

# Discussion of “Representation of People’s Decisions in Health Information Systems: A Complementary Approach for Understanding Health Care Systems and Population Health”

Najeeb Al-Shorbaji<sup>1</sup>; Elizabeth M. Borycki<sup>2</sup>; Michio Kimura<sup>3</sup>; Christoph U. Lehmann<sup>4</sup>; Nancy M. Lorenzi<sup>4</sup>; Lincoln A. Moura<sup>5</sup>; Alfred Winter<sup>6</sup>

<sup>1</sup>Knowledge, Research and Ethics, e-Marefa, Amman, Jordan;

<sup>2</sup>School of Health Information Science, University of Victoria, Victoria, British Columbia, Canada;

<sup>3</sup>Medical Informatics Department, School of Medicine, Hamamatsu University Hospital, Hamamatsu, Japan;

<sup>4</sup>Vanderbilt University Medical Center, Nashville, TN, USA;

<sup>5</sup>Assis Moura eHealth, Porto Alegre, RS, Brazil;

<sup>6</sup>Institute for Medical Informatics, Statistics and Epidemiology, University of Leipzig, Leipzig, Germany

## Keywords

Population health, learning health systems, health information systems, complex systems thinking, social theory

## Summary

This article is part of a For-Discussion-Section of *Methods of Information in Medicine* about the paper “Representation of People’s Decisions in Health Information Systems: A Com-

plementary Approach for Understanding Health Care Systems and Population Health” written by Fernan Gonzalez Bernaldo de Quiros, Adriana Ruth Dawidowski, and Silvana Figar. It is introduced by an editorial. This article contains the combined commentaries invited to independently comment on the paper of de Quiros, Dawidowski, and Figar. In subsequent issues the discussion can continue through letters to the editor.

## Correspondence to:

See list of authors’ addresses at the end of the article

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With these comments on the paper “Representation of People’s Decisions in Health Information Systems: A Complementary Approach for Understanding Health Care Systems and Population Health” written by Fernan Gonzalez Bernaldo de Quiros, Adriana Ruth Dawidowski, and Silvana Figar [1], the journal seeks to stimulate a broad discussion on the future role of health information systems. An international group of experts has been invited by the editor of *Methods* to comment on this paper. Each of the invited commentaries forms one section of this paper.

## 1. Comment by N. Al-Shorbaji

The stated objectives of this study [1] was to: conceptualize the theoretical challenges facing health information systems (HIS) to represent patients’ decisions about health and medical treatments in everyday life; and to suggest approaches for modeling these processes. After making a good analysis of the literature the authors confirmed the need and then the aim of this study which is “to conceptualize patient decisions about health care and the treat-

ment of chronic diseases under new theoretical frameworks”.

Before embarking on commenting on this excellent paper, I thought it would be worth highlighting some of the key concepts used in the paper and will be referred to in the discussion to ensure clear and common understanding as to what the model is trying to represent and whether patients are real partners in healthcare planning and health service delivery enabled by information technology.

- A **decision** is “a choice that you make about something after thinking about it: the result of deciding” [2]. There are of course complex decisions that patients need to make at different stages of their treatment.
- **Empowerment** is “to give power to (someone)” [3]. Empowerment in the healthcare context is associated with enabling and encouragement based on consent.
- **Engagement** is “the act or state of being involved with something” [4]. Engagement is synonymous to commitment, especially when it comes to one’s health affairs.
- **Person-centered approach** is “a non-directive approach to being with another; that believes in the other’s potential and ability to make the right choices

for themselves, regardless of the therapist's own values, beliefs and ideas". Quoted by The British Association of the Person-Centered Approach [5]. People might also use terms such as patient-centered, family-centered, user-centered, individualized or personalized to mean the same thing.

- **Conceptualize** is "to form (an idea, picture, etc.) of something in your mind" [6].

The reasoning given in the study to conceptualize the model using the three dimensions: people, health services and health system attempts to better understand the complex relation between the three elements with clear understanding that people are in the center of health systems and are the target of health services. The satisfaction of people based on recognition of their needs is central to this process. Developing systems and delivering health services that people don't want, need, require or demand would not be good enough. The supply-driven model is not only one-dimensional but usually results in less effective and more costly system. This focus on the supply side of the healthcare system (the biomedical, technological, provider and delivery system side) ignoring the demand side has resulted in less relevant healthcare system. At the same time provision of health services to people with their full understanding of the consequences, expected benefits and risks based on informed consent is central to people-centered health services.

