

*e*Health

Challenges for standardization

1 Information and Communications Technology can make the world healthier

1.1 Some major problems of global healthcare

There are enormous challenges and global differences with regard to the distribution of modern scientifically based medicine and care services. Lack of reasonable basic means for a healthy life such as housing, clean water, enough food and basic education are major problems, which eHealth services cannot solve. War and other social instabilities are other major societal health threats. However, in a large number of also lesser-resourced countries there are possibilities for ICT solutions that can assist the health of people. Some characteristics of the healthcare systems in developing countries are:

- Too few well educated health professionals, many narrow specialties totally absent
- Basic primary health services are performed by persons with little or sometimes no education in scientific medicine
- Unequal distribution of health professionals and services in the country
- Bad infrastructure and low resources makes transportation of patients less of an option
- Many citizens/patients have to handle their health problems without professional help
- The developing countries have all the health problems of the rich (even if frequencies vary) plus a number of specific problems such as infections like malaria, bilharzia etc that are no issue in the rich countries.

In the rich developed countries there are also challenges for the health systems because of a population with increasingly more and more elderly and few to take care of them while new inventions of costly methods makes it necessary also for the richest countries to prioritize what should be done and try to make healthcare more cost-effective. Increased home care and self care is very much on the agenda also in the developed countries. A high level of general education and availability of networks and even home computers (in some countries 50-80 % of the households) creates interesting opportunities for new types of electronic services.

Because of the very large numbers of patients in the developing countries and lack of skilled manpower in the developed world it is not realistic that a major part of the professional health services for the developing countries are done over the network from the rich countries. The major contribution must be in knowledge transfer.

1.2 A vision of the Communicating Health System

ICT solutions for health and eHealth services have been developed a lot, particularly in the last decade. However, the solutions are still much too often isolated islands in a big ocean of emptiness. The goal should be a **Communicating Health System** with the patient/citizens in the center where:

- **All health information** related to a person is made **available for continuous care** over a life time and by different healthcare organizations, in different places (even countries) and representing different professional skills
- **Knowledge based systems are interacting with patient data.** In addition to the scientific evidence for medicine that is already available to a large extent free on the net, the world's leading experts should co-operate to produce easy to use clinical guidelines in electronic form where the individual patient data can directly be taken as input to the decision support and a generated care plan can be managed in the local information system of the provider. The knowledge resources should be adapted to different languages and cultural contexts, different educational skills from patients that are almost illiterate to specialist physicians.
- **Effective co-operation between professionals.** eHealth solutions enable health professionals to work together as a team irrespective of physical distance. Communication of structured information in health records with defined terminologies and some laboratory results and images and process related information is the most important type of information but videoconferencing or virtual reality operation of remote equipment may in a few cases give additional value but high costs makes such solutions exceptional for many years.
- **Active patients are a part.** Patients/citizens are already in a large part of the world using the knowledge resources on the web for health problems, for self care, to find the right healthcare organization or to advise their health professional or for interaction with others in the same situation. Such systems can be expanded and adopted to be used also in less resourced countries where many persons share an available public web terminal. Direct interactions with two-way communication between patients and healthcare organizations/professionals is increasing and will increase a lot once basic security infrastructures are in place allowing safe communication of confidential information. This will lower costs and improve quality of care.
- **All patient cases can be used to generate new knowledge.** Although medical science, which is truly international, is exploding, and the development of molecular genetics has put a new dimension to that our present knowledge is very weak in many areas. Healthcare services for many problems are not very efficient and new medicines create new risks for side effects. ICT can mean enormously improved efficiency in finding new knowledge from all the clinical experiences of natural courses, with observations and diagnostic examinations to treatment results. In addition to improving scientific knowledge, such follow up is part of modern quality management improving the healthcare organizations themselves. ICT and standards for information structuring and representation are essential for this aspect of eHealth to work.

