Youth with ME/CFS: Untangling Complexities in Technology Design to Support Everyday Living

Jorun Børsting
Department of Informatic
University of Oslo
Oslo, Norway
jorubo@ifi.uio.no

Alma L. Culén
Department of Informatics
University of Oslo
Oslo, Norway
almira@ifi.uio.no

Abstract—**In this paper, we argue that the technology design needs to take a more holistic perspective, beyond opportunities offered by the technology development alone. This is especially important when developing technologies for complex contexts, such as healthcare, and for users who are at risk. Furthermore, we present a sense-making process, informed by tools and methods from social science, complex systems design and design thinking, and intended for human-computer interaction designers and researchers to broaden their understanding of entanglement of technology, users, and the design context. This is particularly important when working in a new application area, where one is not an expert. We illustrate our approach by exploring if and how digital tools could support youth with Myalgic Encephalomyelitis (ME), also known as a Chronic Fatigue Syndrome (CFS), to better cope with everyday challenges. Informed by previous research related to our field of inquiry, we combine ethnographic research, Actor-Network Theory adapted for design, and Giga-mapping (a complex systems design technique). We find that this combination of methods and techniques supports deeper reflections over the domain complexities, and makes it easier to avoid designing technologies for adolescents with ME/CFS that do not offer real support in day-to-day living.**

Keywords-complex systems; sense-making; ME/CFS; ANT; healthcare; design thinking.

I. INTRODUCTION

This paper extends our previous work [1], presented at the eTELEMED 2016 (International Conference on eHealth, Telemedicine, and Social Medicine), on sense-making when designing new technologies for adolescents with ME/CFS.

Increasing attention is given to diverse self-management applications and technologies that provide support to people with health challenges to improve or maintain the quality of everyday living, sustain active recovery processes or monitor relevant health data. However, the knowledge required to develop such applications successfully is often multi-disciplinary. Thus, human-computer interaction (HCI) researchers and designers need to reach some level of insight into these other disciplinary perspectives to gain a holistic view of new design contexts, beyond the focus on technology alone.

Healthcare related problems can often be labeled as wicked [2]–[4]. Wicked problems have been discussed by

Rittel and Webber already in 1973 [5] but gained additional visibility and attention recently through design-driven approaches such as design thinking [6]. Wicked problems are incomplete, contradictory, changing and interdependent. Working with them is difficult since making changes in one area (e.g., making an app for monitoring health data) may affect other areas (e.g., how and with whom to share information when data shows risks), potentially causing even more challenges and making visible previously unidentified issues. Thus, isolating a problem and proceeding to find a solution for it is not the best way of dealing with problems in complex domains. Rather, untangling complexities and gaining a deeper understanding of the context, gives a possibility to identify underlying issues, patterns and good opportunities for a design that may lead to mitigation of the challenges that users, and others involved, meet (such as medical professional, patient organizations, parents, or teachers). Thus, the design of healthcare technologies that support users and are well situated in the use context requires a broader and deeper inquiry into the nature of problems and their relation to the situated design space [7].

We describe our approach and discuss the initial sense-making in complex domains, a process that enables this broader and deeper understanding of the context, and design options. Our approach is illustrated using the inquiry into the possibility of designing supportive technologies for adolescents with Myalgic Encephalomyelitis (ME), often referred to as the Chronic Fatigue Syndrome (CFS), or ME/CFS. Almost no research results were to be found on the design of new technologies made specifically for this user group. Without understanding challenges that these adolescents meet in their day-to-day life, it is not possible to envision technological solution(s), be it self-management tools, or other systems or services that could be useful in their everyday lives. We, thus, propose a framework for sense-making and finding opportunities to resolve issues that help untangle some of the complexity within a design context.

In recent years, the increase of chronic diseases, in particular among youth, has been significant [8]. Among these diseases, ME/CFS has become a growing concern, not only for those suffering from it and their families, but also for the medical science, governmental health management, and society at large. Tweens and adolescents who are

affected by the illness would be, if healthy, considered to be willing adopters and users of technology [9]. However, even for their healthy peers, intensive use of technology may lead to negative health consequences [10]. Thus, for those with ME/CFS, it is crucial that technology does not introduce a new set of problems or worsens their health condition [11].

From this perspective, we consider youth with ME/CFS to be a group of vulnerable users [12]. The vulnerability is to be understood as a set of risks that these adolescents are exposed to. Understanding these risks, and how to reduce or eliminate them, is a step towards understanding design and technology design spaces when considering designing for and with this user group.

Furthermore, the understanding of the design space in complex contexts may require an understanding of several different fields pertinent to the context. Understandings can be at the micro-level (e.g., how a specific solution affects the user) and understandings at the macro-level (such as social, cultural and governmental influences on the design space). We have chosen Actor-Network Theory (ANT) as a tool that can help produce rich descriptions of the interrelated social and material processes at different levels [13][14], Giga-mapping to represent and communicate our thinking about design, and finally, a firm focus on users and use. ANT is borrowed from Science and Technology Studies (STS) and Giga-mapping from System Oriented Design (S.O.D). In combination, for HCI researchers and designers, they offer a new tool for initial sense-making. We find that the approach helps develop and communicate insights efficiently, increases awareness of a broad range of issues and points to their interconnectedness. Finally, it engages HCI researchers in innovative and exploratory practices within an unfamiliar design context and enables critical reflection on own position and values. As a consequence, the process points in a more informed manner towards areas where prototyping is helpful, and when finishing prototypes to the extent that they can be used in real life use explorations is essential [15][16][17]. In this work, however, we focus only on how we gained insights and not on any specific solutions.

The paper is structured as follows: the contextual background is covered in Section II, including relevant research findings on ME/CFS and technology design, and describing the methodology, methods, and tools (design thinking, ANT, and Giga-mapping). Our first expert session is described in Section III and analyzed, using ANT, in Section IV. Section V addresses the combined approach of ANT and Giga-mapping. Section VI describes the Giga-mapping workshop. The second expert session is presented in VII. Section VIII showcases the first realized technology design. The conclusion and the future work follow in Section IX.

II. BACKGROUND

Previously published research work is a usual starting place when exploring a new application domain. In the case addressed in this paper, some understanding from several disciplines is needed. First and foremost, design for adolescents, in particular, those with health challenges, is often outside the main research focus within the HCI.

Designing for children is a well-established subfield of HCI, with developed tools, methods and methodologies. The work with adolescents has not attracted the same kind of attention. In the case presented in this paper, adolescents are exposed to numerous health and other risks and can be seen as a vulnerable user group. To understand risks that they are exposed to, grasping what it means to be an adolescent living with ME/CFS is crucial. Empathy [18], interviews, observations, and other methods may be used to gain insight into lives of adolescents with the illness. However, some familiarity with basic scientific results from current and published medical research on the condition is also necessary, even though it is outside of our main field of competence. The medical research results helped to identify a broad set of risks that adolescents with ME/CFS face, including isolation and stigma.

We divide this section into four parts A) medical understanding of the condition and associated risks, B) review of previous research, focusing on technology for ME/CFS, C) design thinking and vulnerable users, D) pragmatic use of ANT and mapping in design.

