Ethics in the field of ICT for independent living and home care

- Some findings from the 'ICT & Ageing Study' -

Lutz Kubitschke

empirica

Research context

- Commissioned by the European Commission, Directorate General for Information Society and Media, unit ICT for Inclusion.

- Duration: 2008 - 2009

- Core research team: empirica wrc WORK RESEARCH CENTRE fortec

- Supported by and national correspondents in 16 selected countries:

Relevance of ethics in the 'ICT & Ageing' domain

- Relevant in any field of human activity and endeavor

  … but in the ICT & ageing field

- Combination of characteristics of many of the technology applications in question and the vulnerabilities / needs of older people brings ethical issues strongly to the fore

What are ethics about ?

- Many ethical theories and perspectives, but less hands-on experiences and operationally useful guidance to the 'ICT & Ageing' field

- Put simply, ethics in this field are about what stake holders 'should' do as the right thing :
  - for the good of those who are targeted as users
  - for the good of those who are collaterally affected
  - for the common good more generally

The many levels of ethics in the 'ICT & Ageing' domain

- **Research ethics**:
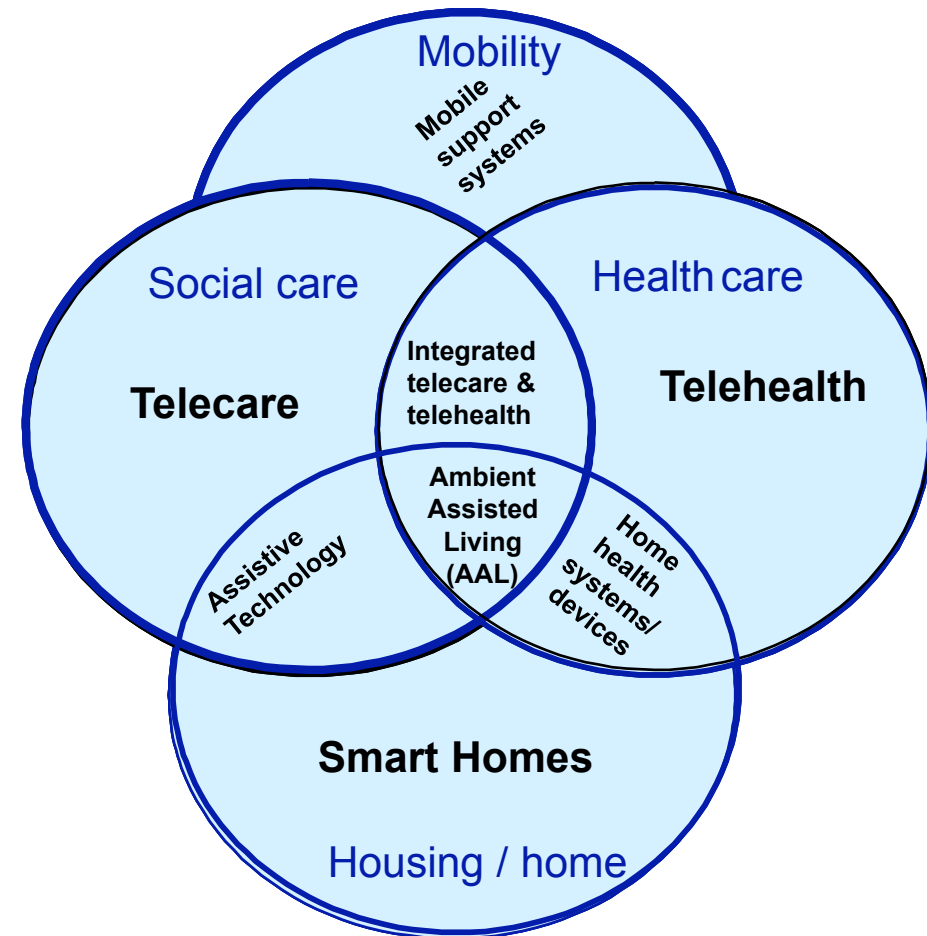 - organisations / individuals developing / testing technologies
  - those designing features & functions of ICT applications / ICT-enabled services

- **Deployment ethics**:
  - organisations implementing ICT within their services repertoire
  - staff working with clients

- **Distributive ethics:**
  - society / governance systems
  - organisations implementing ICT within their services repertoire

Research ethics

- **A lot more attention to ethics in clinical / biomedical research when compared with social research and socio-technical RTD**

- **For clinical research with human beings, widely accepted ethical principles formulated (Belmont Report, 1979):**
  - respect for person (e.g. personal dignity)
  - beneficence (e.g. do no harm, maximise benefits)
  - justice (e.g. no unfair burden)

- **Some issues of application in the ICT & Ageing field:**
  - informed consent (e.g. comprehension, voluntariness)
  - assessment of risks and benefits (e.g. system/devices reliability)
  - selection of subjects (e.g. equlity of participation)
  - data privacy (e.g. anonymised reporting of testing outcomes)
  - ...

Distributive ethics

- **Macro-ethical perspective:**

  – fair distribution of and access to quality/preferred services across the society/country (e.g. ICT-based forms of support)

  – research priorities and resource allocation (e.g. economically vs. socially driven research)

- **Micro-ethical perspective:**

  – fair distribution of and access to quality/preferred services across client/user subgroups of fully-up-and running ICT-based services (e.g. 'creaming and dumping' in client/user selection)

  – fair sharing of the burden of care between formal services and informal supporters (e.g. shift of 'point of care' into the home)

Deployment ethics

- **Implementation planning/strategy**
  - Up-front assessment of possible ethical impacts of implementation strategy (e.g. distribution of risks/benefits to stake holders)
  - Adherence to binding/non-binding ethical value frameworks (e.g. regulation/legislation, codes of practice)
  - …

- **Enrolment**
  - Adequacy of available technology/application vis-à-vis the client's need and intended outcomes (e.g. benefits expected to arise for the client)
  - Reasonableness of any potential burden placed on the client (e.g. when installing / maintaining equipment) and/or others (e.g. family)
  - …

- **Operation**
  - Adequate guidance / training / on-demand support to clients re operation of equipment (e.g. in routine usage and emergency situations)
  - Ensuring ability / free decision of client to withdraw from the services at any time without fear to experience negative impacts (e.g. loss of care services more generally)
  - …

Some conclusions

- Ethical issues not a major deployment barrier up to now, but can be expected to come more to the fore in future
  (according to national experts from 16 countries)

- Many aspects of ethics in the 'ICT & Aging' domain no simple 'black-or-white' matters
  (e.g. ethical dilemmas such as service effectiveness vs. data privacy)

- 'Contextualisation' of generic ethical principles and guidelines often not straightforward

- Need for ongoing informed dialogue/opinion forming, guidance/ promotion and - where appropriate - codification cutting across established domain boundaries

Further information

For further information see **www.ict-ageing.eu**:

- ✓ Final study report

- ✓ Country profiles

- ✓ Compilation report on ethical issues

- ✓ Case studies

- ✓ Workshop report