Information Society and Health: Linking European Policies

European Commission
Information Society and Media

Linking European Policies

This brochure has been produced by Information Society Policy Link (ISPL), an initiative of DG Information Society and Media that aims to link information society projects with European policy-makers across a wide range of policy domains.

More than 3000 projects from information society programmes are being analysed, identifying a wealth of concrete results that support EU policies across all of the principal policy areas. By exchanging information and experiences, the Information Society Policy Link initiative helps to leverage the benefits of these activities for European policies. We are here to make the link.

For Project Consortia, we can help you to:

- Organise policy workshops and events targeted at the European policy community.
- Make introductions to policy-makers in European institutions and national administrations.
- Make contact with relevant and complementary projects and initiatives funded under other European programmes.
- Identify means to further exploit policy aspects of your results, including through further research, deployment and regulation.

For Policy-makers in the EU institutions and Member States, we can help you to:

- Maintain awareness of information society activities relevant to your policy domain.
- Identify promising projects and results within DG Information Society and Media's portfolio.
- Explore ways in which Information Society developments can support the implementation and monitoring of European and national policies.
- Build a dialogue with DG Information Society and Media on future needs and research requirements.

This brochure is one of a series describing projects' policy contributions and achievements covering around 20 policy areas. A separate series focuses on policy initiatives under i2010, the European Information Society for Growth and Employment. In addition, the initiative organises workshops to stimulate dialogue between researchers and policy-makers on key policy issues.

All publications plus information on policy workshops and other news are available via the ISPL website at:

http://ec.europa.eu/information_society/activities/policy_link/

> Foreword

Health is moving centre-stage in European policy. As well as contributing to citizens' quality of life, health is an important part of the solution to a number of key challenges facing Europe such as population ageing, security threats or labour shortages. Improving health will help meet the overall Community goals in these areas. As such, health has a role to play in achieving Europe's full potential for prosperity, solidarity and security.

These objectives are reflected in the proposed Programme of Community Action in the Field of Health (2007-2013), which constitutes the health component of the renewed Lisbon strategy for growth and jobs. This new health policy seeks to align future health action with wider Community policies and programmes. Information and communication technologies (ICT) is one such policy, where research and innovation are paving the way towards completely new approaches to healthcare provision.

The increasing impact of ICT in health is recognised in the i2010 initiative, a European Information Society for Growth and Employment. It proposes a series of practical and applied actions for eHealth under the i2010 strand on inclusion and improving quality of life. Actions are designed to speed the take-up of eHealth solutions, remove obstacles to deployment, and support the growth and competitiveness of the eHealth industry.

I welcome this brochure as an illustration of how innovation in ICT is contributing to European policy for a healthier society.

Viviane Reding

European Commissioner for Information Society and Media

> Challenges for Health

Health is an important priority for Europeans. We expect to be protected against illness and disease. We want to bring up our children in a healthy environment, and demand that our workplace is safe and hygienic. When travelling within the European Union we need access to reliable and high-quality health advice and assistance.

Healthcare is facing huge challenges. New drugs and advances in medical technologies are opening the way to more effective treatments, while the unravelling of the human genome is leading to totally new treatment regimes. Clinical practices are changing, too, requiring health practitioners to collaborate across disciplines and organisational boundaries. The whole philosophy of healthcare is shifting, towards placing a greater emphasis on health promotion and disease prevention, treating patients at the point of care, and moving towards more proactive self-care. All this is set against an important backdrop of an ageing European population and ever-increasing societal expectations of health.

Patients are coming to expect a single point of entry to healthcare services that cuts across organisational boundaries and health services. Healthcare organisations are embracing the opportunities presented by the e-revolution. Providers are looking for ways to deliver health services to the patient as promptly and as locally as possible, while supporting contact and collaboration between healthcare professionals and patients throughout the care episode. Standardised patient medical records already assist the exchange of information between specialist hospital departments. Frequently hospitals have to work with other health agencies and providers as well. Clinical information is shared between different organisations and specialties, such as pharmacies, and social and care services. Increasingly, this need extends beyond traditional care environments into the home itself.

The European Union has a vital role to play in the health arena through the obligations placed on it by the European Treaties. This role is being explored further. Community actions complement the Member States' national health policies – as specified in Article 152 of the Treaty – and at the same time bring European added value. Cross-border health threats – for example influenza – and also effects of free movement throughout Europe of both patients and medical personnel need the integrated and coordinated response achieved through better sharing of information at the European level.

> Health Policy

The EU Health Strategy, set out in May 2000, aims to integrate all EU health-related policies and concentrate resources where the Community can provide real added-value, without duplicating the work of the Member States or international organisations.

