EHCR / PHR
Past – Present - Future

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MEDIZINISCHE UNIVERSITÄT INNSBRUCK

MEDIZINISCHE STATISTIK INFORMATIK GESUNDHEITSÖKONOMIE

Content

- Definitions of the eH/M/P/C…-Record
- **Past** developments
  - Lessons learned
- **Present** problems and challenges
- **Future** developments
  - Why are we there, where we are?
  - Research questions
- Conclusion

Many universities have a department for the history of medicine?

Department / Institute for the history of medicine:
N=1480 / 73.600
Department /Institute for the future of medicine:
N=0 / N=0
Google: 10.05.2007

Do you know a department for the future of medicine?

eHealth: Definitions

- The **51 unique definitions** that we retrieved showed a wide range of themes, but no clear consensus about the meaning of the term eHealth. We identified 2 universal themes (**health and technology**) and 6 less general (commerce, activities, stakeholders, outcomes, place, and perspectives).

- E-health is all that's **digital or electronic** in the health care industry (Tiemann, 2001)
- **eHealth is connectivity** (Marcus, 2003)
- Encompasses all of the information and communication technologies (ICT) necessary to make the health system work (Int.Telecomm. Univion. 2004)
- New business models using technology to assist healthcare providers in caring for patients and providing services. (Sternberg 2004)
- Jadad A. et al: What Is eHealth (3): A Systematic Review of Published Definitions, J. of Medical Internet Res., 2005, 7/1

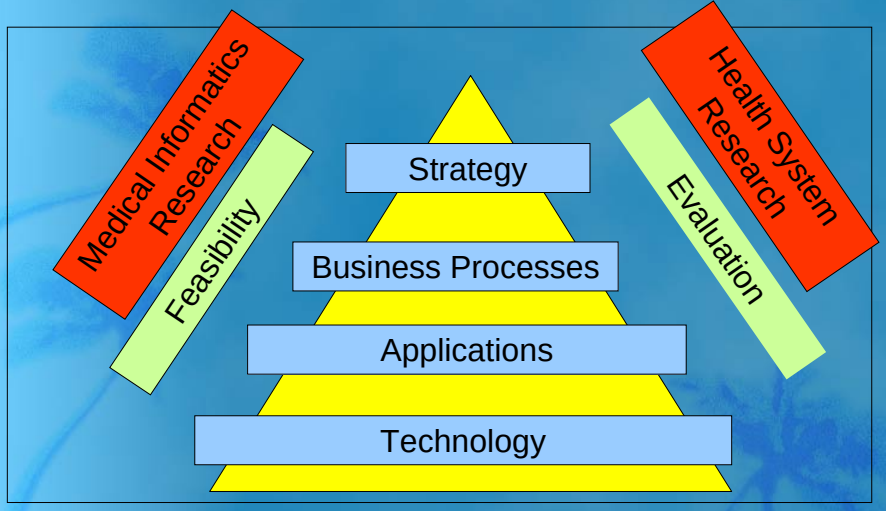
e-Health means:

