HEALTH CULTURES. DESIGNING HEALTHCARE INFRASTRUCTURES AS URBAN INTERFACES FOR SOCIETY PARTICIPATION.

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ABSTRACT
This paper - based on the participatory design research project ‘Health Cultures, Healthcare and Multiculturalism’ - reflects on how we can redesign healthcare infrastructures as urban interfaces for citizens from different cultural backgrounds to participate more actively in society. The project investigates the health care systems and institutions of care in action, and how they develop within the context of a growing multicultural society and the declining welfare state. Via a design anthropological research in different health-related contexts within the city of Genk (Belgium), wherein 54% of the inhabitants come from foreign descent, we studied how these environments function as interfaces for inhabitants’ societal participation and how design can contribute. Based on these findings, we created a tool that supports a critical public debate on the changing role of healthcare in society participation. We also designed future scenarios for healthcare infrastructures as urban interfaces that mediate between more diverse ‘Health Cultures’.

INTRODUCTION
For many, active participation in society is a fundamental aspect of democracy. Although the degree of participation may vary, most people influence society in different ways: they vote, participate in the public debate (e.g. via town meetings) and pay taxes. In Scandinavia, the birthplace of Participatory Design (PD), the idea of democracy through participation is overall well established. PD emerged as a political approach to ICT design as it democratized ICT development and allowed workers to shape their future work and professional roles on equal terms with management and IT specialists (Ehn, 1988). Nowadays, PD is no longer just a tool for workplace system development but an approach to design for participation at large (DiSalvo et al, 2012). It has been demonstrated that PD is an interesting approach to explore certain aspects of participation in society, particularly in large-scale public services such as healthcare. The scope of this paper is to contribute to this particular debate on the role of PD in the design of societal participation via public services, and more particularly via healthcare services.
The presented findings are part of an on-going design research project ‘Health Cultures, Healthcare and Multiculturalism’ (Health Cultures). In this project, we studied how healthcare environments function as interfaces for societal participation of inhabitants in a city and how design can contribute to this. Health Cultures focused on the city of Genk (Belgium) as an in-depth case and is a collaboration between the University of Hasselt, LUCA School of Arts, the Public Centre for Social Welfare of Genk, the city of Genk and the local hospital (ZOL). The research team consisted of four design researchers who were closely guided by a steering group in which representatives of all partners were present. This paper reports on a design anthropological study, carried out in 2017 that took place in five local contexts within the city of Genk. These local contexts were (1) a sports context, (2) an industrial producer of medical prosthesis, (3) a hospital context, (4) a rheumatism centre integrated in a private home environment, and (5) a care and training environment for professional football players. In these contexts, we specifically looked at the daily interactions between the care receivers, the caregivers and the public realm of the city. The observations resulted in field notes, photographs and videos, which were again translated into visual maps. These maps showed how, within these diverse contexts, the different healthcare environments interface between cultures through the support of health data, tools, codes and interactions. In the next phase of the project, a screen installation was created, using the data gathered from the first phase. This screen installation can be used as a tool for the city - and if filled with additional data can be used regionally/nationally – to critically debate the role of healthcare infrastructures in society participation.

Throughout the paper, we explicitly use the concept of healthcare infrastructures as interfaces to mediate more diverse participation? How can we redesign healthcare infrastructures as interfaces to mediate more diverse interactions between different health cultures. We conclude this paper with some more general reflections on how design research can engage with healthcare infrastructures in a context of increasingly diverse (multicultural) ‘health cultures’, to provide ‘open’ and equal healthcare infrastructures and consider them as a tool for societal participation.

Before presenting the case study, the paper provides some background through a literature section discussing healthcare and multiculturality as well as the notion of healthcare infrastructures as interfaces. In the fieldwork section we report in detail on the Health Cultures project, the followed methodology as well as the findings from the five studied contexts and the screen installation. We end with some more general concluding reflections on the politics of design research for healthcare contexts in a growing multicultural society, confronted with the decline of the welfare state.