The world in general and healthcare systems in particular have been influenced by and gone through a series of radical changes. These changes have affected the individual and the society including:

1. Advancement in biomedical research which has opened doors for what is called "precision" and personalized medicine. The term "personalized medicine" is often described as providing "the right patient with the right drug at the right dose at the right time." More broadly, personalized medicine (also known as precision medicine) may be thought of as the tailoring of medical treatment to the individual characteristics, needs, and preferences of a patient

during all stages of care, including prevention, diagnosis, treatment, and follow-up [7]. Major part of personalized medicine is based on gene sequencing and therapy. This simply means one medicine for this patient is not good for another as "cancer, for example" is different between individuals. It requires understanding the individual's illness and delivers the right treatment at the right time. "One size fits-all" approach doesn't work.

2. The advancement in gene sequencing is powered by information technology in particular data processing using supercomputers and complex infrastructure. This advancement has allowed for more genes to map and made it less expensive to undertake. A patient maybe informed that a specific gene is the cause of a disease he has for which (s)he has to make a decision to accept action or wait for something to happen.
3. The advancement and affordability of telecommunication facilities, ubiquity, Internet connectivity, smart phones, sensors, access to data and information and networking have resulted in a more connected citizens who can share with and learn from others not necessarily family members, care providers, friends or colleagues but also people from other countries and cultures. They are now able to contribute to medical and health research using social media, for example.
4. The adoption of the Sustainable Development Goals (SDGs) by the United Nations (UN) General Assembly in 2015 [8], of which Universal Health Coverage (UHC) is one of its targets, emphasized the personal dimension of healthcare services. As a follow up action to the SDGs the UN Secretary General established the High-Level Commission on Health Employment and Economic Growth. The Commission in its report expressed its commitment to achieving the 2030 Agenda for Sustainable Development Goals. The report suggests that reformed service delivery models are required with a move away from hospital care towards a focus on prevention and on the efficient provision of high-quality, affordable,

integrated, community-based, *people-centered* primary and ambulatory care, paying special attention to underserved areas [9]. The need for patient-centeredness has become an important global issue, having been identified by the Institute of Medicine of the United States National Academies of Science as one of six attributes of health care quality, the others being safety, timeliness, effectiveness, efficiency and equity [10].

5. Socio-economic and political changes that have taken place in many parts of the world resulted more movement of people for work, migration and education, creation of global communities of professionals and patients, new economic realities affecting individuals and societies, spread of democratic values and expanding of open access, etc. All these changes pushed for more person-centered policies, services and products. For health, this has meant that people using health and social services should be considered as equal partners in planning, developing and monitoring care to make sure it meets their needs. Culture plays a major role in deciding changes and therefore dictating the level of adoption of a new medication.

Decision-making is a complex process for patients to follow. The decision may range from a simple one such as "to take the medication as syrup or as tablet" to a more complicated "to get pregnant or not" to the most complex "to end life or continue on life-support machine". For patients to contribute to decision-making and for their decisions to be "worth" considering and registering in the health information system it is important to:

1. Ensure that decisions that have been taken and registered are usable and used for better care. Learning from the experience to make the health system a learning organization can be enhanced through the appropriate use of decisions. Personal health and public health can benefit from this only if appropriate measures of monitoring and evaluation are applied. This leads to research on level of satisfaction of patients by the quality of health records and the action taken by the healthcare providers. It can

help in better understanding of the impact of decisions on actions.

2. Ensure the full engagement of patients in their healthcare process. They cannot be just recipients of advice, medication and care. The two-way interaction between the patient and the care giver is essential through communication, more time allocation per patient and a complete and systematic feedback loop. It is widely believed that the more, better and smarter engagement of patients in managing their own care, can result in better health outcomes and consequently more positive their experience.
3. Ensure meaningful empowerment of patients to make a decision or at least ensure their active participation in the decision-making process. Provision of quality, timely and easy to understand information to patient is essential for better decision-making. The role of information in decision-making can be part of an education and learning process towards informed decision making and to provide some level of assurance that a decision that has already been made is the right one. Understanding the process of healthcare and the options available for care delivery will help in better decision-making. Part of the empowerment is to ensure that patients are aware of the type and quantity of data being collected about them. Patients need to know the reason for that and how much relevance this data collection is to their care. Otherwise, they will assume that they are being “used”. This of course is challenged by the culture, the educational level of patients and quality of health literacy programs and availability of appropriate information and education materials.
4. Ensure full understanding of what are the social determinants of health and their impact on the health situation of the patient. Focusing the attention of the healthcare provider on the “biological” determinants of health of the individual will for sure lead to incomplete picture of the diagnosis and the understanding of the cause of disease. This lack of understanding will lead to less than optimum, in best scenario, health

outcomes and will make the system less efficient and more costly. These social determinants of health can be better expressed through the dialogue with the patient including their education, income level, environmental factors, and other cultural values. The care provider doesn’t want to be in a situation when the patient says “(s)he never asked me if I can read and write or if I drink from the tap or bottled water”.

