



Research with a Solidarity Clinic: Design Implications for CSCW Healthcare Service Design

Vasilis Vlachokyriakos^{1*} , Clara Crivellaro¹, Hara Kouki²,
Christos Giovanopoulos³ & Patrick Olivier⁴

**¹Newcastle University, Newcastle upon Tyne, UK (E-mail:*

vasilis.vlachokyriakos1@newcastle.ac.uk); ²University of Crete, Heraklion, Greece; ³Vrije Universiteit Amsterdam, Amsterdam, The Netherlands; ⁴Monash University, Melbourne, Australia

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Abstract. This paper reports on a long-term collaboration with a self-organised social clinic, within solidarity movements in Greece. The collaboration focused on the co-creation of an oral history group within the social clinic, aiming to record and make sense of a collection of digital oral histories from its volunteers and volunteers-doctors. The process aimed to support reflection and shape the future of the clinic’s ongoing social innovation and to transform institutional public health services. Positioning the work of solidarity movement as designing social innovation, the work contributes to CSCW and ‘infrastructuring’ in Participatory Design aspiring to support social activism and social transformation processes. More specifically, through our empirical insights on the process of infrastructuring an oral history group within a social movement; and related insights about their ongoing participatory health service provision—we provide implications for CSCW concerned with its role in institutional healthcare service transformation.

Keywords:: CSCW, Digital civics, Participatory action research (PAR), Participatory design, Service design, Social movements

1. Introduction

The role of design and socio-technical systems in social activism endeavors has a significant tradition in CSCW and HCI. This work departs from a recognition of the ongoing social innovation that unfolds in social movements and local communities, as they creatively respond to local issues (Björgvinsson et al. 2012; Vlachokyriakos et al. 2017), and they work to create the conditions for ‘commoning’ within communities and between communities and researchers (Hillgren et al. 2016; Teli et al. 2020). The role of designers in particular, through this work, has expanded to include the range of activities that are not only about problem solving, and the creation of socio-technical responses to such problems, but also about sense-

making—the political processes through which we come to terms with ‘how things are’ and take a stance on how things ‘ought to be’ instead (Manzini 2014). Building on work that has embraced such political role for designers and design, and that has positioned the work of solidarity movements as social innovation processes (Manzini and Coad 2015), this paper contributes to the question of what other kind of materializations of activism might lend to broader processes of social innovation—in particular in relation to healthcare services.

This paper reports on a long-term collaboration with a solidarity clinic in Greece, as they wished to reflect on the clinics’ ongoing work to provide healthcare for those who cannot afford it. Solidarity clinics are one of the many material expressions of solidarity movements in Greece (e.g. solidarity schools, no-middlemen initiatives etc.), which emerged following the 2008 financial crises and the subsequent collapse of Greek public structures and services (Arampatzi 2016). In 2008, solidarity clinics were developed and established by doctors-volunteers in order to provide health care for unemployed and uninsured citizens. In this paper, we report on a long-term engagement with one such solidarity clinic – the Attica Social Clinic (ASC)^{1 2}, located in the wider area of Athens, Greece. The ASC was founded in 2011 and it is self-organised in terms of its informal operation and collective decision-making practices. It counts more than 400 volunteers that have so far helped more than 7000 people in Greece (see section 3 for more details). Following a Participatory Action Research (PAR) (Hayes 2011, 2014) and infrastructuring (Le Dantec and DiSalvo 2013; Karasti 2014) approach, we worked with members of ASC over the course of three years to respond to their need to reflect on the past successes and failures of the clinic as a way of shaping future trajectories.

Building on earlier engagements, and as a way of opening up participation to this process more widely within the clinic, we led the creation of an oral history group that consisted of 13 volunteers that participated in the co-design of a process for the collection of oral histories from volunteers of the clinic. This work led to the collection of (so far) 17 oral histories that we collectively analyzed to understand the conditions that led to the successes and failures of the clinic to both help people in need, while also contributing to the transformation of the national health system. Such work contributes insights on the socio-political innovation of the social clinic, including implications for shaping its future and the future of health services more broadly. The participatory processes of the clinic and the creative configurations between people, resources and institutions for the delivery of healthcare services speak to CSCW work that aims to re-configure the relations between citizens, service users and public service providers (Balaam et al. 2015; Talhouk et al. 2016; Crivellaro et al. 2019).

¹ All names of social movements and participants are pseudonyms

² The Attica region is the wider prefecture of the city of Athens

More specifically, in this paper through three years of Participatory Action Research (PAR) work, we contribute empirical insights for participatory health service provision that point to healthcare services as commons. We do this through reporting on a co-design approach that used oral history as a method for reflection within the clinic. As such, this paper also contributes to related work that highlights the importance of oral history and storytelling within social movements (Dimond et al. 2013), but also expands such insights by reporting on the process of collectively infrastructuring an oral history group within the clinic. In our discussion, we ground our findings in CSCW by expanding on the role of design and technology in creating the grassroots infrastructures for ‘new institutions’ (Huybrechts et al. 2017) and in the design and delivery of agonistic services in institutional transformation’s projects.

2. Related work

2.1. Infrastructures and infrastructuring

Of relevance to the work reported in this paper are the notions of information infrastructures and the practice of infrastructure-ing. Neumann and Star coined the notion of infrastructure in Participatory Design (PD) as the substance rather than substrate of information systems (Neumann and Star 1996) in an attempt to make visible what remains unnoticed and in the background (Star 1999; Karasti 2014). ‘Infrastructure-ing’ is defined by Karasti et al. as an attempt to underline the processual, ongoing quality of such participatory activities. Work such as this highlights how infrastructuring can be a way of advancing community interests through integrating such participatory, ongoing and processual design activities for extended periods within local communities and civic organizations (Karasti and Syrjänen 2004; Karasti et al. 2006). Such activities of infrastructuring, instead of focusing on the target artefact or service, are mainly concerned with its situated and contextual socio-political parameters (Pipek and Wulf 2009).

The notion of “infrastructures” and “infrastructuring” has been applied to local communities (DiSalvo 2009) in work that echoes the values of Scandinavian PD by focusing on democratic values and heterogeneous means of citizens’ socio-political participation. Of particular relevance to our work, is design for social innovation (Binder and Brandt 2008; Hillgren et al. 2011) and more specifically the work of the Malmö Living Labs (Björgvinsson et al. 2010, 2012). Influenced by Mouffe’s view of democracy as founded upon radical pluralism, contestation and agonistic public spaces (Mouffe 2005). Björgvinsson et al., set out to create the conditions that may enable the reinvigoration of democracy through infrastructuring work with marginalized social movements. Here, infrastructuring is construed as a long-term platform for social innovation. Through embedded living labs, relationships and engagements are developed with local communities in ongoing processes of alignment.

Similarly to the work of the Malmö Living Labs, in past related work (Vlachokyriakos et al. 2017) the authors sought to develop a vision for ‘Solidarity HCI’; an approach and a set of values for an HCI research able to contribute to the emergence and scaling out of Solidarity Economy practices (for more detail, see (Kawano et al. 2009)). Similar work, extend such inquiries to contribute methodological implications for designing social innovation through HCI research (Vlachokyriakos et al. 2018). In such work, through bringing the focus on the negotiations that take place between researchers and members of social movements, the authors contribute a set of methods for undertaking CSCW work within such contested and transformative spaces. Of relevance to such infrastructuring work in participatory design, is also work that conceptualizes care and caring relationships as infrastructure. In the work of Alam and Houston (Alam and Houston 2020), the authors draw insights from feminist care ethics to explore the relations between care and infrastructure, and through an analysis of non-institutional care spaces, they contribute infrastructural conditions for inclusive cities. The work contributes a framework of “care collectives” that remain flexible to accommodate various caring conditions, independent from the caring abilities or inabilities of the caregiver and care receivers.

Overall, researchers who have advocated for infrastructuring as a mode to support participatory design and democratic agonistic practices (Björgvinsson et al. 2012) and caring relations (Jochimsen 2003), have only recently begun to uncover the complexities at play and the relationship between researchers and the communities and social movements with which they work.

2.2. Service design and commons

Such participatory, infrastructuring approach, is particularly relevant for the design of (public or commons) services, when seen as not only complex and relational, but as powerful engines for wider societal transformations (Crivellaro et al. 2019). Services are discussed less as a design ‘object’, but as a ‘means’ for supporting the emergence of a more collaborative, sustainable, creative society and economy. Contemporary debate on the re-design of public services has similarly emphasized the role of co-production and collaborative modes of developing solutions in ‘the design and delivery of services, working with professionals and front-line staff to devise effective solutions’ (Mol 1999: 22).