Building on the 2000 EU Health Strategy and the related Public Health programme (2003-2008), in May 2006 the Commission adopted a Programme of Community Action in the Field of Health covering the period 2007-13. This aims to align future health action more explicitly with the overall Community objectives of prosperity, solidarity and security. Hence, it has three broad objectives:

- **To improve citizens' health security**: Actions will be taken to protect citizens against health threats including working to develop EU and Member State capacity to respond to threats. Objective One will also cover actions in the field of patient safety, injuries and accidents, community legislation on blood, tissues and cells, and international health regulation.
- **To promote health to improve prosperity and solidarity**: Actions will be taken to foster healthy active ageing and to help bridge inequalities, with a particular emphasis on the newer Member States. Steps will be taken to foster cooperation between health systems on cross-border issues such as patient mobility and health professionals. Objective Two will also cover action on health determinants such as nutrition, alcohol, tobacco and drug consumption as well as the quality of social and physical environments.
- **To generate and disseminate health knowledge**: under Objective Three, actions will be taken to exchange knowledge and best practice in areas where the Community can provide genuine added-value in bringing together expertise from different countries, e.g. rare diseases and cross-border issues related to cooperation between health systems. Gender health, children's health and mental health issues will also be addressed. In addition, this Objective will allow for action to expand EU health monitoring and develop indicators and tools, as well as ways of disseminating information to citizens in a user-friendly manner, such as the health portal.

Health interests lie at the centre of people's daily lives. By bringing these issues centre stage and proposing concrete action to meet citizens' needs and concerns, the new programme will help to reinforce citizenship and to reconnect the EU with its citizens.

Many Community policies and actions have an impact on health and health systems across Europe. They are often developed within a different policy logic. Important health determinants cannot be influenced by health policy alone; there is a need for coordinated actions involving other policy areas – such as environmental, social or economic policies. The Commission works with experts in government and academia to improve understanding about the impact of EU policies and actions on health and health systems: how these impacts can be determined and measured, and how they can be taken into account in the policy cycle. Joint strategies and initiatives with other health-related policy areas are an important tool to ensure that health concerns are properly addressed from the start.

> eHealth: Where the Information Society meets Health

Information and communication technologies (ICT) are making important contributions to European health policies, and paving the way towards completely new approaches to healthcare provision. ICT supports a two-fold paradigm shift in health delivery:

- from **symptom-based** to **preventive healthcare** and
- from **hospital-centred** to **person-centred** health systems.

Use of innovative ICT applications and services in healthcare can:

- **Accelerate the advancement** of medical knowledge and **improve the understanding** of disease-related processes.
- **Empower citizens** to become actively involved in managing their own health.
- **Improve** the **prevention** and **early diagnosis** of many diseases, thus reducing overall healthcare costs and improving citizens' quality of life.
- **Enhance patient safety.**
- **Enable cost-effective management of chronic diseases.**
- **Facilitate active ageing** and **independent living** for the ageing population.

These synergies are reflected in the close interaction between the EU's information society policies and activities and those related directly to healthcare.

Policy for eHealth

In support of the overall EU Health Strategy, in April 2004 the Commission adopted an action plan on eHealth – under the eEurope initiative which aims to establish a European eHealth Area.

Since the launch of the eHealth Action Plan, initiatives have been started in all of the Plan's main action lines. They include: patient mobility; interoperability and integration; health cards and electronic health records; best (or good) practices; benchmarking and road-mapping; dissemination activities; conferences and special events; and legal, regulatory and other issues. Particular emphasis has been given to the sharing and publicising of eHealth experiences and best practices, and to coordinating the efforts of Member States through developing regional and national eHealth roadmaps. The Member States themselves are becoming more and more active in the field of eHealth.

Interoperability of health systems and services is a major challenge for individual Member States and for health sector actors. It is therefore a prime consideration for both the European Commission and the Member States under the eHealth Action Plan. Interoperability will help resolve a number of pressing issues facing Europe's healthcare systems and services. These include issues on the supply and demand sides, legal and regulatory issues, market requirements, and demographic and cost pressures. Consequently, interoperability is being tackled at various levels: organisational, technical, functional, and semantic.

The eEurope 2005 Action Plan has been superseded by the i2010 initiative, announced by the Commission in June 2005, which forms the information society component of the renewed Lisbon strategy to boost European competitiveness.

As the use of ICT grows, so does its impact on society. i2010 recognises this in three ways: making sure that ICT benefit all citizens; making public services better, more cost effective and more accessible; and improving quality of life. In the period 2005-2010, therefore, the practical and applied approach to eHealth is covered within the i2010 strand on improving quality of life. Concerns are mainly with contributing significantly to assuring improvements in quality, access, and efficacy of healthcare at the same time as supporting the growth and competitiveness of the eHealth industry.

Implementation of specific i2010 actions on eHealth are supported by a number of independent groups: the **i2010 Subgroup on eHealth**, representing key decision-makers and leaders of national eHealth initiatives in each Member State; an **eHealth Stakeholders' Group**, representing technical, industry, standardisation, user associations and European co-financed projects; and ***ad hoc* expert groups** on emergency data sets and ePrescribing. Prime among these is the i2010 subgroup on eHealth which, among other tasks, is advising the Commission on the development of an EU health interoperability policy as it moves towards a Recommendation on eHealth interoperability in 2007.