A. A medical understanding of adult and pediatric ME/CFS and its effects: the challenging nature of the disease

ME/CFS ME/CFS is a debilitating multisystem illness resulting in a plethora of symptoms that include severe physical and cognitive exhaustion, confusion, difficulties with memory, concentration, sensitivity to light and noise among others, see [19], [20]. What causes the illness remains an enigma, and the condition is presently researched on a broad scale, e.g., [21]. Many theories, ranging from viral infections to psychological stress have been proposed [19]. Some studies suggest that the immune system may be chronically active in people with CFS. This might relate to a theory that ME/CFS is caused by an abnormal reaction to common infectious agents. This theory could link ME/CFS to autoimmune diseases such as the Lyme disease and the Epstein-Barr virus.

A review of thirty-four qualitative studies on ME/CFS, see [22], was done and the authors find that "For sufferers, illness development influenced identity, reductions in functioning, and coping. Physician-specific themes described lack of awareness about ME/CFS and recommended improvement in educational resources. Intersecting themes expressed issues with diagnosis creating tensions and fueling the stigmatization of ME/CFS". Also, some research points in the direction where people with ME/CFS themselves help to perpetuate their condition. For example, Afari and Buchwald state that "current knowledge about chronic fatigue syndrome suggests that genetic, physiological, and psychological factors work together to predispose an individual to the condition and to precipitate and perpetuate the illness" and, further, that "sufferers' perceptions, illness attributions, and coping skills may help to perpetuate the illness" [19, p. 230]. Such results, unless verified carefully, may lead to and perpetuate stigmatization. Other research, such as that of Geelen et al. [23], or Winger et al. [24], offers insight into personality issues relevant for understanding the youth with ME/CFS.

The treatment of those diagnosed with ME/CFS is highly individualized, frequently symptom-based, and includes both pharmacological [21] and behavioral approaches [25]. The most common form of help to those with illness in Norway [26] are self-management courses, offering guidance on how to stabilize the symptoms, find a balance between rest and activity, and adjust to living a life with ME. This is in line with the trend to promote self-management and to, wherever appropriate, foster patient participation in care, and especially so for people with chronic diseases [27]. Self-management often involves the management of medical conditions, behavior, or emotions [28], [29]. For users with ME/CFS, self-management also includes the management of so-called energy modulation. A person with ME/CFS is considered to have a limited amount of energy available for use per day. If an activity takes too much energy, the overuse results in extra exhaustion over a period of time lasting from several hours to several days, leading to increased pain levels, sensitivity and overall aggravate the physical and cognitive condition. The problem is often that a person with ME/CFS do not know what amount of energy is required for an ordinary activity such as, for example, meeting a friend for a cup of coffee. Therefore, the energy modulation management is difficult.

A user study carried out by the Norwegian ME/CFS association [20] found that 40% of people with ME/ CFS did not receive medical help with relieving symptoms caused by the illness. When asked what kind of help they would like to receive from the healthcare sector, they indicated professional assistance with sleep problems, stress management, stomach problems and the general pain relief.

For children and youth with ME/CFS, the situation is additionally difficult because it is harder to make their voice on the matter heard:

"Do children and adolescents suffer from ME/CFS? Simple common sense tells most parents, teachers and doctors that they do and often more severely than adults. Yet there remain a sizeable proportion of professionals in Health Care, Education and Social Services who are still prepared to ascribe the numerous, disabling but seemingly unconnected symptoms of this illness in young people to anorexia, depression, school phobia or dysfunctional family background. All are, at least, agreed that the illness presents a considerable economic, educational and social problem" [30].

Resonating with these findings, and in part, because the illness does not leave visible marks on a person, people with ME/CFS are often dismissed as suffering from psychological problems, or worse, stigmatized by general population [22].

Those diagnosed with ME/CFS have to bear the medical uncertainty of what causes the disease and, as a consequence, the absence of an effective diagnostic test and treatment for the illness [31]. Furthermore, social and political uncertainties and risks are tied to the lack of medical understandings.

The youth is affected by nearly the same rates as adults, from about the age of eleven [32]. For someone to be diagnosed with ME/CFS, the symptoms need to be present to such a degree that they clearly limit person's ability to carry out ordinary daily activities [33]. Youth are classified into four groups: mild (approximately 50% reduction in pre-illness activity level), moderate (mostly housebound), severe (mostly bedridden), or very severe (totally bedridden and in need of help with basic functions) [34].

B. Previous research on ME/CFS in adolescence and technology

As mentioned in the introduction, there is very little in the literature on supporting and assisting people with ME/CFS, including adolescents, using technology. People with ME/CFS, with their multiple challenges at the physical and cognitive level, coupled with reduced tolerance to light and noise, may not be the prime candidates for the use of screens for receiving information, whether the screens are on tablets, smartphones, or personal computers. Yet, all solutions that we could find in the previous research were screen based. While such solutions may be a good option for healthy adolescents, they have limitations for those with ME/CFS. Thus, before deciding on any new technological solutions for adolescents with ME/CFS, one needs to make sure that proposed solutions do not introduce new problems and health risks for their users.

Previous research shows that social isolation and access to education are important challenges facing these adolescents. Several researchers explored solutions in these two directions, studying either the social media as means of reducing isolation, or platforms for education. General use of social media in medical care was described in [35], where authors have analyzed and synthesized 76 articles, 44 websites, and 11 policies/reports and presented findings according to 10 different categories of social media such as blogs, microblogs, social networks, professional networks, thematic networks, wikis, sharing sites and others (represented by the Second Life). Findings, in particular, those related to the Second Life are relevant for adolescents with ME/CFS and have been taken further in the work of Best and Butler [36], [37]. The paper [37] describes how a virtual support center was constructed in the Second Life, featuring meeting areas, relaxation areas, library resources and a gallery of art by and for people with ME/CFS. However, the results of the investigation gave mixed conclusions, possibly reflecting the fact that certain level of mastery of the virtual environment was needed, and that was not possible for all users to accomplish. Also, the physical and cognitive condition of people with ME/CFS may affect their willingness to dedicate energy to learning about new virtual environments. The Second Life application provided information related to the condition and was aiming to address loneliness and social isolation.

Considering the educational platforms for those with ME/CFS, the paper on e-learning, [38], can be pointed out as relevant. In this study, e-learning platforms were explored as an opportunity for children with ME/CFS to participate in classroom activities even though they are staying at home. As the authors state, this is especially relevant to Scotland,

where many live far away from schools. However, the access to school and educational materials is only the first hurdle in receiving regular education and does not address other problems that youth with ME/CFS often have.

C. Design Thinking and Vulnerable users?

Design Thinking may be defined in many different ways. For example, it may be defined as a process that fosters innovative and creative thinking [39], or as an approach to mitigate complex problems through design [6], [40]. Design thinking is also often described as a user or human-centered process, resting on three pillars: empathy with the user, rapid prototyping and abductive thinking [39]. In [41], the authors engage in an important discussion on the role of design thinking in research and designerly practice, suggesting core concepts that include reflexive practice, meaning-making and designerly ways of knowing.

We argue that in complex design contexts, sense-making is also essential. It is to be distinguished from meaning-making, which has to do with design research, practice and designerly ways of knowing. Sense-making, as we use it, applies to the understanding of the context. It requires careful framing and setting of contextual boundaries, balancing the broadness and the depth of inquiries. Giga-mapping, [42], can be viewed as a tool for sense-making. As the name suggests, it allows for mapping and visualization of a variety of perspectives and concerns. The making of a Giga-map facilitates thinking and communication. By its large physical size, it invites participation and collective production of understandings regarding the design context. Furthermore, the context can be mapped out in layers (e.g., understandings on micro, mezzo, and macro levels), fostering further insight into inter-relatedness of problems. As discussed later in this paper, maps, including Giga-maps, are important actors in design networks.

