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Valuing health technology – habilitating and prosthetic strategies in personal health systems

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ABSTRACT

This paper explores the tensions in ICT-driven personal health systems innovation and the impact of these tensions on valuing health innovation for older people. We regard personal health systems (PHS) as configurational technologies and information infrastructures that need to strike a balance between offering standardized health and care packages on the one hand, and providing options for localization and personalization on the other. We use insights from Science and Technology Studies (STS) to conceptualize the configurational dynamics of PHS innovation and emphasize 'generification work' as an important arena for the development, assessment and adoption of personal health innovations. We explore two research and development projects of PHS service-robot platforms and build on Callon's concepts of 'prosthesis' and 'habilitation' to identify two ideal-typical generification strategies in the projects. A prosthetic generification strategy positions the robot as part of a socio-technical agencement that configures older persons into disciplined agency, while a habilitating strategy speaks to them as active actors in the innovation process. We demonstrate how the designers in both projects were often unconsciously led into a prosthetic strategy despite initial intentions to the contrary. We explain this by mechanisms of personalization, needs capturing and *othering*. However, elements of habilitating strategies were also present, although in a less articulated form. We identify these elements and argue that in aging societies, health innovations need to pursue prosthesis and habilitation simultaneously. We conclude our paper with implications for innovation policy and health technology assessment.

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1. Introduction

Demographic aging is one of the drivers behind the trend toward more personalized and patient-centered health and care systems: health policymakers have identified the prevention, (self-)management and treatment of chronic rather than acute diseases as a major challenge (Nolte and McKee, 2008). As a consequence, health technology interventions are increasingly positioned within the wider context of supporting active and healthy aging and independent living (Cabrera and Malanowski, 2009). The arenas in which health technologies

are created and adopted thus shift from those associated with primary and secondary care to wider cross-sectoral settings including domestic environments, home care services, ICT companies, construction firms, etc. (Huch, 2010). The recent attention to TeleCare and eHealth is only one part of this development (Mort et al., 2012; Oudshoorn, 2011; Pols and Willems, 2011). Probably more interesting developments concern full-fledged personal health systems (PHS) in which medical functions move into homes and private lives, where they merge with other non-medical devices and information infrastructures (Codagnone, 2009; Schartinger et al., 2012; Abadie et al., 2011; Peine et al., 2014). These developments suggest that aging societies need to re-think the creation, evaluation, procurement and adoption of health innovation that shifts health and care practices from hospitals to homes,

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and merges treatment and care with prevention and consumption (Peine et al., 2014).

In Western countries, health technology and ICT are increasingly positioned as a solution to the problems usually associated with aging (Oudshoorn, 2011; Roberts and Mort, 2009) – such as the increased prevalence of cognitive impairments in older age groups, the increasing risk of falls and accompanying severe injuries, or the higher prevalence of diabetes, elevated blood pressure and heart diseases. As other contributions in this special issue, especially those of Aceros et al. (this issue), López Gómez (this issue) and Pritchard and Brittain (this issue), show: such solutions for supporting older persons in their homes neither leave the identity of the home nor existing practices of care unchanged. ICT-based health or care interventions engage technology more closely with the lives and practices of older persons, their caregivers and the community environment, but they hardly do so as otherwise neutral interventions (Oudshoorn, 2011). On the contrary, they redefine boundaries (between health and disease, between citizens and patients, between what is considered active and what is not), they limit or enable (sometimes in unexpected ways) agency in one way or the other, and they define new socio-technical arrangements in which responsibilities, actions and interactions are re-distributed among existing and new stakeholders involved with health and care.

In this paper, we strive to link insights from these contributions to recent discussions about the ‘personal health technology revolution’ (Dishman, 2012). To this end, we interrogate how designers imagine the use and domestication of technology. Building further on the work of Pollock, Williams and others in Science and Technology Studies (STS) (Pollock et al., 2007; Pollock and Williams, 2008; Johannessen and Ellingsen, 2009; Williams and Pollock, 2012), we introduce ‘generification work’ as an important arena in which designers interweave such images with broader ideas about the pathways of technology into society. To this end, we present an empirical analysis of two research and development projects on PHS service robot platforms. The paper proceeds as follows: Section 2 introduces our theoretical background and defines the tension between localization and generification as a key challenge in PHS innovation. Section 3 provides the methodological background and case selection rationale for our empirical analysis. In Section 4, we present the two research projects in more detail, and provide insights about how the designers articulate ‘their’ technology together with the values it should provide in the lives of users. In Section 5, we trace how such perceptions were transformed when designers tried to make them generic, i.e., translate them into generic design features. Using Callon’s distinction between ‘prosthesis’ and ‘habilitation’ (Callon, 2008), we identify two ideal-typical generification strategies, and elaborate how they position older persons either as objects of technological interventions or as agents of technological change. The concluding Section 6 explores policy implications for innovation policy and health technology assessment.

2. Aging and personal health systems

Our point of departure is the recent attention to ICT solutions to support aging well, which has led to considerable

funding at European and national levels (see the introduction of this special issue (Peine et al., this issue), also (Cabrera and Malanowski, 2009)). In this context, ICT-driven health technologies have emerged that focus on the monitoring, prevention and management of disease outside of the institutional regimes of primary and secondary care. In aging societies, health care is moving into homes and communities (Willems, 2010) and ICT is expected to play a central role in this process. It integrates health and care technologies more closely with everyday lives and the practices of patients, citizens, caregivers, family members and communities (Dishman, 2012; Asveld et al., 2009; Mort et al., 2009). Older persons are a primary target group in this development. It is thus interesting to explore in more detail how they are imagined and involved in innovation processes of ICT-driven health and care technologies.

2.1. Personal health systems as configurational technology

ICT systems for collecting, monitoring and managing health-related data and providing interventions in home environments have recently been termed *personal health systems* (PHS) (Codagnone, 2009; Schartinger et al., 2012; Abadie et al., 2011). This term emphasizes the expectation that ICT-based health technologies that operate in domestic and community environments will allow for a (more or less) individualized integration with the existing practices and routines of its users. Moreover, a common promise is that PHS will provide for a seamless integration of health and care ICT with existing information infrastructures (Abadie et al., 2011), thus contributing to more age-friendly environments at household, community and regional levels (WHO, 2007). While PHS cover a broad variety of innovations,¹ they share the broad idea that health technology in domestic environments needs to be ‘localized’ to the specific needs, practices and situations of people and their social contexts. In complementing earlier notions like TeleCare or eHealth, the term PHS highlights that ICT-supported health technologies have to find a space within both existing technological infrastructures (interfaces like tablets or TV sets, standards and protocols, available bandwidth, data security, etc.) and existing practices in homes and communities.

Conceptually, therefore, the notion of PHS emphasizes that many ICT-driven health technologies resemble what the recent STS literature terms *configurational technologies* or *information infrastructures* (Fleck, 1993; Peine, 2009; Pollock and Williams, 2010). That is, PHS include a range of (more or less) standardized components whose specific set-up depends on local contingencies, including embodied practices, routines and existing technological infrastructures. A simple example for the configurational nature of PHS is a serious gaming solution for cognitive training (see Zelinski and Reyes, 2009). Such a game can operate as a stand-alone application in an existing domestic ICT infrastructure. It can also operate as part of a more formal rehabilitation trajectory involving data exchange with health or care professionals (making use of domestic as well as regional health or care ICT infrastructure), or it can be used to facilitate social gaming and contests between users (again making use of domestic as well as community ICT infrastructures). The point

¹ A good overview is provided at <http://www.phsforesight.eu>.

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