In a similar vein, more recent research explores the relation between participatory design and the Commons (Marttila et al. 2014; Teli et al. 2016). This work highlights the benefits of intersecting PD processes with spaces and practices of the urban commons, which is particularly relevant for the transformation of public services and the provision of collaborative, commons services. Commoning practices (defined as the collaborative practices in the course of managing shared resources) put weight on the ownership and shared management of goods or services, taking in consideration how actions are influenced by cultural and political aspects and how the public sector

could play a more active role, enabling and engaging people to take part in city's procedures (Seravalli et al. 2017). The application of an infrastructuring approach in the production of commons (as also proposed in (Seravalli et al. 2017)) and within commoning practices, could lead to discovering new ways of collectively organizing common living.

Within this way of thinking about collaborative service design and the commons, the agenda of Digital Civics proposes to explore how digital civic platforms might contribute to such a (re)configuration of service delivery in more relational ways through, for example, peer-to-peer models of service provision (Ratto and Boler 2014; Asad et al. 2017; Seravalli et al. 2017). Critical premises of this agenda include how digital technology might help organizations deliver more resilient services in the context of decreasing resources, how they may support the engagement of citizens and communities to co-create services that better respond to their needs, and how local solutions might be scaled up and out. Through this, Digital Civics, similarly to the design for services agenda (Mol 1999) and design for social innovation (Meroni and Sangiorgi 2011; McCarthy and Wright 2015), hopes to intervene in and unsettle entrenched and unbalanced power relations and move towards more collaborative and relational approaches to service design and delivery through technology.

3. Context

Solidarity Movements (SMs) are informal local collectives, which since 2011, provide social support to people most affected by the financial and refugee crisis (for a more detailed account see (Arampatzi 2016)). The role of these SMs is firstly to cover every day basic needs for food, clothing, education and health services, thus operating as a buffer mechanism in the face of a collapsing public service; and secondly to exemplify spaces where practical alternatives can emerge, be contested and re-worked through experimentations with alternative forms of economy through solidarity, participation and organization (Arampatzi and Nicholls 2012; Arampatzi 2016).

Of particular interest for participatory service design, are the ways through which SMs self-organise to design a service that is both functional (as in providing services to people in need) and transformational, in terms of applying pressure to public services for their lack of resources and funding, staffing and transparency. As seen in previous work, such pressure is applied both through raising visibility about the deficiencies of public services and through creating practical alternatives of a participatory service provision (also referred to as prefigurative politics (Yates 2015)). Such spaces have also been conceptualized in design as agonistic (Mouffe 2000, 2005; Korn and Volda 2015; Vlachokyriakos et al. 2017). In this paper, we are particularly interested in understanding the role that digital technology can play in making visible and scaling out of such services, while also contributing better understandings on what does it mean to design relational services, as also discussed in Digital Civics approaches to HCI research (Olivier and Wright 2015;

Vlachokyriakos et al. 2016; Fan and Zhang 2020). Such understandings are important and timely, especially in times when the widespread application of technologies for automating public service provision (Imran et al. 2014; Huang and Rust 2018) can exacerbate and prolong already existing social injustices and create new ones.

3.1. The Attica Social Clinic (ASC)

The ASC has been operating since 2011 as a self-organised and informal social clinic that provides free primary medical care and medication to all uninsured and unemployed people regardless of who they are or where they come from. It is located in a previously empty building, leased for free by the local municipality, which was selected for its proximity to a metro station (for easier access from patients), while also as an act of resistance as it is located in an area that the government intended to privatise. The group is self-organised in terms of its informal operation (there is no legal entity or someone acting as the legal representative) and collective decision-making practices (no formal hierarchies, decisions are being made by consensus or by vote in public assemblies open to all volunteers of the clinic). ASC has three main principles guiding its operation, daily practises and decision-making: it doesn't accept monetary donations; it doesn't accept any political party involvement within its operation; and it doesn't promote people or organisations for their donations. Since these nearly 10 years of operation, ASC has played a significant role for the organisation of the broader network of self-organised social clinics in Greece. ASC is one of the solidarity movements that transcended the local boundaries of the neighbourhood or city and serves citizens from the whole region of Attica and beyond. Finally, it is important to note that ASC has been regularly donating medicines and other equipment to public hospitals and clinics – indicative of the trust that people put on it and of the deficiencies of the public health system.

Indicatively, from an attempt to quantify the people and work of ASC from December 2011 till May 2018, the social clinic had around 400 volunteers of which 254 citizens (no medical expertise), 65 medical doctors, 18 pharmacists, 22 dentists, 4 dieticians and 8 psychologists. More than 30,000 people have donated or supported the work of the clinic in one way or another between 2011 and 2018. The number of people that were helped from the clinic is 7366 with 64,017 total visits to the clinic (non-unique patients), from people donating medicine and beneficiaries visiting doctors or collecting medicine. 480,000 boxes of medicines have been distributed to individuals with more than 900,000 boxes donated to other social clinics, public hospitals, public clinics, social services, refugee camps and hotspots etc. Finally, the social clinic has given access to 4029 laboratory tests (blood tests, MRIs, axials, cardiovascular etc.) and 128 surgeries to people in need provided to ASC by 43 private clinics in the area of Attica. The social clinic has been meticulous in collecting such data since the beginning of its operation for multiple reasons but mainly for communication (making visible the deficiencies of the national health system and the

need to publicly fund and reorganise it) and legal purposes (making sure that they have a good record of what is happening in the clinic, when and by whom).

4. Methodology: participatory action research

We undertook a Participatory Action Research (Foth and Axup 2006; Hayes 2014) approach, which started in November 2016 when the first author began undertaking fieldwork in Greece to develop relationships with Athens based solidarity movements. Since then, we have been contributing to the social clinic of Attica in various ways: by being a member of the working group for its communications, by publishing the group's newsletters to the various communication channels, by providing technical support with live broadcasts and by participating in public radio talk shows.

Following the first six months of engagements, members of the clinic were invited to a public assembly whose main topic of discussion was the current role of the social clinic in society, the fatigue of its volunteers after nearly seven years of action and possible future directions for the clinic and the movement. Indeed, after ten years from their establishment, SMs were at the time reflecting on their role in society and more specifically how they can maintain their transformative (personal, social and institutional) character without becoming mere substitutes for the public services they aimed to transform. This meeting highlighted the extent to which social clinic members were grappling with the challenge of the sustainability of their social transformation project; it also showed the need to make sense of what they had been doing for the past few years in order to clarify next steps.

Two months after this public assembly meeting, the lead author developed a proposal for the collection of data from the clinic's past and current volunteers in order to record and better understand the lived experience of members of the clinic as to inform future directions. This proposal was shared in the mailing list of the group and drew interest from other members with previous experience in such qualitative methodologies, i.e. three researchers that have engaged with the group in the past and were willing to help and a number of volunteers with previous experience in conducting interviews and designing questionnaires. This resulted in the creation of the Oral History Group (OHG) of ASC, which consists of 13 members from which four had previous experience or education in qualitative collection methods. All participants of this group had no medical expertise and they were mainly involved in the clinic's communications, front desk and pharmacy assistants.

4.1. Co-creating an oral history group

From April 2017 till January 2020 we met with the group more than 25 times, excluding our interview appointments with other volunteers for the collection of oral histories. These included initial discussions about the motivation for undertaking such work, meetings with people that helped with training activities, equipment and workshops for the creation of the supporting materials, the use of the recording

equipment and oral histories transcription. Throughout this time, the oral history group has collected, transcribed and narrated 17 oral histories.

4.1.1. *Collecting the recording equipment*

From the very first assembly in April 2017 and our later involvement in setting up the group, the communications coordinator of the clinic has provided the first author a backpack with some basic equipment that he had collected for undertaking interviews and uploading short videos on social media. Throughout the last two years, and in response to the group's needs, we have collected additional equipment, purchased by the researchers and by crowdfunding campaigns of the clinic. The content of the bag changed through time but in general it consisted of a DSLR camera for video recording, a set of camera batteries, two audio recorders, two tripods, a pair of headphones, an external drive and a backup drive (kept in separate). The bag later also included a folder with the necessary documents – the consent forms, data release forms and interview and how-to guides.