Connect
Communicate
Cooperate

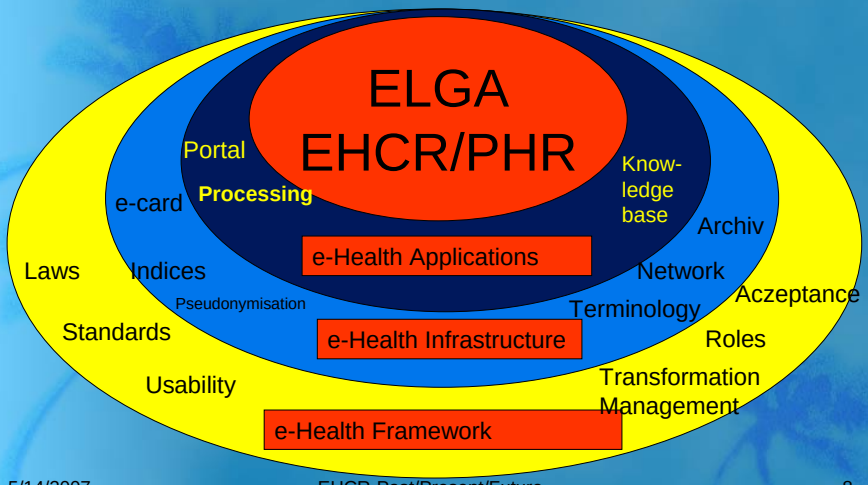
Content of eHealth

- Patient centred electronic health care record
  - In Austria: ELGA … ELektronischer GesundheitsAkt
  - Includes an active participation of the citizen / consumer
- Health information networks
  - Presentation of medical knowledge
- Telemedicine services
- Mobile equipment
  - Monitoring systems
- Decision support systems
- Pro-active systems
- Tools for processing of anonymous data for planning, management, research, …

eHealth Topics



e-Health Model



Electronic ??? Record

- EHR - Electronic Health Record
- EPR – Electronic Patient Record
- EMR – Electronic Medical Record
- CPR – Computerized Patient Record
- **EHCR – Electronic Health Care Record**
- **PHR – Personal Health Record**
- CCR – Continuity of Care Record
- **VHR – Virtual Health Record**

Functions of the EHCR/PHR/… 1

- **Support consumer involvement**
  - Protects privacy and confidentiality
    - Secure access
    - Capacity to provide authorized provider access
    - Capacity to provide direct emergency access
- **Provides an organized consumer view of health related information**
  - Accommodates consumer self care
  - Accesses information for the consumer
- **Supports consumer health care**
  - Includes previous and current diagnoses, treatments, laboratory results, immunizations, …
  - Anticipates future health problems and actions
  - Describes preventive measures
  - Accommodates decision support

Functions of the EHCR/PHR/… 2

- **Supports communication between providers**
  - Supports integrated, collaborative care
  - Supports case and disease management
  - Accesses medical knowledge bases
  - Allows data interchange and record access
  - Allows selective retrieval of information
- **Supports secure communication between patients and providers**
- **Supports patient specific self monitoring and disease management**
  - Accurate entry of medical conditions
  - Accurate entry of medication, monitoring results, …
  - Capacity to evaluate treatment recommendations, wellness checkups, …

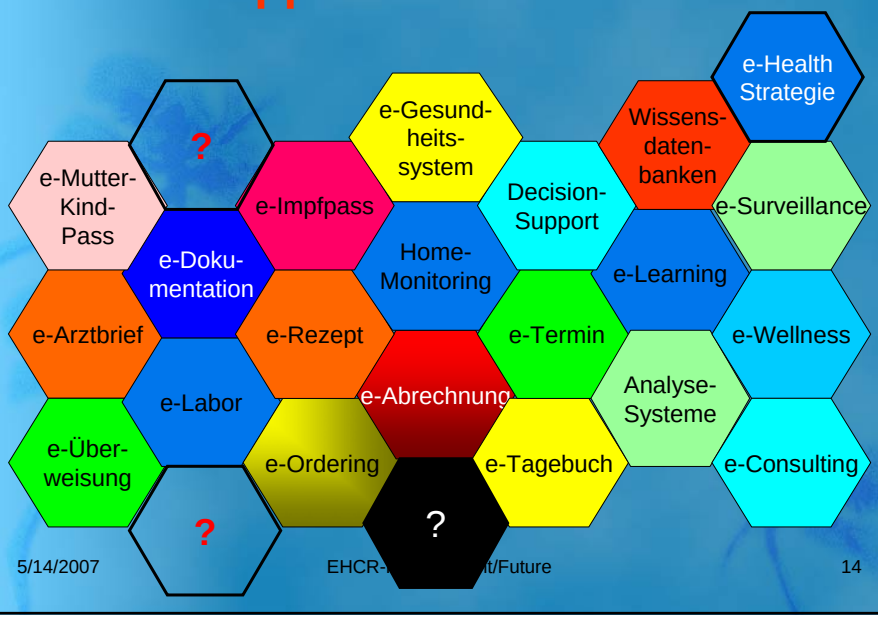
Functions of the EHCR/PHR/… 3

- **Supports clinical documentation**
- **Supports patient management**
- **Supports document, image and bio-signal management**
- **Facilitates administrative tasks**
  - **Supports reimbursement models**
- **Reduces routine reporting**
- **Improves cost-effectiveness practice**
- **Supports best practice evidence based health care**
- **Provides decision support**

