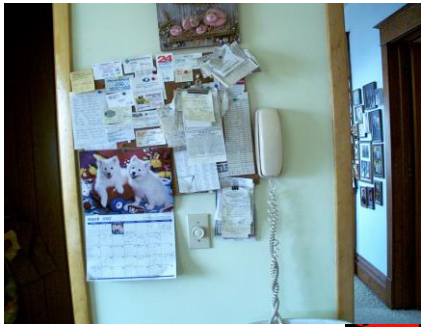
Examples of storing and organizing health information artifacts and spaces





Moen A, Brennan PF. Health@Home: the work of Health Information Management in the Household (HIMH) - implications for Consumer Health Informatics (CHI) innovations. Journal of the American Medical Informatics Association, 2005;12:648-56.

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

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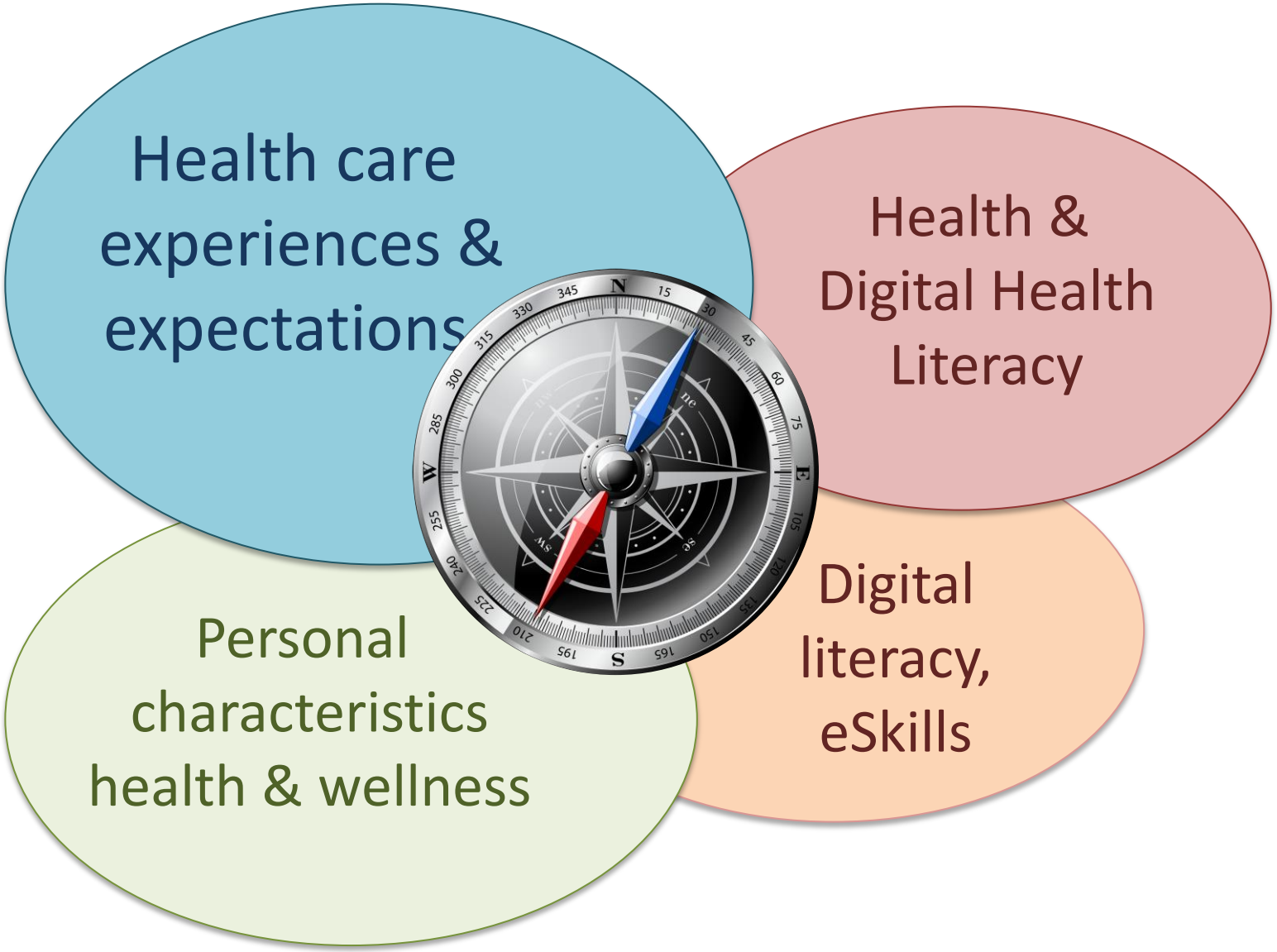
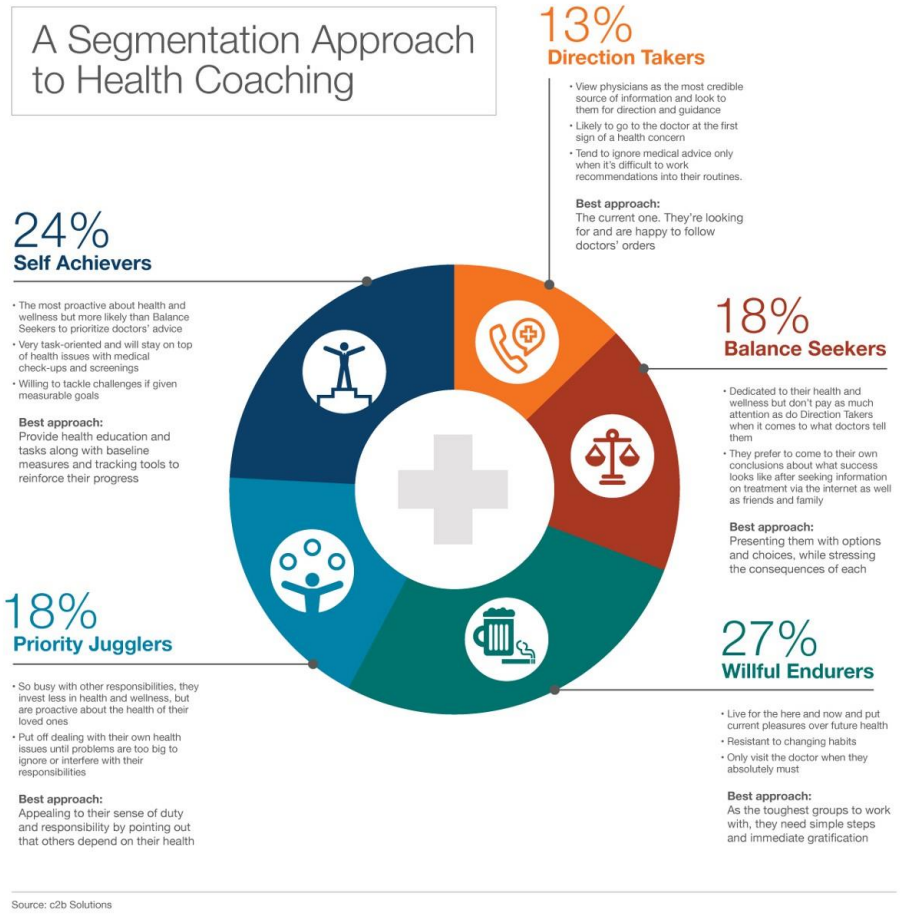
Co-creation → tomorrow's care



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!