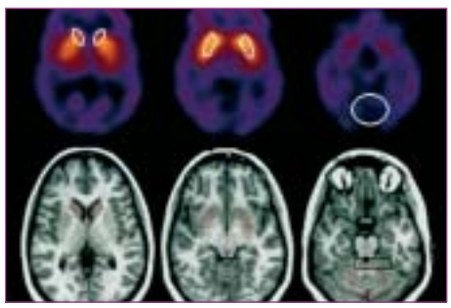
Information Society Activities

Research and Development

The European Commission, through its Information Society & Media Directorate-General (DG INFSO), has supported research activities in **ICT for Health** for almost two decades. This has placed Europe in a leading position in many aspects of eHealth, including the use of regional health networks, electronic health records in primary care and deployment of health cards. These developments have contributed to the emergence of a European eHealth industry.

Research in ICT for Health within the Sixth Framework Programme (FP6) aimed to contribute to the better health status and well-being of all European citizens, to bring economic and productivity benefits to the health systems of all Member States, and to stimulate growth and competitiveness of the eHealth industry in Europe.

Its driving vision is of **an ICT-enabled, citizen-centric health delivery system**, with special emphasis on prevention of diseases and personalisation of care.
The three lines of action are:



- Support to implementation of proven eHealth solutions by following the adopted eHealth Action Plan. Particular attention is paid to the inter-operability of eHealth systems, support to Europe-wide eHealth services, and the promotion and dissemination of best practices.
- Medium term research and development goals target advanced eHealth solutions for patients and health professionals that improve quality of care, and in particular increase patient autonomy, mobility and safety. Focus is on wearable personal health systems and medical decision making.
- Longer term research objectives include new inter-disciplinary topics that can accelerate health knowledge discoveries, bring new benefits to healthcare and promote synergy among related sciences and technologies. Topics considered are biomedical informatics and modelling, and simulation methods and tools for a virtual physiological human.

Projects were also launched to improve the participation of organisations from the new Member States and the Associated Candidate Countries in FP6 eHealth research, to prepare for future international cooperation, and to improve networking and coordination of national, regional and European research activities.

DG INFSO also cooperated with the Directorate-General for Research (DG RTD) on eHealth directions in nano-technologies and nanosciences, knowledge-based multifunctional materials, and new production processes and devices.

Research in ICT for Health will remain a priority under the Seventh Framework Programme (FP7), which will continue to support the restructuring of health delivery systems in Europe. Key research topics will include the next generation of personal health systems that are wearable, implantable or portable; and the virtual physiological human - a computational framework for multilevel modelling and simulation of human anatomy and physiology. Management of health risks and improving patient safety is fast becoming a priority issue in the eHealth and research agendas. User needs and the security, confidentiality, legal and regulatory aspects of eHealth are other top issues.

Other Activities

eHealth is a priority area under **eTEN**, primarily for the practical achievement of eEurope's objectives on eServices. Projects address issues such as health and public health information networks; the use of electronic healthcare and insurance cards; extending the advances in telemedicine to the healthcare sector; and expanding health and related preventative services to a trans-European level. Work is being extended from market studies to include large- and very large-scale pilot actions covering fields such as patient summary, emergency data sets, and ePrescribing.

For the future, and with particular reference to the i2010 strategy, the main initiative will be the **ICT Policy Support Programme**, which is part of the Competitiveness and Innovation Framework Programme. With a budget of €728 million, it will stimulate converging markets for electronic networks, media content and digital technologies, test new solutions to speed up the deployment of electronic services, and support modernisation of the European public sector.

European best practices in eHealth are acknowledged through the organisation of eHealth conferences and exhibitions, and through various other activities such as studies, coordination actions specific support actions and awards. A variety of studies have been launched to improve knowledge of the functioning of the eHealth market and prepare the ground for i2010 initiatives on eHealth and independent living.

> Information for Better Lifestyle Choices

Information Society and Media projects are helping to address European objectives to promote health awareness, prevent diseases and enhance patient safety.

Policy Context

Our health is influenced by a wide variety of social, economic and environmental factors. Tackling these major health determinants has great potential for reducing the burden of disease and promoting the health of the general population. Health determinants include genetic factors, personal behaviour and lifestyles, living and working conditions, access to health services, and general socio-economic, cultural and environmental conditions.

EU action in this area aims to develop policies, strategies and measures which will establish effective interventions to tackle these health influences. As well as actions at European level, this involves encouraging Member States' efforts to develop innovative projects which will stand as examples of effective practice.

The EU Public Health Programme (2003-2008) produces a variety of information and indicators. These include comparable data on health and health-related behaviour of the population (e.g. life styles and other health determinants); on diseases (e.g. incidence and ways to monitor chronic, major and rare diseases); and on health systems (e.g. indicators on access to care, quality of care provided, health human resources, and financial viability of healthcare systems). Health inequalities also form an important dimension of the Health and Consumer Protection Strategy and proposed action programme (2007-2013).

Actions are based on an agreed set of Europe-wide health indicators that will serve as a basis for the European health information and knowledge system. The Health Monitoring Programme's ECHI (European Community Health Indicators) projects have developed a comprehensive list of indicators, which contained about 400 items by the middle of 2005.

