eHealth and ethics in Europe

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Overview

- Introduction
- What is eHealth?
- What is ethics?
- People, process(es), technologies
- From theory to implementation
- *Fora* for debate
- Conclusions
- Wrap-up

What is eHealth?

- Origins
- A journey and milestones
- Where are we today?
- A tale of two (or more) definitions

A tried-and-tested definition

- eHealth as conceived by the eHealth action plan (COM(356)2004, p4)

'[eHealth] describes the application of information and communications technologies across the whole range of functions that affect the health sector.'

Examples: health information networks, electronic health records, telemedicine services, personal wearable and portable communicable systems, health portals, and many other information and communication technology-based tools assisting prevention, diagnosis, treatment, health monitoring, and lifestyle management.

A pending definition

- eHealth as conceived by the Lead Market Initiative in relation to eHealth (forthcoming, p3, due for publication at end 2007)

'eHealth can thus be said to cover the interaction between patients and health-service providers, institution-to-institution transmission of data, or peer-to-peer communication between patients and/or health professionals.'

It can also be said to include: health information networks, electronic health records, telemedicine services, personal wearable and portable communicable systems for monitoring and supporting patients.

And further considerations

- A balance of **access**, **quality**, **and economy** (effectiveness and/or efficiency) ('AQE')

    But is the AQE relationship really an equilateral triangle?

- Adding **provision**, **continuity** (Q), and **safety** ($S = Q$) to the mix

An adaptation of unpublished work by Healy and Purcarea (*circa* 2003)

What is ethics?

- A branch of moral philosophy
- Several schools of thought and action
- Various ethical theories
- Two theories are mostly in current use in applied ethics
- A trend, however, towards mixed models

Normative ethics

- Kantian ethics
  not treating a person as a means to an end
- Utilitarianism (consequentialism)
  having a concern for the greater good

Applied ethics

- Using ethical theories as a point of departure to enable us to act appropriately

  ➢ Toolkit: At any given moment in time; in any specific context with its constraints and criteria; helps give leverage to analyse and know your own position and why (in relation to the theories).

Health and ethics

- Non-malfeasance   (Q/S)
  doing no harm
- Beneficence   (Q/S)
  promoting   wellbeing,   reducing   risks,
  protecting people
- Respect for autonomy (Q)
- Principle(s)   of   justice/equity   (A)

And where - if anywhere - is
the economy (E)?

An adaptation of Beauchamp, T. & J. Childress (2001)

Applied principles in ICT (in eHealth)

'the correct information at the right time, to the right people'

- Security
- Integrity
- Material quality
- Usability
- Accessibility

(Duquenoy, George, and Solomonides, *What ELSE? Regulatory and compliance in medical imaging and medical informatics* (forthcoming)

HEHIP (2003), *A handbook of Ethics for Health Informatics Professionals*, The British Computer Society, 2003 (endorsed by the International Medical Information Association)

People, process(es), technologies

Core issues - people

- ## Citizen and/or patient

  User association, consumer association, carer, advocate, parent

- ## Health professional

  - General practitioner (family doctor), clinician, surgeon, nurse, anaesthetologist, ambulance worker, emergency worker
  - Manager, support staff (receptionist, secretary), accountant, archivist, librarian, clinical researcher
  - Pharmacist, opthamologist, dentist, other medical or health specialist

- ## Health authority representative

  local, municipal or city, regional, national

- ## Policy-maker

  local, municipal or city, regional, national

- ## Industry

  software, hardware, middleware, infrastructure, large, SME, medical devices, imaging, consumer products

- ## IT professional

Core issues - process(es)

- Prevention
- Diagnosis
- Treatment
- Health monitoring
- Lifestyle management

Basket of technologies

- Portals, Web, Web 2.0, social networking
- Electronic health records
- Personalised healthcare (near-to-body, in-body)
- Telemedicine
- Bio-informatics
- Virtual physiological human

Basket of technologies

- Medical (digital) imaging
- Robotics
- Sensor technologies (including bio-sensors)
- Health GRID
- Micro- and nano-technologies
- Photonics

… and so on.

A growing tendency to ....

Converge

An Internet of Things

A 'Google' for Health?