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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

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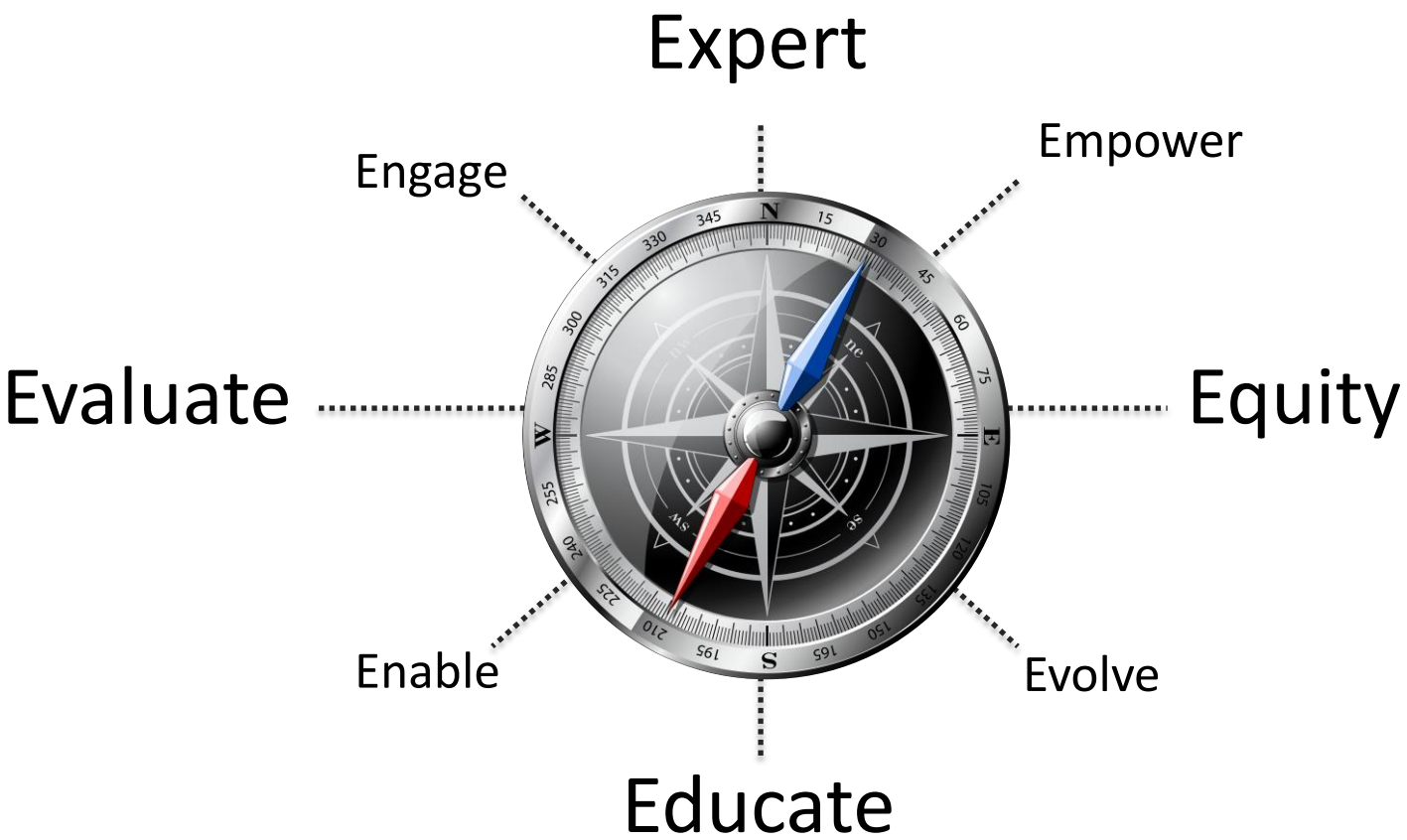
Searching for my digital health compass



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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

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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

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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!

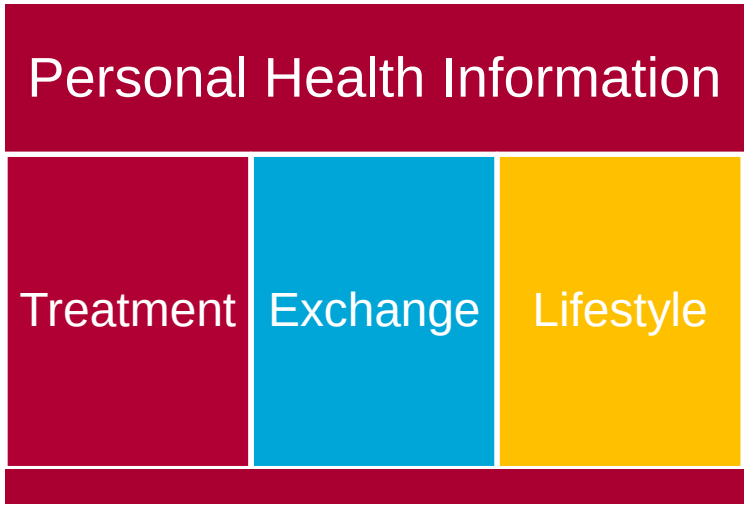
Robert A. Stegwee

Personal Digital Health

Transform to the power of digital

Capgemini Consulting

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

Capgemini Consulting

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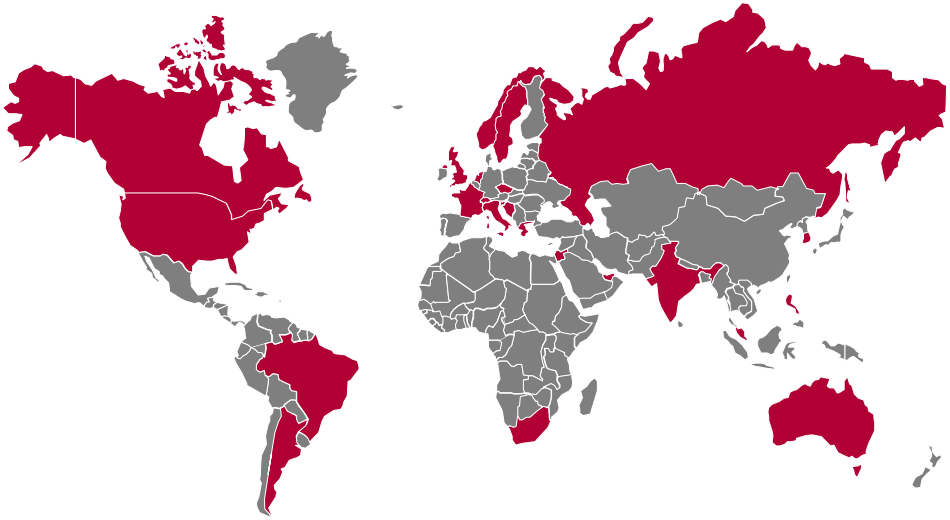
Adoption of Personal Health Records is very limited

- 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



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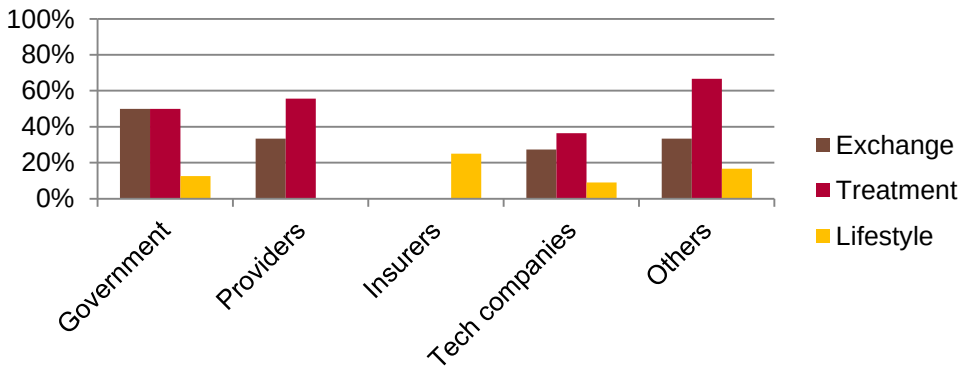
Different strategies are being implemented, with no clear differentiation in success

- 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



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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

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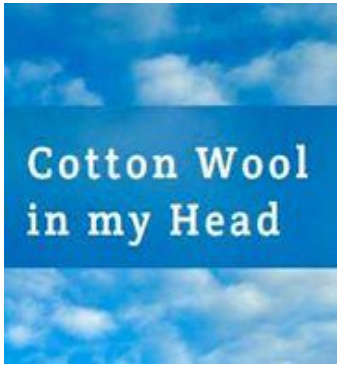
A vision on the role of personal health information for future delivery of health care

- 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

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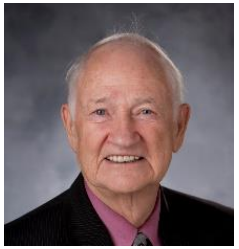

Ed Hammond

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.

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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

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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."

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Index - FHIR v1.0.2

https://www.hl7.org/fhir/index.html

FHIR®© DSTU2

Home | Documentation | Implementation | Resources | Clinical | Administrative | Infrastructure | Financial

Home

This is the Current officially released version of FHIR, which is DSTU 2.
For a full list of available versions, see the Directory of published versions.

0 Welcome to FHIR®

First time here? See the executive summary, the developer's introduction, or the clinical introduction, and then the FHIR overview / roadmap. See also the open license (and don't miss the full Table of Contents or you can search this specification).

DSTU updates:

- Oct-24 2015: Corrections to invariants, generated conformance resources, extension cardinalities, examples

Major Sections:

General Documentation | Implementation & Exchange | Clinical Resources | Administrative Resources | Infrastructural Resources

Quick links:

Documentation
- Resource List
- JSON, XML & RDF

Implementation
- Downloads
- Adapting FHIR for local use

External Links
- Support Links (StackOverflow, Forum, etc.)
- Public Test Servers & Software

FHIR is FREE!!

