Telemedicine Alliance Recommendations for Interoperable eHealth for the Citizens of the EU: Needed Actions if we want it

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Towards a European Perspective of eHealth

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- Why shared eHealth services in Europe?
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Telemedicine Alliance

The Telemedicine Alliance

European Space Agency, European Space Research & Technology Centre (ESTEC), Noordwijk, The Netherlands

World Health Organization - WHO Regional Office for Europe, Office for Integrated Health Care Services, Barcelona, Spain

International Telecommunication Union: Telecommunication Development Bureau (ITU-D), Geneva, Switzerland

European Commission – INFSO DG
Why shared eHealth services in Europe?

• The free movement of persons is one of the four fundamental rights for citizens of the EU, and gives them the opportunity to live, work, establish a business, and study in all EU Member States.

• Health policy makers must ensure that:
  – Healthcare is available for EU citizens who move and are on the move.
  – Is of at least equal access, quality and economy as that of the Member State in which they are receiving care.
  – They must provide emergency services for people travelling on short-term stays for tourism non-emergency services for those residing mid-term or long-term,
  – And monitor and evaluate the relevant data to better plan health system resources.
TMA’s Vision of Citizen-Centred Healthcare
Long-term objectives

• Empower citizens and patients
• Improve and support equal access to care
• Build capacity of the health professionals
• Increase quality and cost/efficiency
• Reduce burden of travel for patients
• Support decision-making by improving information systems and surveillance
• Keep pace with and make use of the same infrastructures as will be provided by the other sectors of eEurope
• Overcome dominating barriers of political, professional and economic nature.
• Coordinate legislation on the use of electronic media now, as well as define financing and reimbursement systems.
• Promote and foster worldwide standardization and interoperability.
Key conditions for success

Expert Interviews

Impediments

The three most important showstoppers to eHealth implementation

Interoperability
Acceptance of eHealth
Legal aspects
Pillars & frameworks of an holistic approach

Policy Framework

Organizational & Social Framework

Care  Education  Administration  Surveillance

Technical Framework
An alternative view – the ‘Egg’

Implementation of eHealth in Europe

Policy Framework

Organizational & Social Framework

Technical interoperability

Security, privacy

Mobile citizen

Transnational services
An alternative view – the ‘Egg’

All eggs need not be identical . . .
An alternative view – the ‘Egg’
But they must be able to communicate with each other . . .
A Strategic Plan in Perspective for the European Commission

- Political
- Organisational & Social
- Technical
Review of the Experts

• The TMA held two workshops to which experts from many fields and countries were invited
  – To give their inputs
  – To review the outputs

• Workshop-I:
  – eHealth Interoperability in Europe

• Workshop-II:
  – Strategy for Implementation
I. I  Develop a legal framework (common guidelines) for health data transfer. This will enable the bi-directional transfer of data between electronic healthcare systems in different Member States.

I. II Bring Member State’s confidentiality and privacy laws into harmony to ensure health data is protected and access is authorised according to European Data Privacy Legislation.

I. III Develop a clear statement on the legal liability for treatment both to cover bilateral and European wide agreements. These must specify which country’s liability laws are applicable in each health service scenario.

Action I: Produce guidelines for cross-border data transfer.
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Strategy II: Create and implement a framework for monitoring and evaluation

Goal: Measure progress towards meeting trans-national citizen’s needs including basic statistics for the number of mobile patients, the quality of care provided, the cost of care provided…etc.

Action II:

Establish comparative indicators for the quality of care

• Web-based, trans-national comparative information on the quality of care by healthcare stakeholders should be made available to citizens to enable them to make more informed and empowered decisions about their own health care.

• A template for patient-driven comparative indicators should be established in order to collect data and compare them in a meaningful manner.
Strategy III: Develop a workflow model to incorporate organisational and social models

Goal: Clear and unambiguous guidelines for all aspects of trans-national eHealth, communicated to those involved, including, administrators, providers of healthcare, citizens, insurers, . . .

Action III: Perform a workflow analysis

• The EC should perform a practical workflow analysis applied to trans-national health services as a prerequisite to designing and implementing interoperable eHealth systems to support mobile citizens.

• Benefits of using an industry standard workflow method include the provision of a well-defined separation of activities, responsibilities, sequences of activities, transitions between activities and data sets required for the transitions.
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**Strategy IV: Create an environment for sharing knowledge of proven (good) practice**

**Action IV:**

Create a repository of existing proven practices

Including:

- Lessons learned
- Examples of successfully implemented applications,
- as well as suitable projects involving trans-national interoperability.

This should be maintained as an accessible reference source.

2006.04.-5 — Medetel
**Strategy V:** Ensure that eligibility to receive treatment can be known at the point and time of care.

This should also include knowledge of reimbursement regulations for both patient and provider and a mutual recognition of availability of health services provided by both Member States and those to which the patient is eligible.

