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Infrastructuring Multicultural Healthcare Information Systems

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Abstract. This paper stresses the need for more research in the field of Participatory Design (PD) and in particular into how to design Health Information Technology (HIT) together with care providers and -receivers in multicultural settings. We contribute to this research by describing a case study, the ‘Health-Cultures’ project, in which we designed HIT for the context of home care of older people with a migration background. The Health-Cultures project is located in the city of Genk, Belgium, which is known for its multicultural population, formed by three historical migration waves of people coming to work in the nowadays closed coal mines. Via a PD approach, we studied existing means of dialogue and designed HIT that both care receivers and care providers in Genk can use in their daily exchanges between cultures in home care contexts. In discussing relevant literature as well as the results of this study, we point to the need and the ways of taking spatio-historical aspects of a specific healthcare situation into account in the PD of HIT to support multicultural perspectives on healthcare.

Keywords. Multiculturality, Participatory Design, healthcare

1. Introduction

The city of Genk is the second largest city in the province of Limburg in Belgium and is known for its mining heritage. The city saw its growth in the first half of the 20th century powered by three coalmines. Due to the presence of coal, the city changed from an agricultural landscape to an industrial site, which led to an extensive search for manpower. This was reflected in three migration waves of people coming to work in the nowadays closed mines: during the 1920-1930’s migrant workers came mainly from Eastern Europe (Poland and Ukraine), in the 1950’s from Southern Europe (Italy, Greece, Spain and Portugal) and in the 1960’s mainly from Turkey and Morocco. Nowadays, these three historical migration waves are still very present in the composition of the city’s population. The organisation of the mines and related services in Genk, and in the broader region, were orchestrated in a top-down manner by the management of the mines who imposed e.g. cultural activities, which they considered as necessary for the wellbeing of the mine workers. The corporation also supported a healthcare system and established social housing. This was reflected in a well-known saying: “no need to think, the mines will do that for you”.

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Our case study concerns migrant workers from the last migration wave in the 1960's and the emerging need of home care services for this population group. These former miners and their families are just recently confronted with the need for geriatric healthcare and feel stuck between the care related traditions and habits of the motherland, the former 'top-down'-organised healthcare system founded by the mines and the current Belgian healthcare system. Many of the elderly ex-mine workers and their families have limited knowledge of the available health services and supportive care in Belgium, as they have been used to the corporate, 'no need to think'-assistance. This leads to different expectations and interpretations of healthcare, including cultural and language barriers, that hinder the communication between care receivers, and the informal and formal care providers.

To address the above-mentioned challenges of older migrants and their care providers, an infrastructuring process was initiated in which various HIT were (re)designed through Participatory Design. Infrastructuring can be defined as a long-term participation process in which social, technical and spatial infrastructures are developed to support communities in addressing issues they are concerned with (e.g. home care) over time [1]. The infrastructuring process generated different low-tech mock-up tools to facilitate the dialogue between the diverse care actors: making their different expectations around healthcare visible and discussable. The focus of this paper is to show the ways in which an infrastructuring process takes into account the spatio-historical roots of a design context, in order to design HIT that embrace multicultural perspectives on healthcare. When we talk about the spatio-historical, we refer to the historical formation of the healthcare system in the spatial context (city, village, neighbourhood etc.) [2]. The work was developed in two diverse contexts: 1) a diabetes education program and 2) a home care provider's admission interviews. The PD process provided insights in underlying issues of the current healthcare system that older migrants and their families face, but also uncovered issues relevant to the broader debate on a multicultural perspective of PD and HIT.

In this paper, we start out by framing our work in relation to infrastructuring and PD, followed by a detailed presentation of the Health-Cultures case study. We conclude with a discussion on the importance of including spatio-historical perspectives in design and infrastructuring processes of multicultural HIT.

2. Theoretical Framing: Infrastructuring

Home care is often a collaborative activity where professional and informal (e.g. family-members) actors cooperate on care for an older adult. Collaborative aspects of home care work have been previously studied (e.g. [3-6]). In most developed countries, including Belgium, less children are born and these countries' population mainly grow today due to a prolonged life expectancy [7] and immigration [8]. As people live longer, the welfare state and the publicly provided care are under pressure and this has led to numerous research projects that investigate, design and develop support for geriatric care and home care [9, 10]. However, even if many countries today balance their decreased birth rate by increasing immigration, few - if any - of the above mentioned projects have had an explicit focus on the challenges and opportunities of multicultural home care and how such a focus can improve home care provision for all.

Our project, Health-Cultures, can be framed within the tradition of Participatory Design (PD). PD was initially focused on engaging workers in the design of, and for,

their workplace [11]. Lately much attention is dedicated to PD processes that are long-term, ongoing and inter-relational infrastructuring processes. This is processes that go beyond the workplace setting to increase the possibilities of communities to give form to their daily life settings. Infrastructuring is thus characterized by the development of supportive tools, techniques and processes that enable communities to deal with issues of their concern in their own local and/or social context [12].