F – Fast (design & implement)

H – Healthcare

I – Interoperable

R – Resources (Building blocks)

8:12 AM
4/18/2016

What is FHIR? (1)

- 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.

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What is FHIR? (2)

- 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

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SMART on FHIR®© – Open Platform Architecture

SOA Orchestration

mHealth

OAuth

FHIR®© REST API

Clinical Element Models & FHIR Data Profiles

SMART™ Web Apps

Children's Hospital Boston

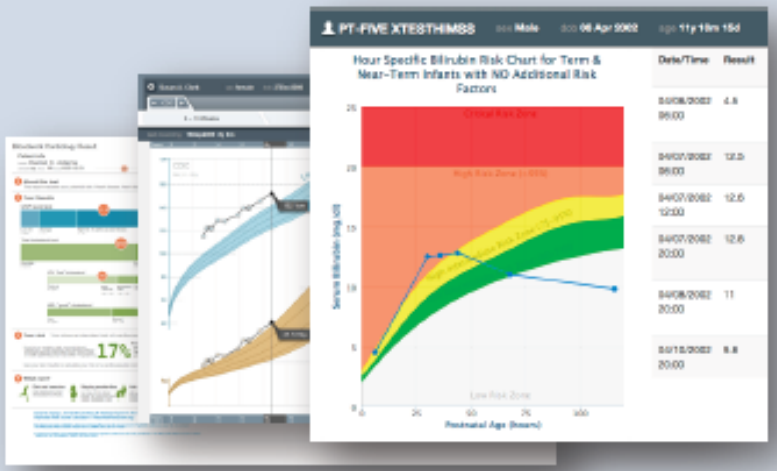
Intermountain Healthcare

visualdx

"polyglot"

HARVARD MEDICAL SCHOOL

Trusted App Registry



http://smartplatforms.org/smart-on-fhir/

Exhibiting Health IT Systems

Cerner
Booth# 6965

Intermountain Healthcare
Booth# 3903

HARRIS
Booth# 1164

hp
Booth# 1949

MyChart - Inbox

https://www.dukemychart.org/home/inside.asp?mode=messages&mbox=1&action=read&id=1

Duke MyChart

Welcome,
William E Hammond

Log Out

Messages | Visits | My Medical Record | Billing | Questionnaires | Resources

William

pulse rate

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 BP's along with that, see if there is room to dial your meds back a bit.

Reply Delete

Back to the Message List

MyChart® licensed from Epic Systems Corporation, © 1999 - 2013.

10:47 AM
4/4/2016

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

Christian Lovis

- Access to knowledge and research strategies that alleviate health disparities
- Set knowledge free !
- Make it matter for us !

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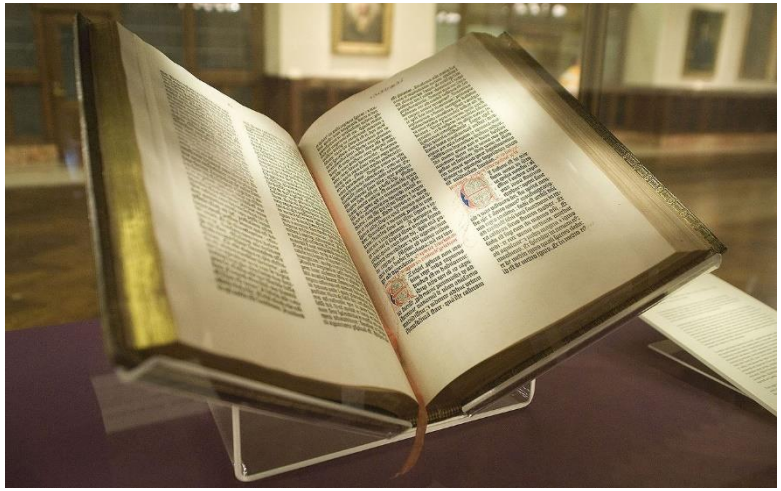
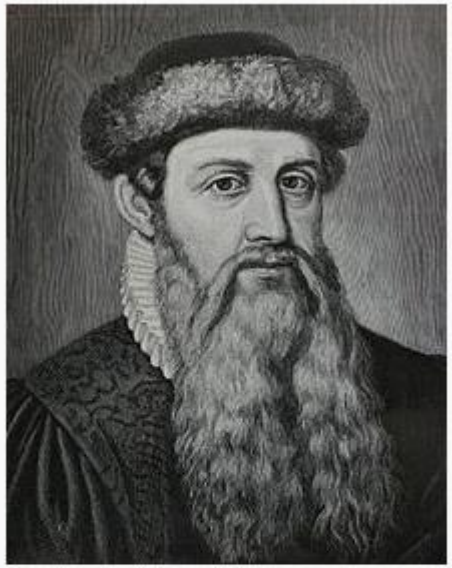
In 1455, Gutenberg completed copies of a beautifully executed folio Bible (Biblia Sacra), with 42 lines on each page. Copies sold for 30 florins each,[23] which was roughly three years' wages for an average clerk. Nonetheless, it was significantly cheaper than a manuscript Bible that could take a single 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]