**Action V:**

*Issue national entitlement and reimbursement statements for trans-national health services from each EU Member State.*

- The EC should encourage EU Member States to state – via an appropriate mechanism - their expectations and the actual situation of entitlement and reimbursement of trans-national health services for their citizens in other Member States.
- These statements should be disseminated to the public to increase citizen awareness of their entitlements, and should follow a common template.
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Strategy VI: Ensure that relevant data in electronic form is available

This means that transfer between electronic health information systems or allowed access from one system to another must be implemented for the treating healthcare professional and citizen.

Action VI:
Provide a citizen driven trans-national web space for health

• The EC should support the creation of a personal health web-space for mobile citizens to empower the citizens/patients to have access to their health data wherever they are and whenever they need it.

• In this web space, the citizen will decide what data is included and what is not, what data can be made accessible and to whom.

• The information and data can be added to the web space by the citizen and may also be fed from other systems with the citizen’s permission.
Strategy VII: Ensure that language and cultural aspects are incorporated

This should include a European Union wide language and terminology translation and recognition of cultural sensitivities incorporated into the system and available at the point and time of care.

Action VII: Create a repository of national health-system procedures and customs for mobile citizens

• In order to help citizens navigating health services while being abroad, the EC should create a repository of national health system procedures and customs for mobile citizens.

• This should include an EU wide minimum basic data sets (including but not limited to an emergency data set), language and terminology translation and recognition of cultural sensitivities.
Strategy VIII: Create a European telecomm’s infrastructure as part of eEurope

Action VIII: Use existing infrastructures for eHealth

• Create a European telecommunications infrastructure as part of eEurope and thus utilise such existing infrastructures for eHealth, which will provide the technical support for the transmission of data in a manner conforming to the data protection legislation in place and which meets the needs of eHealth.

• Although eHealth encapsulates all the main themes of eEurope with its dependence on bandwidth, security, privacy, and user-centred service provision, healthcare standards are usually not incorporated in current telecommunication infrastructures and basic services.

• In order to facilitate an early adoption by Governments, the special needs of the health sector should be taken into account and should benefit from the trans-national experiences of other sectors.
Strategy IX: **Incorporate a set of value added applications into the infrastructure**

Action IX: **Identify and implement a set of achievable key applications**

- In order to increase citizens’ comfort in the reliability and safety of trans-national eHealth systems, a selection of key achievable trans-national applications with appropriate security infrastructures should be identified and implemented.

- Relevant stakeholders (political, technical and end users) should be involved in the process of application selection and implementation, where selected applications are those with a visible impact for citizens related to trans-national health services.

- The necessary standards and profile developments should be provided by a technical / industrial subgroup as well as a reference implementation and specification guidelines for the Member States.
Strategy X: **Develop a central access point for health information standards**

Action X: *Establish one access-point for health information standards for the semantic content, coding classification and ontologies*

- **Goal:**
  - To simplify the search of relevant standards and foster the coordination of eHealth implementation.
  - Provide a unique focal point for the implementation and maintenance of international health information standards.

- **Tasks:**
  - Development and publication of the most needed new-generation concept and terminology systems for clinical use based on ontological research, integrating the legacy terminology initiatives (GALEN, SNOMED, ICD, DRG, etc.)
  - Annual publication of the rate of uptake of these standards
  - Maintenance of a list of development and updating of standards with the latest versions released to facilitate the choice of coding, integrating a transparent process of drafting new standards
**Strategy XI:** **Increase awareness of the importance of existing interoperability-related standards for eHealth**

**Action XI:** Ensure that data-interchange standards are known, understood and implemented by both suppliers and procurers.

- The EC should support activities for increasing the awareness of the importance of existing interoperability-related standards for eHealth.
- Targeted communities should include: Political decision makers, Users, and users-to-be.
- Tasks:
  - Demonstrate that cross-border interoperability is possible and useful with existing technologies and standards;
  - Undertake broad information dissemination activities to ensure that useful interoperability standards are known, understood, and used from governmental to local decision level;
  - Support the development of eHealth standardisation activities within a coordinated interoperability framework as well as test the functionality and practicability of existing standards with simulations on real cases (such as Integrated Healthcare Enterprise ‘connectathons’).
An urgent eHealth application: eSurveillance

• Early Warning System for health risks
  – Are we at risk?
  – do we need an EWS?
  – Is Europe prepared?

• Preparing a European Response to Health Risks
Elements of Surveillance

• Health reporting of infectious or other diseases
• Epidemiological analysis: including data on environment, socio-economic...
• Collection & collation of data, using common methodologies
• Near-real time analysis, profiling
• Statistics and modelling of impacts
• Management of natural and man-made disasters
• Reliability of data, and speed
Don’t compromise principles of data privacy

• Give the citizen power over own data
• Ensure that the citizen preserves the right to grant access to own data
• Remember that:
  – A system is only as secure as its weakest link
  – Most breaches result from internal, rather than external causes
• Where practical, keep data at point of collection, rather than centrally
• Avoid dependence on human administrators
• Utilise anonymisation and pseudonymisation elegantly to maximise return of scientific analyses, while preventing compromising privacy.
ESA Health Care Network (HCN)
(http://www.esa.int/SPECIALS/EHCN/index.html)

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Thank you for listening!

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