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# In Search of a Digital Health Compass to Navigate the Health System

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## Abstract

*Healthcare systems increasingly rely on digital technologies to sustain costs and improve access to quality care. Data drive a wave of automation aspiring to improve productivity by forging connections between health and wellness, medical research, and clinical decision support. Mobile apps and patient-generated data combined with provider recordings pave the way towards personalized care pathways and just-in time access to health services. Navigating the health ecosystem becomes challenging as roles and relationships change. This paper reflects on the digital health compass to navigate the health system using one's own data. Health information technology standards are at the core of the compass, to tap the potential of shared aggregate data and sustain trust. The notion of the patient summary as a window to one's health is used as an example to drive our call for action for health informatics to develop methods to calibrate the digital health compass and feed on 'my data', respecting 'my decision', to fuel 'our ePower'.*

***Keywords:***

Telemedicine; Reference Standards; Personal Health Records

## Introduction

Knowledge is power. Despite extensive investments in digital health technology and incentives for uptake of eHealth consumer services, navigating the health system online is hard. The 2014 digital health literacy survey confirms differences and widening divides [1]. The "Inverse Care Law" proposed by Hart in 1971 [2], seems to apply to eHealth. Availability of, access to, and productive use of advanced medical or social care services and digital health tools, varies inversely with the needs of the communities. In fact, the low adoption of digital health technology and eHealth services among segments of the population underscores persistent disparities in health care.

Barriers and challenges are not to be underestimated as people feel that with excessive use of technology we may lose the human touch. Taking into account culture, education, skills, costs, perceptions of power and role, is essential for successful community actions. These elements come together in digital health literacy, "*the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to address or solve a health problem*" [3], which underpins the knowledge and skills required to construct the digital health compass to navigate the healthcare system. Patients living with an implanted device, coping with chronic disease, engaging in self-care, caring for an elderly relative in deteriorating health, or an ailing child, need a digital health compass. Hyper-personalization enters every facet of our life and personal data on health and behaviors can be used to present information and knowledge, services, and tools, at the right time and in the right way [4].

There is an ongoing shift in the terrain of the health sector from cure to care, where patients, families and informal care givers actively participate. This may be because they want to help [5] or they are expected to make health decisions [6, 7]. We argue that citizens need a digital health compass to unlock the power of their health information, drive their engagement in personal health information management, and identify the most suitable health services for the situation at hand. With the increasing quantity and uneven quality of health data, patient summaries could be the starting point to write an individual's health story.

Patient summaries can point to key information accumulated across health systems, sites and care settings and essential information in planned and emergency encounters. However, this assumes a joint effort to clarify expectations and keep patient summaries accurate and complete [7,8]. The Trillium Bridge project recommended a patient summary standard for people to access and share their health information and to drive incentives for quality record keeping and health professional appraisals[1].

Attending to data provenance, patient summaries complemented with patient-generated data can supplement health services and facilitate a smooth transition to digital health. High quality patient summaries can foster safe and effective care *for or by* an individual in a variety of situations. For example, we may offer our patient summary during an emergency hospital admission. We may use them to seek a second opinion or search health information online, or just to connect health professionals that typically do not exchange information or cooperate.

Experienced users may employ patient summaries in connection to personal health records to monitor their health and engage in health decisions. They may collect personal observations to complement or expand on existing data, to support self-care and follow up on health management activities. A data culture would take us further, to where we use patient summaries to safely engage in personalized navigation of the internet and network with people facing similar health issues.

Progress however, is slow. Reasons can be summed up with low digital health literacy. For the most part, patients and informal caregivers are not excited by available digital health tools. Either they do not trust them, or do not know how to use them. To make matters worse, many health professionals are not comfortable with recommending specific digital health tools to their patients. Limited sharing of information and under-developed cooperation among patients, informal care givers and health care professionals leaves untapped the potential of data for informed health decisions. Resistance is fueled by the need to protect our privacy, dignity, integrity, and individuality. Where

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[1] http://ec.europa.eu/newsroom/dae/document.cfm?doc_id=11039

the Internet of Things (IoT) meets health care, a plethora of tools, gadgets, and apps overpromise and under-deliver on improving health and wellness and supporting an active lifestyle. They score low in actionable knowledge, partly because disconnected from health and social care services, they hinder personal efforts to share intimate information, while preserving one's self-reliance, autonomy, and freedom of choice.