Contribution of ICT

ICT have the potential to offer new approaches to disease prevention and treatments, early diagnosis, and enhancement of patient safety. ICT-based solutions and services provide citizens with tools that enable them to be better informed about health risks and lifestyle choices. An intelligent networked environment also allows health professionals to monitor the health status and manage the care of individual patients dynamically.

Continuous Monitoring to Reduce Risks from Heart Disease

Cardio-vascular disease (CVD) is the leading cause of death in Europe. More than 20 per cent of Europeans suffer from chronic CVD and Europe spends hundreds of billions of euros each year on diagnosis and treatment. A healthy and preventive lifestyle combined with early diagnosis is an effective weapon in the fight against CVD and could save millions of lives and healthcare costs.

HEARTS, an IST-FP5 project, developed a system for continuous monitoring of patients using non-invasive wearable sensors. These gathered biometric signals such as electro-cardiograms and gradually built up a pattern of the wearer's health behaviour. Departures from the expected pattern trigger alarms. The added value of the HEARTS system is its decision support capability which suggests appropriate responses to individual alarms, based on the patient's medical history and normal patterns of behaviour, to the healthcare professionals responsible for the patient.

Aiming to take monitoring of cardiovascular diseases one stage further, IST-FP6 **MYHEART** is integrating advanced medical sensors into textiles to create intelligent biomedical clothes. The system uses continuous or periodic monitoring of vital signs to make diagnoses, detect trends and react to the results. All of the information processing is done while the device is being worn and can be communicated either to the user or to the professional medical services.

Having investigated and evaluated an initial set of 16 application ideas, the project is now focusing on four application concepts. These address healthy people or people at risk (fitness and illness prevention), patients after an event (rehabilitation) and chronically ill patients (disease management).

ICT research in FP5 was first to place emphasis on supporting the delivery of health services to citizens. A cluster of projects aimed to support citizens in staying healthy through personal health systems that help disease prevention, health promotion and delivery of home care. The FP5 coordination action **ACTIVE-HEALTH** provided a common platform for these projects to exchange knowledge with each other and with the medical community. It also addressed issues such as interoperability of the products developed.

This effort has continued in FP6, with more emphasis on integrated systems and services and on the personalisation of health systems and care. Related activities include the integrated projects **PIPS** and **MYHEART** (see boxes). Another FP6 project, **OFSETH**, aims to extend the capabilities of wearable solutions for personal health monitoring, through the integration of optical fibres technology into functional textiles.

Making Lifestyle Choices Easier

A support environment to help users in their day-to-day decisions on health and lifestyle is the focus of the **PIPS** project. This will improve healthcare delivery models, while creating possibilities for healthcare professionals to access relevant, updated medical knowledge and for European citizens to choose a healthier lifestyle.

Using the latest ICT devices (such as mobile phones and PDAs), PIPS provides all the necessary information at the point of decision (home, supermarket, restaurant, gym), thus allowing people to follow their general practitioner's instructions on therapy and nutrition. In addition, PIPS enables healthcare professionals to access all the medical information necessary to define a 'healthy plan' tailored to the patient.

A proof of concept service offered nutritional service to diabetic patients, providing them with a remote assistant for their clinical monitoring and nutritional support. For example, when shopping, patients could use their mobile phones to check if a product fitted into their diet. They could also make trusted internet searches for advice on managing their condition or for news of innovative treatments.

> PROJECT DETAILS

ACTIVE-HEALTH - Active Environment for Health Promotion and Disease Prevention
sguillen@itaca.upv.es • www.hon.ch/Project/ActiveHealth.html

HEARTS - Health Early Alarm Recognition and Telemonitoring System
stefano.romani@datamat.it • http://heartsproject.datamat.it/

MYHEART - Fighting Cardio-Vascular Diseases by Prevention & Early Diagnosis
joerg.habetha@philips.com • www.extra.research.philips.com/euprojects/myheart

OFSETH - Optical Fibre Sensors Embedded into Technical Textile for Healthcare Monitoring
grillet@multitel.be • www.ofseth.org

PIPS - Personalised Information Platform for Life and Health Services
alberto.sanna@hsr.it • www.pips.eu.org

> Does eHealth Pay?

A series of policy studies are exploring the cost-benefits and the legal implications of eHealth systems and services. The results should accelerate the take-up of eHealth initiatives at national and regional levels.

Policy Context

The application of ICT in health – eHealth – offers new possibilities for improving almost every aspect of healthcare, from making medical systems more powerful and responsive to providing better health information to all Europeans. The impact of eHealth is as diverse as the sector itself, encompassing the quality of health-related web content, patient data security, and telemedicine technologies. It also successfully tackles administrative headaches for hospital staff, doctors and patients, and much more.

Indeed, this is a very data-intensive sector.

Achieving these benefits, however, is complex and long-term. Healthcare systems are immensely complicated, both in terms of organisation and technologies. Health data are also particularly sensitive, so individuals' health information must be protected.

Many of these priorities, such as data privacy and public health, have a European dimension. Health authorities throughout Europe are now learning actively from each others' experience, sharing in building roadmaps and action plans. Co-ordinating research and development across Europe is helping to accelerate the development of new eHealth technologies.

