



HIGH-LEVEL WORKSHOP ON INNOVATION IN HEALTHCARE

Wednesday, November 16, 2011
Brussels, Belgium

REPORT & RECOMMENDATIONS

The German Marshall Fund of the United States (GMF) would like to acknowledge the generous support of the U.S. Mission to the EU (USEU) for this project, as well as the contribution of Accenture in facilitating the workshop.

The views contained in this report do not necessarily reflect those of GMF, the USEU, or the workshop participants and contributors.

A year after the European Commission and the United States Department of Health and Human Services signed a memorandum of understanding on cooperation surrounding health related information and communication technologies, it is time to build on these accomplishments to “promote individual and community health while fostering innovation and economic growth.”

Evolutions in the healthcare industry and in information and communication technologies (ICTs) present opportunities for increased collaboration between the United States and the EU in promoting regulatory cooperation, sharing best practices, and maximizing resources, as encouraged within the Transatlantic Economic Council (TEC).

In this context, the German Marshall Fund of the United States (GMF) and the U.S. Mission to the EU gathered in Brussels a small high-level group of experts from both sides of the Atlantic, policy makers, academics, and private sector representatives, to produce a set of concrete policy recommendations on innovation and healthcare. These recommendations, which the following report outlines, will be shared with relevant transatlantic policy-makers and stakeholders.

Executive Summary

This report summarizes the challenges, solutions and key recommendations identified at a high-level transatlantic workshop held on 16th November 2011 to consider how best to accelerate the adoption of innovative technologies as a 21st century solution for global healthcare.

Due to our ageing society, a key challenge will be the reducing proportion of the population who are of working age and financially underpinning national health systems. A second key challenge is the rising incidence of chronic diseases amongst young and middle aged populations, particularly those relating to new lifestyles and obesity. To cope with these shifts in resource and demand, it is now vital to involve patients and healthy individuals in self-care and health maintenance.

Most individuals wish to play a more active role in their own health management, but need to be valued and to be given appropriate tools through which to participate. This participation may cover a spectrum from clinician directed monitoring (self-testing), through patient tailoring of treatment (self-management) to fully autonomous prevention and care (co-production of health).

Next-generation eHealth investments therefore need to target systems that support person-centric information capture, meaningful information sharing, point-of-decision harnessing of patient-tailored knowledge, virtual team workflows and an emphasis towards empowering individuals, families and social networks. The increasing availability and capability of personal health record systems, smartphones, near-patient measurement devices, intelligent and friendly ICT applications and computable medical knowledge make this a tangible and near term possibility.

However, challenges such as market fragmentation, paternalistic models of professional accountability, lack of legal clarity about self-care, and inflexible reimbursement models all discourage efforts to promote self-care. Further work is also needed to improve interoperability standards and on the governance of distributed information sources including clouds. These are critical barriers to scaling up and widely deploying person-centered eHealth services.

The Memorandum of Understanding on cooperation surrounding health related information and communication technologies, signed in 2010 by the European Commission and the United States Department of Health and Human Services, provides a vital underpinning to transatlantic cooperation on these barriers. There is now a need to build on this Memorandum through policy and complementary measures that remove barriers and promote the development, deployment and use of innovative ICT solutions to improve individual and community health and to deliver economic growth.

Key strategic recommendations

1. Business models for healthcare services must be adapted to better encourage efforts towards having healthy citizens and good clinical outcomes that are aligned between payers/insurers and providers.
2. New reimbursement models must be designed and effected to give preferential return for investments in sharing care with patients and for richer empowerment services (focusing on long term conditions).
3. Codes of professional practice need to be developed for high quality patient education and support of self-care and health promotion, which must be endorsed by professional bodies and professional insurers to give confidence across all stakeholder groups.
4. Codes of practice and legal clarification of accountability are needed for care organizations and individual practitioners receiving and using patient provided health information.
5. Procurement guidance is required for regional level organizations to encourage more interoperable and standards based eHealth solutions.

