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# The Global People-centred eHealth Innovation Forum

Guest Editors  
**David Novillo-Ortiz and Alejandro R Jadad**

European eHealth conference, hosted by the Health  
Ministry of Spain in Barcelona, 15 to 18 March 2010

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# THE GLOBAL PEOPLE-CENTRED EHEALTH INNOVATION FORUM

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# Knowledge management as a key element for healthcare quality

*Pablo Rivero Corte*

The National Health System (NHS) is the public service most valued by citizens in Spain. Therefore, continuous improvement of its quality and safety is a constant social demand. In this sense, the use of information and communication technologies (ICTs) has special relevance because it permits a better service, and also optimises the use of resources and increases efficiency in public expenditure.

In Spain's NHS, composed of 18 regional health services working together, some 4.5 million people are served each year outside of their place of residence. In this way these tools facilitate geographical mobility of citizens and increase cohesion between regions.

Digital health has been a clear commitment of Spain's government in the past decade and we have promoted it in the framework of the European Union (EU) Presidency in 2010, following the recommendations adopted during the Swedish Presidency for developing digital services to improve healthcare for Europeans.

The year 2010 signifies the beginning of an innovative policy and institutional framework for the EU, in which the new European agenda must address challenges for our societies such as economic recovery, job growth, population ageing and the sustainability of public services. These aims rest on the basic principle of promoting social and economic inclusion of all citizens.

eHealth is one of the instruments to be used. Experience tells us that ICT applied to healthcare contributes to achieving healthy citizens by innovation that improves their lives and work conditions and social and territorial cohesion.

The work that we have undertaken as the Ministry of Health, Social Policy and Equality, together with the Autonomous Communities, has allowed the complete implementation of an individual health card for every citizen and a digital clinical

record. Also planned is the development of the digital clinical history network for the NHS and the electronic prescription of medicines during 2011.

The main beneficiaries of this innovation are citizens and health professionals. People who move from one community to another can be treated successfully by professionals with secure access to clinical data. Medicines can be dispensed at any pharmacy without a paper prescription. Services are better managed, avoiding duplication of tests and errors due to a lack of information on clinical records.

The availability of a system for exchanging information throughout the NHS has been basic to the project development, with a fast and highly secure central node and a common database for health insurance cards.

Secondly, eHealth is a source of wealth in any country. These developments improve quality, safety and accessibility in the Spanish NHS, and at the same time encourage innovation and competitiveness between companies that have participated.

As a basic tool for better management of our welfare policies, eHealth technologies are a huge investment in employment and innovation. A profitable investment produces measurable benefits in the economy, increasing the productive potential and employment.

Its deployment in the Spanish NHS has been made possible by the institutional collaboration of the government and the Autonomous Communities: a model based on research, development and new technologies that will allow growth and, especially, provide the benefits of the welfare state, which Europeans have spent 30 years building.

While several Autonomous Communities developed tools for digital health more than 10 years ago, the biggest promotion has been accompanied by the so-called *Plan Avanza*, a special agreement between the Ministry of Health, Social Policy and Equality and the Ministry of Industry, Trade and Tourism.

This plan has a budget of €448 million—€205 million funded by the Autonomous Communities—for the 2006–12 period, and has strengthened the basic infrastructure necessary for the digitisation of health. Among other things, more than 60 000 computers have been installed in 6000 health centres staffed

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by 250 000 working professionals, which provide assistance to more than 33 million citizens.

In order to ensure a secure and high-quality flow of data a consensus between national authorities, either from the central or autonomous governments, is a primary element for efficiency in a decentralised and capillary NHS such as Spain's. This enabled us to agree on mechanisms for unambiguous identification of each person in the NHS to provide key access to clinical information, and also allowed us to agree a common minimum content of the information in safe conditions of access and use.

After this first phase of development, we expect further efforts in the development of knowledge and new tools that will allow us to share information safely and effectively.

Furthermore, Spain is involved in the European project epSOS, supported by 12 EU countries (plus Spain, Austria, Sweden, Czech Republic, Germany, Denmark, France, Greece, Italy, Netherlands, Slovakia, UK), which is the first step towards healthcare improvement for European citizens abroad. Through this project health professionals will be able to access confidentially and in their

own language relevant clinical information about patient health (what drugs they are taking, allergies, chronic diseases, etc), allowing a better understanding of the causes of each patient's illness and expedite treatment.

The project aims to ensure the compatibility of different systems of digital clinical records regardless of the language used and technological orientation, and without requiring the adoption of a single system across Europe.

Spanish commitment in this area during the EU Presidency has led us to propose and carry out actions to integrate and promote more eHealth in European policies.

Spain wants to strengthen leadership and political commitment to eHealth and to convince citizens and professionals of its benefits. For this it will be imperative to provide legal clarity and to ensure data protection.

Finally, we proceed on the path of innovation, convinced that information management and knowledge and process improvement are the best ways to ensure the competitiveness, sustainability and quality of our NHS.

**Competing interests** None.

# eHealth governance: the Spanish approach

Esther Gil Zorzo,<sup>1</sup> Luis Lozano<sup>2</sup>

## What do we understand by governance?

The Royal Spanish Academy defines governance as: *The art or way of governing having as its objective the achievement of sustainable economic, social and institutional development, by promoting a healthy equilibrium between the state, civil society and the market economy.*

If we understand eHealth government as the management, implementation and support of information and communication technologies (ICTs) in healthcare, we can interpret eHealth governance as:

*The management, implementation and support of ICT in healthcare having as its objective the achievement of sustainable economic, social and institutional development, by promoting a healthy equilibrium between the state, civil society and the market economy.*

## What have been European Union achievements in eHealth?

### Strategies, initiatives and action plans

eHealth has had a key role in the eEurope Strategy since its launch in 1999 and the subsequent action plans: eEurope 2002, eEurope 2005 and i2010.

eHealth is also one of the European Union's (EU's) first six lead market initiatives, given the increasing importance of the eHealth industry. National and regional health networks, electronic health records (EHRs) and deployment of digital health cards have contributed to an emergent eHealth industry, with the potential to become the third largest industry in the sector, after pharmaceuticals and imaging and medical devices.

The first eHealth action plan was adopted in April 2004 seeking to boost the creation of national eHealth infrastructure

systems, EHR and patient summaries as well as to ensure their interoperability.

### High level and ministerial conferences

Since 2003 a series of ministerial and high level conferences have taken place yearly: 2003, Brussels; 2004, Cork; 2005, Tromsø; 2006, Malaga; 2007, Berlin; 2008, Portoroz; 2009, Prague; 2010, Barcelona.

### EU funding instruments

A series of EU policy and financial instruments have contributed to funding European and national projects of eHealth: Seventh Framework Program (FP7) ICT Programme; Competitiveness and Innovation Programme (CIP), ICT Support Programme; structural funds, in particular the European Regional Development Fund (ERDF).

The FP7 and the CIP support the development of eHealth projects and networks, for research, development, demonstration and innovation. For high-scale deployment of eHealth, Spain provides an example of a wide use of the ERDF, as described at the end of this article ('Supporting eHealth').

## eHealth: a priority for the Spanish Presidency

eHealth has been a priority for the Spanish Presidency in the first semester 2010, during which Spain has developed a strategic framework: *from accumulated experience towards a vision for the future, driving a new action plan and developing and promoting ministerial agreements.*

### The vision: how do we see the future?

The year 2010 marks a breaking point in EU institutional and policy development, with the Lisbon Agenda coming to an end and a series of strategic documents being reviewed in the framework of the new EU Agenda 2020.

The Spanish Presidency had the vision of an eHealth policy totally integrated in the EU Agenda 2020, in particular the digital agenda, contributing to its main goals of economic recovery, growth and employment and economic, social and territorial cohesion.

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This global vision could stimulate further development of post-2010 policy objectives, such as:

- eHealth for a healthier Europe: ensuring quality and continuity of care in the European health area;
- eHealth for sustainable growth and employment: a healthy citizen for an efficient economy;
- eHealth for innovation and social change: technological and social creativity and innovation to improve living, working and ageing conditions;
- eHealth for economic, social and territorial cohesion: eHealth as a determinant of competitiveness.

### A new eHealth action plan

Through the development of programmes and conferences a huge amount of knowledge and experience can drive a renewed action plan, facing new European challenges such as economic crises, an ageing population, sustainability and efficiency in the public sector and economic, social and digital inclusion.

### Ministerial agreements

On 1 December 2009, Council of the European Union (EPSCO-Employment and Social Affairs) under Swedish Presidency adopted conclusions on ‘Safe and efficient healthcare through eHealth’, recognising the need for further political leadership and to integrate eHealth into health policy in order to develop eHealth services on the basis of public health needs.