THE UNDERSTANDING OF CARE AND CULTURE

The last decades, we have witnessed a switch to a patient-centred paradigm within the field of healthcare. This has had many advantages, like more care for the patient within the healthcare system. However, this paradigm has also foregrounded the concepts of self-care and self-management that have expanded responsibilities for care receivers, their families and communities as they are considered as active participants in their own continuous care and treatment (Marceglia, Fontelo & Ackerman, 2015; Saltman, 1994, Scholl et al, 2014). Due to recent technological innovations, patient empowerment has also changed: online platforms and smartphone applications give people the opportunity to document, collaborate, seek information and share experiences among a network of clinicians and other patients (Ammenwerth et al., 2017; Crotty, 2017). However, this focus on patient empowerment and the designed tools is also closely related to the neoliberal governance model wherein the individual to a large degree has to take responsibility for the risks she/he faces (Bansler & Kensing, 2010).

In order to prevent the patient-centred paradigm to be only caught in a neoliberal model, it can also be considered to as a cooperative healthcare model that entails the active involvement of all related parties (care receivers, caregivers, professionals, community) (Moll, 2012). This model puts more focus on cooperation within the community. What we have investigated further with an eye on trying to answer the earlier-mentioned research questions, is how this social network (or community) is rooted in the public realm. Depending on different neighbourhoods, cities, regions, countries and organizations, the field of healthcare is differently defined, structured and organized. For
instance, national healthcare services differ from country to country; each using different models, but also sharing a lot of similarities. Different health cultures are also intertwine(d) in the past, present and future of this public realm. Designers can take this collective and publicly embedded aspect of healthcare into account by looking into its political dimension, which we frame through the collective concept of ‘politics’, defined by Mouffe (1993) and Rancière (2009, p. 25). Both scholars describe politics as collective processes of dis-sensual reconfiguration of ‘common sense’ between actors on different scales: people, institutions (e.g. hospitals or companies) and materialities (e.g. technologies and spatial artefacts) (Huybrechts, Benesch & Geib, 2017).

This view on healthcare as a publicly embedded practice, offers a different view on the term ‘culture’ or ‘health culture(s)’. We consider healthcare infrastructures such as healthcare information systems or hospital buildings as contingent, social and historical constructs where different cultures come together (Bowker & Star 2000) via dis-sensual interactions between diverse actors. Culture is thus not viewed as the determining or limiting factor. Hence, we follow Pearson (1986) by not focusing on ‘multiculturalism’ as a term, since it talks in terms of minority and majority. By using the term ‘multiculturalism’ problems are seen as a mismatch between cultures that can be solved, which can result in solutions that ignore the political and structural aspects of society. This can lead to “multicultural essentialism” wherein ethnic groups are perceived as absolute categories, often resulting in oversimplification and stereotyping (Culley, 1996). We thus rather see healthcare infrastructures as heterogeneous constructs that have undergone transformations over time due to numerous negotiations (Danholt & Langstrup, 2012). When giving form to these healthcare infrastructures that mediate between different health cultures (materialized through forms of digital self-management, e-governance, services, etc.), specific attention is paid to how these infrastructures are currently designed for diverse care providers’ and receivers’ to meet and exchange in a mutual beneficial way. The aim of this paper is to go beyond finding strategies to cater ‘solutions’ for inhabitants coming from different cultures to interact with healthcare infrastructures, but rather give form to their political dimension: their historically grown qualities that support diverse viewpoints, backgrounds and perspectives of diverse health cultures to meet.

In this framing, healthcare infrastructures do more than solving problems, but become zones for dis-sensual reconfiguration of common sense. They can thus be considered as ‘interfaces’ in the definition of systems of co-dependence between people and a larger structure of “very disparate frameworks and modalities” (Drucker, 2011, p. 5). Therefore, this paper focuses on how healthcare infrastructures were given form (visually, through sound, etc.) as interfaces to support people in navigating through it as well as starting exchanges with other people, frameworks and modalities. We pay specific attention to the non-verbal aspects of how these healthcare infrastructures are conceived as interfaces. The goal is to understand and further develop these infrastructures as consciously or less consciously designed interfaces between diverse groups, rooted in the public realm.

