How can legal preconditions and ethical insights help increase professional trust in eHealth?

Samantha A. Adams and Anton Vedder
s.a.adams@uvt.nl

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Understanding Society

the Netherlands as case

- Interesting case
  - Well-known for advanced digital infrastructure
  - High access and use percentages for internet and mobile technologies
  - Notoriously public failure of national EPD, owing to political concerns
  - Slow uptake of mHealth;
    - Categorized by Wendy Currie (October 2014) as 'follower' rather than 'front runner' (together with France, Germany and Belgium)
      http://vitaltransformation.com/enabling-technologies-for-better-patient-outcomes-live-streaming-from-the-europena-health forum-gastein/

- Large policy push for more "e" and "m" in healthcare
  - 2013-2014: 2-3 major policy reports + high-profile letter from Minister
  - 2014: EU mHealth Green Paper + addendum

- Funding programs advocate *socially responsible research and innovation* (RRI)
  - Less attention for "already known" sectors, i.e. eHealth
  - Picked up in the private sector, mostly by larger companies

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Reasons for slow uptake of "e" and "m" in Dutch healthcare

- Dutch physicians (and health-sector managers) indicate: ethical and legal uncertainty is a primary reason for *not* adopting these innovations
  - Ideals of patient self-management, empowerment, etc have consequences for professional functioning
    - Concerns about legal liability
  - Much of the regulatory framework surrounding and supporting health care needs to be updated
    - At least 6 relevant national laws
      » 4 health-sector-related laws are non-ICT specific
      » 2 laws related to ICT, only 1 is health specific

- Developers often have insufficient knowledge of (legal) requirements and risks

- Intended users (patients *and* professionals) not included, included too late or become 'token' participants in design and development

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Tensions (non-exhaustive list)

- Market rhetoric and ideology
  "anybody's game"

- Development and "scaling up" takes longer than standard funding cycles

- Government actors claim interest is in improving citizen health

- More interest in 'social robustness' as part of responsible research and innovation

- 'Personalized' and 'unobtrusive' technologies better align to user needs

- Distinction between medical device and lifestyle assistance becoming "fuzzy"

- Search for one-size-fits all solutions

- Mutual dependencies; successes are exception, rather than rule

- Developers and/or institutions juggle a two-pronged strategy due to 'uncertainty'

- Also have economic interests, some preclude social scientific research

- Often reduced in practice to informed consent and data protection

- Raise a number of ethical, legal and social issues

- "Lifestyle" apps close to "care" have (legal) consequences for technology

- Variations in technology and types of care

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How to secure trust?

- Look to a more structured framework for 'socially responsible research and innovation' (e.g. Stilgoe et al 2013)

    - Involves including actors much earlier in conceptualization, research and development of innovations
    - Abandons distinction between development and implementation as separate phases
    - Examines the role of social power relations and both existing and potential governance structures
        - Includes shifting focus from what law cannot do or what it prohibits to what it *can* do and how to work within the *possibilities* it offers
        - TILT: examine how ethics and legislation can play a more instrumental role as framework that creates conditions of interactions and delineates boundaries between actors

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However…

- Is a tricky process

- Involves some experimentation in practice

- Also runs risk of tokenism

- Law as "framework that creates conditions of interaction" is fragile notion
    - Current laws must strike a delicate balance between protecting patients and not overburdening professionals
    - Collective action dilemma's
    - Non-acceptance, especially in highly-regulated, protected fields

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