To further develop common action, the Spanish Presidency emphasised two aspects: further integration of eHealth in European policies; and the implementation of reinforced governance mechanisms to:

- reinforce leadership and political and strategic commitment;
- build confidence and acceptance, in particular in professionals and patients;
- bring legal clarity and ensure protection of health data;
- solve technical problems and facilitate market development;
- make eHealth an important issue in regard to competitiveness, growth and employment, information society, innovation and cohesion.

### A new governance initiative

The EPSCO Council recognised the importance of eHealth as a tool to:

- improve quality and patient safety;
- modernise national healthcare systems;
- increase their effectiveness;
- make them more accessible to all;
- meet individual needs of patients, health professionals and challenges of an ageing society.

The Council gave a strong political mandate to member states:

- for eHealth cooperation and interoperability implementation;
- to create a European coordination platform;
- to identify specific areas for cooperation;
- to initiate the development of a sustainable member state mechanism for leading European eHealth.

By mandate of Secretaries of State in Stockholm, the Spanish Presidency, in collaboration with the former Swedish presidency, assumed leadership to ensure continuity in the development of a new governance model. Agreed policy goals are as follows:

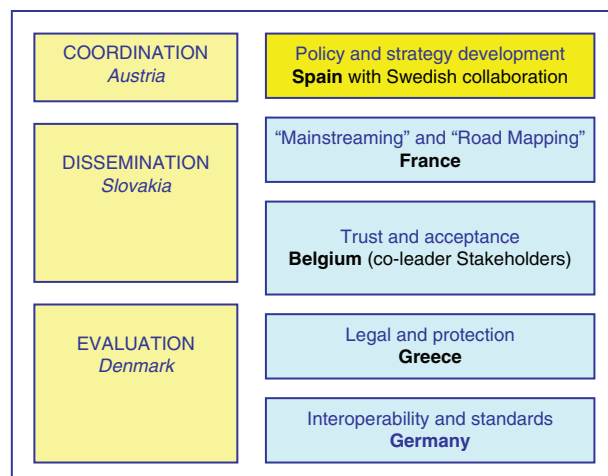
- quality and continuity of care and social welfare in European Health provision: eHealth for health;
- efficient use of healthcare resources: eHealth for economic recovery;
- user-centred innovative services: eHealth for innovation;
- sustainable growth and employment: a healthy citizen for an efficient economy;
- local and regional development: eHealth for inclusion, cohesion and wellbeing.

### The governance model

European cooperation is organised at three levels:

- political, high level national representatives with responsibility for designing and implementing health and eHealth policies;
- strategic, advisers and/or senior officials who have a key role in developing national strategies for eHealth;
- operational, experts and representatives of national, regional and/or EU-wide projects and/or pilot projects which are deploying eHealth services.

The high level group of Secretaries of State fully agreed in Barcelona the following structure, in which Spain has assumed leadership for policy and strategy development in collaboration with Sweden.



## Conclusion: the Spanish experience

Spain is a large country with more than 45 million inhabitants and a land area of 500 000 km<sup>2</sup>. It has a decentralised political system, particularly with regard to health.

In recent years Spain has made a strong move to ICT deployment in the National Health System (NHS), coordinating efforts and funding from responsible Ministries for Health, Industry and Information Society and the Autonomous Regions (AC). In the new EU governance mechanism the Spanish experience can serve as an example of interpolicy and interterritorial collaboration in the development of cross-border eHealth services.

### The Spanish healthcare system: basic features

The Spanish Health System is composed of 18 regional health services (RHS) coordinated by the NHS.

Basic principles are as follows:

- universal coverage;
- public funding;
- integration of the RHS in the NHS;
- regional organisation of health areas and basic health zones;
- developing primary healthcare with emphasis on promotion, prevention and rehabilitation activities.

An interterritorial Council (Consejo Interterritorial del Servicio Nacional de Salud de España) acts as coordinating body: national ministry chairs and the Regional ministers are the members.

### eHealth in the NHS Quality Plan

Within its six main areas of action, the NHS Quality Plan, adopted in 2006, includes the use of ICT for improving healthcare services.



Over the past 15 years, despite some diversity in functional designs, all regions have coincided in five major lines of action:

- a reliable system for user identification, the individual health card;
- development of EHR;
- integrated processes for provision of pharmaceuticals;
- previous appointments on line with primary care doctors and specialists;
- devices for remote diagnosis and treatment (telemedicine).

The NHS Quality Plan embraces these common lines, extending their benefits to the NHS as a whole, within its equity, quality and innovation strategy.

The availability of a system of interchange of information in the NHS, with a central node of communications, providing agility and maximum safety, is fundamental to the development of interoperability.

A common database has been created for all RHCards, which provides an exclusive NHS code of identification for every citizen.

Thirty scientific societies have participated in the analysis and proposal for common content in the clinical reports. Other societies, in the fields of health law and bioethics and civic society associations, have collaborated for functionalities and conditions of access and use of the information.

A project for digital health records in the NHS was formally agreed with the Regional ministers in the Interterritorial Council of 10 October 2007.

### Supporting eHealth: Plan Avanza's Health in Line

The Government of Spain, through the Plan Avanza, undertook a determined initiative with the project Health in Line, implemented through an agreement between the National ministers responsible for health and industry and the public entity Red.es.

With €448 million for the period 2006–2012, of which €243 came from the general administration and €205 from the Autonomous Regions, Health in Line complements the efforts developed by the Regions in four areas:

- incorporation of all RHCards in the common NHS database;
- support to the regions in the deployment of EHR, with NHS interoperability elements;
- extension of the systems of electronic prescription—dispensation of medicines;
- strengthening the NHS central node of services, guaranteeing the ability to interoperate.

Health in Line is already paying off. The current situation of deployment is as follows.

## Health on Line: deployment situation 2006–9 (Source: Red.es, eHealth in the NHS 2010)

### *Healthcare centres connectivity*

More than 70% of hospitals and specialist centres have connection speeds of over 6 Mbps and 91% of primary care health centres are connected to their respective corporate networks through speeds of over 1 Mbps.

### *Electronic prescription in the NHS*

Roll out of electronic prescription and eDispensing has been accomplished in three regions: Andalusia, the Balearic Islands and Extremadura. These services are now available in all their primary care health centres and pharmacies.

Five regions—the Canary Islands, Catalonia, Galicia, the Valencia Autonomous Region and the Basque Country—are expanding the service. The others have already begun the first phase of their projects.

Forty-two per cent of Spanish pharmacies can dispense medication electronically.

Forty per cent of primary care health centres have an electronic prescription system that allows eDispensing. This service is available for 26% of the population.

In 2009, 18% of the medicines dispensed in Spain were handled electronically.

### *EHRs in the NHS*

Considerable progress has been achieved in integrating EHR at the primary care level. Health centres in 10 Autonomous Regions, Ceuta and Melilla have access to a centralised or integrated EHR system and the other regions are rolling out their solutions.

Ninety-eight per cent of the primary care health centres have an EHR system (off-the-shelf or turnkey solution).

Seventy per cent of NHS hospitals have an information system that includes patient management functions and a clinical workstation, deployed by the RHS as part of its regional EHR project.

Eighty-seven per cent of general practitioners (GPs) and paediatricians working in primary care health centres have access to an EHR system.

Eighty-eight per cent of the population have a primary care EHR.

### *Online appointments in the NHS*

By 2009, the internet appointment service had been rolled out in primary care health centres in 11 Autonomous Regions, four more are implementing it and another has already begun its pilot project.

In 2006, three regions had the service in their health centres so that citizens could make online appointments with GPs and paediatricians, another four were implementing the service and one had a pilot project. In 2009, more than 12 million appointments to see paediatricians and GPs were requested online.

Eighty-six per cent of Spanish citizens are registered at the 3321 primary care health centres that offer the internet appointments service.

In 2009, 37 million citizens could benefit from the online appointment service in the NHS, which represented a 67% increase over 2 years.

### *National health interoperability, a priority for the Spanish government*

On 3 September 2010, the Spanish Government Council of Ministers approved by royal decree the minimum set of data that must be contained in the EHR in the whole of the Spanish territory. This royal decree develops the specifications contained in the basic law on patient's autonomy and rights and obligations regarding information and clinical documentation, and on the law on cohesion and quality in the NHS.

ICT is increasingly widespread in the NHS and has become a common tool in daily work. In a decentralised health system, with 4.5 million people each year receiving medical care in a region different from its own, it is necessary to extend the benefits provided by ICT to the national level.

Main milestones in the deployment strategy have been the data warehouse for EHCards common to all the AC; the establishment of common content, features and conditions of access and use of data; and the EHR project for the NHS, agreed with the AC in the Interterritorial Cooperation Board. The Spanish Government is going to support the EHR project through the *Avanza Plan*, in a new phase with an investment of €101 million by the central government and €94.2 million by the AC.