When a design context has users at risk in centrum, the term 'vulnerable users' is often used. In [11], authors argue that the term 'vulnerable' should not be seen as stigmatizing. Rather, it implies a set of risks that users are exposed to. When identified, these risks are helpful in defining design goals that aim to reduce or eliminate them. They further argue "the awareness of risks/vulnerabilities in a design situation may be helpful in designing better products for vulnerable people" [11, p. 3]. Thus, in design for and with vulnerable users, risks need to be recognized and mapped out already in the initial, sense-making processes, prior to engagement with any concrete design ideas. For example, adolescents suffering from ME/CFS often have limited ability to read from digital devices, or even just look at a smartphone or computer screen (due to the sensitivity to light). Thus, they may be at risk of not being able to use any screen-based solutions because of their illness symptoms.

When working with vulnerable users, it is important to take into consideration ethical concerns as part of the reflection and meaning-making. Ideally, both the sense-making and the design processes should include real users, in co-design setting. With vulnerable users, this may not always be possible. Those speaking on their behalf must be able to represent them well, i.e., need to be able to convey their interests, challenges, and experiences.

D. Pragmatic use of Actor-Network Theory and mapping

We propose pragmatic use of ANT to inspire analysis of design opportunities in the initial, sense-making phases of a design process. This aims at creating a holistic picture around adolescents with ME/CFS, communicated and represented by for example, a Giga-map. The process helps to explore opportunities for technology to offer support in their everyday lives. It also helps to imagine and discuss consequences of future technologies before they are made.

ANT is traditionally deployed as a framework to gain knowledge about heterogeneous networks, consisting of diverse human and non-human actors. The inclusion of non-human actors differentiates ANT from other social theories employed in information systems research. ANT focuses on both the social and the technical factors involved in the research case; all the social-technical elements are incorporated into networks of actors/actants. Therefore, ANT can also be used to theorize about digital artefacts. Latour describes the concept of networks: "Behind the actors, others appear; behind one set of intentions there are others; between the (variable) goals and the (variable) desires, intermediate goals and implications proliferate, and they all demand to be taken into account" [44, p. 100]. The social-technical focus implies analyzing both the visible (the technical/objects) and the invisible (the social) and then distinguishing the relationships between them. Those relationships can be both semiotic and material simultaneously. Combined, they constitute a network of actors that acts as a whole [45]. Tatnall and Gilding (2005) argue that ANT can be particularly useful for studies in areas that involve consideration of political and social issues in information systems. They further mention interface design, usability testing, and the use of distributed systems within organizations as examples of possible application areas [46].

Currently, there is an increasing focus on how ANT could be fruitful in the collaborative design of digital artefacts [14], [47], [48]. Stuedahl and Smørdal state that "involving ANT concepts in co-design does help to frame co-design processes within the wider context and consequences of emerging knowledge development" [49, p. 204]. A number of other researchers focused on ANT and design. For example, Schoffelen, in [50], is concerned with designing visualizations that make things public, to interest and engage people in participatory processes. Storni, in [14], explored how ANT can be used to offer an alternative perspective to co-designers, focusing on "a convention from Latour's call for risky descriptions to a call to design things together" [14, p.167]. He further argues that ANT suggests three general turns to rethinking co-design and participatory design practices. The first turn addresses the question of what to design? It also involves the idea to first design actor

networks, and then look for ways to map them. He further describes the resulting maps as not only descriptive but also as supporting participation in the design process. The second turn concerns the question of how to co-design and suggests the idea of designing as actor-networking (in public). The last turn, described as epistemological, involves what Storni describes as "moving from the idea of the designer as a network prince to the idea of the designer as an agnostic Prometheus" [14, p. 167]. Storni suggests that making maps is a way towards holistic and democratic design. The maps are themselves actors in the network, drawing things together through visual problematization, and equally importantly, offering everyone engaged in the design process to add, transform, remove, critique or highlight its elements.

III. THE FIRST EXPERT SESSION

As mentioned in the introduction, this study is informed by previous research on ME/CFS, and it uses a combination of ethnographic methods, research results, and analysis inspired by ANT and Giga-mapping to tease out real problems and design opportunities related to assistive technologies for young people with ME/CFS.

Regarding user research, we have organized a session with experts on ME/CFS. These experts have an in-depth knowledge of ME/CFS, also personally, or through their immediate family. They are in daily contact with children, youth, and adults with ME/CFS, and their families. Therefore, they have a broad, professional and personal knowledge of what it is to live with ME/CFS. These people came from 1) the Norwegian ME organization [26], 2) an organization that provides support to families of those with ME/CFS, 3) ME/CFS youth organization and 4) a medical doctor. The session lasted for close to three hours. A short part of the meeting was dedicated to getting to know what they do at the organizational level. The insights gained are incorporated in Fig. 1 and 2.

The session was also used to discuss future technologies that could provide some support in everyday lives for those with ME/CFS. Given the aforementioned deep knowledge the group shared, many design opportunities for future technologies, as well as novel uses of existing technology, were considered. Some of the suggestions that do not exist today, were brought up. We present some opportunities for design below.

The first opportunity was related to education, an important area for adolescents. It was an online e-learning solution with streamed lectures, accessible anytime. It was brought up that most young people with ME/CFS want to follow up on their studies, but they have to be able to take a break when needed. This addresses the need for a flexible educational system.

The second one was an App designed with a critical design approach with a specific focus on how the energy levels are different for people with ME/CFS. The App could simulate the amount of energy needed for simple everyday tasks to reduce prejudice and increase general understanding of the illness.

The third suggestion was another App that could be designed for self-management of the illness. The App could provide reminders to rest. It could also give short advice on things that have worked for others, which they could try to reduce illness symptoms. The App could also measure sound levels and give warnings when the levels are too high. Since exposure to high sound levels is known to increase illness symptoms, the App could also help visualize this, by showing sound measurements and giving reminders to use earplugs in spaces with high sound levels, e.g., when using public transportation. General personalized everyday reminders were also seen as valuable, as an increase in disease symptoms may lead to memory problems.

The fourth suggestion was an electronic diary that could be used to register symptoms daily. The knowledge and awareness gained through daily activities and their effects on illness symptoms were seen as valuable. This diary could also be a tool to explain better the current health status to healthcare professionals and social workers. For this diary to be used in periods with increased illness symptoms, it would be of utmost importance that the self-rating process is simple to conduct.

The fifth suggestion was related to wearable devices, such as the Fitbit. People with ME/CFS experienced the possibility of tracking activity, sleep patterns and energy expenditure as desirable. It was suggested that similar wearable technology, tailored to the needs of people with ME/CFS, could be valuable.