The Internet of Things (ITU, 2005)

- 'A combination of [various] developments will create an Internet of Things that connect the world's objects in both a sensory and an intelligent manner.' ITU (2005) *An Internet of Things*. International Telecommunications Union, Geneva

- The combination of technologies includes large databases and networks, item identification, sensor technologies, miniaturisation, and embedded intelligence.

Connected health

- ## Electronic health records and patient summaries

  eHealth interoperability means contributing 'to enabling the provision of a means of **authorised healthcare professionals to gain managed access to essential health information about patients, subject to the patients' consent, and with full regard for data privacy and security requirements**. Such information could include the appropriate parts of a patient's **electronic health record, patient summary, and emergency data** from any place in Europe: within countries, in cross-border regions, and between countries.'

Shifting from theory to implementation

- **Research**: internationally, 40+ years of developments; in Europe, close to 20 years of research and technology development co-financing
- **Policy**: 7-year plan for policy convergence (the eHealth action plan and *i*2010,aiming for 2010); massive health systems (and health strategy) review
- **Deployment**: Competitiveness and Innovation Programme, Policy Support Programme - large-scale pilots on electronic health data, emergency data sets, and ePrescribing; all the European Member States
- **Market**: this year - renewed focus on eHealth market

Sidebar: legal and economic issues

- **Legal and regulatory aspects of eHealth**
  - ➢ **By end 2009, European Commission and Member States:** provide framework for greater legal certainty of eHealth
  - ➢ **Legally eHealth (2006)**: range of case studies that can be used in teaching and training (data protection, data privacy and confidentiality, product liability; competition law)
  - ➢ **Policy conclusions**: review legal uncertainties in data protection, product liability, and competition law; dissemination of legal knowledge and consumer protection issues; eHealth information infrastructure guideline(s)
  - ➢ **Current call for tender:** (closing date - 12 September 2007)
- **Economic aspects of eHealth**
  - ➢ **Outcomes: *eHealth is Worth it. The implemented benefits of implemented eHealth solutions at ten European sites*** (2006)
  - ➢ **Continuation:** work done in Good eHealth project (2006-2008)
  - ➢ **Current call for tender:** (closing date: 13 August 2007)

Fora for debate on ethics

- The *agora*, the *forum* (*fora*), where you are today (our life, this life, other lives)
- Your place of study or work, occupation or profession
- Your political sphere
- Other parts of the onionskin

Karlstad - or wherever we are today

- The lecture hall
- The workshop
- Over lunch
- Over a drink
- Out in the sun or avoiding the rain

A framework for ethics of computing

- IFIP special interest group, 9.2.2, founded *circa* 1995
  - ➤ collecting cases and codes of ethics in international computer societies
  - ➤ *Ethics of Computing: codes, spaces, for discussion and law**
  - ➤ Governance of the Internet
  - ➤ Criteria and procedures for developing codes of ethics or of conduct
  - ➤ [PENDING] Professional ethics groups: suggestions for functions, form, and structure

* Berleur, J. and K. Brunnstein (editors) (1996) *Ethics of Computing: codes, spaces, for discussion and law.* Chapman and Hall

European Group on Ethics

- founded in the late 1990s
- reports to the European President
- body of experts (lawyers, philosophers, ethicists) who take further expert advice
- offers Opinions (non-mandatory advice or guidance) on key ethical issues
- increasingly Opinions are related to either health and/or information and communication technologies

stem cells, bio-medical research, clinical research in developing countries, genetic testing in the workplace and *via* the Internet, ethical issues in healthcare in the Information Society (1999), ICT implants (2005). nanomedicine (2007)

Conclusions

- Ethics matters
- Ethics is not just theory, it is day-to-day practice
- Ethics is not just what we think, it is what we act and do
- The first job is to get informed

Wrap-up

- 'Motherhood and apple pie' …. makes it sound easy
- But there are many tensions and contentions
- Ethics is a process
- Start from where you are, choose an area that concerns you (not necessarily eHealth), and get active
- Good luck, have fun, and make your legend a safe journey!

Your further feedback and follow-up

- For more issues on eHealth, please access:
  http://ec.europa.ec/information_society/ehealth/

- Other interesting sources of info: eHealth insider; eHealth COM; euroactiv (link to health and eHealth)

- Please give me feedback at:
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