Furthermore, the Spanish government adopted in the Council of Ministers on 10 September 2010 a new version of the Quality Plan for the NHS. The new plan includes a main objective of increasing the use of ICT to improve citizens' care, with the goal of raising transparency and consolidating an information system for the NHS which is reliable, timely and accessible by citizens and professionals.

The new Quality Plan and the Council of Ministers' operational decisions are a clear reflection of the priority that the Spanish government affords to quality, innovation and transparency in the health sector and its commitment to driving continuous improvement in the NHS. This policy is paying off, as healthcare is one of the public policies most valued by Spanish citizens.

**Competing interests** None.

# The Global People-centred eHealth Innovation Forum

*Alejandro R Jadad*

We all want a health system that promotes health, rather than just treats disease. We want services that are responsive to our culture and sensitive to our unique needs. We want responsible and integrated care, available anywhere, to anyone. We want a health system that is sustainable, and viewed as an essential component for the generation of wealth and wellbeing in society, not one that is viewed as a drain on the economy.

Although it is widely recognised that information and communication technologies (ICTs) can offer solutions to the many barriers that hinder achieving this level of ‘people-centredness’, there is little evidence of progress in their use. In addition, there appear to have been no systematic efforts to bring together world-class leaders who are willing to promote collaborative efforts to make eHealth innovation meaningful and relevant to the public.

*A ‘People-centred health system’ is one that enables individuals to take control and responsibility for their own health (wellness) and healthcare, to access the knowledge needed to make informed decisions about their health and illness, and to partner with others to ensure the best possible outcomes.*

Canadian Association for People-Centred Health (<http://www.capch.ca>)

The Ministry of Health and Social Policy and Red.es of Spain felt that the 2010 European Ministerial eHealth Conference (<http://www.ehealthweek2010.org/>) created a unique opportunity to sponsor a global People-centred eHealth Innovation Forum, which was designed to start filling this gap.

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## Specific objectives

The forum, which took place in Barcelona on 17 March 2010, brought together leaders in the area of people-centred eHealth innovation, from different regions of the world (online appendix 1: [http://phi-group.org/wp-content/uploads/2010/12/BMJ\\_Satellite\\_Forum\\_Appendix\\_3\\_Manifesto\\_People-centred\\_eHealth\\_Forum\\_1009173.pdf](http://phi-group.org/wp-content/uploads/2010/12/BMJ_Satellite_Forum_Appendix_3_Manifesto_People-centred_eHealth_Forum_1009173.pdf)).

The objectives were to:

- act as a think tank with a common goal of promoting people-centred health enabled by ICTs;
- encourage and foster large-scale international collaborative projects to accelerate the emergence of people-centred health systems enabled by ICTs;
- promote shared agendas to engage the public as a partner and a driver in such projects.

## The event

The forum followed a pre-established agenda (online appendix 1: [http://phi-group.org/wp-content/uploads/2010/12/BMJ\\_Satellite\\_Forum\\_Appendix\\_3\\_Manifesto\\_People-centred\\_eHealth\\_Forum\\_1009173.pdf](http://phi-group.org/wp-content/uploads/2010/12/BMJ_Satellite_Forum_Appendix_3_Manifesto_People-centred_eHealth_Forum_1009173.pdf)).

*The term ‘eHealth Innovation’ encapsulates the conceptualisation, design, development, application and evaluation of new ways of using existing or emerging ICTs to achieve optimal levels of health and to promote the sustainability of the health system.*

Centre for Global eHealth Innovation (<http://www.ehealthinnovation.org>)

After brief welcome remarks by Messrs. Pablo Rivero (Spanish Ministry of Health and Social Policy) and Sebastian Muriel (Red.es, Spanish Ministry of Industry), I provided a high-level overview of the rationale and desired objectives for the forum.

Once the scene had been set, the participants introduced themselves. They also expressed their gratitude to the sponsors of the forum for having brought together representatives from all of the inhabited continents to discuss collaborative

efforts around people-centred health enabled by eHealth innovation.

Most of the international participants accepted the invitation to make a short presentation to stimulate group discussion. These included:

- Ms Esther Gil: An overview of the eHealth governance framework that had been endorsed by member states of the European Union the day before during the ministerial eHealth conference.
- Dr Simon Eccles: A summary of the main challenges and successes of the UK's National Health Service (NHS) Connecting for Health, the largest publicly funded eHealth initiative in the world.
- Dr Nancy Lorenzi: A challenge to the group to support the creation of 'human infrastructure' and 'translation resources' to promote the effective adoption of eHealth innovations by all groups of relevant stakeholders and also the efficient transfer of knowledge across linguistic boundaries.
- Professor Mordechai Shani: Complementing Dr Lorenzi's challenge, he called for a collective effort to support the emergence of a 'support network', a collection of technological and human resources that could improve the management of chronic diseases.
- Dr Alexander Martynenko: An illustration of the role that mathematical and computing models could play as catalysts of eHealth innovation, particularly in cases that involve mobile telecommunication devices.
- Dr Sarah Muttitt: An outline of ongoing efforts in Singapore to introduce electronic health record there, coupled with an ICT infrastructure designed to improve the efficiency of the health system.
- Dr Yuri Quintana: A high-level description of the history, evolution, challenges and successes of Cure4Kids, the largest effort in the world to use eHealth innovation to combat a major disease, in this case childhood cancer.
- Professor Xiao Shaobo: A plea for the effective blend of social sciences in any effort to promote eHealth innovation, and a call to the group to support current large-scale health reform efforts in China.

After these presentations, the entire group agreed that it was essential to separate opportunities arising in the 'formal' and the 'informal' health system. The formal system is the established apparatus, with institutions staffed by health professionals, run by managers and focused on the provision of healthcare services to patients. The informal system is a loose and dynamic ecosystem composed mainly of members of the public who are using ICTs (mostly social media and mobile telecommunication devices) to complement or enhance the formal system.

Within the 'formal' system, the following options were proposed:

- Coordinated scalable projects in select regions of the world:
  - In China: Professor Xiao proposed the development of a large project focused on primary care reform and family-centred initiatives. The timing was considered ideal, given that the country has embarked on a major health system reform effort that could benefit from innovative uses of ICTs.
  - In Uganda: Dr Mukooyo suggested the possibility of positioning his country as an ideal environment to bring together multiple mHealth (mobile health) applications and optimise their role within the system, particularly in relation to clinical and public health services. Dr Kay told the group that WHO is supporting a review of over 180 reports of projects in this area, which could act as an invaluable foundation for any decisions in this area.
  - Internationally: I reported ongoing efforts to develop living laboratories across the world within the context of the Maimonides Project (online appendix 2, sent to participants in advance: [http://phi-group.org/wp-content/uploads/2010/12/BMJ\\_Satellite\\_Forum\\_Appendix-2\\_Maimonides\\_Project\\_Summary\\_Core\\_1009173.pdf](http://phi-group.org/wp-content/uploads/2010/12/BMJ_Satellite_Forum_Appendix-2_Maimonides_Project_Summary_Core_1009173.pdf)). These laboratories are real-world settings in which simulated future scenarios could be enacted, refined and evaluated, and the foundations created for efforts to scale up successful interventions. Participating countries include Canada (York Region in Ontario), the USA (Rhode Island), Israel (Galilee Region), Brazil (Aracaju State) and Spain (Balearic Islands, Basque Country and Andalusia). Dr DiLucca also offered the organisation he leads and its catchment area in Argentina as a potential mini-living laboratory that could be available to the group for pre-testing and refinement of people-centred eHealth innovations.
- Support to leaders of large publicly funded eHealth programmes to incorporate disruptive interventions in their ongoing or upcoming projects:
  - Dr Eccles expressed strong interest in getting input and guidance from the group about opportunities to enhance the value of the projects supported by the NHS Connecting for Health initiative, particularly in relation to the role of the public, and disruptive technologies to accelerate the transformation of the system.
  - Dr Muttitt asked members of the group for support for an upcoming telehealth initiative in Singapore. The participants agreed to work with her to shape the planned call for proposals, to review submissions and to explore ways

that could lead to better engagement from telecommunication companies, particularly in mHealth solutions. In addition, she sought volunteers to work with her on how to promote the sustainability of health portals, positioning them as effective interventions to promote behaviour change.

- Dr Freidman underlined the need to foster optimal levels of education among health professionals and the public about people-centred issues.
- Within the 'informal' system, Dr Lorenzi emphasised the opportunity that exists to support the creation of a robust global 'people infrastructure' as an essential element for the transformation of the health system. In other words, achieving a people-centred health system will require the right vision, strong leadership and robust technological resources and, most importantly, a critical mass of people prepared to change the way they do things in a fundamental way.
- With the rapid development of social media and networks, we could identify and support efforts emanating from civil society, particularly youth. Groups such as TakingITGlobal (<http://www.tigweb.org/>) could be great allies. On the other hand, there are also opportunities within existing health-related thematic networks, such as Cure4Kids (<https://www.cure4kids.org/ums/home/>), which are already engaged in large-scale initiatives on health promotion, disease prevention and behaviour change (eg, tobacco cessation efforts, mentoring of community leaders, leadership development programmes).