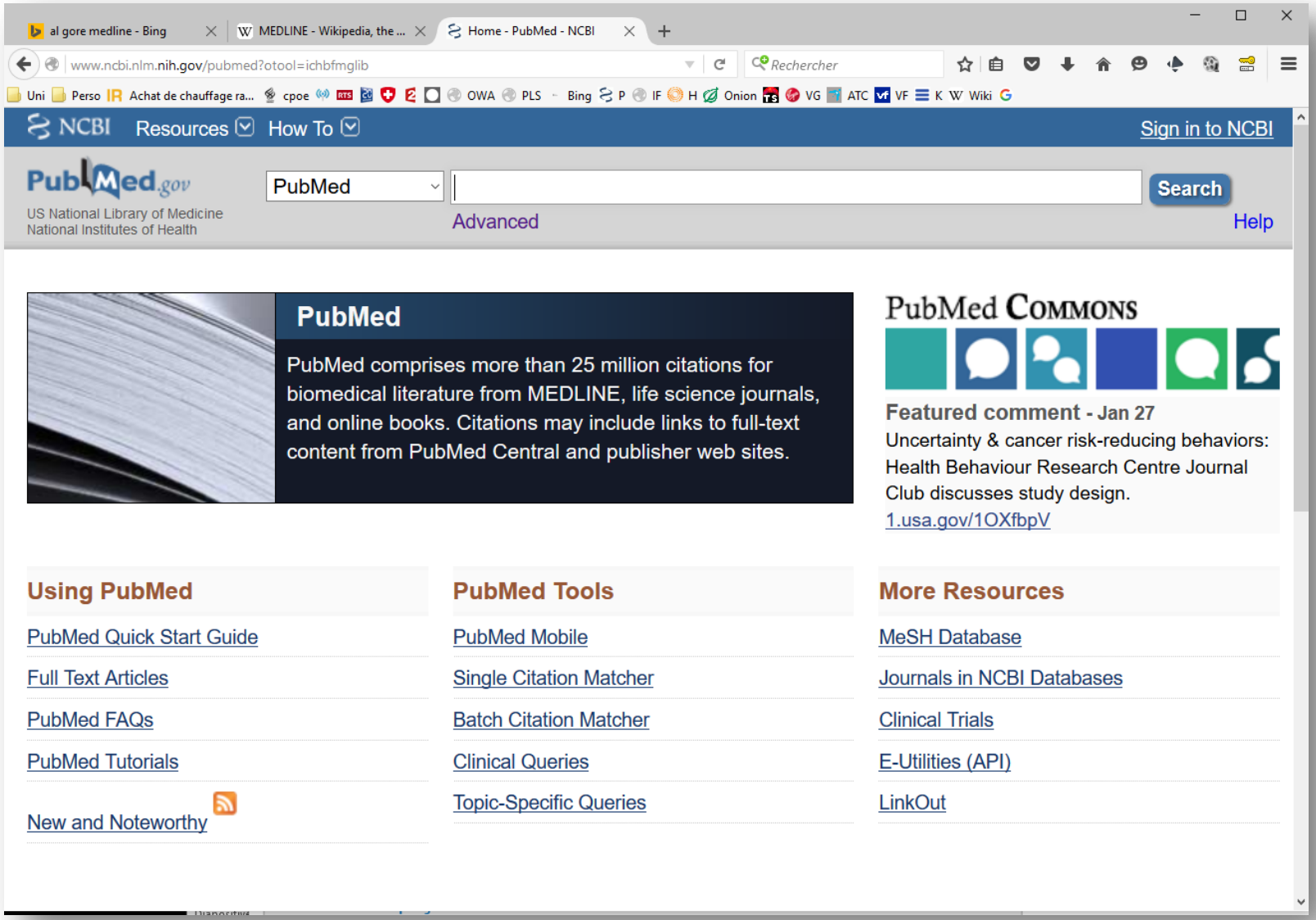


Johannes Gutenberg

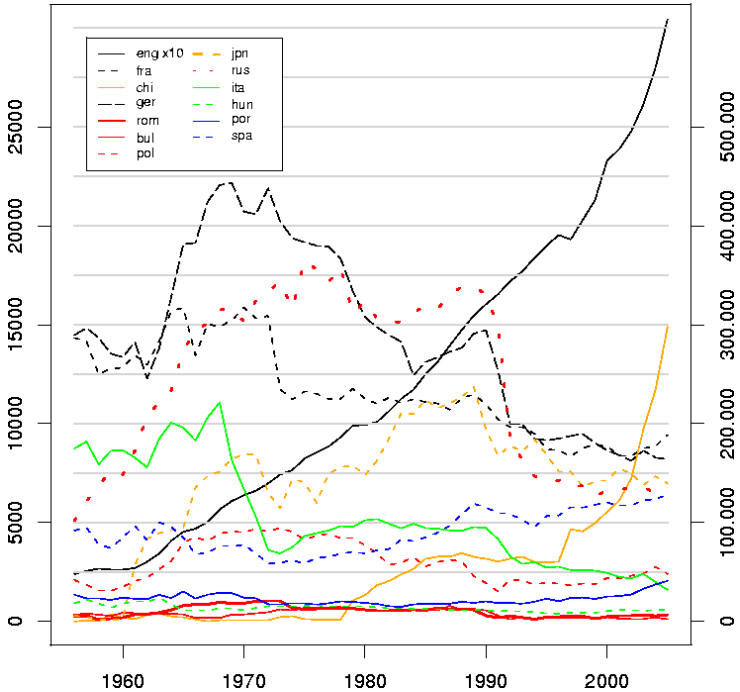


Born	Johannes Gensfleisch zur Laden Gutenberg c. 1398 Mainz, Electorate of Mainz
Died	February 3, 1468 (aged 70) Mainz, Electorate of Mainz
Occupation	Engraver, inventor, and printer
Known for	The invention of the movable-type printing press
Religion	Catholic

1455, first Bible printed by Johannes Gütenberg



June 1997, Medline **free and open access** during public ceremony by VP Al Gore

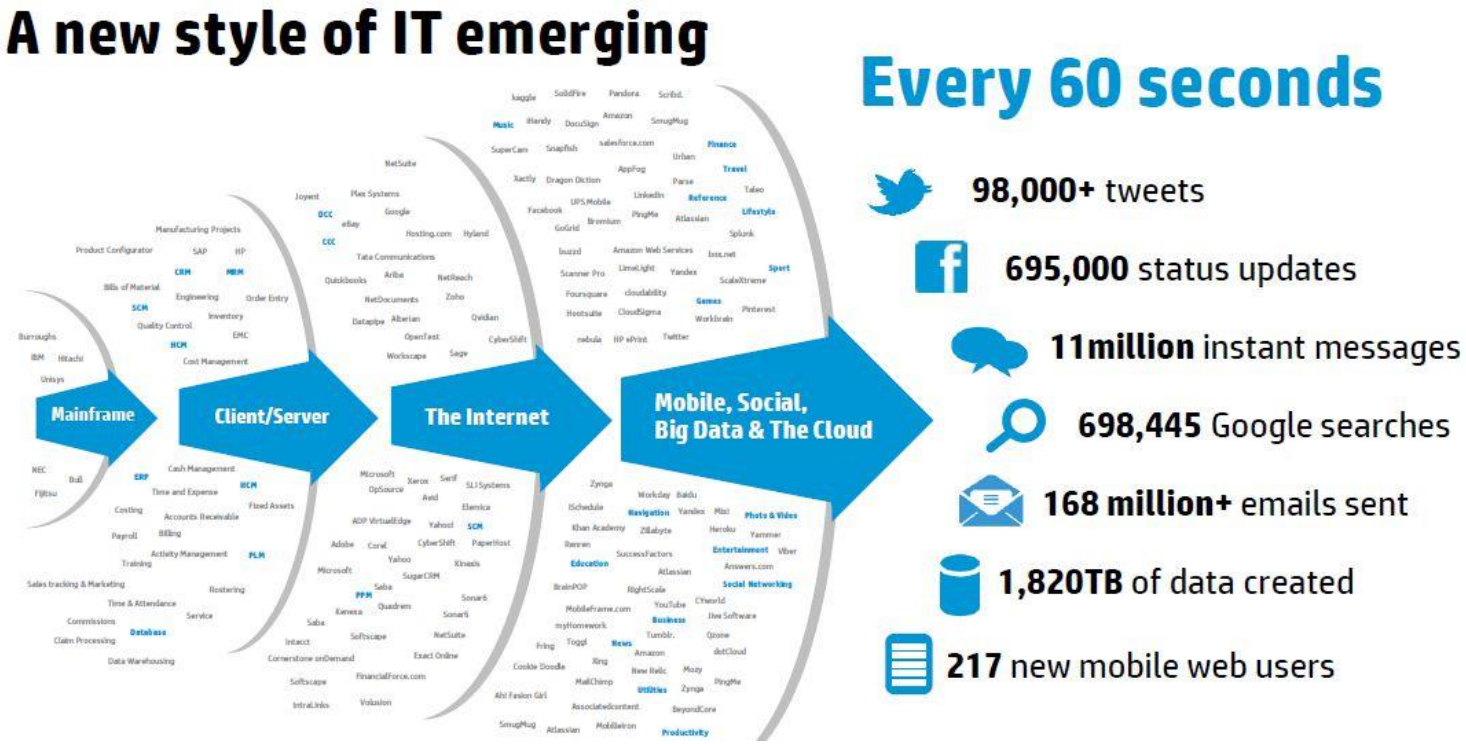


http://dan.corlan.net/medline-trend

Information tsunami

~4’000 papers indexed/day

The BigData era



Kalakota, R. (2012, October 22). Sizing "Mobile + Social" Big Data Stats. Retrieved from http://practicalanalytics.wordpress.com/

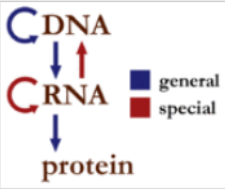
Wiki4Alps: Photograph a monument, help Wikipedia and win!

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 1956[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.*



Information flow in biological systems

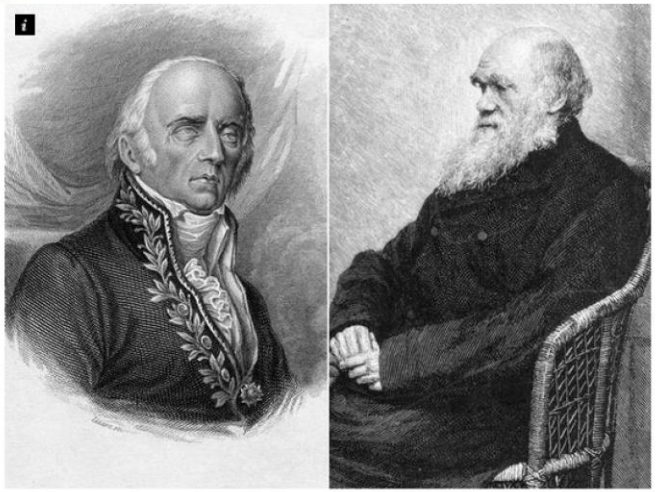
The central dogma has also been described as "DNA makes RNA and RNA makes protein,"[3] a positive statement which was originally termed the sequence hypothesis by Crick. However, this simplification does not make it clear that the central dogma as stated by Crick does not preclude the reverse flow of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

Crick had misapplied 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).[2]

Contents [hide]

The smell of fear can be inherited, scientists prove



Study shows scents associated with terror may be passed on for two male generations

nature neuroscience

Parental olfactory experience influences behavior and neural structure in subsequent generations

Brian G Dias[1,2] & Kerry J Ressler[1–3]

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 (*Olfr151*) 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 *Olfr151* pathway. Bisulfite sequencing of sperm DNA from conditioned F0 males and F1 naive offspring revealed CpG hypomethylation in the *Olfr151* 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-