Representation of people’s decisions in health information systems requires full understanding of:

1. The motivations of individuals, communities and people at large for approaching health systems and sources of satisfaction of the system;
2. The environment in which people live considering the social determinants of health;
3. The personal knowledge processing cycle as what do people do with the information they acquire from care givers and the system at large;
4. The optimum configuration of the health system and health information systems that are designed to fulfill such objectives.

Drilling down to health information systems components and the use of information and communication technology, or digital health, poses risks and has limitations in representation of people’s decisions, including:

1. Inadequate infrastructure. Digital health depends on robust, secure, affordable, reliable, resilient, trustworthy and interoperable information infrastructure. The risk is that lack or weakness in any element of this infrastructure may hamper the digital health development and consequently representation of patient’s decision;
2. Increased inequality. The increase of information in society is not evenly acquired by every member of society: people with higher socioeconomic status tend to have better ability to acquire information due to digital literacy and infrastructure. The risk is that there is a fear of increasing inequality through isolation and inability to make sound

decisions by people and their representation;

3. Affordability. Moving from public health approaches to personalized medicine enabled by digital health may increase the cost of healthcare delivery which will contribute to inequality and leaving those who cannot afford behind. The risk is the potential discrimination against those who cannot afford ultimately resulting in powerless patients;
4. Ethical considerations. The increase in volume of personal health data in formal systems and in social media has started to pose issues of ownership, privacy and confidentiality. The risk is a fear that through representing the patient’s decision for use in research and/or commercial interests, ethical principles are compromised and therefore decisions are compromised;
5. Little benefit to public health. Research on and big push towards personalized/precision medicine are on the increase and more funding is being allocated for it. The risk is that research is not conclusive in terms of benefit to public health and population in general.
6. Medical informatics education and education of healthcare professionals generally is short of producing qualified professionals who understand and value patient’s decisions as partners in health. The risk is that the healthcare profession will continue to be lagging behind and not leading when it comes to people-centered care.

## 2. Comment by E. Borycki

De Quiros, Dawidowski and Figar’s paper entitled the “Representation of People’s Decisions in Health Information Systems: A Complementary Approach for Understanding Health Care Systems and Population Health” [1] outlines a new and important lens through which we as health informatics researchers and health information technology professionals need to view the citizens, families and communities in our country and globally. Historically, health information systems (HIS) were designed and used by health professionals (i.e. physicians, nurses) to collect

data about patients, support health professional decision making and improve the efficiency, effectiveness, quality and safety of health care processes. With this in mind health informatics researchers and professionals designed HIS with this lens or view in mind. We focused on developing HIS that collect data about and focus on the individual patient: documenting information about the patients' physiologic state and psychological health. Our focus was to document the signs and symptoms of disease and identify ways to treat disease effectively and efficiently to lower the cost of health care. HIS were also used to improve the quality and safety of the health care we provided to individuals based on the unique and individual physiologic and psychological health of a single person. HIS served two purposes: to improve the health of individuals and to improve the quality, safety, efficiency and effectiveness of health care.

The paper authored by de Quiros et al. asks health informatics researchers and health information technology professionals to make a significant departure from that view. The paper argues that traditional HIS (e.g. electronic health records, clinical information systems) do not fully capture a citizen's decision making, the context of their individual lives that influence decisions, the communities and contexts that they live in and the global world itself and its impacts on the health of the individual. The paper makes the argument that HIS captures only a limited amount of information about individuals and that there is a need to understand the contexts in which individuals make their health related decisions (e.g. family, community, country and the global world). The authors also argue for the need to use theory from the sociology and public health literatures to inform the development of new HIS modeling processes to improve the quality of the data collected by HIS so that governments have a better understanding of reasons (beyond physiologic and psychological status) that influence the health of the individual (i.e. the contextual aspects of the world around them).

This view challenges us as health informatics researchers and professionals who are working in the field. Our historic

tendency has been to collect physiologic and psychological information about the individual. Now we must begin to view the individual in the context of their own world – their family, community, country and the global environment. There is a need to change HIS and our thinking about HIS. In essence we have seen these changes happening in many countries. Research has emerged identifying areas known as "blue zones", where individuals and communities in these areas of the world have long healthy productive lives, living independently in communities [11]. Research has also shown that there are limits to treating chronic illnesses yet, there is a need to quickly respond to the emergence of a new disease or disease outbreaks in a new part of the world effectively and efficiently [12]. We have seen individuals and communities respond to health issues using technologies that were not initially intended to be used as health information systems. The examples of these occurrences are significant and increasing in occurrence. Individuals and communities have launched social media campaigns to raise awareness about specific health issues (e.g. outbreaks of disease or environmental hazards) [13], educate about how to prevent disease (e.g. provide information about how to avoid being infected by the Ebola virus) [14] and draw attention to unique aspects of rare disease and commonly experienced diseases that need to be further studied by health professionals (e.g. through social media platforms such as PatientsLikeMe®) [15].