1.3 eHealth services required

The following are examples of services where ICT have been used/can be used to improve health systems efficiency and quality. There are surely many others some of which will be invented over the coming years if basic tools become available from standards and infrastructure.

1.3.1 Education for health professionals at different levels

This could be a new important priority for international action. The requirements are enormous and large-scale education of health professionals in developing countries is the only realistic solution to reducing the gaps in health service provision.

Distance learning can take many forms from making teaching material available on the web to

interactive programs, broadcasted lectures with streaming video/audio, individual and group discussions using tools from high quality VCT to simple netmeetings with real time audio and a common still image/texts. Even advanced haptic user interfaces can be used for training of advanced operating techniques e.g. for endoscopic surgery.

The challenges are less technical. Standards exist and technology that is decreasing in cost. However, the generation of the educational knowledge and training resources requires a lot of work and international co-operation. Adaptation to basic state of the art to different presentations formats and languages and a possibility to distribute free of charge to the users in developing countries requires new type of financing and co-operation between academic centers and other types of educational ICT tools and international organizations.

1.3.2 Knowledge bases as encyclopedias and interacting with individual data

Scientifically based knowledge on diagnostic procedures and interpretations as well as recommended treatment protocols should be made globally available through the networks. The users are both health professionals at different skills and the citizens/patients. International organizations should ensure that such knowledge resources of high quality could be made available to all countries appropriately adapted to local languages etc where necessary.

If individual patient data from a local electronic health record should be able to interact with such knowledge systems, standards for information representation are a major issue. This will greatly enhance its usefulness and allow seamless operation where knowledge systems can also provide background review and critiquing/proposals even if not explicitly asked. This has been shown to be very effective in selected special hospitals but should be made a universal resource. Particular areas where a lot is available and much is to be gained concerns the interpretation of laboratory results and the characteristics including interactions of pharmaceutical drugs.

For image interpretation, both from X-ray, MRI and ultrasound etc that requires special equipment to be generated and more traditional photos from the skin, the ear or the eye, large databases should be made available to assist the professional conducting the interpretation. Perhaps even the citizens in case of dermatology.

1.3.3 Communicating health records

Different health care organizations need to be able to communicate structured health records electronically. It may be between different levels of care such as primary care to a hospital or over different geographical borders. The major requirement is for a store and forward service with standard e-mail techniques, today mainly SMTP but still X400 MHS is used in several European countries for health messages. The lack of implemented standard structures for electronic health record is a major difficulty. There are promising standardization activities going on in CEN and ISO that should be given strong support particularly with implementation and national and specialty customization.

Structured health records should in some cases be able to contain multimedia representation with different possibilities for changing the rendering of the primary captured image objects.

However, for global health issues it is much more important to be able to communicate structured texts including laboratory results and interpreted images where relevant than the highly demanding images.

A major issue for interoperability of health records even if the new basic structure standards are used is to have available templates for different uses and large international reference terminologies for different purposes, lists of findings, diagnoses, procedures etc. Some of the best are only available on a

commercial basis at costs prohibited for developing countries. International co-operation and governmental steering may be required.

Communication of electronic records is the basis also for effective collection of statistics for public health surveillance, very much required also in developing countries.

1.3.4 Service requests and report messages

This has been one of the first uses of ICT for health with standards started in the 1980ies but with the 1990ies presenting several solutions used in fairly large scale but to varying degrees also in rich highly developed countries. These are firstly services where lab tests are sent electronically from a lab often attached to a hospital to different clinical departments and to the primary care health centers serviced by that institution. Other examples are service requests and booking electronically of e.g. diagnostic imaging services.

1.3.5 Requests for interpretation of images

This is a special form of service request messages that due to the often very high amounts of data involved requires special consideration on required bandwidth. These are very useful examples of working eHealth services, which surely are going to expand a lot in a near future with existing techniques.