Advancements in Genetic Engineering

Mastinu, Adv Genet Eng 2015, 4:1
http://dx.doi.org/10.4172/2169-0111.1000e114

Open Access

Editorial

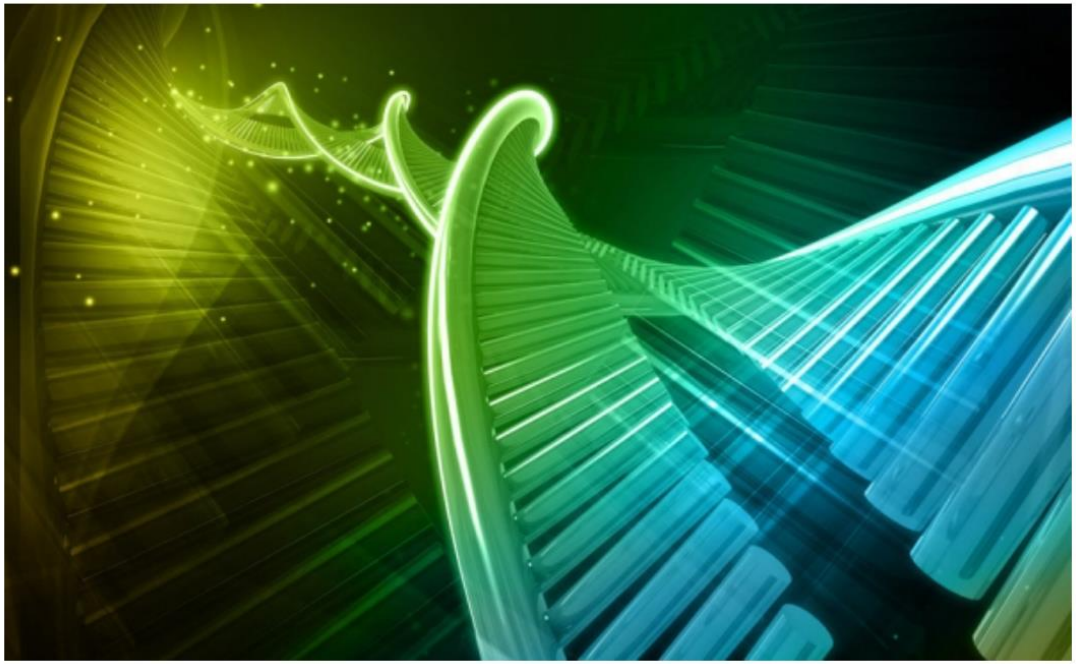
Epigenetics: The Revenge of Lamarck?

Andrea Mastinu*
University of Brescia, Viale Europa 11, 25131 Brescia, Italy
***Corresponding author**: Andrea Mastinu, University of Brescia, Viale Europa 11, 25131 Brescia, Italy, Tel: +39 030 2988; E-mail: andrea.mastinu@unibs.it

Sixth DNA Base Discovered By Scientists?

0 Comments Like 189 Share 189 Tweet 16 G+1 3 Text Size

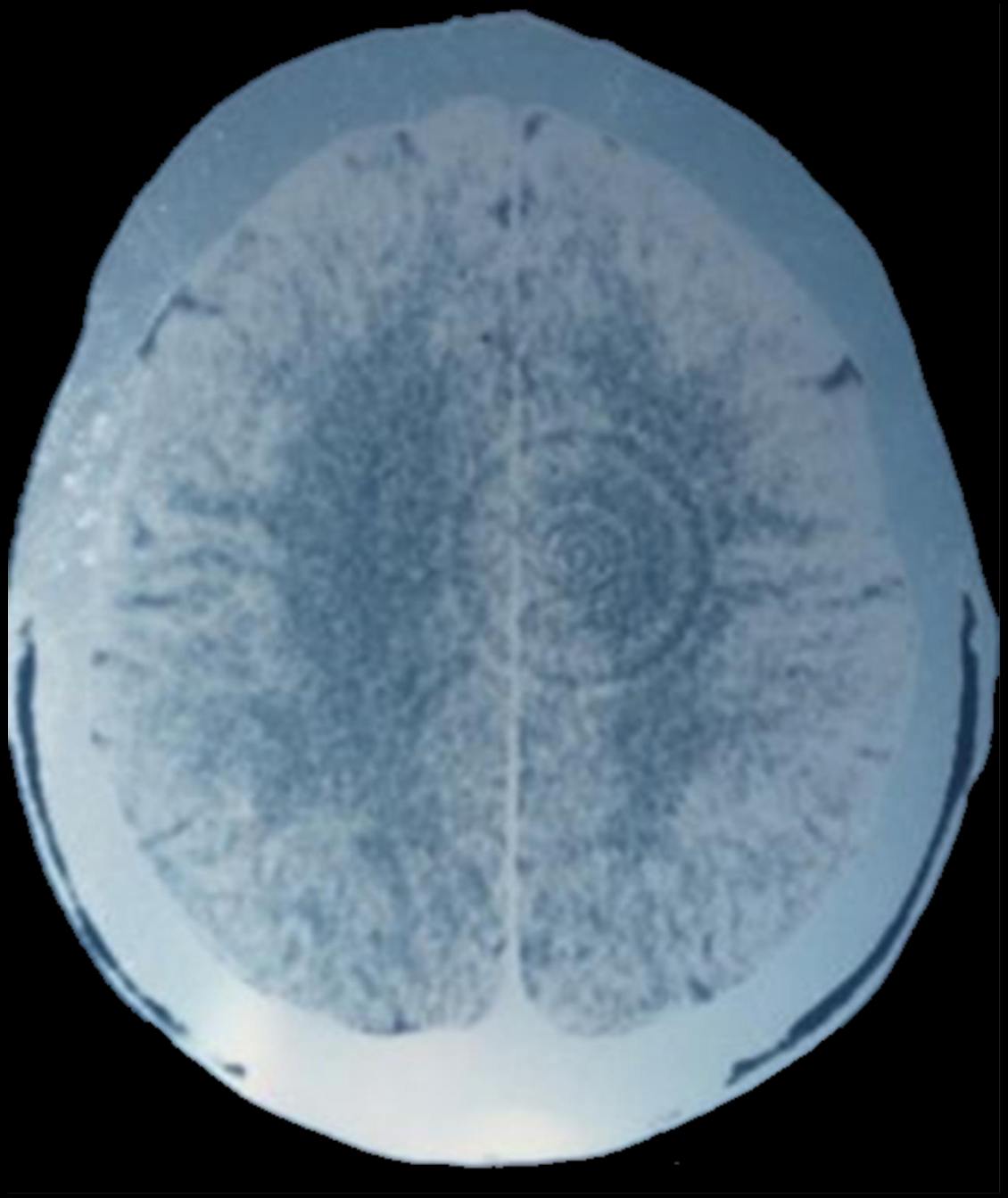
By Jenna Iacurci May 05, 2015 12:35 PM EDT



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.