As de Quiros and colleagues have suggested, traditional HIS must evolve to help us understand the effects of context, community, country and global environment upon health. There is a new urgency and need to integrate other types of data into electronic health records. As the authors point out, greater emphasis needs to be placed on collecting data about the social context of the individual. There is a need to understand the economic context that the patient lives in; for example, understanding the economic conditions a patient lives in will provide insights into health as some patients may not be able to buy medications to manage their chronic illnesses due to the cost of the medication (and this may affect health) [16]. There is also a need

to understand family context. Health is often constructed within a family context; for example, loss of a job by one or both parents in a family may lead to choices that influence health. Here, you may have the situations where families cannot buy healthy foods to eat as they do not have enough money to pay for an apartment and all the food they need for that month. Choices may be made at the family level to forgo meals in order to maintain their home in an apartment building [17]. Community context also needs to be considered. Communities as a whole may experience health related issues and events. Individuals who live near factories may have high cancer rates. Here, a community intervention may be needed to improve government regulations to reduce emissions of environmental pollutants [18]. Community events may also include natural disasters that influence health long term, such as flooding, earthquakes and tsunamis. Such events have significant impact on psychological and then in turn physical health [19]. As de Quiros et al. suggest HIS needs to capture these experiences to address psychological and physiologic impacts of such experiences.

All of these examples suggest a need to model and develop more sophisticated HIS that not only captures individual data about health and illness, but the context in which the individual lives. This may involve integrating public health information systems with electronic health records, providing clinicians with information about the incidence and prevalence of disease using digitized maps to understand the interactions between individual, community and geography on health, developing community interventions based on HIS, and raising awareness among governments about these interventions. As the authors of the article indicate, this cannot be instituted until new modeling approaches are developed to design and redesign existing HIS. Such work is critical as we know that context influences the prevalence and absence of disease and aspects of context can lead to improvements in health and disease.

In summary, the work of de Quiros et al. puts forth a challenge to health informatics researchers and professionals to model, de-

sign and develop the next generation of HIS – HIS that takes into account context for individuals so that we as local, country and global societies can understand the role of context in affecting health and develop interventions that can improve health and quality of life into the future at a community, country and global level.

### 3. Comment by M. Kimura

It is clear that, as stated in this paper [1], social, occupational, and lifestyle patient data in electronic medical records are not carefully handled. Unlike laboratory results, diagnostic reports, or physician’s notes, these items are displayed as though they are one-time characteristics, although they are actually dynamic. In addition, it is correct that these characteristics are addressed in positivistic hypothesis. However, “negative” (or absent) characteristics also provide important information. It is appropriate and timely for IOM to define SDH to address this problem.

To deal with these characteristics in the electronic medical record system of a healthcare provider, an IT system could easily be developed. The problem is in finding ways that healthcare professionals could input, update, and/or delete the information in a timely manner considering their busy workflows. In Japan, healthcare insurance is provided by individual companies or organized companies, although the costs approved in the reimbursement tariff of procedures are the same. Some companies’ insurance organizations, motivated to cut expenses, collect information on these characteristics directly from their workers. They analyze them with reimbursement claim data and health checkup data from healthcare providers [20, 21].

However, this paper argues against the idea that causal reduction is merely dangerous. Yes, it is dangerous; however, we were unable to connect deductions from signs and symptoms to diagnoses or appropriate therapies. This paper mentions that SNS data will encourage us to take account of these characteristics. Yes, these data are directly from patients’ site fields, which are very difficult to obtain, but SNS data are typically based on positivist hypotheses.

Thus, before investigating these characteristics, we must ensure that our healthcare providers are asked to make diagnoses and treatment plans, or how can people’s health be maintained? Obviously, governments serve in the latter role, but do patients or citizens want to entrust their healthcare to the healthcare provider offered to them [22]?

### 4. Comment by C. U. Lehmann

In their manuscript in *Methods of Information in Medicine*, de Quiros et al. [1] address an important aspect of health care – the notion that people’s decisions and choices impact health outcomes. They offer a new framework proposing the study of health assets (networks, family relations, communities, associations), community clinical trials (e.g. a school based intervention to improve cardiovascular health), and simulations/analytics. They postulate that using this framework will allow healthcare providers and public health officers to make better prediction of health outcomes.