Throughout the forum there were repeated comments, led by Dr Quintana, about the need to refine the notion of 'people-centred health enabled by eHealth', from its definition, through the identification of themes, to the selection of outcome measures to assess the impact of any related activity. There was a strong appetite for a meeting in 2011 that could bring together leading individuals and organisations to discuss and refine these issues, ideally following a year-long systematic effort to engage them in virtual (preparatory) interactions.

At the end of the forum, a short document that summarised the main messages and wishes expressed during the day was presented to the group for their consideration as a manifesto to motivate other individuals and organisations to support the activities identified during the forum, and to strengthen any existing or future formal collaborative efforts on people-centred health enabled by eHealth (online appendix 3: [http://phi-group.org/wp-content/uploads/2010/12/BMJ\\_Satellite\\_Forum\\_Appendix\\_1\\_Global\\_People-centred\\_eHealth\\_Forum\\_Barcelona\\_100317\\_AGENDA3.pdf](http://phi-group.org/wp-content/uploads/2010/12/BMJ_Satellite_Forum_Appendix_1_Global_People-centred_eHealth_Forum_Barcelona_100317_AGENDA3.pdf)). After a few suggestions on how to improve its wording, most of the participants expressed their personal support, and some were willing to present it to their corresponding organisations for their endorsement.

At the end of the forum, the participants expressed their satisfaction with the progress made during the day, and confirmed their commitment to continue the development of collaborative efforts to accelerate the transformation of the health system, world wide.

**Competing interests** None.

# PAHO/WHO: eHealth conceptual model and work programme for Latin America and the Caribbean

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## The Pan American Health Organization

The Pan American Health Organization (PAHO) functions as the technical health agency of the Organization of American States as well as the regional office for the Americas of WHO, and enjoys international recognition as part of the United Nations system. Member States include all 39 countries of the Americas including Puerto Rico as an associate member.

As part of its knowledge management and communication strategy, PAHO is developing a series of projects and initiatives for every country office, specialised offices, centres and member states. The PAHO eHealth programme's goal is the improvement of public health in the Americas through the use of innovative information and communication technology (ICT) tools and methodologies and will showcase PAHO's engagement with the concepts and initiatives of the Information Society, Public Health 2.0, Medicine 2.0 and eGovernment in the region of the Americas.

## eHealth in the United Nations

In 1998, the document 'Health for all in the XXI century',<sup>1</sup> requested by WHO, recommended the adequate use of health telematics in the general policy and strategy of health for all. During the same year, resolution WHA51.9<sup>2</sup> also defined the lines of work concerning cross-border advertising, promotion and sale of medical products using the internet.

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In 2003, the Summit on Information Society addressed cyber health as an ICT application which could improve the quality of life of the population. In 2004, the report EB115/39 and the resolution EB115.R20 stated that it was necessary for the member states to define cyber health strategies based on the principles of transparency, ethics and equity for the development of the necessary infrastructures and multisectoral collaboration in the public and the private sectors.

In 2005, the 58th World Health Assembly established the following as the foundation of WHO eHealth strategy:

- to participate in the development and promote the use of norms, standards, guidelines and information and training materials;
- to reinforce the capacity of member states to deal with health issues by integrating eHealth applications into health systems in order to improve performance, care delivery and information mechanisms;
- to foster public–private partnerships in research and development for priority eHealth systems and applications for the benefit of the member states;
- to support capacity building and to provide technical assistance and policy guidance on implementation of eHealth applications;
- to investigate, analyse and document the impact of policies and interventions on the health of the population, including social and economic ones, related to information and communication technologies.

In this way, the first steps were taken for the development of the eHealth strategy and agenda for the Member States.

## eHealth strategies: definition, characteristics and impact

The word eHealth was selected because tools such as *Google Insights for Search*<sup>3</sup> (programme of search statistics which compares volume patterns across specific regions, categories, time frames and properties) state that during the past few years eHealth was the most frequently used word when

internet users searched for information on this topic, in addition to other important terms such as telehealth, telemedicine or digital health.

According to the Wikipedia definition,<sup>4</sup> ‘eHealth’ (also written e-health) is a relatively recent term for healthcare practice which is supported by electronic processes and communication. The term is inconsistently used: some would argue it is interchangeable with healthcare informatics and a subset of health informatics, while others employ it in the narrower sense of healthcare practice using the internet. The term can encompass a range of services that are at the interface of medicine/healthcare and information technology.”

Scientific literature addresses seven recurrent topics to be considered in the context of Health 2.0 or Medicine 2.0<sup>5</sup>: patients and consumers, Web 2.0/technology, professionals, social networking, change of healthcare, collaboration and health information of content.

Each eHealth strategy aiming at ensuring its appropriate development and implementation should consider the following aspects: first, all players in the public and private sectors should work coordinately and transversally in the health and technology sectors; moreover, it is important that all stakeholders (healthcare authorities, healthcare professionals, the pharmaceutical industry, scientific professional associations and societies and, undoubtedly, patient associations and the population) play a part in this process from the very beginning; an institutional plan should be in place to guarantee the implementation of the processes and, lastly, every strategy should have a responsible person to monitor all phases of development from the beginning to the evaluation.

Since Morris Collen stated in 1970<sup>6</sup> that “physicians should enter their medical orders directly into the computer”, eHealth has experienced significant improvement: digitalisation of clinical and administrative documents, access to health information and healthcare support using the internet and the social web, healthcare identification cards, electronic clinical history, electronic prescription, telemedicine services and mHealth services (mobile devices), tHealth (through television) and even uHealth (ubiquitous health). These services can be analysed from different points of view:

From the *innovation* point of view, eHealth facilitates the elimination of barriers among people, institutions and health services, and is changing work processes, increasing the efficacy of information management, strengthening individual and collective knowledge (easier and more rapid introduction, access and retrieval of information), improving communications, interaction and risk management and patient safety by supporting clinical decision-making, ensuring evidence-based decision-making and narrowing the gap

between knowledge and action in public health interventions and policies.

From the *socio-sanitary* (the convergence of social and health services) point of view, applying technology to the healthcare processes can improve patient and population quality of life by more personalised, integrated and seamless healthcare services, and by reducing waiting times and giving better access to professionals, regardless of their physical location.

From the *economic* point of view, it is estimated that the benefits of using the technology will be observed in 3–13 years, but these changes, at least in relation to electronic health records and ePrescribing investments, depending on the size of the project, will probably lead to increased effectiveness, improved commitment for complex decision-making, enhanced rationalisation of available resources and evidence-based prioritisation of needs.

From the point of view of convergence much remains to be done in order to reduce the digital and information gap in a context of technological, cultural, cognitive and generational convergence, and we have posed the following challenges that we regard as opportunities:

- universal access to health services with improved quality of healthcare;
- extension of social services through health systems based on primary healthcare;
- available, competent and motivated health workers;
- real-time reliable sources of information for decision-making;
- knowledge and information sharing within and between dispersed populations;
- follow-up and surveillance systems through mobile and wireless communication devices (eg, expanded programme of immunisation);
- real-time learning objectives for distance learning and training for the development of skills and motivating primary healthcare teams;
- social networking methodologies and tools for disaster and emergency situations;
- access to public health certified and open-access content;
- access to specialised medical care to increase capacity at primary healthcare level
- convergence of electronic health initiatives around the world;
- web-based mobile applications for healthcare management;
- fast technological changes;
- new role of digital governance;
- new models of technical cooperation in the context of ‘national digital agendas’ and ‘electronic administration initiatives’;
- active participation in the International Summit of the Information Society, with focus on health;

- investment in the connectivity of national governments with the support of the development banks;
- increased interest in public–private partnerships.

### Strategic and conceptual eHealth model for the Americas and the Caribbean

“This will be the century of networks, connectivity and interdependency, which will make it possible for us to overcome the time and space barriers and open possibilities that were unimaginable to improve the life quality of our people. If we promote these networks to exponentially multiply the available social capital in order to link people and institutions within a large mesh of support and inclusion for all the people of the continent, we will have taken a fundamental step towards eliciting knowledge and experience in new forms of exchanging technical cooperation for sustainable human development.” The words of PAHO/WHO director, Dr Mirta Roses, in her 2003 inaugural speech, already presaged the institution’s eHealth strategy with the aim of establishing a model of institutional governance which would allow the consolidation of a regional vision and the collective introduction of a strategy and a digital agenda in the region.