3. Case study: Health-Cultures

We define our project Health-Cultures as a PD and infrastructuring process where people from different cultural communities are supported to deal with healthcare issues in their own context. The aim of Health-Cultures was to design HIT for older care receivers and their (informal and formal) care providers coming from, and representing, different cultural communities in Genk, specifically in a home care setting. The project started as activities in our design research laboratory, FabLab Genk (www.fablabgenk.be). The FabLab focuses on the design of open source information technologies in long-term participatory processes with non-expert users from the local community [13]. The open source philosophy of the FabLab was a key aspect of Health-Cultures. This philosophy is reflected in the FabLab's working method of providing anyone with free access to the lab and its manufacturing equipment, including training, provided that the FabLab user shares his/her designs with others. In this way, others can use, rework and appropriate existing designs in accordance with their own needs. As a result, the openness of the HIT tools in the Health-Cultures project catered for evolving individual and community needs and new care challenges that might arise.

3.1. Health-Cultures: setting the stage

Health-Cultures was carried out for two years in the city of Genk. The design research team consisted of four researchers - two product designers and two social scientists - who worked in two contexts: in the design and research lab of FabLab Genk as well as in home care situations. Health-Cultures followed six Turkish and Moroccan elderly in their dialogues with their immediate social environment as well as with relevant stakeholders involved in both their formal and informal home care. These stakeholders are for example family members, the imam and the mosque, the general practitioner (GP), the nurse, local retailers, home care organisations, the local hospital, interpreters etc. Although these care receivers are frequently in contact with the care system, they still experience a lot of conflicts with it. Being part of the last migration wave related to the mines (arriving in Belgium in the 1960's) they struggle with different views and expectations on healthcare.

To learn about how to design HIT that contribute to a multicultural perspective of healthcare, we investigated the contradictions that are part of the dialogues that develop between the care receiver and the care providers from different cultural backgrounds in a specific spatio-historical context. Contradictions are understood as tensions that exist between the people subject to home care (e.g. older people with diabetes), their care providers and the spatio-historical context they are part of (e.g. care receivers living in Flanders, a region in Belgium, raised in a largely Moroccan community of which most of its members migrated during the period in which the mines were still open versus

caregivers from the same region grown up in a mostly Flemish community). We look at how these contradictions are dealt with via the introduction and use of certain tools (e.g. a standard diabetes information leaflet) that provoke a certain engagement with the rules and customs that exist in these communities (e.g. Ramadan) and the roles different people take on (e.g. care receiver, professional and informal care provider). The central idea is that the ways these contradictions are dealt with in daily life can inspire the design of future HIT that support both care receivers and -providers; for instance to deal with challenges they experience in a multicultural care context [13], [14]. The ‘lens’ we use to design and evaluate future HIT is based on Engeström’s model of collective activity (i.e. activity system model), which understands activity as “subject-object-community” interaction. Central in Engeström’s model is that activity systems are in constant development, which is driven by different types of contradictions (Figure 1) [14]. Using this model, different iterations were carried out (5 phases) in which different contractions (10 models available in appendix) were tackled through the design of low-tech prototypes for two care organisation in the city of Genk. While writing, the tools remain low-tech in nature, but will be further developed into digital HIT through additional iterations. The different prototypes inform us about the design of these future digital HIT, namely that they need to be reflexive, non-verbal, adaptable to different care contexts (by care provider as well as by care receiver) and provide alignment of time.

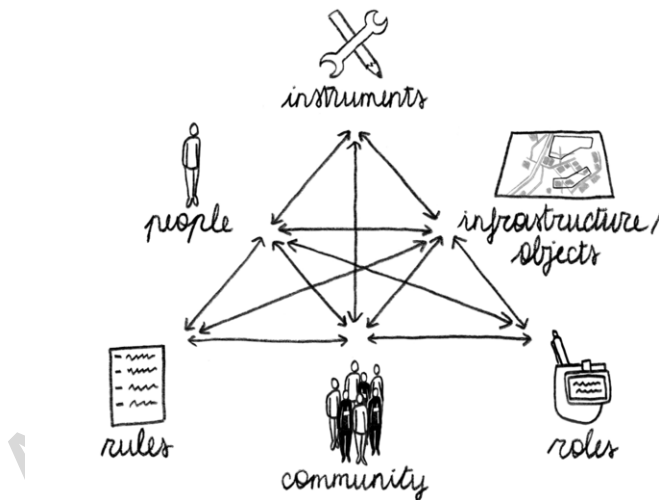


Figure 1: Engeström’s model of collective activity [14].

3.2. Background: multicultural healthcare

In an exploratory literature review and interviews, we mainly focussed on elderly who are part of the Turkish and Moroccan communities in Genk and their informal and formal care providers. We interviewed care receivers, care providers, GP’s, directors of elderly care homes, social workers, an organisation that provides home care services (called *In-Z*) and diabetes educators from a Belgian home nursing organization (called *Wit-Gele Kruis*). 10 in-depth semi-structured interviews were conducted, investigating a set of predefined topics. These topics included (1) the specific spatio-historical back-

ground of the involved people, organisations, communities and neighbourhoods; (2) the way professional care providers and care receivers organise their home-based care tasks and (3) how the available (HIT) tools support them in this organisation. This provided insight in the three main actors in our activity model: the care receiver, the care providers and the city context (cf. Figure 1).