De Quiros’ approach is limited to viewing humans as a “swarm”, where individuals are being accredited with the property of their communities, families, neighborhoods, or associations. The authors neglect to include the individual and her/his psychological makeup in this model. Specifically, the authors neglect to include the notion of individual beliefs and preferences that factor decidedly into decision-making. To clarify this point, let us consider the case of two women living in the same neighborhood, working in the same company, both involved in a community activist group to provide more green spaces to their neighborhood. Both women are pregnant and prenatally diagnosed with a condition that will be lethal once the fetus is born. One of the woman labels herself as a “pro-life” advocate, while the other is “pro-choice”. These individual preferences (with the same counseling, same prenatal care, same obstetrician) will most likely result in very different outcomes of the pregnancy – one fetus will be born to die shortly after birth while the other most likely will die during an abortion. De Quiros et al.’s model could

not account for the differences in this outcome.

Decisions by individuals are made on their perception of reality. And reality is a very fluid concept that is highly individual. To quote the US comedian Stephen Colbert “Facts matter not at all. Perception is everything. It’s certainty” [23]. Prior beliefs will alter how an individual perceive her/his environment and will alter the perception of reality. While de Quiros et al. account for beliefs and perception at the “swarm” level by attributing group membership to altering health care decisions, they neglect that individuals will frequently make decisions that are contrary to their peers’ beliefs. Thus, as far as I can see, their model does not account for the deviation we will see on the individual level.

Especially when it comes to end-of-life decisions, we frequently see fundamentally different approaches even between individuals of similar background. Because discussing the preferences of an individual as it comes to end-of-life decisions can improve care and quality of life, lead to the end-of-life experience desired by the patient [24, 25], and decrease the cost of care [26], we have managed to find a way to successfully document them in electronic health records [27]. We account for the person, who wants “everything done” to prolong life to the last minute, and we also accommodate the desires of individuals, who do not want to be dependent upon machines and request limited or no resuscitation. Because end-of-life decisions are so important, we – at the cost of having to question the patient or his/her surrogate at every encounter about the preferences – have managed to include these preferences in a decision model [27]. However, these preferences are limited to one decision only and cannot be used to enhance de Quiros’ model or predict other health outcomes.

There is ample evidence that patients’ wishes and preferences influence medical decisions. Patients may opt for treatments that have been found to be inefficient or unnecessary according to existing evidence. In dermatology for example, the patient’s preferences has been shown to factor into the management in 7% of outpatient visits [28]. There are plenty of reasons why including patient preferences in the medi-

cal decision making process is appropriate. Satisfied patients are more likely to be compliant; however, patient decisions may lead to the trade-off between best medical options versus patient desires.

It seems obvious to postulate a need to record the individual patient's preferences and beliefs routinely in electronic health records (EHRs). Despite this need, only a handful of instruments exist that allow clinicians to record patient preferences and priorities for care in primary care settings in patients with multiple medical problems, [29] however, to our knowledge none of these instruments has been implemented to date in the electronic health record. Given the importance of patient's preferences in health outcomes, there is an urgent need to implement these instruments in EHRs and test their effect on outcomes. Not only will recording of preferences make decisions between equally effective treatment options easier for providers, they will also extend the proposed framework by de Quiros et al. and will improve our ability to predict patient adherence and compliance and ultimately health outcomes.

In conclusion, de Quiros et al. have offered an interesting model to determine the effect of patient's preferences on health outcomes. The model however seems to be limited as it does not account for the individual patient's preferences, beliefs, biases, and dislike. As long as we do not capture these items, any prediction based on demo-

graphic, genetic, and population based measures will remain incomplete and imprecise at best.

**Acknowledgment**

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**5. Comment by N. M. Lorenzi**

The use of technology and computers has changed the world! We are all smarter and more knowledgeable because of the computer systems that have databases upon databases available. But what if we made the computers even smarter? What if they could actually reason as if they were a person and could help us think things through as individuals?

The authors of the article "Representation of People's Decisions in Health Information Systems: a complementary approach for understanding health care systems and population health" present a compelling case for incorporating "people's decisions" into our health information systems. What is one step towards the potential predicted to help individuals with their decisions?

We all have access to health related information. The information is from

multiple databases and some information is basic and some is not basic. Some of the information is our personal health information that may come from many sources. How does an individual not educated in any of the health disciplines – medicine, nursing, pharmacy, etc. – understand what the information means for her or him?

In recent years the "technology" component of the information system has been dominant. Meaning we need to know how to "work" the technology. If you do something that the computer "does not like" what you entered, it will not work. The question is if we are going to address some of the complexity that now exists in health information systems, what do we need to do to first to create a system that supports people?