6. Investments are needed in education of the clinical workforce and of society in the use of health IT, in supporting self-care, and how the public can critically assess Internet resources.
7. Investment is needed into evaluations (including standardized metrics) to better demonstrate evidence of clinical and economic outcomes, and containment of risk, from self-management and patient empowerment eHealth solutions.
8. Strong leadership is needed to actively champion relevant initiatives that accelerate the adoption of eHealth innovations.

Conclusion

Action is needed by governments, by health system payers and providers, and by industry to take forward these recommendations and thereby accelerate the adoption of innovative eHealth solutions. There are opportunities here for increased collaboration between the United States and the EU in developing joint strategy, promoting regulatory cooperation, sharing best practices, and maximizing resources, as encouraged within the Transatlantic Economic Council (TEC). This cooperation should focus on interpretability standards, regulatory inhibitors such as privacy standards and liability issues, and on novel reimbursement models.

Background: Engaging patients in healthcare - opportunities and challenges

Patients and healthy individuals can, and increasingly wish to, play an active role in their own health management. Indeed there are growing societal pressures to recognize the central role of the public as informed and autonomous partners in decisions about their personal health care, the safety, efficacy and acceptability of treatment choices, and in service priority setting. We have known for years that individuals can acquire considerable expertise in managing illness and preventive health if they are valued and are given appropriate resources through which to participate. This participation covers a spectrum from clinician directed monitoring (self-testing), through patient tailoring of treatment (self-management) to fully autonomous prevention and care (co-production of health).

Personal health record systems, the proliferation of smartphones, the capability of near-patient measurement devices, intelligent and friendly applications, connectivity, and computable medical knowledge make this a tangible and near term possibility. However, progress towards the realization of this opportunity needs acceleration: facilitation and incentivization. This concept paper outlines some of these opportunities and the present barriers that inhibit wide scale adoption. It suggests some areas in which innovation is needed in order to achieve this acceleration.

Opportunities

Due to our ageing society, a key challenge for health systems will be the changing balance between persons at working age and those in retirement: a decreasing number of working people will be financially underpinning health care for an increasing number of people no longer in the labor force. To cope with this resource change, it will be mandatory to involve patients, their families and friends to a larger extent in the management of those who become frail, sick or dependent on long-term care. In other words, we can no longer afford not to involve patients and families as part of the health care system: this is an opportunity!

A second key challenge is the rising incidence of chronic diseases amongst young and middle aged populations, particularly those relating to new lifestyles and obesity. There is increasing sophistication in disease treatments, and more illnesses are becoming long-term conditions (such as HIV). This requires greater co-operation between professionals of different disciplines working in different locations, knowing each other's care goals, progress made and any difficulties encountered. The need goes beyond the basic sharing of records of what has been done (the traditional EHR), to sharing each other's clinical care strategy, options and logistic constraints, to determine optimal ways of aligning efforts (the smart EHR). Sharing information, knowledge, objectives and choices with patients is a minimum level of engagement we should be aiming for: many healthcare providers are already starting to do this. Investing in richer co-production models of prevention and treatment offers real opportunities to improve healthcare affordably and with greater patient satisfaction. In co-production, patients and healthy individuals make personal choices about attention to risk factors, disease management and the levels of functional capability and longevity they wish to aim for; information/knowledge resources are co-owned between professionals and individuals equally, and mutually shared.

The promise of the semantic web is of information objects that are richly indexed by knowledge models and bound to collaborating components within a distributed computing ecosystem, bundled as smart services that interact with each other to deliver personalized (tailored, relevant and prioritized) information that supports the decisions and actions of individuals and communities. Future services will be able to collaborate to deliver an integrated and holistic solution to its users. Smart services are needed to facilitate virtual team collaboration, to optimize care and protect against omissions and errors. Co-production needs to be delivered through such smart services that both empower individuals to self-care and connect them to relevant actors and services when needed. Next generation health care needs to harness such a capability!