First on the level of the care receiver, we learned that many older migrants are caught in a struggle between their traditional views on healthcare (e.g. traditional healers in the Moroccan community), the system they are used to (healthcare provision as it was provided by the mines) and the Belgian conventional healthcare system they are currently referred to [15, 16]. The knowledge of the available offer of services and care in Belgium is often limited, which is reflected in a lower level of access to health resources among these migrants, and in particular to primary and preventive care. People from the Turkish or Moroccan community in Genk are less likely to have a referent general practitioner or to take part in vaccination and preventive screening programs. In relation to elderly care, very few elderly from these communities demand institutional elderly care or use social services that are not linked to curative healthcare (home care, meals on wheels, and hospice care) [15]. This means that the 'hard' medical and technical curative care tasks are privileged among care receivers over the softer, well-being related care tasks. For instance, people prefer consulting a doctor when medication is needed over paying professional care to assist in daily home care tasks (washing, cooking, etc.).

Second, we gained insights on the care providers. Concerning the informal care providers in the migrant community, we identified a taboo related to handing over home care to people outside the family since it might give the impression that the children can or will not take care of their parents. Also, in many families both men and women work full-time and cannot take care of their parents(-in-law), which conflicts with the previous expectations of a care-providing role in the family. Therefore, especially in migrant families that use less professional home care services, the adult children and daughters-in-law share the care responsibilities amongst each other. Furthermore, the formal care providers indicated that the wishes and habits related to care of the migrant elderly are often not clear to them (due to cultural or religious differences or language barriers) or conflict with their own (organisational) rules and routines. For example, many elderly from Turkish communities wish to be washed under running water as this act of big cleansing (or *Ghusul*) is essential in their religious experience. However, this demands additional time-consuming efforts from the care providers who normally use washbowls for the hygienic care.

Finally, we gained insights about the neighbourhood or city. The interviews showed that the historical background (traditional views and practices) of migrants and the specific neighbourhood where they live, are important defining elements in the migrants' relation with the Belgian healthcare system. In Genk, the first generation migrants was traditionally very protected and supported by the mining environment: the mines provided healthcare for their workers and families by establishing local hospitals and setting up different care facilities (e.g. centres to treat tuberculosis). After the closing of the mines, people suddenly had to find their own way in the Belgian healthcare system. Interviews showed that the most popular access points for these migrants to Belgian healthcare institutes are currently the citizen service of the municipality, the 'Public Centre for societal well-being' and the health insurance.

The literature and interviews showed that a multicultural perspective on designing healthcare technologies could be supported by catering for a better dialogue in the

triangle of the migrant care receivers, their professional and informal care providers in relation to the specific spatio-historical context. Therefore, the need emerged to research and design a low-tech prototype of a HIT tool that could provide the different actors (care receivers, informal and formal care providers and care organisations) with insights in the spatio-historical context, cultural differences and the opportunity to renegotiate the different roles, rules and expectations. This led us to the following research question that guided the research and design of the HIT tool: “*How can PD of HIT contribute to a dialogue between the migrant care-receiver, their professional and more informal care providers in a concrete spatio-historical context?*” (cf. Appendix, Figure 4).

3.3. Participatory approach

In the design research process of the future HIT, three phases were worked out: (1) looking at the spatio-historical context of the specific healthcare context (the relation subject-community-object), (2) observing the present context of the healthcare system, and (3) the design and evaluation of future multicultural HIT in two contexts. We used a PD approach aimed at involving different cultural communities in the issue of care as equally as possible, via (a) engaging them in participatory visualisation workshops that reveal the historically grown contradictions between different care receivers and -providers, (b) participatory observations making use of visual sketching in the homes of members of these communities, paying close attention to the contradictions that occur in their daily healthcare context and (c) collaboratively prototyping future HIT with professional and informal care providers and care receivers from different cultural backgrounds to overcome the discovered care related contradictions in (1) and (2).

3.3.1. The spatio-historical context: Participatory visualisations and ‘dialogue tools’

To develop a first prototype of the HIT tool, the design team looked at the spatio-historical context. The team organised participatory workshops with approximately 30 participants (from Turkish and Moroccan communities in Genk and their formal and informal care providers) in which visualisations were made of the spatio-historically grown ideas on healthcare. The participatory visualisation workshops especially showed - because of the history of top-down ways of communicating in the mines - that older migrants in Genk have little tradition in negotiating about their care. For instance, they chose to follow or ignore the instructions of the diabetes educator, instead of negotiating about a treatment that better fits their needs and habits. Therefore, in the next phase more attention is dedicated to designing tools that facilitate or inhibit daily ‘dialogue’ about experienced contradictions (cf. Appendix, Figure 5).