The sixth suggestion is a Social technology specially designed for people with ME/CFS, to meet and seek support from other people with the illness. It was expressed that it was much easier for people with ME, in most social settings to connect in a meaningful way with other people that also have the illness. Within the ME community there is a strong sense of community, but for adolescents, new ways to connect with peers that also have the illness could be helpful.
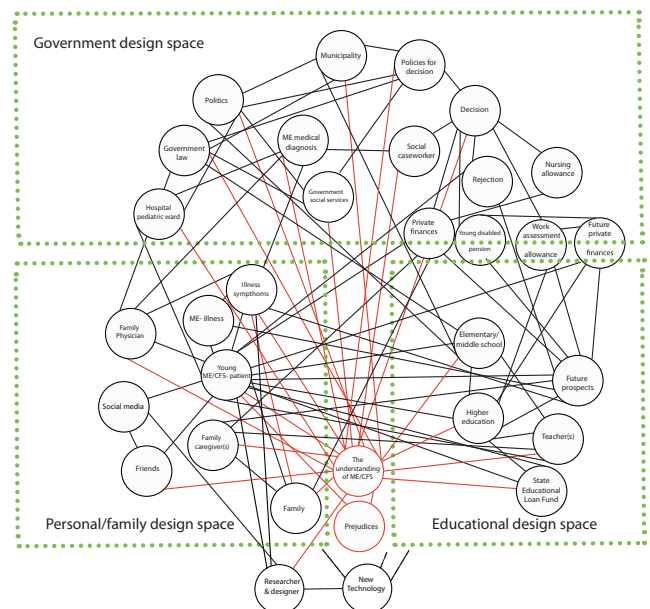

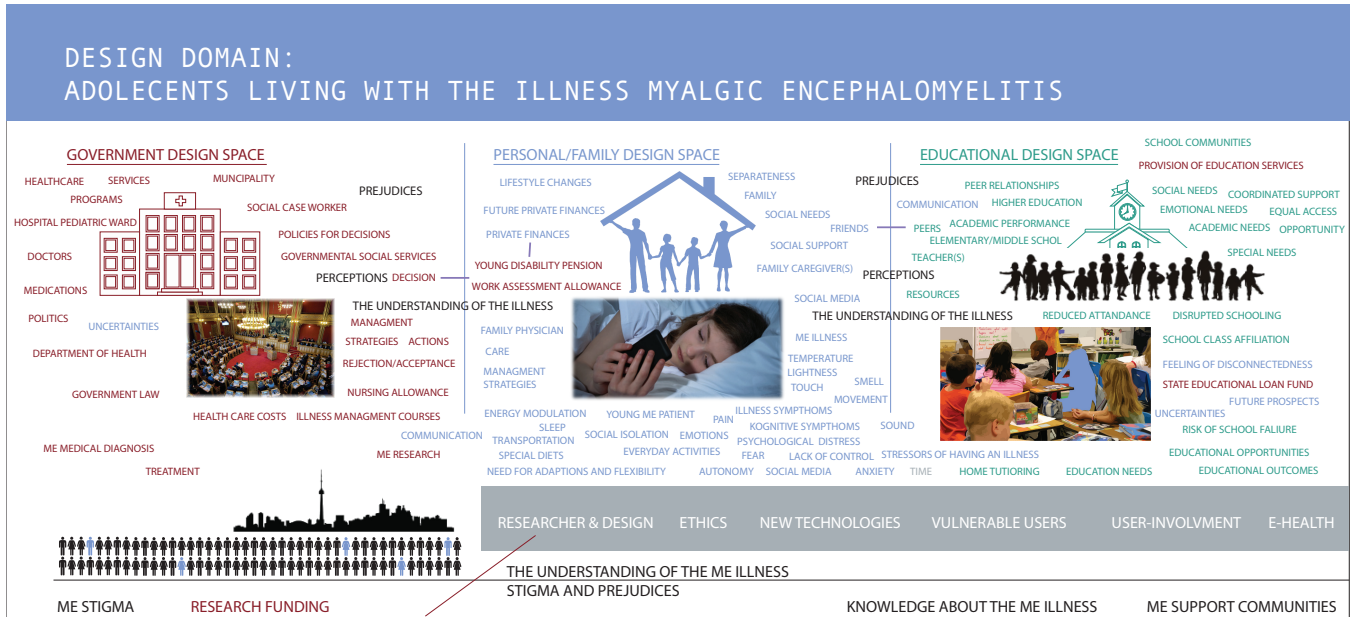Figure 1. The first iteration of combined Giga-mapping/ANT.

Figure 2.   The new visualization of ANT/Giga-map.

IV.   ANT ANALYSIS OF THE EXPERT SESSION

Instead of considering any one of the mentioned suggestions as an automatic lead toward a design, and in isolation from other factors that influence people living with ME/CFS, we performed an extensive analysis, focusing on all of our data collected from the session with experts. The identified actors and issues from the expert session were also compared to findings from the relevant research literature. At first, the traditional ANT analysis was applied, but then, a more pragmatic, design and technology-oriented approach was deployed, in line with papers such as [14] and [48]. The result is shown in Fig. 2. The image is a visual representation, a Giga-map, at the macro level. All the relations shown are necessary for the initial sense-making process and following technology introduction. Each relation explicitly or implicitly contributes to a discussion around technology that could, in some way, aid adolescents with ME/CFS. Three large associated areas of the network emerge, related to what we named Personal/Family, Educational and Governmental design spaces. At present, those spaces are not strongly connected, and connections within each one of them are sparse. As mentioned earlier, also in the literature, there were very few results from HCI research within the research domain found.

In Fig. 1, a circle represents an actor and lines represent relations between actors. The number of actors shown is limited to the actors identified in the data analysis from the sense-making session with experts on ME/CFS. From an ANT perspective, all the relations presented in Fig. 1 is relevant to the development of the new technology. The actors in the case of research are characterized by their differences that affect the network. Actors in the network are both human (such as the ME/CFS sufferer, family members, hospital doctors and school teachers) and non-human (such as politics, prejudice, economics, and social media).This is

called *symmetry* in ANT, where the non-human actors are integrated in the network in the same way as human actors. They all have a role in and influence on the network. These roles and influences are not predefined but continuously evolve. For example, a family member may consider himself or herself to be without prejudice in other situations, but in the network representing the youth with ME/CFS, they still can think that the adolescent is lazy rather than sick, and so contribute to maintaining the prejudice around the disease.

A concept in ANT is *material agency*. *Agency* can be seen as the actors 'capacity for influence' or the 'capacity for action' within the network [51]. As mentioned, all the different enrolled actors have a role and some influence in the network. *Agency* can be important to consider in early sense-making processes. Firstly, for the new technology design to be successfully adopted by the user group. The technology has to have some level of agency to not become obsolete within the design space. Secondly, because the technology introduction and use over time will potentially influence the agency of other actors in the network. This can be especially important with a vulnerable user group were unintended harmful effects due to such changes in agency can be particularly damaging.

The differences in patients' illness symptoms will give different results for the individual affected by ME/CFS. The level of illness impact on personal health is highly fluctuating not only on a day-to-day basis but also from person to person. The patients and different people interacting with the patient are also heterogeneous actors. They bring their different personalities, competencies, and experiences into the network. The knowledge of how these cases are currently is crucial for successfully identifying a technological design opportunity and this knowledge is gained through the relation with the people with ME/CFS.

Adolescents, various people that they interact with, as well as non-human entities also form several different

heterogeneous networks. This directly relates to the wickedness of problems related to defining technologies that aim to help youth to have a better life, given their illness. Not only do adolescents suffer from the condition to varying degrees, but their health changes from day to day and period-wise as well. This changeability needs to be addressed as part of the sense-making.