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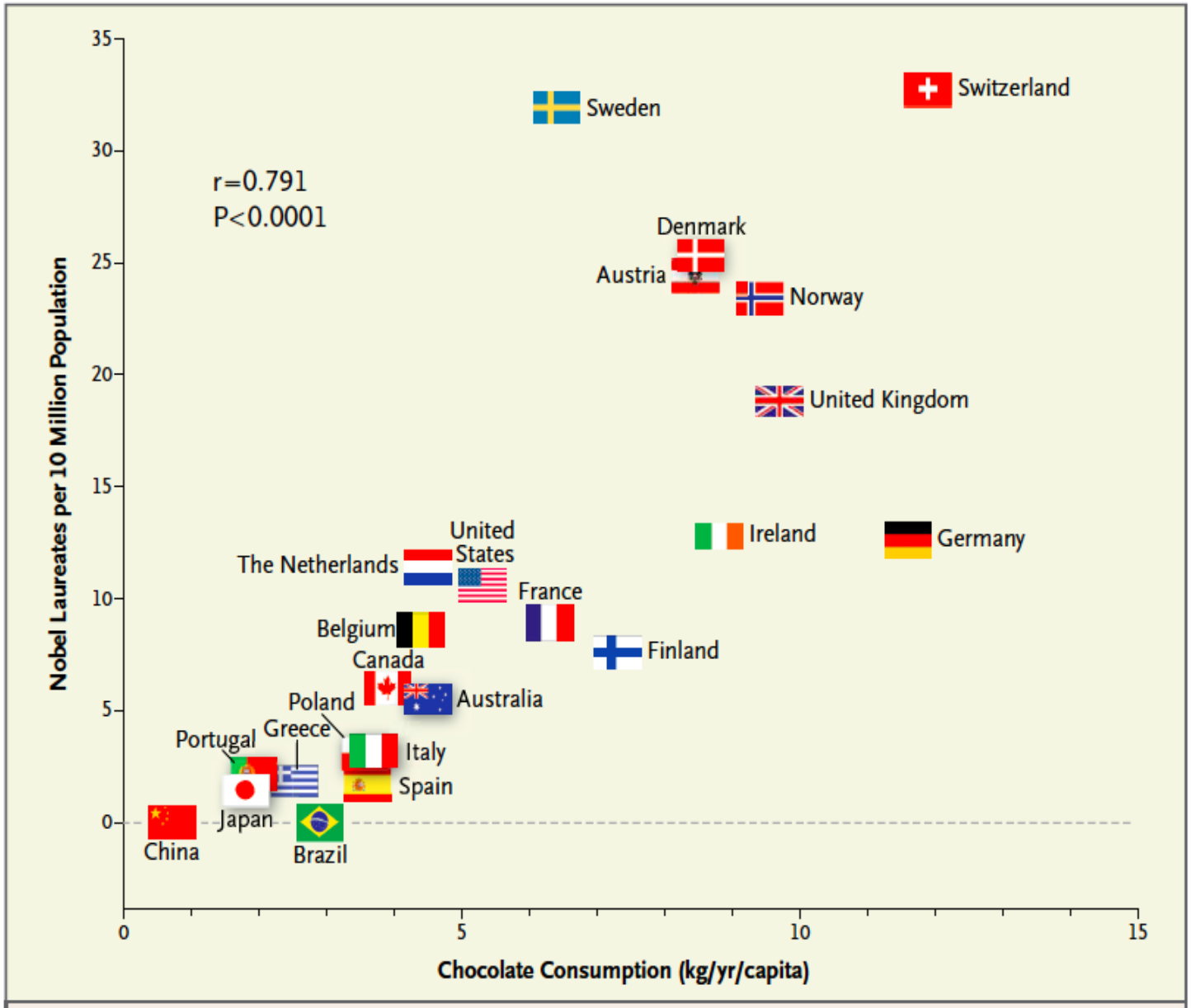
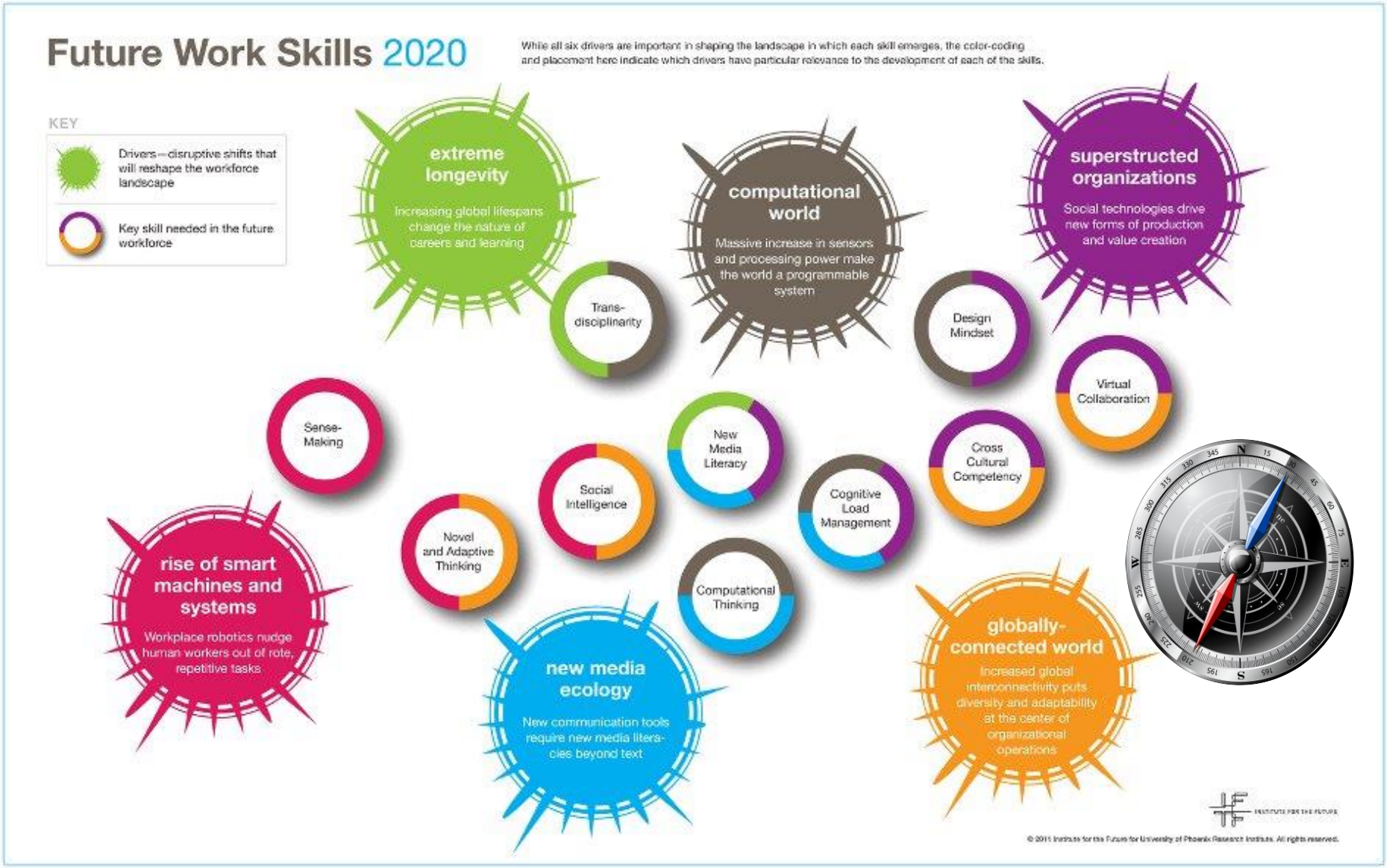


Figure 1. Correlation between Countries' Annual Per Capita Chocolate Consumption and the Number of Nobel Laureates per 10 Million Population.

New competences



Catherine Chronaki

My Data - My Decision – our ePower

patient engagement, *myHealthData,* tailored, adaptive and actionable health experience for individuals, families and communities.

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My Data …

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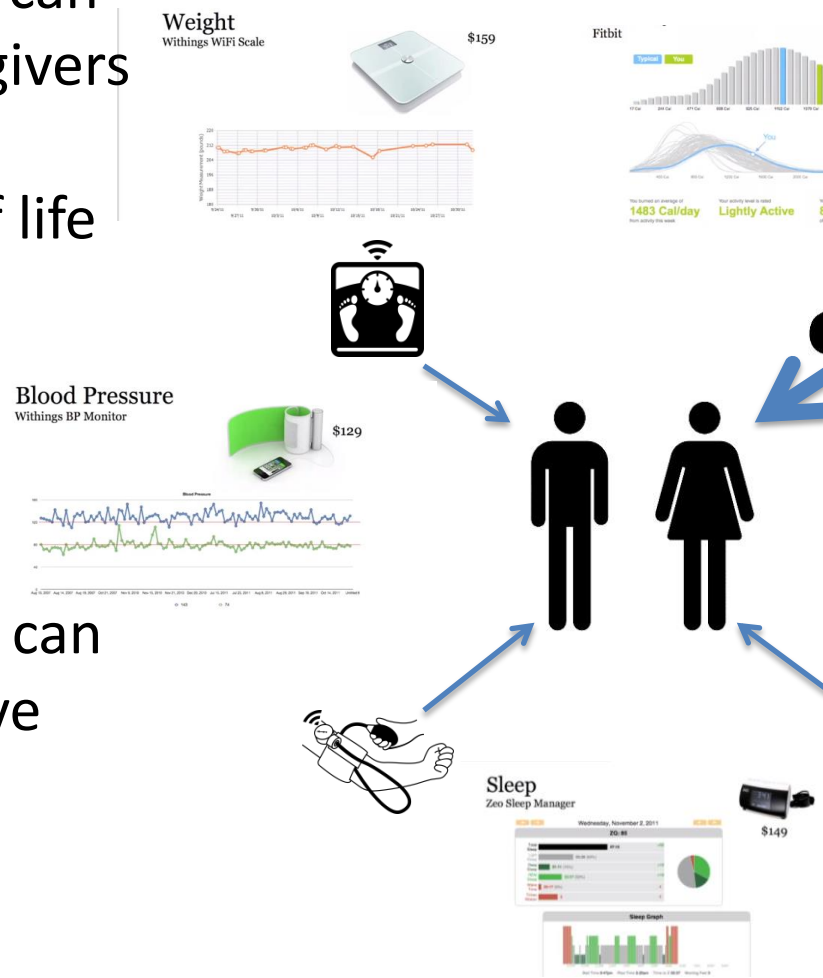
Know the effects of medication you take or not...