Policy actions to support this were set out in the 2004 eHealth Action Plan. Key targets include: identifying a common approach to patient-identity data by the end of 2006; identifying interoperability standards for health data by the end of 2006; and, looking ahead to 2008, supporting the deployment of health information networks based on fixed and wireless broadband, mobile infrastructures and Grid technologies.

Over time the contribution of eHealth initiatives will repay dividends in terms of: better choice and services for patients; better use of the resources invested in health systems across Europe; greater economic growth and more sustainable development for the Union as a whole; and the concrete benefits of European integration that are coming ever closer to citizens in their everyday lives.

Assessing the Economic and Productivity Impact of eHealth

eHealth systems and services are becoming more and more widely used in medical and healthcare environments across the EU. European and national policy goals for eHealth applications have been introduced steadily; indeed, more actively since 2004.

Relatively little reliable evidence has been available on the economic and clinical impact of using ICT in delivering high quality healthcare. The impact of eHealth is potentially enormous but it has been difficult to measure, especially some of the benefits. Evaluations often take only one perspective, such as a financial orientation, or the view of a single stakeholder.

The **eHealth IMPACT** study has addressed these shortcomings. It has:

- Developed a generic framework for assessing and evaluating eHealth applications and services, focusing on economic performance and measurement tools for quantitative indicators.
- Identified good practice examples of eHealth applications across Member States and across the whole eHealth domain, integrating the experience and lessons learned from these examples into the method.
- Applied the method and measurement tools to ten sites, each with proven eHealth applications and reflecting the diversity of health systems within the EU.

The model developed fits a wide diversity of applications, such as clinical settings or supply chain solutions. Included costs comprise the initial and continuous eHealth investments, such as those in ICT and change management, as well as healthcare running costs. Special attention has been paid to identifying the benefits to, and impact on, citizens. At the same time, benefits to all potential stakeholders have been analysed.

The concept of cost-avoidance – i.e. the cost of achieving the same levels of performance without using ICT – is important in identifying benefits. Achieving similar performance levels without the use of ICT is often either prohibitively expensive, or not attainable at all.

The model was applied initially to two eHealth application sites: NHS Direct Online in the UK and Kind en Gezin's vaccination database in Flanders, Belgium. Based on these initial experiences, the model was then refined and applied to a further eight sites. The results from each case show the economic impact of eHealth systems and services is high sometimes unexpectedly so. Aggregating them indicates a positive, sustainable economic impact in a virtual health economy over fifteen years.

In parallel with this work, the study assembled a portfolio of about 90 cases of good practice in eHealth for its online database, mainly using secondary literature. These and the other results are accessible through the website. They will be explored further in the Good eHealth study.

Overall, the study not only encourages organisations to adopt eHealth systems and services but also provides them with a robust and tested methodology for measuring their economic effectiveness.

The Legal Dimension of eHealth

Although eHealth systems and services are becoming more widely accepted, there are a number of potential legal and regulatory issues relating to the practice of eHealth service delivery and the use of eHealth tools.

Legally eHealth studies the legal and regulatory aspects of the eHealth Action Plan. The analysis, which should be complete towards the middle of 2007, will cover various areas of EU legislation, such as data protection, product liability, consumer protection, competition law, e-commerce, and public health. Its analysis of European data protection legislation in relation to eHealth has already been completed.

The study is identifying the existing framework of EU law relating to eHealth and making a knowledge base related to this available online. It is also developing a series of simple, descriptive case studies that explore and highlight some of the issues created by gaps or ambiguities in current law. Recommendations will be made for extending, amending or clarifying existing legislation or regulation.

> PROJECT DETAILS

eHealth IMPACT - Economic and Productivity Impact of eHealth
alexander.dobrev@empirica.com • www.ehealth-impact.org/

Legally eHealth
celine@ehma.org • www.fundp.ac.be/recherche/projets/page_view/en/06159001/

> Joining up eHealth Solutions

Interoperability has an important role to play in the development of a European infrastructure for eHealth and supporting the development of a European eHealth area.

Policy Context

The eHealth Action Plan, adopted by the European Commission in April 2004, shows how information and communication technologies can be used to deliver better quality healthcare Europe-wide. It covers a wide range of applications ranging from electronic prescriptions and computerised health records, to using new systems and services that cut down waiting times and reduce undesirable events. It also facilitates health information exchange between healthcare organisations so as to support continuity of care and to enable new models of working.

The Action Plan sets out a roadmap for greater use of technologies, new services and systems, built around the objective of a 'European eHealth Area'. It identifies practical steps to achieve its goals through work on electronic health records, patient identifiers and health cards, and the faster rollout of high speed internet access to enable optimum interactions among healthcare professionals and with the general public. It also calls on Member States to develop national and regional eHealth strategies. Thanks to this plan, by the end of the decade, the EU should be well-placed to measure the impact of eHealth technologies on the quality and efficiency of services, as well as overall productivity.

