

Studying how researchers and developers interact with informal carers during an innovation project

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Marc Steen, [marc.steen@tno.nl](mailto:marc.steen@tno.nl)  
TNO Information & Communication Technology

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Marc Steen, Consultant

# About me, and context

I work at TNO Information & Communication Technology (Delft, NL), a not-for-profit research and development organisation

Part-time PhD programme at the University for Humanistics (Utrecht, NL), with supervisors:

- Hugo Letiche (University for Humanistics, “humanization of organization”)
- Jan Buijs (Delft University of Technology, “management of innovation”)

# Goal of presentation

- Quick overview of my paper (you may read it online)
- Discuss further study into “ethical qualities of R&D”

# Topic

“Empathic”, “participatory” or “human centred” design.

How researchers and developers interact with end-users – *in this case: informal carers, people who provide care for a person with dementia, living at home, often their partner or sometimes their parent* – in order to inspire and inform their innovation project.

They try to design together with these informal carers.

# Question

How do these *interactions (with these end-users)* relate to *decision making (during the design process)*?

*(not a straightforward, inductive process...)*

## Example of how end-users may react...

John Thackara, then project leader of *Presence a* project with the goal to develop ICT to help the elderly:

*“Piss off!” [...] “We don’t need your patronising help, you designers. If you’ve come here to help us, you’re wasting your time; we don’t want to be helped, thanks just the same. [...] If you could kindly change your attitude and help us explore how we will live, then perhaps we can do something together.” (Thackara 1999:p.8-9)*

## Approach – work in progress

Study one R&D project (2004-2007, 40 people, multi-disciplinary project team, nine organisations).  
Focus on one part (in which I work): develop and evaluate a *we-centric* telecom product/service.

1. Participant observation -> Two conference papers: “police officers” and “informal carers” (this paper)
2. Discussions with project team members -> Taped and to be analysed (working, book chapter)
3. Interviews (storytelling) with individual project team members -> End of 2006, write in 2007

# Main observation: Many “redundant” activities

## Interactions with end-users:

- Pauline, Edith: **Large scale survey** with 300+ *dyads* (*person with dementia + informal carer*) – needs study
- Annelies, Martin, Julia: **Observations and interviews**
- Annelies, Martin, Rachel: **Cooperative design**

## Articulating project goals:

- **Project goal:** To develop and evaluate “we-centric” telecommunication
- Articulating “a problem to solve” took **several meetings**
- “WeCare” (we-centric telecom product/service) was (re-)invented **several times**

<i>Timeline</i>	<i>Activity</i>	<i>Problem</i>	<i>Solution</i>
End of 2004		Communication and cooperation	A we-centric service
March 2005	Kick-off meeting, video	The problems of dementia	
April 2005 – Summer 2006	Literature and large scale survey	“Problem domains” of people with dementia and of their informal carers	
Dec 2005	Questionnaire about product ideas		Informal carers’ reactions to product ideas
Aug 2005	Ad-hoc observations and interviews	Informal care can be very demanding (A)	
July 2005	Project meeting	The person with dementia has no/little daily activities (B)	
August 2005	Writing a paper, and positioning we-centric	Emotional and social problems (different from information needs)	Idea for a we-centric service (different from DEM-DISC)
September 2005	Project meeting	The informal carer receives little help or support (C)	
November 2005	Project meeting	Combination problems A, B and C	Lighten the informal carer’s burden of having to care alone; Facilitate others to take up tasks
March – May 2006	Designing with end-users: 1 <sup>st</sup> and 2 <sup>nd</sup> rounds of interviews	3 situations with related social/emotional problems	
June 2006	Creative session		3 ideas: TimeBank, Caring Home; and Localisation
August 2006	Designing with end-users: 3 <sup>rd</sup> round of interviews	Facilitate informal carers to support others, and be supported by others – via communication and cooperation	TimeBank

interactions

interactions

interactions

decisions

decisions

decisions

decisions

decisions

decisions



# Why?

Why this repetition and redundancy?

Why is this project not conducted in a more linear way?

Why is the process of articulating a problem and developing a solution so messy?

*(STS scholars may find these questions easy ... but for many practitioners – researchers, developers, designers, managers, etc. – these are interesting...)*

Several angles: the need to gather allies; different ways of reasoning; and representing end-users

## The need to gather “allies”

“Allies” must become interested and stay interested. A “research” effort (not “development”) is sometimes

*“like a reception where the invited guests have failed to show; in their place a bunch of unruly louts turn up and ruin everything” (Latour 1996:p.72)*

In this case: People from different organisations with different approaches: e.g. a social psychologist at a medical university department, an industrial designers at a media lab.