4.1.2. *Co-creating the interview guides*

One of the key challenges of this process was to create the interview guides as it required to incorporate multiple and diverse categories of questions and perspectives about this process. It took us four workshops of three to four hours each to come up with a final version of three full interview guides. The different guides reflected on the different categories of people involved at the clinic, ASC's volunteers, beneficiaries (i.e. patients) and medical doctors. In most of these sessions, each member of the OHG was taking notes, while the "researchers" were coordinating and taking more structured minutes. We contend that the informal and impromptu structure of these meetings was key for the 'non-experienced in research' members to develop an agency in this process. This structure and process reinforced their sense of being experts of their own space and thus created a third space between the experts in data collection (i.e. researchers) and the experts in self-organisation (i.e. social clinic members) (Muller and Druin 2012). Storytelling was an important medium through which OHG members contributed to the conversations for the creation of the interview guides (as also reported in similar oral history work with social movements (Rafael 1997)). The researchers' attempt to drive a discussion about the possible future role of the social clinic, resulted in the sharing of strong stories within the group related to the trust that citizens have put on the clinic, the changing of citizens' perception of medicine and pharmaceutical practice, and others.

Following an oral history methodology (e.g. (Anderson et al. 1987)) (which share characteristics and have been used widely for participatory and experience-centred design as well), we framed the questions with the individual (volunteer or beneficiary) as the central focus of the inquiry. The interview guide thus included several themes: a theme with questions related to the roles that volunteers took in the clinic and their motivations; about the organisation of the social clinic, the various activities and how the various working groups were formed and interacted; the governance and

decision-making and the basic values of the groups and how these were enacted; etc. We also created additional guides for the beneficiaries of the clinic and for the clinic's doctors. The beneficiaries' guide included additional questions such as their perceptions of the main differences between the services of the national health system and the social clinic. In the medical doctors' guide, we asked questions about the medical practice and how it compares with their professional environments, the differences between patients and colleagues at the clinic compared to their paid medical practice, the innovation that the organization of the social clinic can bring to clinical practice, and ways that such self-organised clinical practice can transform the public health sector.

4.1.3. *Undertaking the oral history interviews*

The interviews were undertaken in pairs – one person having the role of the lead interviewer, while the other being mainly responsible for the setting up and maintenance of the technical equipment. In most interviews however, both members asked questions, in ways that in most cases complemented each other. As a result, at the time of writing of this paper, the group has collected 17 interviews in total which were transcribed and analysed collaboratively (see sections below).

4.1.4. *Transcription and analysis*

After the collection of 17 interviews, we met to discuss the process of transcribing the audio and video recordings. The researchers chose Wreally's Transcribe tool³ as way of making easier for non-experienced members to transcribe their interviews. The transcribed interviews were then assigned to members of the OHG for analysis. As expected, the researchers played an important role for facilitating the process of analysis for less experienced members.

We used a thematic analysis approach (Braun and Clarke 2006), aiming for an inductive analysis of the data, while also aiming at coming up with both descriptive/summative themes and more reflective themes. The former could be used for future communications of the clinic, while the latter as an input for the future of the clinic and implications for health service transformation. Less experienced (in qualitative research) participants contributed mostly to the descriptive themes, while with the help of two of the researchers that did an initial coding of the data, more reflexive and relational themes emerged (see section 6). Members of the OHG were advised to go through the transcripts that they were the lead interviewer and annotate/tag points of possible interest in a descriptive way. This resulted in descriptive or summative tags such as “to be used for communications”, “personal experience”, “proposal for future transformations” etc.

In total, the analysis of these 17 interviews (of around 90 min each) resulted in the creation of 13 themes with multiple sub-themes, covering various possible future

³ <https://transcribe.wreally.com/>

transformations of the clinic, communication strategies, self-organisation and solidarity practices, etc. For the purposes of this paper, we report on the four themes that more closely respond to the aims of this paper. More specifically, we focus on the themes that point to implications for the design of systems for health services, namely referring to: medical and pharmaceutical practice transformations, the tension between professionalisation and agonism, and care and burnout. We believe that these selected themes contribute rich empirical insights for the designing of participatory health service provision. As the analysis undertaken in highly inductive, later in our discussion, we more strongly relate these findings with the role of CSCW and participatory service design for developing caring and agonistic healthcare infrastructures.

5. Findings

In this section we report on the successes and failures of the ASC in providing solidarity health services. From these insights, we later draw implications for service design and the role of socio-technical systems in supporting such a commons service design.

5.1. Medical practice

The data collected through the oral histories indicate the successes and failures of the self-organised clinic in involving doctors in the decision-making processes of the group and changing deeply entrenched perceptions about the role of doctors in society. Their participation in the clinic's operation only as medical practitioners, rather than as "equal members" of a self-organised structure, is discussed as one of the failures of the clinic to transform social and cultural preconceptions. Nonetheless, our data suggest the development of a different, participatory practice of medicine which resulted from different human relations within the structure, in addition to the lack of access to state-of-the-art medical examination equipment.

5.1.1. *Doctors' participation*

Our data point to the indifference of doctors in part taking in the organizational processes of the group, not contributing to the other group initiatives (e.g. demonstrations for opening the access to the NHS for all, helping out with writing press releases and applying pressure for policy change etc.) and not participating to the structure's decision-making assemblies: "it is indicative that from the many doctors, only 2-3 of them were consistently coming to the coordination and assembly meetings. And there were many doctors back in the days". Doctors, just like any category of volunteers in the clinic (e.g. reception volunteers of various shifts, pharmacists etc.) are organized through working groups with periodic assemblies. According to one of our participants: "The doctors' working group never met – actually, they did meet once, big deal! [...] and there are important issues to meet and

discuss. They were not interested. Issues like how they can make use of donated equipment, issues with appointments and practice. They just wanted to come here, to do their shift, help people and that's it. They never met”.

As per our participants, coordination and communication with doctors was done at an individual level by one of the founders of the clinic who is also a doctor and had taken such a role. For the majority of our participants, this was because of established power relations entrenched in society: “most of them [medical doctors] think that they are in a position of power towards others” (pharmacist, M). Such perceptions have an impact on the non-hierarchical organisation of the social clinic. This was discussed with one of our interviewees when asked about established hierarchies within the social clinic: “Hierarchy, no, but we all know that doctors are a special category. I don't know how this sounds, but there is a level of arrogance in their profession. For some of them, this is very much the case and they make it visible as much as possible. Others are very approachable; you could chat with them” (reception desk, F).

5.1.2. *Hierarchies and preconceptions*

This was understood as the reflection of culturally established hierarchies in Greek society: “it is very noticeable, in the Greek society at least, we have raised up doctors very highly [in status] as a society and as patients. It shouldn't have been the case so much. But also themselves [the doctors], they seek that recognition and increased status”. For some participants, even though such perceptions of the status of medical doctors within the social clinic are inevitable for an open structure, as it inherits the characteristics of the wider society, some interviewees indicated how the clinic didn't engage enough in attempts to change such perceptions. For example, one participant, a medical doctor herself, with long experience in social movements notes: “I was impressed with how many people [within the clinic] have this attitude [towards doctors], because ok, society has this “magician of the tribe” thing and it gets transferred here as well. But we couldn't stop it! As if it's the natural state of things. They [other volunteers] were saying [to us]: “but he is a doctor”. So what? It never occurred to them that in this space, at some point that we had to clean, a doctor could volunteer to come and clean. This was beyond them as a possibility”. Such perceptions of doctors as a ‘special’ category of volunteers is justified by other participants considering the important role that doctors had for the viability and operation of the social clinic – even though this argument also applies for other groups of the clinic such as the reception or the pharmacy. Others, similarly to the quote above, highlighted that even though this is an attitude that doctors bring from their professional practice, other volunteers of the clinic reinforce that power relation with their attitude towards them.