The rest of this paper is organized as follows. The next section presents the vision of the digital health compass and its relation to health information interoperability standards that link fragmented sources of information. The case of the patient summary illustrates how the compass may work from the perspectives of health systems, eHealth consumers, the healthcare workforce, and the eHealth market (see Figure 1). Then, "my data", "my decision", "our ePower" complete the vision of the digital health compass with a call for action to the medical informatics community that can help shift the narrative towards safe and trusted use of health data to benefit individuals and the society as a whole.

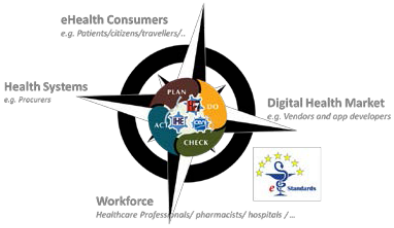

*Figure 1– A Digital Health Compass to Navigate the Health System.*

## Digital health compass

A digital health compass with knowledge of a person's digital health literacy profile can point to eHealth resources that foster personal control and empowerment. Different dimensions need to be considered to understand how a digital health compass can support safety, prevent harmful events, and assist in managing efficient, connected services of high quality and relevance in the digital health ecosystem. Health data standards, open interfaces, and a culture of sharing increase trust. Complementary initiatives to health information technology standards are the Dublin Core Metadata Initiative (DCMI) headings, the HONCode labelling online health resources, and W3C guidelines for usability and accessibility building confidence in navigation.

### Standards in the digital health ecosystem

Health information technology standards are required to provide common metadata about digital health products and assemble fragmented information scaling up and sustaining digital health literacy [5, 9]. Standards developing organizations work together on standards to meet the health information needs of people within and across health facilities. The value of data and the increasing focus on patient experience, dictates global cooperation on open standards emphasizing mobile use.

### *HL7 FHIR*

In HL7, this trend is reflected in Fast Healthcare Interoperability Resources (FHIR), a new standards initiative seeking to liberate data for population health and precision medicine in the context of learning health systems. FHIR is based on a set of modular components or *Resources*, which are small discrete units of exchange with defined behaviour addressable using URLs. Resources are combined into profiles to solve practical clinical and administrative problems. *Resource extensions* and *profiles* facilitate the addition of data that are not part of the core, which follows the 80/20 rule i.e. cover the top 80% use cases and most frequent functionality. The overall approach is web-based (i.e. RESTful API), service driven, and supports adaptation and portability of components moving program code with data as *resource bundles*. A robust FHIR resource *maturity framework* tracks the stability and extent of world-wide adoption of every resource. The version of FHIR balloted in 2015 (DSTU2), includes 27 clinical resources along with supporting financial, conformance, workflow, identification, and infrastructure resources. The high appeal of FHIR can be attributed to its vibrant and committed implementation community, available tools, services, and data to learn, explore, and experiment with minimal cost in time or money. ClinFHIR is such a tool specifically designed for clinicians[2]. With more integrated and specific systems and more information available in real-time, "live" sharing of health data becomes the new norm, and FHIR resources are the ideal vehicle for digital health literacy. It is these characteristics of HL7 FHIR that allow it to function as infrastructure for interoperability and innovation, by connecting the dots from user experience to data exchange on the wire.

Standards for consent management [10] support the aim to increase security, trustworthiness and transparency of digital health services making individuals and organizations comfortable with sharing or donating data to the community. ISO/TC215, CEN/TC251, and HL7 with active participation from regulators like EMA and FDA, work on standards for the identification of medicines. The openMedicine[3] project focused on the identification of medicinal products throughout their lifecycle with particular emphasis on cross-border ePrescription and eDispensation. Combining this information with the personal health data of the patient fuels innovation. For example, one can imagine strolling into a Pharmacy and consulting an app on over the counter medications most appropriate for them. We may also consider active personalized medication leaflets that adapt to their health and lifestyle offering alerts and enhancing medication compliance. Essential to the digital health compass is the use of reference clinical terminologies that contribute to higher data quality. SNOMED CT is active in this area with consistent efforts in user-interface terminologies to pave the way towards individualized digital health services.

### *Health on the Net code of Conduct*

The Health on the Net code of conduct or HONcode [11] is a process metric to determine if the construction and maintenance of a website conform to approved standards of excellence. The HONcode is used to certify health websites with content respecting the HONcode criteria (see Figure 2). Compliance to the HONcode of conduct is reflected by displaying the HONcode seal. The HONcode contributes to the digital health compass by helping individuals make informed choices in accessing trustworthy content. Extensions of HONcode for health and wellness apps can be envisioned as a natural next step.