HEALTH CULTURES

To grasp how health cultures meet through different healthcare infrastructures as urban interfaces, the PD project ‘Health Cultures, Healthcare and Multiculturalism’ (Health Cultures) was set up in the city of Genk. The data collection and analysis was carried out by four design researchers who were guided by a steering group, a mixed group of representatives of the two main partners in the project (two universities and two independent designers) and of the main healthcare institutions in the city, being the city planner and the intercultural mediator of the hospital, a representative of the public centre for social welfare and the diversity and equality department of the city.

In the first phase of this project, we conducted 10 in-depth observations (one day of following the perspective of the caregiver, one of the care receiver for each of the five studied contexts) and 16 semi-structured interviews in the period from June until December 2017. These observations and interviews were carried out in five urban healthcare contexts that were selected based on their diversity and in consultation with the steering group. In order to go beyond the social community and look into how they were embedded in the public realm of Genk, we selected very particular contexts:

- In the context of the hospital in Genk, we talked to the lead architect, a policy advisor, the coordinator of the Synaps park project (transforming the hospital campus), the head of intercultural mediation, an intercultural mediator on the floor, a female Belgian doctor and a Moroccan male patient of the sleep clinic. The different interviews made clear that the triangle between the care receiver, caregiver and the public domain in this context is under continuous development. One example is the Synaps Park project that embodies the current shift the hospital is undergoing from a monofunctional car-driven environment into a healthy, dynamic campus for users of the hospital buildings as well as people from the neighbourhood.

- In the case of the sport infrastructure, the field data focused on the strategies for interaction between the cultures of two different sport organizations (A and B) and the coordination of this process, executed by the coordinator of the sport infrastructure, appointed by the city.

- In the case of an industrial infrastructure producing prosthetics, we studied the interactions
between the customers, craftsman/workshop workers and the manager - who interfaces between the company, the health institutions in the city and the care receivers.

- In the context of **home-practice based care**, we studied the rheumatism centre, which is a medical centre situated in a private house in Genk. It was and still is a home-practice, where a private apartment and a medical practice are situated in the same building. Here, the interactions between the caregivers and care receivers, mediated by elements present in the interior space, were studied.

- **A health practice mediated through the body** as infrastructure was studied via a medical department of an international football club KRC Genk. It allowed us to get more grip on the increasing role of self-management of the (i.e. “Doctor You”) in an international professional sports environment, with people coming from different cultures. In professional sports the body is continuously monitored, by medical professionals, but also by the sport-professionals themselves.

In these specific contexts, all located in the city of Genk, we looked at the daily interactions between ‘care receivers’ and ‘caregivers’ as well as other actors that interface between these groups within the public realm (e.g. civil servants, domain specific city managers etc.). The observations and other field data (field notes, photographs, audio) resulted in videos that were later translated into visual maps that show how different kinds of data, tools, codes and interactions mediated between the diverse health cultures within these contexts. These mediations provided us with more insights in how the current design of healthcare infrastructures as urban interfaces facilitates interactions on a micro-scale (between the caregiver and care receiver) and on a meso and macro-scale (with urban, regional and national public services). At the end of this first phase (June 2018), experts from the five studied healthcare contexts were invited to provide feedback on the created visual maps. In the second part of the project, a screen installation was created to trigger debate between all involved actors and on future scenarios for healthcare infrastructures as interfaces that mediate societal participation.

In the following part, we will discuss how different tools, data, codes and interactions were used in the five different contexts to mediate between care receivers, caregivers and the public realm. We will also address how the findings from the five contexts led to the creation of a screen installation to trigger critical debate.