Society for Participatory Medicine

- 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.



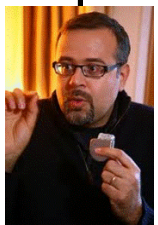
GS1

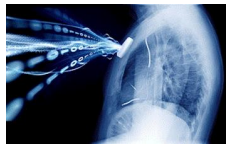
ISO International Organization Standardizati

HL7 FHIR

ePatients

- Empowered
- Educated
- Engaged
- Enabled





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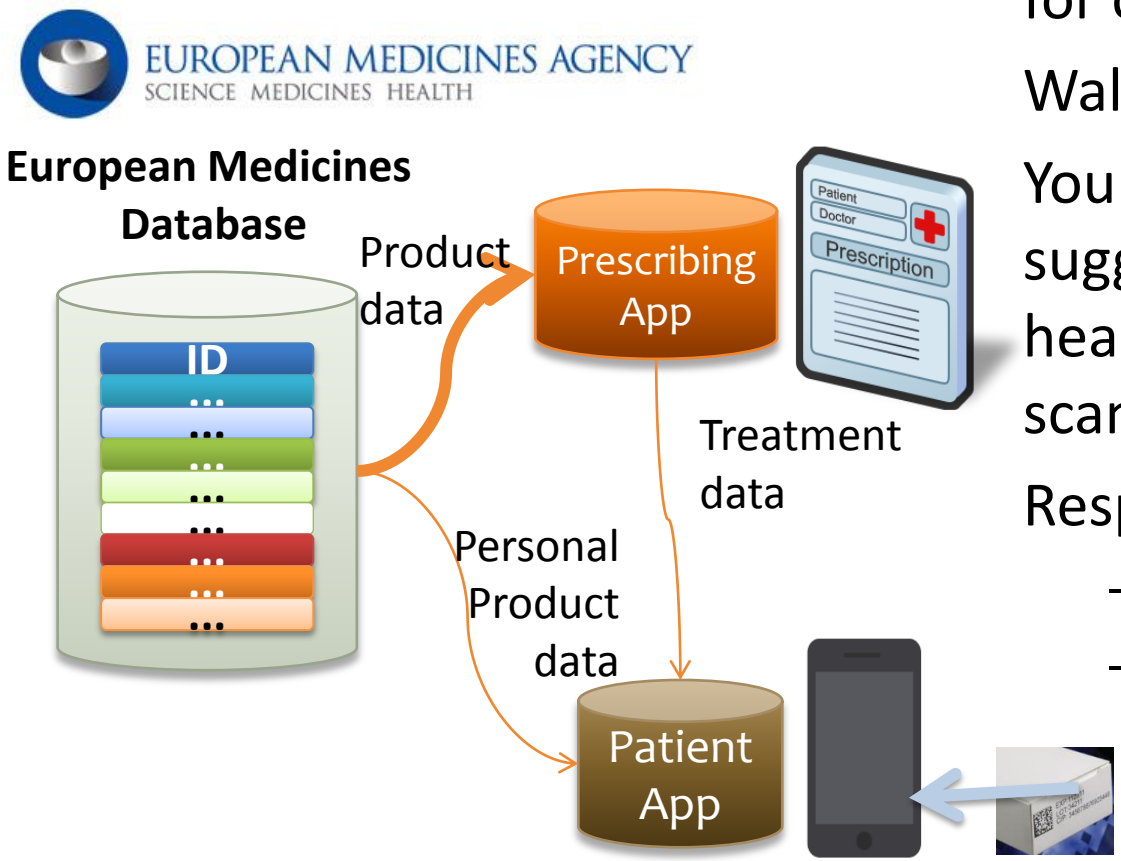
My Decision ..

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 poducts

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sign in register kit 0

23andMe

welcome ancestry how it works research buy help

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

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Our ePower…

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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

g/helpanotherway/1

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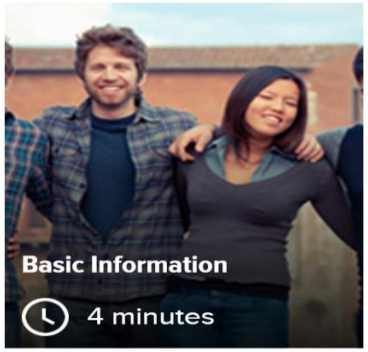
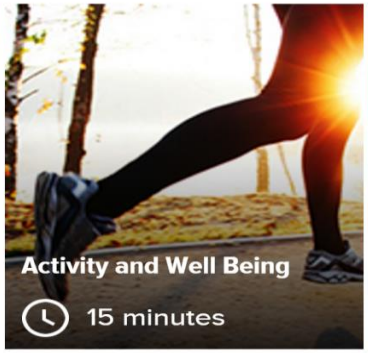
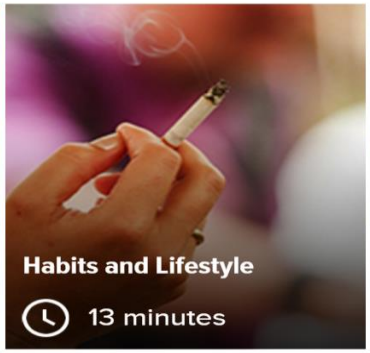
Welcome to the team—lets fight some heart disease!

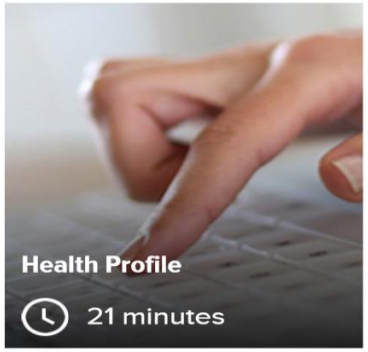
Being a **hero** isn't always glamorous, and since information is our main weapon against heart disease, we need to collect some to get you baselined. Here's what we need for you to officially get your stripes.

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









Sound good? Let's get started!

Get started →

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patientslikeme®

Already a member? Sign in.

conditions, symptoms, treatments...

Live better, together!™

Making healthcare better for everyone through sharing, support, and research

Join now

(it's free!)

Learn from others
Compare treatments, symptoms and experiences with people like you and take control of your health

Connect with people like you
Share your experience, give and get support to improve your life and the lives of others

Track your health
Chart your health over time and contribute to research that can advance medicine for all

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babylon

Everyone's personal health service.

WHAT WE DO

EVERYONE'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

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Health eHeart Alliance

"Pioneer new ways to empower patients in improving research, care and quality of life for heart patients."

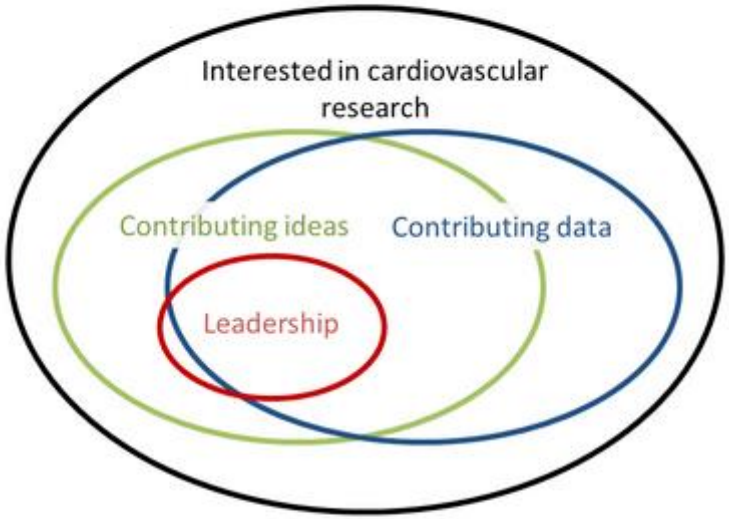

Figure 1. Membership in The Health eHeart Alliance
The Alliance welcomes anyone declaring their interest in cardiovascular research, defines participation broadly, and expects different levels of engagement

The Health eHeart Alliance

The Health-eHeart Alliance

A Patient-Powered Research Network for Cardiovascular Health

- 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.