Key to achieving a European eHealth Area is developing eHealth solutions that are interoperable – different ICT systems designed by different companies that are able to work together on the same application or in the same context – in and across Member States. Interoperable eHealth solutions will enable healthcare organisations and professionals to collaborate. In addition, the various stakeholders are cooperating and involving themselves to resolve any legal, organisational and policy barriers.

A preliminary report written by representatives from Member States and various eHealth stakeholders published in September 2006 recommends the steps necessary to reach these goals. These cover political, social and regulatory issues; appropriate processes and structures to achieve eHealth interoperability; technical standardisation; semantic interoperability; and certification and authentication processes. The result of this process will be a set of guidelines on eHealth Interoperability which will be issued in 2007, as well as an agreed process to implement this set of guidelines in the Member States and at EU level.

Both the IST and eTEN programmes have actively supported , and continue to support, the development of more interoperable eHealth solutions as part of a European eHealth infrastructure and the deployment of interoperable solutions and interfaces.

Electronic European Health Insurance Cards

An illustration of the emerging European eHealth Area is the European Health Insurance Card (EHIC) giving European citizens access to healthcare services when visiting another Member State. The EHIC replaces the E111 and related forms carried by tourists, students and workers whilst travelling, studying or temporarily posted in any EEA country.

While the current EHIC is a simple paper or plastic document, an electronic version of the EHIC (eEHIC) is being validated in the eTEN projects **NETC@RDS** and **NETC@RDS for eEHIC**. The electronic version of the card – which is due to be rolled-out over the next five years – will be able to provide additional services, such as improved cross-charging between European healthcare providers. The technical base was created by various activities in health smart cards initiated in Member States, as well as trials under previous European R&D projects and pan-European initiatives (e.g. the eEurope Smart Card Charter).

The current phase – the second of four – is evaluating a number of large-scale demonstrators for an eEHIC offering advanced services. It will demonstrate new administrative processes for use by public health insurance and healthcare service providers when dealing with travellers or temporary residents, and will also evaluate technical interoperability between different national cards. These have included live applications at the 2004 Olympic Games and 2006 World Cup.

[1] eHealth Action Plan, part of COM(2004) 356(final): eHealth – Making Healthcare Better for European citizens: An action plan for a European eHealth area.

[2] "Connected Health: Quality and Safety for European Citizens", eHealth Interoperability Report, http://europa.eu.int/information_society/activities/health/docs/policy/interoperability_report_draft21082006v03.pdf

Towards a European Research Area in eHealth

While healthcare remains a national responsibility, it is more and more recognised that European cooperation can become a powerful tool in supporting Member States to achieve their respective health system objectives. The **eHealth ERA** coordination action is supporting the planning of national innovation-oriented eHealth R&D as the basis for better implementation and faster deployment. The project surveys and analyses eHealth roadmaps and R&D programmes across Europe, identifies common priority issues, and develops a roadmap for joint actions. Among many other activities, the project has launched a public eHealth website on national eHealth strategies, implementation activities and R&D programmes.

Interoperability Frameworks for European eHealth

Building on the activities in Member States, the results of European research and technology development, and learning from international efforts, the eTEN project **i2-Health** is initiating a process for accelerating the deployment of interoperable eHealth infrastructures and applications for trans-European use. It focuses on fundamental interoperability issues (like identification of actors, organisations, adequate measures to achieve interoperability, integration tests and certification) and analyses key topics relating to e-prescription and messaging. Most importantly, it develops a roadmap and concrete projects involving all relevant actors, guided by an open discussion process among Member State health authorities.

The electronic health record (EHR) is now centre-stage in the national health informatics strategies in Europe. There is a need for interoperability standards that can permit clinical computer systems to share health record data while preserving faithfully the clinical meaning of the individual authored contributions. **Q-REC**, an FP6 specific support action, is helping to create an efficient, credible and sustainable mechanism for the certification of EHR systems in Europe. It will define formal methods and create a mechanism for the quality labelling and certification of European EHR systems, in primary and in acute hospital care settings.

Semantic Interoperability for eHealth Systems

Despite current harmonisation efforts, Europe is still a long way from having common solutions and approaches on aspects such as clinical data models, clinical practice, terminology systems and EHR; nor is it realistic to expect this to be achieved in the foreseeable future. Hence, considerable emphasis is placed on semantic interoperability – the ability to 'translate' between different data standards – in eHealth systems and infrastructures. Some projects work with international organisations using a topdown approach, while others focus at the grassroots level on practical, web-based applications.

RIDE is a roadmap project for interoperability of eHealth systems which places particular emphasis on semantic interoperability issues. It will prepare the ground for future actions as envisioned in the eHealth Action Plan by coordinating various national efforts on eHealth interoperability. Also concerned with semantic interoperability issues, **semanticHEALTH** aims to develop a European and global roadmap for research and deployment of eHealth systems and infrastructures. The participation of international experts, including representatives from the World Health Organisation, gives the project a global dimension.

ARTEMIS meanwhile is developing a peer-to-peer infrastructure for the interoperability of medical information systems. It enables healthcare institutions to exchange EHRs in an interoperable manner through semantically-enriched web services and semantic mediation.