Barriers to success

Existing national eHealth investments have so far focused on basic infrastructures to establish national information networks, organization centric systems such as enhanced hospital information systems, workflow support such as appointment booking and ePrescriptions, but have made limited impact on the actual delivery of care and no real impact on citizens and their engagement. Most importantly, there remains a critical gap in the design and delivery of health care services that fails to harness the contributions of patients and healthy citizens.

Innovative engineering is steadily increasing the monitoring and even treating capability of smaller, more portable and more wearable devices. Intelligent and more attractive software makes these progressively not just easier but more appealing to use, and usable by many. Information standards have been published by Standards Development Organizations such as ISO and HL7, and cross-vendor integration interfaces developed by IHE, Continua and others. However the meaningful interpretation of device-generated data, including vital metadata and patient level context, is not yet interoperable at scale. Communications tend still to be point to point: each device communicating patient information to dedicated applications which know how to interpret it. To scale up we need a diversity of devices for a patient - their virtual connected environment - to interoperate smoothly via the EHR with the other systems, services and applications used by the treating clinicians. This requires a richer level of semantic interoperability than we have today, more robust multi-system patient identification, and harmonized access policies and services. These critical dependencies need strategic investment.

Much of personalized medicine has so far paid attention to the differences in genetic make-up between individuals, but this view is too limited because it is focused on the application of molecular medicine or predictive modeling as isolated characteristics rather than addressing the biological and sociological complexity of each individual. A significant translational challenge exists: not just to align the semantics across these areas of bio-science but to recalibrate the largely theoretical models of a phenotypic subject with the heterogeneity of real people, and to better leverage this new knowledge in individualized care pathways.

Challenges such as: market fragmentation; historic and paternalistic models of professional accountability; lack of legal clarity about self-care; and inflexible service, insurance and reimbursement models that discourage efforts to promote self-care are all key barriers to scaling up and widely deploying person-centered eHealth services.

Areas for innovation

Next-generation eHealth investments need to target systems that support person-centric information capture, meaningful information sharing, point-of-decision harnessing of patient-tailored knowledge, virtual team workflows and an emphasis towards empowering families. This includes developing friendly and convenient devices and portable applications that are adaptable to diverse kinds of user (expert, non-expert, healthy, very ill, computer literate or not, of different cultures etc.), and investing in patient/citizen education. Health professional acceptance is vital, as is their education in mentoring self-management and providing incentives for change. The safety and governance of shared models of care needs re-thinking, as does their risk management. Models of accountability and liability will also need to change.

These changes are, in part, needed because patient centered services will include actors whose contributions conventional health services today largely ignore: social care, domiciliary care, health charities, complementary therapists, families, physical and on-line social networks etc. In our design of future systems we also need to recognize that people are part of families and communities, and do sometimes share and collaborate with others (for example, Patients Like Me). Healthcare and eHealth services probably have a lot to learn from the social computing paradigm about ways in which people will in future interact, share information and collaborate, and their attitudes to privacy in these contexts.

Many innovations of this kind already exist, largely as pilots. We need to extract the innovation success factors from these and learn how to scale them up in size, sophistication and across countries.

This high-level transatlantic workshop was convened and attended by the U.S. Ambassador to the EU, the German Marshall Fund of the United States and the European Commission, in order to consider how best to accelerate the adoption of innovative technologies as a 21st century solution for global healthcare. The meeting, which had strong cross-sectoral representation, considered the drivers and opportunities, examples of success, and the key enablers that are now needed in order to remove barriers and to achieve a widespread scaling up of eHealth innovations.

The key issues identified in the workshop, and recommendations arising from it, are summarized in the next section of this report.