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Eric Topol on change…

Old Medicine	New Medicine
Population-Based	Individualized
One-Off, Doctor's Office	Real-Time Streaming, Real World
Doctor Ordered Data	Patient Generated Data
Doctor's Notes, Unshared	Our Notes, Patient Edited
Information Owned by Doctors and Hospitals	Information Owned by Rightful Owner
Expensive, Big-Ticket Tech	Cheap Chips, Moore's Law
Data Limited	Panoromic

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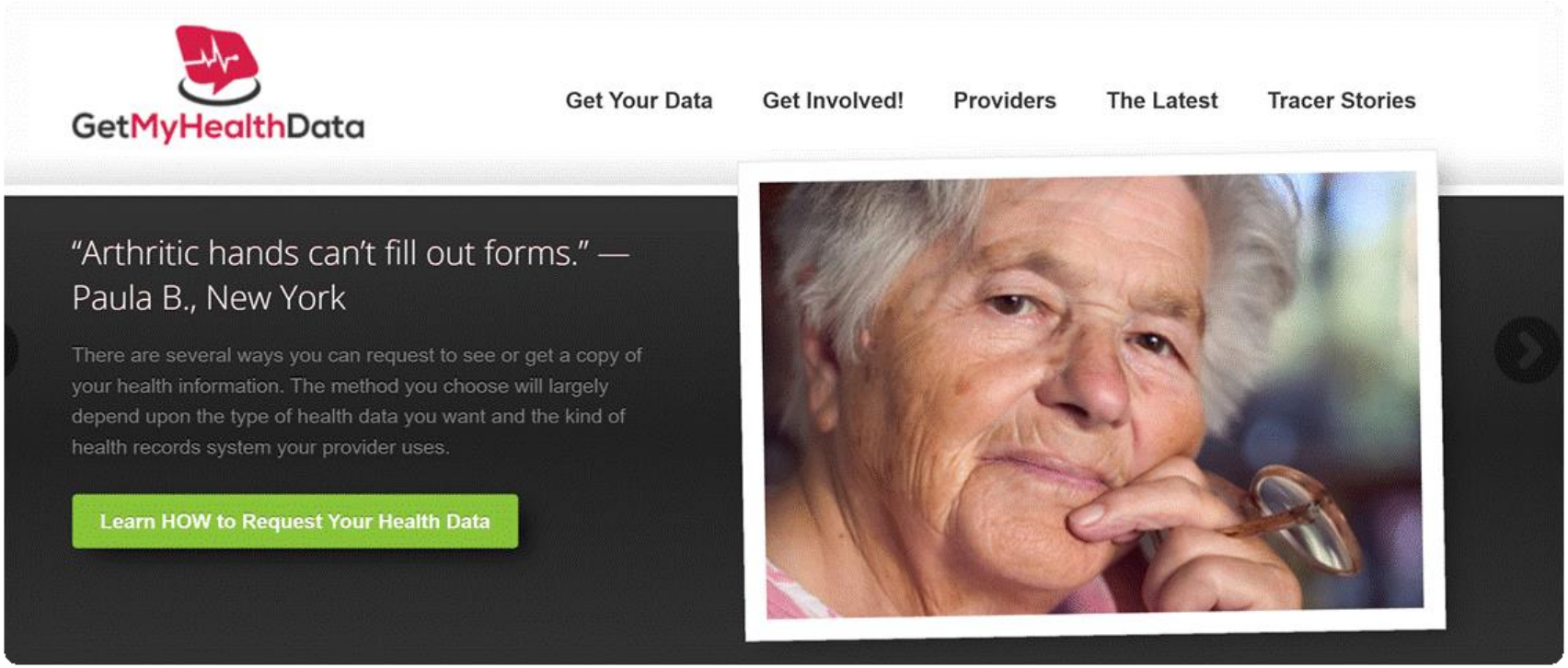
Maybe we should just … *Liberate* the data



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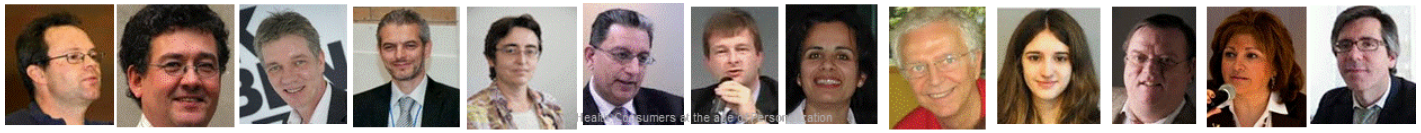
Shaping a new standards culture for large scale eHealth deployment

- 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 ***e*Standards**:
  - 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

www.estandards-project.eu


eHealth Standards and Profiles in Action for Europe and Beyond

Deliverable 3.1
The case for formal standardization in large-scale eHealth deployment


eHealth Standards and Profiles in Action for Europe and Beyond

Deliverable 3.3
Initial Draft Roadmap for Essential Standards Development

- **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:

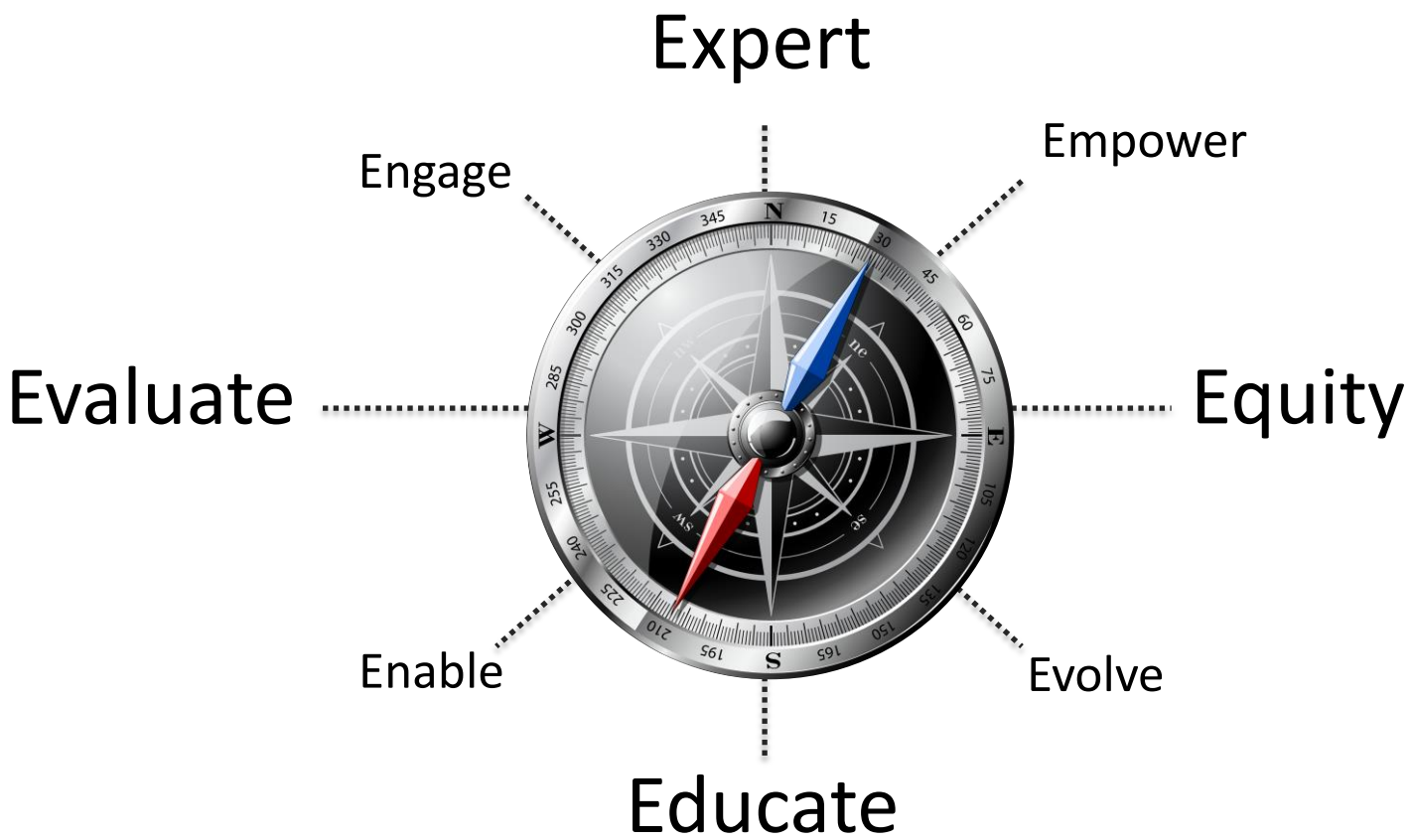
#3 enable flow and mixed use of health data…

#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



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