> PROJECT DETAILS

ARTEMIS - A Semantic Web Service based P2P Infrastructure for the Interoperability of Medical Information
asuman@srdc.metu.edu.tr • www.srdc.metu.edu.tr

eHealth ERA - Towards the Establishment of a European eHealth Research Area
era@empirica.com • www.ehealth-era.org

i2HEALTH - Interoperability Initiative for a European eHealth Area
i2-health@empirica.com • www.i2health.org

NETCARDS and NETC@RDS for eEHIC
noel.nader@sesam-vitale.fr • www.netcards-project.com

Q-REC - European Quality Labelling and Certification of Electronic Health Record Systems
georges.demoor@ugent.be • www.eurorec.org

RIDE - A Roadmap for Interoperability of eHealth Systems in Support of COM 356 with Special Emphasis on Semantic Interoperability
asuman@srdc.metu.edu.tr • www.srdc.metu.edu.tr

> A European Information System for Organ Donation

Sharing information from national organ and transplant databases is helping to ensure better use is made of organs donated for transplantation.

Policy Context

Organ transplantation is currently a common technique used in medicine. Transplants of liver, kidney, heart, lung, pancreas or small bowel are generally the only treatments for terminal organ failure. Over the past decades, the number of organs donated and transplantations carried out in the EU has risen steadily, with good results in terms of life years gained and improvements in quality of life.

The organ transplantation process is complex, and is not risk free either to the donor or the recipient. Under article 152 of the Amsterdam Treaty, the Commission is required to consider the need to identify, monitor and control the factors influencing the quality and safety of organs used for transplantation at European Union level. There is currently no EU directive concerning organ transplantation but existing directives concerning the donation and handling of blood, tissues and cells are relevant.

A severe shortage of organ donors and the very short time frame during which organs can be successfully transplanted remain the major obstacles preventing the full development of transplant services and impose a severe limit to the number of patients who benefit from this form of therapy. Almost 10 people die every day in Europe while waiting for an organ, and the mortality rate in patients waiting for a heart, liver or lung transplant is between 15% and 30%. Currently, there are around 40 000 patients in Europe on waiting lists for an organ donation.

Thus, although organ transplants have saved thousands of lives and transformed the quality of life of thousands more, many people will not have that opportunity, as the demand for organs is never met. At present, there are few exchanges of organs between Member States, and national requirements with regard to safety and quality procedures vary widely. Organ trafficking is also a key issue.

To address these issues, in June 2006 DG Health and Consumer Protection launched a public consultation on the future of organ donation in Europe. The consultation aimed to identify the main problems encountered in organ donation and transplantation, to determine the extent to which measures should be taken at EU level to help to solve these problems and to invite ideas on what EU initiatives could be taken.

Sharing information on organ donation

Clear Information that cannot be misinterpreted is critical to organ donation and transplantation. Medical authorities need to be able to match donors to recipients quickly and accurately, and then locate the organ and instigate the transplant. At present this information is held within national registries maintained by the Member States. An overall integrated information and communication system could significantly improve the efficiency of organ donation and transplantation in Europe and save many more lives.

The eTEN project EURODONOR brought together eight European donor and transplant centres from Belgium, Greece, Italy, Netherlands, Spain and UK, to set-up a European-level internet-based service that provides a common structure and means to access of accessing their combined organ and donor databases. This European Donation and Transplant Activity Registry provides up-to-date and reliable information on national organ and transplant databases, and therefore enables operators to improve the matches offered to European citizens.

The first phase, completed in mid-2004, established a European level registry based on common protocols for gathering and presenting essential medical data. A reliable, web-based prototype enquiry service was tested successfully under operational conditions. This can be accessed by all registered EU institutions, health professionals, medical associations, public and private organisations, citizens and patients.

The EURODONOR system is now accepted by eleven countries. Furthermore, SP-CTO, a Committee of Experts on organ transplantation set up under the Council of Europe, has adopted EURODONOR's glossary (standardised terminology) for transplant data collection. Similarly, the World Health Organisation has adopted EURODONOR's database structure.

A follow-up eTEN project, EUROCET, started in September 2005 and involves 20 partners from 12 Member States. It will extend the registry to collect official and updated figures on the organ, tissue and cell donation and transplantation activities of participating countries. Data will be available both to professionals and general public through the EUROCET portal, which will also deliver information and news related to this field.

In particular, for the first time EUROCET brings together tissue banks from European countries to discuss data standards and assess the impact of a 2004 Directive on national legislation concerning quality and safety standards. It will improve the exchange of information between experts and make the whole process more transparent. It will also provide a way to inform citizens, giving them the knowledge tools to fully understand all issues related to the transplant process.

> PROJECT DETAILS

EURODONOR - European Donors and Organs Registry
paolad@iss.it • www.eurodonor.org/eurodonor

EUROCET - European Registry for Organs, Tissues and Cells
eurodon@iss.it • www.eurodonor.org/eurocet

> Genetic Information for Personalised Healthcare

The convergence of bioinformatics and medical informatics has the potential to create new genetic-based diagnostic and therapeutic tools. This, in turn, will lead to a more personalised approach to healthcare.