5.1.3. *Participatory public health*

The members who were interviewed for an oral history, pointed to the broader need for more proactively including doctors and other staff and beneficiaries in

organisational and decision-making practices in order to change these well-established preconceptions. While discussing the characteristics of the clinic that can be transferred to a public health system, the participatory operation of the clinic and its mixed (in terms of patients, doctors, pharmacists and other staff) working groups was discussed as transformational: “It [participatory operation] can definitely be applied [in the national health system] as long as the way the hospital system works change. There could be mixed groups of doctors, nurses or patients [...] that they have suggestions to offer which doesn’t exist at the moment. Even consultations once every six months that could bring together doctors, pharmacists, nurses and patients to discuss what could change, even if this is not about how resources are managed”. This can enable people in power make more holistic decisions, taking into account patients and beneficiaries needs: “[...] the people that create and implement health policy at a hospital or national level, they can get another opinion from patients and they can change the way they deal with things. In many cases, everyday routine doesn’t allow us to see beyond the field that this routine defines. Someone else, who doesn’t need to have studied medicine or pharmaceuticals, might be seeing things differently and suggest solutions and changes that at the end of the day it will be for their benefit [...]”.

Even though our participants didn’t have any concrete suggestions for more organically including doctors in other clinic’s activities (and indeed this is one of their main “failures” as a participatory and horizontal structure), the majority of them referred to how medicine was practiced within the clinic as one of the most significant transformations (at a personal and possibly at an institutional level).

5.1.4. *Doctor-patient relations*

For some participants the fact that the doctors were participating altruistically in the clinic is by itself a step towards changing societal perceptions of their ‘higher status’. Nonetheless, this was not enough to change the power relation between doctor and patient; as noted by one of the participants, a doctor in profession but a volunteer in the communication group of the clinic: “none of the doctors who came here worked substantially differently [compared to their professional practice]. They worked differently in that they were not paid – not to be underestimated of course, it is important [...] It never stopped this hierarchical relationship, that I am the doctor and you are the patient”. Other participants however referred to volunteers’ attempts to more holistically understand the problems that patients were facing and conveyed a more dialogical approach to healthcare: “The characteristics that could be applied to a NHS have to do with the relationship between beneficiary and the people that help – either a doctor or pharmacist – to change a misconception. In public hospitals there is this power relation between a doctor or pharmacist with the patient. And this is built in these last 40 years, that you will do what I say and how I say it; while the patient has an opinion, it’s not possible to make decisions about someone else’s body without asking them. This is something that we experience in ASC [...] what we call as an “equal relation”. You talk with the patient and you ask their opinion, [...] you at

least explain the decision to them. How many times have we been to doctors and they say “take these and come back in a month” (pharmacist, M).

5.1.5. *Holistic medical practice*

Discussing with medical doctors about the differences between their professional medical practice and their participation in the social clinic, they cited the, in some cases, frustration when patients didn't show up for appointments (typical as many were traveling from areas far from the clinic). In such occasions, more experienced members played a key role in making doctors understand that they need to get out of their conventional medical practice, “the 20-minutes-a-patient attitude”, while also spend time to talk to other volunteers and patients. Another differentiating factor was that at the clinic, doctors reported that they have faced very difficult cases of patients, not typical in their professional practice. For example, a psychiatrist who works as a private doctor while also being a volunteer at ASC comments: “There were very difficult cases [at the ASC] – and this is the difference with my office; I don't have such cases at the office– and when we did have such cases, we were sharing them with other volunteers. You discussed it with the people at the reception, whoever was around at that time”. Such discussions about incidents between some of the doctors and other volunteers were cited as important for coping purposes, as especially the psychologists and psychiatrists had to deal with very problematic cases for long-term periods.

Many participants mentioned that in many cases lack of access to medical equipment and examinations (e.g. blood tests), which however contributed to the establishing of a different (even if still hierarchical) relationship between doctor and patient, and a different practice of medicine. Indeed, this was cited by many as one of the most innovative aspects of the self-organisation of the clinic. As one of our participants (a male doctor and one of the founding members) explains: “the doctors here had to practice what they learned at the university, that is, they had to practice medicine with their hands, ears and eyes; A traditional diagnosis through looking at the patient, chatting with the patient, smelling the patient. And this has created a special relationship between patients and doctors”. This also required from doctors to gain a deeper understanding of patients' conditions: “some people here understood that we have to treat the patient and not the disease. This was understood by many people as it is very practical. You don't only treat pneumonia here, you treat the whole package”. The participant here refers to the particular socio-economic backgrounds of the people that visited the social clinic. For example, our participants have shared compelling accounts of doctors asking patients with high blood pressure to avoid salt, while they could only access fresh food at soup kitchens, something that by necessity led to a more holistic practice of medicine: “For example, in one case the doctor said “with these drugs, no salt at all!” and the patient responded by saying “doctor, I eat in soup kitchens, how can I not eat salt?” or similarly for people that had to take antibiotics three times a day after food while having access to food once a day”. As a result, the doctors and pharmacists had to, through discussion, understand

the background and living conditions of the patients in order to diagnose and recommend a therapy that fits with patients' living conditions.

5.2. Pharmaceutical practice

In the first years of its operation, as the need for doctors was higher, the social clinic had a small medical storage that the doctors had direct access to when needed to prescribe drugs. Through the years, as the number of patients and scale of the clinic increased, the social pharmacy has become a separate working group (and the biggest room in the clinic) with pharmacists and assistant volunteers helping out with receiving donated medicine, storing the medicine in an alphabetical order, checking expiry dates etc. This has also been necessary as the very particular needs of the beneficiaries of the clinic, combined with (in some cases) the lack of medicines, required additional attention from volunteers for the distribution of appropriate therapies: "At the beginning the pharmacy operated with pharmacists but it was very frequent that doctors gave medicine to patients themselves. This wasn't functional as the doctors didn't keep records for the medicines they were giving away [...]".

5.2.1. *Recycling medicine*

One of the most impactful practices of the clinic, and indeed of all the social clinics in Greece, is the collection (through donations to the clinics) of unwanted medicines and their distribution to people that cannot afford to buy them (recycling of medicines). Through the years of operation, raising awareness about the lack of, and recycling of, medicine has been one of the biggest societal transformations of the social solidarity clinic(s). As one participant that is supporting the closure of the social clinic as she believes it has lost its transformative and agonistic character comments: "ASC and other social clinics at the moment do something important, recycle medicine. This is needed, and in my opinion, this is the main contribution of ASC at the moment".

From a complete lack of any initiatives that would recycle medicine, the ASC has built a network of donors across the country and it counts more than 30 K citizens donating unused medicine: "We have a large network of citizens, this is widely reported by big agencies as well, that bring us medicine from their homes; I estimate that within these six and a half years of operation there should be around 30,000 individuals that bring medicine through their local pharmacies or themselves directly". This of course creates challenges when you have to rely on donations to cover the needs of patients of various conditions and needs: "The prescription might require you to take it [a medicine] for two or three months, but here we might not have endless supply, I mean we are not a private pharmacy that as long as it sells, it buys; we have medicine based on the donations that we receive from households that have it in excess because a patient changed therapy, or died". This requires volunteers to plan ahead, combine active ingredients if needed to maintain stock and

provide patients with maximum of one month's prescriptions to make sure that they can cover the needs of multiple patients.

Talking about practices of the pharmacy that could be transferred to a public health system, one of the participants underlined: "In a public hospital or in a private clinic its [recycling] very different as it [medicine] gets charged. It's a matter of policy. Whether they have packets of 100 and they give you the two pills that you need or whether they open a completely new package and charge you with it. That's a matter of policy. So you can't talk about recycling there. You can only do recycling if for example public hospital X gives medicine to public hospital Y, so cover needs between hospitals". In general, ASC has been involved in a number of activities to make visible the defects of the national health system in relation to how medicines are purchased and distributed and the corruption and mismanagement that is involved through this process. ASC's medicine recycling activities in that sense, in addition to allowing people to have access to the medicine that they need, has the role of making visible the deficiencies of the national health system and argue for a its appropriate management and resourcing.

5.2.2. *Workarounds and patents*

Our interviewees have pointed to the workarounds that they have to employ when doctors prescribe medicines that are expensive due to patents or they are not available due to a lack of donations. As one of the pharmacists explain: "There are the various drugs that come out and which then [after years] lose their patents and come out as generic [cheaper] drugs. For example, cholesterol medicines are widely used; there is a new drug that came out, [name of drug], which is an improved version of [name of drug] as it combines two active ingredients but is so much more expensive and have no cheaper alternatives. And the public hospitals prescribe these to patients". This results in volunteers having to make combinations based on the active ingredients of prescriptions to cover patients' needs: "We have to make combinations; for example [name of drug] is prescribed for cholesterol and we often do not have it. In many cases we are forced to combine two other active ingredients that make [name of drug]. We work in a very different way from a pharmacy out there, here I need to come up with a solution to the problem on the spot."