3.3.2. The present context: Participatory observations

In the second phase, the design team looked at the present context to further develop a prototype of a HIT tool that could enable dialogue. We carried out participatory observations that forced us (because of the language barrier) to focus on non-verbal dialogues and exchanges between care receivers from Turkish and Moroccan communities and their care providers. More specifically, we observed the daily patient interactions with a diabetes educator of the Wit-Gele Kruis and those of two home care workers from In-Z in different home care-situations (e.g. cooking, cleaning etc.). The observed impressions were not only documented in words, but also in sketches as a visual and

unobtrusive translation appropriated to this private environment. After analysing both the textual and visual observation reports, insights showed that people observed felt uncertain in negotiating care. Thus, the prototype of the HIT tool should do more than supporting visualisation of the spatio-historical context and negotiating about roles and rules: it should support all parties to gain more *agency* in this relation.

For instance, in the case of the diabetes educator, the care receivers were often reluctant to tell honestly about their problems and obstacles in dealing with diabetes. This is related to pragmatic reasons, such as a language barrier of Turkish and Moroccan care receivers, but also because of a fear to disturb their rituals (e.g. Ramadan), a desire to pursue a strong image of (themselves in) their social network and a lack of experience in negotiating with care providers. Care receivers often remain quite passive in their communication and do not make their preferences and ideas explicit to care providers. However, at some moments they use quite controlling communication and express their desires in the form of checklists and reminders, as was clearly shown in the case of the home care workers. On the other hand, care providers often deal with their own uncertainties in their relationships with care receivers (e.g. how to deal with nudity) via a very hands-on and practical approach, which allows routinely treatment of daily challenges based on their work experience. In daily practice, both care providers as well as receivers demanded more agency in the care process. Especially in the case of the home care services offered by In-Z, care providers wanted to be a decisive agent, having impact on the household and not merely being an executor of checklists made by the care receivers. At the same time, care receivers do not want to feel like passive consumers of a prescribed treatment, but want to negotiate about boundaries and desires in relation to their specific traditions, needs and rituals.

The HIT tool could support these parties to provide each other with more agency, instead of them needing to take agency, via controlling or routinely communication. To explore how to make this possible, we looked at how this provision of agency to both parties took form in current daily practice. Both care-providers and receivers gave explicit attention to a reflexive dialogue on and recognition of the human relationship, in order to avoid the pitfall of mutually controlling relations, standard procedures, etc. that are typical in dealing with the above-mentioned uncertain situations. The data (i.e. observations, interviews and participatory mappings) showed particularities of these human dialogues in multicultural exchanges in care contexts (cf. Appendix, Figure 6).

Firstly, to overcome contradictions that are rooted in cultural differences via a reflexive dialogue in the observed home care situations, the dialogue between the care provider and the care receiver was carried out and perceived to a great extent in a non-verbal way. When entering a new care context, care providers all use a unique approach to talk about lifestyle values, interests, hobbies and beliefs. However, language was indicated as an important barrier to this unique approach in multicultural healthcare. Most of the older care receivers did only speak their native language (i.e. Turkish, Arabic or Berber language) while the care providers only spoke theirs (Dutch). Therefore, new tools and infrastructures (such as a specific body language and visual charts) were tried out by the participants to overcome the language-contradiction. Normally, care providers pay great importance to small talk, as a way to get to know the care receiver. Instead, due to the language barrier, the care providers used particular spaces and moments where care takes place as elements to support dialogue. For instance, the data showed that daily objects are important mediators in this non-verbal communication. For instance, during one of the observations the physiotherapist uses a man's walking stick to demonstrate exercises.

Secondly, next to the importance of non-verbal qualities, the data analysis showed that the dialogue should provide an overview to support reflexivity. Many care receivers were overwhelmed by the different care providers (e.g. diabetes educator, physiotherapist, home care worker, GP, nurses, social workers, etc.) and experienced a loss of control over their own care situation. Dialogue supporting alignment between the different care providers is thus important, but it is not self-evident, especially in situations where a lot of non-verbal nuances (i.e. rituals, spaces or objects) need to be shared. Most HIT designed to facilitate this alignment focus on sharing factual information (appointments, medication etc.) between care providers. Yeter, a migrant woman with ALS - who could only communicate via body language and a special reading and speech computer - had a large flip-over in her living room that summarises her weekly program of care-related visits (GP, physiotherapist, etc.), desires and questions. Besides providing her and her family with an overview, the different care providers used the flip-over to communicate important messages (e.g. when to take medications, appointments, etc.). While this tool supports alignment, it also leads to an overload of private textual and visual information being displayed publicly in her living space.