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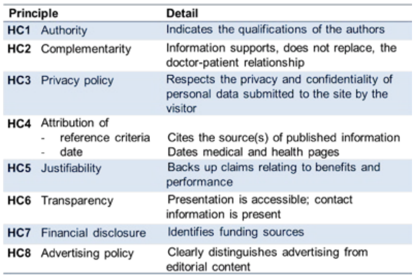
[2] https://fhirblog.com/2016/11/06/clinfhir-profiling-walk-through/

[3] www.openMedicine.eu and www.assessCT.eu



| Principle | | Detail |
|---|---|---|
| **HC1** | Authority | Indicates the qualifications of the authors |
| **HC2** | Complementarity | Information supports, does not replace, the doctor-patient relationship |
| **HC3** | Privacy policy | Respects the privacy and confidentiality of personal data submitted to the site by the visitor |
| **HC4** | Attribution of | |
| | - reference criteria | Cites the source(s) of published information |
| | - date | Dates medical and health pages |
| **HC5** | Justifiability | Backs up claims relating to benefits and performance |
| **HC6** | Transparency | Presentation is accessible; contact information is present |
| **HC7** | Financial disclosure | Identifies funding sources |
| **HC8** | Advertising policy | Clearly distinguishes advertising from editorial content |

*Figure 2– Principles Underlying the HONcode of Conduct.*

Health information technology standards assemble fragmented sources of health information, nurturing trust. Answering how different standards fit together and how joint products are governed and adapted to the changing needs of the community is essential. This is expressed in the vision of the eStandards project[4] imagining: "…a *global eHealth ecosystem where people receive timely safe and informed health care, anywhere around the globe and interoperability assets fuel creativity, entrepreneurship, and innovation, as digital health standards nurture large-scale eHealth deployments and enable co-creation with trusted dialogs on costs and plans that drive great expectations.***"** eStandards cooperates with the health informatics community on a roadmap for cooperative standards development, to form the core of the digital health compass.

## The case of patient summaries

Patient summary initiatives to make health information available to patients and families are supported by the EU Directive 2016/679/EU on Data Portability. The directive states the right of individuals to transfer their personal data from one electronic processing system to another, in a machine readable format. Combined with Directive 2011/14/EU on patients' rights to crossborder healthcare and Directive 2013/37/EU on re-use of public sector information, patient summaries can be rethought as a tool for digital health innovation.

As part of the digital health compass, the patient summary helps individuals use their data and collect observations to develop the knowledge and confidence to select digital health tools that are right for them and engage productively in the digital transformation of the society. Patients, families and informal care givers join forces with the health team supported by research and development policies that advance digital health literacy. Health informatics supported by information technology standards and open application interfaces can serve as catalysts in the continuous improvement of data quality and the nurturing of trust relations in networks that transcend organizations, health systems and countries.

Trillium Bridge recommended that the patient summary includes at a minimum problems and procedures, medications and implantable devices, vaccinations, and allergies. Additional data to be included are labs, diagnostic images, and encounters. With FHIR resources one may retrieve specific sections of the patient summary or combine them in a clinical document. The low initial cost of working with FHIR opening up data sources traditionally behind organizational walls, helps shape the data sharing culture essential to construct the digital health compass.

Patient summaries can feed dashboards, the starting point in the search of health professionals for more detailed health information about a patient. Patient generated data can be summarized in this dashboard to assess progress towards achieving mutually agreed health goals supported by digital health literacy interventions. On the community level, patient summaries could help keep track of the health needs of the population and become an indispensable tool for evidence-based policy.

For the digital health compass, co-creation of patient summaries by patients, health professionals, and informal care givers comprises elements of digital health literacy, trust, and service provision. The key element of digital health literacy is understanding of health information for care, wellness, prevention, and engagement. To co-create in trust, data integrity of contributions from patients and providers and stewardship when sharing, interpreting, and complementing health information are essential. Finally, an element of service provision rooted in health experience and team play, advocates to liberate the data in the name of innovation and progress.