# Different ways of reasoning

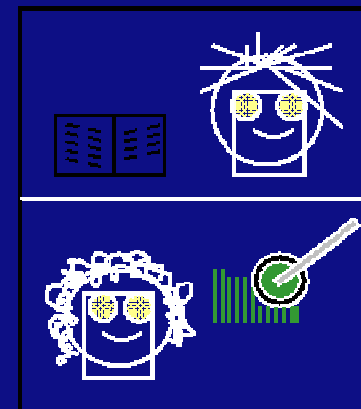
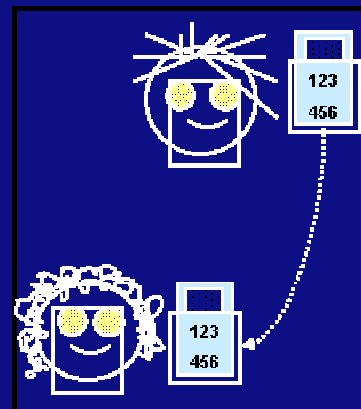
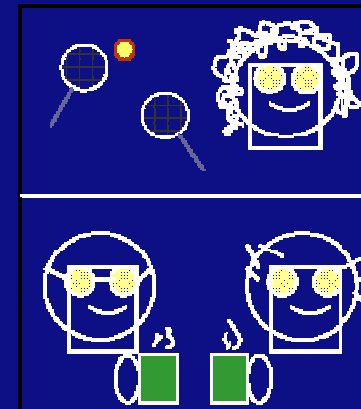
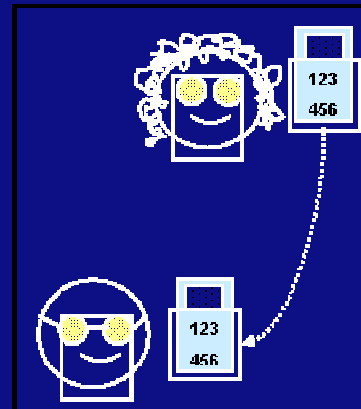
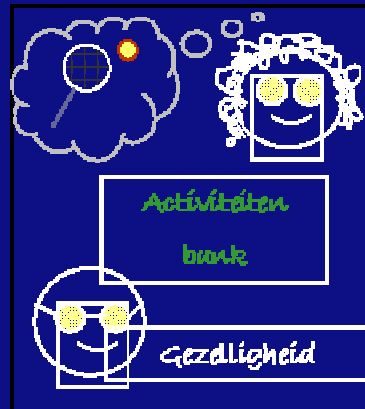
- Deduction – maths, logics:  $p + p > q \dots$  conclude  $q$
- Induction – science:  $p_1 > q_1, p_2 > q_2 \dots$  speculate  $p > q$
- Abduction – history, medicine:  $q + p > q \dots$  speculate  $p$
- Inno-duction – design: imagine  $q$  (desired situation) and  $p$  (problem to solve)  $\dots$  imagine  $p > q$  (solution of that problem) – many (implicit) decisions
  
- Social science as “documenting reality”, vs. Design as “changing reality” (Haddon & Kommonen 2003)
  
- In this case: Friction between project team members (constructive discussion, things run better currently)

# Representing end-users

End-users were *represented*: 1) project team members portrayed them; and 2) project team members acted as their spokespersons.

- Pauline, Edith: The “CANE” survey’s concepts, e.g. “met needs”, “unmet needs”, 25 “problem domains”; and statistical analyses. They have been working with people with dementia and informal carers for years.
- Annelies, Rachel, Martin: Made “personas” and “a day in the life of...” (Cooper 1999), and “storyboards”. Similar to “configuring of end-users” (Woolgar 1991) or “script” (Akrich 1992)

# “Storyboard” for TimeBank



# Further study into ethics

*“STS scholars have been shying away from explicit normative or ethical discussions”* (Poel & Verbeek 2006) (cf. Harbers 2005; Winner 1993)

What do I mean with ethics?

- When I have to make a decision, and rationality or morality cannot help, there is an aporia, an undecidability that makes “the very possibility of choosing” possible (Jones 2003:p.228-9)
- The idea, from STS, that actors are within a network of relations. Ethics then happen *between people* (sorry, no *actants...*), in their interactions, *not* within a person’s inner life.
- How do researchers’ or developers’ interactions with end-users relate to their decision making? E.g. to privilege one problem (neglect another), prioritize one solution (marginalize another).

# Openness/otherness and closure/self

I look at R&D as a balancing between two movements  
– and neither is good/evil (*not* that kind of ethics):

- Towards openness/otherness – interact with end-users to learn from them or cooperate with them
- Towards closure/self – stay within the project's scope, and prioritize problems or solutions accordingly

One project team member said, jokingly: *“Our need is to do something about that problem”*

(Re)reading Levinas, Derrida and commenters – the other, knowledge (grasping), ethics, deconstruction

# Thank you for your attention!

- Questions
- Suggestions
- Discussion
  
- [marc.steen@tno.nl](mailto:marc.steen@tno.nl)
- [www.marcsteen.nl](http://www.marcsteen.nl)