3.4. Research and design of future HIT

Based on the insights of the field research two versions of a low-tech multicultural HIT were co-designed with the involved design researchers, the care receivers and the care providers as a way to gain insights in the requirements of a fully-fledged HIT multicultural dialogue tool. The low-tech prototype was developed for the daily care context of older people from Turkish and Moroccan communities in relation to the diabetes education of the home nursing organization Wit-Gele Kruis and used for two years. The tool was made in two versions: one small visualisation tool on A3-sized paper, which was part of the existing educational kit Wit-Gele Kruis already used and one bigger A1-sized tool, which is used to present an overview of the care situation in the care receiver's home. Both visualisations contain circles, with a figure in the centre representing the care receiver (Figure 2). A horizontal axis divides the map in two sections; a blue section on top and a green one on the bottom. In the green section, the care receivers can share elements about their personal history and interests (e.g. chess), their spatial context (e.g. daily visits to the local tea room) and important objects in their lives (e.g. a walking stick). The objective of this section is to support the care receiver, their family and care providers to indicate actions and preferences that are specific for their lifestyle. In the blue section, the care receivers and providers can make actions and preferences explicit to the care situation. To position this information in the sections, the toolkit contains stickers, representing care- (e.g. medicines) and lifestyle-/cultural related elements (e.g. hygienic care, religion, etc.) that are organised in five different thematic fields, each represented in a different colour. The toolkit for diabetes education consists of stickers related to (1) Medication, (2) Exercise, (3) Food, (4) Monitoring (e.g. checking blood glucose values, yearly eye examination, etc.) and (5) Lifestyle. In figure 2, for example, the care receiver indicated that she exercises daily (working in the garden and swimming), likes to drink a glass of wine during dinner (green section), but that she is uncertain about how this contradicts with taking her diabetes medication (blue section). The items placed close to the centre are the ones prioritised by the care receiver, while the items further away from the centre are less prioritised by the patient or require less assistance. The care receivers thus prioritise themselves and discuss these prioritised items with their professional care providers

tion (in the circle), with the objective to engage in a dialogue with their care providers. In this case, the visualisation and the set of stickers were handed over in an A4 folder (Figure 3). The tool was discussed at the start of the care process and kept in the home of the care receiver.



Figure 3: Tool for home care at In-Z.

During a period of one year, the tool was designed, redesigned and used in home care. Based on data gathered from observations, some conclusions were drawn. Also this tool provided a mainly non-verbal overview of both the history of the care relations, their current state and mutual expectations about them. Care receivers, their social network and care providers appreciated the quick overview as well as the possibility to align among each other, while everyone maintains control over their own care needs or tasks. Furthermore, the flexibility to communicate and adjust the provided care on a daily basis supported a feeling of agency among all parties involved. This required reflection on how to prioritise and communicate quickly what is most important for someone in specific situations. In the case of In-Z there was less resistance against the visual language in comparison to the case of 'Wit-Gele Kruis', which can be related to a low literacy level of many of the employees of In-Z. Furthermore, the low-tech character of the toolkit was experienced as positive, since it is convenient to take to people's homes and does not require any digital skills (often not present among both care receivers and care providers). At the same time, similar to the case of 'Wit-Gele Kruis', the fact that the toolkit fails to enable tracking and visualising the decisions for all actors was seen as a disadvantage. On the level of reflexivity of the dialogue that was facilitated by the tool, we observed that participants reflected more explicitly on a daily basis on their actions (e.g. questions, tasks, etc.) and also were able to trace back how the care had developed over time. The tool helped new care providers, who just started working in a certain home, to relate to previous conversations the care receiver(s) had with other care providers in terms of (changing) needs or preferences related to their home care. During our observations, In-Z requested the possibility to implement more subjective aspects (e.g. humour, interests, small talk) in the toolkit, as they form an important part of the day-to-day interactions (cf. Appendix, Figure 8).

4. Discussion

In this discussion we zoom in on working with a multicultural perspective on PD of HIT. We critically assess how the lens of multiculturalism changes our understanding of PD and infrastructuring, by putting forward the spatio-historical as an important factor. This discussion is important since there exists considerable critique on focussing on multiculturalism in relation to healthcare. As Pearson [15] indicates, to focus on multiculturalism gives way for talking in terms of minority and majority and limiting the problems between both as a mismatch between cultures that can be solved through *“tinkering with cultural differences until there are “equal components” on each side” this then “will get the balance — and therefore communication and understanding — right and solve the ‘problem’”* [15]. This can result in a solution that ignores the political and structural aspects of society and risks in locating the cause of the ‘problems’ in the minorities themselves. Culley [16] identifies another challenge that lies in “multicultural essentialism” wherein ethnic groups are perceived as absolute categories and fall into the trap of oversimplification and stereotyping. In our study we tried to tackle both points of critique by underlining the spatio-historical perspective and the unique approach that the designed tool offers on the dialogue between the different actors.

Firstly, this prototype resisted looking at cultural groups as opposing entities and instead to define solutions by explicitly demanding to look at the care receivers’ and providers’ history with the healthcare system. In this way it does not only look at the here and now but foregrounds where one came from, what one’s perspectives and visions once were, and, now are and relates this to the specific spatial context where care is taking place. Design-oriented activities in PD and infrastructuring are inherently focused on designing the future. However, the history of where people and – also - material artefacts (such as hospital buildings) come from is thus put forward much more explicitly in multicultural design contexts. We thus learned that in a design process of HIT in which many cultures are involved, we also have to look backwards into the lives of these people. We continuously had to question what the roots are of the diverse care providers’ and receivers’ understanding of a certain care situation.