Furthermore, the analysis revealed two mediators. Mediators are entities that increase difference among actors and, thus, should be carefully studied [52]. The mediators that we have distinguished impact how our society currently faces people with ME/CFS. In Fig. 1, the actors in the network, the two mediators are marked with red circles. They are the Understanding of ME/CFS and Prejudice. The Understanding of ME/CFS is seen as a contributing factor that defines relations between those with ME/CFS and many other actors in the network. It influences, for example, how the social service caseworkers or physicians handle youth with ME/CFS. The Prejudice seeks to impose its version of reality on those with ME/CFS. Prejudice may determine what people perceive and in turn how they act towards people suffering from ME/CFS. As one person from our expert session said: "If one could only eliminate the burden of the shame that many people with ME/CFS live with and shift the focus to acceptance and to living their lives as best as possible, the quality of their lives would be so much better." The red edges drawn in Fig. 1 between the Understanding of ME/CFS and other nodes are also relevant for Prejudice as an actor in the network. However, the two are co-dependent: as the knowledge about, and understanding of, the ME/CFS increase, prejudice decreases.

The various actors have different roles and tasks, which are not predefined but evolved and given on the specific network of actors. In this network, the policies of governmental social services might result in rejection when the patient applies for governmental work assessment allowance, but with a patient with a different disease, this might be granted. This way the policies of governmental social services (which are the same for both patients) have a different impact on the lives of patients based on their diagnosis. The governmental social services caseworker might also have different predefined perceptions of ME/CFS compared to other diseases such as cancer. Another caseworker might have an entirely different perception of ME/CFS patients, which influence their judgment of the patient's need for governmental work assessment allowance.

The role and agency of the parent with a child diagnosed with ME/CFS changes based on the magnitude of their disease symptoms. For some, the disease debilitates the child from performing everyday tasks or staying in touch with friends. The parent could then take responsibility for some of these tasks, altering the parent-child relationship and their agency as a parent. The focus can shift from giving the child independence to a focus on the child as completely dependent on care from the parent. The delegation of tasks could cause the parent to go from not interfering in their child's social life to actively mediating their social interactions with friends by acting on behalf of their child.

Currently, the ME/CFS patients have to comply with the diagnostic criteria that apply to be diagnosed with ME/CFS. They also have to comply with policies of the State Educational Loan Fund and Governmental Social Services, to receive student loans or social benefits. These policies could be seen as a program of action, which the ME/CFS patients have to adhere to. These programs of actions are based on strong inscriptions. Therefore, it is not easy for ME/CFS patients to oppose these policies. This creates a big conflict in the network since the policies demand that one cannot study (not even part-time) and receives financial support from governmental social services. This is problematic for ME/CFS patients based on how their disease symptoms vary on a day-to-day basis. Young people with ME/CFS could often study if it were possible to do it at their pace. This should be provided without having severe economic consequences for the ME/CFS sufferer, and they should not have to deal with losing their student rights, such as they would today. Now people with ME/CFS encounter many roadblocks when trying to finalize their education. Therefore, there is a lack of alignment between the interests of those with ME/CFS and Governmental Social Services/ The State Educational Loan Fund. This lack is also visible in the current dire need for more medical research, treatment options and education of the general public to improve the general knowledge about the ME/CFS disease. Alignment means that the actors more or less share the same goals and motives.

To achieve stability, there has to be a process of compromising the interests of the welfare system and the ME/CFS patients. To make the network stable and aligned the result from the translation need to be agreed upon by all the actors. To increase knowledge about the disease might be an important step to remove some of the prejudice and these brick walls ME/CFS patients encounter in our society and to achieve alignments of the actors in the network. Further alignment could be archived by changing the policies of Governmental Social Services and providing flexibility and tailored solutions that better comply with the nature of the ME/CFS disease.

V. ANT AND GIGA-MAPPING

In the previous section, the research case is addressed by focusing on developing actor networks. The network describes divisive issues, the political and social dimensions. This is described by Storni (2015) as a part of the first turn in using ANT in design processes. The second part of this first turn is to look for ways to make these designed actor networks visible. Giga-mapping is an often used approach to making things visible in design processes, drawing upon design skills like making visual descriptions that foster communication and visual thinking. Giga-mapping is also a designerly way of dealing with super-complexity, which is highly relevant to our research case and its wicked problems. We argue that ANT and Giga-mapping complimented each other's strengths and weaknesses and used combined; it provides a powerful tool in sense-making processes. All relations among actors are significant for the initial sense-making process. This fits well with the Giga-mapping

approach since it requires that the map includes everything, without ordering or giving personal meanings to the different elements involved. All the actors, explicitly or implicitly, contribute to the discussion around technology that could aid adolescents suffering from ME/CFS. ANT, on the other hand, was used as a lens to make connections and to group the different actors involved in important design spaces. Jointly, ANT and Giga-mapping provide a tool for critical reflection in the early sense-making phase of trying to understand adolescents with ME, and the situated design space related to technology that could be useful in their lives. In this research we, therefore, started by designing actor networks, then we used Giga-mapping to make these networks visible. The numerous challenges related to ME/CFS are not easy to solve and clearly relate to the main characteristics of wicked problems. We have proposed a holistic approach to sense-making when considering technology design for adolescents with ME/CFS. Using a literature review, a sense-making session with experts, ANT, and Giga-mapping, we gained insight into what ME/CFS is, developed the empathy with youth suffering from it. ANT provided rich descriptions of the complex design context and Giga-mapping visual representations of relations that emerged as relevant. They also helped to define possible areas of interest for design (Personal/family, Educational and Governmental). The outcome shows that our analysis aligns with a few studies from the literature that we have described: education and social arena are important. We initially found the Governmental space not as readily available to us as researchers/designers. However, one possible early design focus could be on increasing the general populations' knowledge about illness, thus helping to reduce prejudice and stigmatization. Based on our initial sense-making process, we argued for a focus on the Educational design space, both based on the current and future importance for the youth with ME/CFS and based on how the other children in their class can learn about ME/CFS. As mentioned, knowledge about ME/CFS is of utmost importance to reduce prejudices.

The developed Giga-map served three proposes for our research process. These relate to the questions of what to design? Who should be involved and aware of important issues? How should knowledge be developed and documented? Firstly, it helped us to increase our understanding of the design case and what to design for these users. Secondly, we also wanted to use the developed Giga-map as a design artifact that supports participation in the design of new technologies for youth suffering from ME/CFS. As mentioned, there is also limited previous research on technology design for ME/CFS sufferers; technology interventions have to be aware of and sensitive towards the manifestation of the ME/CFS illness and the attached political and social issues. Again, addressing the wickedness of the problem, the many challenges related to ME/CFS are not easy to fix and cannot be solved by any one single technological 'solution.' Instead, we focus on generating awareness within the community and the field of design by making things public through the Giga-map aiding to inform policy-makers and designers concerning youth

suffering from ME/CFS. Using design as a powerful tool to make concerns about co-habitation and democracy visible. Fostering participation from relevant communities could prove to be the best way to address the wickedness of the problem. Thirdly, we want to use the initially developed map together with new Giga-maps and thick descriptions from the ANT analysis and our qualitative research, as a way of documenting design processes and technology developments addressing wicked problems.
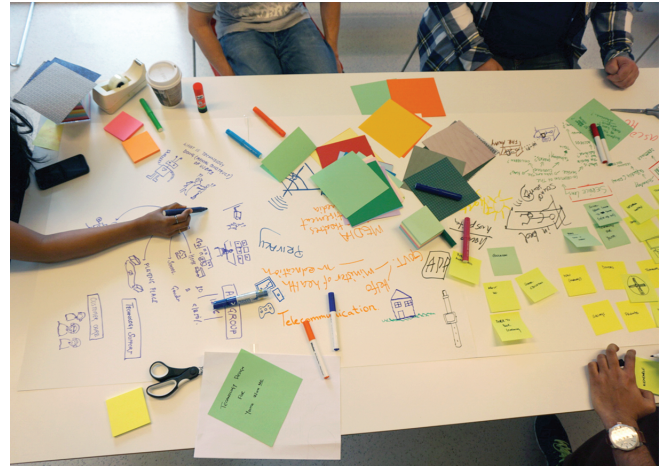

Figure 3. The Giga-map workshop.