Functions of the EHCR/PHR/… 4

- **Provides a legal account of events**
- **Provides justification for actions**
- **Supports quality improvement**
  - Provides online access to knowledge base
  - Supports the integration of guidelines
- **Supports the management of health care facilities**
- **Supports population health care**
- **Provides evidence for development and evaluation of programs**
- **Supports clinical and health related research**
- **Supports medical education**
- …

e-Health Applications and Portal



eHealth Vision

- An ubiquitous management of health by supporting the processes of all health care professionals by using information technology with special attention to privacy and data safety
- In some years all necessary data are available electronically for the person who has the right to access to this data
  - Independent of time and location

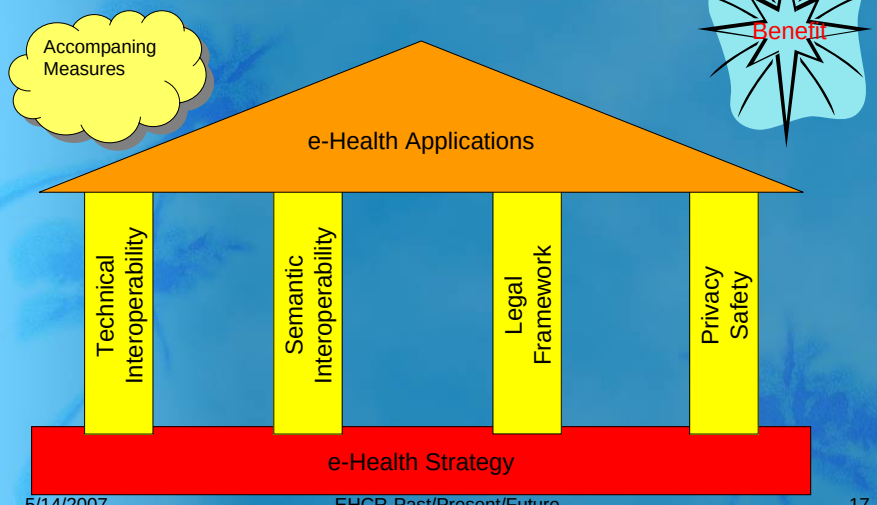
Strategic goals of eHealth

Technical and Semantic Interoperability

- Improvement of the quality of health care
  - by streamlining processes
  - by integrating processes
    - Improvement of the efficiency, effectiveness, safety, timeliness, …
- Online access to patient centred data for an optimal treatment and better patient management
- Online access to best medical knowledge
  - For citizen
  - For professionals
- Access to data for a better management of health care institutions
- Data for planning, quality assurance, research, …

Integrated health care

eHealth Areas



PHR: Personal Health Record

- Personal Health record systems are more than just static repositories for patient data;
- They combine data, knowledge and software tools, which helps patients to become active participants in their own care.

Tang, 2001

Advanced Features of a PHR /1

- Vital signs recording
- Graphing and trending of health data
- Visit data
  - Remind function
  - Online booking, scheduling and notification of appointments
- Health goals and planning
  - Daily living habits
- Wide range of interactive multimedia quality assured medical educational sources

Advanced Features of a PHR /2

- Links to health care services
  - Links to health care services and providers
- Events listing
- (Live) data exchange with health care providers
- Communications with patient groups
- Product shopping
- Drug interaction checks
- Emergency access

Usability of the PHR: extended

- Offer error prevention and error handling
- Enable shortcuts for frequent use

- Provide good consumer health terminology
  - Provide multimedia explanations to complex terms
  - Provide translation of common phrases into medically valid concepts

Functionalities of the PHR

- Providing secure access to personal medical information
- Providing and organizing **summary** of personal medical information
- Portal to patient-specific **consumer-level** health care information
- Providing **interpretive** information about medical data
- Serving as a database for patient-specific **self-monitoring and disease management**
- Providing patient-centered **portability and shareability**