To stay with "from the ground up" and supporting people, ► Figure 1 focuses our attention to the people side of the equation and understanding. The center of the diagram starts with PEOPLE! No matter who we are or where we live we all experience life challenges and many are health challenges.

I read a book by William E. Wallace, Michelangelo: The Artist, the Man and his Times [30]. Today we highly revere Michelangelo and his work. However, in reading the biography Michelangelo had some of the same challenges that people experience today. Some of his challenges included moving from one city to another and finding a place to live, not getting paid and therefore not being able to buy appropriate food to eat and becoming sick because of his living conditions and lack of appropriate food. He was a brilliant person but he still experienced the positives and negatives of daily living. None of us in the world have a 100% perfect, beautiful, untouched life.

There are pockets of things that happen every day and nothing is as disastrous as a diagnosis that could mean death. People with their respective challenges are the center of ► Figure 1 as each individual presents a unique challenge because of their knowledge, their social environment, their home environment, when/where they were born, the food they eat, the choices they make, etc. From each individual we form millions in the world and while we

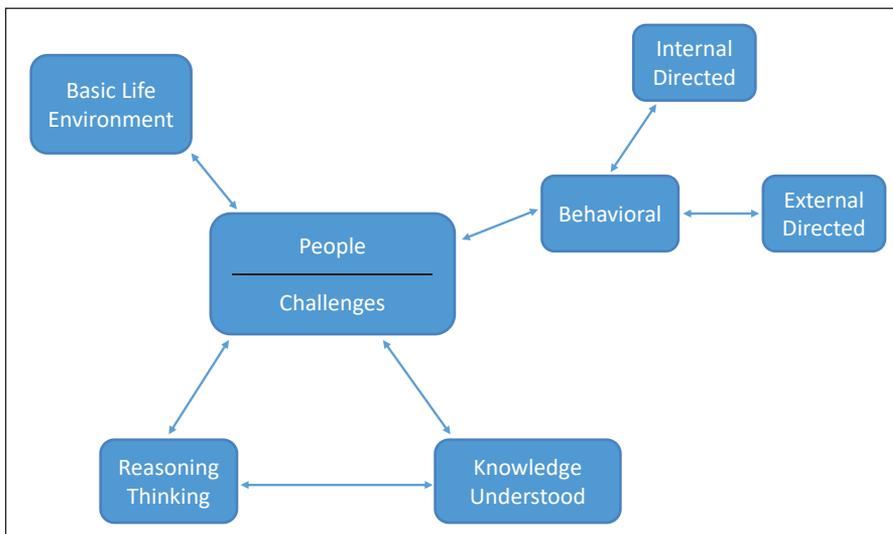


Figure 1 Impact on a person's decision

each have our individual decision process we all want the same personalized care that meets our needs and helps us move forward. This is a challenge not only for technology but for anyone working in the healthcare area.

Surrounding the People center are four areas that represent different components that impact the challenges of people. The others are (1) Behavioral (Internal Directed and External Directed), (2) Knowledge Understood, (3) Reasoning/Thinking, and (4) Basic Life environment – food, finances, living environment, etc.

### Behavioral

We have behaviors that we know are right and wrong and yet sometimes we do not live those behaviors. We know we should exercise, we know we should be within a certain weight range, we know we should not eat certain foods or drink certain liquids in excess but that does not stop us from engaging in that behavior.

As the authors of the main article indicated some people are more “internal directed” meaning that they are not as influenced by other people. At the same time some people are more “external directed” meaning that they often take their actions and efforts from other people. It is easy to see in group behavior that people act similar to how their group acts. If someone in the group smokes the probability that many in the group will smoke is higher. If there is one teenage suicide in an area there may be a mini epidemic of 4–6 other suicides. If a friend is someone who exercises regularly or runs marathons, etc. then an external directed person will be more likely to exercise.

### Knowledge Understood

Another area is knowledge and understanding. Some people could understand but they may not have the education to understand. If there is one thing that is very complex it is healthcare.

### Reasoning/Thinking

René Descartes said “I think therefore I am”. Whether we understand the information or not a person still needs to make a decision and will need to think about what to do.

### Basic Life environment

Abraham Maslow created a hierarchy of needs that begins with the “physiological”, namely – food, clothing, shelter, etc. We might consider adding finances to this area as providing the means to support the basic life environment.

Think about if you were in a doctor’s office and you have a disastrous diagnosis, say cancer. They start to ask you and tell you a lot of things. They ask you what you want to do but you are probably so overwhelmed with the diagnosis that you missed half or more of what they are saying.

What if the information systems of the future had visual graphics to explain options in an easy to understand regardless of your understanding of the healthcare system or your educational background or where you are? What if we had demonstration pilots that could test this? The information systems must be supporting of the patient so that each can make better choices.