The PAHO eHealth conceptual model is based on three main components: (1) access to information, (2) access to educational material and (3) interaction management in the Web 2.0 context, which includes the physician–patient relationship and all aspects of telemedicine and telehealth. These components are within the framework of a process which follows a strategic pathway that runs from identified needs to innovative solutions as well as the recording of lessons learnt, which enable the constant improvement of the cooperation model.

The PAHO/WHO eHealth programme acts as the strategic response to the Health Agenda of the Americas<sup>7</sup> and develops jointly and in coordination with the model started by WHO in the European region, which focuses on:

- obtaining a political and strategic commitment from the countries of the Region of the Americas and the Caribbean;
- building trust and acceptance;
- providing legal and ethical clarity as well as ensuring the protection of clinical personal data;
- working on and developing issues related to interoperability;

- linking eHealth policies with competitiveness, innovation and research policies, as well as with cohesion and social inclusion policies.

PAHO’s eHealth programme will be supported through an eHealth portal (<http://www.paho.org/ict4health>) and will be supported by the organisation technical advisory group in related topics.

The adoption of information and communication technologies will herald improved quality of life of patients and population in the next few years as well as communications between institutions and individuals. PAHO will continue working hard so that health information can be regarded as a public good, and so that its open and equitable access can be considered part of the economic and social development of the countries<sup>7</sup> in order to comply with the statement of intent established in the Health Agenda for the Americas: “A region where each individual, family, and community has the opportunity to develop to its greatest potential.”<sup>8</sup>

**Competing interests** None.

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# Beyond the gadgets: socioeconomic, educational and political implications of people-centred health enabled by eHealth

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People-centred health remains the aim of many organised healthcare systems. By allowing individuals to take control of their own care its quality can be improved and the burden on the provider can be reduced. eHealth is a prerequisite for this shift. In order to allow clinicians and patients to have access to individual health information either two constantly synchronised copies should be made or the data need to be held in such a way that they can be securely accessed by both. Either solution calls for electronic records with good security and access controls.

The introduction of new information and communication technologies (ICTs) into healthcare has attracted a higher level of publicity<sup>1,2</sup> than in many other industries. This is in part because healthcare has a high public and political profile, partly because of the large costs involved and partly because it poses a challenge to the status quo, triggering strong reactions from users and staff. Healthcare spending in Organisation for Economic Co-operation and Development economies in 2007 averaged 8.9% (16% in the USA, 8.4% in the UK).<sup>3</sup> Yet ICT spending in healthcare remains lower than in other industries despite the large-scale eHealth programmes in the USA, England, Canada and other countries.

Politicians are naturally drawn to projects offering success in a timescale which accords with the political process. This is rarely true of large-scale information technology (IT) programmes. The time needed for full adoption of new technology is long and,

especially in the hospital sector, the return on investment takes many years.<sup>4</sup>

Even the most patient-centred healthcare ICT system will require a degree of 'central' provision. This may be provided by the individual healthcare provider, a healthcare organisation or the regional or national government. If one of the desired outcomes is the ability to share healthcare information, either for coordination of an individual's healthcare or to collate information to better plan population health, then a measure of cross-organisational standardisation will be needed. For example, England has produced a unique patient identifying number (the National Health Service number<sup>5</sup>), together with the infrastructure necessary to provide this at the point of care, to ensure safe record transfer and linkage between providers.

## Economics

Recent economic events have created fiscal challenges resulting in burgeoning public debts and reduced private consumption. While further tightening of purse strings will have an impact on many investments, the demographic realities of an ageing population and growing global epidemic of chronic diseases will require continued improvements in healthcare supported by health information technology (HIT). During the height of the American recession in 2009, the Obama administration earmarked US\$19 billion for HIT through the American Recovery and Reinvestment Act as part of a larger effort to transform America's archaic health system. Similarly in Singapore, to achieve the government's vision of integrated care, investments like the National Electronic Health Record (NEHR) for all its citizens by 2015 will provide the foundation for further investments in eHealth.

When combined with transformational efforts, eHealth promises the delivery of a safer, efficient and reliable people-centred

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care. When adopted, eHealth solutions like the electronic health record (EHR) enable clinicians to access longitudinal patient information, resulting in reduced errors in diagnosis,<sup>6–9</sup> medication,<sup>10–13</sup> duplication of diagnostic procedures,<sup>14–17</sup> and also increases in productivity<sup>18</sup> and quality of care.<sup>19–21</sup> Its value is further enhanced through secondary data usage for public health planning, surveillance, research and education.

Cumulative savings from the USA's HIT efforts are estimated to be US\$261 billion over 10 years.<sup>22</sup> As for Singapore, it was estimated that the NEHR alone, over the same period will achieve break-even in year 7 or 8 with an impressive return on investment of 45%.<sup>23</sup> A further example of demonstrated value can be found at the Department of Veteran Affairs, where successes include its much publicised telehealth implementations. It is estimated that the department's cumulative benefit of HIT investments stands at US\$3.09 billion as of 2007.<sup>24</sup>

As we move into the era of personalised medicine, the convergence of technologies will further create non-tangible value through greater patient satisfaction by giving power to individuals and extending access to care. Outside the realm of clinical benefits, investments in eHealth will have other multiplier effects on the economy. Akin to large infrastructural investments in sectors such as transportation, eHealth investments will result in higher workforce productivity through general improvements in health. Its programmes will also result in jobs and wealth creation, which in turn lead to a higher gross domestic product. Nevertheless, eHealth's true value can be unlocked only through strong leadership support, backed by changes in policy, financing and, most importantly, a change of attitude by patients and providers.

## Education

A consensus exists that accessibility, quality and cost are major problems confronting healthcare provision throughout the world. The application of ICTs to the delivery of healthcare services is often heralded as central to improving this state of affairs. Many applications of computer science and ICT to healthcare have fostered true revolutions (eg, digital imaging), yet the promises of eHealth, beyond information exchange, are felt by many as yet to come.

Implementation of leading-edge technologies such as hospital information systems and EHRs is still beleaguered by failures and although this is a situation affecting many complex application domains aside from healthcare,<sup>25</sup> it nevertheless merits full attention by the healthcare informatics community. In this sense, the question how informatics might help provide better healthcare for more people is probably better answered by reference to 'domestic' aspects of our trade than is often thought.

Although many of the variables leading to failure or success have been apparently identified,<sup>26</sup> and their importance goes without saying, there seems to be an excessive weight attributed to managerial aspects and not enough emphasis placed on intrinsic technical aspects. This bias exists in the realm of the IT profession and also in the business world as a whole. It is our contention that whereas great advances have been made in the research arena (ie, ontologies for terminology management and models such as openEHR, among many others), these findings are not permeating to the world of everyday applications either quickly or thoroughly enough.

One of the major challenges for the successful implementation of healthcare IT projects is better (and quicker) bridging of the gap between research and practical application and improved training of healthcare IT professionals and doctors alike in the theoretical foundations of medical informatics (MI). Such an objective requires solid training in both computer science and medicine.

It is noteworthy that at the intersection of healthcare and computer science, a whole new set of knowledge has emerged<sup>27</sup> (standards, data models, etc) which can only be learnt and used through explicit training in its details. Thus, for example, openEHR models and the HL7 RIM require a full understanding of healthcare organisations and the object-oriented formalism known as unified modelling language. In that sense, health informatics education should probably adopt more of a trans-disciplinary approach (where professionals should be trained in the basic topics both of computer science and medicine) rather than the classical multidisciplinary or interdisciplinary approaches, where a health informatician is viewed as a facilitator between IT and medical professionals. Young MI trainees receiving this sort of education would when they finally arrive at executive positions consider advanced concepts in MI as a normal part of any project and not far-fetched theoretical constructions. Such an approach would help to solve the 'business alignment of IT' conundrum<sup>28,29</sup> in a far more efficient way, and the effective contributions of informatics to better healthcare would be streamlined.

## The patient perspective

Population demographics are changing in the developed world, as people live longer and increasingly develop long-term conditions related to lifestyle and old age. These significantly increase the burden on health services (Department of Health, unpublished observations).<sup>30–33</sup> Clinicians have been slow to promote self-care to their patients, using digital aids.<sup>34</sup> Health services struggle to deliver sickness-focused healthcare with an ageing population of ill-equipped patients.

A digital revolution in healthcare is inevitable, spurred on by the unsustainability of the current paternalistic model, based on

rapid face-to-face consultations and the expectations of generations who now transact most of their business online. It depends on growing clinician and public confidence in health technology. It could be speeded up by changes to public and professional education. It is a significant and threatening issue for some clinicians and patients, who must be supported to make the change.