– **Kim, 2002**

VHR: Virtual Health Record

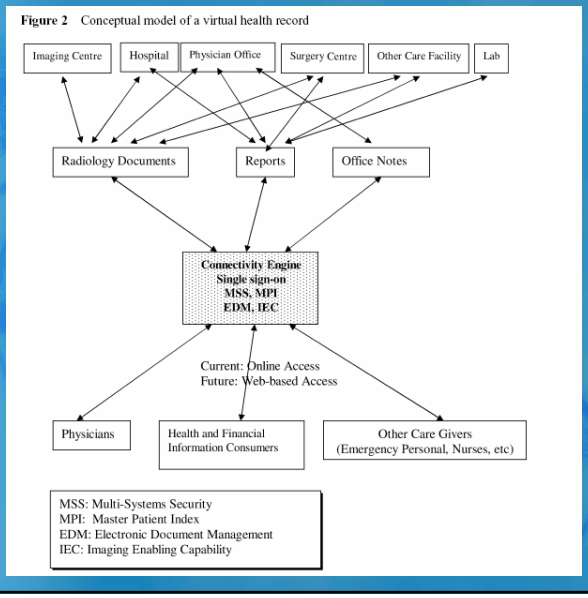
- A collection of health related data, information and knowledge about a single person, identified by a unique identifier
- Located in a variety of information systems at different locations on different media

- **Components of a VHR:**
  - A "connectivity engine"
  - A single sign-on
  - Multi-system security
  - Enterprise-wide Master Patient (Member) Index
  - Electronic document management
  - Workflow, automatic routing of electronic documents
  - Image enabling capabilities

Lander ML., 2003

Model of the VHR

Figure 2 Conceptual model of a virtual health record



Hough CBH, 2005

From the Viewpoint of Data Usage

- **Past** – destroying already digital data
  - Transforming data into pdf
- **Present** – not destroyed, but not usable
  - Missing standards
- **Future** – processing data

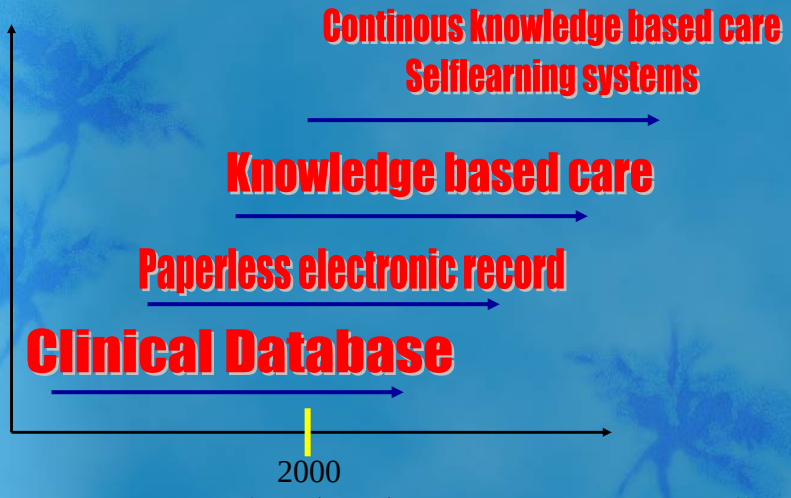
eHealth from the Quality Viewpoint

- **Past** – Structure quality
- **Present** – Process quality
- **Future** – Outcome quality

Storage of medical knowledge

- **Past** – Memory based
- **Present** – Paper based
- **Future** – IT based, digital

Developement of Healthcare Information Systems



Past

- **Paper based**
  - Digital paper
  - Scanned documents
- **Disease orientated**
- **Provider orientated**
  - Isolated systems
- **Proprietary technical solutions, few standards**
  - Standards are not available
- **Unstructured documents**
  - Free text
  - No standardized terminology