What if we could use social networking to connect people in groups for more positive behavior in more positive areas so that even if they live alone they are interconnected? What if our research looked at not just random control trials but had research in actual settings? What if we applied the principles of behavior and organizational behavior or thinking behavior for systems, how can we change the world now that we have technology so embedded in order to create a better and stronger place for every individual?

We have definitely started our journey to the future. The authors of the representation of people’s decision recognize that we must now incorporate other components into our health information systems as we move forward. What if as one other step we created a way to help people make better life decisions?

## 6. Comment by L. Moura

Professor Fernan Quiros’s “Representation of People’s Decisions in Health Information Systems: A Complementary Approach for Understanding Health Care Systems and Population Health” [1] is a great paper that

paves the way to disruptive and innovative approaches to conceiving, developing and deploying health information systems. My comments are extensively motivated by my experience as a devoted Health Informatics practitioner and my passion for the theme, rather than a scientific approach that, I am sure, will be thoroughly provided by other colleagues.

In order to highlight the importance of the changes that are embedded in Professor Quiros’s article, I take the liberty to describe part of my personal journey, which certainly is similar to that of most health informaticians born in the Fifties.

As an MSc student, in 1977, at COPPE, in Rio de Janeiro, my research was focused on online real-time cardiac arrhythmia detection from a single ECG lead. The machine available for that was a DEC PDP-12 limited to 16 kilobytes of memory and an ability to sample signals at more than 1 KHz. The important thing here is that processing was restricted to one ECG lead. No other information from the patient was taken into account. That was about all researchers could do then.

Around that time, Professor Roger Mark, of MIT, and colleagues, assembled together a collection of samples of ECG signals, properly classified beat-by-beat by specialists. The remarkable MIT-BIH Arrhythmia Database [31], a true knowledge base, at first in analogic magnetic media and later on stored and distributed digitally, was used by researchers throughout the world in order to learn and moreover develop and test new arrhythmia detection methods. Still, the database contained very limited data on the patients themselves.

In 1986, at Imperial College London, my PhD research was focused on the 3D reconstruction and processing of medical structures, from series of images that were properly segmented. The software was developed on a MicroVAX II with impressive 16 Megabytes of memory and a high-resolution color display. Again, all that was possible was to look at the set of images and explore the coherence among them, thus trying to extract shapes and measures from them. All knowledge available from the structures needed be coded in the segmentation process. For instance, by knowing that the arteries’ cross-sections were

"roundish", the search algorithm would favor structures shaped that way [32]. There were no resources – hardware, methods and software – that would allow representing structures (coronary arteries) as part of a larger environment (the heart, the thorax and the human body) nor were there resources for representing other relevant clinical or non-clinical data.

As mentioned in the paper by Dr Quirós, today, the unbelievable increase in computational resources, their availability and popularity, the relevance and omnipresence of manual and automatic data collection imposes a completely different approach.

It is possible, nowadays, to address cardiac image processing by describing the typical heart as a structure within the thorax with four-chambers and so on and so forth [33].

The notion of five V's (velocity, volume, variety, veracity and value) associated with Big Data, brings in at least two innovative concepts that can contribute to the change proposed in the article: a) data enrichment, which means exploring data from additional sources – typically public, such as prevalence of diseases and other health conditions in a region associated with the patient and b) turning private data into public, by giving back information to an individual or organization as long as such subject agrees to give their information back for purposeful and ethical use.

Big Data is a term that, although new, has been somewhat devalued even as a buzzword by excessive use. However, living in a world like ours, vividly marked by Big Data, means data models and their representation, processing, analysis and conception need to move from focusing on a single object a time (a signal or an image, for example) to describing the full environment (at least its most important parts) and processing all relevant objects and their relationships simultaneously.

Such concepts are at the core of Dr Quirós's article. Health information systems have evolved constantly from billing and administrative activities to clinical purposes. However, they are still restricted to the patient and their clinical data, collected within or by health care organizations and for health care purposes. Such systems

need to move beyond the Electronic Health Record as we have known it, although we have barely got there!

Let's take the example of Social Determinants of Health (SDH). Understanding individualized SDH as "clinical data" to be represented in the EHR makes great sense. In Brazil, part of the Family Health Strategy includes collecting data on the household – such as sanitary conditions, number of kids, number of people, beds, and even toothbrushes – and keep them as a Family Health Record [34].

However, associating individual SDHs to patient readmission, for example, is still at early stages of development. The correlation is clear, though modelling it in its full extent is not an easy task [35, 36, 37]. Diagnostic Related Groups (DRG) are likely to evolve to encompass complexities that come from SDHs [38]. For example, a patient admitted as an inpatient to a hospital, with acute myocardial infarction who is undergoing a financial or a family crisis is, at least in principle, at a greater risk of readmission.