During the next decade control of healthcare needs to move from the clinic to the home. Professionals should be trained to help people care for themselves effectively rather than remove the burden of care from their shoulders. Clinicians could be rewarded for achieving goals set by their patients, and monitored by them from home. A variety of digital aids will support people to keep themselves well.

The public must be trained for its changing role. At birth, children should get a personal health record that they tailor increasingly to their own health needs. At school, they should learn about personal health management and the digital tools available to help them.

Online services can help people who need care self-diagnose, book appointments and order prescriptions. Patients outcomes are improved by education and inclusion in agreed care plans,<sup>35</sup> therefore systems should share plans with patients and allow individuals to record the care they give themselves. When needed, patients can monitor themselves (eg, blood pressure or glucose) and are alerted if anything needs to change. They could even order routine tests for themselves and get the results, with explanations, minimising the burden on the healthcare system.

The internet already allows people to network with their peers with similar health problems to exchange 'real-world' solutions. Social networks are an underexploited source of information for those commissioning services or doing research. Although people may see their clinicians less often in the future, technology can ensure they feel continuously cared for by the remote support they receive. In this way eHealth can harness the power of patients and information to help defuse the demographic time bomb.

**Competing interests** None.

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# People-centred healthcare systems: opportunities and challenges

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People-centred healthcare systems aim to empower people with their healthcare decisions, make information more accessible and enable more autonomy.<sup>1–12</sup> The goal is to promote well being as much as to treat disease, and to create more collaboration among providers, patients and their families, thus reducing costs and improving health outcomes. Throughout the world growing populations and rising costs are challenging healthcare systems. In numerous countries, healthcare providers cannot meet the needs of many individuals and groups owing to limited budgets, time and staff. An ageing population and rapidly increasing rates of chronic diseases could overwhelm most healthcare systems.<sup>13–19</sup>

Although information and communication technologies can connect healthcare providers with each other and the consumers they serve, no group, organisation or government has overcome the roadblocks to implementing a wide people-centred health system. Ideally, such a system would put the needs of the public first, enable individuals to take greater responsibility for managing their own health and health services and promote optimal levels of health and resource utilisation. In this paper, we explore a vision for future people-centred healthcare systems that could provide better access to information and decision-making tools for patients, healthcare providers and

the general public. We also examine key challenges to creating such systems.

## The people-centred healthcare vision

Healthcare organisations often talk about patient-based or patient-focused care. The vision for a people-centred healthcare system goes beyond being patient-based or patient-focused. A people-centred health system enables people to take control of their own health and wellness and strives to support them in that endeavour through multiple means.<sup>8–12</sup> One major ‘means’ is information. Within a people-centred healthcare organisation, information is provided to patients and also to the families who care for and support them, as well as to other people who support wellness. In addition to patients and families, healthcare professionals themselves are key stakeholders in a health system. They provide care and also make health information available and understandable. Other groups within the vast healthcare system, such as government healthcare agencies, regional and local public healthcare units and non-profit groups and non-governmental agencies, are also integral parts.

Various definitions of people-centred healthcare systems have appeared from the 1940s through 2010.<sup>1–12</sup> One early vision<sup>3</sup> noted, “people need care when sick; they need preventive services; they need workable information. The needs do not change: perception of need changes. Expectations of how and to what extent needs can be met also changes.” Another view defines e-patients as individuals “who are equipped, enabled, empowered and engaged in their health and health care decisions ... where there is an equal partnership between e-patients and health professionals and the systems that support them.”<sup>8</sup>

The Canadian Association for People-Centred Health<sup>9</sup> bases its concept on four key principles: (1) responsibility—people are responsible for their health and wellness; (2) autonomy—people make their own decisions affecting their health and wellness; (3) informed health management—people have the information needed to manage and make informed decisions about their health and wellness; (4) partnership—people partner with healthcare providers to ensure the best possible outcomes. The Society for Participatory Medicine describes *participatory*

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*medicine* as “a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners.”<sup>10</sup> The Markle Foundation defines a *person-centred health system* as one “that will make available the most effective professional and institutional resources to assist people when they can no longer manage their own health without that help.”<sup>11</sup>

In 2001, the US Institute of Medicine<sup>12</sup> wrote: “The current health care delivery system is not robust enough to apply medical knowledge and technology consistently in ways that are safe, effective, patient-centred, timely, efficient, and equitable. As we strive to close this gap, we must seek health care solutions that are patient-centred, that is, humane and respectful of the needs and preferences of individuals.” This report noted the importance of integrative medicine as a means of addressing the mental, emotional and physical needs of patients during the healing process and the need for greater patient involvement in healthcare.

### Why create people-centred healthcare now?

Incidence of chronic disease in populations around the world continues to accelerate rapidly,<sup>13-19</sup> and some healthcare providers

emphasise the need for prevention and education before an individual becomes a patient. Most healthcare systems do not embrace these health-related activities as part of care because they are not billable or reimbursable. Global surveys of the public show that people are frustrated and unhappy with their health services.<sup>20-23</sup> Most are not participating in healthy living programmes. Nor is technology playing a major role in promoting healthy living and self-care programmes. Consumers are expressing interest in more electronic access to their healthcare providers.

There is an opportunity to bring more healthcare services and prevention information to the public. Information and the timely delivery of educational and decision-making materials are essential to effective prevention and public health strategies. Before prevention and public health education can be used as part of a true people-centred health system, information flow among key stakeholders must be improved.

### The complexity of health knowledge exchange

Information flow among healthcare consumers, professional healthcare providers, government agencies and private corporations involved in healthcare is often fragmented or non-

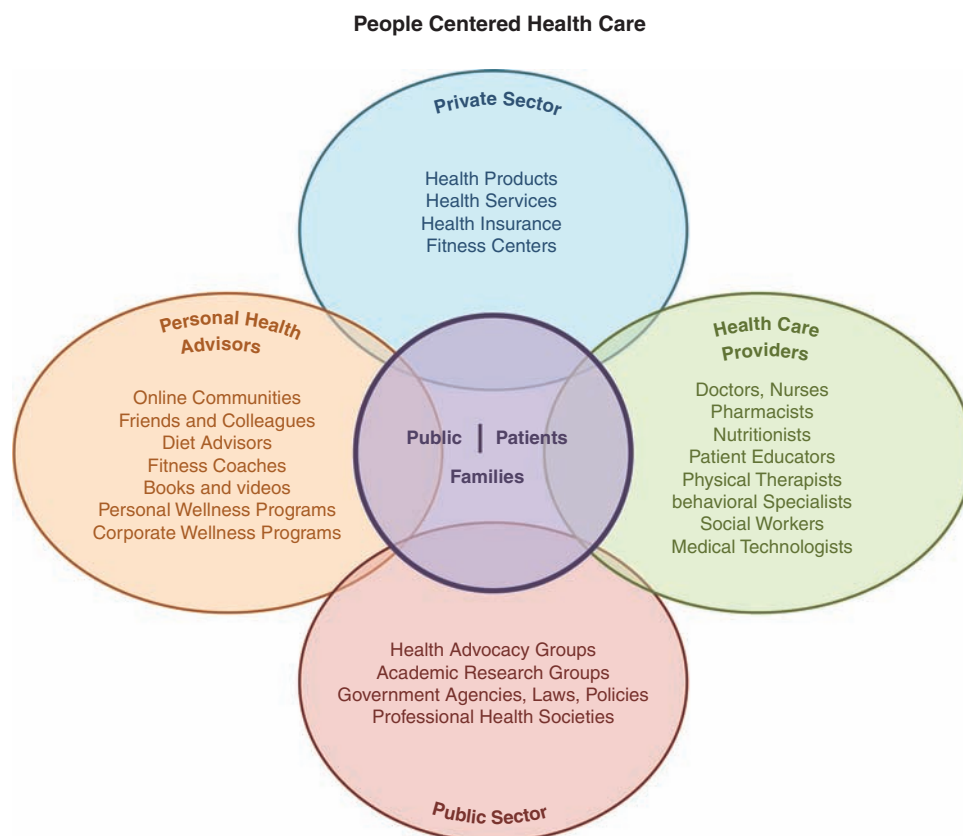
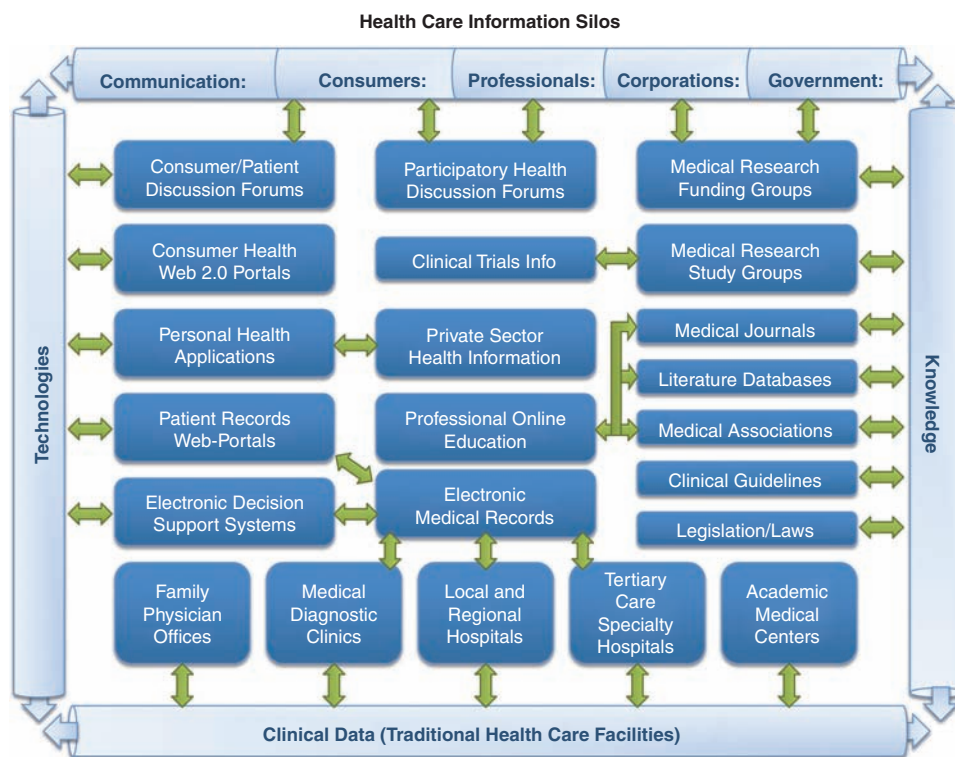