*Figure 3– Dimensions of the Digital Health Compass.*

Personal experience is key in understanding the perceived impact on a person's life, disease progression and expected outcome and impact of treatment options for individual patients in relation to their lifestyle choices. Tools for capturing, analysing, and relating all this data are becoming available with the person at the centre! First hand experts are the levers to adoption and they are not by definition technology driven. Frequently they are suffering from cognitive impairments and mutual trust is essential for them to willingly share the effects of the disease on their daily life and for technology experts to meet their needs. They are the ones who can tell us the real story behind the effects of this disease and its diagnosis, from their own experience with the disease. However, although patient needs should drive demand, frequently patients are inthe back seat, while sustainability of the health system, shortages in the workforce, fear of the unknown market regulation and traditional roles drive. Thus, we need to examine the perspective of health systems, workforce, consumers, and market guided by the core dimensions of the digital health compass: educate, enact, evaluate, empower, evolve, enable, and empower, shown in Figure 3.

### Perspective of health systems

The perspective of health systems centers on cost containment, performance, and quality care. Digital health services routed in a data culture can help unlock productivity in health care. Platforms inspired by the sharing economy can bring tangible improvements in administrative automation, networked knowledge, and resource orchestration for higher productivity [12]. In 2015, Uber Health was able to deliver 2000 flu shots in 35 cities over 4 hours. However, countries in Europe still lag behind in patient empowerment and appreciation of network effects [13]. Collecting and analyzing data, health systems can measure the degree to which people are confident when navi-

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[4] www.estandards-project.eu

gating health services online, booking appointments or accessing their health information. Health systems may also share resources with other health systems to increase productivity.

Patient summary services linked to productivity and incentives can engage patients in their health goals in partnerships with the health team. Establishing incentives for high quality recording or assembly of patient summary data can directly improve data insights guiding interventions with direct impact on increased productivity, and patient satisfaction. Note that the concept of health system navigators is not new. It was first introduced by Harold Freeman in 1990[5]. Assisted by medical students, patients are able to navigate the logistical, emotional, and frequently cultural barriers of receiving care. Patients are assisting in assessing the situation and choices, articulate objectives, evaluate alternatives and reach decisions. In the end, healthcare is analog and human touch is paramount. Digital health tools can help fill the intention gap!

**Perspective of health providers and the workforce**

From the perspective of health providers and the workforce, maintain cutting edge competences is essential. The rapidly unfolding technological environment leaves health professionals perplexed and confused in front of *well-informed* or *arrogant know-all* patients that need to be "de-googled". On the other hand, personalized treatment demands a partnership with the patient. For the workforce, the digital health compass needs to preserve the balance of roles in new quality relationships catalyzed by technology. Human relationships and empathy are challenged by complex knowledge-based remote cooperation. Self-care or care between care make physical encounters rare and precious.

**Perspective of the digital health market**

The digital health market is seeking opportunities to match demand and supply of digital health services. Established practices and a long standing *fee for service* reimbursement model of care, hinder adoption of innovation. Consider the case of the personal health record (PHR) as a digital organizer of personal health information. PHRs provide treatment support with self-management options. They facilitate sharing and exchange of health data with healthcare providers, suggest healthy lifestyle options, and track exercise, health and fitness. However, PHR adoption is not wide-spread and willingness to pay is low. Healthcare systems and government spending drive the market.

A recent study in 25 countries and 6 continents, revealed that most PHRs never go beyond the pilot stage of 100 -1000 subscribers. The study notes that some government strategies have succeeded in scaling up health information exchange between citizens and the health system. In contrast, the lifestyle focus of tech companies in the consumer market does not contribute to PHR initiatives across countries. Experience, preferences for engagement, health coaching, and use of digital health information are at an early stage. The promise of data fails to deliver market value. Exceptions to this rule marking future trends are patient advocacy groups that sponsor clinical trials and mediate prompt transfer of clinical results to routine patient care.

The eStandards project identified several gaps to be bridged by cooperative standards development including creating a reliable mix of patient and provider generated health data. Additional gaps identified were bridging health professional guidelines with clinical information models and terminology initiatives, establishing regulatory clarity, and attending to localization and adaptation of user requirements with a clear connection to procurement. Lastly, eStandards highlighted the need for clear governance and maintenance of standards sets supported by open tools and data to leverage different speeds and cycles in sharing and integrated fragmented data. The bimodal practice of managing separate but coherent styles of work leveraging predictability and exploration is promising for diffusing health innovation matching technology supply with patient demand.

**Perspectives of citizens and informal care givers**

Citizens and households need to manage health information. Their methods vary in sophistication, time relevance, robustness, and creativity. Health information managers employ idiosyncratic tools and strategies to keep track of health data over time. Active involvement in health decisions is frequently expected and needed, as they navigate health systems to the best of their abilities seeking the best options. The first step to moving online is accessing and acting upon personal health information stored in health systems that are called to play a critical role in digital health literacy of both patients and the workforce.