Secondly, the tool is open to unique approaches. The dialogues via the tool never make use of a generalisation of “the Moroccan population” or an over-categorization through statements such as “Turks resist”, etc. In this sense, the goal of the proposed tool goes beyond the focus on healthcare for multicultural inhabitants of the city of Genk and can be beneficial to healthcare recipients in general. The multicultural perspective is thus a lens through which we reflect on the encounters with and in healthcare systems. The aim of this paper is to go beyond finding strategies to cater ‘solutions’ for the multicultural inhabitants, but rather to support healthcare systems in accommodating for personal needs and challenges. Culture is thus seen as a lens through which the social interactions with the care-sector unravels and less as determining or limiting factor.

5. Conclusion

The case of Health-Cultures stressed the importance of taking the spatio-historical aspects into account in infrastructuring processes that deal with multicultural perspectives on healthcare. As a literature review and explorative interviews showed, people’s (i.e. migrants’ from Moroccan and Turkish communities) perceptions, expectations and

routines related to healthcare are strongly shaped by their confrontation with the different healthcare systems (i.e. the one from the motherland, the one they got acquainted with when working in the mines and the current Belgian healthcare system). It appeared to be fruitful to use Engeström's model of collective activity as a model to both research and prototype multicultural HIT, because it explicitly allowed us to take into account the relation between the care actors and the spatio-historical city context.

Engeström's model supported us in developing prototypes that start with visualising the personal histories that both the care providers and receivers have with the healthcare system in a specific spatio-historical context. In this sense, the prototyped HIT tool wants to overcome the danger of just becoming a communication tool to discuss current problems and desires but starts from the latent visions and expectations on healthcare. Since care providers and -receivers need to have *agency* in the care process, the tool offers all actors a space, a point of reference wherein they can recognise themselves, while moving in and outside of the home and the professional care environment. This also relates to research carried out by Kyng and Grönvall [17, p. 390], who learned that the aesthetics of artefacts that are used in PD processes are preferably readable by different participants. The aesthetics of this tool involves the explicit visualisation of the care receiver in two different zones – one more personal and one related to professional care – and the use of visual icons that can be flexibly placed and adapted via the repositionable stickers. It visualises in a readable way the complexity of negotiations over time, such as the evolving relations between care receivers and care providers. By representing these evolving relations, the tool allows both parties to experience more agency.

Furthermore using Engeström's model to prototype the tools supported the development of a more reflexive dialogue on this spatio-historical context and how it evolves over time (cf. Appendix, Figure 4-8). The observations showed that in their daily exchanges participants created tools for non-verbal communication, unique to the specific care situation. This need for a unique approach is also confirmed by Kyng and Grönvall [17], who state that it's important to acknowledge that the use of the home and its objects is always unique and the design should consider this diversity of both the homes and its residents. That is why the tool took on a flexible, non-verbal form or language, stressing subjectivity in dialogue. The importance also became clear of designing a HIT that can easily adjusted by the care receivers as well as care providers - supported by the designers and the tools in the FabLab - to fit it in their own situation, work routines and spatial contexts. In the In-Z case the visual language was experienced as positive, because of the low degree of literacy in the Dutch language among care providers and care-receivers. In the diabetes care case the professional care providers and the care receivers experienced the iconography as childish, also because of the feeling that care receivers already have, namely being patronized and controlled. There is a great need for research into the role the visual language has in the experience of agency and literacy of the caregivers and -receivers. Essential is that the tool places a representative of the care receiver visually central as a way to stress the uniqueness and personal character of every care situation. The tool appeared to be helpful for the different care providers (e.g. the general practitioner, physiotherapist, cleaning help, family members) and the care receivers in self-reflecting on, planning and coordinating care in space and over time. There appears to be a need for HIT that support planning and coordination in space (see e.g. making a clock out of tasks) and over time. The low-tech character of the toolkit was experienced as positive in these activities, since it is easy to handle in different locations. However, the low-tech tool does not allow cre-

ating digital traces of the history of what was visualised. Therefore, in future development of the HIT the participants agreed there should be a focus on creating a memory base of dialogues between care receivers and -providers.

In general this infrastructuring process has showed us that multiculturalism as a frame does not restrain how we design the future of HIT. It rather opens it up by pointing to the importance of, on the one hand, the spatio-historical and, on the other hand, the unique personal perspective in infrastructuring. The actual HIT we designed are low-tech prototypes, but point to some clear challenges for designing HIT in an increasing multicultural society.

