New challenges for health IT - design fit for life

Geraldine Fitzpatrick
Institute of Design and Assessment of Technology – HCI Group
Vienna University of Technology

Meeting the challenges of long term care & aging population
At ‘home’

Wellness

Shared

Professional care
Management

In institution

Self & informal care network

Treatment

Professional care network

Self care

Systems & infrastructure

In institution

Dedicated

Episode

Different design spaces...

Technology as key enabler

At ‘home’

At institution

Self & informal care network

Devices

Professional care network

Integrated Everyday life!

Dedicated Episodic

Design4Health...

At ‘home’

Design fit for LIFE [quality of]

In institution

New design challenges!

Design fit for CARE

Integration
Sensemaking

Diversity

Dedicated Episode

“If I’ll get old later but on my terms if I can keep learning and adapting and if we can keep compensating for the things that happen” [Jim]
Collage of stories... acknowledgements

- Motivating Mobility Project – UK EPSRC
  - Nottingham, Sheffield-Hallam, Southampton, Dundee, Oxford, Dundee
  - Madeline Balaam, Eric Harris, Lesley Axelrod, Ann-Marie Hughes, Stefan Rennick Egglestone, Anna Wilkinson, et al

- eHome Project – Vienna
  - TU Wien (FORTEC), CEIT, BMVIT, FFG, Treventus
  - Marjo Rauhala, Eva Ganglbauer, Florian Güdenpfein


- Various other projects...

Design for

Appropriation
Integration
Adaptation
Into
Spaces
Routines
Social context

Spaces: What ‘real’ homes are like
Lesley Axelrod et al

Sam’s house

Kitchen
\%bathroom

Sitting room
\%bedroom

Aesthetics & appearances matter

“We do not want our homes looking like a clinic or a hospital”
(Blythe et al, 2005)

Aesthetics & appearances matter

“house is full of things I want”
“I don’t want my bathroom to look like a hospital ward”
(Alan Newell, 13 July, D4H2011)

eHome LUI

„Space is space!“
[Elisabeth]

„Perhaps a brown frame instead of black. Then it would match the furniture better“
[Edeltraud]
“Leaving the medication out for everyone to see [...] would depict a sick person, which was in sharp contrast to the picture she wanted to give her guests – that of a meticulous woman living in a tidy home.”

[Stinne Aaløkke Ballegaard PhD thesis; Palen and Aaløkke CSCW06]
Contended ‘shared’ resources & spaces

Design for
- Appropriation
- Integration
- Adaptation
- Into
  - Spaces
  - Routines
  - Social context

Design4Health…

Design for
- Collaborative sensemaking
- Compliance, control, surveillance
- Interpretation

Moving care into the home
- Telecare, remote monitoring, …

Physiological monitoring
- Telecare systems
  - (eg Docobo)

Safety/security monitoring
- Assistive Technologies
  - (eg Tunstall)

Evidence?
- DoH ‘self care’ reports
  - 2006 (Fitzpatrick et al)
  - 2007 (Dost)

WHO/HOW do we understand and use the data?

Monitoring Issues…

Moving care into the home
- Activity / lifestyle monitoring, …

Evidence?
- Systematic review
  - Brownsell et al, JTT, June 1 2011

- Mostly pilot studies
- Evidence weak
- When and how changes trigger call for help?

What will it be like to live with this?

[MIT House_n]
e.g. Dealing with eHome ADL data

Making sense of activity in daily life eHome

What outcomes for whom?

Highest category of logged calls:

false alarms

Re-think as infrastructure? Value-add?

Collaborative interpretation

Implantable cardioverter-defibrillator devices (ICD)
[Andersen et al IJMI 2010]

‘Interpretation work’
- Numbers ***
- General condition
- Pt’s own interpretation

Telemonitoring *** - clinicians experience problems interpreting (ICD) data
⇒ myRecord

[Andersen et al IJMI 2010]
**Collaborative interpretation**

**Design4Health…**

eDiary – Diabetic pregnant women

[Aarhus et al. ECSCW2009]

**Design for diversity**

Over time, across individuals …

‘Patient empowerment’ & engagement … & (dis)engagement

*Implicit ‘normative’ agendas?*

**From compliance to ‘educated’ personal control**

“Now its use goes beyond […] its appropriation takes the form of a deeper entanglement with the intricacies of real life where doctors are no longer in the picture.

From being an instrument of compliance, the glucose meter has become a means of self-management and self-determination where the levels of glucose can be tweaked and adjusted to gain increasing control over the disease.”

[Storni 2010]

**Design4Health…**

**Diverse experiences … different choices**

**Diversity over time**

changing needs, abilities, energies, engagement…

Self motivation

Autonomy & choice …

patient says ‘NO’!

Function & ability

Example: eDiary

[Aarhus et al. ECSCW2009]
Challenges re-thinking the role of clinician

In conclusion

More complex dimensions

Systems & infrastructure
- At home
- In institution
- One of many
- Autonomous
- Choice
- Motivation
- Self & Informal control
- Devices
- Professional control
- Passive
- Invisible
- Main focus
- Prescribed
- Imposed
- Schedule
- Visible
- Schedule

How we conceptualise design for health at home matters

- Patients
  - NOT a healthcare problem to be solved
  - autonomous individuals making necessary adaptations to live quality life ... within specific psycho-socio-cultural-economic-spatial-etc contexts
  - Health only one of many concerns/factors
- Home
  - NOT extension of the hospital / clinic
  - "my space", a safe comfortable environment, full of memories and stuff that I like and want, where I am in control
  - Negotiated shared space
- Clinician
  - NOT "controller/monitor" of care
  - support, guide, advisor, educator, coach, collaborator

Designing for home care – fit for life

- Requires different design sensitivities
  - Ownership, autonomy, choice ...
  - Practical constraints of space & skills ...
  - Aesthetics, fit ...
- Fit for life
  - Opportunities to meet clinical needs and meet personal ‘quality of life’ needs – value add
- Designing for
  - Appropriation, integration, adaptation
  - Collaborative sensemaking
  - Diversity

Challenge to us as designers

Reflective practitioners

- What values and normative models are we implicitly (or explicitly) inscribing in our designs for health at home?

- What outcomes for whom are we designing for and measuring?

Designs to *live* with