# Co-designing infrastructures

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**Abstract** The paper builds on an ongoing research project striving to reduce hospitalization of elderly citizens with dementia (ECwD). In the research project sensor technologies are used to gather large amounts of data to speak on behalf of the ECwD about change in their behaviour. But in order for the data to create value, network-building efforts made by the project researchers is needed, as the case illustrate. Inspired by the framework of participatory infrastructuring we illustrate how front-stage as well as back-stage activities leads to negotiations and translations of concerns and data in a process of network-building together with a multiplicity of users and other actors such as ECwD, their loved ones, caregivers, sensors, researchers, municipalities, companies and nursing homes.

## Introduction

Big data is on everyone's lips these days. Especially within healthcare, big data is said to hold amazing potential in terms of population health management, clinical decision support to allow for better informed decisions, and prediction of disease progression (Lazarou et al., 2016; Raghupathi & Raghupathi, 2014). Thus, as Raghupathi and Raghupathi concludes: '*big data analytics has the potential to improve care, save lives and lower costs* '(2014, p. 1). Within the field of healthcare dementia is an interesting area where big data may be of particular use as assistive technologies such as sensors has the potential to speak on behalf of some of the elderly citizens with dementia (ECwD) which is no longer capable of expressing their own emotions and symptoms of a disease. For instance, sensors of varying kinds can measure biometrics such as pulse and heart rate, fall sensors can measure where citizens walk and whether ECwD suddenly fall, while GPS trackers measure

their whereabouts so they can be found if they stray and get lost etc. The data from all these sensors can be seen as big data: *'a collection of data elements whose size, speed, type, and/or complexity require one to seek, adopt, and invent new hardware and software mechanisms in order to successfully store, analyze, and visualize the data'* (Belle et al., 2015, p. 1). Dementia is not only interesting as the people suffering from this condition require a lot of help but also because a vast increase in number of ECwD is expected in the future. Studies estimate that in 2030 around 75,6 million people worldwide will suffer from dementia – and the number even increases to 131 million people by 2050 ("Dementia Statistics," 2018). The majority of this group lives in nursing homes and is thus very dependent on having dedicated caregivers who knows them and can detect signs of illness. If the caregivers fail to do so, the disease might not get noticed and treated resulting in hospitalization and in worst case in the death of the ECwD.

This paper builds on preliminary work and findings from an ongoing Danish research project PACE (Proactive Care for Elderly People with Dementia) striving to reduce hospitalization of elderly citizens with dementia. Using PACE as a case study we draw upon participatory design and Actor-Network Theory (ANT) to illustrate how big data is only one of the actors in a larger network comprising a multiplicity of actors such as ECwD, their loved ones, caregivers, sensors, researchers, municipalities, companies, legislation, research institutions and nursing homes. Our argument is, that in order to reap the benefits of big data analysis the point is not only to build suitable algorithms but rather to co-design an infrastructure which according to ANT require network-building activities. Bødker, Dindler & Iversen (2017) from the participatory design tradition refer to such network-building activities as participatory infrastructuring. Building on their research, this paper describes and analyses the negotiations and translation currently taking place as part of the network-building in PACE.

## PACE: Preventing hospitalisation of ECwD

Having dementia causes severe challenges both to the citizens themselves, their relatives but also to the healthcare system. For instance, studies show that a higher level of comorbidity is found among people with dementia (Bynum et al., 2005), which calls for extra coordination between the clinicians and the elderly citizens in order to report symptoms. If not reported, this may result in inadequate treatments and hospitalization. Thus, both from a citizen and a socio-economic perspective it is essential that hospitalizations must be avoided.

PACE wish to explore how the use of big data can contribute to detect changes in practices and behaviour among ECwD by combining already existing technologies such as different sensor technologies to speak on behalf of ECwD. Thus, PACE builds on the work of Lazarou et al. who advocates that *'Smart systems can improve the quality and variety of information monitored from specific measures of*

*physiological signs and behavioral patterns and translate them into accurate predictors of health condition and disease progression'* (2016, p. 1562).