Even though our participants have underlined the difficulty of doing such matching on the spot, they also referred to the motivation that this process provides: "We don't have the capacity to work in an a la carte way here [compared to drug stores]. We get in a process of asking "what am I going to do now" and "how am I going to ask him [the patient] to leave without the medicine" and "what can I give him instead". And this is different. You gain things from this process; from this creative attempt to help in one way or another."

5.3. Professionalization vs contestation

In addition to the medical and pharmaceutical practices of the ASC, our participants surfaced an interplay between the professionalization of the self-organised clinic and its more dynamic and contested social movement character. On the one hand the clinic was run as a public or private hospital and in many cases managing resources more efficiently to formal healthcare organisations, while on the other, the self-organisation practices and horizontal decision-making structure at this scale was a participatory experiment with its justified and wanted setbacks.

As one participant mentioned, as there was no other such example of a self-organised clinic at this scale, volunteers had to come up with solutions and processes on the go to manage the multiple crises that the clinic was facing: “There was no past experience of such a structure, either for how to organise the clinic or the pharmacy. So everyone that came here brought their soul and their experience. We walked a road that we were collectively making.” This led volunteers in bringing their experience and expertise from their professional practice – e.g. from pharmaceutical companies, private pharmacies and clinics, business and management. As one participant, an ex-employee of an international pharma company, describes: “My experience at the international company helped me to be able to better communicate within an organisation; it helped me to be able to suggest solutions based on a model of work that I had experience on; while also I brought my experience in managing crises, these were in business, but in a way we don’t do anything else here. We manage one crisis after the other in an extreme level.”

For many of our participants, such professionalism of the clinic’s members is one of the most significant factors for its success. In our interviews, many members indicated how people and beneficiaries visiting the clinic for the first time thought that they are a public organisation or charity: “The organization of the clinic has been very good since the beginning. [...] These people brought a fresh attitude and positivity which wasn’t the case in other movements carrying old stereotypes. They organized this [clinic] as a “business”, meaning efficiency, operating properly, as a company, a professional clinic. They were people who had no social movements experience, but experience in business administration, work organization, etc., which gave it a different character and freshness”. This “freshness” enabled the clinic to organise the work of dozens of volunteers for helping thousands of beneficiaries. The efficiency of the organisation of work in the clinic, combined with a good communication strategy, contributed to the clinic to both help people in need, while also making visible the injustices of the national health system. One volunteer responsible for the social media and website of the clinic comments about the strategies for mobilizing people around their cause: “I think that the good organization and the communications team played a very important role. You just had to inform a large number of people of what you are doing”. Similarly, communications were also very important for getting the clinic known internationally. Such communications were key for the making injustices visible and contributing to the opening of the NHS to all

citizens. As one participant, a MD with significant experience in social movements says: “The good thing about ASC was that it was making a fuss. A lot of fuss about things. And it owes a lot for its operation, that it became known etc. to that there were 1-2 people that had the know-how in communications, they were themselves very good in communicating and they make it known”.

Such communications were key for the clinic to have an impact in policy making at a national (or even European) level, support structures were created in other EU countries to support the clinic by donating medical equipment or raising its depends to the EU: “It helped a lot that citizens in Europe reacted to our call for help. They began making the first structures in 2013, self-organised citizens in Europe – Germany, Switzerland then Belgium and Luxemburg, Italy, France – structures were created only for helping ASC. [...] These structures worked in the same way, we told them that for us is not so important to send us medicine, we can get these from within Greece, what we want is a European outcry [for the impact of austerity] [...] And so we started “exporting resistance to Europe”. Mainly in Germany, with speeches, events etc.”

For some participants however, the “professionalisation” of many of its processes, from internal communications through mailing lists, to external communication strategies and relations with EU support structures, and the relatively with other structures, rigid ‘work’ arrangements had a negative impact on the clinic’s transformational and social movement character: “This [professionalism and experience in business] when the movement is rising works positively. When you are retreating however, it has many negative aspects. People [...] didn’t have much experience [in practices of social movements], they didn’t understand why they had to come to an assembly. They were saying, I am here to do my job and help people that need it, why should I come to meetings? [...] For example, the coordination team never worked as it was supposed to, meeting in a weekly, bi-weekly basis. Most of the coordination was happening through emails, online discussions, like we are a company and we have a project to solve.”

5.4. Care and burnout

The issue of fatigue and burnout of many of the clinic’s members was one of the main reasons (in addition to socio-political factors) that led to discussions about the future form and possible transformation of the clinic. Many participants raised concerns about how and whether such initiatives protect their members from burnout and how can processes be put in place to ensure that people receive the help that they need. As one of our participants, a former MD at the clinic says: “at the beginning there was a lot of excitement, and we all gave everything we had and got quickly exhausted. But myself with some others, we set ourselves limits. But in general, the “institution” [meaning the social clinic] didn’t put limits to protect people. It [the social clinic] believed that it can do anything; a feeling of omnipotence, [...] it’s the other side of self-organisation, it requires safety nets that the state for example has in place”.

The same participant expands on the issue of what contributed to the burnout of its members: “people here were put in a position to face very difficult situations [of patients] and such huge responsibility... the fatigue however is not because of this. It was a burnout from things we were seeing and hearing about. And to always give to others, while you shouldn’t have had, you should have taken something for yourself. You were also in need, and that was what was important”. One of the characteristics of solidarity movements is this reciprocal support that both members of the structures and beneficiaries receive. Through such quotes our participants underline how such a reciprocal relation was lost or became secondary. One participant summarises what she thinks are the factors that contributed to the fatigue of the clinic’s members: “[...] the self-preservation of this “institution” that didn’t happen, the extreme generosity, the fantasy of omnipotence, the denial of participating in some state processes later on to contribute to changes in the healthcare sector”.

In some cases however, the close relationships between members of the group of the same shift played a therapeutic role; for example, one of the psychologists described an incident where she was unfairly blamed by a relative of a patient where the volunteers of the reception supported her in reading the medical file of the patient and discussing possible ways forward: “I checked his [the patient’s] file, I went to the reception, which played a therapeutic role for me at the moment. I sat at the reception, we took his file, we looked at it all together; he had severe health problems, he had COPD and he hasn’t been to the doctor for months [...] And then after we order coffee, we talk, and emotionally discharge. I think people that worked as social clinics had to emotionally discharge. All of us, we needed a lot of discharge. The people that came to in there, it was a big trauma. Unprecedented”.

As a result, for the members of the clinic any future transformations should include putting together the processes to protect its members for burnout by setting limits and creating the conditions for people to receive support when they need it. According to one of our participants, this can be done through more frequent reflection and discussion about how many patients can the clinic take care of and ways for its volunteers to also receive the support they need: “If an “institution” that tried to cope with such pressing issues, cannot process what each one of us [volunteers] takes from this space, why do we come, when do we need to stop giving, it [the institution] also can’t put a break.”

6. Discussion

CSCW researchers have previously used storytelling to support social activism (Dimond et al. 2013) and to support critical reflection about people’s socio-political realities and contexts — including their uneven power relations and unfair societal structures (Fox and Le Dantec 2014; Crivellaro et al. 2016). These works showed the critical role that materialising histories plays in fostering recognition and understanding of social issues and practices, that can foster different forms of social activism. In the case reported in this paper, the collaborative process of working with

the Attica Social Clinic to create an oral history group and collecting oral histories supported not only reflection on their positioning in society, but was also a way to explore and clarify what the social clinic's approach to healthcare might contribute to innovating and transforming traditional healthcare institutions. The social clinic's day to day practices are mundane articulations of particular value systems and, as such, are in themselves materialisation of social activism. Yet, the process of recording and analysing the oral histories, played an important role in supporting the group coming to terms with existing contradictions within the social clinic, such as the way doctors' hierarchies were maintained in social clinics; as well as its social innovations, such as their dialogical health care practice, and recycling of medicines.

6.1. Infrastructuring and institutioning the commons

Our motivation for engaging with solidarity movements has, since 2016, been about exploring and developing ways in which CSCW research could play a role in supporting and scaling (up and out) solidarity practices. As such, our work, can be regarded as a form of infrastructuring social innovation (Björgvinsson et al. 2010; Hillgren et al. 2011; Manzini and Coad 2015), in that it focused on creating the spaces for activists to come together and reflect on future directions, and deploying already available open-source technologies as a method of prototyping innovations. From the outset, we committed to long-term collaborations with solidarity movements, and our approach recognized them as designers and social innovators of an emerging solidarity economy, where our contribution was to facilitate their ongoing infrastructuring activities.