Figure 1 People-centred healthcare stakeholders.

**Table 1 Challenges to effective sharing of health information**

Challenge 1	Defining the key stakeholders and goals of a people-centred healthcare system
Challenge 2	Motivating stakeholder groups to communicate efficiently across healthcare systems
Challenge 3	Developing common understanding and shared expectations of desired services and outcomes among stakeholders
Challenge 4	Improving the technologies for public access to personal healthcare data and information
Challenge 5	Developing successful models for prevention and public health education that are effective and sustainable
Challenge 6	Developing strategies to involve and engage patients, their friends and families in this new system
Challenge 7	Narrowing the bench-to-bedside gap. The interval between research studies and the clinical use of information at the point-of-care can be as long as 24 years



**Figure 2** Health information sources and information flows.

existent owing to a lack of technology adoption and incentives to communicate.<sup>24-27</sup> Figure 1 illustrates a comprehensive model of a people-centred healthcare system that includes prevention and public health as key components. In many low-income countries, people lack access to high-quality healthcare services and seek help from various individual services, such as small pharmacies or healers, unconnected with other health systems. Even in more industrially developed societies, many healthcare providers are unable to collect and share information efficiently among themselves or with patients and their families, either because of incompatible technologies or lack

of financial incentives. Figure 2 shows some of the sources of healthcare information and how this information could flow between stakeholders.

Existing workflow models frequently introduce errors, hamper productivity and make data sharing difficult among distributed healthcare systems.<sup>28-31</sup> Technology could provide new ways for stakeholders to communicate with each other and advance more desirable healthcare outcomes. Innovations in digital technologies, when properly used, could overcome the logistical barriers to information sharing by introducing more efficient methods for collecting, sharing and storing data, and providing better tools

to support data analysis and improve clinical decision-making and health outcomes.<sup>32–35</sup>

## Challenges

In order to ensure effective communication of information within a people-centred healthcare system, several challenges will need to be overcome, as summarised in table 1.

One of the first challenges in creating a people-centred health system is identifying the system's key stakeholders, beginning with patients or consumers.<sup>36–39</sup> In many healthcare systems, a person is considered to be a patient only after he or she exhibits observable symptoms or after he or she is given a clinical referral or diagnosis. However, many people who have not been identified as patients have existing medical conditions that put them at substantial health risk, including those who are obese, mentally or chronically ill or who are ill but do not have symptoms or a diagnosis. Defined as patients or not, all consumers are stakeholders in the system. Another challenge is determining the role of a patient's family in the system. Often, healthcare systems do not view family members as key stakeholders, and services focus exclusively on the patient.

Defining the key stakeholders and goals of people-centred healthcare systems (challenge 1) depends on each country's funding models for healthcare and the cultural values its citizens place on healthcare services.<sup>40–44</sup> The USA is currently restructuring its healthcare system. In many countries private and public healthcare systems overlap. Groups such as the Society for Participatory Medicine (<http://www.participatorymedicine.org>) are bringing together stakeholders from various disciplines to discuss future health systems. Leaders from all sectors will need to act jointly to help develop visions of people-centred healthcare systems.

Challenge 2 is to motivate stakeholder groups to communicate efficiently across healthcare systems.<sup>45–55</sup> Lack of communication reflects the absence of both an effective system for sharing information and perceived benefits for participants. It perpetuates missed opportunities to improve point-of-care clinical practice and prevention activities. In some instances, improved health outcomes and reduced costs might encourage data sharing as, for example, in the implementation of common treatment protocols for collaborative research.<sup>45</sup> One way to communicate health information is through online social networks. There are social networks<sup>46–54</sup> for patients (<http://www.PatientsLikeMe.com>), physicians (<http://www.sermo.com>), academic researchers (<http://network.nature.com>), biomedical scientists (<http://www.scilinks.org>), professional medical personnel (<https://www.Cure4Kids.org>) and laboratory scientists (<http://www.labspace.net>). To maximise the benefit of these networks, we will need to find ways to bridge communications among these

groups, possibly through semantic indexing technologies.<sup>55</sup>

Challenge 3 is related to developing common understanding and shared expectations among providers and consumers.<sup>20–23</sup> Healthcare providers and consumers sometimes do not understand each other's expectations. Bridging these gaps in expectation and understanding will be important. Surveys show that consumers have difficulty understanding the healthcare system.<sup>20</sup> Increasingly people want to access some of their services via the internet, and doing so could reduce some frustrations and wasted time.<sup>21–23</sup> To overcome this challenge, we need continued discussion among stakeholders to define the desired services and health outcomes, and improve the ease of use of online tools for consumers<sup>56–58</sup> and professionals.<sup>59,60</sup>

Challenge 4 is to improve the technologies for public access to personal healthcare data and information.<sup>61–64</sup> People-centred health systems must include access to clinical records and personal health record platforms distributed among various providers.<sup>61,62</sup> Some personal health record systems, such as Microsoft Health Vault (<http://www.healthvault.com>) and Google Health (<https://www.google.com/health>), attempt to consolidate information from various providers. However, to be effective, these technologies must operate among the various levels of technology, provide privacy controls and must ensure that only accurate data are transferred.<sup>63</sup> Future systems will need to be designed with interoperability<sup>64–68</sup> to access data from multiple providers, and interoperability should be measured and incentivised. To overcome this challenge there will need to be greater adherence to information standards. The problem is not that we do not have standards for data interchange, but that groups cannot agree on which standards to use. Leadership from government and key providers will be needed to accomplish greater standardisation. We will need to evaluate the cost of these systems,<sup>69–71</sup> have effective strategies for introducing new technology<sup>72</sup> and also quality-of-life indicators from the perspectives of patients and the general public.<sup>73–77</sup>

Challenge 5 is to develop successful models for public health education and prevention programmes that are cost effective, yield useful and measurable health outcomes and are scalable and sustainable. Many large-scale public health initiatives have been developed to help deal with issues such as nutrition,<sup>78,79</sup> exercise,<sup>80–82</sup> smoking,<sup>83</sup> yet despite billions of dollars of research and public health expenditure, obesity, heart disease and preventable cancers remain large public problems.<sup>84–86</sup> There needs to be greater urgency placed on new models, incentives and rewards for successful prevention programmes. The current approaches are not yielding scalable or sustainable solutions. Since the problem is complex, we will need new approaches that combine multiple disciplines such as medicine, public health, engineering, social sciences and need to create

new innovative solutions to these problems. New training programmes in eHealth and public informatics are examples of this emerging multidisciplinary approach to problem solving.<sup>87–90</sup>

Challenge 6 is how we can develop the opportunities and strategies to effectively involve and engage current/future patients and their families in the new system. This challenge revolves around building trust in the patient-centred healthcare model. Connecting patients with information and personal action for change will require a number of strategies and processes that will be dependent on local cultural norms. We will need innovations in health technologies and healthcare delivery that connect patients, families and health providers together.<sup>91–94</sup> Another approach is to design new hospitals with prevention in mind and with education and collaboration areas built into the design of the buildings.<sup>95 96</sup>

Challenge 7 is related to synthesising information collected from clinical experience and research studies for use in practice. New research discoveries can be integrated into clinical practice guidelines or continuing education materials for healthcare professionals. The time required for research results to be incorporated into practice, or knowledge used at the point-of-care can be as long as 24 years, and translation is sometimes delayed by regulatory oversight.<sup>97 98</sup> Clinical data are often collected by multiple healthcare groups such as hospitals, clinics and diagnostic laboratories. These groups are often independent and distributed making the analysis and synthesis of data difficult, and often impeded by the lack of a framework or system for sharing information. There are some free tools which can be used to find current research information such as PubMed Central for biomedical journal literature, ClinicalTrials (<http://www.clinicaltrials.gov>) for clinical research studies and the National Guideline Clearinghouse (<http://www.guidelines.gov>) for clinical practice guidelines. Better public search tools are needed to search, interpret and analyse the data to support decision-making.<sup>56–60</sup> Denmark has made significant progress in electronically connecting its healthcare institutions<sup>40 40a 41 99</sup> and providing patient rights and information and ranks first in a recent European survey,<sup>100</sup> but more will need to be done locally, regionally and globally.