VI. THE GIGA-MAPPING WORKSHOP

For the developed Giga-map to function as a means to document the pre-technology introduction design context, and in such a way that it could help other designers or researchers gain the knowledge we acquired through our sense-making process. It is imperative that the map is to be understood by others that do not necessarily possess prior knowledge about the design context. In fact, it is a question whether the Giga-map can be fully understood by other people than the ones who created them. To gain more perspectives on the design context and how others perceive our initial mapping of the design context we conducted a workshop, with four participants in addition to the researchers. It was immediately found that our map did not transfer the information to others that we had incorporated into the map. While as stated the map was useful for us in our initial sense-making, when we were trying to grasp and gain an understanding of the wicked problems in our research and design context, they were not successful as carriers of that knowledge to others. Keeping in mind that the Giga-map technique is not intended to 'tame' problems or be arranged or structured in a way that simplifies or in other ways bias the interpretation of reality. The rest of the workshop was used to explore how to make improvements.

We found that instead of showing the actors on our map by text and circles, it is much better to use icons or illustrations when possible. It was also stated that when trying to identify technology design opportunities the service lens from Design thinking could prove to be fruitful. In our

next iteration of the Giga-map, we actively used these two findings.

Figure 4.   The robot from our first technology design case.

VII.   THE SECOND EXPERT SESSION

To validate the identified concepts and topics that should be included in the Giga-map, we performed a second expert session. The participants were the same as those who participated in the first session, except that the ME youth organization had a different representative participate in this second session. In this session, all the issues and concepts identified in the first expert session were made into cards inspired by [53][54][55]. The participants then sorted the cards and discussed the topics displayed on the cards. Even though we did validate that the most critical issues were included, we found the number of cards, the combined visual information, and the card sorting techniques to not fit well with the user group and the cognitive illness symptoms, mainly problems with memory and thought. To continue with the session, we had to start showing only one card at a time that was then discussed. This way we validated the importance of the identified topics. To get the participants to make an overall structure of all the cards that made sense regarding placement on the Giga-map was on the other hand not possible. We did, however, get much more information about the different topics and how they were relevant in their everyday living and life with the ME/CFS illness in general. The cards that especially generated much data in the

interview was Governmental Social services, Private finances, Politics, Stigmatization, friends, ME support community, School, transportation, Education, Illness perception and knowledge in society, Everyday life activities, illness symptoms, energy modulation. The data collected were photographs, observation notes regarding the card-sorting method, and detailed notes recording the participant's answers made by two of the facilitators.

VIII.   THE FIRST TECHNOLOGY DESIGN CASE

Our first technology design case focused on youth with ME/CFS, builds on all the insights from the initial sense-making process. The case involves the use of a little robot avatar to physically represents a child at school, giving a sick housebound child a view of the classroom in a non-demanding way, through the remote use of the robot supported by an iPad or smartphone app. This design possibility is being explored through collaboration with a start-up company called 'No Isolation,' who developed a robot avatar in parallel with our research on ME/CFS. The robot avatar aims to combat the harmful social isolation, which many young people experience due to illnesses or physical injuries. The youth with ME/CFS is a separate case of the research on the usefulness of the robot and its impact on children's lives. The hope was that the robot would prove to be a tool enabling them to fulfill their education, reduce their exposure to social isolation from their peers and, thus, give them a better starting point for their adult lives.

Figure 5.   The robot from our first technology design case.

For a more thorough description of this study and our findings see [16]. The study involves nine participants that have used their own robot avatar placed in their homes and schools as part of our research. All participants except one that had an illness recovery are at the time of writing this article still using the robot avatar in its final commercial version. One finding from the robot avatar study is how beneficial the flexibility of instant access to the classroom is for youth with ME/CFS. A user having a day or even just an hour with decreased illness symptoms could spontaneously login and get some teaching and reduce their exposure to social isolation that day. This result relates to the finding in the first expert session of how education has to provide

flexibility and that it is an advantage if the student with ME/CFS do not have to use energy on transportation to get access to classroom teaching. The flexibility of instant classroom access, illness accommodations to better fit with the energy modulation and the social benefits also is connected to the Educational design space and Personal/Family design space as shown in Fig. 2. However, this benefit also comes with a challenge related to the energy modulation, with a perfect balance between use and rest the technology could work in sync with the challenging nature of the energy modulation attached to the ME/CFS illness. There is, however, issues related to potential overuse and negative impact on illness symptoms. This mentioned possibility of a worsening of illness symptoms is one possible unintended harmful consequence of the technology introduction. Another unintended consequence could be if the users were pressured by others to overuse or if resources used to provide special education was withdrawn, a resource that was reported as successful for the youth with ME/CFS that has home tuition tailored to their educational needs. If such support were removed as feared by some parents in our study, the technology introduction would result in providing the users with a poorer educational offer. This is an example of how the technology introduction also affects the Governmental design space. Another example of how the Governmental design space is relevant for the robot avatar is that the Norwegian law was not formulated with the robot in mind. Thus, the placement and use of the robot in the classroom received many legal concerns, problems, and questions. Therefore, In December 2016 the Ministry of Education started working on addressing some of the issues surrounding the use of the robot avatars. They examined what the law says about the use and how to relate to it [56][57]. Furthermore, this effect also illustrates the robot avatars material agency, through the relations to other actors, the robot avatar has a capacity for action and influence on the network.

That politicians are supporting access to the technology for everyone, is crucial in providing the technology to families with low-incomes or parents that have reduced incomes since they are providing care for their loved ones suffering from ME/CFS. If the cost of the robot and its use is too high, it could result in increased class differences between families of low and high income. We observe that some parents and physicians of the users in our study, have taken the initiative and contacted the media and politicians to support access to the technology for others. A new actor in the network is the commercial startup company developing the robot. Being part of a business, they have to maintain high enough unit price for the robots not to go bankrupt. Therefore, there is a negotiation between the needs of the families of ME/CFS sufferers, which need the price low enough so that the technology is accessible to everyone that needs it and the company that needs profit to stay viable. This negotiation of the cost also involves the possibility of politicians making the robot available through the welfare system in Norway. As mentioned there are current efforts done to convince the politicians to take action and include the robot in our welfare system. These efforts come from

people within ME organizations, a user's pediatric physician, teachers, and parents.

Regarding the stigmatization of people with ME/CFS, we have not gotten any reports from our users stating that these robots were perceived as stigmatizing to use or own, more specifically they were reported by peers as cool or neutral. For people within the ME/CFS community, it was perceived as particularly positive that youth suffering from ME/CFS was included in the study, in the same way as children suffering from less stigmatized illnesses like cancer. Seeing how popular the company has become for young people, how the study puts focus on the importance of providing technology support for young people with ME/CFS, could help increase the understanding of ME/CFS in our society.