Similarly, to Lazarou et al. PACE explores the potentials of sensor technologies and big data. However, rather than mainly focusing on adopting and inventing new hardware and algorithms (which is often the case of project involving big data) the PACE project seeks to take a participatory design approach to co-designing an infrastructure of people, software, sensors, institutions and a new user interface that acknowledge the practices of the caregivers at nursing homes and provides valuable insights enabling them to take even better care of the ECwD. We argue that this entails staging spaces for negotiation between actors to allow for translation of the results generated by big data into something which is meaningful for the caregivers, the ECwD, their loved ones and at the same time creates value for the healthcare system.

# Theoretical framework: Participatory design and infrastructuring

Involving users in the development of healthcare equipment is not new as private companies do recognize the importance of understanding their 'users' in order to design solutions which 'meet their needs' (Shah & Robinson, 2006). As several studies illustrate, engaging users will increase the success rate of the products, reduce the risk of failure and ensure long lasting products and services (Shah & Robinson, 2008).

Particularly the participatory design tradition stemming from Scandinavia provides methods for engaging users and other actors to actively contribute to the design process as they see 'users' of varying kinds *"… as the true experts in domains of experience such as living, learning, working, etc."* (Dubberly & Sanders, 2008, p. 13). The core values of this design tradition are democracy and change and participatory design promotes the idea that the people who are going to use the solutions should also have a say in their design and development (Bratteteig & Gregory, 2001).

Bødker et al suggest the notion of participatory infrastructuring, where infrastructuring work is linked to the sustainability of the design projects meaning continuous involvement over time. What is special about participatory infrastructuring is the analytical focus on how infrastructuring (interplay among people, organisations and levels of political authority) ties into existing networks, and how front stage *as well as* back-stage activities is used to obtain this anchoring and constant involvement (Bødker et al., 2017). Front stage activities refers to workshops and co-design settings while the back-stage activities refers to *'preparations, negotiations, and political work that fundamentally shapes the set-up and outcomes of the entire process'* (Bødker et al., 2017, p. 250). Both are equally important, as the

back-stage activities are an essential part of staging what Pedersen and Clausen terms Negotiation Spaces (Pedersen & Clausen, 2017).

In the PACE project examples of actors from different political levels would be local ECwD, their loved ones, private companies, public municipalities. Whereas government legislation initiatives provide a way for the new network to anchor and thus sustain after the traditional design process ends. However, traditionally the participatory design literature does not occupy itself with networks, and sometimes neglects the central role of objects in negotiations. Thus, we turn to Actor-Network-Theory (ANT) for a vocabulary related to infrastructuring as network-building through translations.

## Network-building

The combination of participatory design and ANT is not unexplored as for instance participatory design researchers like Björgvinsson et al. (2012) have drawn upon ANT to investigate and give a vocabulary to the processes of network-formation, translation, alignment of knowledge and diverse actors in design processes. ANT is a constructivist approach where the word actor refers to both human and non-human entities giving a voice to ECwD, doctors, caregivers, loved ones as well as prototypes, drawings, sensor technologies and algorithms. Thus, the design process is seen as a "*collective interweaving of people, objects and processes*" (Björgvinsson et al., 2012, p. 130). The formation of socio-technical assemblies is central in design as the goal of many design processes is to form a stabile network. But before the network or infrastructure become stabile, the actors go through a process of translation. Storni (2012) argue that such translation processes is often associated with numerous negotiations of the matters of concern of multiple actors. Matters of concerns are (as opposed to matters of fact) characterized by being rich, complex, surprising and constructed (Latour, 2004) which makes them political and open for discussion, negotiation, conflict and compromise (Björgvinsson et al., 2012; Latour, 2005). A key enabler in these negotiations are traditionally material objects such as mock-ups, prototypes, post'its, graphs etc. However, in our case also algorithms , sensor-technologies and user-interfaces are central objects as they together with the traditional prototypes and drawings have the potential ability to perform as intermediary objects (Boujut & Blanco, 2003; Vinck, 2012). These intermediary objects *represent* knowledge and *perform* as an important actor in the translation, production and negotiation of data and knowledge.