**FINDINGS**

The most important **interactions** between care receivers, caregivers and the public realm were mediated by people who functioned as interfaces through different roles and in different contexts. The role of the intercultural mediator in the context of the hospital is a striking example of a person who interfaces not only between caregivers and care receivers but also between different health cultures, in this case often people coming from the different, very multicultural neighbourhoods in the city. This professional role of intercultural mediator appeared as an important one as they know the health cultures and habits of the care receivers. These intercultural mediators fulfil several tasks: providing information and knowledge, educating caregivers about how to deal with cultural differences, translating or looking for an appropriate interpreter as well as connecting caregivers and care receivers. In the hospital of Genk - one of the five contexts - six intercultural mediators (two for the Italian, one for the Moroccan and three for the Turkish community) operate on a daily basis. During one of the observations in which we followed one of the intercultural mediators assigned to the Italian community, he stated “it is important that we not wear some sort of uniform since we don’t want to be considered as another caregiver, we operate between caregivers and care receivers. We are the in-betweens.” (Interview M.P., 11th of October 2017). Although this role of the intercultural mediators is specifically linked to the hospital context, people in other contexts (e.g. secretary in a medical centre, trainers, etc.) take on the same tasks. In the context of the local sports infrastructure, the different trainers bring people who have little experience in doing sports in contact with health coaches and caregivers (e.g. when assisting people with diagnosed heart conditions). In contrast to the hospital context, it became apparent that the sports context is less language-centred. This was also corroborated by the coordinator of the sports infrastructure who states: “Language is never an issue in sports, because sports is a universal language” (Interview J.S., 18th of January 2018). The trainers also mediate between the health institutions of the city and care receivers. For instance, they created a walking program in collaboration with the hospital in order to promote walking activities in the vicinity of the hospital.

Besides people, also different **tools** are used as interfaces between care receivers, caregivers and the public realm. The different tools that were used by both care receivers and caregivers and different actors active in the public realm to interact within the five contexts were digital tools, personal devices, medical tools as well as sports equipment. Tools, like visualizations or plastic models of body parts or brains (Fig. 1) facilitate the communication on complex subjects in the context of the hospital and medical centre. But also in the context of a local healthcare company that produces prosthetics; tools and materials like plaster prototypes fulfil this interfacing quality. Some tools are also internationally known: for instance the whistle in the football context indicates when a sports movement is done wrong (Fig. 2).
When studying the five different healthcare related contexts, it became clear that in each context a colour coded system is used for different purposes. For instance, the hospital uses a color-coded signalization (combined with a letters) to navigate people throughout the hospital. In the sports context, colour codes are used to make clear which different tools and which zones are best used for which kind of sport disciplines (Fig. 3).

In the context of the rheumatism centre (a medical centre housed in a residential building) a colour coded system is used to indicate accessibility: blue refers to public spaces where care receivers have access to whereas the colour red is used to indicate private spaces of the building (Fig 4). When looking at the context of a local healthcare company that produces prosthetics, a colour codes system was used to arrange order: different colours are not only used to indicate for which body part (e.g. arms, back, legs, feet) prostheses are being ordered but also baskets in different colours are used to track (on a weekly basis) the flow of the production process (Fig 5).

In all of the studied contexts, different kind of data are used as interface between caregivers, care receivers and the public realm. For instance, medical data in the form of digital or physical files are used and stored in the hospital, the medical centre but also in the medical department of an international football club. But also in the sports context, they make use of digital data (e.g. the Strava app to connect with other people all over the world when walking/running/cycling) to discuss progress and health related issues with care receivers, caregivers and sport organizations. The medical department of the international football club in fact really relies on health data that are collected through different interfaces: the footballers receive daily iPad questionnaires that evaluate their sleeping pattern, mental and physical state of mind and also GPS tracking is used. Parts of these data are used to study their performance on the field, whereas more intimate-personal info is kept private. Whereas the health data in this context are mainly digital ones, during the production process of prosthetics the care receivers’ data are handed over by the caregivers on paper forms to the local healthcare company.

This fieldwork supported us to investigate how caregivers and care receivers from different cultural backgrounds currently collaborated in exchanging on healthcare and what the “interfacing” aspects were of the healthcare infrastructures: the tools, data, codes and interactions. We also looked further than the traditional...
health context (e.g. hospital) and investigated new practices that supported the care receiver in collecting, interpreting and sharing personal health data, complementary to the official medical records and interactions.

DATA ANALYSIS THROUGH SCREEN INSTALLATION
The analysis of the data focused on the interactions between care receivers, caregivers and the public realm in these different contexts. As already became clear in the findings section, we learned from a first verbal clustering of the interviews and visual clustering of the visual material that the dominant ways to give form to healthcare infrastructures as interfaces between diverse groups of people were colour codes, classification systems, visual languages and specific materials.