Flying Barbers

- During the 14th and 15th centuries, the Black Plague wiped out a vast number of university-trained physicians, and barbers became increasingly relied upon for medical procedures. "Flying barbers" traveled from town to town, setting up tents and offering their services. In 1540, Henry VIII united the Company of the Barbers and the Fellowship of Surgeons with a royal decree and created one unified trade guild — the **Company of Barber-Surgeons. Barbers** and surgeons remained joined in this way for more than two centuries…." CPBS.
  - http://www.connectingforhealth.nhs.uk/newsroom/worldview/protti13/

Artist - Craftsman - Scientist

The stethoscope

- The stethoscope, invented in 1816, is considered by many to be the **first 'true' medical technology.**
- However, its anticipated use was not initially assured: "That it will ever come into general use, notwithstanding its value, is extremely doubtful; because its beneficial application requires much time and gives a good bit of trouble both to the patient and the practitioner; because its hue and character are foreign and opposed to all our habits and associations" (London Times 1834).
- Today the stethoscope is a familiar status symbol carried in every doctor's 'black bag.'
- As Leyden describes it, "The stethoscope made objective diagnosis possible by providing the physician with greatly enhanced audible clues to the patient's physical condition. Previously, doctors had to rely primarily on the patient's descriptions of his or her symptoms, which often were unreliable and, sometimes, even misleading."
  - http://www.connectingforhealth.nhs.uk/newsroom/worldview/protti9/

The digital stethoscope

- Online signal analysis
- Automatic transfer to a database

Lessons Learned /1

The problem of the health care system is not only medicine, it's the organisation of health care!

Lessons Learned /2

High quality health care is a process, which depends very much on information!

Present, 2007.05.11 +/-

- **Paper and digital based**
  - **Digital and/or paper**
  - Scanned documents
  - Media mix
- **Disease orientated**
  - Managed Care and disease management models
- **Provider orientated**
  - Isolated systems for single provider or organizations
- **Insufficient usage of standards: HL7, DICOM, XML, …**
- **Many proprietary technical solutions**
- **Unstructured documents**
  - Free text
  - Information is destroyed: numerical values are transformed into pdf
  - Little or no standardized terminology
  - Some coding, e.g. for reimbursement

Work in progress!

Weakness of PRESENT ICT-Systems

- Limitations to the process of data entry and validation
- Insufficient support of (interdisciplinary) work flow
- Lack of effective procedures for error prevention
-
- Insufficient structured documents
- Low capability of data processing

PRESENT Healthcare Challenges

- Improving quality of care
- Better information and communication at the point of care
  - E.g.: support documentation, data analysis, scientific knowledge presentation
- Enhance productivity
  - E.g. support teams
- Increase efficiency by organizing workflows
- Reduce costs
- Pro-active support of health care providers
- Integrating the citizen / patient in his own health care
- Privacy and security

Crossing the quality chasm

- Providing
  - Safe
  - Effective
  - Efficient
  - Timely
  - Patient centered
  - Equitable
- health care

IOM, 2001

Awarness of the problems!

Find the best solutions!

The Future, 20xx

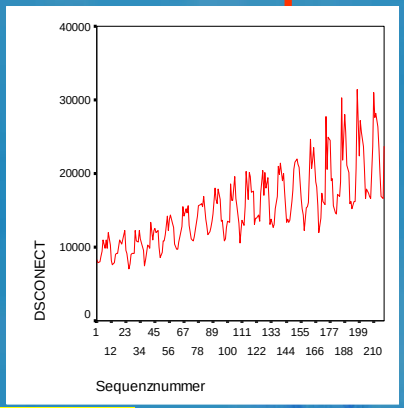
- **Cheaper**
- **Faster**
- **Better**

- Complete digital
- Integrated
- Mobile
- Structured
- Standardized
- Secure

Are we ready for the future?