1.3.6 Administrative messages

There are many examples of the world where administrative messages related to payment of health services sometimes with prior authorization before services are performed, constitute good examples of making the health care systems more effective using ICT. In e.g. France more than a thousand million electronic messages are sent for billing of health services each year in a national system.

1.3.7 Electronic prescription and medication information

These could be regarded as extracts of the health record or service requests but are most often treated in a special group because of its importance and special regulation. Medicine costs are in developed countries around 20 % of total health care spending and there is a large demand from governments and other bodies to make this more effective using electronic communication to the pharmacy and often to a payment body. Separate but related are the strong requirements for electronic availability of at least the medication part of the health record can be communicated to different healthcare professionals as authorized. This includes both prescriptions but also history of medication and changes to dosage etc. Various types of services are developed with access to a web page for viewing to e-mail, Corba and SOAP services.

1.3.8 Real-time consultation services

There has been a lot of projects globally also with ITU support where real-time consultation, telemedicine in a restricted meaning has been deployed for particular services. They can include only Videoconferencing between professionals, often with the patient present in one end for discussing a specific case. Often other special information from images or special signals from physiological monitoring, EKG etc has been accompanying the consultation. Despite the varying success of such eHealth consultations partly due to unresolved issues of financial steering, the group is convinced that such services will continue to grow and have an important role in different contexts. When special medical data is needed, special standards are required.

2 Standards for eHealth

2.1 Intersector standards provide the basis for eHealth

Even if there are requirements for some health specific standardization and indeed a lot of activity has occurred and is ongoing, it is important to state the basis for successful communication for health depend on inter-sector standards. Standards from ITU-T and ISO/IEC provide the solid basis but also other bodies such as IETF and W3C are important providers of new techniques for communication, which have rapidly become used in health services.

Health care actors should be better in providing their requirements to the intersector standardization activities such as the ITU-T work on multimedia communication.

2.2 Health informatics standardization

About 15 years ago a number of initiatives for standards in specific health domains was started and used successfully for some examples of store and forward messaging. The European federation of national standards bodies, CEN with now 22 countries, started in 1990. The US based HL7 in 1988.

The situation now is quite complicated with several bodies working de facto with members from many countries, such as DICOM without being a formally accredited standards body and several organizations partly working with overlapping issues. An international ISO/TC 215 committee was started in 1998 with now 24 active member countries and a promising standardization programme but so far very few standards published and ready for use. ISO/TC 215 gathers representatives of health care organizations and the work has progressed well towards global consensus on many principles of health information representation and the production of useful guidance documents. However, the central structures required for interoperability of health records or specific messages have not been brought into ISO yet also awaiting ongoing harmonization between Europe and the US as represented by HL7 and CEN.

An important exception though is the work on medical device communication, which is now pursued as joint CEN/ISO/IEEE work with many useful standards for implementation near publication.

Various national standards bodies have also produced useful contributions that are forwarded to international adoption through the ISO process. ASTM in the US, Standards Australia, France, Japan and Canada are some examples.

3 Action plan for co-ordination of standards activities

3.1 Joint forum for planning co-ordination

A planning group with representatives of major organizations involved in eHealth standardization shall be formed which also includes representatives of some international health related stakeholders such as WHO.

The following organizations will start this group: ITU-T, ISO, CEN, DICOM, IEEE, WHO

The task is to increase information about ongoing standards activities in the respective organizations, avoid duplication and enhance co-operation where appropriate.

3.2 An action for international information about standards for eHealth

An activity should be started within ITU-D with the assistance of the above-mentioned planning group to disseminate information about available standards for eHealth and ongoing activities of different organizations. This activity may involve the web, conferences and special seminars and courses in different countries. There will be an emphasis on the needs of the developing countries.

This will also include dissemination of information on relevant intersector standards for eHealth.

3.3 Pilot project demonstrations

ITU-D shall in its further work with pilot projects in developing countries make a special effort of ensuring that standards are used and demonstrated