To sum up, for the technology introduction to be successful for the users, it is critical that other actors are enrolled like teachers, parents, and politicians. Keeping the energy modulation in mind and together with the users, they all have to contribute to providing a successful technology introduction outcome. Our case illustrates how a technology seen, as a new actor in the network, becomes a catalyst of change affecting many of the actors in the pre-established network, changing roles and introduce new actors. The technology aims to mainly focus on providing users with access to education and reduce social isolation from their peers. A deeper more thorough ANT inspired analysis uncovers how the introduction of this technology sparks and in some cases demands changes, affecting many more of the actors in the network than intended by the technology development initially targeting the Educational design space. In fact, we saw that the robot avatar has a strong presence in all the design spaces displayed in our Giga-map.

The process of developing the Giga-map supported by ANT resulted in a productive process where our understanding of the design context was simultaneously enriched. During our first technology introduction in this design contest, the developed map provided the recognition of invisible issues and possible problems that should be addressed in the redesign of the robot or the adopted strategies for use. The awareness of matters such as a low understanding of the illness or possible issues related to stigmatization. Served as a constant reminder to ask difficult questions during research and when envisioning further use. Both concerns are in nature human and all humans involved could be possible carriers of attitudes or wrongful understanding of ME/CFS that could result in robot users being stigmatized or to get worse if the energy modulation is not attended to. Essential questions then became what power does the various human actors in the design context have about the user or the use of the robot? How could the robot or the interaction be designed to lower the chance of such ill effects?

IX. CONCLUSION

We have argued that sense-making is a crucial step in understanding complex design domains in HCI, as exemplified by the task of identifying technology design opportunities aimed to support everyday life of adolescents

with ME/CFS. Published research results and ethnographic methods were used to understand risks associated with having ME/CFS. ANT and Giga-mapping were used to analyze and visualize input from sessions with experts. The ANT analysis primarily made us aware of the problems related to the low level of knowledge about ME/CFS in our society, and how those having the illness risk stigmatization. It became clear that numerous problems adolescents with ME/CFS face in our society cannot be solved by one technological 'solution,' but instead have to be addressed in a holistic way, by several actors including families, schools, peers, politicians, health-care providers, and research communities and others. The use of Giga-mapping helped to visualize all these crucial actors, including the authors, and relations among them. The utilization of rich descriptions and Giga-maps throughout the design process is also a way of annotating, documenting, reflecting on and sharing of divisive concerns and lessons learned. As this is a messy and unstructured process, we need to mention that the communicative value of Giga-maps that we produce to others than ourselves, is very low. The map had to be visually re-interpreted to make essential issues from the sense-making analysis approach visible (understandable) for the HCI research community. We, therefore, encourage some testing of the visual representation to make sure that it conveys the information as intended.

Our analysis uncovered three main design spaces relevant to our research case: educational, government and Personal/Family. While there are many different relations between actors within these spaces, and different levels of granularity that can be represented, when it comes to technological solutions these seem to be rather well separated, indicating many opportunities and challenges when working on boundaries between them. Further, we argue that these design spaces can aid in framing how potential new research projects, design concepts or technology artifacts relate to issues within the situated design space.

We believe that the approach, as presented in this paper, successfully combined methods and techniques that can guide HCI designers and researchers to conduct a broad inquiry and sense-making for new, complex design domains, where it is not easy to find solutions that work for all. Instead, the approach offers a way to gain a profound and vital understanding of the problem space.

ACKNOWLEDGMENT

REFERENCES

[1] J. Børsting and A. L. Culén, "Sense-Making in Complex Healthcare Domains: The Role of Technology in Every Day Lives of Youth Suffering from ME/CFS," Presented at the eTELEMED 2016, The Eighth International Conference on eHealth, Telemedicine, and Social Medicine, 2016, pp. 236–242.

[2] B. W. Head and J. Alford, "Wicked Problems Implications for Public Policy and Management," Adm. Soc., vol. 47, no. 6, pp. 711–739, Aug. 2015. 1955.

[3] S. Waddock, "The Wicked Problems of Global Sustainability Need Wicked (Good) Leaders and Wicked (Good) Collaborative Solutions," J. Manag. Glob. Sustain., vol. 1, no. 1, pp. 91–111, Jun. 2013.

[4] R. Buchanan, "Wicked Problems in Design Thinking," Des. Issues, vol. 8, no. 2, pp. 5–21, Apr. 1992.

[5] H. W. J. Rittel and M. M. Webber, "Dilemmas in a general theory of planning," Policy Sci., vol. 4, no. 2, pp. 155–169, Jun. 1973.

[6] J. Kolko, Austin Center for Design, Wicked problems problems worth solving. Austin, Texas: Ac4d, 2012.

[7] J. Redström, "Towards user design? On the shift from object to user as the subject of design," Des. Stud., vol. 27, no. 2, pp. 123–139, Mar. 2006.

[8] J. M. Perrin, L. E. Anderson, and J. V. Cleave, "The Rise In Chronic Conditions Among Infants, Children, And Youth Can Be Met With Continued Health System Innovations," Health Aff. (Millwood), vol. 33, no. 12, pp. 2099–2105, Dec. 2014.

[9] E. A. Witt, A. J. Massman, and L. A. Jackson, "Trends in youth's videogame playing, overall computer use, and communication technology use: The impact of self-esteem and the Big Five personality factors," Comput. Hum. Behav., vol. 27, no. 2, pp. 763–769, Mar. 2011.

[10] R. L. Punamäki, M. Wallenius, C. H. Nygård, L. Saarni, and A. Rimpelä, "Use of information and communication technology (ICT) and perceived health in adolescence: The role of sleeping habits and waking-time tiredness," J. Adolesc., vol. 30, no. 4, pp. 569–585, Aug. 2007.

[11] A. L. Culén and A. Karpova, "Designing with Vulnerable Children: a Researchers Perspective," in Human-Computer Interfaces and Interactivity: Emergent Research and Applications Book, IGI Global, 2014, pp. 118–136.

[12] A. L. Culén and M. van der Velden, "The Digital Life of Vulnerable Users: Designing with Children, Patients, and Elderly," in Nordic Contributions in IS Research, Springer Berlin Heidelberg, 2013, pp. 53–71.

[13] B. Latour, "On using ANT for studying information systems: a (somewhat) Socratic dialogue," Soc. Study Inf. Commun. Technol., pp. 62–76, 2004.

[14] C. Storni, "Notes on ANT for designers: ontological, methodological and epistemological turn in collaborative design," CoDesign, vol. 11, no. 3–4, pp. 166–178, Oct. 2015.

[15] P. K. Chilana, A. J. Ko and J. Wobbrock, "From User-Centered to Adoption-Centered Design: A Case Study of an HCI Research Innovation Becoming a Product," in Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems, New York, NY, USA, 2015, pp. 1749–1758.

[16] J. Børsting and A. L. Culén, "Experiences with a Research Product: A Robot Avatar for Chronically Ill Adolescents" Smart Technology Applications in Business Environments. IGI Global. 8. pp. 159 - 183, 2017.

[17] A. L. Culén and A. Følstad, "Innovation in HCI: What Can We Learn from Design Thinking?," In Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational, NY, USA, 2014, pp. 849–852.

[18] A. Gasparini, "Perspective and Use of Empathy in Design Thinking," in ACHI 2015, 2015.

[19] N. Afari and D. Buchwald, "Chronic Fatigue Syndrome: A Review," Am. J. Psychiatry, vol. 160, no. 2, pp. 221–236, Feb. 2003.

[20] G. J. Bringsli, A. Gilje, and B. K. G. Wold, "The Norwegian ME Association National Survey Abridged English Version." The Norwegian ME Association, 2014.