Prediction – statistical viewpoint

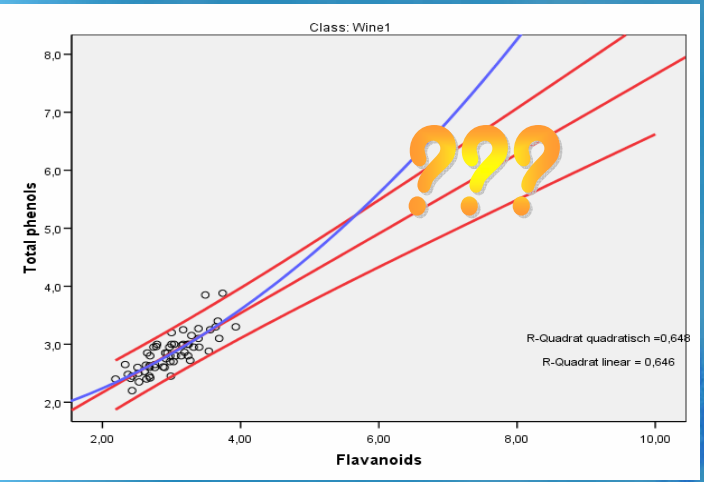
- Autoregressive Integrated Moving Average Model: ARIMA
  - Model order p,q



$$z_i = \phi_1 z_{i-1} + \phi_2 z_{i-2} + \ldots + \phi_p z_{i-p} + a_i + \theta_1 a_{i-1} + \ldots + \theta_q a_{i-q}$$

a_i...independent, normal distributed random variables

Prediction by Regression Models



- Consumer demand for personal health records (PHR) and the capabilities provided by regional health information organizations (RHIO) will change healthcare, just as automatic teller machines have changed banking.
  - Marion Ball, 2006

New technologies in health care

- Advanced imaging
  - Construct functional 3D images
- Molecular imaging
  - Analysis of metabolic activities
- System biology
  - Understanding how genes work in a biological system
  - New drugs

More precise diagnoses!

Treat causes, not symptoms!

Future of the EHCR / PHR / …

- Paperless, digital
- Health orientated
- Citizen / patient orientated
- Seamless
  - Process orientated
  - Integrated care
  - Team orientated
- Knowledge and evidence based
- Outcome orientated

Based on standards for technical and functional issues!

FUTURE: Content

- Structured documents
- Standardized terminology
  - Multilingual terminologies
  - Genomic data
- Standardized storage of images, vital signs, …
  - Results
- **Ready for further processing**
- Data models, data integration
  - Meta data

FUTURE: Documentation

- Based on clinical standards and guidelines
  - Documentation of deviations from standards
  - Using templates or archetypes or …
- Standardized terminology
- Use of standardized nomenclatures / ontologies
  - SNOMED-CT
  - ICD-10 / ICD-10
  - UMLS
  - **MeSH**
    - **Link to scientific literature**
- Less free text

Free Text or structured?

- Can computer interpret free text?
- What is the granularity of structured information?

- Free text analysis
  - Extract concepts
  - Extract codes
- Transforms them into a standard terminology
  - SNOMED-CT, ICD-11, UMLS, MeSH,…
  - International catalogue of procedures?
    - Description by OWL – Web Ontology Language
    - Formal description of a domain an its relations

From the Communication to the Architecture Paradigm

- Characteristic of the components
  - Open – distributed
  - Scalability
  - Flexibility
  - Separation of logical and technical views
  - Semantic interoperability
    - Interoperability at a service level
    - Common terminology and ontology
  - High security, safety and privacy

Archetypes

- Archetypes are descriptions of valid Entries, Sections and Compositions. These are expressed in a formal manner which enables them to be shared between systems.
- Reusable, formal model of a domain concept

- Example:
  - A blood pressure archetype represents a description of all the information a clinician might want to report about a blood pressure measurement, and may include some aspects which are mandatory.

- Archetypes model information
- Ontolgies model reality

OpenEHR, 2006

Best knowledge at the point of care

- Access to knowledge base
  - Scientific literature
  - Evidence based medicine
  - **Ongoing clinical trials**
    - EMEA database
    - Local/national trial database
- Language for the presentation of medical knowledge
- Standards for the presentation of clinical pathways and guidelines

Information Therapy - iHealth

- Information based health care
- Better information
- Better choices
- Better health

Psycho Therapy
Pharma Therapy
Logo Therapy

What is Information Therapy?