References

- [1] C. DiSalvo, A. Clement, and V. Pipek, "Participatory design for, with, and by communities," in *International Handbook of Participatory Design*. Simonsen, Jesper and Toni Robertson (Eds). Oxford: Routledge, (2012), 2012, pp. 182–209. DOI: <https://doi.org/10.4324/9780203108543.ch8>
- [2] R. White, "What is spatial history." Stanford University Spatial History Project, 2010. <https://web.stanford.edu/group/spatialhistory/cgi-bin/site/pub.php?id=29>
- [3] E. Grönvall and M. Kyng, "On participatory design of home-based healthcare," *Cogn. Technol. Work*, vol. 15, no. 4, pp. 389–401, 2013. DOI: <https://doi.org/10.1007/s10111-012-0226-7>
- [4] O. Amir, B. J. Grosz, K. Z. Gajos, S. M. Swenson, and L. M. Sanders, "From Care Plans to Care Coordination: Opportunities for Computer Support of Teamwork in Complex Healthcare," in *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, New York, NY, USA, 2015, pp. 1419–1428. DOI: <https://doi.org/10.1145/2702123.2702320>
- [5] K. A. Amsha and M. Lewkowicz, "Observing the Work Practices of an Inter-professional Home Care Team: Supporting a Dynamic Approach for Quality Home Care Delivery," in *Proceedings of the 11th International Conference on the Design of Cooperative Systems*, 27–30 May 2014, Nice (France), 2014, pp. 243–258. DOI: https://doi.org/10.1007/978-3-319-06498-7_15
- [6] T. Bratteteig and I. Wagner, "Moving healthcare to the home: The work to make homecare work," in *Proceedings of the 13th European Conference on Computer Supported Cooperative Work*, 21–25 September 2013, Paphos, Cyprus, 2013, pp. 143–162. DOI: https://doi.org/10.1007/978-1-4471-5346-7_8
- [7] G. Gesano, F. Heins, and A. Naldini, "Regional challenges in the perspective of 2010," in *Regional Disparities and Future Challenges*, ISMERI Europa, 2009.
- [8] C. Bossen, L. R. Christensen, E. Grönvall, and L. S. Vestergaard, "CareCoor: Augmenting the coordination of cooperative home care work," *Int. J. Med. Inf.*, vol. 82, no. 5, pp. e189–e199, 2013. DOI: <https://doi.org/10.1016/j.ijmedinf.2012.10.005>
- [9] G. Fitzpatrick and G. Ellingsen, "A review of 25 years of CSCW research in healthcare: contributions, challenges and future agendas," *Comput. Support. Coop. Work CSCW*, vol. 22, no. 4–6, pp. 609–665, 2013. DOI: <https://doi.org/10.1007/s10606-012-9168-0>
- [10] F. Nunes, N. Verdezoto, G. Fitzpatrick, M. Kyng, E. Grönvall, and C. Storni, "Self-care technologies in HCI: Trends, tensions, and opportunities," *ACM Trans. Comput.-Hum. Interact. TOCHI*, vol. 22, no. 6, p. 33, 2015. DOI: <https://doi.org/10.1145/2803173>
- [11] J. Simonsen and T. Robertson, *Routledge International Handbook of Participatory Design*. Routledge, 2012. DOI: <https://doi.org/10.4324/9780203108543>
- [12] C. A. Le Dantec and C. DiSalvo, "Infrastructuring and the formation of publics in participatory design," *Soc. Stud. Sci.*, vol. 43, no. 2, pp. 241–264, 2013. DOI: <https://doi.org/10.1177/0306312712471581>
- [13] M. Bauwens, "The Political Economy of Peer Production," *Post-Autistic Econ. Rev.*, vol. 37, no. 3, pp. 33–44, 2006.
- [14] Y. Engestrom, "Learning by expanding," *Hels. Orienta-Konsult. Oy*, 1987. DOI: <https://doi.org/10.1017/cbo9781139814744.002>
- [15] M. Pearson, "Pearson M (1986) The politics of ethnic minority health studies In Health, Race and Ethnicity (Rathwell T & Phillips D eds), Groom Helm, London, pp 100-116," London: Groom Helm, 1986.
- [16] L. Culley, "A critique of multiculturalism in health care: the challenge for nurse education," *J. Adv. Nurs.*, vol. 23, no. 3, pp. 564–570, Mar. 1996. DOI: <https://doi.org/10.1111/j.1365-2648.1996.tb00020.x>
- [17] E. Grönvall and M. Kyng, "Beyond Utopia: reflections on participatory design in home-based healthcare with weak users," in *Proceedings of the 29th Annual European Conference on Cognitive Ergonomics*, 2011, pp. 189–196. DOI: <https://doi.org/10.1145/2074712.2074750>

6. Appendix

The authors' use of Engeström's model to identify contradiction and prototype the HIT tools are visualised in Figure 4-8.