In conclusion, I truly believe we live the onset of this new and relevant wave of change that needs to be fully understood and should drive our efforts towards the future.

Maybe, by working with a wider and richer picture and broader concepts we will be able to make more value out of clinical data and use eHealth to deliver better health services at affordable costs throughout the world.

Finally, I thank and congratulate Hospital Italiano de Buenos Aires and Dr Fernan Quirós, in particular, for the seminal work they have done on this and other subjects.

## 7. Comment by A. Winter

Fernan Gonzales Bernaldo de Quiros and his co-authors impressively illustrate the challenges of patients' decision making [1]. Following the constructivist approach we can never be sure to know a patient's preferences in decision making, because every decision and even every talk with relatives or friends about a health question to be decided on will construct new preferences and will alter the context of the patient.

Thus, instead of trying to automatically make decisions for patients we rather should empower patients to make informed decisions on their own authority. According to one of the earliest papers on patient empowerment [39] this requires not only "(a) the provision of optimal care" but "(b) the enhancement of individual patient power, (c) the development of a strong consumer voice in policy decision-making processes, and (d) societal attitude change". This means especially "understanding the interpersonal and social dynamics" [39] of patients and their diseases.

Thus a shift of perspective is needed when designing information systems in health care. Since decades we as Medical Informaticians mainly shared the perspective of health care professionals and care delivery organizations and tried to solve their problems in providing optimal care for patients. However, patients' problems are different from those of professionals and cannot be solved by the same IT solutions and approaches. Let us look for example at an outpatient unit. From the care provider's perspective there are so many patients to be cared for and there is a need for health IT to optimize workflows in the unit with respect to efficiency. Such IT solutions have to run at the care provider's site. However, from a citizen's perspective, who is suffering from some health problems, there may be so much health care providers and outpatient units to select from (or there is no one) and a visitation of one of them has to be arranged with job and family duties, public travel opportunities, financial issues and other personal restrictions. Hence there is a need for IT covering and integrating all aspects of a citizen's life, i.e. not only her or his disease but all "interpersonal and social dynamics" as well. Such IT has to support orchestration of various services [40] and will run in the citizen's living room or at her or his smartphone.

This shift of perspective does not only require replacing one kind of informaticians' customer, i.e. health care professionals by another kind of customer, i.e. citizens and patients. Moreover, it requires specific methods for constructing information systems and their components. For example, requirements engineering meth-

ods based on the analysis of potential users' activities and decisions [41] may fit very well for exploring professionals' requirements on software. However, they are hardly applicable for patients suffering from incredible pain or from dementia and have to be adapted to their special needs and capabilities. Furthermore, from a patient's perspective it is not a good idea to store her or his health data simply in care providers' institutional databases – no, "It's time for health record banking" [42].

Obviously, it's time for a shift of perspective being in fact a paradigm shift from a patient as object towards a patient as subject and thus towards empowering patients to select health care services on their own authority. It's time for customer-induced and especially patient-induced orchestration of complex services [43].

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### Addresses of the Authors

Najeeb Al-Shorbaji  
Vice-President for Knowledge, Research  
and Ethics  
e-Marefa (www.e-marefa.net)  
P.O. Box 2351  
Amman 11953  
Jordan  
E-mail: shorbajin@gmail.com

Elizabeth Borycki  
School of Health Information Science  
University of Victoria  
Victoria, British Columbia  
Canada  
E-mail: emb@uvic.ca

Michio Kimura  
Hamamatsu University, School of Medicine  
Department of Medical Informatics  
1–20–1 Handayama  
Hamamatsu 431–3192  
Japan  
E-mail: kimura@mi.hama-med.ac.jp

Christoph U. Lehmann  
Biomedical Informatics and Pediatrics  
Vanderbilt University Medical Center  
2525 West End Ave, Suite 1475  
Nashville, TN 37203  
USA  
E-mail:  
christoph.u.lehmann@vanderbilt.edu

Nancy M. Lorenzi  
Vanderbilt University Medical Center  
2525 West End Ave, Suite 1475 (Room 120)  
Nashville, TN 37203  
USA  
E-mail: nancy.lorenzi@vanderbilt.edu

Lincoln A. Moura  
Assis Moura eHealth  
Rua Miguel Tostes, 230  
90430060 Porto Alegre, RS  
Brazil  
E-mail: lamoura@uol.com.br

Alfred Winter  
Leipzig University  
Institute for Medical Informatics, Statistics  
and Epidemiology  
Haertelstr. 16–18  
04107 Leipzig  
Germany  
E-mail: alfred.winter@imise.uni-leipzig.de