To make more collective sense of the data and - maybe even more importantly - debate the gained findings and insights between all the involved actors in the different contexts (i.e. caregivers, care receivers, actors operating in the public realm and the researchers of the Health Cultures project); we created a creative, generative screen installation that searches for visual similarities between the collected visual data of our design research process (codes, tools, data, interactions and collective public infrastructures related to health). The tool is mainly aimed at nurturing the imagination, pushing the boundaries, and stimulating the debate around health infrastructures in the city and how they potentially can function as interfaces between diverse health cultures. People who engage with the tool can explore the existing ways of mediating between different health contexts through visual data, codes and tools and imagine alternative ways (Fig. 6).

![Figure 6: Screen installation](image)

The screen installation was displayed as part of the exhibition ‘Politics of Design’, but can also be operated through a computer. It randomly shows the ‘interfacing’ aspects of particular healthcare infrastructures - via tools, data, codes and interactions - currently in use in the five studied contexts. The visual similarities between these interfacing aspects are matched through an algorithm and show the audience the current existing ways to interface in health contexts. The particular way in which they are shown (visually similar aspects), aimed to invite people to imagine future healthcare infrastructures as interfaces between diverse care receivers and caregivers in healthcare related activities. In the exhibition this installation wanted to engage with people in a discussion on the politics of healthcare infrastructures. The installation was also used in a co-design session in the hospital of Genk. We invited the different people (caregivers, care receivers and other actors related to the different healthcare contexts) with whom we engaged during the fieldwork, the members of the Health Cultures steering group and other healthcare experts (designers, care professionals, etc.). During this session, the screen installation was presented to all participants who could engage with the generated data and – in a second step - imagine how they would inform future healthcare infrastructures as urban interfaces. After the exhibition and the co-design session, we evaluated the use of the screen installation through interviews. It became apparent that the value of the installation lies in its artistic quality that fosters a critical debate among its audience on healthcare and its role in society participation, which postpones an immediate quest for solutions.

DISCUSSION
By collecting visual data from five health related contexts in the city of Genk and integrating these data in a screen installation as a means to stimulate the debate on future healthcare infrastructures as interfaces, the outcomes of the Health Cultures project confirmed a need for healthcare infrastructures to be further developed as interfaces that voice all people involved in a healthcare situation. These interfaces should provide people with the opportunity to express how different cultures give form to their health. This contrasts with most existing health platforms or systems that first of all define what is considered to be healthcare within existing medical fields and that mainly focus on communicating how the system works to people from different cultures. The findings of Health Cultures led us to formulate some points of concern on the level of the healthcare infrastructure as interface in relation to how it is interwoven with the public realm of Genk (local public roads, its links to EU projects etc.). Following concerns were foregrounded and will be further worked out in a third stage of the Health Cultures project as design scenarios: (1) the need for healthcare infrastructures to become interfaces for self-documentation and negotiation on health in professional environments between caregivers and care receivers, (2) the need for infrastructures as interfaces that support self-documentation and negotiation on health, while moving through the city; (3) the need for healthcare infrastructures to become interfaces for ethical approaches to self-documentation and negotiation of intimate/private data.

In all the studied contexts, healthcare infrastructures paid attention to their interfacing aspects to support communication between care receivers and caregivers about physical and mental wellbeing. However, they generally appeared to be rather top-down organized. For
instance, intercultural mediators are hired by the hospital to support people coming from different cultures to understand the health context, daily health questionnaires are provided to football players from different cultures to collect personal health data and subsequently monitor their health according to the rules of the medical professionals, etc. However, in these systems there is little to no room for personal interpretation or preferences on health: e.g. the way the football players or care receivers would like to organize their health or collect and store their own personal data. Thus, there is a need for healthcare infrastructures to organise their ways of interfacing in order to provide more room for both care receivers’ ways of dealing with health as caregivers visions on health related issues. This way of giving for to these interfaces supports a new kind of public realm to develop where different care cultures meet more frequently and more qualitatively.