## Conclusions

The need to evolve people-centred systems is increasing owing to rising levels of chronic disease.<sup>13–19</sup> Chronic disease, according to the WHO, comprises the major chronic conditions of heart disease and stroke (cardiovascular disease), cancer, chronic respiratory disease and diabetes. Over half of the deaths in the world are due to just four chronic conditions—diabetes, lung diseases, some cancers and heart disease—caused by three risk factors—smoking, poor diet and lack of physical activity.

A WHO report<sup>13</sup> notes that “chronic disease epidemics take decades to become fully established; given their long duration, there are many opportunities for prevention that require a long-term and systematic approach to treatment. Health services must integrate the response to these diseases along with the response to acute, infectious diseases.”

Given how complicated it is to develop people-centred healthcare systems, why do it? The increasing incidence of chronic diseases and the associated rising healthcare costs have made this a global urgency.<sup>15</sup> The need to find cost savings and improve health outcomes has become critical in many countries. Meeting this need is unlikely in the current fragmented healthcare systems. To provide more effective prevention and proactive consumer healthcare systems, we will need to develop more integrated people-centred healthcare systems. Overcoming challenges 1–3 are essential first steps if we are going to have a consensus roadmap for the future. New solutions are required that are cost effective and scalable. A new multidisciplinary approach is needed. We need to act on the basis of common needs and shared goals. Such a complicated collaboration will require trust, vision, leadership and innovation.

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# Human-centred eHealth: current opportunities, challenges and the way forward for China

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## The opportunity

Information and communication technology (ICT) is a global catalyst for change.<sup>1</sup> In 2009, China's State Council passed a long-awaited medical reform plan which promised to spend ¥850 billion (US\$123 billion) by 2011 to provide universal medical service to the country's 1.3 billion population.<sup>2,3</sup> This impetus was fuelled by growing public criticism of soaring medical fees, a lack of access to affordable medical services, poor physician-patient relationships and low medical insurance coverage.<sup>4</sup>

The potential of ICTs to contribute to health system transformation in China is recognised but there is as yet little progress<sup>5</sup> or inclusion in the national strategy. The purpose of this article is to illustrate key factors that could facilitate or hinder the use of ICTs to promote optimal human health (known as human-centred eHealth or HeH), through strengthened relationships between healthcare professionals and patients; continuous and sustainable joint efforts between healthcare teams and families; and alignment of hospitals and communities to improve health equitably throughout the population.

According to Wang and Gu,<sup>6</sup> although China now has three major eHealth networks, most Chinese people cannot afford the cost of telemedicine services, especially in rural areas, where they are most needed. Mobile phones are easier to obtain and less prone to corrupt public sector practices than fixed land-line telephones. As a result, the migration of the internet and

internet applications into mobile phone systems will have tremendous technological implications for eHealth in China.<sup>7</sup>

The evidence presented here underlines the remarkable potential that exists for technologies that do not require traditional telecommunications infrastructure, such as mobile phones, enabling China to leapfrog a stage and to join other countries at the leading edge of the use of ICTs to accelerate the transformation of the health system.

In this article, the first of a series that will appear in multiple publications, we present the results of an initial high-level exploratory analysis of secondary data on the levels of penetration of telephones (both land line and mobile), personal computers (PCs) and internet access in different provinces of China. The data were obtained from the Ministries of Health (MOH),<sup>8</sup> Science and Technology (MOST),<sup>9</sup> Education (MOE)<sup>10</sup> Human Resources and Social Security (MHRSS),<sup>11</sup> Industry and Information Technology (MIIT)<sup>12</sup> and Finance (MOF).<sup>13</sup> The formulae that support the analyses are available upon request.

## The challenges

Realising the promise of HeH in China is hindered by a combination of low levels of school enrolment, high illiteracy rates, low per capita incomes, high service fees and weak ICT connectivity.

On average, provinces in China have 16 fixed telephone lines, 14 mobile phone subscribers, 17 internet users and 18 PCs per 100 inhabitants. This is compounded by disparity in the levels of ICT connectivity and use across provinces, with sharp drops between those with high- and low-income levels. For example, while there are 61 fixed telephones per 100 people among upper-middle income provinces, the number drops to 11 among people in low-income provinces. The number of PCs per 100 people, on the other hand, drops from 32 among upper-middle income provinces to two PCs in their low-income counterparts. The figures for mobile phone subscribers and internet users drop from 73 and 58 to 11 and 6, respectively.

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Another challenge is implementing comprehensive information quality and data governance standards at all touch points in the system.<sup>14</sup> These include the creation and continual review of data quality and data governance policies, external audits to verify compliance and extensive education and training in information quality management best practices.

## The way forward

Internationally, a number of policies and strategies are available to support China's development towards realising sustainable eHealth usage. We have already alluded to the recent resolution of the Spanish Healthcare System<sup>15</sup> and Canadian Association for People-Centered Health's Academic Research Collaborative<sup>5</sup> that underscore the potential role of ICT in health. The National Population and Health Sciences Data Sharing Platform, and the National Population and Family Planning Commission all advocate massive investment in ICT and internet connectivity. There is a growing realisation among bilateral and multilateral donor agencies of the need to support investments in ICT infrastructure and internet connectivity in China.

The advent of mobile phones, particularly 'smart' phones, presents an important opportunity for the practice of HeH in China. In addition, we view the integration of satellite-enabled communication with WiMAX technology as complementing the building blocks to provide equitable eHealth in Chinese rural areas.<sup>16</sup> This coupled with applications that promote the continuity of services between the community and healthcare organisations, and new open innovation programmes to train a new workforce, will prove invaluable to those committed to providing services that meet the needs and expectations of people who use them.

Providing an environment for equitable growth of eHealth services as part of its stewardship role will require that each provincial government in China implements carefully crafted action plans, which may benefit from:

1. Support from key leaders at MOH, MOST, MOE, MHRSS and MIIT to develop priority areas, and a comprehensive policy and a legal and strategic framework to guide and nurture the growth of ICT, while at the same time ensuring that HeH principles are deeply embedded within that framework.
2. Making information quality and data governance best practices a priority in system design, development and operation to assure quality and effectiveness of all eHealth information, including special emphasis on information quality education and training, health data standard and regulations for all stakeholders.
3. Investing in rural information technology in order to attract external investment in ICT in those areas, and ensure competitive prices of eHealth services.

4. Making strategic investments in ICT infrastructure, including mobile phone installation, equipment (eg, computers, servers, networks) and internet connectivity in the entire health system with special attention to rural areas.
5. Strengthening human capacity for judicious use of ICT at all levels of the health system in pursuit of public health goals and objectives.
6. Embarking on information technology (IT) training and eHealth demonstrations, with emphasis on initiatives targeting people living in rural areas.
7. Tapping into the eHealth-related initiatives/projects that are at various stages of development in other countries and international organisations.
8. Holding global eHealth conferences and forums regularly to bring together world-class leaders, researchers and practitioners who are willing to promote collaborative efforts to make eHealth innovation meaningful and relevant to the public.

## Conclusion

HeH offers opportunities for improving equity in access to health interventions. However, its role in efforts to transform China's health system faces a number of challenges: high illiteracy rates, low education enrolment rates, dearth of qualified IT professionals, low per capita incomes, lack of ICT infrastructure and limited internet connectivity.

In order to improve access to healthcare, especially for the 0.75 billion people who live in rural areas and 0.15 billion who live in urban areas as migrant workers, there is an urgent need to boost the availability and use of eHealth services. Thus, universal access to eHealth ought to be a core component of the strategic plans in all provinces in China. Each province ought to develop a clear road map that will, over time, enable its citizens to realise that vision 'our health in our own hands'.

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