In the case reported here, the focus of our work was to help shape spaces for critical reflection on the social clinics' practices, through the creation of an oral history group and the collection of oral histories. Our contribution to this long-term collaborative process included the provision of the required equipment, the construction of the interview guides and the collective analysis of the oral histories. This in turn, fostered a collaborative evaluation of the practices of the social clinic with a particular focus on its transformative character and pinpoint the meaning of this work and what its future should be.

Our insights point to the internal collaborative practices for delivering healthcare services and collective governance; the tensions that such collaborative practices create among the members of the clinic, and how such tensions are inherited from well-established cultural norms about the role of doctors, other professions and patients within healthcare. Nonetheless, the creation and sustaining of the self-organised social clinic through more equal (than in private and public health systems) relations between its members and no monetary transactions, has manifested an example of a different type of an informal 'institution' in healthcare. Such an exemplar institution comes in dialogue with the national health system either directly, by press releases that underline the lack of funding and adequate management of the public health system, or indirectly through patients' experiences. As such, the

operation of the social clinic, serve as an example of a different configuration of people, resources and practice of medicine, one that expands people's imaginary for what is possible. In this sense, the work contributes to recent conversations in participatory design in relation to the high-level concepts and practices of institution-ing (Huybrechts et al. 2017) and common-ing (Marttila et al. 2014; Hillgren et al. 2016; Teli et al. 2020)—by providing empirical insights in relation to the work of activists in creating new types of institutions.

Critically, the operation of the social clinic—as materialised in the oral histories, serves as an example of a different configuration of people, resources and practice of healthcare—one that expands people's imaginary for what might be possible. In this sense, the solidarity clinic's day-to-day practices are already a form of pre-figurative politics (Yates 2015; Asad 2019) or if seen in relation to other institutions and interactions between them as “institution-ing” (Teli et al. 2020). As such the making of the oral history group was an effort to materialize this prefiguration in a form that enables reflection on the successes and failures of such work. This drew a particular focus on how their work could contribute to the transformation of the national health system more widely. In the following sections we further reflect on these points.

6.2. Agonistic service design

Personal, institutional and societal transformation is arguably one of the goals of any activist movement. The social clinic volunteers' reflections are articulations of ongoing transformations, that are acting out interpersonally within the clinic and externally through the clinic's interactions with other public, private or third sector institutions. Yet, here we discuss the approaches that the clinic developed to enter in dialogue with other healthcare institutions and the public sector in order to initiate processes of transformation.

Arguably the clinic's ability to mobilise people to donate medicine and join as volunteers, is the result of a combination of a set of skills that people brought from their own professions and a common vision of universal access to healthcare services through participatory and transparent processes. Our findings show how previous experience in project management, administration and effective external communication meant that the clinic was able to go beyond what other similar activist initiatives had managed to achieve. Social media, mailing lists, Google groups and live press releases have all played a significant role in this regard. While social media use for making things visible is common in social movements (Costanza-Chock 2012; Kow et al. 2016), in the ASC it was used strategically as a way to evidence the existing healthcare systems and institutions' inadequacies through accounts of personal experience and accounts of the solidarity clinics practices—as a way of demonstrating alternative modes of organising a more socially just healthcare system. This was a way to enter in agonistic dialogue with healthcare institutions and politicians and reach the wider public and people at scale.

Such a communication strategy and expertise was regarded fundamental by many in the clinic, also as it served to point out how social movements roles might be more about the creation of dialogical agonistic spaces between organisations and individuals within healthcare for the purpose of transforming the wider public sector system— rather than replacing or substituting it. Lodato and DiSalvo discuss the ways that institutions constraint participatory endeavours by restricting more meaningful engagement and by imposing certain ideologies (Lodato and DiSalvo 2018). In the case of the ASC, the communication tactics that the group employed through the professional expertise of its activists, created spaces to negotiate and attempt to transform healthcare in their own terms. Such insights were made possible through the reflective accounts of the clinic's volunteers that took part in the oral history group and the interpretations that they contributed on the oral histories collected.

Such communication tactics were fuelled by the efficiency in the administration of the clinic, something however that was picked by some of the oral histories as being problematic for a social movement. Through the years of its operation the taken-for-granted procedures inherited from volunteers' professional experience suppressed the transformational character of the clinic. This was also further exacerbated by the fatigue and lack of participation from some of the clinic's founding members. Here we see the role of design as important for solidifying the social processes to maintain the agonistic and confrontational character of such activist structures. In terms of technology design, the use of mailing lists and Google groups for the sharing and collective editing of draft press releases, could be complemented by templating tools that direct activists in drafting communications that can create the conditions for institutional and policy transformation. This can be for example, by facilitating the collection of, and prompting the use of evidence from their day-to-day activities [e.g. (Manuel and Crivellaro 2020)] or by visualising information in ways that make visible current injustices [similarly to (DiSalvo 2012)]. Such technologies might then result in instead of coming at odds with and 'normalising' social movements' inclusive and participatory practices (Ghoshal et al. 2020), to contribute in maintaining their agnostic and transformational character. Open-source software projects in this space (e.g. GNU health) have developed software for people and information management for such social clinics, which contributes to the creation of additional such exemplar healthcare structures. Here, drawing from our empirical data, we contend that in addition to free and open software, created through equivalent participatory processes, we need to focus on designing socio-technical systems for such activist initiatives to come in dialogue and transform public institutions.

6.3. Caring human-centered healthcare infrastructures

The oral histories of our participants, brought to the forefront a holistic practice of healthcare that problematises current trajectories fuelled by its increasing privatisation and financial pressures caused by public spending cuts in many countries in Europe and Western societies. This results in organisational cultures where

time-bounded medical appointments adds pressure to doctors to undertake as many appointments as possible, reducing opportunities for human contact and relations and rendering the healthcare experience to an ‘automated process’. As such, current practices in healthcare are based on probabilities and trial and error approaches to prescription of the ‘right’ medications without any in-depth understanding of the person the medication is for. The application of technologies to such practices as a way to further automate healthcare diagnostics currently run the risk to amplify the existing relational void between care provider and receiver; while potentially having serious negative impact on the provision of healthcare, particularly for vulnerable populations by adding further barriers to healthcare access. Our insights tell accounts of such vulnerable individuals, who already struggle to access healthcare, by for example not having the resources to pay for medicine. Yet, the social clinics volunteers’ accounts also tell of the caring relations and practices (Mol 2008) that emerged in the solidarity clinic—where doctors took time to understand patients’ living and health conditions holistically and develop a longer-term understanding before prescribing therapy. Our collaborators described this approach as being about developing equal relations with the patients and centering of the person in the relationship, not the disease. While the design and integration of new and emerging technologies in healthcare services (e.g. bots, machine learning diagnostics, etc.) are currently concerned with issue of transparency in healthcare systems (Holzinger et al. 2017), what we learn from the work of the solidarity clinics is that CSCW and HCI design should be designed instead with the ways these might foster opportunities for the creation of caring relations and dialogical approaches in healthcare—as a way to recover a fractured health care system.

What our findings also show is the weariness that comes with daily activist practices; from participating to the oral history group to the day-to-day practices through which, in effect, the social clinic materialises. Our experiences and the experiences of the ASC members speak of the ambivalent dimension of care—as both something that nurtures care, but also as something that has a distressful dimension (e.g. burn out). The process of materialising the labour practices of the social clinic through the digital archive—as a material doing in the sense of de La Bellacasa (de La Bellacasa 2011), prompted the people of ASC to focus on the need of caring for those who care about others and the operations of the social clinic (Jochimsen 2003).

In addition to a holistic practice of medicine, our findings point to the clinic’s efforts to establish collaborative and equal relations between doctors, other volunteers and patients towards developing a healthcare system that can be understood as commons (Marttila et al. 2014). The oral histories point to the successes and failures of the clinic to do so, due to established preconceptions about hierarchical relations between doctors and other professions. We contend that such difficulties also stem from established socio-technical configurations in healthcare that the clinic inherited from the expertise that people carried from their professional practice. Here, it is important to reflect on the design of processes and technological systems that

mediate and support a different type of relations between healthcare staff; these for example can be systems that make visible the contributions of everyone in the delivery of healthcare services, and systems designed to create spaces for dialogue that cut across the boundaries of communities of practice within healthcare institutions. Rather than implying the creation of antagonistic (or gamified) relations between categories of health staff, here we refer to technologies that can enable a more collaborative relationship while making visible the interdependence of various professions and expertise for healthcare. Our data underline the importance of support staff (such as reception volunteers and others) for both the practice of a more human-centred medicine and for the care they provided to other members of the clinic – referred to by one of our participants as therapeutic. This was cited as of particular importance when the “institution” doesn’t have the processes to take care of the people that are supposed to provide care. We contend that the careful designing of socio-technical systems for healthcare has the capacity to disrupt culturally established hierarchies, by cultivating commoning relations in its organisation and governance.

