The Digital Life of Vulnerable Users:  
Designing with Children, Patients, and Elderly  

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Abstract. Vulnerability is about being at risk and it is often understood as the effect of limited physical or cognitive capabilities, such as age, frailty or illness. Vulnerable people are frequently excluded from the design of technologies that could in fact support them in tackling these risks. This paper explores designing with three vulnerable groups: children with special needs, chronically ill teenage patients, and isolated, or afraid of being so in the near future, elderly adults. We choose three distinct groups in order to show the breadth and variations in the ways in which people may be vulnerable. We looked at their digital lives and possible new risks and dependencies created by the use of digital technologies. Designing with vulnerable people is practically, methodologically, and ethically challenging. We show how methodological and reflexive sensibilities help to address these challenges and keep the design process on track.  

Keywords: Vulnerable users, interfaces, teenage patients, children with special needs, elderly, design of privacy, reflexivity, social networks.  

1 Introduction  
Information and communication technology (ICT) is no longer limited to desktop computers. It is ubiquitous and pervasive, permeating everyday objects and activities. The increasing availability and use of digital technologies in our daily lives – at home, in our neighborhoods, at work, in school, etc. – suggests a new form of digital living. Living the digital life brings new opportunities, possibilities, and challenges. It also brings new dependencies, such as the fear of losing access. In the case of the elderly, we see also the fear for having to use these technologies [1].  

Not everyone is equally served by the opportunities and possibilities of digital technologies. In the 1990s, the term the digital divide was used to describe the people(s) and countries excluded from access to digital technologies, in particular the Internet. In the early years of the 21st century, a more sophisticated view on the digital divide developed. It was not simply about ‘haves’ and ‘have nots’, but about social inclusion and effective use [2, 3].  

In HCI, a similar development is described. The first wave of HCI focused on better human-machine fit, on usability. The second wave, originating in cognitive
science, emphasized theories of what is going on not only within a computer, but also in a human mind. HCI is currently in its third wave with its focus on experience design and situated design [4]. There is more talk about socio-materiality, phenomenology, design thinking, dialogue, values, social issues etc. and much less talk about the design-as-engineering approach of the earlier waves of HCI.

Similarly, interface design has moved from design for the average user [5] towards recognition that there is no such thing as an average user. This line of thinking has continued and culminated in “design for all” [6] and universal design [7]. Such technology design for all strives to design for human diversity, social inclusion, and equality.

There are people and groups of people who are still excluded from the digital life. Digital exclusion is often described as related to age, gender, and/or socio-economic status. In this paper, we take a closer look at vulnerable users and their use of digital technology. In the literature, vulnerable users are often described as people at risk because of their age, frailty, diagnosis or limited capacities, both physically and cognitively. In our view, the term ‘vulnerable user’ is an inclusive term. All of us may become vulnerable users at one time in situations such as illness, temporary disability, or inability to deal with some new technology in our environment.

Vulnerable user groups provide additional challenges for designers, due to the lack of appropriate design methods, difficulty in communication or the difficulty to empathize with vulnerable users’ experience of the world [8], given their often reduced motor skills or cognitive and/or social abilities.

In this paper, we consider three groups of vulnerable users: young learners with developmental, cognitive, physical or emotional impairments, chronically ill teenage patients, and elderly adults living alone. The aim of the paper is to discuss how technology or interface design processes with and for vulnerable users can look like in practice. We present a design case involving each of the selected vulnerable user groups. We discuss 1) some of the challenges in uncovering the needs of these user groups; 2) challenges in applying known methods for designing with users, in particular participatory design; 3) challenges in modifying known methods or finding new ones that work better for these specific groups; and 4) some of the ethical challenges involved in working with vulnerable users.

Other researchers and research communities have been concerned with vulnerable users. Prior work included research into homeless persons, elderly suffering from dementia, children with special needs, and others. For example, [9] considers children to be vulnerable online and classifies them as vulnerable due to economic, social, psychological, or physical factors. However, much of the prior work does not consider vulnerability through the lens of designing technology with these users. One noteworthy and recent exception is the CHI 2013 workshop on “Designing with and for Vulnerable People”, see [10], in which papers covered different aspects of addressing vulnerability through design were presented. The workshop papers addressed vulnerable groups such as homeless, isolated elderly, bereaved, demented elderly, vulnerable women in secure hospital settings, children with special needs, people with low health literacy and others at risk socially, physically, cognitively or economically. The workshop’s focus was similar to that of this paper (we participated with a position paper on children with special needs), bringing forth challenges of designing in sensitive contexts with people at risk. In spite of challenges, studies with