The data analysis of both the visual data as well as the results of the co-design sessions around the screen installation, also showed that the existing ways of interfacing by the healthcare infrastructures were quite bound to a specific location or site (e.g. intercultural mediator in the hospital, the coloured lines in the sports infrastructure). Thus, it was discussed that in the future, there could be enhanced attention for designing interfaces that allow care receivers and caregivers to explore and share how they experience, receive and produce healthcare in different areas of the city (routes): e.g. mapping personal running routes (of footballers or people that use the city sports infrastructure) or the routes medical products travel. During the co-design workshop, we brought together members of the sports and health organizations in the city, in order to make health running, biking and walking routes throughout the city/region. They pointed to public services they had developed, such as a the ‘social map’ of the city and the ‘green healthy links’ by the region. In the workshop they reflected on how these existing initiatives could be made by and for people from different cultures based on the visual codes that are already used in the sports centre and are known to most of the people in the city; based on the routes that medical products follow, making use of already existing colour codes of the healthcare company. The routes could guide people towards more specialized centres within the city space. For instance, the colour codes (blue and red for domestic (private) and public services) in the rheumatism centre could inspire the ways in which similar codes can be repeated throughout the entire city.

A last challenge that was discussed lies in how healthcare infrastructures as interfaces can bridge between private data and how they relate to issues of public importance (e.g. the performances of the football players or the quality of the environment (e.g. air quality of industrial zones)) as well as who manages and moderates these data.

These 3 discussed concerns lead the design researchers – supported the people involved in the co-design sessions - to explore some first design ideas that were slowly prototyped in the field. We explored the design possibility of self-documented health walks between A and B using mobile tools to discuss complex issues (e.g. the working of brains) as well as walks to relax, support each other, etc. During the Health Cultures process, our research team has explored this via a mapping and two live interventions. In 2017, the research team developed a clear and comprehensible map of the paths that care receivers, caregivers and neighbours can walk through the woods in the vicinity of the hospital. Furthermore, on one of the crossroads an ‘open air room’ was constructed with benches and a map of this “caring” soft connection network to attract both care receivers, caregivers and others (e.g. people living in the area) to use these paths more frequently (e.g. during their lunch break). In 2018, a second mapping was carried out, monitoring people’s movements inside and outside the hospital (in collaboration with a group of dancers). The hospital’s parking space appeared to be one of the most intensely used crossroads in the environment. Via a live intervention of a performative installation, the parking space was transformed into a meeting space. Instead of being only used by cars, it became a space full of semi-public meeting rooms for interest groups to discuss dietary food, particular exercises and for people to start collaborative walks or runs together etc. These mappings and interventions show the potential of turning healthcare infrastructures into interfaces that enable a larger diversity of people to learn about and develop personal, collective paths and meeting points in the city that they can use for health purposes.

CONCLUSION: HEALTHCARE DESIGN AS POLITICS

If our healthcare infrastructures are to be tools for everybody’s participation in society, health care systems and institutions of care as public services need to critically tap into the recent evolution to a more multicultural society. They also need to take into account the shift of responsibilities from the government and healthcare institutions towards the individual care receivers. The Health Cultures project explicitly explored healthcare design - and more specifically healthcare infrastructures - as ‘politics’; a zone where different voices meet and negotiate. During the project, we explored how healthcare infrastructures as urban interfaces could more explicitly be designed to give form to this political space, not by just shifting the responsibility from healthcare institutes and governments to individuals, but rather by mediating a shared critical debate between care receivers, caregivers and the public realm.

During the Health Cultures project, we experienced that the integration of healthcare in the city space and its engagement with very diverse actors in society, was considered important by the government of the city we
worked in. Therefore, the city invests in infrastructural developments to provide for spatial and information infrastructures that can become meeting points for people from diverse cultures to interact qualitatively on healthcare related issues. Thus healthcare has crossed the boundaries of the healthcare institute, which fits in the shift towards a cooperative healthcare model that entails the active involvement of all related parties (instead of a patient-centred paradigm). Although we are already witnessing a focus on the role of the community within this model, we believe that the notion of community needs to be extended from the social network of the care receivers towards the public realm in which they live. In the Health Cultures project, first steps were made to root this social network in the public realm. This was carried out through the design of a screen installation that supports critical debate on this issue and is based on visual data gathered from the field. In this phase of the project, triggering this debate - through a co-design process - is maybe even more important than the concrete ideas for urban interfaces it has generated.

REFERENCES