



TERVEYDEN JA HYVINVOINNIN LAITOS

The challenges of health ICT and vulnerable people

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Ethics, HICT, vulnerable people

Layout:

- Premise: All patients are more or less vulnerable
- Claim: HICT is often not treated as health technology
- Question: What if we started to treat it as such?
- Answer: We would conduct a thorough health technology assessment (HTA) including ethical analysis, before implementing
- How is such HTA done what would it look like?



Define Health ICT, vulnerable people?

- “Health ICT”: technologies relevant to health that facilitate communication and the processing and transmission of information by electronic means
 - Includes everything from television programs to the interactive internet resources and personal digital assistants
- Impossible to say how HICT as such influences vulnerable people
- “Vulnerable”: all *patients* are somehow vulnerable
 - Need rights, protections
 - Different technologies make different people vulnerable
- Need to identify these technology-specific groups
- Need to develop an approach for evaluating and introducing new HICT's, safeguarding vulnerable people



HICT is not treated as health technology

In contrast to HICT:

- Developing pharmaceuticals is guarded by rigorous processes and safeguards, incl. ethics committees
- Introducing pharmaceuticals requires approval, which requires the producer to proof benefit
- Continuous follow-up of unexpected side-effects is required
 - Technologies must benefit, and not harm, *patients*
 - Drug companies have huge liabilities if patients are harmed



In contrast to HICT...

- Evidence-based medicine institutions continually follow and appraise the evidence of effectiveness
- Formal health technology assessments are conducted on many technologies before uptake
 - Improving?
- As a result:
 - Knowledge base on HICT poor on medical standards
 - Implementation often done under uncertainty
 - Attitude to implementation relatively careless
 - Especially regarding harming patients.



How to assess HICT? General approach:

- Health technology assessment (HTA) approach should be broad, multidisciplinary
 - Not just costs and intended effects
 - Also analysis of safety, social, organisational, ethical, legal aspects of technology
- Technologies are socially shaped
 - Real world affects technology use and visa versa
 - Technologies have unintended/hidden consequences
 - Lab results may not match real world effects
 - Assessments need context-specificity
- Ethics should be integrated, not added, into the HTA
 - Implementing technology has ethically relevant effects
 - Technologies carry – and challenge - values
 - HTA is value laden



How to assess HICT? Issues to consider

1) Is the technology a new, innovative mode of care?

- The consequences of totally new models of care are likely to be more difficult - but more important - to predict than the consequences of replacing an old technology
- The literature and research base on novel topics may be narrow.



Issues 2: technologies carry values

- Can the technology challenge religious, cultural or moral convictions or beliefs of some groups or change current social arrangements?
 - E.g. family hierarchies, birth control, privacy ideals
- These groups are vulnerable to implementation of technology
 - Acceptable alternatives may be needed
 - Not solving value-conflicts risks uptake and use



3: Hidden/unintended consequences?

- Technology may be used for other than the intended purpose
 - Humans use technologies for their own ends
- Even intended use may have unintended side-effects
 - Context defines how many technologies actually work
 - E.g. HICT-illiterate patients may drop out
- Technologies have effects on many other stakeholders than just the intended targets
 - E.g. technologies may change/disrupt division of tasks, information, power and money between different professionals, payers and patients
 - Should be openly assessed & discussed

→ Real-world consequences should be evaluated



4: Patients right to autonomy?

- Technology may increase or limit possibilities for autonomous choices
 - Information and communication necessary for autonomous decision
 - Generally a big hit – but equality of access?
 - Will people also have right to choose whether to use Health ICT or not?
 - In many cases not
 - Legal regulation?



5. Special care of vulnerable people?

- “Traditionally” vulnerable = non-autonomous
 - Unconscious, mentally handicapped, demented, children, psychiatrically ill
- At risk, as many HICT require cognitive skills?
 - Specific support may be needed
- New HICT’s especially to support the rights and well-being of these groups
 - Automatic health monitoring, locating, alarming etc?
 - Who will decide on the use of these?



6. Beneficience / non-maleficience

- Usually the patient should decide on the balance of benefits and harms in health care
 - Not always with Health ICT
- Who should balance the benefits and harms of HICT?
 - IT-department, physicians, patients, politicians?
 - What decision-making processes are needed?
- HICT often affect many other stakeholders
 - E.g. relatives, other patients, organisations



7. Human integrity and dignity

- Dignity = people have intrinsic moral value
 - HICT may risk reducing people to information, to means, commodified, to health maximisation etc.
 - Cost-effectiveness, utilitarianism is not enough
- Integrity = possibility to live according to ones moral convictions and commitments
 - One size fits all – attitude to technology
 - Balance of control, trust and honesty in health care
- Technological imperative
 - What can be done will be done



8. Challenges to traditional roles, ethos

- Technologies may change the relationship between physician and patient or interfere with professional ethics, values or culture
 - Sometimes deliberate, poorly anticipated
- Rights and moral integrity of health professionals?
- Technologies that align with professional ethics may be more likely to be implemented



9. Justice, solidarity, fairness?

- Equality of opportunity vs. health equality?
 - Healthy, young people are more prone to new HICT
 - Safeguards to guarantee access according to need
 - Reimbursement mechanisms
- Caregivers?
 - HICT might change roles, burden



10. Legal and moral rights

- Even if rights do not change, HICT might change their realisation
 - i.e. privacy and internet: ease of access will be a great change, even if information content and principles are unchanged
 - Will vulnerable people keep their privacy?
- Is current legislation adequate?



In sum:

- Health ICT should be approached with similar seriousness than other health technologies
- To estimate the effects of Health ICT's on vulnerable people, a ethically and socially sensitive Health technology assessment would be idea
- To start doing these, try the EUnetHTA core model
 - Issues presented adapted from that model
 - Integrates ethics into HTA
 - www.eunetha.net, Saarni et. al. Bull WHO 2008



Thank you

