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Designing for Sustainable Caring Communities – the CareComLabs Framework

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Abstract. The CareComLabs framework intends to provide a design and research space which in the long-term has the potential for setting up a collaborative learning space which serves both, a fruitful environment for developing appropriate socio-technical measures for ageing and caring at home, and to create structures which help the patients and community stakeholders in sustaining practices in the long-term, after the end of the project.

Introduction and Motivation

Adequate long-term care for people with chronic health conditions is one of the most pressing issues of our times (World Health Organisation 2015). Many CSCW researchers are exploring how IT systems might be employed as meaningful components in homecare settings supporting multi-actor networks (e.g. Procter et al., 2014), and addressing sensitive issues of ageing at home in a human- and value-oriented perspective (Leong et al., 2016; Light et al., 2015). The human- and value-oriented as well as participative stances in socio-technical design communities find an analogy in the conceptual care approach of “caring communities”: “*Caring*

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communes (or communities) in essence are concerned about sustainability, children, integration, values and spirituality, towards others, towards the sick and the dying and the bereaved” (Klie 2016, p. 198). *Caring communities* is increasingly seen as an inspiring concept for healthcare research and policies. It defines a set of characteristics and orientations that communities and its members have or aspire achieving. Hence, *caring communities* is both a normative and an analytical, and always process-oriented, concept. Caring communities are characterized by co-responsibility, co-production and the acknowledgement of interdependency and reciprocity that expands beyond families (Klie 2016).

The purpose of this paper is mainly conceptual and it takes two complementary perspectives: It, in the first place, focusses on homecare and elaborates on the question of – against the background of the growing needs for sustainable homecare arrangements – how new cultures of care might be fostered by means of participatory research. The second perspective is a methodological viewpoint, linking participatory care research with the conceptual frameworks of Design Case Studies (Wulf et al. 2015) and Praxlabs (Ogonowski et al. 2018). By linking both strands, we strive to develop a perspective on technology development in sensitive settings under the perspective of sustainability in design (Meurer et al. 2018).

The CareComLabs framework intends to provide a design and research space which has the potential for setting up a design and action space which serves both, an environment for developing appropriate socio-technical measures for ageing and caring at home, and to create structures which help the patients and community stakeholders in sustaining practices in the long-term, after the end of the project.

Project Setting and Methods

The project CareComLab aims at exploring and adapting the concept of caring communities in order to stimulate an overall shift in the field of home care work. In order to reach this sustainable shift, community based participatory research (CBPR) (Minkler & Wallerstein, 2008; Wallerstein et al., 2018) will be at the heart of the project, framed in an overall living lab/Praxlab research design (Ogonowski et al., 2018) which will comprise three different pilot communes in Switzerland. Each CareComLab connects interested stakeholders from government and non-government organizations, profit and non-profit and civic society that contribute to fostering home care for people with comprehensive care needs. Furthermore, it strives to reach out and engage additional actors, not yet linked to care work in order to expand the project’s reach and root the caring community idea. The three CareComLabs will work interdependently, i.e. they constitute individual Living Labs, but are connected through workshops to exchange experiences. CareComLabs will span and exceed the entire project period and hence coordinate a broad range of activities (with varying intensity) throughout the project. They will (I) co-produce empirically grounded original insights into comprehensive home

care needs and services, (II) strengthen, expand and adopt existing and initiate, assess and adjust novel local caring community initiatives and (III) participatory evaluate processes and gained insights for knowledge transfer. These three parts follow a circular, rather than a linear logic.

On Sustainability in Home Care Arrangements

Designers and researchers are often led by a strong motivation to create a workable IT-based solution that will make a difference for those people, communities or organizations that appropriate it, helping them to develop their practices: for them sustainability is about how to achieve a lasting effect in the target setting that may even stimulate further developments. In discussing health interventions Altman (1995) articulates this goal by defining sustainability as ‘the infrastructure that remains after a research project ends’: this infrastructure includes ‘consideration of interventions that are maintained, organizations that modify their actions as a result of participating in research, and individuals who, through the research process, gain knowledge and skills that are used in other life domains’ (p. 527).

Research that demonstrates the sustainability of IT-based solutions, especially in the field of homecare or ageing at home is scarce, with some exceptions (e.g. Meurer et al. 2018, Müller et al. 2015). But sustainability is a larger issue that also requires studying *the conditions within and beyond a research project* for a design result to be appropriated, maintained and eventually further developed. It is helpful to conceptualize designing for sustainable IT-based solutions as taking place in a multi-dimensional space and that combining participatory research work from the care and social sciences with participatory design and Praxlabs conceptions may provide new ways for thinking about sustainable IT design in homecare settings.

Co-Production of Technology in Sensitive Settings

This project focuses on situations in which comprehensive home care is needed for people with multiple chronic conditions. A solution approach being pursued during the last decade is technology support. But studies show that socio-technical infrastructures including multi-stakeholder networks are necessary for meaningful and sustainable technical support and that solely “parachuting in” technology will not prove successful for sensitive settings such as long-term care (Ekeland et al., 2012; Greenhalgh et al. 2015). Taking individual preferences to stay at home seriously, this project explores ways to expand caring responsibilities from individuals and families to local communities. Through participatory fieldwork with communes and communities, this study provides knowledge in order to develop future-oriented, sustainable, affordable and acceptable models of technology-supported, community-based long-term home care.

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