Patients are best placed to have the most complete picture by being present in every encounter in a personal capacity. However, health confidence, health status, personal wellbeing, etc., combined with preferences for engagement, digital confidence, skills and capabilities including language, length, reading age, etc. affect their ability to use digital health tools and resources. Standards and quality labels reflect capabilities to connect and assess resources. Citizens make deliberate choices of sharing health related information, choosing to actively solicit, share or protect information pertinent to their conditions or health problem [14|. Patients want access to their health data, and appreciate opportunities to do so. Meanwhile, more and more, they share their experiences in online social networks and trust the feedback received.

With the Internet of Things, mHealth tools and apps add to the body of tools to manage data from the environment. IoT offers insights to the activities in the home, and the plethora of information sources and health related activities citizen engage in and perform [15]. Robust strategies to differentiate and handle health information emerge:

- *Just–in–time*, i.e. information and/or artifacts are with me at most times
- *Just–at–hand*, i.e. information and/or artifacts are visible or stored in readily accessible, highly familiar locations in a household
- *Just–in–case*, i.e., information and/or artifacts, either personal health files or general health information resources, are kept away, but are easily retrievable
- *Just–because*, i.e. information and/or artifacts of temporal relevance, kept in the household until storage strategy is assigned [16].

These human approaches to managing health information reflect strategies for maintaining confidentiality and privacy, bridge provider-generated and patient-generated data, and reduce fragmentation of health data providing support in the "care-between-care" period guiding inter-visit care actions [17].

**Call for action: My data, my decision, our ePower**

In this multifaceted health information ecosystem, our call for action is paramount. Adoption of innovations proceeds at the

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[5] http://www.hpfreemanpni.org/

speed of trust and issues of trust apply especially to the perspective of citizen and health providers. In our call for action we see collaboration and co-creation and where both digital health literate citizens and the health team see the relevance and value of accurate patient summaries. This implies that citizens become able and empowered to identify, appraise, and use their health information purposefully, and transform it into specific, trusted, and actionable knowledge applicable to the health reality at hand. Thus, health information should be relevant, regardless of source as health professionals or the citizen self are aligned to make sense of it in a sort of trialability that fosters large scale adoption, sharing and use [18].

### My data

Individual knowledge and capability to manage one's health, to get appropriate help when needed and engage in shared decision-making are part of Health literacy. It emphasizes *motivation, knowledge and competencies to access, understand, appraise and apply health information* to all aspects of citizens' health judgments and decisions in everyday life [19]. Adding on the ability to appreciate and use productively digital health tools can be reflected in using patient summaries as the passport to this health journey.

### My decision

Information relevant for the specific circumstances will help assemble information to participate in tomorrow's care.  We expect more productive interactions and co-creation where the *personal dimension*; socio-demographic factors, Health and Digital Health Literacy span the full spectrum of "worried well" and the "really ill". *Digital literacy* boosts skills and capabilities to participate, and advance technology readiness. Marketing recognizes *Self Achievers*, *Priority Jugglers*, *Direction Takers*, *Balance Seekers*, and *Willful Endurers*. Taking into account the behavioral profile of an individual can help calibrate their compass. Moreover, the Health Confidence Score (HCS) is a short generic measure of a person's confidence to engage fully in their health and care measuring knowledge, self-management, access, and propensity to shared decision-making [20]. These are essential elements of advancing digital health literacy in a process that respects individuals allowing freedom of choice on when, how, and what digital health tools to use.

### Our ePower

Empowering the citizens (patients, families and carers) to support a continuum of care across a range of services can relieve pressure on governments to provide more cost-effective and efficient health services improving health outcomes and encouraging citizens to manage their healthy life course. Beyond socio-demographic aspects that challenge adoption of digital health technology and a culture of sharing data that could drive routine evidence-based decision making.

## Conclusion

The vision of the digital health compass as a navigation instrument that allows us to make sense of digital health innovations has been presented using patient summaries as an illustrative example. We argued that eHealth literate citizens are empowered and can make better choices. With increased digital health literacy, citizen can identify, appraise and use more health information resources, and transform them into trusted, actionable knowledge applicable to the situation at hand. Understanding one's health data is a foundation for empowerment. Co-creation and participatory design facilitate the design of information visualizations that are understandable and actionable, promoting active engagement. Cooperative use of standards is the key to creating a trusted infrastructure for innovation, since innovation travels at the speed of trust.

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