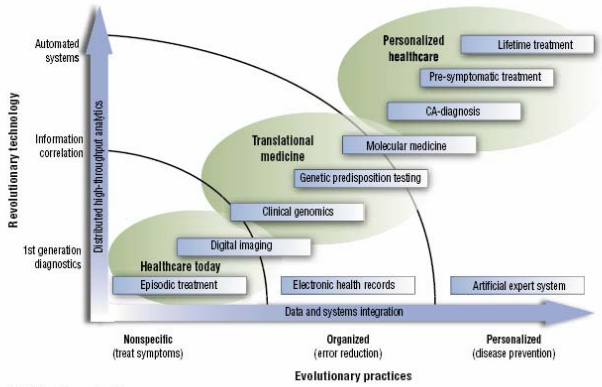
- Information can help to improve your health
- Information can help to save life

Revolutionary Technology Evolutionary Health Care

- "Scientific advances and discoveries, as well as new technological capabilities, will be **revolutionary**. Innovation in the practice of medicine will be **evolutionary**. The combination of revolutionary technologies and evolutionary practices form information-based medicine will shape the future of personalized healthcare."
  - http://www.connectingforhealth.nhs.uk/newsroom/worldview/protti9/

eHealth Market Trends

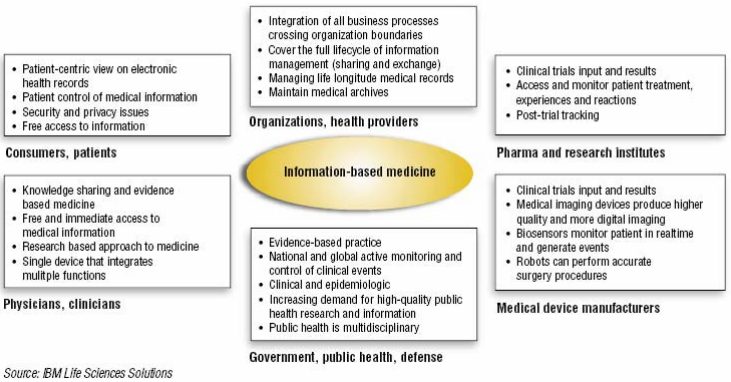
Figure 1: Market trends and drivers: revolutionary technologies and evolutionary practices.



Source: IBM Life Sciences Solutions

Information based medicine

Figure 3: Information-based medicine ecosystem.



Source: IBM Life Sciences Solutions

Genomics / proteomics / ..omics

- Standardized storage of huge amounts of data
- Support for the analysis of these data
  - Online genetic information systems for health care providers
- Personalized medication
- Personal risk profile ???

FUTURE: Usability

- Easy to use EHCR / PHR
  - Ease of navigation
  - Assistance
- Support and ability to find desired information
- Design: Site presentation and layout
- Fast
  - Time to complete tasks
- Interactive
- Pro-active

Provider Personal User Profile

- Specific view of a **provider** on the EHCR
  - Avoid information overflow – filter information
  - Functional, role based access
  - Different views: GP, cardiologist, urologist, …
  - Automatic selection of user specific items
    - User “relevant” items
  - Preprocessing of data
    - E.g. time course of laboratory data
      - Significant trends, changes, outliers
- Features have to be extracted automatically and used as an extension of the MPI
  - E.g. ICD-11

FUTURE: Pro-active systems

- Data (pre-) processing
- Data presentation
- Decision support
  - Integrated in online ordering
- Image recognition
- Reminder systems
- **Personal health care agent**
  - Personal health related knowledge finder
    - Based on the personal health profile
    - Learning systems

Machine Learning
Artificial Intelligence

FUTURE: Robotics

- Virtual planning of health care interventions
  - Simulation of operations
  - Simulation of physiological outcomes
- Online process control
- Self learning systems

eHealth Cyberspace

- Learning with virtual patients
  - Interactive multimedia textbooks
  - Virtual medical universities
- Planning of procedures on real data

Telemedicine Services

- Integration of Telemedicine services in the workflow
- Tele-Radiology
- Tele-Pathology
- Tele-Ophtalmology
- Tele-Dermatology
- …
- **Tele-Consulting**
- …
- Tele-Psychiatry
- Centers of excellence
  - 24h * 7 days

FUTURE: health care administration

- Many administrative data are a side product of medical documentation
- Automatic extraction of features – classification terms