# The PACE research approach

As previously mentioned, the primary aim of PACE is to prevent hospitalisation of ECwD. The primary nodes in the new network-in-the-making are two Danish nursing homes Skovhuset and Ryetbo, who sees a potential in allowing sensor

technologies to help the caregivers in their efforts to identify early signs of a beginning disease such as urine infections or pneumonia among ECwD. PACE also involves researchers from Aalborg University (AAU) who are experts in participatory design activities and who's first task was to identify indicators of sickness. These indicators are used in a big data analysis, done by researchers from the Technical University of Denmark (DTU), who will be designing an algorithm based on these indicators. Further, PACE also includes a supplier of sensor-technologies. Alongside the human actors in the network, the PACE participants also automatically bring an assembly of other human actors and objects which forms the different institutions such as electronic patient record systems, the administrators of the systems, the legislation and rules of conduct from the municipalities and many other.

The research is based on a combination of qualitative and quantitative research. The qualitative research is carried out by the authors and include ethnographic interviews, desk research, workshops, observations and informal meetings with a variety of actors. The quantitative part of the research entails analysing data generated from sensor technologies and developing an algorithm that is comparable with the existing electronic patient system.

In present time, the project is 1,5 year into its 4 fours of running. The sensor technologies currently chosen for the purpose of data collection consists of existing products or products almost ready for market launch. Based on the initial identification of indicators the sensor technologies were selected based on their ability to measure these indicators. At this point in time, four technologies are included in the research: sensor floor, emergency system, radar and a biosensor padge. These four technologies can provide the project with unique data on the following parameters:

| What is measured? | Floor | Emergency System | Radar | Bio Sensors |
|---|---|---|---|---|
| EKG | | | | X |
| Heart frequency | | | X | X |
| Respiration | | | | X |
| Position | | | X | X |
| Fall | X | | | X |
| Step counter | | | | X |
| Temperature | | | X | X |
| Contact | | X | | |

Figure 1: Overview of sensors and of what they measure

The next step after selecting the sensor technologies is to translate the indicators into something that can be measured. This step is crucial as it affects the results of the big data analysis. For instance, as apathy is one of the indicators, the DTU researchers will look for less walking around on the sensor floor. And similarly, with the other indicators.

# Negotiating concerns

As already indicated, the participatory design researchers initiated their search for indicators of deterioration of health for the ECwD as these would provide the DTU researchers with a starting point in terms of building algorithms and searching for patters in the data. So, our first task in the research project was trying to understand and identify *what* to look for in the sensor data. Through desk research we identified a number of potential indicators of possible sicknesses such as frequent toilet visits, increased anger, apathy etc. We soon learned that the effects of dementia present itself in different ways, and also that no dementia expert or other expert could possibly give one fulfilling answer as to which indicators to look for. So, we expanded the network to include actors such as experts in dementia (doctors, nurses, dementia coordinators etc.), nursing home staff, and patient associations. Through roll-the-snowball techniques new actors were identified, and meetings where set up. These meetings can be seen as negotiation spaces (Pedersen & Clausen, 2017) that was staged to negotiate a number of potential indicators. A central actor in these negotiations was a set of game pieces with icons and wording representing an initial list of eleven indicators (see figure 2). These pieces acted as intermediary objects (Vinck, 2012) illustrating and representing indicators, mediating between the researchers and the dementia experts, and translating knowledge from one spaces to the next by introducing new game pieces based on feedback from the previous experts. While building a shared knowledge on indicators of sickness the negotiations also had the effect that the consulted experts also became translated to be part of the new network that the PACE project was about to build up.