[21] Ø. Fluge et al., "Benefit from B-Lymphocyte Depletion Using the Anti-CD20 Antibody Rituximab in Chronic Fatigue Syndrome. A Double-Blind and Placebo-Controlled Study," PLoS ONE, vol. 6, no. 10, e26358, Oct. 2011.

[22] V. R. Anderson, L. A. Jason, L. E. Hlavaty, N. Porter, and J. Cudia, "A review and meta-synthesis of qualitative studies on Myalgic Encephalomyelitis/chronic fatigue syndrome," Patient Educ. Couns., vol. 86, no. 2, pp. 147–155, Feb. 2012.

[23] S. M. van Geelen, G. Sinnema, H. J. M. Hermans, and W. Kuis, "Personality and chronic fatigue syndrome: Methodological and conceptual issues," Clin. Psychol. Rev., vol. 27, no. 8, pp. 885–903, Dec. 2007.

[24] A. Winger, M. Ekstedt, V. B. Wyller, and S. Helseth, "'Sometimes it feels as if the world goes on without me': adolescents' experiences of living with chronic fatigue syndrome," J. Clin. Nurs., vol. 23, no. 17–18, pp. 2649–2657, Sep. 2014.

[25] P. White et al., "Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial," The Lancet, vol. 377, no. 9768, pp. 823–836, Mar. 2011.

[26] Norwegian ME Association (in Norwegian only): me-foreningen.com/. Accessed on April 12th, 2016.

[27] H. Holman and K. Lorig, "Patient self-management: a key to effectiveness and efficiency in care of chronic disease," Public Health Rep., vol. 119, no. 3, pp. 239–243, 2004.

[28] J. M. Corbin and A. Strauss, "Unending work and care: Managing chronic illness at home," vol. xviii. San Francisco, CA, US: Jossey-Bass, 1988.

[29] K. R. Lorig and H. Holman, "Self-management education: history, definition, outcomes, and mechanisms," Ann. Behav. Med. Publ. Soc. Behav. Med., vol. 26, no. 1, pp. 1–7, Aug. 2003.

[30] E. G. Dowsett and J. Colby, "Long-Term Sickness Absence Due to ME/CFS in UK Schools," J. Chronic Fatigue Syndr., vol. 3, no. 2, pp. 29–42, Jan. 1997.

[31] M. E. B. Smith et al., "Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Systematic Review for a National Institutes of Health Pathways to Prevention Workshop," Ann. Intern. Med., vol. 162, no. 12, pp. 841–850, Jun. 2015.

[32] A. Farmer, T. Fowler, J. Scourfield, and A. Thapar, "Prevalence of chronic disabling fatigue in children and adolescents," Br. J. Psychiatry, vol. 184, no. 6, pp. 477–481, Jun. 2004.

[33] National Collaborating Centre for Primary Care (UK), "Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (or Encephalopathy): Diagnosis and Management of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (or Encephalopathy) in Adults and Children," London: Royal College of General Practitioners (UK), 2007.

[34] B. M. Carruthers et al., "Myalgic Encephalomyelitis: International Consensus Criteria," J. Intern. Med., vol. 270, no. 4, pp. 327–338, Oct. 2011.

[35] F. J. Grajales III, S. Sheps, K. Ho, H. Novak-Lauscher, and G. Eysenbach, "Social media: a review and tutorial of applications in medicine and health care," Journal of medical Internet research, vol. 16, no. 2, 2014 Available: http://www.jmir.org/2014/2/e13/. [Accessed: 18-Jan-2016].

[36] K. Best and S. Butler, "Second life avatars as extensions of social and physical bodies in people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome," Continuum, vol. 27, no. 6, pp. 837–849, Dec. 2013.

[37] K. Best and S. Butler, "The Necessity of Control for Computer and Internet Users with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome," Inf. Commun. Soc., vol. 16, no. 7, pp. 1042–1060, Sep. 2013.

[38] A. K. Sheridan and members of the C. P. G. E. of C. with M. (Scotland), "Exploring E-learning provision for Children with ME in Scotland," Educ., vol. 2, no. 1, pp. 78–80, Jan. 2013.

[39] T. Brown, "Design Thinking," Harv. Bus. Rev., vol. 86, no. 6, pp. 84, 2008.

[40] T. Brown and J. Wyatt, "Design Thinking for Social Innovation (SSIR)," Stanford Social Innovation Review, 2010.

[41] U. Johansson-Sköldberg, J. Woodilla, and M. Çetinkaya, "Design Thinking: Past, Present and Possible Futures," Creat. Innov. Manag., vol. 22, no. 2, pp. 121–146, 2013.

[42] B. Sevaldson, "Giga-Mapping: Visualisation for complexity and systems thinking in design," Nordes, vol. 4, Mar. 2011.

[43] O. Hanseth, M. Aanestad, and M. Berg, "Guest editors' introduction: Actor-network theory and information systems. What's so special?," Inf. Technol. People, vol. 17, no. 2, pp. 116–123, 2004.

[44] B. Latour, "Aramis, or, The love of technology," Cambridge, Mass: Harvard University Press, 1996.

[45] J. Law, "Notes on the theory of the actor-network: Ordering, strategy, and heterogeneity," Syst. Pr., vol. 5, no. 4, pp. 379–393, Aug. 1992.

[46] A. Tatnall and A. Gilding, "Actor-Network Theory in Information Systems Research," 2005.

[47] Y. Akama, "Being awake to Ma: designing in between-ness as a way of becoming with," CoDesign, vol. 11, no. 3–4, pp. 262–274, Oct. 2015.

[48] A. Yaneva, "Making the Social Hold: Towards an Actor-Network Theory of Design," Des. Cult., vol. 1, no. 3, pp. 273–288, Nov. 2009.

[49] D. Stuedahl and O. Smørdal, "Matters of becoming, experimental zones for making museums public with social media," CoDesign, vol. 11, no. 3–4, pp. 193–207, Oct. 2015.

[50] J. Schoffelen et al, "Visualising things. Perspectives on how to make things public through visualisation," CoDesign, vol. 11, no. 3–4, pp. 179–192, Oct. 2015.

[51] M. Aanestad, "The camera as an actor design-in-use of telemedicine infrastructure in surgery," *Computer Supported Cooperative Work (CSCW)*, vol. 12, no. 1, 2003, pp.1-20.

[52] E. Sayes, "Actor–Network Theory and methodology: Just what does it mean to say that nonhumans have agency?," Social Studies of Science, vol. 44, no. 1, pp. 134-147, Feb. 2014.

[53] W. Hudson, "Playing your cards right: getting the most from card sorting for navigation design," interactions, vol. 12, no. 5, pp. 56-58, 2005.

[54] A. L Culén and M. van der Velden, "Making Context Specific Card Sets-A Visual Methodology Approach: Capturing User Experiences with Urban Public Transportation," International Journal on Advances in Intelligent Systems, *8*(1&2), pp. 17-26. 2015.

[55] M. M. Sommervold and M. van der Velden, "Transition cards: Designing a method with and for young patients," IADIS International Journal on Computer Science & Information Systems, vol. 10 no. 2, 2015.

[56] P4 (in Norwegian only): www.p4.no/nyheter/--problematisk-med-robot-i-klasserom/artikkel/689010/. Accessed on May 29th, 2018.

[57] The Norwegian Ministry of Education (in Norwegian only): https://www.udir.no/regelverk-og-tilsyn/finn-regelverk/etter-tema/Skoleeiers-ansvar/bruk-av-robot-i-undervisningen/. Accessed on May 29th, 2018.