Workshop key points summary

Main drivers and opportunities

1. Epidemic of chronic diseases
 - 1.1. ageing populations
 - 1.2. changing lifestyles
2. Reduced healthcare budget
 - 2.1. reduced taxation income
 - 2.2. rising costs of hospital based care
3. Growing societal interest and levels of education/awareness about health
4. Maturity of the technologies to support self-care
5. Healthcare is increasingly data intensive, and time critical in its information needs
6. Potential to create growth, new markets, new jobs

Example eHealth innovations already in progress (but needing acceleration)

- ePrescriptions
- electronic health records (EHRs)
- Multi-channel service centers: health centers promoting healthy lifestyles, self-care, tele-monitoring as well as conventional multi-professional primary care
- Smart wearable devices, smart homes

Example resources on eHealth innovations (need strengthening)

- epSOS project is exploring barriers and developing solutions for cross-border care across Europe
- Renewing Health project is exploring better forms of health technology assessment
- The new European Innovation Partnership (EIP) will publish best practices and an exchange platform for health and active ageing innovations
- WHO runs a knowledge gateway, allows a variety of stakeholders to share best practices

Most significant barriers

- Reimbursement models: inhibit new models of care
- Technical barriers: interoperability needs to be prioritized
- Regulatory inhibitors: privacy standards, licensing issues, liability
- Skills gap amongst professions, and patients

Key success factors (enablers)

1. New business models

- 1.1. Healthcare service models
 - 1.1.1. reimbursements for providers supporting self-care services
 - 1.1.2. incentives for successful self-care: to individuals and to care providers
 - 1.1.3. care centered on the citizen
 - 1.1.4. improved care co-ordination
 - 1.1.5. care focused more on prevention: emphasize the preventive measures we know to be effective
 - 1.1.6. recognize that some populations are quite migratory (business, students, some elderly) - support and reimburse care delivered across geographical boundaries
 - 1.1.7. leverage crowd sourcing and social networks
 - 1.1.8. integrated payer-provider models may find innovations easier to finance
- 1.2. Health IT marketplace
 - 1.2.1. new ways to cost/license eHealth applications (e.g. like an App Store?)
 - 1.2.2. engage industry partnerships in developing relevant end-to-end (holistic) eHealth services
 - 1.2.3. different model for the reimbursement of large scale investments in new technology solutions e.g. PPP

2. Technology

- 2.1. interoperability standards need to be prioritized, and then enforced
- 2.2. open standards are the key
- 2.3. bridging the standards gap is needed (also review standards overlaps)
- 2.4. better privacy management
- 2.5. ICT infrastructure needed to support distributed care e.g. in homes, workplaces
- 2.6. scalable systems to integrate data from multiple sources
- 2.7. better use of clouds
- 2.8. SME engagement is vital
- 2.9. support industry alliances e.g. Continua, COCIR, IHE
- 2.10. develop common guidelines for sensors
- 2.11. provide certification for proven eHealth/self-care solutions

3. Workforce skills

- 3.1. technology skills
- 3.2. build on industry led "academies"
- 3.3. clinical knowledge management skills: how to be better information users and knowledge creators
- 3.4. build on academic health informatics education programs
- 3.5. need to define new career structures that value health informatics expertise
- 3.6. virtual team collaboration: skills and motivations: *co-operability*

4. Societal engagement

- 4.1. encourage individuals to be more active in their health maintenance and care
- 4.2. promote models of shared responsibility for healthcare
- 4.3. educate populations about health, prevention and chronic disease management
- 4.4. educate populations on how to critically assess Internet resources
- 4.5. educate populations about health IT and eHealth services
- 4.6. develop educational resources on self-care for specific conditions
- 4.7. enlist expert patients to help others: social networking
- 4.8. accept that not everybody feels ready for self-care

5. Governance

- 5.1. governance of citizen-contributed health information
- 5.2. governance of health clouds
- 5.3. promote the value of data “not collected here”
- 5.4. codes of professional practice in supporting self-caring patients
- 5.5. professional risk management of shared clinical decision making
- 5.6. healthcare organizational risk and accountability for shared-care services
- 5.7. success of patient empowerment will need backing from professional bodies
- 5.8. recognize that eHealth is no longer an R&D topic: it is a deployment and change management issue
- 5.9. foster a culture that every niche healthcare specialty is NOT different: all need to co-operate and share information
- 5.10. collaboration of all stakeholders is needed for the necessary holistic changes to occur
- 5.11. make better use of information & analytics: knowledge driven healthcare
- 5.12. take advantage of upcoming EU legal framework on telemedicine
- 5.13. strong national and EU leadership is essential