7. Conclusion

This paper contributes a number of materializations of activism that respond to this special issue and contribute to CSCW work more broadly. More specifically, we reported on the materialization of activism against austerity to a self-organized social clinic; the subsequent materialization of the clinic’s medical and pharmaceutical practices in the co-creation of an oral history group and a set of oral histories from past and current volunteers; and finally, implications for the role of design in creating the grassroots infrastructures for ‘new institutions’. In our discussion, we more specifically focused on what activists on the ground have done, and what our role as researchers can be, to create the conditions for such participatory healthcare institutions. Agonistic service design, informed by recent work in adversarial design and agonism, was discussed as a way that design can bring grassroots initiatives in dialogue with public institutions in an attempt to transform them. While finally, in our last discussion section, we contribute implications for the careful designing of socio-technical processes in healthcare; ones that can disrupt culturally established hierarchies and cultivate commoning relations. We believe that such insights build on socially informed CSCW work and contribute to the designing of participatory socio-technical systems in healthcare.

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References

- Alam, Ashraful; and Donna Houston (2020). Rethinking care as alternate infrastructure. *Cities*, vol. 100, no. 1, pp. 102662.
- Anderson, Kathryn; Susan Armitage; Dana Jack; and Judith Wittner (1987). *Beginning where we are: Feminist methodology in oral history*. Routledge, pp. 94-112.
- Arampatzi, Athina (2016). The spatiality of counter-austerity politics in Athens, Greece: Emergent 'urban solidarity spaces'. *Urban Studies*, vol. 54, no. 9, pp. 2155-2171.
- Arampatzi, Athina; and Walter J. Nicholls (2012). The urban roots of anti-neoliberal social movements: The case of Athens, Greece. *Environment and Planning*, vol. 44, no. 11, pp. 2591–2610.
- Asad, Mariam. (2019). Prefigurative design as a method for research justice. *CSCW 2019: Proceedings of the ACM on Human-Computer Interaction, November 2019*. New York: ACM Press, vol. 3, no 200, pp. 1–18.
- Asad, Mariam; Christopher A. Le Dantec; Becky Nielsen; and Kate Diedrick (2017). Creating a sociotechnical API: Designing city-scale community engagement. In *CHI 2017: Proceedings of the 2017 CHI conference on human factors in computing systems, Denver, US, 6 May – 11 May 2017*. New York: ACM Press, pp. 2295–2306.
- Balaam, Madeline; Rob Comber; Ed Jenkins; Selina Sutton; and Andrew Garbett (2015). FeedFinder: A location-mapping mobile application for breastfeeding women. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems, Seoul, Korea, 18 April – 23 April 2015*. New York: ACM Press. pp. 1709–1718.
- Binder, Thomas; and Eva Brandt (2008). The Design: Lab as platform in participatory design research. *Co-Design*, vol. 4, no. 2, pp. 115–129.
- Björgvinsson, Erling; Pelle Ehn; and Per-Anders Hillgren (2010). Participatory design and democratizing innovation. In *PDC 2010: Proceedings of the 11th Biennial participatory design conference, Sydney, Australia, 29 November – 3 December 2010*. New York: ACM Press, pp. 41–50.
- Björgvinsson, Erling; Pelle Ehn; and Per-Anders Hillgren (2012). Agonistic participatory design: working with marginalised social movements. *CoDesign*, vol. 8, no. 2, May 2012, pp. 127–144.
- Braun, Virginia; and Victoria Clarke (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, vol. 3, no. 2, pp. 77–101.
- Costanza-Chock, Sasha. (2012). Mic check! Media cultures and the Occupy movement. *Social Movement Studies*, vol. 11, no. 3, August 2012, pp. 375–385.

- Crivellaro, Clara; Alex Taylor; Vasilis Vlachokyriakos; Rob Comber; Bettina Nissen; and Pete Wright (2016). Re-making places: HCI, 'Community Building' and Change. In *CHI 2016: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, San Jose, US, 7 May – 12 May 2016*. New York: ACM Press. pp. 2958-2969.
- Crivellaro, Clara; Rob Anderson; Daniel Lambton-Howard; Tom Nappey; Patrick Olivier; Vasilis Vlachokyriakos; Pete Wright. (2019). Infrastructuring Public Service Transformation: Creating Collaborative Spaces between Communities and Institutions through HCI Research. *ACM Transactions on Computer-Human Interaction (TOCHI)*, vol. 26, no. 3, pp. 1-29.
- de La Bellacasa, Maria Puig. (2011). Matters of care in technoscience: Assembling neglected things. *Social Studies of Science*, vol. 41, no. 1, pp. 85–106.
- Dimond, Jill P.; Michaelanne Dye; Daphne LaRose; and Amy S. Bruckman (2013). Hollaback!: the role of storytelling online in a social movement organization. In *CSCW 2013: Proceedings of the 2013 conference on Computer supported cooperative work, San Antonio, US, 23 February – 27 February 2013*. New York: ACM Press. pp. 477–490.
- DiSalvo, Carl (2009). Design and the Construction of Publics. *Design Issues*, vol. 25, no.1, pp. 48–63.
- DiSalvo, Carl (2012). *Adversarial design*. The MIT Press.
- Fan, Jenny; and Amy X. Zhang (2020). Digital Juries: A Civics-Oriented Approach to Platform Governance. In *CHI 2020: Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems, Honolulu, US, 25 April – 30 April 2020*. New York: ACM Press. pp. 1–14.
- Foth, Marcus; and Jeff Axup (2006). Participatory design and action research: Identical twins or synergetic pair?. In *PDC 2006: Proceedings Ninth Participatory Design Conference, Trento, Italy, 31 July – 5 August 2006*. New York: ACM Press. pp. 93-96.
- Fox, Sarah; and Christopher Le Dantec (2014). Community historians: scaffolding community engagement through culture and heritage. In *DIS 2014: Proceedings of the 2014 conference on Designing interactive systems, Vancouver, Canada, 28 June – 2 July*. New York: ACM Press. pp. 785–794.
- Ghoshal, Sucheta; Rishma Mendhekar; and Amy Bruckman. (2020). Toward a Grassroots Culture of Technology Practice. *CSCW 2020: Proceedings of the ACM on Human-Computer Interaction*. New York: ACM Press, vol. 4, no. 1, pp. 1–28.
- Hayes, Gillian R. (2011). The relationship of action research to human-computer interaction. *ACM Transactions on Computer-Human Interaction (TOCHI)*, vol. 18, no. 3, pp. 1-20.
- Hayes, Gillian R. (2014). Knowing by doing: action research as an approach to HCI. In *Ways of Knowing in HCI*, Springer, pp. 49–68.
- Hillgren, Per-Anders; Anna Seravalli; and Anders Emilson. (2011). Prototyping and infrastructuring in design for social innovation. *CoDesign*, vol. 7, no. 3-4, pp. 169–183.
- Hillgren, Per-Anders; Anna Seravalli; and Mette Agger Eriksen (2016). Counter-hegemonic practices; dynamic interplay between agonism, commoning and strategic design. *Strategic Design Research Journal*, vol. 9, no. 2, pp. 89-99.
- Holzinger, Andreas; Chris Biemann; Constantinos S. Pattichis; and Douglas B. Kell (2017). What do we need to build explainable AI systems for the medical domain? ArXiv Preprint. <https://arxiv.org/abs/1712.09923>. 11 May 2021.
- Huang, Ming-Hui; and Roland T. Rust (2018). Artificial intelligence in service. *Journal of Service Research*, vol. 21, no. 2, pp. 155–172.
- Huybrechts, Liesbeth; Henric Benesch; and Jon Geib (2017). Institutioning: Participatory design, co-design and the public realm. *CoDesign*, vol. 13, no. 3, pp. 148–159.
- Imran, Muhammad; Carlos Castillo; Ji Lucas; Patrick Meier; and Sarah Vieweg. (2014). AIDR: Artificial intelligence for disaster response. In *Proceedings of the 23rd International Conference on World Wide Web, Seoul, Korea, 7 April – 11 April 2014*. New York: ACM Press. pp. 159–162.
- Jochimsen, Maren A. (2003). Caring Conceptualized as the Result of an Effective Caring Situation. In *Careful Economics*, Springer, pp. 75–83.