*Figure 2. Illustration of how indicator cards were used in engagement with a variety of actors*

What became apparent from these negotiations (besides new indicators such as difficulty for the caregivers in performing personal care due to increased anger and discomfort) was that all engaged experts agreed, that each indicator is only relevant if there is a *change in behaviour*. For instance, frequent toilet visits do not indicate illness if the ECwD always has frequent toilet visits. Another important learning was, that such changes in behaviour is not necessarily a sign of illness, but

might be an indication of e.g. over- or under-stimulation. Thus, during the negotiations under- and overstimulation of ECwD emerged as a new matter of concern to be explored. Our response to this was to engage a team of Bachelor's students, who further investigated this concern. They staged negotiation spaces with props such as design games, personas etc. and invited ECwD, caregivers from Skovhuset and relatives into negotiations around how to ensure a right level of stimulation of the ECwD and keep track of extraordinary activities such as physiotherapy, birthdays etc. so this information would feed into the big data collected by the sensor technologies. The students ended up developing an app, in which relatives and caregivers could upload pictures of these extraordinary activities and tag the ECwD so they were linked to specific activities. The app provided a transparent way for the relatives to see that the caregivers engaged the nursing home residents in fun activities, while at the same time providing the caregivers (and PACE researchers) with insights as to why there might be changes in the behaviour of the residents. After graduation, the students have continued their work, and are now a sub-partner in PACE.

In line with the previous work on participatory infrastructuring we also initiated the process of expanding the network by tying the PACE network-in-the-making to existing networks and infrastructures. In Hillerød municipality where the nursing home Skovhuset is located, they have an electronic patient record (EPR) system called Nexus where all information on the nursing home residents is documented. To ease the workload of the nursing home caregivers PACE strives to integrate the results of our algorithm with the local patient record system. Thus, we have initiated negotiations with the municipality as well as with the private company developing the EPR to provide us with an API. Even though it is still quite early in the project and we have not produced any algorithm and only gathered some initial data from 6 residents, it is a central part of the participatory infrastructuring activities to also enroll municipality representatives in the PACE network. We (the AAU researchers) have had several meetings with representatives from the municipality IT department in an effort to involve this key actor in the network. In these spaces the municipality representatives were introduced to illustrations of the project setup, and based on these encouraged to voice their own concerns and how they could see their own role in the project. Thankfully the municipality representatives were very supportive and thus an ongoing task in the project is to keep these actors in the loop and nurture the good relationship. Furthermore, the help from the municipality has proved central in designing the informed consent documents that are necessary for collecting the data. This has been an ongoing effort as it is important for the municipality who owns the nursing home to make sure that none of their citizens' rights are violated. Because many of the ECwD are not capable to sign these informed consents on their own, it is also an ongoing task to nurture the relationship with their relatives as they are the ones who can sign on behalf of the ECwD. Thus,

we have arranged relatives-cafés at both nursing homes to tell about the project and answer any questions they might have.

Recently, we have also staged and facilitated workshops with nurses and caregivers at the nursing homes to initiate a second translation of the project. Thus, we need to translate the results from the big data analysis into something that provides value for the practices of the caregivers. In order to do so we have used what might be termed back-stage work (having project meetings, info-meetings, meetings with the municipalities) to stage these workshops.

As we are now 1,5 year into the research project we have tried to make every activity carried out (whether it be a back-stage or a front-stage activity) count as one step in the direction of participatory infrastructuring.

## Conclusion

In this paper we conclude that one of the most important elements of design is to build relationships between actors that can forms a stabile network. This is obtained through staging spaces for negotiation which foster a translation process where each actor develops their own identities and roles in the network. In PACE we have initiated this process by inviting a multiplicity of actors to participate in negotiations about diverse matters of concerns. The first negotiations focused on identifying indicators. The next negotiation revolved around the translation of the indicators into something that can be measured with sensor-technologies. And when the big data analysis is conducted, the results will be translated into something that provides value for the caregivers. The essential thing here is, that the caregivers themselves are involved in this development process.

Despite the research project is still only 1,5 year into its activities, many front stage and back stage activities has already been conducted. Each of these represents one step towards building and expanding the network through participatory infrastructuring. Thus, even though the PACE project is designing an algorithm, we are indeed also (and perhaps more importantly) co-designing an infrastructure to support and sustain the use of the designed algorithm in a way that it provides value for all actors in the network.

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