Policy Context

The field of genetics is increasingly important in a health policy context. Nearly every disease has a genetic component, to some degree, and our increasing knowledge of genetics is opening up possibilities for many new medical treatments.

Genetic determinants are important constitutive factors for individual health. The identification of disease susceptibility genes, as well as the somatic mutations underlying specific diseases such as cancer, can provide a wealth of new information vital to a more thorough understanding of many common illnesses. Such knowledge can be used both to better diagnose diseases and to identify new personalised treatments or more specific drug targets.

Genetic screening raises many ethical, social and legal concerns, in particular in relation to confidentiality and privacy of personal and genetic information. These impact on areas such as life and health insurances, occupational safety standards, etc., and will undoubtedly have important bearings on the health and well-being of European citizens. These ethical, social and legal aspects of the application of modern genetics are being followed closely at European level.

Synergies between Medical Informatics and Bioinformatics

Building on decades of advances, molecular and computational biologists are now able to develop very detailed models of cells, tissues, organs, organisms and populations. At the same time, clinical research has led to a better appreciation of the molecular basis of disease. Clinical scientists are amassing information that is helping them to decipher how variations in people's genetic make-up can affect their likelihood of developing conditions such as cardiovascular disease or diabetes, or of developing an adverse response to particular drugs.

Sitting at the interface between bioinformatics and medical informatics, the emerging discipline of biomedical informatics is key to unlocking the potential of recent advances in delivering new diagnosis and treatments.

Research under ICT for Health is helping to bridge this divide. The IST-FP6 project study **SYMBIOmatics** reviewed the state-of-the-art in biomedical informatics in Europe with a view to identifying synergies with medical informatics and opportunities for new areas of research. It gathered the views of European experts and used bibliometric and data-mining methods to identify and analyse the content of relevant scientific literature.

In June 2006 the findings of this study were presented and discussed at an open meeting of experts in bioinformatics and medical informatics, policymakers and other interested parties. The results of this meeting are being synthesised into a second White Paper documenting the state-of-the-art in biomedical informatics in Europe, and identifying and prioritising opportunities for future research. This will provide an important input to discussions on future research policy.

Biomedical Informatics to Support Individualised Healthcare

INFOBIOMED, an FP6 network of excellence, brings together leading research groups from 10 Member States. By building European research capacity, it aims to provide the push necessary for biomedical informatics to become an established scientific discipline key to the future of European healthcare. It builds on the IST-FP5 project BIOINFOMED, which produced a detailed agenda for future research in bioinformatics and medical informatics.

The INFOBIOMED network has launched an ambitious research plan covering much of this agenda. One of the main focus areas is data interoperability and management. In the post-genomic era, biomedical researchers and practitioners will need to manage larger amounts of data. The project is undertaking a thorough study of data characteristics and knowledge representation systems, mainly ontologies, currently used in medical informatics and bioinformatics. New methods and tools being developed will enable practitioners to integrate clinical and genetic data and share the resulting knowledge.

Pilot applications are investigating the use of genomics approaches in drug discovery, fighting infection, chronic inflammation and colon cancer. Major efforts in researcher training and mobility are also underway.

Also concerned with the crossover between the bioinformatics and medical informatics fields, three FP6 integrated projects **@neurist**, **ACGT** and **Health-e-Child**, aim to develop in the near future grid-based healthcare platforms and integrative decision support systems for the management and support of heterogeneous medical data. These new biomedical platforms will be useful to stimulate and further facilitate exchange of both clinical and genetic information to ensure faster diagnosis and more efficient and personalised treatments.

Each of the integrated projects will focus on a specific disease. @neurist will address brain aneurysms and haemorrhage, ACTG will have a particular focus on two forms of cancer (breast cancer and paediatric nephroblastoma), whilst Health-e-Child will mainly address paediatric diseases such as heart, inflammatory diseases and brain tumours.

> PROJECT DETAILS

@neurIST - Integrated Biomedical Informatics for the Management of Cerebral Aneurysms
alejandro.frangi@upf.edu • www.aneurist.org

ACGT - Advancing Clinico-Genomic Clinical Trials on Cancer
remi.ronchaud@ercim.org • www.eu-acgt.org

Health-e-Child - Health-e-Child
joerg.freund@siemens.com • www.Health-e-Child.org

INFOBIOMED - Structuring European Biomedical Informatics to Support Individualised Healthcare
info@infobiomed.org • www.infobiomed.org

SYMBIOmatics - Synergies in Medical Informatics and Bioinformatics
symbiomatics@ebi.ac.uk • www.symbiomatics.org

KK-76-06-220-EN-C

Further Information

Information Society Policy Link initiative
Coordinator: Eoghan O'Neill
e-mail: infso-is-policy-link@ec.europa.eu
http://ec.europa.eu/information_society/activities/policy_link

Health and Consumer Protection DG
John F Ryan, john-f.ryan@ec.europa.eu
http://ec.europa.eu/health

Information Society and Media DG
ICT for Health Unit, ehealth@ec.europa.eu
http://ec.europa.eu/information_society/ehealth

Europe's Information Society: Thematic Portal
http://ec.europa.eu/information_society