- Karasti, Helena (2014). Infrastructuring in participatory design. In *PDC 2014: Proceedings of the 13th Participatory Design Conference, Windhoek, Namibia, 6 October – 10 October 2014*. New York: ACM Press, vol. 1, pp. 141–150.
- Karasti, Helena; and Anna-Liisa Syrjänen (2004). Artful infrastructuring in two cases of community PD. In *PDC 2004: Proceedings of the eighth conference on Participatory design: Artful integration: interweaving media, materials and practices, Toronto, Canada, 27 July – 31 July 2004*. New York: ACM Press. pp. 20–30.
- Karasti, Helena; Karen S. Baker; and Eija Halkola (2006). Enriching the notion of data curation in e-science: data managing and information infrastructuring in the long term ecological research (LTER) network. *Computer Supported Cooperative Work (CSCW)*, vol. 15, no. 4, pp. 321–358.
- Kawano, Emily; Thomas Neal Masterson; and Jonathan Teller-Elsberg (eds) (2009). *Solidarity economy I: Building alternatives for people and planet. Papers and Reports from the 2009 U.S. Forum on the Solidarity Economy*. Center for Popular Economics, Amherst, MA, USA.
- Korn, Matthias; and Amy Volda. (2015). Creating Friction: Infrastructuring Civic Engagement in Everyday Life. In *Proceedings of the Decennial Aarhus Conference on Critical Alternatives, Aarhus, Denmark, August 2015*. Aarhus: Aarhus University Press. pp. 145-156
- Kow, Yong Ming; Yubo Kou; Bryan Semaan; and Waikuen Cheng. (2016). Mediating the Undercurrents: Using Social Media to Sustain a Social Movement. In *CHI 2016: Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems, San Jose, US, 7 May – 12 May 2016*. New York: ACM Press. pp. 3883–3894.
- Le Dantec, Christopher A.; and Carl DiSalvo (2013). Infrastructuring and the formation of publics in participatory design. *Social Studies of Science*, vol. 43, no. 2, pp. 241–264.
- Lodato, Thomas; and Carl DiSalvo (2018). Institutional constraints: the forms and limits of participatory design in the public realm. In *PDC 2018: Proceedings of the 15th Participatory Design Conference, Genk, Belgium, 20 August – 24 August 2018*. New York: ACM Press. pp. 1–12.
- Manuel, Jennifer; and Clara Crivellaro (2020). Place-Based Policymaking and HCI: Opportunities and Challenges for Technology Design. In *CHI 2020: Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems, Honolulu, US, 25 April – 30 April 2020*. New York: ACM Press. pp. 1–16.
- Manzini, Ezio (2014). Making things happen: Social innovation and design. *Design Issues*, vol. 30, no. 1, pp. 57–66.
- Manzini, Ezio; and Rachel Coad (2015). *Design, when everybody designs: An introduction to design for social innovation*, MIT Press.
- Marttila, Sanna; Andrea Botero; and Joanna Saad-Sulonen (2014). Towards commons design in participatory design. In *PDC 2014: Proceedings of the 13th Participatory Design Conference, Windhoek, Namibia, 6 October – 10 October 2014*. New York: ACM Press. pp. 9–12.
- McCarthy, John; and Peter Wright (2015). *Taking [a] part: the politics and aesthetics of participation in experience-centered design*. MIT Press.
- Meroni, Anna; and Daniela Sangiorgi (2011). *Design for services*. Gower Publishing, Ltd.
- Mol, Annemarie (1999). Ontological politics. A word and some questions. *The Sociological Review*, vol. 47, no. 1, pp. 74–89.
- Mol, Annemarie (2008). *The logic of care: Health and the problem of patient choice*. Routledge.
- Mouffe, Chantal (2000). *The democratic paradox*. Verso.
- Mouffe, Chantal (2005). *On the political*. Psychology Press.
- Muller, Michael J.; and Allison Druin (2012). Participatory design: The third space in human-computer interaction. *The Human-Computer Interaction Handbook: Fundamentals, Evolving Technologies, and Emerging Applications*. Hillsdale, New Jersey: Lawrence Erlbaum Associates. pp. 1125–1154.

- Neumann, Laura J.; and Susan Leigh Star (1996). Making infrastructure: The dream of a common language. In *PDC 1996: Proceedings of the Participatory Design Conference, Cambridge, US, 13 November – 16 November 1996*. New York: ACM Press. pp. 231–240.
- Olivier, Patrick; and Peter Wright (2015). Digital civics: taking a local turn. *Interactions*, vol. 22, no. 4, pp. 61–63.
- Pipek, Volkmar; and Volker Wulf (2009). Infrastructuring: Toward an integrated perspective on the design and use of information technology. *Journal of the Association for Information Systems*, vol. 10, no. 5, pp. 447.
- Rafael, Adeline R. Falk (1997). Advocacy oral history: A research methodology for social activism in nursing. *Advances in Nursing Science*, vol. 20, no. 2, pp. 32–44.
- Ratto, Matt; and Megan Boler (2014). *DIY citizenship: Critical making and social media*. MIT Press.
- Seravalli, Anna; Mette Agger Eriksen; and Per-Anders Hillgren (2017). Co-Design in co-production processes: jointly articulating and appropriating infrastructuring and commoning with civil servants. *CoDesign*, vol. 13, no. 3, pp. 187–201.
- Star, Susan Leigh. (1999). The ethnography of infrastructure. *American Behavioral Scientist*, vol. 43, no. 3, pp. 377–391.
- Talhok, Reem; Sandra Mesmar; Anja Thieme; Madeline Balaam; Patrick Olivier; Chaza Akik; and Hala Ghattas (2016). Syrian refugees and digital health in Lebanon: Opportunities for improving antenatal health. In *CHI 2016: Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems, San Jose, US, 7 May – 12 May*. New York: ACM Press. pp. 331–342.
- Teli, Maurizio; Angela Di Fiore; and Vincenzo D’Andrea (2016). Computing and the common: an empirical case of participatory design today. In *PDC 2016: Proceedings of the 14th Participatory Design Conference, Aarhus, Denmark, 15 August – 19 August 2016*. New York: ACM Press. pp. 1–10.
- Teli, Maurizio; Marcus Foth; Mariacristina Sciannamblo; Irina Anastasiu Cioaca; and Peter Lyle. (2020). Tales of Institutioning and Commoning: Participatory Design Processes with a Strategic and Tactical Perspective. In *PDC 2020: Proceedings of the 16th Participatory Design Conference, Manizales, Colombia, 15 June – 19 June 2020*. New York: ACM Press. pp. 159–171
- Vlachokyriakos, Vasilis; Clara Crivellaro; Christopher A. Le Dantec; Eric Gordon; Pete Wright; and Patrick Olivier. (2016). Digital Civics: Citizen Empowerment With and Through Technology. In *PDC 2016: Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems, San Jose, US, 7 May – 12 May 2016*. New York: ACM Press. pp. 1096–1099.
- Vlachokyriakos, Vasilis; Clara Crivellaro; Pete Wright; Evika Karamagioli; Eleni-Revekkha Staiou; Dimitris Gouscos; Rowan Thorpe; Antonio Kruger; Johannes Schöning; Matt Jones; Shaun Lawson; and Patrick Olivier (2017). HCI, Solidarity Movements and the Solidarity Economy. In *CHI 2017: Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems, Denver, US, 6 May – 11 May 2017*. New York: ACM Press. pp. 3126–3137.
- Vlachokyriakos, Vasilis; Clara Crivellaro; Pete Wright; and Patrick Olivier. (2018). Infrastructuring the Solidarity Economy : Unpacking Strategies and Tactics in Designing Social Innovation. In *CHI 2018: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, Montreal, Canada, 21 April – 26 April 2018*. New York: ACM Press. pp. 1–12.
- Yates, Luke. (2015). Rethinking prefiguration: Alternatives, micropolitics and goals in social movements. *Social Movement Studies*, vol. 14, no. 1, pp. 1–21.