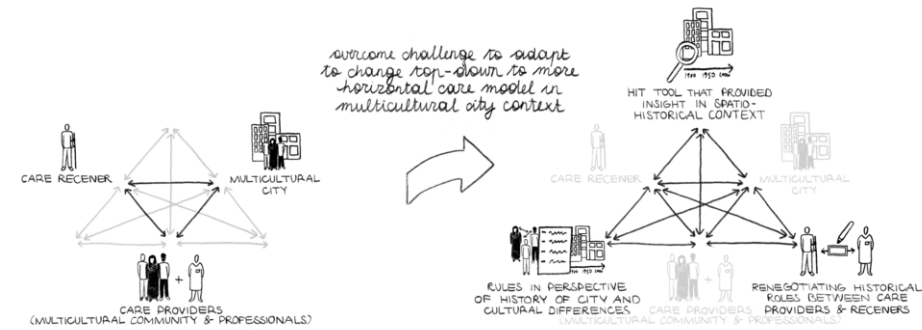


Figure 4: better dialogue in relation to the specific spatio-historical context.

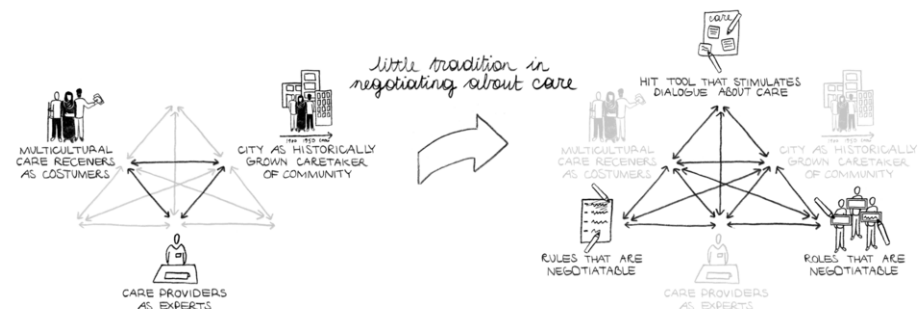


Figure 5: tools for daily 'dialogue' about experienced contradictions.

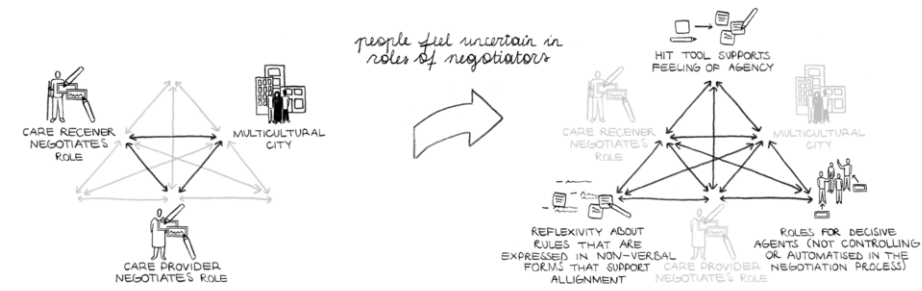


Figure 6: uncertainty related to negotiating about care.

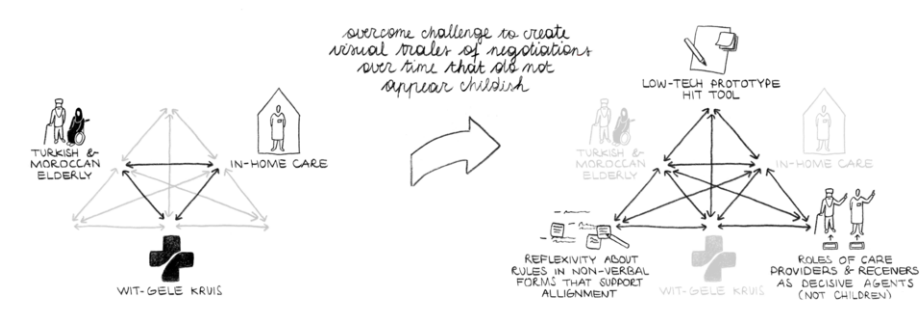


Figure 7: creating of visuals that are not perceived too childish

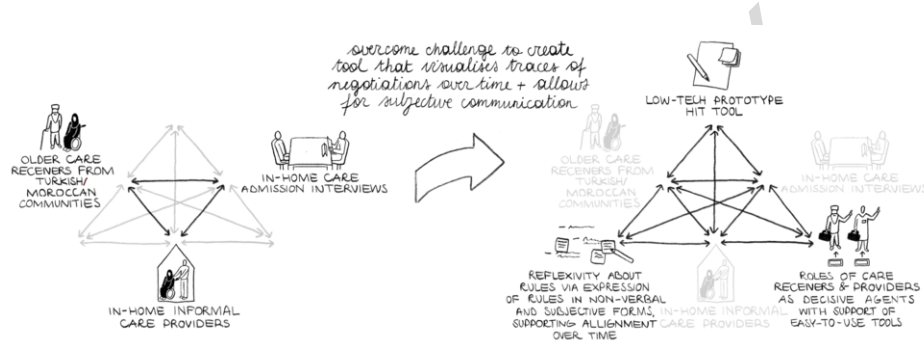


Figure 8: Low-tech HIT tool for subjective communication