FUTURE Management of Health Care Providers

- Competition by quality
- Quality performance rewards
- Patient centered interdisciplinary team based cooperation
- Ressource management

FUTURE: Health Politics

- Responsibility for the strategic goals
- Responsibility for the eHealth infrastructure
- Responsibility for technical and semantic standards
- Responsibility for legislation regarding privacy and safety
- Responsibility for quality assured patient and health care provider information

eHealth and Public Health

- Surveillance
- Informed prevention
- Quick response to outbreaks
  - Based on clinical data
    - Including genomic data
- Improved analytical epidemiology
  - Better understanding of environmental, genetic, social factors
  - Disease mining

Health Care Financing Models

- Episode of care
  - Instead of fragmented elements
- Patient management models
  - Disease management
    - Chronic disease
- Prevention
- ICT support for patient empowerment

The Patient of the Future: Earnest Sickl

- In German: Ernst Krankl
- The health record:
  - Multi-morbid, previous sportsman
  - Allergies, asthma, diabetes, high cholesterol, high BMI, artificial knee, …
- At the moment: heart and circulation problems
  - ICD-11 Codes: K47.11, S007, …

Mr. Sickl´s PHR

- Electronic weight and diabetes journal
  - Weight and blood sugar measurements are sent to the handy and from there to a database
  - Automatic analysis of the data for trends, outliers etc.
  - In the case of problems a message is sent automatically to his healthcare provider
- Because of his bad compliance his medication is marked by nano-technology
  - He gets an automatic reminder to take the medication
  - His waste basket is equipped with a sensor
  - If he puts the medication in it, a signal is sent to his health care provider

FUTURE Research Challenges /1

- Models, concepts for the representation and communication of medical content
- Computer assisted structured and standardized documentation
- Representation of medical knowledge
- Representation of clinical practice standards and guidelines in information systems
- Usability
- Presentation of patient data
- Processing of patient data
  - Decision support
  - Learning systems
- eLearning system

FUTURE Research Challenges /2

- User interface for mobile equipment
  - Barrier free access
- Who has the best solution for the implementation of a certain standard?
- Artificial agents for searching best knowledge based on patient / provider profiles
- Integration of data from genomics, proteomics, …
- Re-organization and transformation management of the health care and social system with respect to eHealth
- Cost – benefit analysis
- Evaluation of the development of eHealth
- …

Electronic health records: useful tools or high-tech headache?

Nelson R., Am J of Nursing, 2007

The eHealth Looser

- Paper industry
- Ball pen industry
- Snail mail

- Medical wizards
- Miracle healer

The eHealth Winners

- Citizen / patients / consumer
- Health care providers
- ICT-industry

- Research

- Financier?

Conclusion

- eHealth is more about understanding people and processes, developing new models of care than about technology
  - Don´t forget the patients and the health care providers
  - Start transformation management
- ICT is the necessary and appropriate tool
- Innovation in health care has to be evolutionary
- eHealth is the synergistic effect between modern knowledge based medicine and ICT
- eHealth is fit to face the challenges of the 21st century
- We need more incentives to implement eHealth

Scope of the eHealth Strategy /1

- **Documentation**
  - Structured
  - Standardized nomenclature / terminology: ICD-10, SNOMED, UMLS, MeSH
  - Standard architecture for documents
  - Standardized document header or envelope
- **Communication**
  - Based on standards
    - SOAP (XML, UTF8, MIME)
      - E.g. Letters for names of foreign citizen
    - IHE
    - HL 7 (V3)
    - DICOM
    - Recommendations from CEN TC 251
  - Secure and save
  - Hardware specifications for mobile equipment
    - ISO / IEEE 11073

Information autonomy of the citizen!?

Scope of the eHealth Strategy /2

- **Archiving and identification management**
  - Key card
  - Role concept for access
  - Long term availability
  - Fast access
  - Registries and archives are organized by a trusted party
  - "A document should exist only once!"
  - Protocols of access
- **Processing**
  - Decision support
  - Implementation of clinical pathways
  - Analysis for planning, quality assurance, management, financing, …
  - Scientific use