6. Procurement support

- 6.1. guidance on which standards to include in procurements, and which must be mandated
- 6.2. promote key eHealth success factors that should be taken into account
- 6.3. balance local needs with global interoperability standards
- 6.4. need a structured way to describe solutions and their assessments, to allow them to be compared
- 6.5. examples of portfolios of products that can work together to deliver a holistic eHealth solutions
- 6.6. examples of successful business models
- 6.7. need better training for procurers

7. Evaluations

- 7.1. better defined outcome measures for eHealth innovations
- 7.2. standardized measures to permit comparability
- 7.3. recognize that better care may mean longer life and more downstream illnesses: focus on quality of life outcomes
- 7.4. more investment in formal evaluations of eHealth deployments
- 7.5. more research into the real risks, and successful mitigations
- 7.6. more economic evaluations
- 7.7. recognize the long time lag to show results: find better proxy outcomes
- 7.8. recognize that eHealth adoption is usually part of a wider set of health service changes: harder to isolate the direct impact on outcomes
- 7.9. collate and disseminate the emerging evidence of benefits

8. Political/Strategic

- 8.1. foster transatlantic solutions: build on the MOU and a joint population of 800 million
- 8.2. but, recognize the MOU brings no new sources of funding to put it into effect
- 8.3. significant financial incentives are needed for eHealth innovations and for technology (meaningful) adoption
- 8.4. need structural funds
- 8.5. governmental level intervention is needed to change the accountability of healthcare systems to allow for shared responsibility with patients/citizens
- 8.6. Data Protection Directives need to be fit for purpose: balancing the societal value of shared information with the privacy of individuals
- 8.7. regulatory environment needs to facilitate cross-border care and cross-border information flows
- 8.8. governments should demand the use of open standards

Priority strategic measures needed to achieve “better for less” from eHealth solutions

1. Adapt business models for healthcare services to better encourage efforts towards having healthy citizens and good clinical outcomes that are aligned between payers/insurers and providers.
2. Design and adopt new reimbursement models to give preferential return for investments in sharing care with patients and for richer empowerment services (focusing on long term conditions).
3. Develop codes of professional practice for high quality patient education and support of self-care and health promotion, which must be endorsed by professional bodies and professional insurers to give confidence across all stakeholder groups.
4. Define codes of practice and legal clarification of accountability for care organizations and individual practitioners receiving and using patient provided health information, including use of clouds & crowd sources.
5. Develop and propagate procurement guidance for regional level organizations to encourage more interoperable and standards based solutions, explore the role of Pre-Commercial Procurement.
6. Health systems must be seen to strongly endorse patient-empowering services: reward senior managers and health professionals for successes in this.
7. Invest in patient education on the value and acceptability of their greater role in care, on how to understand and use EHRs and PHRs, and how to critically assess Internet resources.
8. Promote professional education in mentoring patients, supporting self-care and in trusting and using patient provided information.
9. Develop clear career structures for eHealth innovators, support new job creation.
10. Invest in research on the risks and mitigations from the wider adoption of self-care.
11. Invest in evaluations (including standardized concepts and metrics) to better demonstrate evidence of clinical and economic outcomes from eHealth solutions, especially from empowerment scenarios.
12. Promote and disseminate good practice in scaling up eHealth solutions: success case studies, success factors and lessons learned.
13. Use PPP funded initiatives to overcome specific barriers: semantic interoperability, data usage and sharing, patient identification.
14. Provide specific support for industry backed collaborations to tackle barriers, and to adopt and promote standards.
15. Consider certification for patient empowering eHealth solutions, and an equivalent to meaningful use.
16. Appoint strong leaders to actively champion relevant initiatives that accelerate the above changes.

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