



# The Invisible Work of Users in Telemedicine

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Nelly Oudshoorn  
University of Twente, The Netherlands

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# Widespread interest in the role of users in technoscience

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1. Designers and policymakers: 'user-centred design'
2. Social movements: claim to have a say in the development of medical therapies and consumer products
3. Research agendas of S&TS, cultural and feminist studies: rethinking user-technology relations

# Shift in conceptualizing users



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- Traditionally, users have been seen as passive recipients of technoscience
- Currently, users are viewed as active agents of technological change
- Users as co-producers of technologies  
*(How Users Matter, Oudshoorn and Pinch (eds) MIT Press 2003)*



# Rethinking the role of users in telemedicine

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- In dominant discourses the work of patients and health care professionals is made invisible
- 'Computer replaces cardiologist' (ICT Zorg Nieuwsbrief 2003)
- What kinds of invisible work are implicated in the material narratives of telemedicine?



# The study of invisible work

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- Introduced in S&TS by scholars working in the tradition of symbolic interactionism: Anselm Strauss, Leigh Star
- Articulation work: 'work that manages the consequences of the distributed nature of work' (Schmidt and Simone, 1996)
- Useful approach to study invisible work related to network technologies (telemedicine): all actors will have to perform articulation work

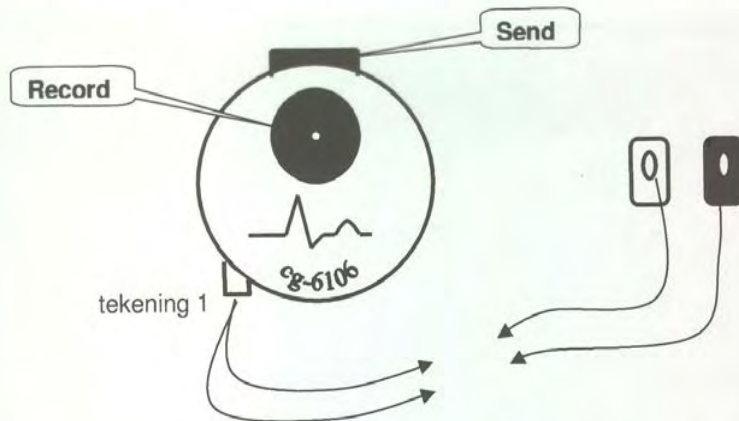


# The invisible work of patients

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- Example of telemonitoring technologies for heart patients
- Patients are expected to play an active role in the diagnosis of heart problems
- Tasks previously conducted by health care professionals are delegated to patients

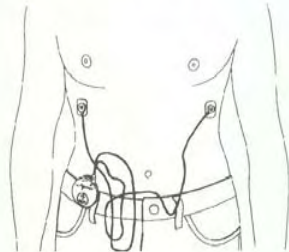
## Gebruiksaanwijzing voor de Holterfoon CG 6106



Het apparaat op de aangegeven wijze (tekening 2) aanbrengen. De zwarte elektrode links op de borst plakken, de witte elektrode rechts en de holterfoon met de klip achter de broekband klemmen. Zorg dat de stekkers goed bevestigd zitten.

### 1. Opnemen van een E.C.G.

- A
- De "Record" knop aan de voorkant van het apparaat indrukken tot een pieptoon te horen is (zie tekeningen 1 en 3)
  - Als het geluid stopt is de opname afgerond.



tekening 2



## *Tasks of patients*

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- Instrumental tasks that rely on procedural or practical knowledge (Lehrer 1990)
- Visible work: is included in instructions given to patients
- Invisible work: patients as diagnostic agents





## *Articulation work of patients*

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- Patients have to manage one of the major consequences of distributed diagnosis: they are expected to catch the right moment to register an ECG that shows their heart rate dysfunction
- Very difficult task that touches the very heart of the technology



# Why it is difficult to choose the right moment to make an ECG

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## **Difficult to make ECGs at night:**

*'I have serious rhythm disturbances at night and I don't feel so well then therefore I did not make an ECG' (survey 4: woman, age 76)*

## **Problems related to multiple diseases:**

*'I have other complaints as well (gullet and stomach) and found it difficult to tell the difference' (survey 19: woman, age 53)*

## **Problems due to poor health:**

*'Sometimes I felt very weak and almost fainted. At such moments you don't think of the recorder at all. When it was over I thought that pushing the button did make no sense anymore' (survey 27: woman, age 84)*



## *Domestication work-1*

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- Domestication work: work involved in 'taming' technologies (Silverstone)
- Incorporation: occurs when technological objects are used and incorporated into daily life
- Temporal shifts in daily routines



## *Domestication work-II*

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- Conversion: the processes in which the use of technological objects shape relationships between users and people outside the household
- Example: the use of phone contacts between patients and physicians at the telemedical centre



# *Identity work*

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- Technologies as identity projects
- Identity work of individuals confronted with illness consists of emotional work to learn to cope with a failing body
- Diagnostic technologies mediate and intervene in this process by providing the means to pass the grey zone of doubt: becoming classified as a patient or a healthy person



# *The dual invisible work of patients*

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1. Patients have to 'read' the technology:  
they have to learn to master the new technology
2. Patients have to 'read' their bodies:  
they have to perform identities related to bodily (in) competencies



# The invisible work of health-care professionals

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- Home-care nurses: inclusion work (Rommes 2002). Reassuring patients about their abilities to master the new technology
- Physicians at the telemedical centre: articulation work and intimacy work.



# Invisibility and its implications

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- Implications for designers and health-care professionals

Neglecting invisible work of patients and health-care professionals during the design and the instructions for patients may lead to 'technical monsters' (Akrich 1995)





# Implications for patients

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- Ignoring the invisible work of patients may lead to selective use and non-use
- Individuals who don't meet the 'requirements' scripted in technologies run the risk of being excluded of the new digital health care services



# Implications for social theory

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- Implications for how we understand **work**: invisible work involves more than articulation work
  1. domestication and identity work (patients)
  2. Intimacy work (physicians)
  3. Inclusion work (nurses)